

Shame and Alzheimer's Disease: Navigating the Emotional Journey Together

By Nicole Mathura-Price

A diagnosis of Alzheimer's disease can feel like an overwhelming shift in reality. For those who have been diagnosed, their families, and caregivers, it's not just about memory loss or cognitive changes—it's also about the emotional toll it takes, especially when it comes to feelings like shame and grief. Whether you're just beginning to notice signs, or if you're caring for someone you love, understanding these emotions and how they relate to Alzheimer's can make a world of difference in coping with the disease.

The more we sit in compassion with our shame, the less power our shame has over us. This idea is echoed in Atul Gawande's *Being Mortal*, which explores the importance of dignity, autonomy, and emotional well-being when facing life-altering conditions. Alzheimer's is not just a medical diagnosis—it is an emotional journey that requires kindness, both to ourselves and to our loved ones.

Shame and Alzheimer's: Understanding the Emotional Burden

Shame often quietly accompanies Alzheimer's disease—not just for the person diagnosed, but for their loved ones as well. It can manifest in different ways:

- For individuals with Alzheimer's, forgetting things, feeling confused, or struggling to recognize someone they care about can lead to embarrassment or fear. It's easy to feel like they are losing themselves, but these moments of loss are a symptom of the disease, not a reflection of their worth.
- For caregivers and family members, feelings of guilt and frustration can arise—guilt for not being able to do more, frustration when things feel out of control. These emotions are normal and do not signify failure. Shame is an emotion tied to the disease itself, not personal fault.

What to Do After an Alzheimer's Diagnosis

Receiving an Alzheimer's diagnosis is one of the hardest moments a person can face, but there are steps that can make the journey easier for both those diagnosed and the people around them.

For Individuals with Alzheimer's:

- Acknowledge Your Feelings It's okay to feel sadness, frustration, or anger.
- Focus on What You Can Do Engage in activities that bring joy and maintain a sense of identity.
- Plan for the Future Addressing healthcare, finances, and legal matters early can offer peace of mind.
- Seek Support Joining a support group can provide a compassionate space to process emotions.

For Caregivers:

- Recognize Your Emotions Caregiving can be exhausting, and acknowledging your emotions is essential.
- Educate Yourself Understanding Alzheimer's helps manage symptoms and reduces helplessness.
- Establish a Routine A predictable schedule helps provide comfort for both caregiver and patient.
- Practice Self-Care Taking breaks and seeking support allows caregivers to continue providing compassionate care.

For Family Members:

- Learn About the Disease Knowledge fosters compassion and helps in navigating challenges together.
- Offer Emotional Support Listening and providing encouragement can ease feelings of isolation.
- Assist with Planning Helping with care options and financial planning ensures the person's wishes are respected.

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The Power of Community Support

As Ann Voskamp beautifully said, "Shame dies when stories are told in safe places." In her book *One Thousand Gifts*, she reflects on gratitude and the power of embracing life's imperfect moments. Sharing experiences in a space where we feel heard and understood helps lessen the burden of shame.

At **Franke Tobey Jones**, we offer dedicated **support groups for individuals affected by Alzheimer's and dementia**, creating a safe and compassionate environment for sharing and healing. Through these connections, the burden of shame can be lessened, and healing can begin.

Join Our Support Group for Partners of Loved Ones with Dementia

Caring for a partner with dementia can be an emotional and challenging journey—but you are not alone. Join us for a **Support Group for People Whose Partners Have Dementia** on **Wednesday, April 16, at 3 PM**.

This gathering provides a safe space to share experiences, gain support from others facing similar challenges, and receive guidance on caregiving complexities. The group is limited to **12 participants** to allow for meaningful discussion.

RSVP is required—please contact **Sarah Doerner** to reserve your spot and receive the location details. We look forward to supporting you on this journey.

(To participate in the Holistic Wellness programs, you must be an FTJ Wellness member.)

Additional Support Resources

- Alz.org Support Group at Cogir at The Narrows
 - O Contact Leah Amyakar at 206-369-2544
 - o Meets 1st Saturday of each month
- o Alzheimer's Hotline (open 24/7): 800-272-3900
- O Website for resources and support: alzwa.org
- O Other Support Group Meetings (Call 800-272-3900 for more details):
- o Tacoma: 1st Thursday, 11:00 AM 1:00 PM (in person)
- O Tacoma: 1st Wednesday, 10:00 AM 12:00 PM (in person)
- O University Place: 1st Tuesday, 1:00 PM 2:30 PM (in person)

A Journey of Compassion and Understanding

Alzheimer's is never an easy road. By educating ourselves, seeking support, and practicing kindness, we can navigate this journey with dignity and love. **Shame does not define you or your loved one**; it is simply one part of a much larger emotional journey. And as you move through it, know that **you are not alone**.

As the book *Being Mortal* reminds us, the way we care for one another at the most vulnerable times in life defines the quality of our experience. Together, through **compassion and community**, we can transform shame into connection and face Alzheimer's with courage and love.

For more information, please call Franke Tobey Jones at 253-752-6621