

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.

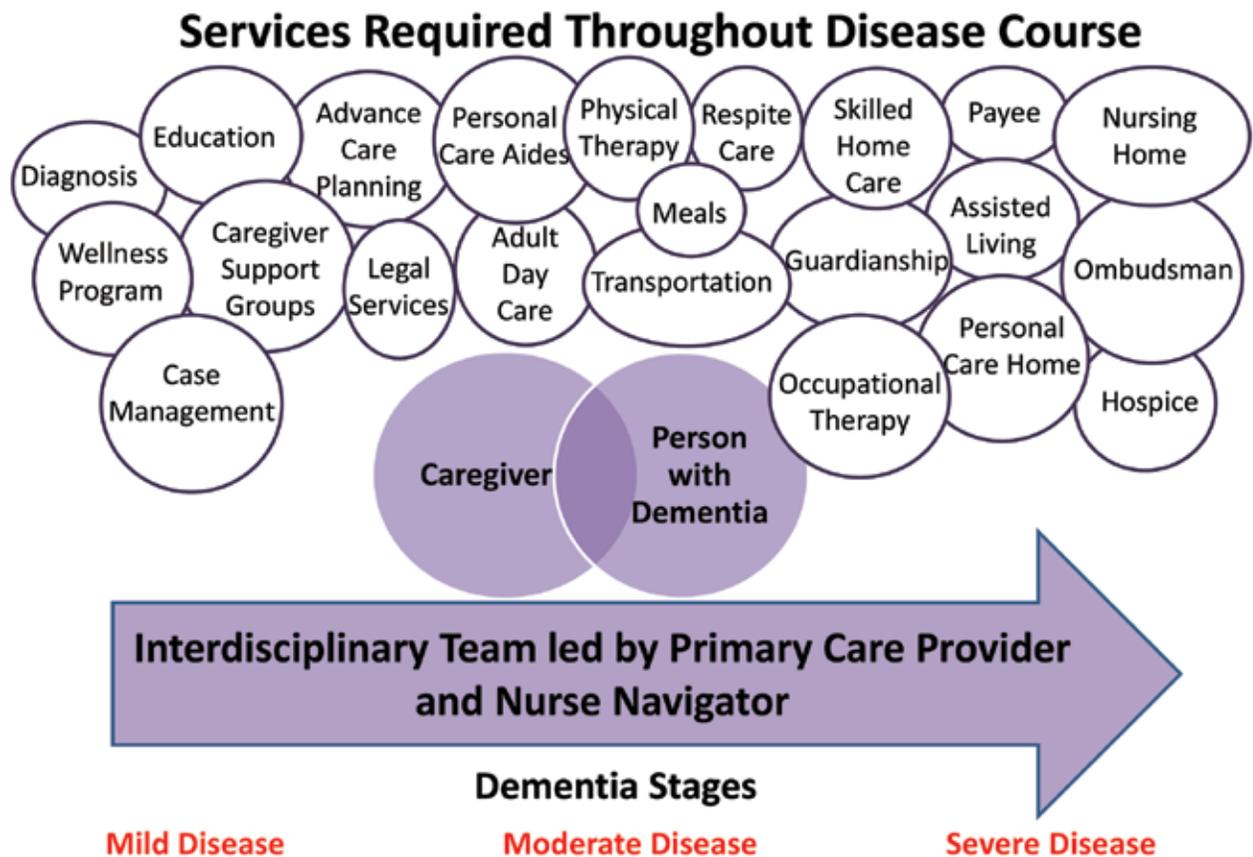
Recommendations

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.