

### BULLETIN

Dane County Caregiver Program  
Area Agency on Aging of Dane County

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## **Ambiguous loss is the death of a dream or relationship with no funeral.**

*—Pauline Boss, Psychologist and Educator known for her pioneering work on ambiguous loss*

Ambiguous loss is a term originally described by Dr. Pauline Boss in the 1970s to define a situation where there is a lack of clear information or resolution regarding the loss of a loved one. It happens when a loss is unclear, ongoing, or hard to define. And, because it's not always recognized by others, it can feel especially isolating. Traditional grief, though painful, has process and rituals to help us. Ambiguous loss leaves us stuck. The person we care for is still present but they are also gone in significant ways.

There are two primary types of ambiguous loss:

**Physical Absence with Psychological Presence.** In this type of loss the person we care for is physically absent but still emotionally or psychologically present. An example would be a missing person or someone deployed in the military or affected by war.

**Physical Presence with Psychological Absence.** This type of loss is often experienced by caregivers. Their loved one is physically present but that person has undergone dramatic change affecting their emotional or cognitive presence. Examples include a person with dementia or severe mental illness.

If you're caring for an older adult—especially someone living with dementia—the feeling that your loved one is “there but not there” is a common experience. Some caregivers for persons with dementia have described it as losing someone “in pieces” as their memory, communication, or personality changes over time.

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Caregivers for individuals with a diagnosis of Alzheimer's or a related dementia may experience a slower progression of cognitive decline in their loved one over a period of years. There is a particular grief in facing a future of care and all that requires. Other caregivers are experiencing their lives as usual when an accident causing traumatic brain injury, brain damage due to anesthesia, stroke, or other sudden event happens and that particular version of their life disappears.

I've listened to caregivers express related loss over a common dream they had held as a couple. Some older adult caregivers, particularly when they are caring for a spouse, have had to come to terms with a long-held vision of retirement that can no longer be realized, or even one that has come to a screaming halt.



In addition to missing their person and all they brought to the relationship, the caregiver is also grieving the very different life they are now living with that same person. This stage of life, in the way they had planned for, is gone. All these situations can create chronic stress as caregivers may feel like they are subject to great uncertainty, always bracing for the next change.

You may recognize ambiguous loss if you've experienced things like:

- Missing the relationship you used to have, even while you're still providing care every day
- A sense of constantly adjusting to a moving target—new symptoms, new needs, new safety concerns
- Grief that comes and goes, sometimes triggered by small moments (a familiar song, a holiday, a change in routines)
- Guilt for feeling tired, frustrated, or relieved when you get a break

### **Why Understanding Ambiguous Loss Matters to You**

If you've ever felt unreasonable for grieving someone who's still alive, you're not alone. If you've struggled with guilt about mourning a relationship that technically still exists, your feelings make perfect sense. Ambiguous loss affects millions of people, yet many suffer in silence because they don't have words for what they're experiencing.

### **Ideas to Help You Cope**

- Name it. Simply recognizing "this is ambiguous loss" can reduce self-blame and help you explain what you're going through.
- Let mixed feelings be true. You can love someone and still feel exhausted. You can grieve and still have moments of connection. Both can exist at once.
- Shift the goal from "closure" to "meaning." Caregiving often doesn't provide closure. Instead, focus on what helps you get through—small routines, support, moments of calm, and realistic expectations.

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- Find your people. Support groups (in-person or virtual), caregiver counseling, or even one trusted friend who gets it can make a big difference—especially when the loss is hard to describe.
- Focus on what’s still here. This isn’t about forced positivity. It’s about noticing what still connects you: a shared laugh, holding hands, music, familiar prayers, favorite foods.

Dr. Pauline Boss, a leader in grief research whose theory of ambiguous loss provided the framework for understanding and coping with complex and unresolved forms of grief, further details her work with ambiguous loss and how it affects caregivers (including her own story) in the video interview below. She explains the idea of “both and” thinking—where we can hold the idea that our loved one is both here and also gone. Dr. Boss explains that living with ambiguity is huge, and for caregivers to continue to function we must find a way to both cope with something terrible and find something that is wonderful—perhaps children and grandchildren, for example.

Dr. Boss also asserts that caregivers, in general, have trouble with agency. In the caregiving role, you are outside of your own control. You cannot control the disease process or how it affects your care partner. As a result, caregivers need things that *are* within their own control to keep balance. It is worth pursuing an understanding of how this way of thinking may work in your life as it can make an important contribution to your mental health. Spousal caregivers experiencing significant emotional mental strain have a 63% higher mortality risk over a four-year period compared to non-caregiving peers. Finding a way to ease the stress and discover something under your control each day is important. Dr. Boss is also a strong advocate of caregivers using options for help to free ourselves to have critical social connections.

***Click on the photo below to watch an interview with Dr. Pauline Boss on ambiguous loss.***



### **Resources and Support:**

**Dane County Area Agency on Aging , Dane County Caregiver Program:** Jane De Broux, Caregiver Specialist  
Phone: 608-381-5733, Email: [debroux.jane@danecounty.gov](mailto:debroux.jane@danecounty.gov).

**ADRC of Dane County**– caregiver support, dementia resources, options counseling  
Call 608-240-7400 8:30 am—4:00 pm, Monday—Friday

**Alzheimer’s Association 24/7 Helpline: 800-272-3900** – anytime support, education, and local referrals

**NEW! Support group for caregivers experiencing Ambiguous Loss. See page 4 for details.**

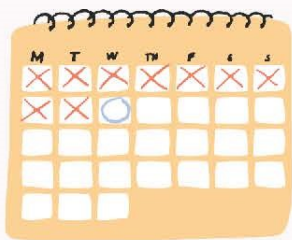
—Jane De Broux, Caregiver Specialist  
Dane County Caregiver Program

# Ambiguous Loss Support Group

FOR CAREGIVERS



This group offers a safe, welcoming space for those navigating anticipatory grief or loss. Through education, shared conversation, and mutual support, we come together to understand the journey ahead with care. All are welcome to attend. Participation is optional but encouraged.



2nd Thursday of the month

Starts on April 9<sup>th</sup>, 2026

10-11:30 am

Virtual meetings by Zoom

To register via Zoom: [click here](#). For more information, email [danedcs@danecounty.gov](mailto:danedcs@danecounty.gov), or call the ADRC at 608-240-7400.

Hosted by the Aging and Disability Resource Center of Dane County (ADRC) and the Area Agency on Aging (AAA).



## Monthly MIPPA Moment:

### Medicare Has Got Your Back

Do you have diagnoses related to chronic low back pain? Acupuncture is an ancient needle-based healing practice involving a technique where providers stimulate specific points on the body, most often by inserting thin needles through the skin. Acupuncture can be covered by Medicare for those who qualify.

**Medicare Part B can potentially cover up to 12 acupuncture visits in 90 days for chronic low back pain.**

Medicare covers an additional 8 sessions if you show improvement.

Chronic low back pain defined by Medicare as lasting 12 weeks or longer, having no known cause (for example, it's not related to cancer that has spread, or an inflammation or infectious disease), and pain that isn't associated with surgery or pregnancy. **Not all providers can give acupuncture, and Medicare can't pay licensed acupuncturists directly for their services.** You must get acupuncture from a doctor or another health care provider (like a nurse practitioner or physician assistant) who has both a Masters or doctoral level degree in acupuncture or Oriental Medicine from a school accredited by the Accreditation Commission on Acupuncture and Oriental Medicine and a current, full, active, and unrestricted license to practice acupuncture in the state where you're getting care.

See more here: <https://www.medicare.gov/coverage/acupuncture>.

*Adapted from SHIPTA and CMS.gov. For more MIPPA Program information, call MIPPA Program Specialist, Leilani Amundson, at 608-240-7458. This project was supported by the Wisconsin Department of Health Services with financial assistance, in whole or in part, by grant number 2101WIMIAA, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.*



**Date**
**Time**
**Topic**
**A LEADING VOICE FOR CAREGIVERS**

**All sessions are available on your choice of Zoom or telephone only!**

**Tuesday  
April 7**
**1:00 pm Eastern  
12:00 pm Central  
11:00 am Mountain  
10:00 am Pacific**

**Supporting Independence & Dignity: Managing Self-Care in Dementia with Hollie Lowe, MA, LPC, NCC** *Dementia is a progressive brain disease that can change a person's ability to manage everyday self-care tasks such as dressing, eating, bathing, and toileting. These changes are not a lack of effort. They are the result of changes in the brain. Join us to better understand the "why" behind these shifts and learn practical, compassionate strategies that help a person living with dementia maintain their highest level of independence and dignity.*

**Thursday  
April 9**
**11:00 am Eastern  
10:00 am Central  
9:00 am Mountain  
8:00 am Pacific**

**Truth, Lies, and Compassion: Ethical Communication in Dementia Care with Elliot M Sklar, PhD and Lucy Barylak, LMSW** *This presentation explores the ethical and practical challenges of truth-telling in dementia caregiving. It examines when honesty supports well-being—and when compassionate redirection or "therapeutic fibbing" may be more appropriate. Through real-world scenarios, we'll consider how caregivers can navigate these complex moments with empathy and respect.*

**Tuesday  
April 14**
**12:00 pm Eastern  
11:00 am Central  
10:00 am Mountain  
9:00 am Pacific**

**Comunicarse de manera efectiva on Maxine P. Vieyra, Alzheimer's Association** *A través de este taller, aprenderemos cómo la demencia afecta la comunicación. Describir cómo un enfoque centrado en la persona puede ayudar a la comunicación. Compartiremos estrategias que le ayuden a comunicarse con una persona que vive con demencia.*

**Tuesday  
April 21**
**1:00 pm Eastern  
12:00 pm Central  
11:00 am Mountain  
10:00 am Pacific**

**Managing Family Conflict About End-of-Life Decisions with Barry J. Jacobs, PsyD** *Only one-third of Americans have filled out an advance directive to let family members know what care they do or don't want in the event they are unable to speak for themselves. That leaves many adult children to guess about what an aging parent with severe dementia would want—opening the door for intense debate and even fighting among those siblings. In this highly interactive workshop with psychologist Barry J. Jacobs, Psy.D., co-author of *The AARP Caregiver Answer Book*, we will talk about the importance of advance directives but also how adult children can draw upon their parent's beliefs and values to make the right decision for them. Case illustrations will be used throughout.*

**Wednesday  
April 22**
**11:00 am Eastern  
10:00 am Central  
9:00 am Mountain  
8:00 am Pacific**

**La presentación explica el síndrome vespertino with Isabel Maria, Agencia de Ancianidad del Norte Centro Texas** *La presentación explica el síndrome vespertino, una confusión y agitación que ocurre al final del día en personas con demencia. Se analizan causas como el estrés, necesidades no satisfechas y el entorno, y se ofrecen estrategias para mejorar el cuidado. También incluye recursos locales para apoyar a cuidadores. **\*\*Sponsored by the North Central Texas Caregiver Teleconnection\*\****

**Tuesday  
April 28**
**2:00 pm Eastern  
1:00 pm Central  
12:00 pm Mountain  
11:00 am Pacific**

**Caregiving Without a Roadmap: Insights for Cancer Caregivers with Melina Pineyro, MPH** *Behind every cancer diagnosis is a caregiver — a parent, partner, sibling, or friend — quietly navigating medical appointments, emotional strain, and financial pressures. This webinar explores the lived experiences captured in *Caregiving Without a Roadmap: Insights from Cancer Caregivers*, a national listening-session report developed by the National Alliance for Caregiving in partnership with CancerCare. Through real caregiver stories, we'll examine the gaps in support, the emotional toll of caregiving, and the practical realities that often go unseen.*

*Are you looking for a leadership opportunity?  
Are you passionate about the policies and programs that affect aging adults in Dane County?*

# AAA of Dane County is now recruiting for our Advisory Council!



**Apply here:**

link: <https://forms.office.com/g/WBydvUwfw5>

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scan to apply:



## The Area Agency on Aging is recruiting for our new Advisory Council.

Our Advisory Council is made up of older adults, family caregivers, and community leaders who advise and assist the Area Agency on Aging of Dane County (AAA) on all matters relating to:

1. The development, implementation, and evaluation of the Dane County 'Aging Plan' in accordance with the Older Americans Act.
2. The coordination of community-based services for older adults and their caregivers.
3. Identifying unmet needs.
4. Serving as a link between the AAA, older adults, service providers, and the community.

Members help review community needs, comment on policies and programs, and make sure services are coordinated, accessible, and responsive, especially for people with the greatest economic and social need. It's a meaningful way to use your voice and experience to improve aging services locally.

### Who Should Apply

Dane County residents with lived experience or professional/community experience related to aging, including:

- Older adults (including underserved older persons)
- Family caregivers, advocates, and community members
- Service providers and community leaders
- Individuals representing the general public

You can submit your interest in joining our Advisory Council using the QR code or web address on the attached flyer, or through our website: <https://www.dcdhs.com/Area-Agency-on-Aging>

Check it out!

**Have a voice. Make an impact. Help improve aging services.**



# STAY CONNECTED

to combat loneliness  
and social isolation



Goodman  
Community Center

## Protect your physical and mental well-being

Isolation can  
lead to higher rates of:

- Heart disease
- Weakened immune system
- Depression
- Early death

Social isolation emerges from a lack of relationships, or contact with or support from others. We can feel lonely or isolated even with friends and family.

### You may be at risk if you:

- Live alone or can't leave home
- Lack a sense of purpose
- Had a recent loss or life change
- Are a caretaker
- Feel alone or disconnected from others

### What can I do?

See reverse for more info on  
**Goodman Community Center's**  
Phone Pals program (and more)!

# Get connected with a PHONE PAL



Volunteers from RSVP and Goodman Community Center are available to chat over the phone with anyone who may be experiencing isolation, living alone or simply looking for conversation.



Calls with your **Phone Pal** can be short or long, and can occur on a weekly or monthly basis according to your preferences.



WHERE VOLUNTEERS  
MAKE A DIFFERENCE

## Other GCC programs to help you stay connected

- **Weekday meals** – We serve a delicious lunch Mon. - Fri. and home-delivered meals.
- **Activities** – Join us for fun games, conversations, classes, outings and good company.
- **Fitness and wellness** – Various exercise classes and activities designed for older adults.

For more info about older adult programs at GCC, contact Gayle at 608-204-8032 or [gayle@goodmancenter.org](mailto:gayle@goodmancenter.org), or visit [goodmancenter.org/older-adults](http://goodmancenter.org/older-adults).



For even more connection, contact **NewBridge** at 608-512-0000 or **Madison Senior Center** at 608-266-6581 for information on their current programs.

