

MONTANA

Alzheimer's and Dementia

State Plan

**Addressing the Current and Future Needs
of Individuals and Families
with Alzheimer's Disease and Related Dementias**

December 2016

The state plan is a
Call to Action
to improve dementia care in Montana communities.

Letter of Support from Governor

OFFICE OF THE GOVERNOR STATE OF MONTANA

Steve Bullock
GOVERNOR



Mike Cooney
LT. GOVERNOR

June 14, 2016

I am pleased to recognize the important work of the Montana Alzheimer's Disease & Related Dementias Workgroup.

According to the Alzheimer's Association's *2016 Alzheimer's Disease Facts & Figures* report, there are 19,000 people living with Alzheimer's or a related dementia in Montana and another 49,000 family members and friends providing their care. In every corner of this state, families are struggling with the stress of caring for loved ones who are experiencing the debilitating effects of degenerative brain diseases.

In response, a voluntary group of essential stakeholders: healthcare professionals, advocacy groups, state agency officials, legislators, care providers, family caregivers and passionate citizens came together to form the Montana Alzheimer's Disease & Related Dementias Workgroup. Over the ensuing months, this group conducted extensive research, collected data, held town hall discussions with hundreds of Montanans, and examined best practices in dementia care. This thorough evaluation by the Workgroup culminated in the development of priority areas and action steps to prepare Montana to meet the immediate and future needs of people affected by these devastating diseases.

Montana's Alzheimer's and Dementia Action Plan: Addressing the Current and Future Needs of Individuals with Alzheimer's Disease and Related Dementias identifies 11 major goals that will support the needs of individuals and families living with Alzheimer's disease and related dementias. I am committed to continued and collaborative work to achieve these goals.

We owe a debt of gratitude to the Montana Alzheimer's Disease & Related Dementias Workgroup for their diligence and devotion to this effort. Montana now has a framework to cooperatively address the full range of issues surrounding Alzheimer's disease and related dementias. While the scientific community seeks treatments and curative therapies, Montanans will continue working together to improve the vital services and supports for individuals and families facing the disease today.

I am also pleased to light the Capitol Dome purple on June 20th, 2016 in honor of the "Longest Day," an event during summer solstice that highlights the journey of those living with this disease and the experiences of their families and caregivers.

A handwritten signature in blue ink, appearing to read "S Bullock".

STEVE BULLOCK
Governor

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The state plan is available online at MTalzplan.org

1. Executive Summary

Alzheimer's disease and related dementias are irreversible, progressive brain diseases that affect millions of Americans. These feared diseases slowly destroy brain function, leading to cognitive decline, behavioral disorders and decreased functional abilities. Of the most frequent causes of death in the nation, dementia related diseases are the only ones that cannot be prevented, cured, or effectively treated. Dementia places substantial emotional, physical, and financial stress on affected individuals and their family members.

Dementia research is gradually gaining support, yet progress towards finding curative or therapeutic treatments has been slow. Researchers still do not understand the disease on a molecular level, making development of effective treatment options difficult. Further and substantial research is needed to better understand disease prediction and progression while developing novel care delivery interventions to improve health outcomes.²

The slow pace of innovation, along with the substantial costs associated with dementia, has created momentum around the world to develop strategic plans. The United States has adopted a goal to prevent and treat Alzheimer's disease and related dementias by 2025, a goal shared as well by Canada, France, Germany, Italy, Japan, and the United Kingdom. Multi-government agencies have committed to improving dementia care including the World Health Organization and the United Nations.

Private organizations are also dedicating resources including The Global CEO Initiative on Alzheimer's Disease, a group of Fortune 500 companies committed to accelerating dementia research. Alzheimer's stakeholders around the globe are searching for new data, new insights, and new tools to prevent and treat the disease.²

Similar to many places around the world, Montana faces significant public health and financial

crises due to the projected prevalence of dementia in the near future. Because Alzheimer's disease and related dementias predominately affect the elderly, staggering increases in the prevalence of dementia are expected as the baby boomer generation ages. This will result in an enormous impact on families, caregivers, and health and social service providers, and will cause substantial increases in health care costs.

Anecdotal evidence from Town Hall meetings held across Montana reveal the current health care system for persons affected with Alzheimer's disease and related dementias lacks coordination, does not meet the needs and desires of Montanans, and is financially unsustainable. The state lacks sufficiently trained and knowledgeable health care workers, availability of support services for families and caregivers, and appropriate and affordable long-term care options.

The Montana's Alzheimer's and Dementia State Plan—Addressing the Current and Future Needs of Individuals and families with Alzheimer's Disease and Related Dementias was developed by the Montana Alzheimer's Disease/Dementia Work Group—a voluntary group of health care professionals, advocacy groups, stakeholders, caregivers, educators, and citizens who have been affected by dementia and are passionate about improving dementia care in Montana.

The Work Group recognized the existing inadequacies and concluded that Montana must be proactive in addressing the impending crisis dementia poses. Based on extensive research and data collection, Town Hall discussions with hundreds of Montanans including Native American populations, and examination of approaches taken in other states, the Work Group developed goals and action steps to address the numerous issues surrounding Alzheimer's disease and related dementias throughout the state.

The Montana Alzheimer's and Dementia State Plan prioritizes 11 major goals that envision the creation of a health care system in each community able to manage the needs of individuals living with Alzheimer's disease and related dementias and their families throughout all stages of the disease. These goals rest on the assumption that all persons should be able to experience the highest quality of life while maintaining independence and choice regardless of socio-economic status, rural or urban residence, income, race, religion, or sexual orientation.

Each goal area includes recommended action steps crucial to reaching these goals. These action steps range from significant policy changes to improved education and awareness to development of practical resources for individuals living with dementia and for their families. Some of these steps will require financial resources; all will require commitment, cooperation and courage.

The 11 major goals of the Montana Alzheimer's and Dementia State Plan are to:

1. Promote public awareness and understanding about Alzheimer's and related dementia diseases.
2. Encourage all health care providers to recognize and diagnosis dementia early in the process and appropriately refer individuals and families to community resources.
3. Ensure that Montanans with dementia and their caregivers are aware of, and have access to, Montana-specific materials regarding legal and financial planning.
4. Promote person-centered care, ensuring that Montanans with dementia are able to age in place in the least-restrictive setting while maintaining a high quality of life.
5. Maintain adequate numbers of health care workers who are trained to meet the needs of the population experiencing Alzheimer's disease and related dementias.
6. Promote dementia-friendly communities in Montana where individuals and their caregivers are treated respectfully and have opportunities to actively participate in community life.
7. Reduce caregiver burden and stress by promoting systemic changes in medical and

social systems, and employment practices that will support and empower caregivers.

8. Expand the availability of high-quality, affordable home and community-based services that meet the needs of individuals living with dementia, allowing them to live in the most appropriate and least-restrictive setting.
9. Promote wellness and maintenance of cognitive function at residential care facilities through activities tailored to each individual, and employ staff trained in person-centered interventions and models of care.
10. Provide high quality palliative and hospice care for individuals with dementia during the end of life and support for their families and loved ones.
11. Improve dementia data collection and research efforts in Montana.

To implement and achieve these goals, the Montana Alzheimer's/Dementia Work Group has sought a diversified path of funding sources. From partnerships in the private sector to associations with state agencies, the Work Group has and will continue to promote and pursue grant opportunities, funding initiatives, and legislative proposals to implement the vision of improved dementia care in Montana.

Dementia is an illness with a fatal outcome that is plaguing families with emotional and financial burdens.

Dementia will affect each of us, either personally or through a family member or friend. Citizens across the state are rightly asking for a higher degree of preparedness and responsiveness.

We must be prepared for the growing number of Montanans who will be affected by dementia. Solutions are not simple, yet by working together, Montanans can advance strategies that will result in positive and meaningful impacts for individuals and families living with Alzheimer's disease and related dementias.

The state plan is also a Call to Action for individuals, caregivers, and organizations who are affected by dementia and concerned with improving dementia care in Montana communities.

Although there have been recent public policy victories at the national level over the past decade, dementia remains one of the most critical, unaddressed public health concerns in the United States, making the disease an urgent public health crisis.

Alzheimer's disease demands a bold, collective and rapid response—the time is now to change the course of this devastating disease.

2. Vision Statement

As Montanans prepare to address the challenges associated with Alzheimer's disease and related dementias, we want to assure that:

- **All Montanans** are aware of and comfortable talking about aging issues and topics inherent to the aging process including of Alzheimer's disease and related dementias, legal and financial issues, preparation for end of life care, the need to create aging and dementia friendly communities, and where to find resources and support. Furthermore, the citizens of Montana are aware of how to reduce the risk of dementia, the early signs and progression of the disease, the value and importance of caregivers, and the need for first responders, advocates and citizens to be able to detect and competently support these individuals.
- **Individuals with Alzheimer's disease and related dementias** participate in decision-making to the best of their ability, remain independent as long as possible, and receive dignified, high quality, person-centered care throughout their lives regardless of where they live, their financial status, culture, or gender identity. They are aware of opportunities to participate in research and clinical trials.
- **Family caregivers** experience support as they care for family members with dementia throughout the disease trajectory, are valued for the work that they do, and receive person-centered care for themselves.
- **Health care providers** use evidence-based practices to diagnose and manage Alzheimer's disease and related dementias effectively. They recognize the benefit of early disease detection, a multidisciplinary team approach to care, and early referral to community resources and support. Montana health care providers exist as a work force in adequate numbers, and are valued for the work they do caring for individuals with these complex diseases.
- **Montana policy makers and state officials** understand the public health crisis Alzheimer's disease and related dementias present, including:
 - The financial impacts and potential burdens to Montana's citizens and communities.
 - The need to be prepared to implement policies and systems to strengthen the quality of care provided.
 - The need to sustain the ability of individuals with dementia to live independently as long as possible.
 - The need to support research that proposes innovative ways to more effectively detect, prevent, manage, and support this vulnerable population.

3. Glossary of Terms

Caregiver: Anyone who provides care to a person with Alzheimer's disease or related dementias. Caregivers can be family members, friends, or paid professional caregivers. Caregivers may provide full- or part-time help to the individual with dementia.

Chronic disease: According to the U.S. National Center for Health Statistics, a chronic disease is one persisting for a long time (usually three months or more) and generally cannot be prevented by vaccines or cured by medications, nor do the symptoms disappear on their own. Health-damaging behaviors—particularly tobacco use, lack of physical activity, and poor eating habits—are major contributors to chronic disease.

Dementia: Dementia is not a specific disease. Instead, dementia describes a group of symptoms associated with a decline in memory, thinking, and social abilities severe enough to reduce an individual's ability to perform everyday activities. Alzheimer's disease is the most common type of progressive dementia in older adults, yet there are a number of types of dementia.

Do Not Resuscitate (DNR) Order: A DNR order, signed by a health care provider based on a patient's wishes, instructs medical personnel not to perform life-saving CPR or other procedures to restart the heart or breathing once they have ceased. Once signed, the DNR directive must be placed in the patient's chart. This sometimes take the form of a Physician Order for Life Sustaining Treatment (**POLST**). The POLST form is often more detailed than a DNR order and also includes an individual's wishes regarding how aggressive to be with care (ICU or not, for example) and use of feeding tubes.

Geriatric Assessment Clinic: A clinic dedicated solely to the evaluation and management of medical conditions in older adults, including dementia. These clinics usually help develop a comprehensive plan of care that addresses the individual's medical, cognitive, and functional needs.

Geriatricians: Physicians concerned with the diagnosis, treatment, and prevention of disease in older adults. They specialize in managing conditions specific to aging, including dementia.

Guardian: Guardianship is established by a court order. The court grants the guardian authority and responsibility to act on behalf of another person. The relationship is fiduciary, which means that the guardian is obliged to act in the best interest of the individual for whom he/she is a guardian.

Hospice: A hospice program offers support for dying individuals to live as fully and comfortably as possible. Hospice care is generally provided to individuals with a life expectancy of six months or less. Rather than seeking a cure, hospice care aims to make an individual's remaining time as comfortable and as meaningful as possible. Hospice is a Medicare benefit.

Long-term care facility: A long-term care facility is a nursing home or assisted living center designed to provide a variety of services, including both medical and personal care, to individuals who are unable to manage independently in the community. Many residents in long-term care facilities have dementia.

Medicaid: Medicaid is a joint federal and state program that helps with medical costs for qualified individuals with limited income and resources. Medicaid can also provide benefits not normally covered by Medicare, including long-term nursing home care and personal care services.

Medicaid waiver: States can use the waiver process to test new or existing ways to deliver and pay for health care services in Medicaid and the Children's Health Insurance Program (CHIP). There are four primary types of waivers and demonstration projects, one of which is the Section 1915(c) Home and Community-based Services Waiver. Montana participates in this program to provide Medicaid-funded long-term care services in home and community settings rather than institutional settings. However, only a limited number of people can participate in this program based on the level of matching funds provided by the State.

Medicare: Medicare is a federally-funded government health insurance program for people aged 65 and older and for certain younger individuals with disabilities.

PACE: The Program of All-Inclusive Care for the Elderly (PACE) provides comprehensive medical and social services to certain frail, community-dwelling elderly individuals, most of whom are eligible for both Medicare and Medicaid benefits. An interdisciplinary team of health professionals provides PACE participants with coordinated care. For most participants, the comprehensive service package enables them to remain in the community rather than receive care in a nursing home.

Palliative care: Palliative care includes medical and/or surgical methods to ease the pain of a serious or incurable illness.

Person-centered care: This term refers to health care and social services designed to reflect the individual's unique preferences, values and needs, identified and agreed upon in partnership with the medical providers, the patient, and other family members when appropriate. The goal is for people to be treated as individuals and to receive appropriate and timely care that meets their needs.

Power-of-attorney form: A power of attorney form is a legal document designating someone to act on someone's behalf when making major decisions such as medical and financial decisions when the individual is unable to make those decisions him/herself. Montana has a statutory power-of-attorney form.

Respite care: Respite care provides a caregiver temporary relief from the responsibility and stress of caring for individuals with chronic physical or mental disabilities. Examples of respite care include in-home assistance, a short or long-term care facility stay, or day care programs for adults.

Rural and frontier communities: For the purposes of this plan, rural communities in Montana were those with a total population of less than 25,000.

Urban communities: For the purposes of this plan, urban communities in Montana were those with a total population of more than 25,000. For this report, those counties include Cascade, Flathead, Gallatin, Lake, Lewis and Clark, Missoula, Ravalli, Silver Bow, and Yellowstone counties.

4. Process for Preparing This Plan

A. Process

This plan represents the grassroots effort of several state, local, and national partners interested in improving care and support to Montanans with Alzheimer's disease and related dementias, their families, and caregivers. Work on this plan began in June 2014 and occurred in four phases.

Phase I: Establishing the Montana Alzheimer's/Dementia Work Group

The Montana Alzheimer's/Dementia Work Group was established in June 2014. This state-wide partnership consists of several key national, state, and local partners interested in improving care and support for Montanans with Alzheimer's disease and related dementias, their families, and caregivers.

The Work Group has more than 40 members representing multiple industries and stakeholder groups including:

- The Alzheimer's Association
- The Senior and Long-term Care Division of the Department of Public Health and Human Services
- The Governor's Office
- Other government agencies
- Patient advocacy groups
- Patient advocates and caregivers
- Assisted Living/Long-Term Care facilities
- Senior services agencies
- Regional health care organizations and providers
- The Veteran's Administration
- Educators
- Researchers
- Legislators
- Native Americans
- The LGBT community.

The Work Group recognizes that dementia is one of the most important health care crises of our generation. Dementia is prevalent, underdiagnosed,

and carries significant caregiver burden. It is the costliest disease in America and the sixth leading cause of death in the United States and Montana.

To date there is no effective prevention, cure, or treatment. As the number of individuals with dementia increases over the next decade, their needs and those of their caregivers will increase.

The Work Group concluded that the best way to help our state prepare for the current and future needs of individuals with Alzheimer's disease and related dementias as well as their families and caregivers, was to develop a Montana Alzheimer's and Dementia State Plan.

The Work Group met every other month over the course of two years to begin addressing the needs of individuals and caregivers facing dementia, and creating the state plan.

The goal of the plan is to alert Montanans to this growing health care crisis and identify action steps that will be taken to improve care for individuals with dementia and their caregivers.

To ensure the plan addressed the needs and concerns of all Montanans, Work Group members conducted a state-wide inventory to identify gaps in dementia care resources and services, and held public Town Hall meetings across the state to hear and discuss the challenges, fears, and unmet needs of Montanans caring for individuals with dementia.

Phase II: Conducting a state-wide inventory of existing dementia care resources and services in Montana

To develop a comprehensive action plan, Work Group members identified gaps in dementia care services and resources across the state.

In 2015, the Work Group conducted a state-wide inventory of care and services available for individuals with dementia and their caregivers and families.

The inventory was conducted at a county level, so all Montanans could be represented without regard to where they reside.

Information collected included availability of primary care providers, health care professionals with dementia care expertise, home and community-based providers including residential care, and caregiver resources in each county.

The Work Group members formed several committees to conduct the inventory and used resources provided by the Montana Senior and Long Term Care Division, the Aging Services Bureau, regional health care organizations, professional and advocacy organizations, and Work Group members.

Phase III: Convening Public Town Hall meetings in Montana

For a comprehensive Montana Alzheimer's and Dementia State Plan to be meaningful, it needs to reflect the views, concerns, and recommendations of Montanans from across the state, especially individuals with dementia, their families, caregivers, and advocates.

To ensure this goal was met, in 2015 the Work Group held 13 public Town Hall meetings in 11 urban and rural communities across Montana.

In the same year, public Town Hall meetings were held on seven Native American Reservations and at Indian Health Services centers. Appendix B provides a map of Town Hall meeting locations.

A member of the Work Group facilitated all Town Hall meetings using an open-ended list of questions designed by the Work Group.

Each Town Hall meeting lasted from 60–90 minutes. A total of 428 individuals attended the meetings held in urban and rural communities across Montana.

Town Hall meetings at Native American Reservations and at Indian Health Services Centers drew 153 participants.

Individuals who attended were encouraged to share their views, concerns, challenges and fears about dementia care as well as resources and services available in their communities. They were also given the opportunity to share—in writing—the point they found the most compelling or important for the Montana Alzheimer's/Dementia Work Group to consider or understand related to dementia care and resources.

A Needs Assessment Survey was developed by the Work Group to help identify the most pressing needs facing Montana families with respect to Alzheimer's disease and related dementias. The survey was given to individuals who attended the Town Hall meetings and they were encouraged to fill it out before leaving the meeting.

The survey was also made available to other individuals who could not attend the Town Hall meetings. Of the 286 people who filled out the survey, 71% had attended a Town Hall meeting. Appendix A provides the Needs Assessment Survey and results.

Phase IV: Writing the Montana Alzheimer's and Dementia State Plan

In preparation for writing the Montana Alzheimer's and Dementia State Plan, the Work Group compiled and analyzed the inventory results and identified gaps in dementia care resources and services across the state. Information obtained from individuals who attended the Town Hall meetings and filled out the Needs Assessment Survey was analyzed to determine common themes.

Based on the findings, Work Group members have recommended and prioritized several action steps for all Montanans, including health care providers, professional organizations, advocacy groups, policy makers, and state officials.

Since this was a "grassroots" effort, several Work Group members' partner organizations helped provide funding to conduct the state wide inventory and Town Hall meetings, offset travel costs and host the Montana State Plan website, www.MTalzplan.org.

Alzheimer's disease is a major health care epidemic in the United States and Montana. Only by working together can we create a dementia-capable state and dementia-friendly communities ready to confront this crisis.

B. Acknowledgements

The following Montana Alzheimer's/Dementia Work Group members contributed significantly to the creation and development of the Montana Alzheimer's and Dementia State Plan. Each has a passion for improving the lives of Montana citizens affected by dementia. We express sincere appreciation to all the Work Group members and partner organizations.

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The Montana Alzheimer's/Dementia Work Group thanks the hundreds of individuals from across Montana who shared their personal stories, concerns, and challenges of Alzheimer's disease and related dementias. Their input was critical to shaping the State Plan.

The Work Group also expresses appreciation to the following elected officials and their staffs, for their participation throughout this process:

- Montana Children, Families, Health, and Human Services Interim Legislative Committee
- Offices and staff of: Governor Bullock, U.S. Representative Ryan Zinke, U.S. Senator Jon Tester, U.S. Senator Steve Daines

The Work Group thanks the editors of the state plan including: Joan Miles, Lisa Bay, and Renée Robinson. The Work Group appreciates the contributions from the family of Michael Sample for the front and back cover art for the plan.

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Disclaimer

The statements presented in this publication are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee or other participants in PCORnet.

C. Diversity Inclusion and Cultural Considerations

When considering services for Alzheimer's disease and related dementias in Montana, there are several specific populations requiring special consideration.

To ensure equal access and effectiveness, programs and services must be designed to serve those in rural and frontier communities, racial and ethnic minorities including Native Americans, non-English speaking individuals, veterans, members of the Lesbian, Gay, Bisexual, Transgender (LGBT) community, individuals with younger-onset Alzheimer's disease, individuals with intellectual and developmental disabilities, individuals with traumatic brain injuries including chronic traumatic encephalopathy (CTE), individuals with mobility and/or sensory impairments, and individuals experiencing post-traumatic stress disorder (PTSD) and co-occurring serious mental illness.

The unique barriers, challenges, and issues affecting these special populations should be part of a larger conversation to ensure fair treatment, dignity, respect, and compassionate care for all people experiencing dementia.

Appendix C provides examples of how comfortable environments in health care facilities could be created for all types of individuals.

5. Background

A. Defining Dementia

Alzheimer's disease and related dementias are degenerative brain diseases that damage neurons or nerve cells in the brain that are responsible for cognitive function. Although there are several types of dementia (see Table 1), Alzheimer's disease is the most common type, accounting for 60-80% of cases. All dementias are characterized as a decline in memory, language, and problem-solving skills.

These deficits are often profound enough to affect an individual's ability to perform everyday tasks. Eventually, neuronal damage can affect the ability to carry out basic bodily functions such as walking and swallowing. Individuals in the final stage of the disease are often bed-bound and require 24-hour care.¹

Table 1: Characteristics of the Most Common Dementias¹

Dementia Type	Characteristics
Alzheimer's disease Most common type of dementia	<ul style="list-style-type: none">• Caused by protein plaques and tangles that affect the neurons in the brain• Early stages: difficulty remembering conversations, names, or events; apathy and depression• Later stages: impaired communication, disorientation, behavioral changes
Vascular dementia Caused by blood vessel blockages leading to strokes or bleeding in the brain. The location of the infarcts will determine how the individual's functioning will be affected	<ul style="list-style-type: none">• Initial symptom: impaired judgment or ability to make decisions, plan, or organize
Dementia with Lewy bodies Caused by Lewy body proteins that accumulate in neurons	<ul style="list-style-type: none">• Initial symptoms: sleep disturbance, visual hallucinations, gait abnormalities, visual difficulties• May have Parkinson-like features• May not have memory loss initially
Frontotemporal lobar dementia Caused by significant shrinkage (atrophy) of the brain in the frontal and temporal regions due to neuron damage	<ul style="list-style-type: none">• Initial symptoms include marked changes in personality and behavior with language difficulties• Symptoms may occur at a younger age than what is typical with Alzheimer's disease
Mixed dementia Caused by the combination of pathologic processes of two or more dementias occurring at the same time	<ul style="list-style-type: none">• Characterized by abnormalities of more than one type of dementia• Most common: Alzheimer's with vascular dementia• Almost half of all dementia cases are mixed type

Parkinson's disease dementia

Caused by abnormal protein accumulation such as Lewy bodies or plaques/tangles that cause neuron damage

- As Parkinson's disease progresses, it often results in dementia
- Parkinson's disease is characterized by problems with movement such as rigidity, slowness, tremor, and abnormal gait

There are several types of dementia. Of these, Alzheimer's disease is the most common, the best known, and the most feared. The disease is considered a chronic disease, persisting for a long period with no known cure or effective treatment.

A preclinical phase can begin 15-30 years before symptoms appear. During this time, nerve cell damage begins to take place. If symptoms are reported and evaluated early on, the individual may be diagnosed with mild cognitive impairment. At this stage, individuals may show some degree of memory loss, but are still able to complete such routine tasks as paying bills and managing medications, though these tasks may demand greater mental effort.

Some individuals do not progress past the mild cognitive impairment stage. However, most individuals develop worsening symptoms, and they are ultimately diagnosed with Alzheimer's or some form of dementia. Once diagnosed, three clinical phases are recognized: mild, moderate, and severe, with an average survival rate of 4 to 8 years after diagnosis.¹

Nevertheless, some individuals can live as long as 20 years with Alzheimer's. The stages of Alzheimer's disease and related dementias are presented in Appendix D. While some medical professionals describe these stages a bit differently, the seven-stage approach is used here as it provides a more comprehensive description of symptoms and a clearer roadmap for what lies ahead.

Not all memory loss symptoms are dementia related. Anyone experiencing concerns regarding memory loss should have a thorough evaluation with his/her health care provider.

Although most people develop symptoms of dementia after the age of 65, some individuals can experience signs of dementia beginning as early as their 30s. Individuals with younger onset dementia

experience a greater initial loss of cognitive abilities such as deficits in attention, visual information interpretation, and language.

The trajectory of the disease shows a faster rate of decline compared to individuals with later onset Alzheimer's. The diagnosis of younger onset dementia is often delayed due to the insidious nature of the disease and because the first signs are often ignored or explained away, as stress or fatigue. The disease affects all aspects of one's life—the ability to be in the workforce potentially resulting in increased financial stress, the ability to maintain relationships and support due to loss of intimacy, and the ability to be independent. All of these changes result in a diminished quality of life.³

These individuals may also have difficulty accessing mainstream dementia services often targeted for older adults and may have age restrictions.

1. Alzheimer's Disease and Related Dementias Risk Factors

Age: Most people with Alzheimer's disease and related dementias are diagnosed after 65 years of age. However, people can develop "early onset" dementia with noticeable symptoms in their 30s, 40s, and 50s.

APOE-e4 gene: Individuals who have this gene (20-30% of the population) are three times more likely to develop Alzheimer's dementia. Those with two copies (2% of the US population) are 8–12 times more likely. Researchers estimate between 40–65% of individuals diagnosed with Alzheimer's have one or two copies of this gene.¹

Family history: Individuals who have a first-degree relative such as a parent or sibling 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.

Education: Individuals with fewer years of education are at a higher risk of dementia. Some researchers believe that having more years of education builds a cognitive reserve that helps individuals better compensate for the changes in the brain that could result in dementia.

Social and cognitive engagement: Remaining socially and mentally active throughout life may support brain health and reduce the risk of dementia.

Traumatic brain injury: Brain injury increases the risk of developing Alzheimer's disease and related dementias. Moderate injuries are associated with twice the risk of developing dementia, while severe brain injuries are associated with 4.5 times the risk.

Cardiovascular disease: Evidence shows that the health of the brain is closely linked to the health of the heart and blood vessels. Many factors, such as those listed below, can increase the risk of cardiovascular disease and therefore increase the risk of dementia. Important to note, however, is that these risk factors are modifiable, unlike some of the risk factors noted above.

- Diabetes
- High blood pressure (hypertension)
- High cholesterol
- Obesity
- Smoking
- Unhealthy diet and physical inactivity

2. Alzheimer's Disease and Related Dementias Prevalence

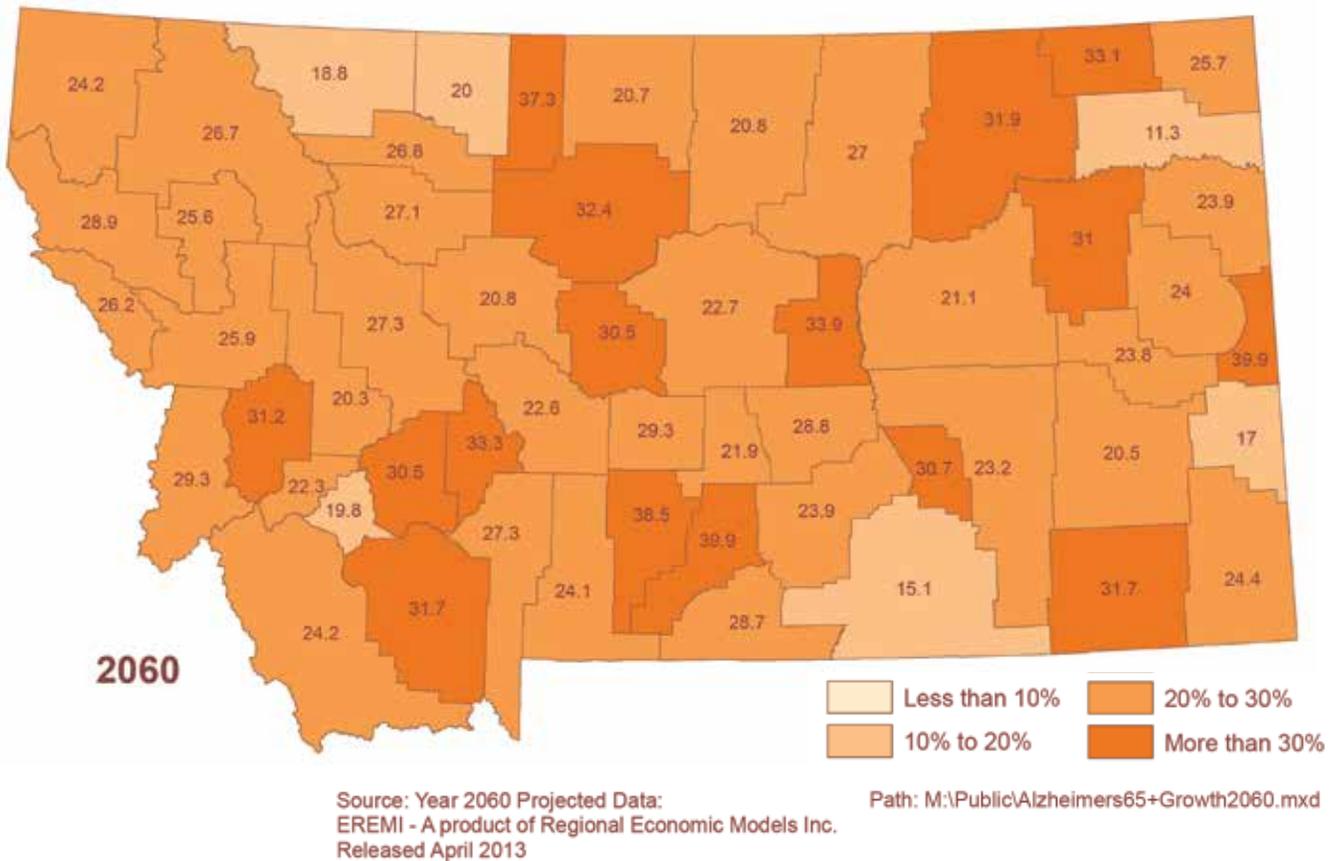
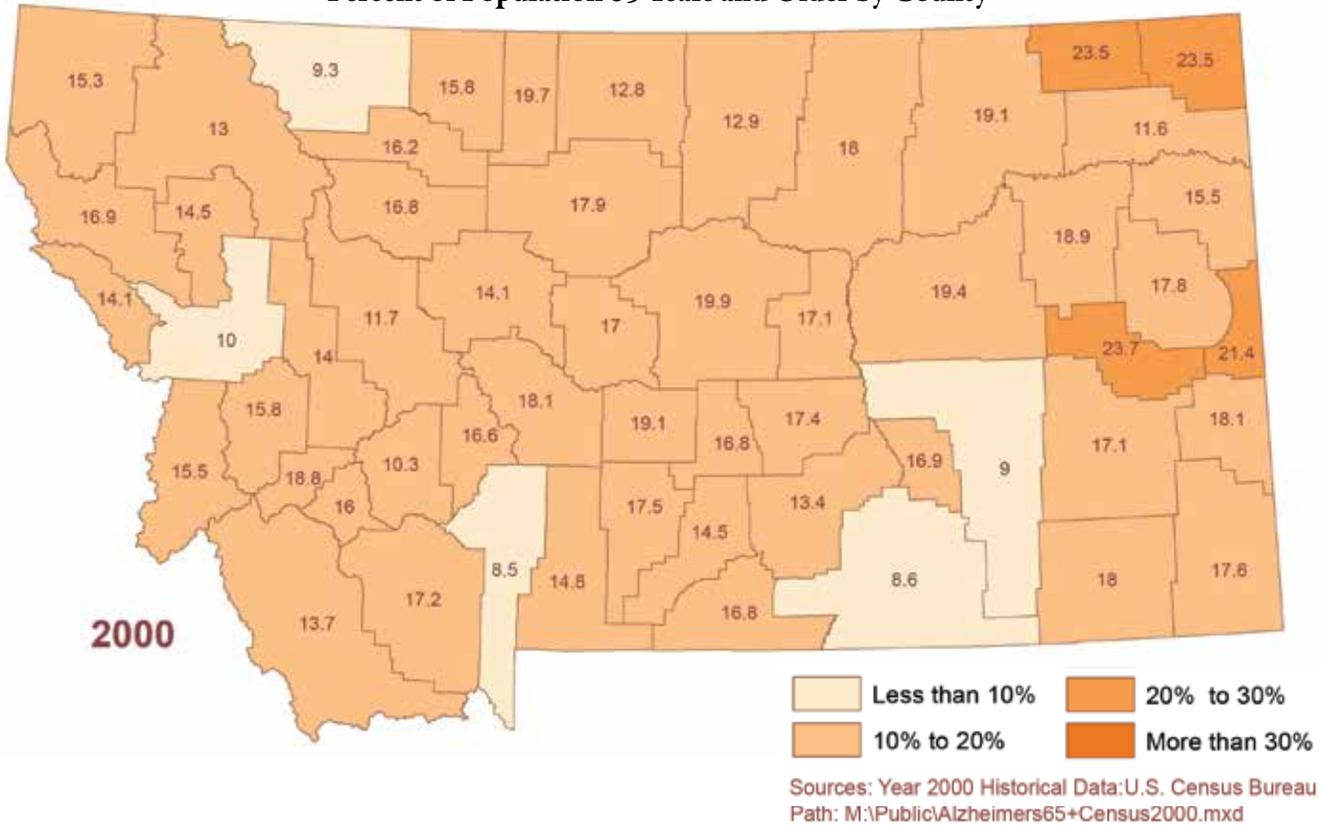
Alzheimer's disease and related dementias are important prevalent chronic health conditions that must be addressed by citizens, health care providers, policy makers, and government officials due to the sheer numbers of those affected and the growing number at risk. As significant as the numbers are now, they are projected to escalate rapidly in the coming years as the baby boomers age.

- In 2016, an estimated 5.4 million Americans are living with dementia.¹ Approximately 476,000 people 65 and older will develop dementia in the United States in 2016.
- One in nine people (11%) 65 and older has dementia while one in three (33%) of people 85 and older has dementia.¹
- A woman's lifetime risk of developing dementia at age 65 is 17% while a man's risk at the same age is 9%. By age 85, women have a 20% lifetime risk while men have a 12% lifetime risk.¹
- African-Americans and Hispanics are more likely than Caucasians to have dementia.¹
- By 2030, the United States population aged 65 and older (an estimated 72 million) will account for over 20% of the total population, up from 14% in 2010.¹
- By 2050, the projected number of cases of dementia will increase from 5.2 million to 13.8 million.¹

Prevalence in Montana

- In 2000, Montana ranked 14th in the nation in percentage of adults 65 and older. By 2025, Montana could rank as high as 3rd in the nation—with the 65 and older population accounting for at least 25% of the population of Montana.⁴
- Some Montana counties will experience over 100% growth in the 65 and older population in the next 20-40 years (see Figure 1).⁵
- In conjunction with rapid growth of the 65 and older population, Montana's working population (25-64 yr.) is decreasing. By 2060, this group will account for less than 50% of the population.⁴ The state-funded programs, such as Medicaid, will be under higher financial stress as the tax base supporting these programs will decrease while demand for services will increase.
- Based on current prevalence rates of Alzheimer's disease and related dementias (11% for those 65 and older, and 32% for those 85 and older), cases in Montana are projected to more than double, from 24,275 in 2012 to 59,761 in 2060, an increase of 146%.^{1,5}

**Figure 1. Comparison of Montana's Aging Population—2000 and 2060
Percent of Population 65 Years and Older by County**

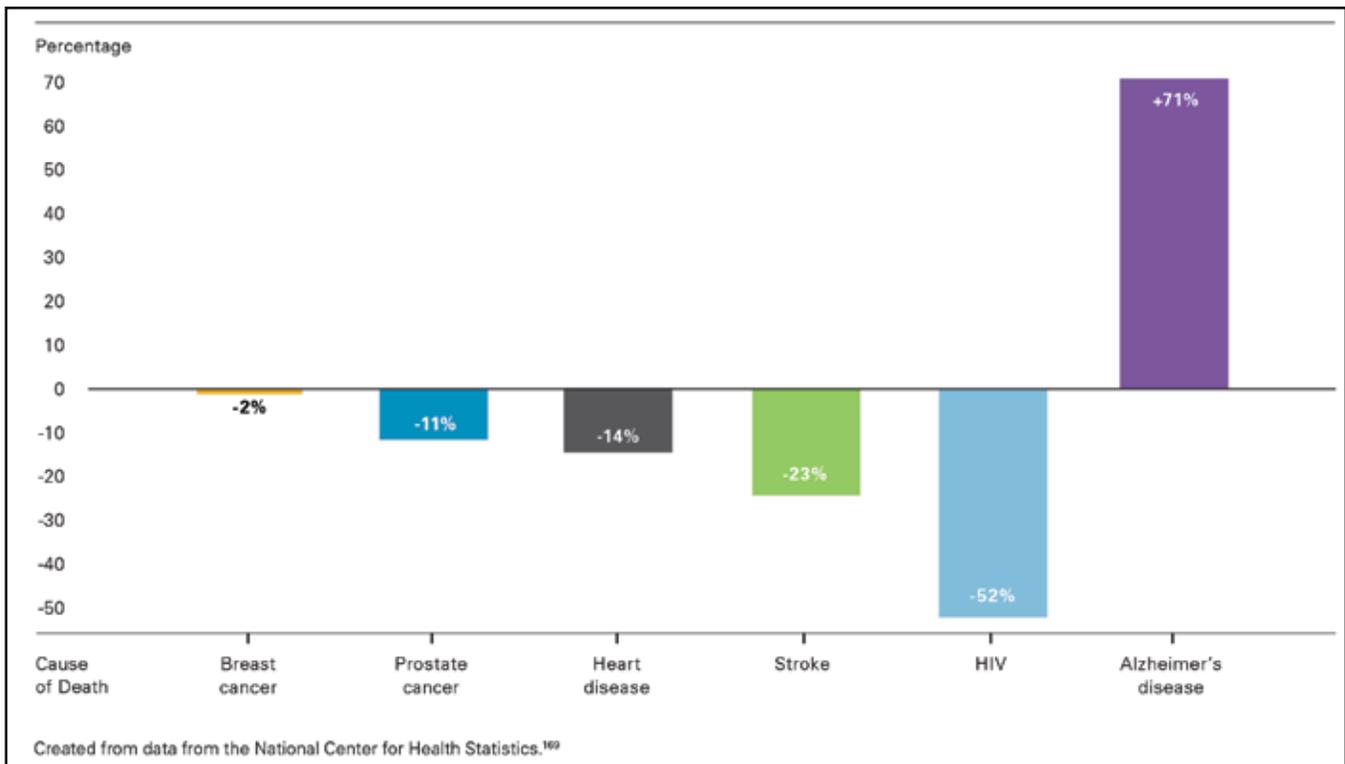


B. Cost of Alzheimer’s Disease and Related Dementias

Alzheimer’s disease and related dementias is currently the 6th leading cause of death in the United States as well as Montana. Of the top 10 causes of death, it is the only one that cannot be prevented, cured, or even delayed. Between 2000 and 2013, most common causes of death, e.g. cardiovascular disease, decreased while deaths attributed to dementia increased by 71% (see Figure 2).

Much of the dementia disease process is spent in a state of disability and dependence. Dementia causes a significant number of deaths as well as an overwhelming number of cases of poor health and disability.¹

Figure 2: Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2013



Source: Alzheimer’s Association Facts and Figures 2016

Alzheimer’s disease and related dementias create a significant public health impact because of their effects on families, caregivers, health and social service providers, as well as state and federal governments struggling to meet the costs to Medicare and Medicaid attributed to individuals suffering with dementia.

The long duration of the disease contributes significantly to this financial burden.

Total payments for health care, long-term care, and hospice are estimated to be \$236 billion in 2016 for individuals with Alzheimer’s disease and related dementias in the United States, 68% of which is covered by Medicare and Medicaid. These costs make dementia one of the costliest chronic diseases to society.

The average annual per-person cost for individuals 65 and older with dementia is \$49,126, ranging from \$28,911 for community-dwelling individuals to \$77,381 for individuals in residential facilities.

In comparison, the average annual per-person cost for individuals 65 and older without dementia is \$15,550. Left unchecked, dementia costs will total over \$1 trillion (in 2015 dollars) by the year 2050.¹

In Montana, \$140 million was expended by Medicaid caring for citizens 65 and older in 2014. This is

projected to increase to \$214 million by 2025, an increase of nearly 53%.⁷ It should be noted these figures are total costs and not dementia-specific.

Medicaid pays for nursing home and other long-term care services for individuals with low income and low assets, services highly utilized by those with dementia.

The Medicaid waiver program is a public assistance program in Montana that provides in-home services and financial support for assisted living expenses for low income individuals, enabling them to reside in the least restrictive living situation.

A waiting list for Medicaid waiver resources has been consistent. Many long-term care facilities across the state operate at near capacity and may place limits on the number of residents on Medicaid they will accept.

Facilities often increase the rate they charge private pay individuals to help defray the losses accrued due to current Medicaid reimbursement rates.

C. Diagnosis and Management

A diagnosis of Alzheimer's disease and related dementias is most commonly made by an individual's primary care provider (PCP).¹ However, most providers do not feel comfortable addressing, diagnosing, and/or managing dementia.⁸ Among those with dementia, only about half have been diagnosed.¹

Significant deficits exist in dementia knowledge among health care professionals. Currently, 97% of all medical students in the United States do not take a course in geriatrics.⁹ Providers seldom use recommended practices in diagnosis and management of dementia.¹⁰

Family members can wait an average of 18 months for a definitive dementia diagnosis.¹¹ Research has shown providers report several barriers to beginning a diagnostic dementia workup early in the disease process including:^{1, 10, 11, 12}

- Absence of clear diagnostic guidelines and reliable screening tools
- Complexity and variability of dementia
- Fear of emotional distress
- Futility of diagnosis for a virtually untreatable disease
- Individual or caregiver wishes
- Lack of financial incentive
- Lack of knowledge
- Lack of resources and specialty care
- Stigma associated with dementia
- Time constraints

Despite barriers and attitudes towards diagnosing dementia, early diagnosis is a prerequisite for improving dementia care as it promotes autonomy and allows the individual to be involved in decision making regarding their future care.^{10, 12, 13}

Increasing the awareness of the diagnosis of dementia among affected individuals and their caregivers is a goal of the Federal Government's Healthy People 2020 initiative.¹ Moreover, the National Institute of Aging suggests an early diagnosis can help preserve cognitive function.¹¹

Early diagnosis is also critical for effective use of newly emerging treatments, based on the theory that treatments will be most successful in earlier stages of the disease.¹⁴

Individuals who have been diagnosed receive higher quality care, have the opportunity to take part in clinical trials, have better decision-making capacity while still competent to understand treatment options, are more likely to follow a treatment plan, and have increased ability to plan for the future.¹

Without diagnosis, individuals, family members, and caregivers are left to fend for themselves to seek out education and community resources.¹¹

Not only do physicians struggle with diagnosing dementia, even when a diagnosis is made, individuals

"Education. We are blessed with a wonderful medical community, but there is still a gap by medical providers hesitating at diagnosis and help with planning and looking at the big picture [with the patient]. Whether they don't know or don't want to be the bearer of bad news, I don't know."

~ Townhall Participant

and their families may not be told of the diagnosis. Fewer than 50% of individuals with dementia and their caregivers report being told of their diagnosis, much lower than most other medical conditions.¹

Of those informed of a dementia diagnosis, 84% stated they were not provided with education about the disease, nor informed on how to care for someone with dementia. Only 7% indicated they received information regarding community resources.¹¹

In Montana, Alzheimer's disease and related dementias diagnosis and management is even more difficult due to the lack of primary care providers, especially in rural and frontier communities. Montana currently ranks 41 out of the 50 states for primary care physicians per capita with 99.7 physicians per 100,000 residents. This is significantly lower than the national average of 120 physicians per 100,000 residents.¹⁵

In 2014, between 20-30% of Montana's population was living in a region designated as a primary care health professional shortage area.¹⁶ Limited numbers of health care providers also limit available treatments options and choices, predisposing the population to poorer quality care, particularly in rural and frontier areas.

According to the National Rural Health Association, only 10% of practicing physicians serve rural areas although 25% of the US population lives in rural areas.¹⁷

Because of the lack of primary care physicians, nurse practitioners and physician assistants are vital to filling the void in health professional shortage areas. Studies show that nurse practitioners can ably render the vast majority of medical care provided by primary care physicians. Additionally, research shows that health outcomes and quality of care is comparable among patients served by nurse practitioners compared with those served by physicians.¹⁶

In some areas of Montana, a nurse practitioner or physician assistant may act as the sole health

care provider in the community. However, there is inadequate data about their use in Montana, nor is there information regarding the comfort level of these providers in managing individuals with dementia.

In more urban parts of the country, geriatricians are a valuable part of the health care team. When a provider does not feel comfortable discussing or treating medical problems facing older adults, such as dementia, a referral can be made to a geriatrician.

Studies have shown older adults have better health outcomes if a geriatrician is involved in care as evidenced by increased independence, higher social and physical functioning, lower incidence of disease, decreased utilization of emergency department and hospital stays, decreased depression, and shorter length of stay in nursing homes.¹⁸

The American

Geriatrics Society recommends one geriatrician for every 300 older adults. By 2030, in the United States, there is projected to be only one geriatrician for nearly 4,000 people.⁹

In Montana, there are currently only seven geriatric providers, including physicians, nurse practitioners and physician assistants, for a population of 160,000 adults 65 and older. This means there is one geriatric provider for every 22,850 older adults.

D. Supporting Caregivers

Caregivers include family members, friends, or paid professionals who provide care to a person with Alzheimer's disease or related dementias. Being a caregiver can be extremely taxing. Because of the stigma associated with dementia, family members and friends may be uncomfortable discussing the disease or interacting with an individual once a diagnosis has been made. This withdrawal of loved ones can be very isolating for both caregivers and individuals with dementia.¹⁹

Family, friends, and other unpaid caregivers provide 83% of the care to individuals with dementia. Currently there are more than 15 million caregivers

“Three different medical professionals provided testing and diagnosis, but provided NO information about how to provide the best care possible. I don't know what's available and who to call for what.”

~ Townhall Participant

in the United States providing unpaid care for individuals with of Alzheimer’s disease and related dementias, working an estimated 18 billion hours annually, valued at \$217.7 billion based on a rate of \$12.17/hour.

During 2015, 49,000 family caregivers in Montana provided an estimated 55 million hours of unpaid care valued at \$679 million.¹

Caregiving Tasks

Caregivers of individuals with dementia spend an average of 171 hours a month in their caregiving tasks, compared with 66 hours a month for caregivers of individuals without dementia. Along with an increased time commitment, caregivers of individuals with dementia face significant financial burdens. Family caregivers spend an average of \$5,155 of their own money annually to cover care costs, making it the chronic disease with the highest out-of-pocket expenses.¹

Many caregivers have cut back on basic necessities including food and medical care for themselves and family members to cover costs of care. In a survey conducted by the Alzheimer’s Association, 28% of caregivers report they ate less or were hungry because they did not have enough money to afford decent meals. The high cost of medical care may contribute to food insecurity for these individuals and their families.

Furthermore, caregivers often spend money from

Typical Caregiving Tasks

- Bathing, dressing, grooming
- Helping with walking
- Household chores
- Manage finances
- Managing behavior symptoms
- Managing paid caregivers
- Meal preparation
- Overseeing medication management with sometimes complex medication regimens
- Provide transportation
- Shopping
- Social activities/companionship

Did you know?

- Caregivers provide an average of nearly 22 hours per week in their caregiving tasks¹.
- Caregivers of individuals with dementia are often unprepared financially and do not understand what insurance covers.
- Caregivers experienced average income losses of \$15,194 annually, with 41% losing 20% or more of their household income¹.

personal savings and retirement accounts to cover costs, thus jeopardizing their own financial security.¹

A 2015 AARP Caregiving in Montana survey found the average age of care recipients was 80 years old, with 90% of care recipients 65 or older. For those Montana caregivers of working age (45-64), 66% provided care to a loved one while working full- or part-time. Two-thirds of these caregivers had to adjust work schedules to meet the care needs of their loved one. Thirty-nine percent reported needing to make weekly adjustments in work schedules.²⁰ These work disruptions for caregivers lead to financial and emotional stress as income and associated benefits become depleted.¹

There are many reasons a person becomes a caregiver. Some feel a desire to keep their loved one at home; others wish to be as close to their loved one as possible; others feel obligated to provide care, sometimes feeling they were given no choice.¹

Caregivers provide a variety of tasks for their loved ones.^{1,20} Managing personality changes and behavioral issues are often the most challenging.¹

As the individual with dementia continues to decline in cognitive and functional abilities, caregiver responsibilities increase, as does the potential for increased financial and emotional stress and the risk of depression and poor health outcomes.

In Montana, 68% of caregivers reported being responsible for medical or nursing tasks. This care is often provided without proper education on how to conduct these tasks. Ninety-five percent of caregivers reported the importance of receiving training on medical tasks so they can provide appropriate care at home.

A vast majority also believe hospitals should keep family members informed of major decisions. They also suggested hospitals should be required to record the name of a patient's family caregiver upon admission and review discharge instructions with the caregiver at time of discharge.²⁰

Nearly 80% of Montana caregivers expressed the need for services that allowed breaks for caregivers.²⁰ This would include respite care, adult day care, and in-home care services.^{1,20}

Case management, support groups, and training programs have also been found to be beneficial to caregivers, helping to relieve the burden of caregiving tasks.¹

Legal and Financial Planning Issues

Early diagnosis is critical so caregivers and individuals with Alzheimer's disease and related dementias can be included in important discussions regarding legal issues and financial planning. The sooner planning starts, the more the individual with dementia can participate and express his or her own wishes. Knowing the individual's wishes helps eliminate guesswork for families and caregivers and allows for the individual with dementia to designate a surrogate decision-maker when necessary.

Legal and financial planning should include:^{16,17}

- Planning for health care and long-term care needs including estimates of possible costs for the entire disease process.
- Making plans for how to manage finances and real estate properties to help cover future health care and living costs.
- Naming another person to make decisions on behalf of the individual with dementia once the individual no longer has the mental capacity to do so.

Involving an attorney or financial advisor in these discussions may be beneficial, especially in the early stages of the disease while the individual is still able to participate in decision-making.

Attorneys can assist in completing certain forms including power of attorney, trusts, and wills.

Financial advisors can help individuals with

"Most people get no legal advice at all. The only reason that he told me is we have such a terrible situation. All the people that I've talked to in support groups or elsewhere never get told what their legal needs are and they don't know. People in our support group didn't even know they should get a Power of Attorney."

~ Townhall Participant

dementia and their caregivers identify ways to manage their finances wisely, discover other potential financial resources and tax deductions, and help avoid poor investment decisions that could deplete finances.

Before an individual can no longer make his or her own health or financial decisions, a power of attorney should be established. In some cases, someone may need to be appointed by the court to become the person's guardian. This may occur when it has been determined by the court that the individual lacks capacity to make his or her own decisions, or in situations where a power-of-attorney has not been established and/or there is not someone to designate as a power of attorney.

Many jurisdictions in Montana have inconsistent approaches to the guardianship process and are in need of volunteer, court-appointed guardians. Current efforts to address guardianship issues include:

- Improving education and public awareness of the importance and role of guardians.
- Adopting national standards and ethics for guardianship cases.
- Standardizing training, monitoring, and reporting of guardians.
- Educating law enforcement and officials about guardianship best practices and limitations on guardians.
- Creating additional local guardianship services throughout Montana.

E. Standards of Dementia Care

1. Treatment

Person-centered care should be a hallmark for treatment of Alzheimer's disease and related dementias. This approach establishes partnerships

among providers, patients, and their family caregivers to ensure that decisions respect patients' wants, needs, and preferences.²¹

Because each case of dementia is unique, care should be tailored to each individual's needs and abilities as well as personal goals. Person-centered dementia care requires a broader lens than the traditional medical focus on how a disease affects only the patient. Instead, the focus is extended to family, caregivers, and support networks.²²

Unfortunately, disease-modifying treatments or cures do not exist for dementia. Between 2002–2012, 244 drug compounds were assessed in clinical trials for treatment of dementia. Only one was advanced to the FDA for approval and marketing. The overall success rate for approval is 0.4%, among the lowest treatment for any medical condition.

Because dementia is not understood on a molecular level, developing effective pharmaceutical interventions has proven quite difficult.²

Medications currently on the market for dementia are meant to treat symptoms such as cognitive decline, however, they do not affect the underlying disease process. Research has shown these medications have only a modest effect on the symptoms, with improvement lasting between 6-12 months.¹ Because of the cost of these medications and their modest effectiveness, there is controversy among health care providers regarding their use.²²

Several other types of medications grouped together as psychotropics may be used to treat behavioral symptoms, particularly if the individual poses a risk of harm to him/herself or others.

However, there has been more focus lately on non-pharmacologic interventions, i.e., those that do not use psychotropic medications to control symptoms, as the first line of treatment and to complement medication therapy. Examples of non-pharmacologic therapy include:²²

- Cognitive-based interventions.
- Cognitive training: Exercises with specific emphasis on memory attention and executive functions.
- Cognitive rehabilitation: Exercises to enhance everyday functions.
- Psychosocial interventions.
- Reminiscence therapy: Revisiting past events and experiences. This may involve photos and personal belongings to trigger specific memories.
- Validation therapy: Promotes and stimulates communication by validating the individual's external reality.
- Physical activity interventions.
- Exercise.
- Redirecting to another task to change the individual's focus.
- Caregiver training.
- Environmental adaptations.
- Decreasing sensory attributes such as harsh or inadequate lighting and noise.
- Using a homelike setting in smaller environments.
- Sensory therapy including music and light therapy.

Dementia Care Goals

- Preserve cognitive and functional abilities to maximize independence.
- Reduce behavioral symptoms.
- Manage comorbid conditions to promote optimal health.
- Reduce safety risks.
- Enhance caregiver well-being, skill, and comfort caring for their loved one.

Odenheimer, 2014

Research concerning individuals with dementia has shown an inconsistency in outpatient medical care, high rates of preventable emergency department visits and hospitalizations, and a large number of unorganized care transitions, indicating a need for system-wide improvements in dementia care.²³

Individuals with dementia have three times as many hospital stays and significantly higher use of skilled nursing facilities than individuals without dementia.¹

Several experts and professional organizations have agreed on a series of quality measures for dementia care that health care providers and organizations should use to measure how well they are managing patients with dementia. These are shown in Table 2 on page 30.

Care coordination using a dementia care navigator (someone trained to help link individuals to information, support, and local resources) could reduce unnecessary emergency room and hospital visits and improve care quality.

Navigators for dementia care have been used successfully in the United Kingdom to connect individuals with dementia and their caregivers with community resources and to provide guidance in dementia care questions. These navigators have been found to enhance the caregiver's and individual's ability to find support services resulting in increased satisfaction with care.²⁴

Table 2: Quality Measures in Dementia Care²³

Indicators	Measures
Staging of dementia	Individuals with a diagnosis of dementia will have documentation of their current stage of dementia, i.e., mild, moderate, or severe, at least once in a 12-month period.
Cognitive screening	A cognitive assessment will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia.
Functional status assessment	A functional status assessment will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia.
Neuropsychiatric symptom assessment	An assessment of neuropsychiatric symptoms will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia.
Management of neuropsychiatric symptoms	An assessment of interventions used to treat neuropsychiatric symptoms will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia who exhibit one or more neuropsychiatric symptoms.
Screening of depressive symptoms	A screening of depressive symptoms will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia.
Counseling regarding safety concerns	A safety assessment will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia.
Counseling regarding driving risks	A driving assessment will be done and reviewed at least once in a 12-month period for all individuals with a diagnosis of dementia. If it is recommended an individual no longer drive, transportation alternatives will be discussed.
Counseling regarding palliative care and advance care planning	Individuals with dementia and their caregivers receive comprehensive counseling regarding ongoing palliation and symptom management and end-of-life decisions AND have an advance care plan or surrogate decision-maker documented in the medical record within 2 years of diagnosis.
Caregiver education and support	Individuals with dementia and their caregivers receive education regarding dementia management and behavior changes AND are referred to community support services within a 12-month period.

2. Multidisciplinary Care

A multidisciplinary approach to care is also important. Individuals with Alzheimer's disease and related dementias can have extensive needs including cognitive, physical, social, financial, and emotional issues.

No single health care specialty or discipline has the expertise to handle the complexity of these domains. An effective multidisciplinary team has a shared goal of providing quality dementia care, recognizing and appreciating each team member's contributions.

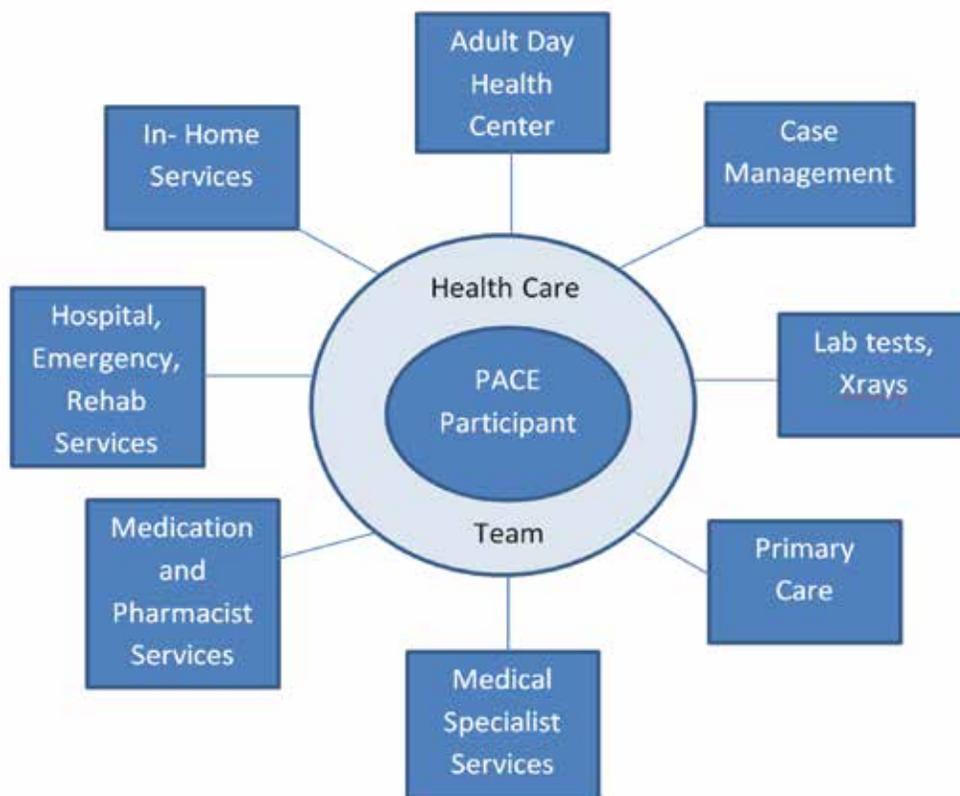
These teams treat individuals proactively, rather than reactionary based on a crisis or change in condition. Multidisciplinary team construction is dictated by available resources including time, availability, finances, and location.²²

Teams can include:

- Community support services
- Dietitians
- Medical providers (physicians, nurse practitioners, physician assistants)
- Nurses
- Physical, speech, and occupational therapists
- Social workers
- Specialty providers (neurologists, psychologists, psychiatrists geriatricians)
- Recreational therapists

A best practice example of multidisciplinary care is the Program of All-inclusive Care for the Elderly (PACE) model.³ This program aims to keep older adults, many who have dementia, in their home communities and avoid institutionalization using a multidisciplinary, person-centered, and coordinated approach to care as illustrated in Figure 3.

Figure 3: PACE Services

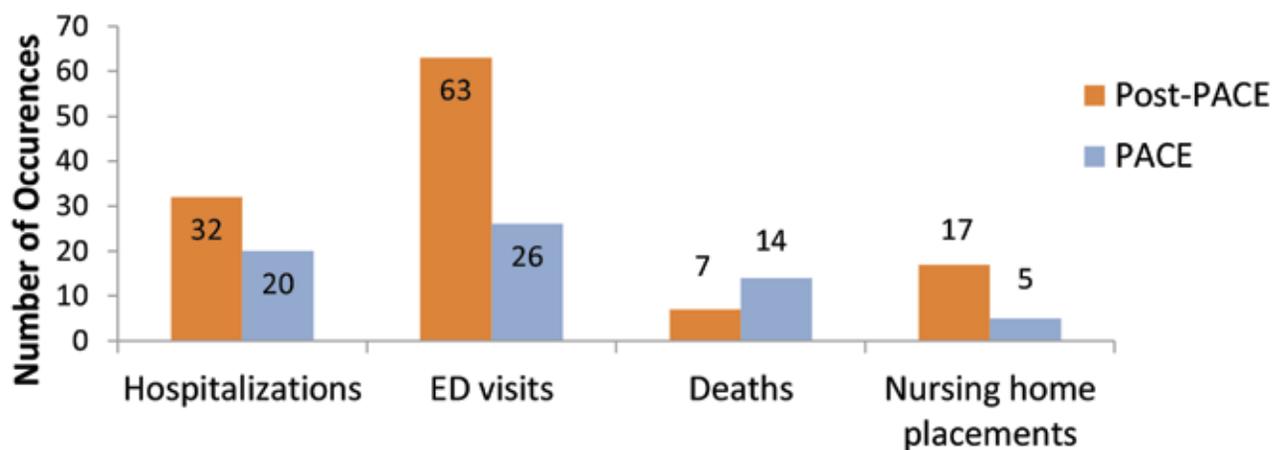


Montana participated in a PACE program from 2009 through 2011, at which point the state discontinued funding the program because there was not the population numbers to support the model in a frontier state like Montana.

When the program was terminated, a research project was conducted to follow the PACE participants for two years to observe health outcomes.

This research demonstrated that after PACE closed, participants had much higher rates of emergency department visits, hospitalizations and nursing home placements, all of which are costly occurrences for the families and Montana (see Figure 4).

Figure 4: Total Medical Occurrences During (2.5 years) and After PACE (2 years)



If the numbers from the PACE program and research project are examined more closely, a nursing home placement for an individual receiving Medicaid benefits costs the program roughly \$5,000/month.²⁵

Comparatively, PACE cost Medicaid roughly \$2,500 per member per month regardless of the care setting, including nursing home. Following PACE closure, there were 17 nursing home placements over the 2-year study period with a cost to Medicaid of more than \$2 million.

For the same amount, Montana could have continued to support PACE for the 34 individuals included in the study over the 2-year period.

Other best practice examples for improving the care of older adults include the use of Acute Care for the Elderly (ACE) units and Nurses Improving Care for Healthsystem Elders (NICHE) programs which aim at improving care of hospitalized older adults.

Unfortunately, neither of these programs exists in Montana, making Montana one of only four states in the country that does not have a NICHE-certified organization.

When hospitalized, older adults are at higher risk for delirium, falls, pressure ulcers, hospital-acquired infections, and other adverse events. Individuals with dementia are at even higher risk for these conditions.

ACE units have been shown to reduce the occurrence and severity of adverse events, thus reducing length of stay and costs.²⁶

NICHE programs educate hospital nurses to identify and assess common geriatric syndromes such as falls and confusion so personalized care strategies can be implemented to improve clinical care and outcomes in hospitalized older adults.²⁷

3. Dementia-Friendly Communities

A relatively new movement in dementia care is the concept of dementia-friendly communities.

The goal of a dementia-friendly community is one in which individuals with Alzheimer's disease and related dementias are empowered to feel comfortable and confident contributing and participating in activities that are meaningful to them.²⁸

Many individuals with dementia do not feel supported or involved in their local communities. They may not know how to contribute in meaningful ways to society and can have a sense of worry, fear, and low self-esteem. Community barriers also exist including stigma or lack of understanding about

dementia and lack of appropriate activities for affected individuals.

In Montana, a best practice example is Lifeside Farms, a program operating in Flathead Valley. This program offers a day program for older adults and people with a disability. Participants share life with the people living on the farm and assist with daily farming tasks. The program is offered at eight locations in Flathead and Lake Counties and is looking to expand. The program is a win-win for participants and farmers.

The dementia-friendly community model has been used in other countries and has been shown to reduce health care costs, improve quality of life and increase community integration for the participants.

Figure 5. Conceptual Model of a Dementia-Friendly Community



Source: www.actonalz.org/sites/default/files/documents/Dementia_friendly_communities_full_report.pdf

F. Health and Social Service Components of Care

1. Home and Community-Based Services (HCBS)

To remain at home, individuals with dementia, as well as their caregivers, require additional support as their dementia progresses. Such support, often referred to as home and community-based services (HCBS), help relieve caregiver stress and burden by providing assistance and providing respite care.

A 2015 AARP Caregiving in Montana survey found most Montanans would like to receive care at home and an overwhelming number (90%) of respondents stated it was very important to provide care to their loved ones at home.

Research studies suggest that many caregivers report feeling unprepared for their caregiving role and do not know how to access available resources.

Yet, by providing caregivers psychosocial and resource support through community-based services, facility placement of individuals with dementia can be delayed by as much as 1.5 years.^{29,30}

Despite a lack of education, unpaid caregivers provide as much as 80% of all caregiving in the United States.³¹

Home and community-based services may include programs such as:

- Adult day care
- Adult protective services
- Aging and Disability Resource Center
- Caregiver education
- Home health aides
- Homemaker services
- Home health services
- Meals on wheels
- Meal sites
- Personal assistant services
- Respite care
- Senior Centers
- Transportation

Unfortunately, many clinicians are not aware of the dementia care services available in their communities and do not readily make referrals. Even when home and community-based services exist in sufficient numbers, there is little systematic approach to their use.³²

Research has shown a significant proportion of primary care providers indicated they lacked knowledge about or confidence in community resources for individuals with dementia. Less than 17% maintained office reference materials for patients and caregivers regarding such resources.³²

There is no data available on home and community-based services referral from Montana primary care providers.

“People who need services, family members for instance, can’t find in the phone book where to go, who to ask, where to get resources. There is too much hurt in this disease, and it is not easy to figure out where to get information and help.”

~ Townhall Participant

Home and community-based services are obtained through private-pay agencies, organizations sponsored by the Area Agencies on Aging (AAAs), or Medicaid-contracted agencies if the individual

qualifies for Medicaid.

Medicare does not cover HCBS except for very limited, short-term skilled home health care, generally following a hospital stay.

According to the 2015 AARP survey, 56% of family caregivers used their own money to provide care for a loved one.²⁰

Montana has ten AAAs that serve every county in the state. The size of the AAAs varies significantly, ranging from one county to seventeen counties in one AAA region in the eastern part of the state. Of the approximately 211,800 Montanans age 60 and over, the AAAs provided services to 58,000 or 27% of the population in 2014.³³

The primary goal of the AAAs is to empower older adults to make informed decisions and easily access health and long-term care options so they can remain in their own homes for as long as possible.³¹

As with most public entities, the AAAs face significant funding challenges. Although the AAAs offer a variety of services, the available services are often not dementia-specific.

Montana low-income adults with dementia requiring higher levels of care may be eligible for Montana's Medicaid waiver program that helps individuals at risk of being institutionalized to remain in their homes.

In 2014, more than 2,500 individuals received waiver-funded services at a cost of \$38.4 million. However, as of February 2016, more than 400 people were on a waiting list for these services. The average number of days on the Medicaid waiver waiting list is approximately 190 days. This does not include the wait time for the Medicaid application, which can take at least 45 days.³³

Key Attributes of Dementia-friendly Communities

1. Ensure early diagnosis and referral to community supports.
2. Provide practical support to enable engagement in community life.
3. Support individuals with Alzheimer's disease and related dementias in whatever care setting they may live.
4. Have consistent and reliable transportation options.
5. Have easy-to-navigate environments.
6. Create respectful and responsive businesses and services.
7. Involve individuals with Alzheimer's disease and related dementias, shaping communities around their needs.
8. Challenge stigma and build understanding.
9. Offer accessible community activities and include individuals with Alzheimer's disease and related dementias in existing community activities.
10. Ensure individuals with Alzheimer's disease and related dementias acknowledge their potential to make positive contributions to their communities.

Alzheimer's Society, 2013

The waiver program also helps defray costs of personal care homes and assisted living facilities. Most Medicaid waiver services in 2014 were provided in assisted living facilities and group homes (52%) with home services a close second at 43%.³³

Assisted living facilities can provide an alternative care setting to nursing home care. In 2010, 42% of residents in assisted living facilities in the United States had dementia.¹

However, similar to home and community-based services, outside of the Medicaid waiver, there are no public funds to help cover assisted living costs. Some individuals who live in nursing homes could be potentially cared for in assisted living environments at a lower cost.

"The Money Follows the Person" program is a Medicaid demonstration program that helps Montana shift its long term care system by reducing the use of nursing homes by increasing the use of home and community based services. The goal of the program is to assist individuals with the transition from institutional settings into the community.

For individuals in this program, the Medicaid dollars used to pay for the costs of nursing home are redirected to pay for assisted living costs or home and community-based services.

However, as of December 2014, only 15 elderly individuals in Montana had transitioned from nursing homes using this program.

Special transportation services for older adults were rated the most important services to help individuals remain at home according to the AARP survey.²⁰

Transportation is a significant issue due to the frontier nature of most of Montana. Even in more "urban" areas of the state, it can be difficult to find transportation options appropriate for individuals with dementia.

Individuals in rural areas often have to travel long distances to service providers with no reliable means of transportation if they can no longer drive. Conversely, service providers have difficulty managing their business costs if they are required to travel long distances to reach clients.

Another important dementia service is respite care. Respite is an umbrella term that describes

services that provide caregivers with temporary relief.³⁴

Respite care may be described by the location in which it occurs—for example, in-home, in-hospital, in-community, drop-in, adult day care, or in a supervised facility.

Respite care is often characterized by being either of short duration (hours), or long duration (days/weekends or longer).

Studies have shown the use of respite services is often low and does not appear to match caregiver need. Indeed, many caregivers of older family members do not realize the need for respite until their own health begins to deteriorate.³⁵⁻³⁷

2. Residential Care

Although most people would like to remain at home, this is sometimes not possible, particularly for individuals with Alzheimer’s disease and related dementias. Approximately 30-40% of older adults with dementia live in a facility compared with 2% of older adults without dementia.¹

Studies have shown much of the time individuals spend in the severe stage of dementia is spent in nursing homes and an estimated two-thirds of those who die from dementia do so in nursing homes.¹

Medicare does not cover long-term nursing home costs. Nursing home costs can be covered by Medicaid once the individual’s personal assets are depleted to the point of meeting Medicaid eligibility.

In Montana, 60% of nursing home residents are enrolled in Medicaid.³³

In 2013, nursing home expenditures accounted for \$143.6 million, 14% of the Montana Medicaid budget.³⁸

In 2014, total nursing home expenditures increased to almost \$162 million and care was delivered to just under 5,000 Montanans. This continues to be the largest expenditure in the state’s Medicaid budget.³¹

Long-term care insurance is another potential

funding source to cover nursing home costs, but such policies are not common in Montana.

The average Medicaid payment for a nursing home resident is approximately \$61,685/year. The actual cost of providing care is approximately \$75,750/year.²⁵

On average, nursing homes lose more than \$38 per resident per day providing care to Medicaid beneficiaries. These financial losses limit the ability of facilities to attract qualified staff as nursing home wages may not be able to match wages in other health care markets. This results in high turnover rates or inadequate staffing levels, and can lead to an increased of closure for nursing home facilities, particularly those in rural areas and can also result in poor health outcomes for residents. Although staffing issues have been noticed anecdotally, no real data on this issue is available in Montana.

In an effort to thwart lost revenue, the culture and existence of nursing homes is changing. More facilities are either limiting the number of Medicaid patients they will accept and are transitioning long-term care beds to short-term skilled rehabilitation beds, or, in the case of critical access hospitals, closing their nursing homes altogether and switching to swing beds.

Critical access hospitals often do not have the

resources to operate long-term care beds, particularly for residents requiring specialized dementia care. Skilled nursing home beds have higher resident turnover rates and are better reimbursed by Medicare and private insurance.

“I didn’t know where to go. My kids said ‘It’s you or him.’ They meant that one of us, my husband or me, was going to have to go (to a facility), my husband because of his symptoms or me because of my fatigue. There’s a saying, ‘A drowning man always takes someone with them.’”

~ Townhall Participant

Behavioral issues can be a significant problem in residential care facilities. Difficult behaviors can be a significant contributing factor of nursing home placement. Small-scale, homelike environments may help reduce behavioral symptoms, increase social engagement, improve residents’ quality of life, as well as increase staff and family satisfaction.^{6, 39-41}

In these small-scale settings, normal daily life is emphasized and residents are encouraged to

participate in meaningful activities and tasks.⁴⁰

One study found that although small-scale facilities reported higher behavioral issues, fewer physical restraints and psychotropic medications were used compared to traditional nursing home

units. Furthermore, wandering is more accepted in smaller environments as a normal behavior of individuals with Alzheimer's disease and related dementias.³⁹

Residential care facilities are increasingly promoting resident-directed care by supporting residents' autonomy and dignity, allowing residents to make their own choices, and encouraging social interactions and participation in meaningful activities. This is in contrast to the traditional medical model of care historically used in residential care facilities, which emphasized basic custodial care, safety, and uniformity.³⁹

The workforce providing care to older adults is also an important component to quality and accessible care. Turnover rates are high, recruitment and retention remain persistent challenges, and facility staff often do not have adequate training to deal with the complex challenges of dementia care.

Although a wide variety of workforce dementia training programs exist, they are not widely used or approached in a standardized format. Appendix E lists dementia training programs available across Montana.

As part of the Affordable Care Act, direct-care workers in nursing home facilities are required to show proof of annual education in the management of dementia. Despite this regulation, training programs are not consistent in facilities across Montana.

The Alzheimer's Association has developed goals and guidelines for clinical care of individuals with Alzheimer's disease and related dementias living in residential facilities. Appendix F lists dementia clinical care guidelines.

Knowledge deficits are particularly noticeable in

Did you know?

The average yearly cost for a private nursing home room in the U.S. in 2012 was \$92,977

The average yearly cost of a basic service assisted living room in the U.S. in 2012 was \$43,756 per year.

Alzheimer's Association, 2016

behavior management.

Montana has only two in-patient behavioral health units that manage geriatric patients, one in Billings and one in Helena. Occasionally, after sending a resident to an in-patient unit for assessment, the referring

facility may decline to take the resident back.

If the in-patient unit is unable to secure another nursing home placement, the last resort may be transferring the resident to the state mental hospital at Warm Springs. This is usually the least appropriate setting for individuals with dementia and results in extremely high costs to the state. The average rate per day in the state mental hospital is \$516.39, of which the state pays 100%. Other states have shown that smaller, more dispersed inpatient units have improved patient outcomes and result in cost savings.⁴²

3. End-of-Life Care

Palliative care and end-of-life discussions should begin early in the disease course to allow for the individual with Alzheimer's disease and related dementias to be part of the decision-making process. Open and honest communication between families and health care professionals is critical.⁴³

Because dementia is a progressive and terminal disease, conversations about the individual's prior stated wishes should be translated into individualized care as the disease progresses.

Hospital stays for individuals with severe dementia have been shown to be more harmful than helpful given the lack of improved outcomes. There can also be significant complications for individuals with dementia including:⁴⁴

- Heightened agitation or delirium
- Limited attention to pain control
- Utilization of harmful restraints
- Higher health complication rates

Conversely, individuals whose surrogate decision-makers had an understanding of complications associated with advanced stages of dementia were

much less likely to have invasive interventions in the last three months of life.⁴⁴

In 2013, the Centers for Disease Control and Prevention (CDC) reported 84,767 died from Alzheimer's disease and

related dementias that year.¹ However, it is likely more Americans had dementia as a contributing factor in death than was captured in CDC data.

Other studies have estimated as many as 600,000 individuals age 65 and older died with Alzheimer's disease and related dementias in 2010.¹ Individuals with dementia frequently succumb to other medical problems resulting from the complications of dementia such as malnutrition and pneumonia.

The way death certificates are completed makes it difficult to determine how many deaths are caused by Alzheimer's disease and related dementias. Differentiating between death with dementia and death from dementia is not always clear. Often death certificates make no reference to dementia, even when the individual has a known diagnosis.

In Montana, 267 deaths were attributed to dementia in 2013.¹

Hospice care can be an important service for individuals with dementia and caregivers at end-of-life. Hospice care provides aggressive symptom management as well as emotional and spiritual support for families.

The main goal of hospice is to allow individuals to die with dignity and respect as comfortably as possible.¹ Hospice can be provided at home, in assisted living facilities, or in nursing homes.

Between 2000 and 2009 the number of individuals with dementia using hospice at time of death increased from 20% to 48%.¹

However, sometimes it is not possible for individuals with dementia to qualify for hospice care due to the difficulty of understanding how long the individual could live if no other terminal medical conditions are present. Hospice was developed under a cancer model of care where predicting mortality, and thus the length of time services would be needed,

Did you know?

The average cost for an individual receiving home and community based services was nearly \$44,000 less per year than for an individual in a nursing home.

Kaye, LaPlante, Harrington, 2009

was fairly straightforward. This is, however, particularly difficult with dementia since the final stages of the disease can often be the longest.¹

Hospice still has a requirement that providers can only make referrals if

the physician believes a patient has six months or less to live. Furthermore, over the past few years, Medicare has been scrutinizing hospice cases, resulting in providers being somewhat leery of accepting dementia patients unless their decline is significant, or they are clearly at the end of life.

Services assisting individuals to die with dignity and respect should not exclude those suffering from terminal Alzheimer's disease and related dementias.

In conclusion, there are many daunting challenges in providing dementia care in Montana and significant costs involved in individuals, families, and Montana Medicaid. In the coming decades, these challenges must be addressed as Montana's population ages if we are to contain dementia-care costs in a way that best serves the individual. The following sections serve to address these issues.

G. Research

While significant amounts of money are spent on Alzheimer's disease and related dementias research, progress towards treatment is slow. Researchers still do not understand the disease on a molecular level, making development of effective treatment options difficult.

Barriers to advancing research include difficulty detecting and diagnosing dementia. Also, the stigma of dementia makes it difficult for individuals to volunteer to participate in research. Existing care models are often fragmented and rarely patient-centered, making it difficult to test and adopt multidisciplinary interventions.

Further and substantial research is needed to better understand disease prediction and progression while developing novel care delivery interventions to improve health outcomes.²

One way treatment options and interventions can

be tested is through clinical trials. Clinical trials are a type of research that offer the opportunity to assess the effectiveness of promising treatments.

The benefit of this type of research is two-fold: participants benefit as they are able to try experimental treatments they would otherwise not have access to, often at little to no cost, and researchers can use the data collected to help advance medical knowledge of how dementia develops.

It is important that individuals with dementia and their family members or caregivers receive information on the availability of clinical trials in their area and how to register. They should also be informed of registries for individuals with dementia.

The slow pace of innovation has created momentum around the world to develop strategic plans. The United States has adopted a goal to prevent and treat Alzheimer's disease and related dementias by 2025, a goal shared by Canada, France, Germany, Italy, Japan, and the United Kingdom.

Multi-government agencies have also committed to improving dementia care including the World Health Organization and the United Nations.

Private organizations are also dedicating resources including the Global CEO Initiative on Alzheimer's Disease, a group of Fortune 500 companies committed to accelerating dementia research. Alzheimer's stakeholders around the globe are searching for new data, new insights, and new tools to meet the goal of preventing and treating dementia effectively.²

Montana has a strong tradition of excellent research that has contributed greatly to the advancement of our understanding of numerous chronic diseases, including Alzheimer's, other dementias, and the application of these research findings.* We need to assure that the most promising evidence-based research projects are advanced and made sustainable.

The Behavioral Risk Factor Surveillance System (BRFSS) is a phone-based survey of citizens 18 years and older across the United States including Montana to assess behavioral risk factors. In Montana, the BRFSS has historically not included questions related to Alzheimer's disease and related dementias, or its burden to caregivers.

In 2016, Montana will add questions from the Cognitive Impairment and Caregiver Modules in the BRFSS survey. Findings obtained using these two modules will be used to inform policymakers and increase public awareness of the societal impact of dementia in Montana.

*Montana's universities and research institutions have been at the forefront of biomedical research for brain disease, mental illness, traumatic brain injuries, and dementia.⁴⁵

6. Findings from Montana Alzheimer's/Dementias Work Group

The following information is the result of work conducted by the Montana Alzheimer's/Dementia Work Group from 2014–2016.

This includes an inventory of health care professionals, home and community-based services including residential care, and the summary of information obtained from discussions with Montanans during public Town Hall meetings held across the state.

The meetings also included conversations with Native American populations conducted on Native American Reservations and Indian Health Services Centers. The concerns, fears, and hopes expressed by Montana citizens echo the challenges outlined previously.

A. Inventory

1. Health Care Professionals

Montana has a shortage of health care professionals, particularly in rural and frontier areas. Eleven Montana counties (21%) do not have access to a primary care physician and another 9% do not have access to a nurse practitioner or physician assistant. Montana currently ranks 41st out of 50 states for primary care providers per capita, with 99.7 physicians per 100,000 residents, as compared to the national average of 120 physicians per 100,000 residents.¹⁵

Further, Montana has a significant shortage of providers specializing in care of older adults and Alzheimer's disease and related dementias, even in urban communities. A noteworthy percentage of counties have no access to specialty providers for this demographic sector, such as neurologists (82%), psychiatrists (71%), psychologists (64%), counselors (54%), and social workers (54%). Although geriatricians have proven to be beneficial when involved in the care of individuals with dementia, there is a shortage nationwide. This is particularly evident in Montana where there are currently only seven physicians, nurse practitioners, and physician assistants specifically trained in geriatric care across the state for a population of just under 160,000 adults 65 and older.

No concrete data are available, but anecdotally, health care organizations across the state are

concerned about a shortage of direct-care workers, especially nurses. Current vacancy rates are concerning, given the aging of the state's population. At the same time, the working-age population is stagnating and even decreasing in some areas of Montana. This may lead to inadequate staffing and a disruption of health care services, particularly as current employees are themselves aging and retiring in higher numbers.

2. Home and Community-Based Services

While dementia services are severely lacking throughout the state, even when services are available, a lack of knowledge persists about availability of community resources among individuals with Alzheimer's disease and related dementias and their caregivers, health care professionals, and service-providing organizations.

Montana citizens indicated during Town Hall meetings that programs offered through Medicaid are very limited and difficult to navigate. The system of long-term-care support services involves numerous funding streams and is administered by a variety of federal, state, and local agencies using fragmented and complex intake, assessment, and eligibility processes.

Town Hall participants also reported frustration with the seeming lack of knowledge and comfort level in diagnosing and managing dementia by medical providers.

Disparities exist between urban and rural and

frontier communities in Montana. Three rural counties have no access to health care providers, in-home services, long-term care facilities, or a hospital. The Area Agencies on Aging (AAAs) admit to a lack of services statewide due to funding levels that have not kept pace with increased demands of an aging population.³¹ The rising cost of providing care coupled with an increased demand for services as the population ages compounds this situation.

The following services are particularly lacking in Montana:

- Dementia case management services—there is only one known case-management organization specializing in Alzheimer’s disease and related dementias in the state.
- Geriatric assessment clinics—there are only five in the state.
- A majority of Montana counties do not have critical dementia care services
 - 63% of counties do not have respite services
 - 67% of counties have one or no organization offering adult day-care
 - 52% of counties have one or no organization offering non-skilled home health service
 - 48% of counties have no hospice services

3. Residential Care

Community housing options for older adults in Montana include low-income senior housing (for persons able to live on their own), assisted living facilities, and nursing home facilities.

Finding these types of housing options in rural and frontier communities, particularly facilities that specialize in memory care, can be difficult.

Thirty-four percent of Montana counties have no access to low-income senior housing.

Twenty-one percent of counties have no access to a nursing home facility, and three counties (Petroleum, Judith Basin, and Treasure) have no access to either an assisted living or nursing home.

“[We need] education, someone to call when presented with unexpected situations, similar to a crisis hotline for the newly diagnosed and caregivers.”

~ Townhall Participant

Availability of residential care across Montana as of February 2015 is outlined in Appendix G.

B. Town Hall Meeting Themes

Thirteen public Town Hall meetings were held in 11 urban and rural communities as well as seven Indian Reservations and Indian Health Services centers to address the current and future needs of people with Alzheimer’s disease and related dementia.

In an article published in *The Missoulian* on June 2, 2015, Kavan Peterson wrote that the Montana Alzheimer’s/Dementia Work Group’s community meetings are “about how we can transform our communities to embrace people living with dementia,” a sentiment that fully applies to both Native American and non-Native American communities.

Conversations were generated from open-ended questions asked to the participants. Participants were given the opportunity to share—in writing—the point they found the most compelling or important for the Montana Alzheimer’s/Dementia Work Group to consider or understand related to dementia services.

A Needs Assessment Survey was also given to participants during Town Hall meetings with encouragement to complete the survey before leaving.

Individuals who completed the survey were asked to identify the most pressing needs facing Montana families with respect to Alzheimer’s disease and related dementias.

The most important issues identified by this

group were the need for information about the types of services available and how to access these services, affordability of services and support for families and caregivers.

Respondents were also

asked an open-ended question at the end of the survey regarding recommendations they might have to improve the care of Montanans with Alzheimer’s disease and related dementias.

The themes of increased service availability, increased education, and increased funding were

continuously reflected in the responses. Inherent in the Town Hall discussions were the differences in level and availability of services facing rural communities.

During several of the Town Hall meetings, participants expressed lack of awareness of existing legal and financial educational resources, while others voiced concern that some resources are only available online. Online access to information has become more common as entities attempt to control their costs. However, families without computers and printers are at a disadvantage. Also, in rural areas, Internet service is intermittent, unreliable, or very slow, which inhibits the downloading of materials.

Another concern was that while the Alzheimer's Association provides a wealth of information on a national level, state-specific materials about legal and financial information are largely unavailable. Individuals may believe they have prepared directives, only to find that these documents may not meet state legal standards.

Native American

Group interviews about Alzheimer's disease and related dementias and its challenges were conducted on all seven Native American Reservations in Montana and at several urban Indian centers with large Native American populations.

Though some national research exists about American, Alaskan, and Canadian Natives on the subject of dementia, much more work must be done to better understand the needs, challenges, and solutions for Native communities.

The findings of the group interviews point out a stark reality, yet attendees also expressed tremendous hope and ideas for the future. Many of the needs expressed reiterated the themes and points made at the urban/rural Town Hall meetings.

However, several issues were unique to Native American communities.

Issues of particular relevance to Native American communities in Montana include:

- Nursing homes and assisted living facilities are present on some Reservations or in geographic areas with large populations. Other more remote Reservations have either very limited beds available, which are not considered a good choice, or alternatives that are many hours away. Placing a loved one in a nursing home or assisted living facility hours away is not a realistic option because of the challenge of not being able to visit regularly. Based on values of interdependence and reciprocity, there is a strong tradition of family members caring for their elders. Having a loved one in a long-term care facility that is hours away can cause significant family distress.
- Financial issues (particularly because of high poverty levels) are also a barrier to placement in facilities, even when it is obviously needed. The requirements and constraints of Medicare and Medicaid spend down guidelines, and the services available through Indian Health Service are both confusing and limit people's access. One urban health care service provider explained that more than 200 people on their client list are eligible and had been pre-qualified for enrollment through Medicaid expansion, yet only a handful had gone through the process to enroll. Furthermore, the cost of between \$4,000 and \$8,000 a month of institutional care, regardless of the source to pay for it, is prohibitive. In addition, program regulations may make offered services incongruent with cultural values.
- Concern was expressed in some communities about instances of observed elder mistreatment and exploitation, with elders who have dementia being most vulnerable. This was particularly troubling to Town Hall participants who indicated their elders should be honored as carriers of tradition and teachers of wisdom.

The Montana service inventory demonstrates that our current resources are woefully inadequate to face increasing demands. At the same time, Montanans across the state have stated loud and clear that we need to prepare ourselves to deal with all facets associated with dementia, so that affected individuals and families can transition through the inevitable phases with dignity and compassion.

Preparing for the years to come will require commitment and courage. Solutions are not simple, but with collective efforts we can begin to address the impending challenges. The following section, Goals and Recommended Action Steps, outlines 11 major issue areas and proposes specific goals and action steps for each. In effect, the plan is a recommended blueprint for the future.

7. Goals and Recommended Action Steps

The following goals and recommended action steps, when implemented, will move Montana towards the creation of a health care system in each community that can effectively manage cases of Alzheimer's disease and related dementias in all stages of the disease.

All individuals with dementia should be able to achieve the highest quality of life, while maintaining independence and choice.

Each individual's health care should be individualized and person-centered, recognizing that everyone experiences dementia differently, with varying symptoms and needs.

Montanans living with dementia should be able to transition through their disease with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, or sexual orientation, in a setting that best aligns with the individual's beliefs, values, and preferences.

To be successful, this health care system will require strong community, regional, and state wide partnerships that promote care coordination and comprehensive disease management, including access to various types of affordable support services.

Health care providers should be adequately educated and trained to recognize early symptoms of the disease and feel comfortable discussing dementia diagnoses freely and openly with affected individuals and family members.

Providers should also have thorough knowledge of community resources so referrals can be made to those resources early and throughout the disease process.

Family caregivers should be valued and supported as an integral part of the health care team.

Goal 1: Public Awareness

Promote awareness and understanding about Alzheimer's disease and related dementias throughout the state to reduce stigma and enhance care.

Educate Montanans about brain health issues and encourage them to institute lifestyle changes where necessary to maintain brain health.

Recommendations

1-A. Support the creation of an Alzheimer's disease and related dementias Facilitator position to oversee ongoing statewide public awareness and brain health initiatives in conjunction with government agencies and private sector organizations.

1-B. Build strategic public-private partnerships to develop and implement a long-term multi-pronged dementia public awareness campaign that provides information about the earliest signs of dementia, and informing how earlier diagnosis and intervention can lead to a more productive and valuable life. Partners should include the following:

1. State legislators and state agency officials.
2. Health care providers and organizations.
3. Allied health professionals.
4. Non-traditional partners such as employers, bankers, financial planners, lawyers, other private sector businesses, religious and civic groups, emergency first responders, and other professionals who may have contact with individuals with dementia.
5. The general public, including individuals at risk, and youth.
6. Individuals with dementia and their caregivers and family members.

1-C. Coordinate campaign efforts with Native American communities and Tribal health leaders.

1-D. Establish a permanent Alzheimer's Disease and Related Dementia Advisory Council to be led by the Alzheimer's disease and related dementias Facilitator, and tasked with implementing the Montana Alzheimer's and Dementias State Plan.

1-E. Facilitate outreach and public-private collaborations for individuals with specialized circumstances and needs including those with Down's syndrome with dementia, traumatic brain injury, high-risk minority populations, people with younger-onset dementia, and developmentally disabled individuals.

1-F. Adopt the action items from The Healthy Brain Initiative Road Map, which, when implemented, assists states in becoming dementia-capable. This is a national initiative coordinated through the United States Centers for Disease Control and Prevention.

Goal 2: Early Detection and Diagnosis

Encourage health care providers, including physicians, specialists, nurse practitioners, and physician assistants, to recognize and diagnose dementia early in the disease process and refer individuals living with the disease and their family members to educational and community resources.

Recommendations

2-A. Improve training of health care workers by providing information regarding recognition of the signs of dementia. This will allow providers to feel comfortable talking with individuals and families about memory issues and diagnosing dementia. Work in conjunction with professional organizations to develop educational requirements on dementia.

2-B. Study patterns of clinical practices throughout Montana to determine barriers to standards of care in detecting, diagnosing and treating dementia.

2-C. Educate health care providers on available community dementia resources and encourage referral of individuals and families to those resources early and throughout the disease process.

2-D. Develop a systematic approach to cognitive screening and management by creating Dementia Comprehensive Assessment and Resource Engagement (CARE) Clinics to serve as regional geriatric assessment units and dementia centers.

Dementia CARE Clinics will be responsible for assessment and early diagnosis of cognitive problems, supporting the use of innovative approaches such as group visits and services such as educational sessions from local community professionals to include lawyers, financial advisors, and social workers.

Goal 3: Legal and Financial Issues

Ensure that Montanans with Alzheimer’s disease and related dementias and their family caregivers are aware of, and have access to, Montana-specific materials regarding legal and financial alternatives, enabling them to execute appropriate legal documents for their circumstances.

Recommendations

3-A. Provide community workshops and webinars about planning for memory loss that focus on legal and financial aspects for those with cognitive impairments.

3-B. Create and provide a Legal and Financial Awareness packet for health care providers to distribute to their patients with dementia, as well as their family caregivers.

3-C. Encourage state agencies and private sector organizations to ensure that Montana-specific legal and financial resources are available for family members and their caregivers on their websites, as well as provide printed copies for Montanans who do not have computers or have difficulty accessing internet services.

3-D. Develop a Legal and Financial Awareness “train the trainer” outreach program for faith-based and volunteer organizations to enable them to assist families who have a member with cognitive impairment.

3-E. Encourage Montanans to consider the inclusion of a dementia provision in their advanced care directives and health care powers-of-attorney.

3-F. Promote the availability of the Department of Public Health and Human Service’s Adult Protective Service’s Referral Line to report abuse, neglect, and financial exploitation of those with dementia.

3-G. Develop a Power of Attorney Registry or Clearinghouse mechanism similar to the Montana End-of-Life Registry that could be accessed by financial institutions or agencies upon permission of the Power of Attorney agent to simplify proof of who has legal authority to act on behalf of an individual with dementia.

3-H. Convene a group of representatives from the Native American reservations to determine how to meet the legal and financial issues they experience regarding dementia care and management.

Goal 4: Person-Centered Care

Ensure that Montana adults with Alzheimer’s disease and related dementias will be able to successfully age in place with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, religious preference, gender identity/expression, or sexual orientation in the least restrictive setting that best fosters his/her current level of cognitive and functional ability, while maintaining a high quality of life.

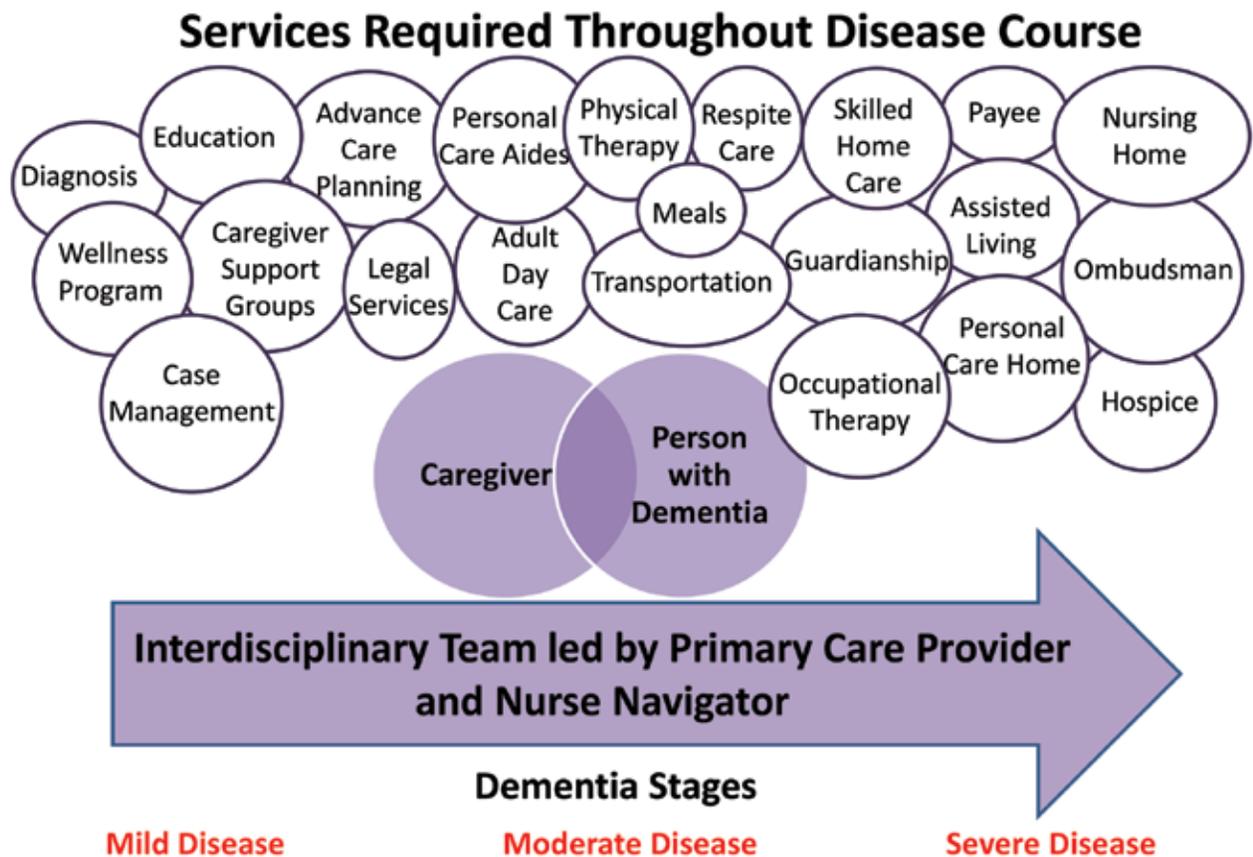
Recommendations

4-A. Train health care providers to design individualized dementia care plans. Encourage physicians and direct care providers to establish a multidisciplinary plan of care at diagnosis to follow the individual throughout the disease process, led by a navigator who will act as the family’s primary contact for medical and social questions.

4-B. Recruit and train dementia-care navigators to be directly involved in the care of individuals with

dementia using the Proposed Dementia Navigator System as a guide, shown in Appendix I. Navigators will help individuals with dementia and their caregivers determine the most appropriate and least restrictive setting for individuals throughout the progression of the disease.

4-C. Promote the creation of peer support groups for individuals with dementia as well as peer support groups for families and caregivers.



Goal 5: Workforce Education and Development

Maintain adequate numbers of direct care workers, aides, nurses, nurse practitioners, physician assistants, physicians, social workers, first responders, and other professionals. Ensure that they receive the appropriate training to meet the needs of the Alzheimer's disease and related dementias population in all care settings.

Recommendations

5-A. Improve access to specialty providers such as psychiatric, geriatric, and palliative care physicians across the state using telehealth services. Telehealth services can provide live interfacing with specialists and other health care providers in communities lacking these medical professionals. Several telehealth/videoconferencing networks exist across Montana. Appendix H lists available telehealth networks.

5-B. Track data related to workforce shortages. Because workforce data collection in the state is inconsistent and incomplete, promote and support legislative efforts to collect standardized data on relevant licensed health care professionals.

5-C. Support the increased use of nurse practitioners and physician assistants to address the needs of individuals with dementia and their caregivers to help fill the gap of physician shortages.

5-D. Promote policy for nurse practitioners and physician assistants in states deemed "frontier" states by the Affordable Care Act, such as Montana, to be reimbursed by Medicare, Medicaid, and private insurers at 100% of Medicare allowable rate if working with vulnerable populations, such as those with Alzheimer's disease and related dementias.

5-E. Develop a state-wide Geriatric Nursing Consortium to standardize and promote geriatric education and research including dementia topics, while encouraging people to consider employment in the field of geriatrics.

5-F. Create education and outreach tools that encourage young adults to seek employment working with individuals with dementia.

5-G. Partner with nursing and other health care professional education programs to promote curriculum development that includes content to provide an interprofessional approach to deliver the skills, knowledge, and abilities to care for individuals with dementia.

5-H. Assist hospitals, nursing homes, and home and community-based service agencies with education for their workforce regarding cultural and clinical competencies in caring for individuals with dementia.

Goal 6: Build Dementia-Friendly Communities

Promote dementia-friendly communities in Montana, where individuals with Alzheimer’s disease and related dementias and their caregivers are treated with respect and dignity, and are actively encouraged to participate in community life.

Make it possible for communities to be proactive in assessing community risk for individuals with dementia, such as the potential for wandering, the need for early intervention in crisis situations, and protection from financial and other forms of exploitation.

Recommendations

6-A. Encourage all community businesses and organizations to adopt dementia-friendly practices, including awareness training for employees. Visibly identify these businesses to assist individuals with dementia and their families in selecting businesses prepared to provide compassionate, respectful services and programs.

6-B. Develop a community-based emergency crisis intervention/prevention program that institutes a “course of action” to mitigate dementia issues for families of all cultures and economic means who find themselves at immediate risk. Situations requiring an immediate course of action from emergency personnel include such things as:

1. A caregiver is admitted to the hospital and there is no one else to care for the individual with dementia.
2. A caregiver passes away and there is no one readily available to care for the individual.
3. The caregiver cannot meet the needs of the individual with dementia who has a sudden/violent change in behavior.

6-C. Promote a standardized means of drawing attention to an individual’s dementia status for law enforcement and first responders such as a bracelet, necklace, or wallet card.

6-D. Implement a program at the Montana Department of Motor Vehicles to properly identify individuals affected by dementia who should not be driving.

6-E. Require training to educate law enforcement and first responders on the best practice methods of interacting with people with dementia. Integrate this training into the current Crisis Intervention Training (CIT) program.

6-F. Work with law enforcement to enhance the current missing and endangered persons alerts.

6-G. Train ‘gate keepers’ (e.g., bank tellers, health care providers, store clerks, home delivery staff) to recognize the warning signs of elder abuse (physical, psychosocial, sexual, financial, and neglect) and provide reporting methods.

6-H. Promote a statewide anti-bullying, anti-elder abuse initiative across various care settings, including in-home services, nursing homes, assisted living residences, senior centers, and adult day programs. Such initiatives should also be employed on Native American reservations.

6-G. Assemble a group of Native American representatives to discuss the cultural needs they may experience in their communities and how to address them.

Goal 7: Caregivers

Reduce caregiver burden and stress by promoting changes in medical, social system, and employment policies that will support and empower caregivers. Promote the availability of caregiver education and support systems in all communities.

Recommendations

7-A. Provide education, training, and easy access to information and help for caregivers and families via a variety of methods including printed materials, in-person education sessions, webinars, on-line meeting sites/videoconferencing, and support groups.

7-B. Promote the recognition and inclusion of a designated caregiver by all care providers involved in the care of an individual with dementia including primary care providers, hospitals, nursing homes, assisted living facilities, respite care centers, and community-based service providers to ensure coordinated care in all settings.

7-C. Create, publicize, and maintain support groups across the state in every community led by trained volunteers or trained facilitators, as a means of education for caregivers and others who may be facing dementia in their families.

7-D. Create curricula and provide training for dementia support group facilitators.

7-E. Expand and publicize available respite care services including those offered by the Area Agencies on Aging under the National Family Caregiver Support Program and the Montana Lifespan Respite Coalition.

7-F. Enlist and educate the faith-based community as resources that can help support families and caregivers facing dementia. Invite faith leaders and parish nurses to applicable training opportunities and request their assistance in disseminating information and materials.

7-G. Educate employers about the issues facing caregivers and families; encourage them to establish workplace policies such as flextime, telecommuting, referral services, on-site support programs, and counseling through Employee Assistance Programs. Provide employers with applicable training opportunities and request their assistance in disseminating information and materials.

7-H. Encourage employers to expand paid/unpaid leave options specific to employees who are caregivers to individuals with dementia.

7-I. Expand Family and Medical Leave Act (FMLA) provisions in Montana to include coverage for adult care.

7-J. Establish state tax credits, similar to the child care tax credit, for caregivers and families paying for direct care services to encourage the use of early intervention and support services, such as adult day and respite care.

Goal 8: Home and Community-Based Services

Expand the availability of high-quality, affordable home and community-based services (HCBS) that meet the needs of the individuals living with Alzheimer’s disease and related dementias, allowing them to live in the most appropriate and least restrictive setting.

Recommendations

8-A. Promote the creation of dementia service coalitions in all communities to increase awareness, promote services, and problem solve to address needs within communities.

8-B. Expand respite care, case management, and memory assessment clinics throughout the state as these services in particular are critically lacking.

8-C. Increase the number of Medicaid Waiver slots available to allow individuals with dementia to live in the most appropriate and least restrictive setting possible.

8-D. Encourage the use of innovative technologies such as telehealth services, home care monitoring, and automated medication dispensers.

8-E. Develop creative transportation options to serve both rural and urban areas, and explore incentive programs for transportation providers who specialize in services that meet the needs of individuals with dementia.

8-F. Routinely conduct a formal needs assessment every 2-5 years to determine dementia care service needs throughout the state and also assess barriers for individuals and families to access needed services.

8-G. Enhance and actively maintain the state-wide centralized database of dementia care services with real-time data regarding available community resources.

8-H. Explore and support creative approaches to financing home and community-based services. Pilot cost-sharing programs for community-based services to improve care choices, increase service options, and decrease financial burden for those currently not eligible for Medicaid.

8-I. Explore and support creative approaches to enhancing and providing home and community-based services on the Native American reservations.

Goal 9: Residential Care Facilities

Promote wellness and maintenance of cognitive function for individuals with dementia living in residential care facilities, including assisted living facilities, personal care homes, adult foster homes, and nursing home facilities, by offering activities tailored to each individual's needs.

Train staff in non-pharmacological treatment of behavioral issues and person-centered models of care.

Recommendations

9-A. Promote consistent use of person-centered models of care in residential care facilities that promote wellness, conservation and maintenance of cognitive function, and individualized quality of life through implementation of activities tailored to each individual.

9-B. Ensure facility staff receives dementia-specific training and are competent in person-centered interventions in caring for individuals with dementia, and are trained in non-pharmacological treatment of behavioral issues. The goal of care should be to meet the individual's needs in his/her current setting and avoid transfers to more restrictive settings.

9-C. Create and expand the use of small memory care facilities/units for individuals with dementia who have difficult behavioral issues in an effort to avoid use of the state mental hospital and inpatient behavioral health units.

9-D. Investigate alternative, creative methods to finance facility-based care.

9-E. Convene a group of representatives from all the Native American reservations to discuss how to best meet the needs of their citizens so they feel safe, and their cultural expectations are being met in residential care facilities.

9-F. Explore the feasibility of establishing assisted living facilities on reservations.

Goal 10: End-of-life Care

Provide individuals with Alzheimer's disease and related dementias who are near the end of life with high quality care focused on a palliative approach, including aggressive symptom management to ease the discomfort and complications in the later stages of the disease.

Recommendations

10-A. Educate health care providers on the importance of having open and honest conversations with individuals and family members/caregivers regarding prognosis in severe dementia and encourage providers to assist families and caregivers to make compassionate choices.

Information about end-of-life decision making including palliative care, hospice, and right-to-die, should be offered to individuals with Alzheimer's disease and related dementias and their caregivers early in the disease process.

10-B. Educate the public about the importance of discussing advance directives and end-of-life wishes early in the disease process to allow the individuals with dementia to be involved in the decision-making process.

10-C. Ensure that individuals with dementia are not excluded from creating a DNR or POLST directive or right to die, allowing end-of-life wishes to be respected and legally recognized.

10-D. Allow individuals with dementia to benefit from hospice care and not be deprived of Medicare-funded services due to the difficulty of determining imminent death.

Goal 11: Research

Improve and grow dementia data collection efforts in Montana, expand Alzheimer's disease and related dementias research opportunities in Montana and develop new research collaborations with organizations and institutions, and increase participation in research studies and clinical trials.

Recommendations

11-A. Implement a statewide data reporting system to improve data collection on dementia prevalence in Montana including hospital admissions, mortality, adult protective service calls and cases, death certificate data, Medicare cognitive assessment data, minimum data set (MDS) cognitive impairment data in nursing homes, etc.

11-B. Implement and maintain the cognitive impairment and caregiver modules in the Behavioral Risk Factor Surveillance System (BRFSS) survey of Montana residents 18 years and older. Ensure that these modules are included often enough to provide accurate and salient data regarding the cognitive health and caregiver well-being of Montanans. Disseminate findings from the BFRSS for use in program and research development.

11-C. Encourage health systems in Montana to use the Medicare Annual Wellness cognitive assessment as a means of enhancing data collection on cognitive impairment.

11-D. Promote accurate death certificate completion, including dementia as a cause of death, to ensure prevalence data is comprehensive.

11-E. Increase the number of studies conducted in Montana related to dementia and develop new research collaborations with organizations and institutions involved in dementia research.

11-G. Identify challenges to engaging participants in dementia research in Montana, including geographic, socio-economic, cultural, or other differences that may discourage participation and implement solutions that will increase participation.

11-H. Promote programs such as the national Alzheimer's Association TrialMatch (www.alz.org/trialmatch) and other registry programs as a way to match individuals with clinical research studies, including those underway at the nation's 29 Alzheimer's Disease Research Centers.

11-I. Conduct and distribute a yearly review and summary of relevant dementia literature in order to keep abreast of local, national, and international findings, and support the creation of a clearinghouse to provide summaries of research findings to Montana citizens.

11-J. Encourage individuals to support funding for dementia research through organizations such as the Alzheimer's Association, state universities, and local research institutions.

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Appendix A: Needs Assessment Survey

Please take a few minutes to share your experience and suggestions about how to improve the services and resources available in Montana to support persons with Alzheimer's disease or related dementias.

1. What is your year of birth? _____
2. What is your zip code? _____
3. What is your gender? _____ Female _____ Male
4. Which of the following best describes you? (please select only one)
 - _____ Person with Alzheimer's disease or dementia
 - _____ Spouse or partner of person with Alzheimer's disease or dementia
 - _____ Son, daughter, or other family member of a person with Alzheimer's disease or dementia
 - _____ Non-family caregiver of a person with Alzheimer's disease or dementia
 - _____ Health-care provider
 - _____ Social service provider
 - _____ Public employee or official
 - _____ Other, please specify _____
5. Do you provide home-based care for someone who has Alzheimer's disease or dementia?
 - _____ Yes
 - _____ No
 - a. If Yes, how many hours do you care for this individual PER WEEK? _____
 - b. If Yes, what type of health insurance does the person you care for currently have? (*check all that apply*)
 - _____ Medicare
 - _____ Medicaid
 - _____ Veteran's benefits
 - _____ Private insurance
 - _____ They do not have any health insurance
 - _____ Other, please specify _____

6. Identify the three (3) most pressing needs in Montana for persons impacted by Alzheimer’s disease or other dementia. (Please rank items from 1 to 3 with “1” indicating most pressing.)

- _____ Information about the types of services available and how to use them
- _____ Access to services
- _____ Quality of services
- _____ Affordability of service
- _____ Support for families and caregivers
- _____ Education and training
- _____ Other, describe _____

Based on your experiences in Montana, please indicate your satisfaction with the following aspects of services and information available to individuals with Alzheimer’s disease or other dementias.

Place an “x” in the appropriate box for each item. 1 = very dissatisfied, 4 = very satisfied

	1	2	3	4	Don’t know
Access to services					
Quality of services					
Affordability of services					
Support for families and caregivers					
Education and training					
Information about the types of services available					
Information about how to use available services					

What recommendations do you have about how to improve the services and resources in Montana that are available to persons with Alzheimer’s disease or dementia? Please be as specific as possible about what you would like to see happen.

Survey Data Results

1. Did you attend a Town Hall meeting?

Yes	204	71%
No	82	29%

2. Survey respondents county of residence

<u>County</u>	<u>Number</u>	<u>(%)</u>	<u>County</u>	<u>Number</u>	<u>(%)</u>
* Cascade	46	16.4%	Prairie	3	1.1%
* Yellowstone	41	14.6%	Rosebud	3	1.1%
* Gallatin	35	12.5%	Golden Valley	2	.7%
* Missoula	30	10.7%	Lincoln	2	.7%
Valley	24	8.5%	Musselshell	2	.7%
Flathead	18	6.4%	Park	2	.7%
Pondera	13	4.6%	Beaverhead	1	.4%
Lewis & Clark	9	3.2%	Carbon	1	.4%
Custer	8	2.8%	Deer Lodge	1	.4%
Fergus	5	1.8%	Granite	1	.4%
Jefferson	5	1.8%	Hill	1	.4%
Ravalli	5	1.8%	Natrona	1	.4%
Silver Bow	5	1.8%	Powell	1	.4%
Liberty	4	1.4%	Roosevelt	1	.4%
Dawson	3	1.1%	Stillwater	1	.4%
Lake	3	1.1%	Toole	1	.4%
Phillips	3	1.1%			

* Urban
Rural

3. Which characteristic best describes you?

	<u>Number</u>	<u>(%)</u>
One with Alzheimer's	8	3%
Family of One with Alzheimer's	142	50%
Caregiver of One with Alzheimer's	16	6%
Professional Service Provider	86	31%
Public Employee or Official	26	9%
Not Specified	4	1%

4. Do you provide home-based care for someone with Alzheimer's or dementia?

Yes	71	25%
No	213	75%

5. If yes, what type of health insurance does the person you care for have?

Health Insurance	Number	(%)
Medicare	57	80%
Medicaid	9	13%
Veteran's Benefits	13	18%
Private Insurance	36	55%
They do not have insurance	3	4%
Other	9	13%

6. What are the most pressing needs in Montana?

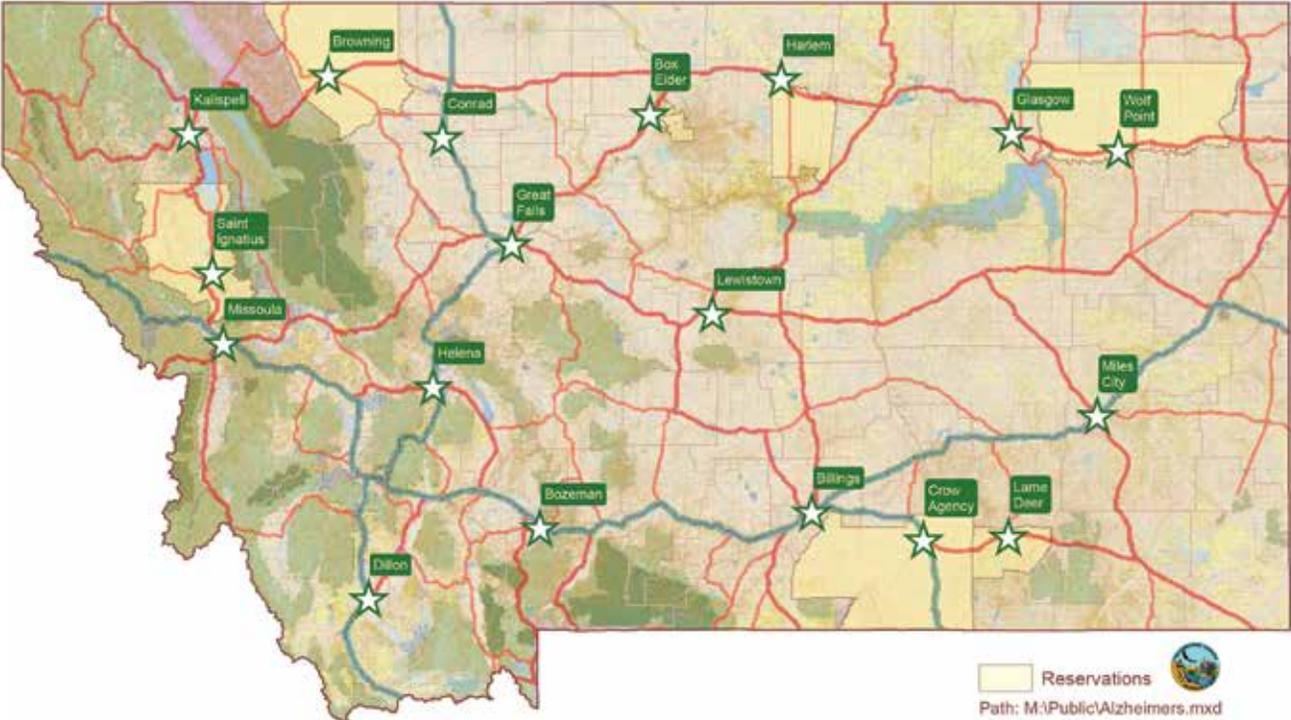
Needs	% of 1st	% of 2nd	% of 3rd	# Prioritized (1, 2, or 3)
Information about types of services available and how to use them	40%	13%	6%	171
Access to services	29%	12%	14%	154
Quality of services	19%	10%	6%	98
Affordability of services	37%	13%	12%	178
Support for families and caregivers	29%	18%	13%	172
Education and training	25%	11%	11%	133

7. What is your level of satisfaction with the following aspects of services and care?

Cell Percentages	1	2	3	4	Don't know
Quality of services	13%	28%	25%	4%	30%
Affordability of services	7%	21%	29%	12%	32%
Support for families and caregivers	26%	25%	16%	2%	30%
Education and training	16%	30%	20%	4%	30%
Information about the types of services available	12%	38%	17%	5%	28%
Information about how to use available services	14%	37%	16%	3%	30%

Appendix B: Map of Montana Town Hall Meetings

Montana Cities Served



Appendix C: Cultural Considerations in Residential Care Facilities

The following areas are examples of how to create comfortable environments for inclusion of all types of individuals.

Intake Forms and Documentation—Because the intake process and forms are often a first encounter for individuals and families, they can be powerful tools in creating a safe and affirming space.

In a safe and confidential space, make sure to ask the individual of their race and cultural preferences as well as sexual orientation and gender identity. If they prefer not to disclose, be respectful. In lieu of terminology such as “husband” or “wife,” use “partner,” “significant other,” and/or “domestic partner” in addition to the traditional “husband” and “wife.”

In lieu of terminology for gender restricted to “male” or “female,” also have a box/line dedicated to “they,” “FTM (female to male),” “MTF (male to female),” as well as a blank line for individuals to self-identify. Transgender and gender non-conforming clients should feel that their gender identity is respected. Ask a client’s gender pronoun and make sure to respect the response. Mis-gendering someone can have devastating impacts.

Modify the definition of “family” to extend to non-biological family and allows clients to assign who their family is. This could be a domestic partner, significant other, and/or friends who have been a significant support in their lives.

Training—Provide a welcoming and affirming environment by offering culturally competent training to employees to ensure respectful and dignified care is being delivered.

There are many resources available for training programs for specific populations such as lesbian, gay, bisexual, or transgender (LGBT).

Facility Accommodations—Policies and practices written into a facility’s by-laws can shape an individual’s sense of safety, and the overall care.

Establish a Non-Discrimination Policy within the facility that declares protections for individuals based on their sexual orientation, gender identity and gender expression, as well as race and other defining characteristics. This can extend to both employees and residents. This sets a precedent for quality care and reaffirms a safe space.

Consider allocating a “Cultural Liaison” to ensure policies are being followed and culturally-appropriate programs are offered.

Consider a cultural support group for residents to come together and feel safe.

Specifically for LGBT residents, consider inclusive signage posted on the door/window to signify the facility is LGBT-inclusive and affirming.

Also, gender neutral restrooms for transgender and some gender non-conforming individuals, including the clients and family and friends who may be visiting them provides a safer and more welcoming accommodation.

Allow residents to dress and accessorize in accordance with their gender or race identity. Assess whether a transgender patient is using hormone replacement therapy, and ensure that staff is informed on how to administer it as needed.

Practices should be in place to ensure partners, friends, or family members in minority populations can visit without the fear of discrimination or mistreatment.

Assure that all staff and caregivers understand the modified definition of family and understand that all are welcome to visit patients.

Appendix D: Stages of Dementia

Developed by the Montana Alzheimer's/Dementias Work Group

Dementia Stages and Characteristics

Needs

Stage 1: Normal Aging

- No deficits
- May be more inclined for workup/prevention if there is a strong family history of dementia.

Clinical Stage: Normal/Preclinical

Wellness and risk-reduction

General wellness and brain health

Advance Planning with help from experts in:

- Legal documents
- Financial (long term care insurance)
- Plan for aging/long term care planning
- End of life wishes

Stage 2: Possible Mild Cognitive Impairment

- Personal awareness of cognitive decline that may be affecting daily life.
- Self-reported symptoms may not be recognizable by friends/family/coworkers or evident on medical exam.

Clinical Stage: Mild Cognitive Impairment

Above needs as well as:

- Wellness and risk-reduction
- Public awareness/Education
- Knowledge of early signs of dementia and what to expect
- Community members are comfortable talking about aging and dementia
- Knowledge of community resources
- Begin building dementia-friendly communities so citizens are comfortable and competent to support individuals with dementia and their families and everyone knows where to go for resources
- Advance Planning/Long-term care planning
- Aging in place plan including accessibility, safety, and security issues
- Personal wishes for aging
- Review of unpaid and paid caregiver options
- Skilled medical provider cognitive examination to evaluate potential causes of memory loss
- Consider joining a memory loss registry

Stage 3: Mild Dementia

- Friends/family/coworkers may begin to notice deficits.
- Problems may be measurable with cognitive testing
- Social and work performance issues
- Decline in ability to plan/organize
- Word-finding difficulty

Clinical Stage: Mild Dementia

Above needs as well as:

Public awareness/dementia friendly communities

- Protocols in place for employees who may have concerns about a coworker's cognitive ability
- Employers support employees in caregiving roles

Medical care

- Skilled medical provider cognitive examination to diagnose dementia
- Diagnosis discussion includes individual and caregiver/family
- Educate on trajectory of disease
- Education regarding appropriate community resources
- Develop pathways for diagnosis and post-diagnosis care individualized to each patient
- Referral to a neurologist or other specialist if warranted

Caregivers

- Caregiver support groups
- Knowledgeable about available resources
- Training in managing dementia at home
- Home and community-based services
- Services provided in a consistent and coordinated fashion
- Adult day care
- Advance planning/Long-term care planning

Research

- Public is knowledgeable about available research studies
- Support ongoing research studies
- Encourage more dementia studies in Montana

Training

- Offer continuing education/certification option for direct-care workers
- Offer training for first responders on how to best handle individuals with ADRD

Policy implications

- Collect public health surveillance data on dementia through BRFSS
- Create policies to support caregivers
- Conduct a formal needs assessment to fully assess the financial impact and burden of disease in communities to effectively develop appropriate policies and determine workforce shortages
- Support incentives for health care workers to pursue careers in geriatrics

Stage 4: Moderate Dementia

- Clear cognitive deficits
- Impaired short term memory
- Difficulty with simple math
- Decreased capacity to perform complex tasks i.e. cooking, cleaning, managing finances, driving
- Reduced memory of personal history
- Possible personality changes
 - More subdued and withdrawn
 - Agitated in challenging situations

Clinical stage: Moderate Dementia

Public awareness/dementia friendly communities

- Improve public safety of individuals with dementia who wander
- Review of driving safety issues

Medical care

- Skilled medical provider cognitive examination to make diagnosis of dementia, if not already done

Caregivers

- Support groups
- Respite care
- Advance planning/Long-term care planning
- Consider legal protective actions such as payee and guardianship/conservatorship roles with help for legal services
- Re-review plan for aging and initiate long term care planning, if not already done

Home and community-based services

- Adult day care
- Meals on Wheels
- Senior center meal sites
- Personal care assistance through in-home care including; dressing, bathing, medication administration, housekeeping, laundry, grocery shopping, and meal preparation
- Transportation
- Assisted living

Policy implications

- Provide affordable assisted living options by increasing reimbursement through Medicaid waiver and increasing the number of Medicaid waiver slots
- Improve wages for direct care workers

Stage 5: Moderately Severe Dementia

- Major gaps in memory
- Confused about time/date and place
- May need assistance with some activities of daily living, i.e. dressing

Clinical stage: Moderate Dementia

- Diagnosis of dementia made if not done already
- Whether at home or in a facility, care is provided by an interdisciplinary team of medical providers i.e. social workers, occupational therapists, physical therapists, speech therapists, nursing

Caregivers

- Advance planning/Long-term care planning
- Review end of life wishes
- Re-review long term care plan
- Consider increased home and community-based services
- Consider placement in a memory care assisted living or nursing home

Stage 6: Severe Cognitive Impairment

(Moderately severe dementia)

- Worsening memory
- May begin to forget names of family and friends
- Significant personality changes
 - May become suspicious
 - May have hallucinations (seeing or hearing things that are not there)
 - May have compulsive or repetitive behaviors
- May wander and become lost
- May need extensive help with activities of daily living
- May need help with toileting and may experience bladder and/or bowel incontinence
- May need help with bathing
- May experience disruption of sleep/wake cycle

Clinical stage: Moderate dementia

Stage 7: Very Severe Dementia

- Loss of ability to respond to the environment
- May lose ability to speak
- May lose functional ability
- Muscles may grow rigid
- May have difficulty walking, sitting up independently
- More extensive help with activities of daily living needed (eating and toileting)
- Swallowing may be impaired

Clinical Stage: Severe Dementia

Above needs as well as:

- Diagnosis of dementia made if not done already
- Provide education on how to manage behavior changes at home
- Improve facilities' abilities to manage behavioral issues to avoid transfer to the state mental hospital

Above needs as well as:

- Diagnosis of dementia made if not done already
- More emphasis on palliative care
- Consider hospice care
- Increase availability of hospice providers, particularly in rural areas

Appendix E: Montana Workforce Training Programs

The **Montana Geriatric Education Center** (MTGEC) provides a multitude of educational topics to various professional disciplines and some support for training for direct care workers and caregivers.

The Center was recently awarded a Geriatric Workforce Enhancement Program (GWEP) grant that provides geriatric education and training to health care workers in order to improve health outcomes for older adults.

Programming will be provided for patients, families, caregivers, direct care workers, health professionals, students, family medicine residents, and faculty in a variety of settings.

Mountain Pacific Quality Health is currently working with nursing home facilities on several training projects including:

- Dementia topics
- Staffing stability to help facilities attract, train, empower, and retain quality help.
- Quality Assessment and Performance Improvement (QAPI) and quality measures to enhance quality of care addressing antipsychotics, activities of daily living, incontinence, pain, depression, falls, pressure ulcers, urinary tract infections, catheters, weight loss, physical restraints, and vaccinations.

Training is provided through webinars, in-services, and/or handouts.

Through the Affordable Care Act, direct care workers in long-term care facilities need to show proof of annual education in the management of dementia. However, dementia training programs are still not routinely done in many facilities.

There are many examples of effective, tested, and validated training programs, including **Staff Training in Assisted-living Residences (STAR)**. This program allowed for improved staff satisfaction and knowledge while improving resident behavior⁸.

The **Hand in Hand training** is another example of this type of training.

The **HealthCARE Montana** grant is a new program in Montana that is revising the curriculum for nursing education and other health professional curriculum in the state. MTGEC is working with this program on the geriatric component.

The HealthCARE Montana program goal is to improve health care training opportunities in Montana at the two-year college level, while enhancing pathways to baccalaureate degrees, and provide successful employment for students with attention to adult learners and veterans, particularly in rural locations.

Montana Area Health Education Centers and the Montana Office of Rural Health have created many programs and committees to support Montana communities and the state's health care workforce, such as the training of Community Health Workers.

The **Montana Hospital Association** (MHA) and the **Montana Health Care Association** (MHCA) also offer training programs on dementia care on a regular basis.

Montana Gerontology Society holds an annual conference providing professional development and continuing education in the field of aging for multiple health care and social service disciplines.

The **National Association of Mental Illness** (NAMI) offers training programs specifically for managing behavioral issues.

The **Alzheimer's Association** offers many training toolkits.

Appendix F: Goals and Guidelines for Residential Care from the Alzheimer's Association

Alzheimer's Association Goals of Care and Clinical Practice Guidelines for Residents with Dementia Living in Residential Care

Goals of Care

Staff and families will act as care partners with residents with dementia to achieve optimal functioning and quality of life.

Staff will use flexible approaches to care to help anticipate needs and prevent problems in order to meet the changing needs of residents with dementia.

Staff will use a person-centered approach to care in managing residents with dementia with an emphasis on consistent care approach throughout all shifts.

Staff will assist residents with dementia to maintain cognitive and functional abilities as long as possible.

Clinical Practice Guidelines

Complete comprehensive and holistic assessments and care plans.

Ensure staffing patterns allow for residents with dementia to have sufficient assistance so their needs are met.

Screen for appropriate nutritional care.

Encourage consistent staff assignments to promote quality relationships between staff and residents.

Promote proper nutrition and hydration given resident preferences and life circumstances.

Reduce risk of falls by assessing underlying causes of falls for the individual.

Assure mealtime is pleasant and enjoyable with ample staff to observe and interact with residents.

Avoid physical restraints by addressing underlying problems that prompt the use of restraints.

Assess pain routinely using a systematic approach to ease distress associated with pain and improve quality of life.

Encourage and support residents with dementia mobility choices, enabling him/her to move about safely and independently. However, unsafe wandering and successful exit seeking should be avoided.

Tailor pain management to each resident's needs and risk profile.

Offer many opportunities for social engagement, respecting resident's preferences, even if that preference is solitude.

Maintain open communication with family members.

Promote a physical environment that is comfortable and inviting, encouraging and supporting independence while encouraging safety.

Appendix G: Availability of Residential Care in Montana as of February 2015

Low-income senior housing

- 159 low-income senior housing facilities across Montana.
- Ratio is roughly one low-income senior housing complex for every 1,000 Montanans age 65 and older.
- 34% of counties do not have a low-income senior housing complex.

Assisted living facilities

- 201 assisted living facilities with a total of 5,643 beds.
- 60 facilities have Category C (memory care) designation for a total of 1,265 beds.
- 123 assisted living facilities accept Medicaid waiver recipients.
- Ratio is one assisted living facility for every 796 Montanans age 65 and older, and only one designated memory care bed for every 126 Montanans 65 and older.

Nursing homes

- 83 nursing facilities in the state with a total of 6,588 beds.
- Ratio is one nursing home for every 1,925 Montanans age 65 and older, and one nursing home bed for every 24 Montanans 65 and older.
- 21% of counties have no access to a nursing home facility and three counties (Petroleum, Judith Basin, and Treasure) have no access to either an assisted living or nursing home.
- 81 out of 83 facilities accept Medicaid.
- 31 nursing home facilities have secure dementia units.
- 35 facilities have a contract with Veterans Affairs (VA) to provide nursing home care to an average of 120 veterans a month.
- The Montana Veterans Home in Columbia Falls and the Eastern Montana Veterans Home in Glendive provide long-term residential care and are operated by the State of Montana. The total operation cost in 2014 for the Columbia Falls facility was \$10.38 million with one-third of the costs covered by federal funding. Total operation cost for the Eastern Montana Veterans Home in 2014 was \$2.9 million with the majority covered by federal funds.

- The average length of stay in a nursing home is 1.92 years. However, the length of stay varies by payer source, as do resident demographics:

Medicaid

- Average length of stay is 2.45 years.
- Average age is 77.
- Medicaid accounts for 60% of nursing home costs.
- Nursing home costs are the largest portion of Montana's long-term-care budget with expenditure of almost \$162 million in 2014.

Medicare

- Medicare only covers short-term skilled stays usually for rehabilitation following a hospital stay.
- Average length of stay is 88 days.
- Average age of individuals covered by Medicare in these facilities is 88.
- Medicare accounts for 12% of nursing home costs.

Private insurance

- Average length of stay is 1.27 years.
- Average age is 85.
- Accounts for 28% of nursing home costs.

Appendix I: Proposed Dementia Navigator System



- Appropriate Referral to initiate discussions, educate, inform, provide resources, establish goals based on current needs (dementia specialist vs. designated agency)
- In-home assessment by licensed practitioner (e.g., RN, LCSW)
- Identify support person or point of contact early on
- Obtain authorizations as indicated for collaboration of the health care team



- Utilize systematic approach to discussing issues and addressing needs
- Perform Medication Review & Education and set standards for routine review of medications and chronic condition status
- Make appropriate referrals based on findings: Physical and or Occupational Therapy, Geriatrician, Pharmacist, Neurologist, Financial Counselor, etc.
- Development of Care Plan
- Completion of immediate goals (Advance Directives, Legal Proxy decision-maker)



- Establish home health plan using non-paid and/or paid services, as appropriate
- Designate point of contact for assisting with on-going management and trouble shooting
- Provide framework for routine review of care plan and additional in-home assessments for detection of problems
- Resource sharing for further assistance, as needed. (hot line vs. direct call to agency)
- Review long-term goals

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