

VA Montana Health Care System- Dementia Caregiver Guide 2016



*Caregiving often calls us
to lean into love we
didn't know possible*

Tia Walker, author

Overview of Dementia

“Dementia” is a general term for the loss of memory and intellectual abilities serious enough to interfere with daily life. Dementia affects not only memory, but also judgement, ability to reason, and ultimately the ability to care for oneself.

There are many causes of dementia and several syndromes that mimic the symptoms of dementia, including depression with apathy, adverse effects from medication, metabolic problems, and structural brain disease. It is important to have a medical evaluation consisting of a history, examination, blood testing, and neuroimaging to rule out other causes of cognitive decline.

The most common cause of dementia is Alzheimer’s disease. This is a clinical diagnosis, meaning that there is not a definitive “test” that proves Alzheimer’s vs. other causes of dementia. “Alzheimer’s” is the term applied to dementia of gradual onset, typically affecting the ability to acquire and retain new information, and often involves impaired judgment and reasoning particularly in ability to handle complex tasks. A change in behavior or personality is also common. Alzheimer’s dementia is a progressive disease, meaning that symptoms (and function) worsen over time. At this time there is no cure for Alzheimer’s disease. However there are some medications and caregiving strategies that can improve safety and quality of life.

Alzheimer’s disease has three stages

Mild-

Changes in personality, suspicious, anxious

Difficulty performing tasks- following a recipe, trouble with driving, paying monthly bills

Problems finding the right words

Diminished judgement and loss of interest

Confusion-may misplace things, forget how things work, lose something and accuse someone of stealing it

Moderate-

Short term memory loss

Hallucinations

Behavioral Changes such as agitation/aggression may occur. These behavioral changes may be triggered by something in the environment

Severe Stage-

Need constant care-inability to care for self

Loss of verbal abilities-can’t make needs known

Uncontrollable movements
Incontinence
Inability to recognize family friends
Inability to sleep
Aspiration risk
Weight loss

Dementia Warning Signs that patients and caregivers may report

- Asking the same questions over and over again.
- Forgetting recently learned information.
- Becoming lost in familiar places.
- Not being able to follow directions.
- Loss of interest in social activities
- Getting very confused about time, people and places.
- Problems with self-care, nutrition, bathing or safety.

Tip: If you notice warning signs request an appointment with you Primary Care Provider for an evaluation and workup.

Dementia Caregivers

Caring for someone with dementia 24 hours a day can be difficult and isolating. A caregiver may find themselves overwhelmed with the daily challenges of providing care and managing behavior problems. The stress can lead to fatigue, depression, and may affect the health of the caregiver. VA strives to empower the caregiver with knowledge, help in the home, and resources in an effort to support the caregiver providing the care for the Veteran.

Caregiving Recommendations

Educate yourself about the disease- there are several web based sites listed below. If you would like printed information, contact you PACT nurse or social worker to request printed information.

Keep structure in the daily activities for your loved one-having minimal changes to the day will be the most helpful. Disruptions to the schedule can cause anxiety and behavior problems. Moving, changing caregivers and routines are all taxing to the person with dementia.

Don't argue reality-The person with dementia does not understand nor remember conversations or previous events, steer your conversation away from the argument, don't engage in the argument or walk away and return in a few minutes.

Keep the environment simple with little stimulation- an environment that is simple and organized is the most therapeutic environment for the person with dementia.

Modify your home for safety-remove throw rugs, keep medications locked away, and remove hand guns. You may need locks on cabinets or doors to prevent harm.

Schedule breaks for yourself as the caregiver-ask your social worker about the respite program, ask your church for volunteers, contact Area on Aging Agency in your county for community programs.

Plan ahead for emergencies- have an action plan in the event you as the caregiver got sick or needed to be away. The VA has a respite program that can help during these times by arranging temporary placement in a local nursing home. Contact your local social worker for more information.

Plan ahead for the future-what would you do if you can't provide the care needed? Ask for help.

Know what your resources are and who your resources are. Keep a journal.

Attend appointments with the Veteran-Request to speak with a social worker.

If your loved one is in a nursing facility set a day and time you visit

Involve your family or friends to help with routine responsibilities

Find the time to do things for yourself.

Available Services

The VA has many programs to help chronically ill or disabled Veterans of any age remain in their homes.

Home Care Services:

- ✚ Caregivers Support
- ✚ Home Maker/Home Health Aide
- ✚ Adult Day Care
- ✚ Home Telehealth
- ✚ Respite
- ✚ Medical Foster Home
- ✚ Home Based Primary Care
- ✚ Hospice
- ✚ Skilled Home Services
- ✚ Veteran Directed Care

Tip: Learn more about Caregiving and Dementia by watching video modules at:
<http://www.ruralhealth.va.gov/education/dementia-caregivers/>

Available Services

One of the goals of the VA is to help Veterans remain in their homes as long as possible and to support Veterans and their caregivers. To do this the VA has created several homebased programs. A Veteran must be enrolled in VA Montana, meet VA- established clinical criteria, and be referred for these services by their primary care physician/ provider. Services may also require a co-pay based on service connected disability. For more information on eligibility contact a VA social worker.

Caregivers Support

This program offers various types of caregiver support services for Veterans of the post-9/11 era. (Qualifications for this program are based on service connection and other eligibility criteria.) For more information **Call them at (406) 447-6797**

Caregiver Support Coordinator

Your local Caregiver Support Coordinator is a licensed professional who can support you by matching you with services for which you are eligible, and providing you with valuable information about resources that can help you stay smart, strong and organized as you care for the Veteran you love. For information from the VA about being a caregiver go to <http://www.caregiver.va.gov/toolbox/index.asp>

Home Maker/ Health Aide Program

This program provides a trained personal care attendant from a licensed home health care agency to come to the Veteran's home and assist him/her with bathing, personal care, housekeeping, laundry, meal preparation, grocery shopping and other services necessary to allow the Veteran to remain in his home.

Contract Adult Day Health Care

This program places eligible Veterans in an outpatient adult day care setting, which provides health maintenance, social interaction, and rehabilitative services to frail, elderly Veterans at VA expense. Contract adult day care is available in limited locations.

Available Services

Home Telehealth

This program provides in-home monitoring of Veterans with diagnoses of Heart Disease, High Blood Pressure, Diabetes, and Lung Disease. Program goals include improved health and reduction in need for visits to the medical center or clinics. The Veteran can use his/her own telephone and be monitored from the comfort of home. A nursing care coordinator manages the Veteran while enrolled in the program.

Respite

Community Nursing Home Respite

VA can provide nursing home respite care days for Veterans who have a live-in caregiver. Respite services are provided in a licensed nursing home that contracts with VA. The program is designed to give caregivers, of Veterans who cannot be left alone, the opportunity to leave home for a vacation or extended period of time.

In-Home Respite

The program is designed to give caregivers of Veterans (who cannot be left alone) the opportunity to leave the home for short periods of time while the Veteran is cared for in his own home by a trained attendant.

Medical Foster Home

Veterans live in private homes that are licensed through the state and monitored by VA. The following services are provided: meals, laundry, transportation, medication supervision, assistance with personal care. For war era Veterans, a Veterans pension may be available to help with the cost of this service. **Call them at (406) 447-6721.**

Home Base Primary Care

This program provides primary care, delivered by a team, to Veterans who have difficulty getting to a VA Clinic for their medical appointments. A nurse practitioner oversees the Veterans medical care through appointments at the Veteran's home. This service is currently limited to Veterans living within 100 minutes of FT Harrison or 100 minutes of Billings. **Call them at (406) 447-6711**

Hospice Services

Hospice services are provided when the primary goal of treatment is comfort rather than cure in a person with an advanced disease that is life-limiting. Services are provided by a multidisciplinary care team and include bereavement care to the Veteran's family. Case management services, medications related to hospice care,

home equipment and homemaker/ home health aide are included.

Available Services

Skilled Home Services

Skilled home health care services are in-home services provided by qualified personnel that include: skilled nursing, physical therapy, occupational therapy, speech therapy, social work services, clinical assessment, treatment planning, treatment provision, patient and/or family education, health status monitoring, reassessment, referral, and follow-up. A VA primary care provider prescribes skilled home health care services when medically necessary and appropriate for enrolled Veterans.

Veteran Directed-Home and Community Based Services

Veterans in this program are given a flexible budget for services that can be managed by the Veteran or the family caregiver. Veteran-Directed Care can be used to help Veterans continue to live at home or in their community. Case management services are provided through Area Agency on Aging. This program may not be available in all areas. Contact your local social worker for more information.

For information on any of these programs please contact your PACT social worker

Fort Harrison: (406) 447-7790

Billings: (406) 373-3565

Anaconda, Bozeman: (406) 442-7790

Miles City: (406) 875-5843

Great Falls: (406) 721-2345

Missoula, Kalispell, Hamilton: (406) 493-3743

Web based resources for information:

- <http://www.ruralhealth.va.gov/education/dementia-caregivers/>
- BrightFocus Foundation: www.brightfocus.org/alzheimers
- Alzheimer's Foundation of America: www.alzdn.org
- Alzheimer's Disease Education and Referral Center: www.nia.nih.gov/alzheimers
- Association for Frontotemporal Degeneration: www.theaftd.org
- Lewy Body dementia Association: www.lbda.org
- www.montana-adrc.com
- <http://www.caregiver.va.gov/toolbox/index.as>

When care can no longer be provided at home

Caring for a loved one with Dementia can be difficult at times and can become unmanageable at home. The VA has programs that support caregivers; we always hope for the best but understand that it is best to have a plan in place if there ever comes a time when the caregiver is no longer able to meet the needs of the person with dementia. Planning ahead is one way to reduce the stress of needing long term care services. Paying for long term care can be a major concern and cause a good deal of stress on families. Knowing what resources are available and what options are available is a place to start.

Subsidized senior housing

Housing for seniors that may include a meal program, housekeeping, and laundry. Rent is based on income and subsidized by state and federal programs.

Assisted Living Facilities

Assisted living facilities generally offer private units or apartments. They provide meals and have support staff to help meet the needs of the residents. Most offer around the clock assistance with medication management/reminders, assistance with housekeeping, and assistance with activities of daily living such as dressing, bathing, and eating. Some facilities offer specialized care for people with dementia. They will have a screening process to be sure they can meet the needs of person before they are accepted. The VA does not pay for these services but there may be VA benefits based on your military service that could help you afford

them. Contact your local social worker for more information.

Nursing Facilities

If the necessary care cannot be provided at home or an assisted living facility then a stay in a Long Term Care facility may need to be considered.

Long Term care facilities offer care for people who require continual nursing care twenty four hours a day. A doctor oversees your care while in a nursing facility and nurses are staffed around the clock. Services such a dietician, occupational therapist, physical therapist, and speech therapy may also be available. Many facilities have special units designed to better care for the patient with dementia. The VA may be able to assist with the cost of Long Term Care depending on the Veteran's benefits from the VA. If a Veteran is rated 60% service connected and unemployable or 70% or more service connected the VA will assist with the cost of paying for long term care. Additionally if the Veteran is eligible for hospice the VA will assist with paying for end of life care. Contact your local social worker for more information.

Choosing a facility that is right for you and your loved one

- Visit the nursing facilities in your area
- Compare the quality of the nursing homes
- Use a check list, what is important to you and your loved one
- What are the rooms like?
- Is there privacy?
- Is it noisy, or have bad smells?
- How is the staff interacting with the residents?
- How often do they give a baths?
- What does the nursing home do if there is a change in my loved ones condition?

Tip: Medicare has created a website call *Nursing Home Compare* that allows you to compare information about nursing homes.

<https://www.medicare.gov/nursinghomecompare/search.html>

Medicare offers a guide for choosing a nursing facility @

<https://www.medicare.gov/Pubs/pdf/02174.pdf>

Paying for Long Term Care

Medicare -pays for short term nursing home stay after at least the three night stay in a hospital. There must a skilled need such as physical therapy, occupational therapy, speech therapy, wound care, intravenous therapy and progress towards the goal of returning home. **Generally Medicare does not pay for long-term nursing home care.**

Personal resources-using your savings and other personal resources to pay for long-term care.

Medicaid-a program for people with limited income and resources. You must fill out an application and qualify for the program. It is based on your income and personal resources. You may have to pay out-of-pocket for the nursing home care each month. *The state can put a lien on your home or other assets.* There are rules for the spouse who is not in an institution. Review the document “Your Guide to Choosing a Nursing Home or Other Long-Term Care” available at <https://www.medicare.gov/Pubs/pdf/02174.pdf>

Long term Care Insurance-each policy is different. Contact the insurance company for the details of your policy.

What if my loved one does not want to go to a nursing facility but I can't take care of them at home

Steps to help you overcome the objections of a loved one's resistance to nursing home placement.

1. Start Early

Ideally, families have relaxed conversations about long term care before a health crisis. Look for opportunities to ask questions like, "Dad, where do you see yourself when/if you are not safe to be home any longer?" Discuss options such as nursing home, assisted living and medical foster home placement.

2. Be Patient

Ask open-ended questions and give your loved one time to answer. For example, if you are the child of a parent with dementia, you can say, "Mom, what's it like to take care of Dad 24 hours a day?" Conversations may be repetitive and veer off-topic. It may take several talks to discover the reason your mother is slow to accept your father's move to a nursing home.

3. Probe Deeply

Ask questions to determine why your loved one refuses help or refuses

nursing home placement -- then you can tailor a solution. "Is it about a lack of privacy, fears about the cost of care, losing your independence, or being away from family?" To build trust, listen with empathy and validate rather than deny your loved one's feelings.

4. **Offer Options**

If possible, include your loved one in interviews or in visiting facilities. Encourage his/her involvement in selecting a facility.

5. **Recruit Outsiders Early**

Sometimes it's easier for your loved one to talk to a professional rather than a family member. Don't hesitate to ask a social worker, a doctor or nurse, a priest or minister -- even an old poker buddy -- to suggest placement is needed.

6. **Prioritize Problems**

Make two lists, one for your loved one's problems/needs and another with the benefits of living in a nursing home. Writing it down and numbering by priority can relieve a lot of stress and clarify why nursing home care may be needed.

7. **Use Indirect Approaches**

If your loved one has dementia, offering **less** information may be more effective at times, You could let your loved one know nursing home staff will be very helpful, will prepare meals, will visit, will help with personal care, and will be there to help throughout the day and night. You don't need to explain every aspect of care that will be provided. This may make your loved one feel less afraid.

8. **Take it Slow**

Start with short nursing home visits if possible by using respite care in the nursing home or by taking tours of the nursing home before placement.

9. **Accept Your Limits**

As long as your loved one is not endangering him/herself or others, let him or her make the decision. You need to accept limits on what you can accomplish and not feel guilty. If your loved one is not able to make health care decisions and if he/she is not safe at home, you can apply to be guardian of person and pursue placement on a secure nursing home unit.

10. **Placement in a Nursing Home**

If your loved one has dementia and is going to the nursing home without his/her agreement, reassure him/her that a good nursing home has been selected and that family will visit often. Be upbeat, reassuring but firm in your decision.

Legal issues- it's best to make decisions about future care while you can still make sound decisions.

Advance Health Care Directive

Durable Power of Attorney- a person over the age of 18 years of age you appoint to makes decision about your health care when you can't. Your durable power of attorney should be someone who knows you well, someone you can trust, and who is familiar with your values, beliefs, and wishes.

Living Will- allows you to write down your medical treatment preferences for your health care. Treatment preferences include heart resuscitation, mechanical ventilation, nutrition and hydration support, mental health preferences and social, cultural, or faith-based preferences.

Financial Power of Attorney-a person who is legally appointed to make financial decision and manage the estate once the person is unable to do so.

POLST- The Montana "Provider Orders for Life Sustaining Treatment" (POLST) form is a document designed to help health care professionals know and honor the treatment wishes of their patients. The POLST form should be offer to individuals who have a serious illness that maybe life limiting. Ask your doctor for more information.

Guardianship/Conservator-a guardian is a person, institution, or agency appointed by a court to manage the affairs of another. A conservatorship is a court-ordered protective relationship whereby an individual is appointed to manage another person's (the ward's) financial affairs after that person has become unable to do so. For more information go to

www.dphhs.mt.gov/Portals/85/sltc/.../5GuardianConservatorships.pdf

When should the dementia patient stop driving?

The dementia patient who is allowed to drive puts many people at risk for harm. Warning signs that a person should not be driving include difficulty obeying traffic signs, confusion, getting lost, near misses or fender benders, trouble with the normal driving tasks. Taking away the right to drive can be very difficult and something that should be considered before a tragedy happens. Having the conversation about the potential of driving problems can be difficult with someone who has limited ability to understand why they need to stop driving. Asking the primary care provider or other respectable figure to have that conversation and writing it down as a doctor's order may be helpful. Evaluating of driving skills can be performed at some VA Medical Centers. Requesting retesting by the Department of Motor Vehicles is one way to get the driver's license removed.

What about firearms?

A person with dementia has a decreased ability to manage emotions and think rationally. Family members should unload, secure, and or remove firearms from the home before injury or death occurs.

Important documents- Create a folder

Birth certificates

DD214,

Social security card

Insurance/Medicare card

Life insurance

Burial Insurance

Home insurance

Car insurance

Medical records- enroll in **My healthVet**- VA's online personal health record, allows you to be part of the care team. You are able review lab results, request appointments, request refills, communicate with your care team and review other medical records <https://www.myhealthvet.va.gov/index.html>

Resource's

Alzheimer's Association. (2011) Basics of Alzheimer's Disease

