

# Dementia Information and Caregiver Support

Dementia is a progressive, irreversible disease of the brain affecting millions of Americans. The disease destroys brain function, which over time leads to a decrease in purposeful abilities.

Of all the causes of death, dementia is one disease that cannot yet be cured, prevented or treated effectively. Although most people develop symptoms of dementia after age 65, some individuals may experience signs of dementia in their 30s. Those afflicted with early onset dementia experience a greater initial loss of cognitive abilities such as deficits in attention, visual information interpretation and language. The rate of decline for early onset dementia is faster than in those individuals with later onset dementia.

*Dementia is an umbrella term that includes many cognitive loss conditions which decrease and destroy brain function over time.*

*Alzheimer's disease* is the most common type of dementia. Caused by damage to the nerves in the brain and their eventual death, it has an expected progression of 8-12 years.

*Vascular Dementia* (multi-infarct) is caused by damage to the blood supply to the nerves in the brain and is spotty and unpredictable.

*Lewy Body Dementia* (LBD) results in movement problems, including falls and stiffness. LBD is characterized by visual hallucinations, nightmares and fluctuations in day-to-day functionality.

*Frontal-Temporal Dementia* effects include rapid changes in feelings and behaviors, difficulty with word finding and problem behaviors including poor impulse control (Heather McKay, 2018).

Different forms of dementia bring different symptoms and behaviors. However, there are some universal traits. One is that the brain begins to shrink and stop working, which affects everyone's lives. The most common universal characteristics include:

- Memory loss, initially the most recent memories, but eventually all
- Diminished language skills; often some basic skills remain
- Dementia steals the ability to understand what others mean and say
- Reasoning and logic are lost
- The familiar begins to seem odd and frightening
- Impulse control is diminished, as are emotional and mood control.

## **Risk Factors for Dementia**

**Age:** 65 and older is most common, early onset can occur in the 30s, 40s and 50s.

**APOE-e4 gene:** Individuals with this gene are three times more likely to develop Alzheimer's dementia.

**Family History:** Those with parents or siblings with dementia are more likely to develop the disease than those who do not.

**Mild Cognitive Impairment (MCI):** Individuals with MCI are more likely to progress to dementia than those without MCI.

**Traumatic brain injury:** Brain injury increases the risk of developing dementia.

**Cardiovascular disease:** Brain health is closely related to heart health. Care should be taken to avoid cardiovascular risks such as smoking, obesity, diabetes, hypertension, high cholesterol and inactivity.

**Limited Education:** Researchers believe that more years of education builds a cognitive reserve that help individuals better compensate for changes in the brain that may result in dementia.

**Lack of Social and Cognitive Engagement:** Remaining socially and mentally active may support brain health and reduce the risk of dementia.

Nationally, dementia is the sixth leading cause of death. While deaths from heart disease have

decreased 11 percent between 2000 and 2015, deaths from dementia have increased 123 percent. Nearly six million Americans live with dementia, a number that is projected to rise to nearly 14 million in the next 30 years.

Currently, over 16 million Americans are providing unpaid care for those affected by dementia, devoting an estimated 18.4 billion hours of care valued at over \$323 billion (Alzheimer's Association, 2016).

In Montana, nearly 20,000 residents are affected by dementia and this number is expected to increase to 27,000 by 2025. In one year, Montana's 50,000 caregivers invest 55 million hours of unpaid care for their loved ones affected by dementia. Everyone will be affected by dementia at some point in their lives either directly or indirectly (Montana Chapter, Alzheimer's Association).

Distance creates sparse resources for caregivers and patients in some areas of Montana. Because caregivers play such an important role in the lives of those living with dementia, it is important to provide resources when possible. Providing care for patients can be all-encompassing and affect every aspect of a caregiver's life. Many demands are placed on caregivers. They face tests of resiliency, problem solving, patience and stamina, and maintaining emotional and physical health is a challenge. Finding support and maintaining a high level of self-care can help caregivers in a stressful and emotional journey.

Developing a personal support plan is recommended for those in a caregiving role. An effective plan may include some or all of these steps:

1. Ask for and accept help
2. Focus on what you can provide, remove guilt for what you can't
3. Set realistic, SMART goals (specific, measurable, attainable, relevant and timely)
4. Update caregiving skills
5. Join a support group
6. Make use of available resources
7. Plan for self-care
8. Watch for signs of caregiver stress

A free packet of information with Montana-specific information called "Legal and Financial Steps and Resources for Caregivers and Others Concerned About Memory Loss" is available from MSU Extension. Included in the packet are MontGuides (fact sheets) about financial powers of attorney, wills, letter of last instruction, Medicaid and long-term care costs, providers orders for life-sustaining treatment, and more. The Montana Alzheimer's Association has also provided three brochures and information about their 24/7 phone help line. An explanation about the Montana Caregiver Act is included courtesy of Montana AARP. For a copy of the packet, contact [khayes@montana.edu](mailto:khayes@montana.edu), call 406-994-3511, or visit [www.msuextension.org/alzheimer](http://www.msuextension.org/alzheimer) to order.

There are many opportunities to find a deeper sense of reward in a caregiving role. It takes an individual with unique skills to manage the daily tasks. As the disease progresses and the patient seems less appreciative, caregiving can become what seems like a thankless task. Perceived in the right frame of mind however, the caregiving journey can include life-affirming rewards in addition to the challenges faced.

## 10 signs of caregiver stress

If you experience any of these signs of stress on a regular basis, make time to talk to your doctor:

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|-----------------------------|------------------|--------------------------|
| 1. Denial                   | 5. Depression    | 8. Irritability          |
| 2. Anger at the person      | 6. Sleeplessness | 9. Lack of concentration |
| 3. Social withdrawal        | 7. Exhaustion    | 10. Health problems      |
| 4. Anxiety about the future |                  |                          |