

# **Community Resources ECHO: Session 4**

February 10, 2026

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# The Emotional Journey: Supporting Families After a Dementia Diagnosis



## **Facing fears: Addressing change, uncertainty, and anticipatory grief**

Exploring the unique realities of the dementia journey



## **Emotional Support and Care Along the Journey**

Supporting families and caregivers - improving care outcomes for everyone



## **The Journey's Destination: Strength, Growth, Resilience**

Mental health benefits that outlast caregiving

# Beginning the Journey

## Challenges faced when getting a diagnosis:

- Early changes may be dismissed, ignored, or missed altogether if the presentation is atypical
- Stigma and fear can lead to reluctance seek a diagnosis
- Complex diagnostic process - though rapidly changing, diagnosis is still mostly a process of elimination
- Provider constraints - lacking training, confidence, TIME
- Healthcare system hurdles - limited access to specialists
- Lack of communication - between providers, systems, families
- Limited treatment options that come with risks (hard choices)



# The Landscape of Change

## Emotional Changes

changes in motivation and emotional regulation abilities

## Cognitive Changes

Changes in thinking, memory, and other cognitive processing

## Physical Changes

Aging, co-morbidities, sleep disturbances, neglected self-care

## Financial Adjustments

Lost work hours, out-of-pocket expenses, LTC cost concerns

## Shifting Family Dynamics

Role changes - child feels like the parent, spouse becomes nurse

## Social Changes

Changing support systems, increasing isolation from friends/family



# Anticipatory Grief

## Denial

"This can't be happening." Ignoring early symptoms or dismissing the diagnosis and its implications. Normal and protective.

## Anger

Frustration and resentment towards [fill in the blank with pretty much anything].

## Bargaining

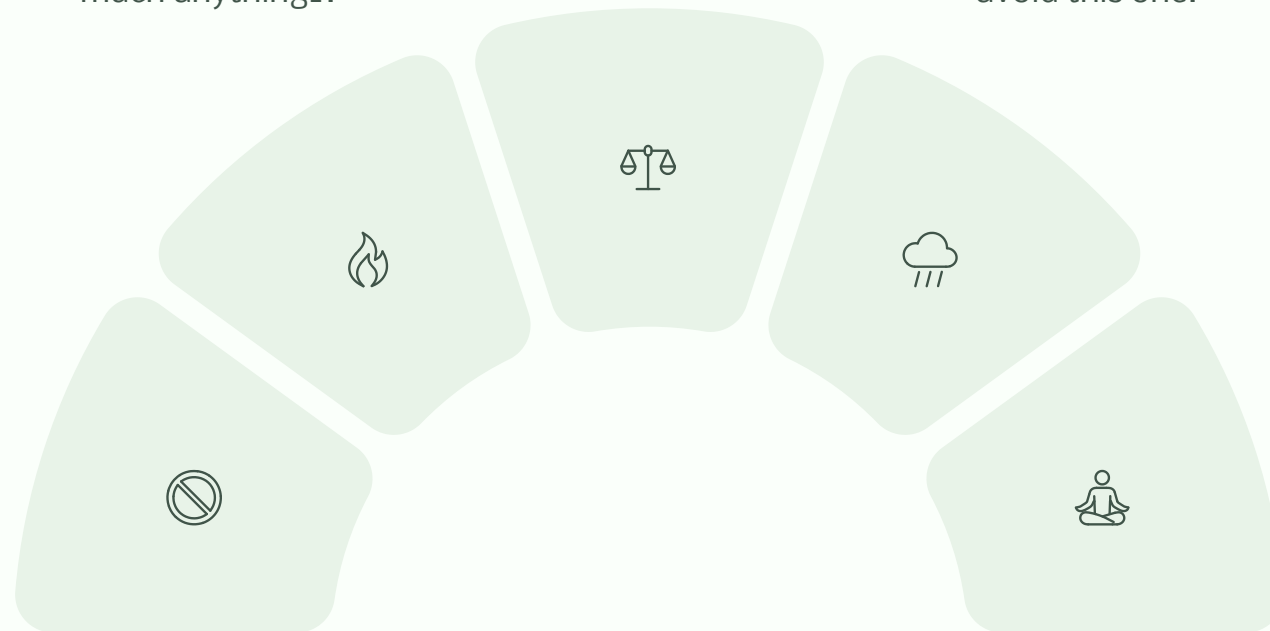
"If only we had..." If statements, trying to "fix" it, negotiating, and GUILT.

## Depression

Overwhelming sadness, feelings of hopelessness, and despair. Best not to avoid this one.

## Acceptance

"We'll face this together." Finding a new normal, adapting to changes, and planning for the future with resolve.



# Emotional Landscape of Dementia

## The DEMENTIA Emotional Spectrum

Persons with dementia and their caregivers experience a complex range of emotions throughout their journey.

- **D**espair, **D**isbelief/**D**enial, **D**epression
- **E**xhaustion, **E**mpathy
- **M**elancholy
- **E**motion vs. intellect struggles
- **N**ervousness
- **T**ired, **T**ense, **T**earful
- **I**ncapable, **I**solated, **I**gnored
- **A**nger, **A**ggression, **A**fraid, **A**ffection, **A**cceptance



# Affective Mental Health Symptoms in PWDs

2021 Study in the International Journal of Geriatric Psychiatry: meta-analysis, 20 studies, 5897 people with dementia

**38%**

**Depression in Mild Dementia**

**41%**

**Depression in Moderate Dementia**

**37%**

**Depression in Severe Dementia**

**38%**

**Anxiety in Mild Dementia**

**41%**

**Anxiety in Moderate Dementia**

**37%**

**Anxiety in Severe Dementia**

**54%**

**Apathy in Mild Dementia**

**59%**

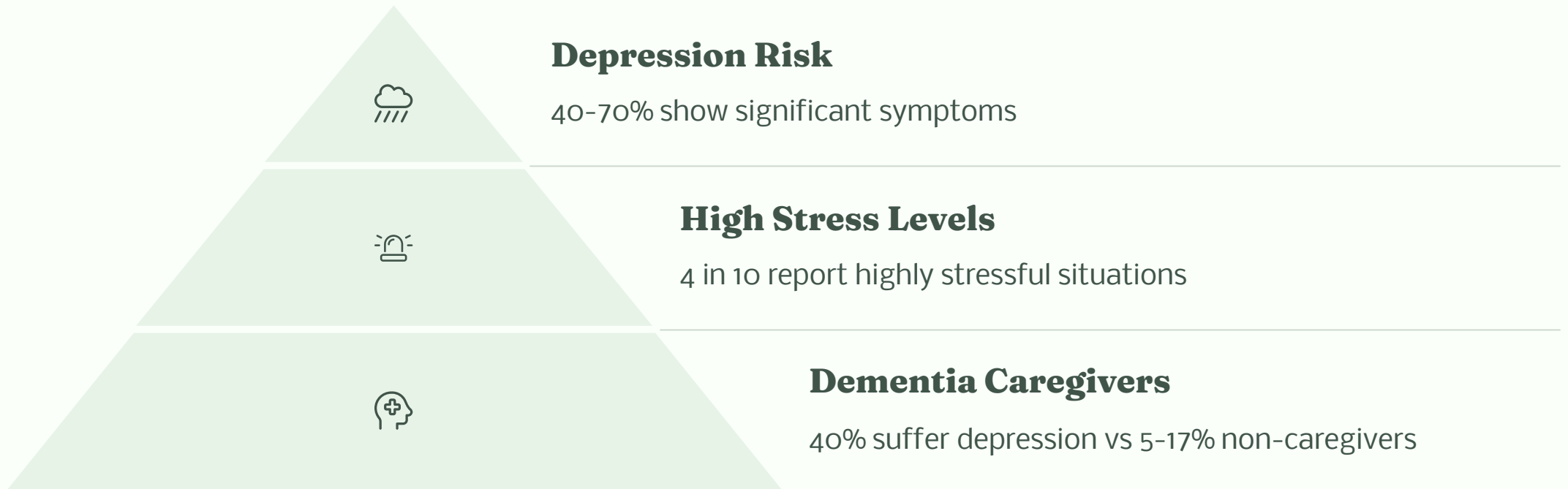
**Apathy in Moderate Dementia**

**43%**

**Apathy in Severe Dementia**

Research shows affective symptoms remain consistently high across all stages of dementia progression. No reports of changes across dementia types.

# Caregiver Mental Health



## Depression Risk

40-70% show significant symptoms



## High Stress Levels

4 in 10 report highly stressful situations

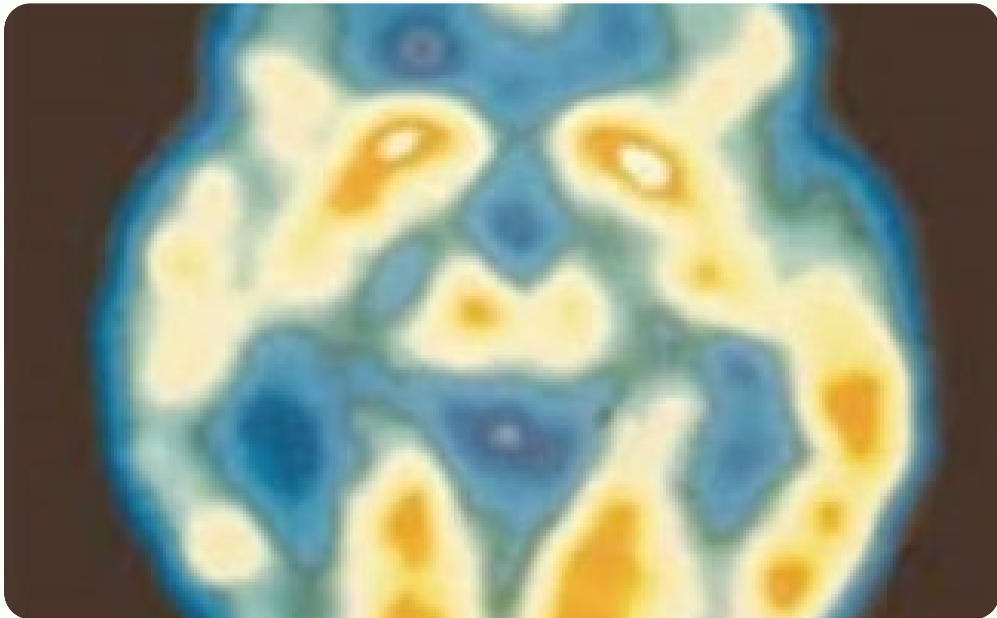


## Dementia Caregivers

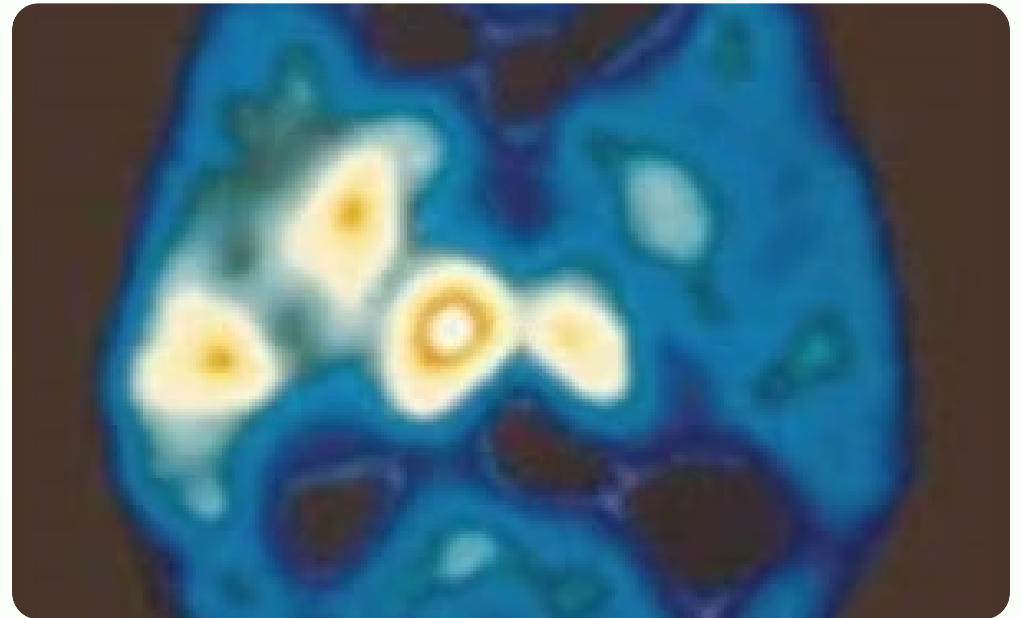
40% suffer depression vs 5-17% non-caregivers

# Your Brain on Caregiving

The Mayo Clinic Foundation illustrates how prolonged stress affects brain function and structure.



**Normally Functioning Brain**



**Caregiver's Stressed Brain**

Reduced activity and grey matter density in the frontal cortex and hippocampus

# Interventions and Mental Health Support for People with Dementia

## Education

Disease-specific learning helps patients understand changes. Cognitive training exercises maintain mental function longer.



## Social Support

Memory cafés and other early stage social engagement activities provide safe social environments. Support groups connect individuals with shared experiences.

## Mental Health Treatment

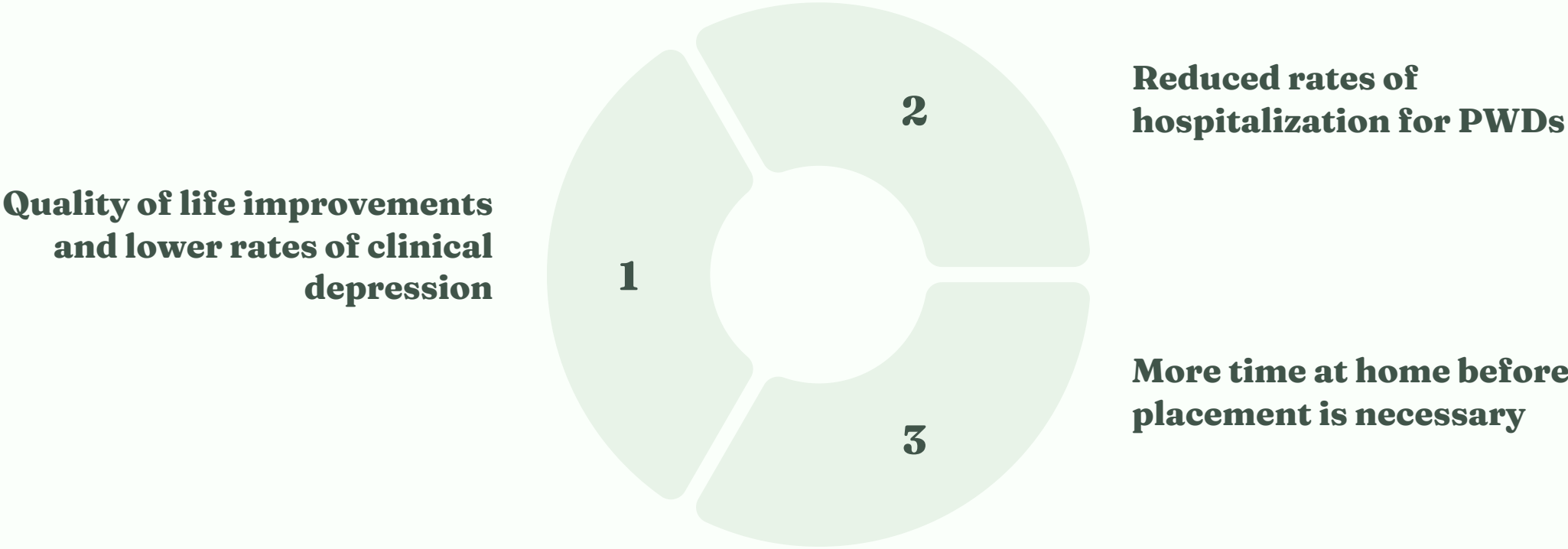
Group therapy builds coping strategies. Individual counseling addresses specific needs. Medication manages symptoms when appropriate.



**Early intervention is crucial.** Effectiveness decreases as dementia progresses. Later stages require greater focus on environmental adjustments and caregiver support.

# The Efficacy of Caregiver Support Interventions

Data shows significantly improved outcomes for family caregivers AS WELL AS the care recipients with similar interventions



# Caregiver Support as Elder Abuse Prevention



## High Vulnerability

Dementia increases elder abuse risk by 5.4-62.3% in community settings.



## Cognitive Decline

Decreased awareness and communication abilities create exploitation opportunities.



## Caregiver Stress

Overwhelmed caregivers without support may resort to harmful behaviors.



## Intervention Impact

Regular support dramatically reduces abuse risk through stress management.

Proactive caregiver support isn't just helpful—it's essential prevention. When we strengthen caregivers, we protect our most vulnerable.

# Along the Journey: Care for the Caregiver



## **Disease Education**

Continuing education that informs, but doesn't overwhelm

## **Social Support**

Support groups and connections that build a community of support that adjusts as the disease changes

## **Mental Health Treatment**

addressing coping skills, communication, and addressing grief, trauma, and patterns of thinking and behavior over time

# **Lasting Change: Mental Health Goals for Caregivers**

## **Creating a Safe Space for Difficult Conversations**

Building trust and openness where caregivers can express fears, frustrations, and difficult emotions without judgment.

## **Understanding Disease & Relationship Dynamics**

Helping caregivers learn to recognize the disease and its complex relationship to their care partner, understanding how dementia affects behavior, personality, and the relationship, separating the disease from the person.

## **Introducing the Practice of "Letting Go"**

This involves learning time management (slowing down), strengthening delegation skills, recognizing when things are out of your control, discerning what things may be "worth the worry," and practicing prioritization and picking your battles.

# Lasting Change: Mental Health Goals for Caregivers

**Noticing patterns** of thinking and how they are tied to behaviors

Familiarizing, **NORMALIZING**, and working through the **grief process** as it occurs

Facing anxiety, practicing and embracing **mindfulness** and the present moment (the "silver lining" of dementia)

Working towards **healthy boundaries** - addressing patterns of codependency

Learning **healthy communication** and conflict skills - both with dementia and with others (family and friends)

# Lasting Change: Mental Health Goals for Caregivers

**Encouraging community**  
and building a social  
support network

Working through past  
**trauma** - both personal  
and generational

Understanding physical,  
mental, emotional  
**limitations** and how to  
work within those limits

Increasing and enhancing an  
understanding of **self-care** (their  
"Emotional Gas Tank")

Strengthening **sense of agency** and  
building resilience

# Questions or Comments?



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