

Caring for People Who Have Dementia

HELPFUL TIPS AND RESOURCES

- Basics of dementia
- Approaching a person who has dementia
- Coping with challenging behaviors
- Stages of dementia
- Support resources for caregivers



Agrace[™]
HospiceCare



People with dementia do not lose the ability to enjoy life; how we help them find joy will need to change as their level of ability changes.

“Dementia doesn’t take away your ability to be a human ... and it shouldn’t take away your humanity.”

— John Evans, MD, geriatrician



Basics of Dementia

Dementia is a general term for “failure” of the brain due to brain cell loss. As more and more brain and nerve cells die off, everything the brain does can be affected. People with dementia have many difficulties in daily life, and their decline is much more pronounced than the forgetfulness we think of with normal aging. Dementia is not reversible.



Here are some of the physical and mental changes a person with dementia may experience:

- Confusion, memory loss
- Poor judgement and decision-making
- Loss of ability to plan, order tasks or solve problems
- Loss of word-finding
- Inability to respond appropriately to others
- Changes in appetite or ability to swallow
- Changes in strength, balance and coordination
- Disrupted sleep
- Inability to verbally express pain and other needs
- Increased skin breakdown
- Depression, anxiety or psychosis (which are treatable, even while dementia cannot be cured)
- Sensory decline, such as tunneled vision, hearing loss, desensitized touch, loss of ability to taste

“Person-centered” Approach to Care

Your goal is to give people with dementia the best quality of life they can have while living with a terminal illness. To do this, care must be **“person-centered.”** What makes the person uniquely “themselves,” even with dementia? What will give the person—and you—the best possible experience during personal care? Consider their background, previous job/career, hobbies, family, likes and dislikes as you choose the best phrases, activities and physical approach to use.

Create a preference card to help all caregivers learn about the person and their daily routine. For example, if your resident used to farm, ask them about their animals and crops. Think of activities that are meaningful to them, such as tinkering, doing chores, being outside or rising early.



Photo by Bec Ritchie



Approaching a Person Who Has Dementia

- 1. Before providing any care,** take a deep, relaxing breath to calm yourself, then gently get the person's attention.
- 2. Approach from the front:** As dementia progresses, a person's vision and hearing may fail. It is best to approach from the front to prevent startling or upsetting them.
- 3. Slow down your physical approach:** It may take longer for a person with dementia to recognize you. Slow down and pause in their presence for 5 to 10 seconds before you start a task.

- 4. Take a side stance:**
Standing directly in front of a person with dementia can be intimidating and make them feel trapped. After you approach from the front, move to side of the person, which lets them feel that they are able to leave the interaction.



demonstrating side approach

- 5. Meet at their level:** If a person with dementia is seated or in bed, crouch down to meet them at their level; this can help them feel comfortable and in control.

Treat with dignity: When you greet a person with dementia, call them only by their preferred name.

Preview your actions: Tell and show what you are going to do, step by step. This might include miming the actions, such as sitting down or taking off shoes.

(Adapted from Teepa Snow, Positive Approach to Care)

Coping with Challenging Behaviors

As dementia progresses, a person can no longer convey their thoughts, needs and emotions. Your interactions may be frustrating—for both you and them. You may begin to see new behavior, such as:



- refusing care,
- wandering,
- agitation, and
- repetition.

Finding the source of the problem

Behaviors are usually caused by either an unmet need or a trigger. You can start by asking:



- Is the person hungry/thirsty?
- Do they need to use the bathroom?
- Do they have uncontrolled pain?
- Is an infection causing discomfort?
- Are they tired?
- What happened right before the behavior started?

If you think something triggered the behavior, think about what happened right before it started. Triggers can be physical, emotional, social or environmental (download the free DementiAssist app from dementia expert Teepa Snow to help identify possible triggers). If you can identify the trigger, how can you avoid it in the future?

Stages of Dementia

Here are some common signs that dementia is progressing:

Early Stage

- Increasing forgetfulness
- Word-finding difficulties

Middle Stage

- Needing extra help with daily activities, such as dressing and grooming
- More difficulty communicating
- Personality changes, unusual behavior
- Trouble seeing and understanding where objects are in relation to themselves (spatial perception)

Late Stage

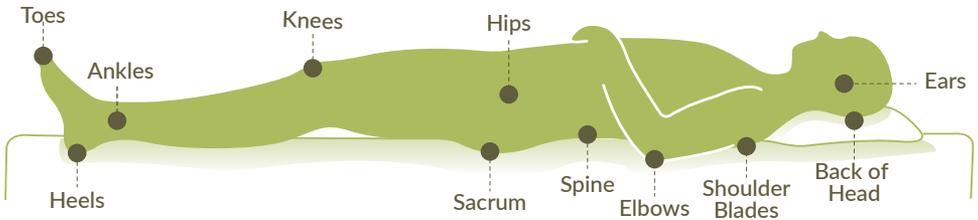
- Becoming dependent on others to do daily activities
- Difficulty changing positions, moving arms and legs
- Cannot have conversations or talk

“Until there’s a cure,
there’s care.”

—Teepa Snow, dementia expert

Care needs during late stage dementia

- **Provide oral care**, such as mouth moisturizer and lip balm, at least every 2 hours or more often, as needed.
- **Reposition the person** every 2 hours to help prevent skin break down. Check “boney prominent” areas for redness or sores (such as the back of the head, shoulder blades, elbows and heels).



- **Offer food and fluids**, but know that diet changes may be appropriate over time. This is because the ability to swallow decreases as dementia progresses and may go away completely in the person’s last days. Feeding or giving fluids to a person who cannot swallow may cause choking or lead to aspiration pneumonia (caused by food or liquids “going down the wrong way” and getting into the airway/lungs).

Hospice Memory Care Suites at Agrace

Agrace HospiceCare now has 12 Hospice Memory Care Suites on our campus in Madison. This secure unit is for people who are eligible for hospice (or already enrolled with Agrace) and have dementia or other memory care needs.

Call (608) 327-7117 to discuss admission or hospice eligibility.



Learn more at agrace.org/memory

Support for Patients and Caregivers

Caring for people with dementia is not easy, but there is help!

Organizations

ADRC (Aging and Disability Resource Center)

dhs.wisconsin.gov/adrc | (800) 514-0066

Your local ADRC is a state-supported local agency that provides information on programs and services available to people who are aging or living with a disability. ADRCs often serve a single county (or just a handful of counties). They can give information on local long-term care options and will help you apply for programs and benefits.

Alzheimer's & Dementia Alliance of Wisconsin

alzwisc.org | (608) 232-3400

The Alzheimer's & Dementia Alliance of Wisconsin provides education, personal consultations, resources and advocacy support for people touched by dementia.

Alzheimer's Association

alz.org | 24/7 Helpline: (800) 272-3900

The Alzheimer's Association provides information on Alzheimer's care, support and research for people touched by Alzheimer's.

Wisconsin Alzheimer's Institute

wai.wisc.edu | (608) 265-9122

The Wisconsin Alzheimer's Institute provides information, resources and support to people living with dementia and their families, loved ones and caregivers. Additionally, they have memory clinics that are staffed with providers familiar with diagnosing and treating dementia.

Literature

THE CAREGIVER HELPBOOK: Powerful Tools for Caregivers

Legacy caregiver services

HOW TO SAY IT TO SENIORS: Closing the Communication Gap with Our Elders

David Solie

SHARE THE CARE: How to Organize a Group to Care for Someone Who Is Seriously Ill

Cappy Capossela & Sheila Warnock

SURVIVING ALZHEIMER'S: Practical Tips and Soul-saving Wisdom for Caregivers

Paula Spencer Scott

Support Groups

Alzheimer's Association, Wisconsin Chapter:

alz.org/wi/helping-you/support-groups

Memory Café Directory:

memorycafedirectory.com

Memory cafes are social gatherings for people living with dementia and their family and loved ones. They provide an opportunity for engagement, socialization and support for all. Visit the web address above to find Wisconsin Memory Cafes near you and enjoy a “dementia-friendly” outing with your loved one.

Aging and Disability Resource Centers:

dhs.wisconsin.gov/adrc/consumer

Choose your home county from the map to see your local ADRC. Each ADRC offers different types of support for family caregivers, depending on county need.



References:

- Alzheimer's Association. Inside the Brain. [online] Available at www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour_part_2
 - Alzheimer's Disease and Dementia. (2018). Stages of Alzheimer's. [online] Available at www.alz.org/alzheimers-dementia/stages [Accessed 7 Dec. 2018].
 - Alzheimer's Society. (2019). Risk factors for dementia. [online] Available at www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia.pdf
 - "Dementia: Symptoms, Causes, Types & Treatments." [online] Available at www.dementia.org
 - Dr. Kenneth Robbins, MD, MPH, 2019
 - Positive Approach to Care, Teepa Snow, [online] Available at www.teepasnow.com
 - Wisconsin Department of Health Services. (2018). Population Demographics. [online] Available at www.dhs.wisconsin.gov/dementia/demographics.htm
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Self-care Tips for Caregivers

- Find a reasonable balance between caregiving and your other responsibilities.
- To avoid burnout, take time for self-care (sleep, down time, healthy eating, spirituality).
- Recruit other family to share caregiving duties or hire part-time professional caregivers.
- Attend support groups to share ideas for caregiving and coping with stress.

Agrace HospiceCare
(800) 553-4289 | agrace.org

Agrace Caregiver Education
agrace.org/caregiver