Isolation in Family Caregivers of Persons Living with Dementia: Mitigating Risk of Prolonged Grief Disorder

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"All the lonely people
Where do they all come from?
All the lonely people
Where do they all belong?"

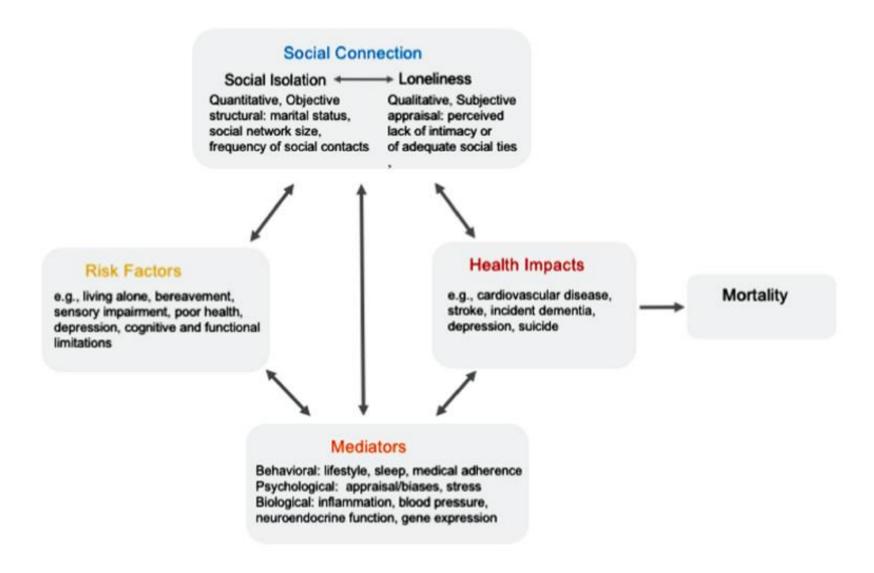
Eleanor Rigby by Lennon and McCartney

Social isolation and associated loneliness

 According to the National Academies of Sciences, Engineering and Medicine—

Prior to the pandemic

- 1/3 of adults 45 years and older feel lonely
- Loneliness is feeling alone—it is subjective
- 1/4 of older adults are considered socially isolated
- Social isolation is a lack of social connections—it is objective

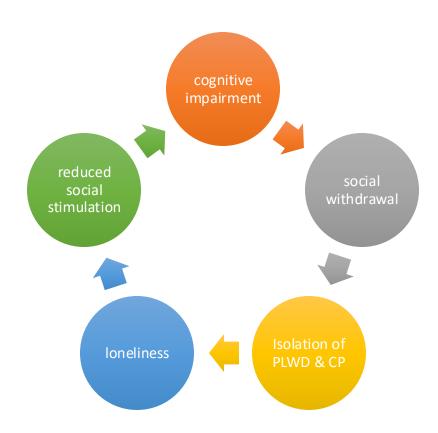


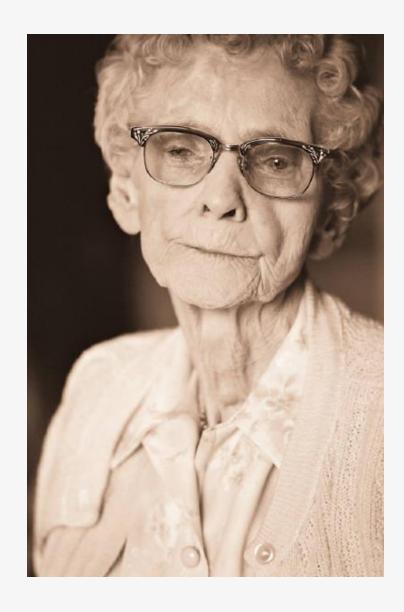
Adapted, National Academies of Sciences, Engineering and Medicine, 2020 and Holt-Lunstad and Smith, 2016. As presented in Doanvan & Blazer 2020

How to prevent/break this cycle—the pre-pandemic approach

- Health care & self-(mental)health care
- Address natural losses (widowhood, death of friends/family) with additional human relationshipsprogressively over the life span
- Shared stimulating activities that are both social and intellectually engaging
- Proactive support for family care partners
- Emphasize interdependency (vs independence)
- Learn a balance between solitude and engagement

Dementia, social isolation and loneliness





The risk of social isolation and loneliness

- Social isolation significantly increased a person's risk of premature death from all causes, a risk that may rival those of smoking, obesity, and physical inactivity.
- Poor social relationships (characterized by social isolation or loneliness) was associated with a 29% increased risk of heart disease and a 32% increased risk of stroke.
- Loneliness was associated with higher rates of depression, anxiety, and suicide.
- Loneliness among heart failure patients was associated with a nearly 4 times increased risk of death, 68% increased risk of hospitalization, and 57% increased risk of emergency department visits.
- Social isolation was associated with about a 50% percent increased risk of dementia.

Structural solutions

- Neighborhoods = congregate living = COMMUNITY
- Supported activities—
 - Education (Osher) Centers, Senior Centers with a variety of social and health promoting programs
- Formal supports-
 - Adult day centers
- Family supports—
 - Advance care planning, rituals
 - Caregiver education





Caregiver support (usual-excellent care)

- Psychoeducation
- Peer support
- Resource information
- "taking a break"
- FOR MOST FAMILY CPS THIS IS SUFFICIENT





Finding Balance as A Caregiver

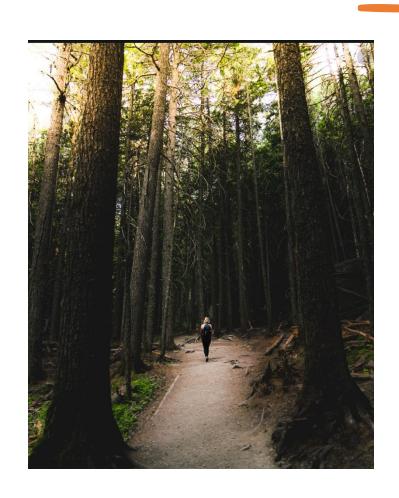
"I never loved but one man in my life, and I have lost him twice?"

Roxanne, in Cyrano de Bergerac





Caregiving may be a burden...or a blessing...often both... but it is always a journey







It's a long game...
You will need ...

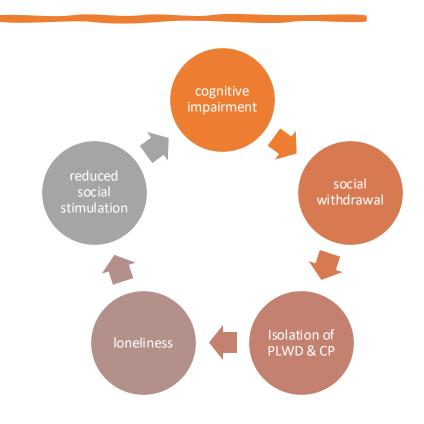
Skills Stamina Time Companions

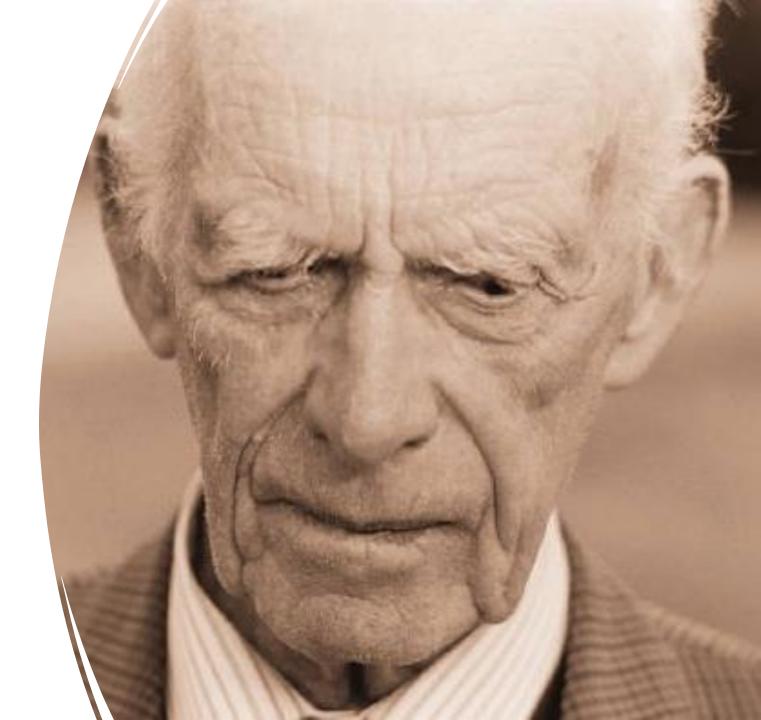
"Companioned Isolation"

Family caregivers often report feeling lonely and isolated despite spending significant time with their care partner or recipient, according to the Family Caregiver Alliance.



Dementia, social isolation and loneliness





How to prevent/break this cycle—

- Health care & self-health care
- Address natural losses (widowhood, death of friends/family) with additional human relationships-progressively over the life span
- Shared stimulating activities that are both social and intellectually engaging
- Proactive support for family care partners
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...how do we find balance?



Compassionate Communities

"The more people are anchored in communities where they feel connected, protected and respected, the more people are ready to reach out and experiment. The less they feel connected, protected and respected, the more they'll want to build walls to protect themselves from change."

Thomas Friedman, "Thank You for Being Late: An Optimist's Guide to Thriving in the Age of Accelerations."

In a healthy community community members, that is, the citizens of that community are:

• **Connected**-they live lives within a safety net of care that supports healthy inter-relationships and is characterized by trust, and equips citizens to navigate the wider world.

- Respected-they are they are listened to, cared for, cared about, and encouraged to share their own gifts and talents with each other and with the larger world. They are honored for being who they are just that is enough—not for what they do or have.
- **Protected**-the young, the old, the suffering are shielded from harm, are nurtured, and resourced when harm happens.

"sistering"



You will not always be a caregiver

It's important to keep the "you" of you for your postcaregiving journey



The best reason to find balance...

The person you are caring for

needs you

...and needs you to be your "best you"

The "best You" deserves replenishment



A caregiver's meditation....



Pre-Loss Group Support

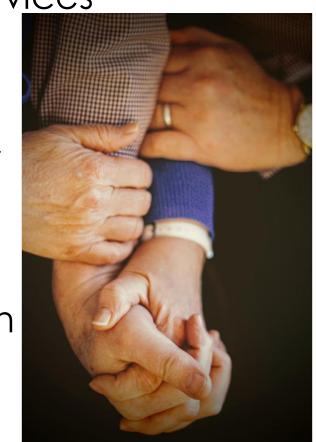
A 10 session group facilitated by social workers to prepare family caregivers for the final stages of dementia family caregiving.

Developed and evaluated by Caring Connections

Presently offered at Jewish Family Services

Veterans Administration Family Caregiver Program

U of U Geriatrics Clinic-Aging Brain Clinic (GUIDE)



Recent systematic reviews have indicated that lack of preparedness and negative pre-loss experiences are most predictive of poor bereavement outcomes and advocated for targeted support to CPs who are at risk of adverse bereavement outcomes.

- Schulz, R., Boerner. K., Shear, K., et al. (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. The American journal of geriatric psychiatry, 14, 650-658.
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Comprehensive family caregiver support should include appropriate preparation for the death of the person living with dementia.

Background

- Dementia family caregiving may span more than a decade and places many family care partners (CPs) at risk for poor bereavement outcomes
- Estimates of prolonged grief in bereaved dementia family CPs range from 10-20%



Prolonged Grief

 A state of prolonged, ineffective mourning associated with functional impairment, medical morbidity, cognitive impairments, and suicidal ideation.

 Unlike normal grief, PG is characterized by unabated maladaptive thoughts, feelings, and behaviors that obstruct adjustment.

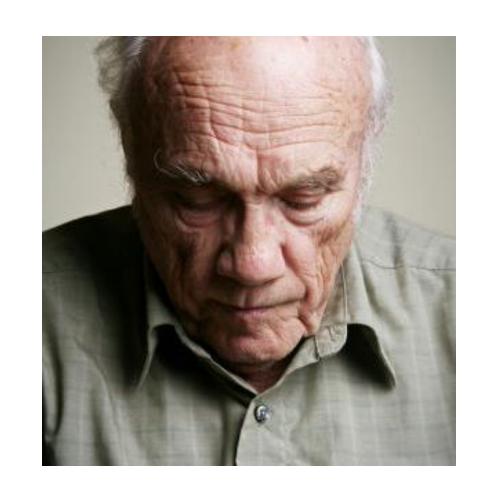
Which Family Care Partners are at Risk for Prolonged Grief?

- inability to accommodate relationship change
- positive view of the caregiving role
- perceived gratifying communication with the PLWD
- high expressed affection by the CP, and
- high perceived caregiving burden
- Nursing home admission also contributes to risk for poor bereavement in high-risk dementia CPs; those who cared for their PLWD at home evidence still higher risk upon nursing home placement

Supiano, K. P., Luptak, M., Andersen, T., Beynon, C., Iacob, E., & Wong, B. (2022). If we knew then what we know now: The preparedness experience of pre-loss and post-loss dementia caregivers. Death studies, 46(2), 369–380. doi.org/10.1080/07481187.2020.1731014

Our earlier work assessing family caregivers in the final months before the death of their person living with dementia revealed those caregivers who:

- experienced the family member's decline as traumatic,
- strongly expressed concern for loss of the caregiver role,
- reported unavailable support, and
- difficulties anticipating a new life
- reported <u>inadequate death preparation</u> and <u>difficulty making meaning</u> of the illness and death.





Pre-Loss Group Support (PLGS)

We adapted our efficacious Prolonged Grief Group Therapy (formerly Complicated Grief Group Therapy) intervention for bereaved dementia caregivers for soon-to-be bereaved dementia CPs at risk for prolonged grief to facilitate healthy death preparedness and eventual bereavement—Pre-loss Group Support (PLGS).

PLGS is a 10-session multi-modal therapeutic group intervention for family CPs administered by social workers/mental health clinicians.



Research trajectory

Adapted the CGGT intervention for CG in bereaved dementia caregivers for soon-to-be bereaved dementia caregivers at risk for CG to facilitate healthy death preparedness and eventual bereavement—Pre-loss Group Therapy (PLGT).

Used empirically validated procedures for developing psychosocial intervention manuals and created PLGT participant manuals and facilitator manuals.

Implemented and evaluated Pre-Loss Group Therapy in three psychotherapy group cohorts with family CPs at-risk for prolonged grief whose person living with dementia (PLWD) had a life expectancy of 6 months or less and resided in a nursing home (Pl/co-l facilitators.

Pragmatic trial in 6 nursing homes with trained NH Social Workers.

Pragmatic trial with 8 varied agencies serving PLWD & family CPs (current study).

- The primary purpose of this first project was to determine if telehealth-delivered Pre-loss Group Support (PLGS) reduces CG risk in family CPs of PLWD who are at risk for prolonged grief, when delivered by nursing home SWs trained in PLGS via telehealth, as demonstrated by lowered pre-loss grief risk and improved preparedness for death.
- We proposed telehealth delivery to address service access challenges posed not only by the pandemic, but by geography. Telehealth delivery extends PLGS reach and sustainability.
- The first study was a pragmatic clinical trial that will concurrently evaluate the feasibility and acceptability of telehealth-delivered PLGS training of nursing home SWs, and satisfaction, adoption and maintenance of all stakeholders.
- The current study moves PLGS UP the DISEASE TRAJECTORY- preventative

Theoretical framework

 Dual-Process Theory – Stroebe & Schut loss oriented coping, restoration oriented coping & oscillation

 Meaning Reconstruction Theory— Neimeyer

addresses the capability of grievers to accept the loss, realize growth, and reorganize personal identity in the context of loss

- PLGS Intervention elements focus on the relationship between the family CP and their PLWD, how memories of life together and illness are interpreted, and strategies for creating a life without the PLWD.
- psychoeducation,
- motivational interviewing,
- cognitive-behavioral techniques,
- prolonged-exposure techniques,
- memory work,
- mindfulness, self-care and
- meaning-reconstruction activities.
- supportive other (three sessions)

Table 1. Brief summary of Pre-loss Group Therapy sessions

Session	Activity	Theoretical	Therapeutic	Treatment
		Approach	Approach	Goals
1	Psychoeducation		Joining	Normalize
	The story of your family		Dementia	caregiving stress
	member—the story of		education	Increase
	the illness			socialization/reduc
				isolation
	You as a caregiver	Loss-Oriented	Exposure therapy	Situational
	The story of what is coming (1^{st})	coping		anticipation
	Mindfulness education	Mindfulness-	Mindfulness	Self-care skills
	& Meditation practice	based Stress		
		Reduction		
		(MBSR)	n.	7 10
	Explanation of		Distress	Learn self-
	homework, distress		tolerance/emotion	monitoring
	scoring Check in You as a		regulation	Personal
2			Joining Cain Support	
	caregiver- and homework review		Gain Support	accountability
	Developing goals	Restoration-	Motivational	Preparedness
	Preparedness goals &	Oriented	interviewing	Self-care
	self-care goals	coping	merviewing	son care
	Meditation practice	MBSR	Mindfulness	Self-care skills
3	Check in You as a		Joining	Personal
	caregiver-and		Gain Support	accountability
	homework review-group feedback			
	Supportive Other visit #1			Increase

Training Materials & Procedures

Pre-Loss Group Support for Family Caregivers of Residents with Dementia

Katherine P. Supiano, PhD, LCSW

On behalf of the Alzheimer's Association

AARG 21-846414





Study (1)

- 3 Veterans Homes
- 3 NHs with sufficient PLWD
- All facilities were highly rated on Medicare.gov
- 4 were located in rural locations in Utah (western US).



Results from Pilot Study

Participants in PLGS realized significant improvement in their pre-loss grief and in reported preparedness for the death of their family member.

Participants evidenced lowered pre-loss grief severity and improvement, as measured by facilitators.

Participants also realized significant improvement in meaning making, particularly as a sense of peace and a reduction of loneliness.

Study (2)

• 8 Varied Agencies:

Adult day care, hospice, home health, community health care programs-large/small

Located 6 States across US



Interventionists

- Recruited and enrolled
- 1 full day training in all PLGS treatment elements and procedures
- Facilitator and Participant Manuals
- Available supervision
- Treatment fidelity evaluation using "Audit and Feedback" assessment

Introduction to PLGS: examples of treatment elements

The story of what is coming

[video clip]

Supportive others

[video clip]

Preparedness goals & Selfcare goals

Goals Worksheet

	Preparedness Goals by end of Group		Self Care goa	Self Care goals by end of group		
Harde Most (st distress					
10 _						
9						
8						
4 						
3						
2						
1						
Easies Least	t distress					
		For Next Week—Se	ssion			
	eparedness goal is					
Expec	ted distress	Actual Distress	_			

Imaginal conversations

[video clip]

Memory Integration

Week 4, 8 & 9

Pre-Loss Group Support Pleasant Memories Worksheet

1. List ______ 's most likeable characteristics.

2. Describe the most enjoyable times you had with ______.

Pre-Loss Group Therapy Difficult Memories Worksheet

1.	What are some of your least favorite memories of	

What were some of ______ 's annoying traits?

As you remember your earlier years with _____ what do you wish had different about ____ ?

4. Is there anything about _____ that you won't miss?

Pre-Loss Group Therapy Integrated Memories Worksheet

1. What are some of your most favorite memories?

2. What are some of your <u>least favorite</u> memories?

3. What are and were 's most endearing traits?

4. What are and were some of ______ 's most annoying traits?

3. What are some of the things you love and loved most about _____?

Clinical Takeaways

- Dementia family caregiving may span more than a decade and places many family CPs at risk for poor bereavement outcomes.
- Prolonged grief remains under-recognized, under-diagnosed, and undertreated in this population. Few efforts to address the prevention of PGD have been identified.
- This study is the first known application of proven therapeutic strategies to address PG applied to dementia CPs prior to PLWD death to mitigate PG.
- PLGS brings the additional advantages of group support, addressing the social isolation common among long term family CPs.
- The results of this study support prior research recommending specialized preventative treatment for dementia family CPs at risk for PG upon death of their PLWD.



"Do not be daunted by the enormity of the world's grief. Do justly, now. Love mercy, now. Walk humbly, now. You are not obligated to complete the work, but neither are you free to abandon it." Talmud (attributed)

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