



For the Lifespan: The Caregiver Guide

Module 2

Dementia and Memory Loss



Objectives

After completing this module, participants will be able to:

- Define dementia and memory loss.
- Recognize medical and social components of dementia.
- Understand how to support the person you care for at home.
- Identify available community supports and care.
- Understand legal planning for the future.
- Understand the importance of planning for the future.
- Identify when it is time to transition to a community setting.



Family Feelings



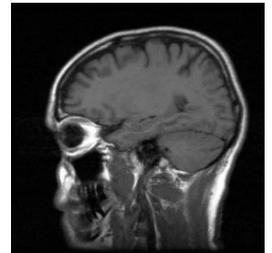
Steps in acknowledging dementia in a family member:

- Acknowledging the reality of the situation, and honestly assessing how the future may unfold for this person.
- Understand the grief you are feeling.
- Feelings of anger, guilt, fear, and anxiety are normal for a caregiver to experience.
- These feelings of loss need to be felt, validated, and then released. You are on a challenging road, but information and support will help.



Dementia and Memory Loss

- Dementia is a very general term for loss of memory and other intellectual abilities serious enough to interfere with daily life.
- Dementia is a chronic brain disorder affecting normal thinking that can't be reversed.
- There are over 80 different types of dementia.
- Alzheimer's is the most common form of dementia.



Types of Dementia

- Alzheimer's disease
- Vascular dementia
- Mixed dementia
- Parkinson's disease
- Huntington's disease
- Brain injury
- Mild cognitive impairment



Behavioral Changes, Actions, and Reactions

Keep a daily journal for at least seven days before seeing the physician, if you are concerned about Alzheimer's, that address these issues:

- Memory loss that disrupts daily life.
- Trouble planning or solving problems.
- Confusion about place or time.
- Poor or decreased judgment.
- Withdrawal from work or social activities.
- Change in personality or mood.



Risk Factors

- The greatest risk factor is age. Nearly half of the people over age 85 have a form of dementia.
- Family history and genetics are a risk factor. People with a parent, brother, or sister with dementia are more likely to develop it than someone who doesn't have a first-degree relative. Dementia diagnoses are higher in the Latino and African-American communities.
- Other risk factors might include vascular/heart disease and serious head injury.



What to Tell the Doctor

- Symptoms your care recipient is experiencing.
- History of when the symptoms began.
- How the symptoms are exhibited (diary).
- If the symptoms have worsened over time.
- The doctor will review medical history, and evaluate mood and mental status with a series of questions. Physical examination and diagnostic tests will be performed. Neurological examination (i.e., brain imaging) will be done.

Important Questions to Ask the Doctor

- “Where is my care recipient in the disease progression?”
- “What does the future look like for him/her?”
- “What new treatments are available?”
- “What can I do to make my home safe and comfortable?”
- “What support services are available in this area?”
- “Are there any clinical trials available to participate in?”



Seven Stages of the Disease

- Stage 1: Normal functioning – No symptoms.
- Stage 2: Very mild cognitive decline – Might be normal age-related changes or could be the early signs of dementia.
- Stage 3: Mild cognitive decline – (May be early-stage Alzheimer's) Friends/family may notice changes which may include greater difficulty performing tasks in social and work settings, losing or misplacing valuable objects, increased trouble with planning/organizing.



Seven Stages of the Disease (cont.)

- Stage 4: Moderate cognitive decline – (Mild/early Alzheimer's) Forgets recent events, greater difficulty doing complex tasks like planning dinner, paying bills or managing finances, forgetful about personal history, becomes moody, withdrawn.



Seven Stages of the Disease (cont.)

- Stage 5: Moderately severe cognitive decline – (Moderate or mid-stage Alzheimer's) Person needs help with day-to-day activities, unable to recall address or phone number, confused about where they are or what day it is, trouble with math, and needs help choosing proper clothes for the weather. Continues to eat and toilet independently. Still remembers significant details about themselves and family.



Seven Stages of the Disease (cont.)

- Stage 6: Severe cognitive decline – (Moderately severe or mid-stage Alzheimer's) Memory worsens, personality changes, person needs significant help with daily activities, tends to wander and get lost, remembers own name, has trouble remembering personal history, increasing incontinence, difficulty sleeping, behavior changes including delusions and suspicions about caregivers.



Seven Stages of the Disease (cont.)

- Stage 7: Very severe cognitive decline – (Severe or late-stage Alzheimer's) Loses ability to respond to environment, speak, or control movement; needs help with daily personal care, eating, and toileting; muscles become rigid, and swallowing can become impaired.



Critical Considerations

- Durable Power of Attorney (DPOA) for legal and financial decisions on behalf of the person.
- Healthcare Power of Attorney (HPOA) for healthcare decisions on behalf of the person.
- The DPOA and HPOA should meet with your care recipient's physician and attorney to establish authority to handle future medical and legal needs and decisions.
- A copy of the certified, recorded Health Directive and DPOA should be placed in the medical record.





Helpful Tips



- A schedule of daily care should be decided to provide for your care recipient's needs that includes the activity to be accomplished (cleaning the house), who will do it (the niece), when it will be done (on Thursday), and how often (weekly).
- One important safety feature will be a Physician Order for Life Sustaining Treatment (POLST) form, secured to your refrigerator door, which outlines to emergency personnel your care recipient's preference for life-support in the event 911 is called. Please speak further with your physician about this. Forms are at: <http://health.utah.gov/hflcra/forms.php>

Helpful Tips (cont.)

- Remove from the home all important legal, financial, medical, and historical documents; as well as checkbooks, jewelry, credit cards, bank debit cards, computer passwords, and any weapons (guns, kitchen knives, etc.) for safekeeping elsewhere.
- All medications and over-the-counter medications need to be out-of-reach and/or locked up so the person receiving care cannot access them.



Practical Strategies



Communication – When speaking with your care recipient:

- Try to stand in front.
- Make eye contact.
- If appropriate, touch their shoulder or arm lightly to help them focus.
- Speak softly and slowly as you use simple language and phrasing.
- Try to be direct and avoid too many questions.
- Allow extra time for a response.

Practical Strategies (cont.)



Bathing:

- Can forget to bathe, how to bathe, why bathing is needed, be afraid of bathing, or think it's too complicated. Try using a little water. Create a schedule. Warm up the room, use nice towels, play soft music, and be pleasant. The lack of privacy can be upsetting. If so, cover them. Try a sponge bath.

Eating:

- A person with dementia will often forget if they ate, what was eaten, or where they last ate. Caregivers can help by providing meals and snacks at the same time every day and serve them in the same location in the home.

Wandering and Pacing



- May quickly become confused and agitated. Might not understand what's going on or who people are. Might feel anxious or be overstimulated by noise or activity. One symptom of confusion is wandering.
- Maintain a calm and quiet environment. Predictability in schedule is helpful. Be gentle, calm, and quiet in voice and demeanor, don't make any sudden movements.
- Have the person wear a metal bracelet with name, address, phone number, and the words "Memory impaired" on it. Put a card in clothing with the same info. Have a recent photo. Alzheimer's Association offers a Safe Return program, requires registration on their website.

Driving



- Loss of driving privilege is often the first and can be the most devastating loss of independence.
- One of the first signs of early dementia can be getting lost while driving. Many patients have this happen and are afraid to tell because they don't want to lose their independence.
- The family needs to make the right decision for everyone, including other drivers on the road.
- All sets of keys need to be removed from home.

Caring for a Person with Dementia

- Primary characteristic needed is patience.
- Remember neural pathways are frayed or broken and new ones can't be made. 
- Person often can't remember simple tasks.
- Be respectful, be creative, and flexible.
- Try to avoid stress, create peace.
- Talk about pleasant past memories or sing childhood songs. 

Validation



- The validation approach has been proven useful.
- Caregiver moves into the reality of the person with dementia (time, place, person) and then slowly validates their feelings to bring them to a more calm and content state.
- When the caregiver is in tune or connected, they can move them to another topic or direction that may be more pleasant.

Redirection

An often-used strategy when supporting individuals with dementia is to redirect their thoughts and activities so they will focus on something more desirable. As a caregiver, do not contradict what the person is saying or tell them they are “wrong.” Use redirection to engage them in positive memories or to a schedule they have used before.



Strategies for Daily Living

- Individuals need to stay as engaged as possible.
- Don't introduce new activities—vary simple well-known ones.
- Try very simple activities and a predictable routine.
- Maintain same routine for self-care and meals.
- Post a calendar to help track what happens next.



Care Options

The progression of care typically follows this pattern:

- Aging in Place at Home
- Adult Day Care
- Assisted Living
- Nursing Home



Financial Considerations

2013-average cost of care in a nursing home--\$81,000+

2013-average cost of assisted living setting--\$42,000+

Explore: Long-term care policies, Medicaid, Medicaid waivers, Veterans Aid and Attendance, private funding.

Medicare does **NOT** cover nursing homes, just in-patient hospital care.



Choosing a Residential Care Setting in the Community

First check with the Utah Department of Human Services Licensing (www.hslic.utah.gov) to find out which residential settings in your area are legally licensed.

It's wise to ask the facilities you're considering to show you their most recent health and safety inspection report. Module 3A, Caring for Older Adults with Chronic Health Issues, includes a thorough discussion of residential facilities licensed in Utah.



Take a Break



Ideas to Relieve Stress

- Meditate
- Use positive self-talk
- Exercise
- Eat well-balanced nutritional meals
- Avoid stimulants (caffeine, nicotine, etc.)
- Enjoy a balance in my life
- Take breaks
- Develop a consistent sleep routine
- Take a nap
- Spend time with others
- Set realistic goals for myself
- Give myself permission to NOT be Super-Human



Things to Remember



- Remember to take good care of yourself by staying positive, exercising regularly, getting enough rest, eating nutritiously, using good body mechanics, laughing, relaxing, and doing something enjoyable when you can.
- Always believe in yourself and your abilities.
- Remember that you have the strength, courage, compassion, and wisdom to succeed.
- Thanks for your participation.