

Insights Into Dementia: Supporting Meaningful Connections

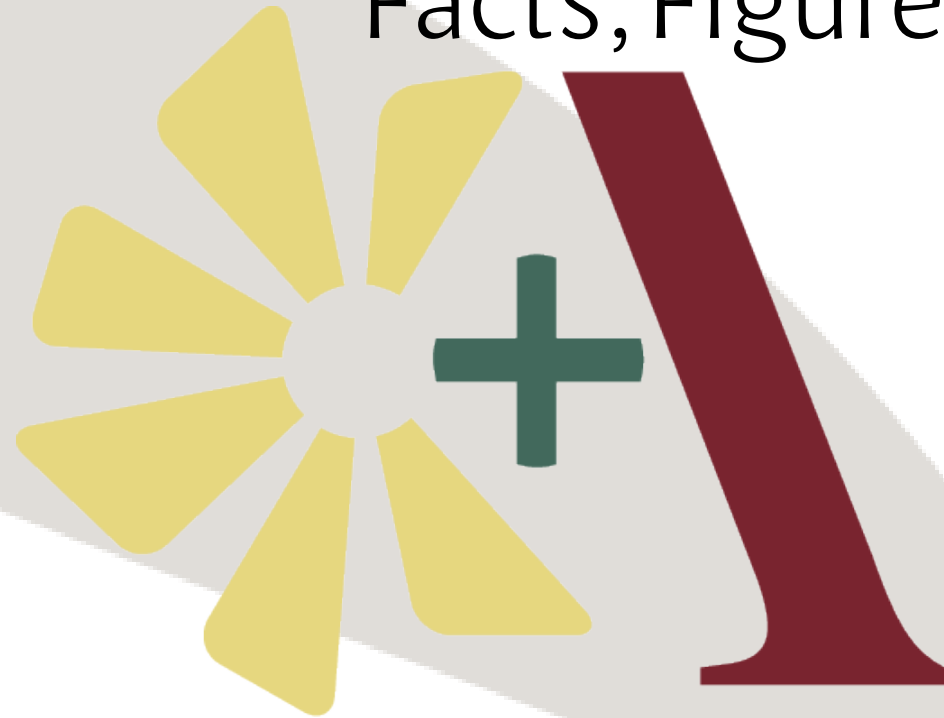
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What We Will Learn Together:

- 🌱 Dementia & Alzheimer's Facts, Figures & Statistics
- 🌱 Warning Signs
- 🌱 Behaviors
- 🌱 Communication Techniques
- 🌱 The Emotional Journey
- 🌱 Memory Techniques
- 🌱 Some Available Support & Resources
- 🌱 When is it Time for Hospice Support?
- 🌱 Closing Conversation

Dementia & Alzheimer's –

Facts, Figures & Statistics



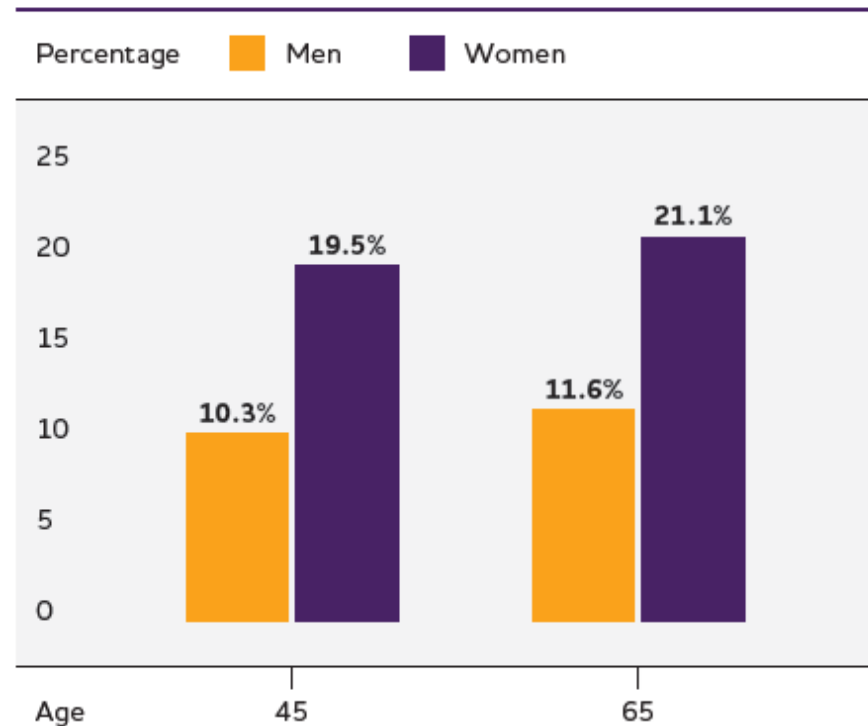
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2026 Facts & Figures

- An estimated **7.4 million** Americans are living with clinical Alzheimer's dementia.
- Deaths due to Alzheimer's disease **more than doubled** between 2000 and 2024, increasing **134%**.
 - During this same period, deaths from heart disease - the leading cause of death in America - **decreased**.
- Nearly **13 million** Americans provided more than **19 billion hours** of unpaid care, valued at more than **\$446 billion**.
- More than **772,00,000 more** direct care workers will be needed by 2034 to care for those living with dementia - more new workers than in any other single occupation in the United States.
- In 2025, the national cost of caring for people with Alzheimer's and other dementias is projected to be **\$409 billion**.
 - By 2050, these costs could rise to nearly **\$1 trillion**.

Population Differences in Alzheimer's Prevalence

Estimated Lifetime Risk for Alzheimer's Dementia,
by Sex, at Ages 45 and 65



Created from data from Chene et al.³⁴⁰

- Almost two-thirds of Americans with Alzheimer's are women
- Older Blacks/African Americans and Hispanics/Latinos are **disproportionately more likely** than older non-Hispanic whites to have Alzheimer's or other dementias
- Population-based studies for other population groups are needed

Maine Statistics

- Roughly 29,000 people age 65+ in Maine are living with Alzheimer's disease.
- 66,000 people are serving as unpaid caregivers. That means 1 out of every 21 people in our state is caring for someone with Alzheimer's disease. AND they are providing \$103 million hours of care valued at \$3 billion!
 - 71.5% of caregivers have chronic health conditions & 16% are in poor physical health
 - 30.5% of caregivers have depression
- 1,494- Number of people in hospice with a primary diagnosis of dementia = 19% of patients in hospice

Demographics of Alzheimer's Caregivers

- **Two-thirds** of caregivers are women, and **one-third** are daughters
- **One quarter** of dementia caregivers are “sandwich generation” caregivers, taking care of both an aging parent and child
- **More than half** of primary caregivers take care of their parents
- **About one in three** caregivers is age 65 or older



Dementia

An umbrella term for loss of memory and other thinking abilities **severe enough to interfere with daily life.**



Alzheimer's

Vascular

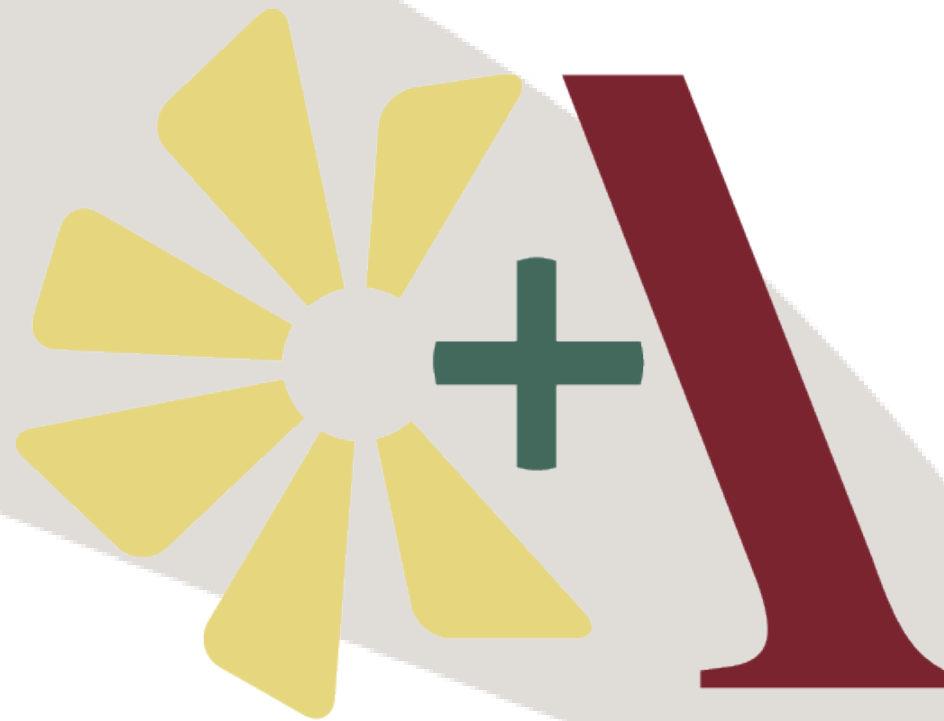
Lewy body

Frontotemporal

Other, including Huntington's

Mixed dementia: dementia from more than one cause

Warning Signs





10 Warning Signs of Alzheimer's

1. Memory loss that disrupts daily life

2. Challenges in planning or solving problems

3. Difficulty completing familiar tasks

4. Confusion with time or place

5. Trouble understanding visual images and spatial relationships

6. New problems with words in speaking or writing

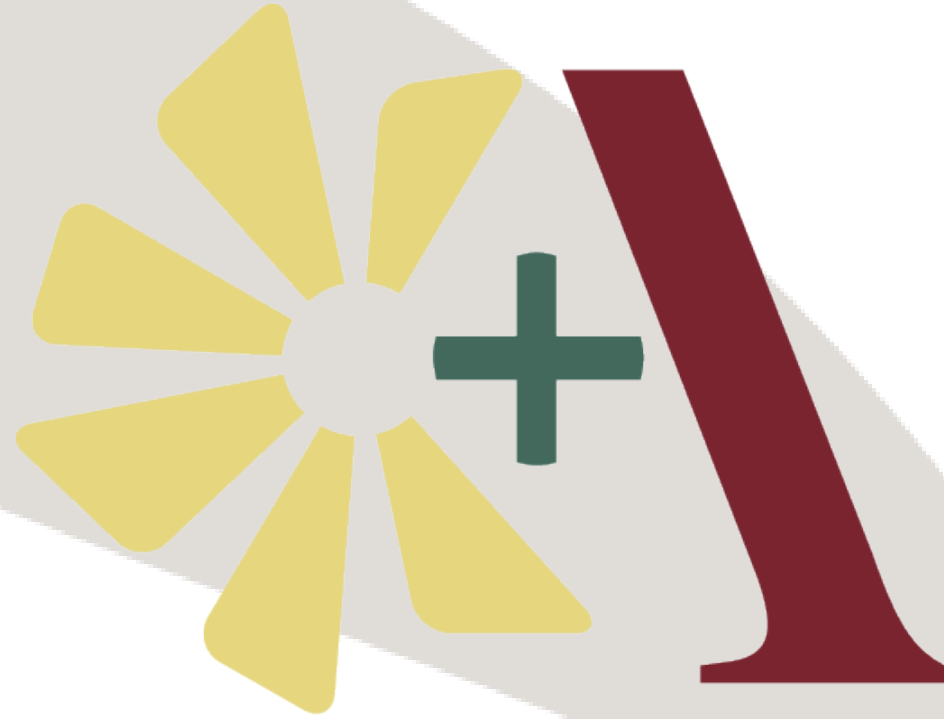
7. Misplacing things and losing the ability to retrace steps

8. Decreased or poor judgment

9. Withdrawal from work or social activities

10. Changes in mood and personality

Behaviors



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Dr. Claire Sexton
Alzheimer's Association



What Causes Changes in Behavior?



- The disease causes brain cells to break down
- These changes in the brain make it harder for the person to understand the world around them
- The person may have trouble knowing what's real, what's safe and what is the right thing for them to do



Behaviors are a Form of Communication



- People living with dementia react to what they think, feel or need from the people and the world around them. These reactions are a form of communication.
- Caregivers must connect with the person to figure out what they are trying to tell you with their behavior.
- These behaviors are not related to the person's true feelings about you or other people. Try not to take them personally.

Common Dementia-Related Behaviors



Anxiety and agitation

The person may show feelings of restlessness



Aggression and anger

The person may have verbal or physical outbursts



Suspicion and delusions

They may believe things that are not true



Getting lost or wandering

The person may walk or move around with or without a known reason

Katie B.
Caregiver



Triggers for Dementia-Related Behavior

External

Internal



Physical

This can be a result of pain, discomfort or other unmet physical needs

Social

This can include being around people who stress or bother the person

Environmental

This is when things happening around the person cause stress

Personal

These come from inside the person, such as feelings they may be experiencing

Non-Medical Approaches to Dementia-Related Behaviors



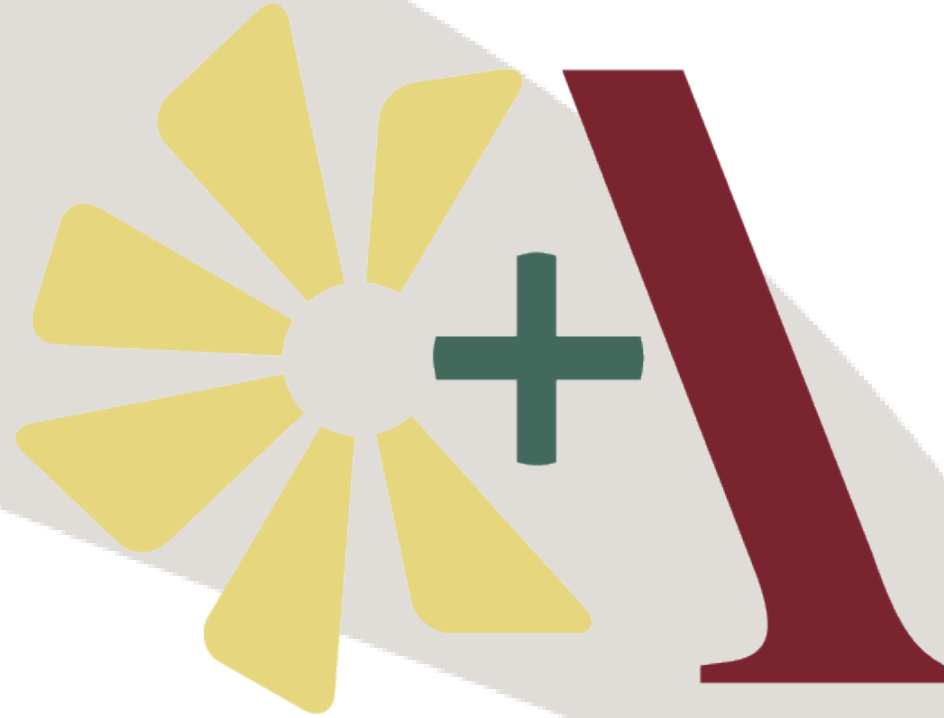
- A non-medical approach should always come first
- It should focus on giving physical and emotional comfort
- This approach can help identify and meet the needs of a person who has trouble expressing themselves
- Use what you know about the person to help manage or reduce the behavior

Four-step approach to addressing behaviors



- 1 Detect and connect
- 2 Take care of physical needs
- 3 Help with emotional needs
- 4 Review and plan for next time

Communication Techniques



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How does dementia affect communication?



Alzheimer's and other dementias cause **damage to brain cells**



These changes in the brain affect **memory, thinking, behavior and communication skills**



Communication changes are **caused by the disease, not the person**

Communication changes

- often the earliest sign of



Changes vary from person to person, but common ones include:

- Difficulty finding the right words
- Repeating familiar words, phrases and stories
- Describing an item when they can't think of the word for it
- Forgetting what they were talking about in the middle of a sentence
- Difficulty organizing words in a way that makes sense
- Going back to speaking in their native language
- Speaking less often
- Using hand gestures more than speaking

Judith R.

Caregiver



Knowledge Check

Which of the following are ways that people communicate?

Talking and listening

Attitude and tone of voice

Facial expressions and body language

All of the above



Communicating Effectively

Which of the following are ways that people communicate?

Talking and listening

Attitude and tone of voice

Facial expressions and body language

All of the above



Communication comes from our words, attitudes and tone of voice. It also comes from our face and body movements. It includes listening, which can sometimes be more important than talking.

Applying a Person-Centered Approach to Communication

1

Treat them with respect and dignity



- Use knowledge of the person's likes, dislikes and communication preferences
- Call the person by their preferred name
- Avoid talking about the person as if they are not there
- Avoid correcting them
- Validate their feelings

Applying a Person-Centered Approach to Communication

2

Include the person living with dementia in conversations



- Talk directly to the person
- Speak slowly and clearly
- Use a calm tone of voice
- Acknowledge what the person says
- Help them engage in conversations that are meaningful to them
- Have conversations about family and friends and your lives, including things you have done together

Applying a Person-Centered Approach to Communication

3

Be patient



- Give the person time to decide what they want to say
- Avoid interrupting
- Try not to speak for them
- Give them choices
- Connect in the moment

Applying a Person-Centered Approach to Communication

4

Limit distractions



- Find a quiet place that has few distractions
- Get rid of extra noise and visual distractions
- Have one-on-one conversations
- Keep conversations simple
- Turn off or turn down the sound of the TV
- Put away your phone

Katie B.
Caregiver



Applying a Person-Centered Approach to Communication

4

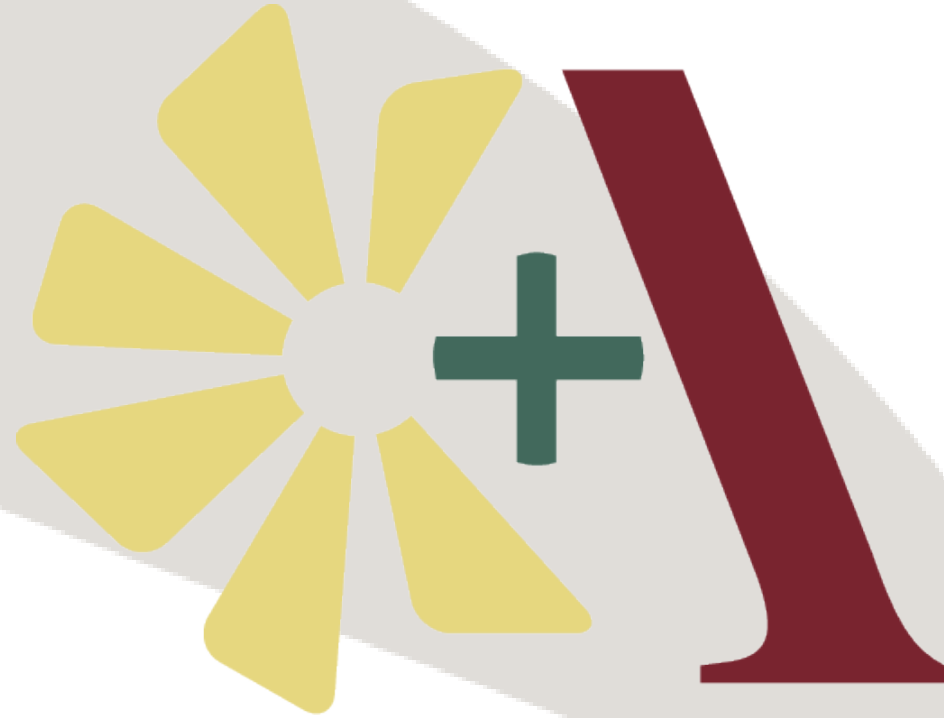
Use nonverbal communication

It can be helpful to know how to send and receive messages without using words

- Use positive body language and facial expressions
- Use hand gestures, like pointing to an object
- Make eye contact
- Use gentle physical contact
- Use touch, sight, sounds and tastes as other ways to communicate



The Emotional Journey



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The Caregiving Journey

Learning that someone you care about has been diagnosed with Alzheimer's or other related dementia can be life-changing.

Coming to terms with the diagnosis requires time.

Emotions You May Experience as a Care Partner:

Denial- Short-term could be a healthy coping mechanism, while long-term could affect quality of life & vital planning

Fear- Of the progression and challenges in providing care- may prevent you from focusing on the present

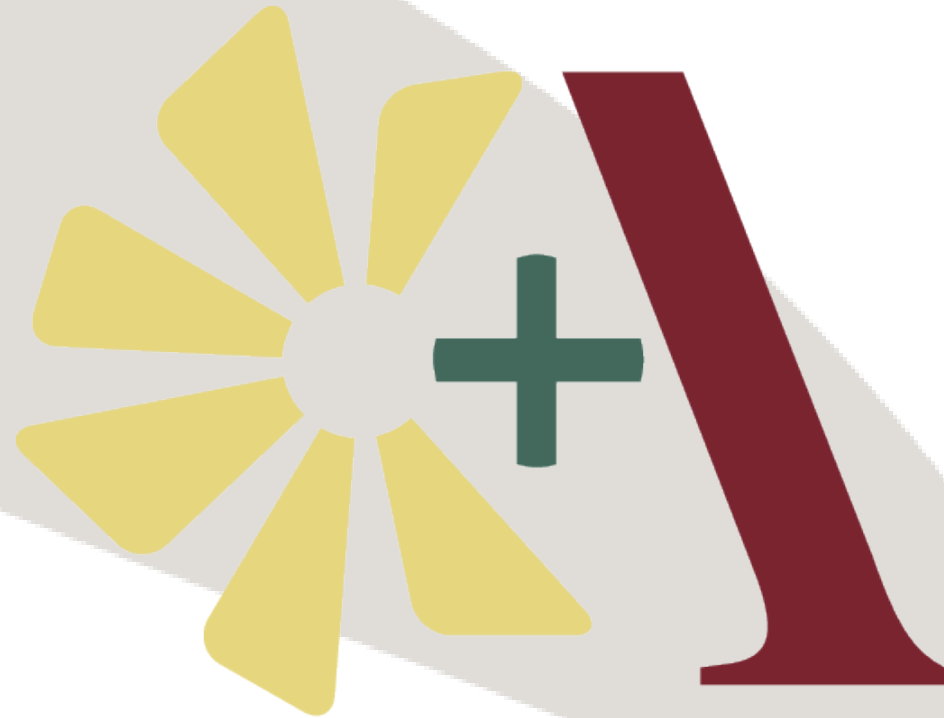
Stress / Anxiety- Uncertainty about what to expect as the disease progresses & how to support your loved one

Anger / Frustration- Anger towards the diagnosis & resentment about your role might be changing

Grief / Depression- Anticipatory grief can cause depression. It is important to seek support, i.e. support groups, connect with other caregivers, therapy, in home help with personal care and chores, rest, practice healthy habits

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Memory Techniques



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Using and Choosing Memory Techniques

- 🌱 People remember things in different ways. This means some strategies will work better for some people than they will for others. Try them out and see which ones work best for you. See if other people can help you with some of these strategies.

Techniques to Consider



A problem-solving approach



Using mental pictures

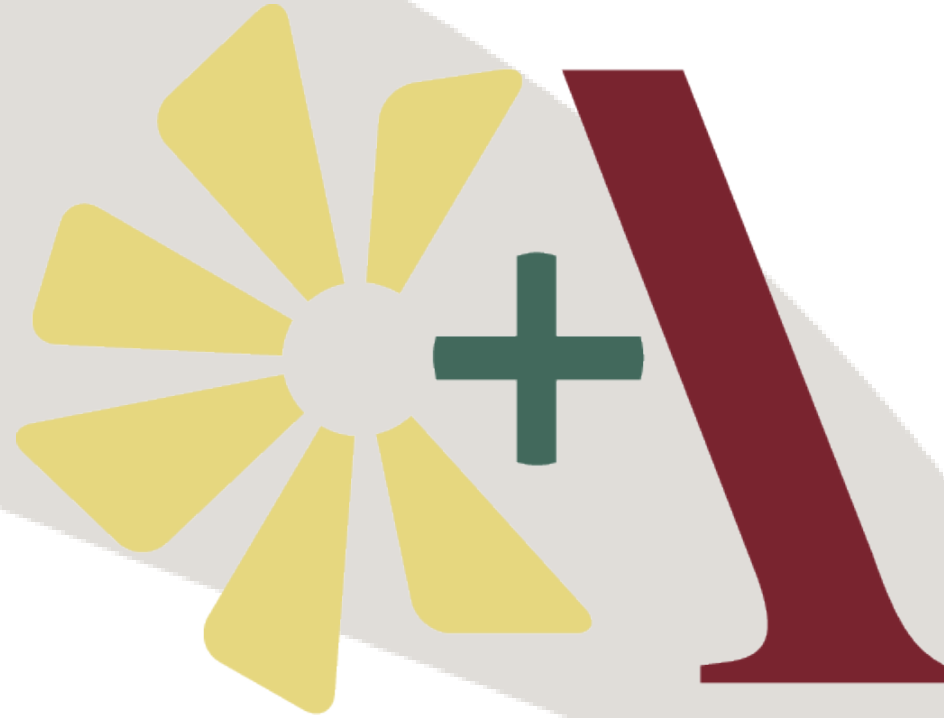


Jogging your memory



Using words and rhymes

Some Available Support & Resources



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GUIDE Program - Guiding an improved Dementia Experience

GUIDE is a 7 -year pilot , no-cost program for eligible individuals living with dementia and their caregivers

GUIDE offers:

- Personalized dementia care and support
- Services to help individuals age in place
- Resources to promote caregiver well-being
- Guidance to navigate care with confidence and compassion

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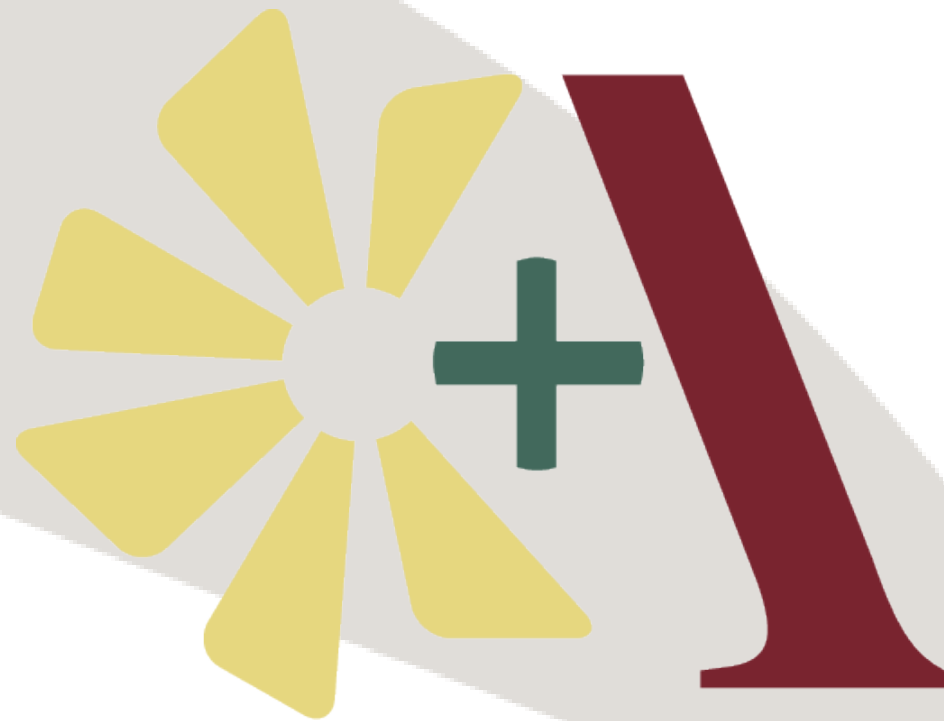
Getting Started With **GUIDE**

- Eligibility requirements:
 - Medicare Part A & B (not Advantage plans)
 - Live in Maine
 - Have a CMS-approved dementia diagnosis
 - Reside in a private home, memory care, or A/L facility
- Complete a comprehensive assessment with the GUIDE team and receive Medicare approval
 - Review of cognition, daily activities, dementia stage, care needs and dementia support

Other Resources

- ❑ Area Agencies on Aging- 5 in Maine (Respite Programs, In-Home Care Info, Meals on Wheels)
- ❑ Alzheimer's Association- alz.org- 24/7 Helpline: 800-272-3900
- ❑ Maine Alzheimers Chapter – alz.org/maine
- ❑ Maine Hospice Council- mainehospicecouncil.org
- ❑ Andwell Health Partners - (207) 289-3649
- ❑ Ask the Experts – Hospice Education Webinar Library
- ❑ See Resource Handout for Additional Resources

When is it Time for Hospice Support?



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When to Enter Hospice

Under U.S. Medicare rules, people with dementia or Alzheimer's disease do not qualify for hospice based on diagnosis alone but on functional decline and expected prognosis.

The Fast Scale – Late Stage 7

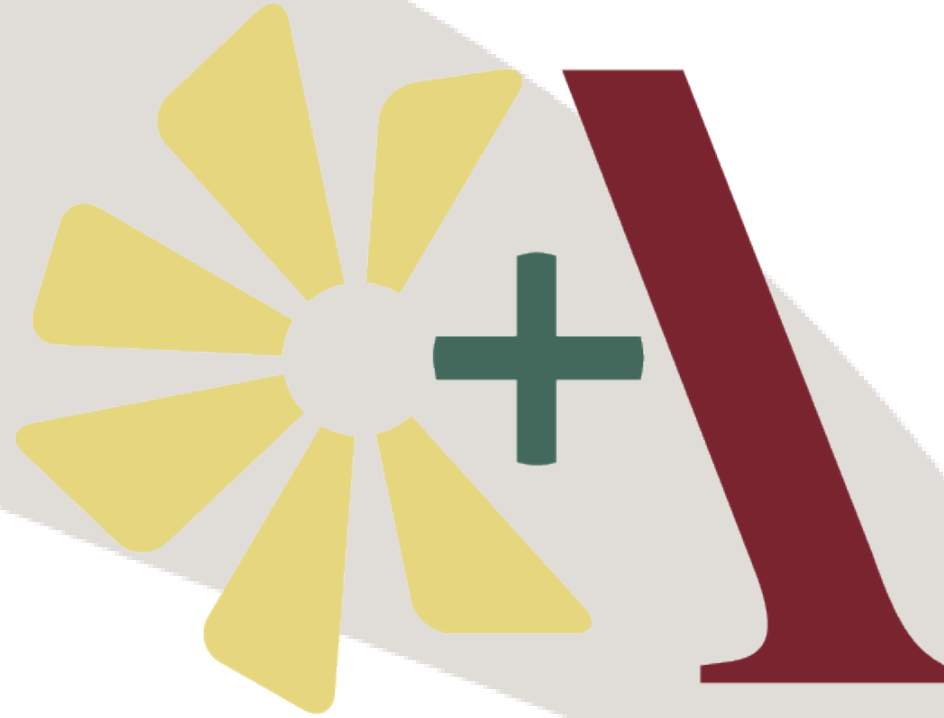
- ❑ Unable to walk independently
- ❑ Unable to dress or bathe without help
- ❑ Urinary or fecal incontinence
- ❑ Loss of meaningful speech
- ❑ Total dependence for ADLs

Dementia Alone is Not Usually Enough

Medicare also expects evidence of medical decline supporting a 6-month prognosis

- Significant weight loss
- Recurrent infections
- Pressure ulcers
- Repeated hospitalizations
- Difficulty swallowing
- Need for modified diet
- Dehydration or reduced oral intake

Closing Conversation



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Questions & Answers

Thank you!

Amy Angelo, Alzheimer's Association

Kim Crabill, Andwell Health Partners

Kimberly Mann, Andwell Health Partners



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For Health. For Life.

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