

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

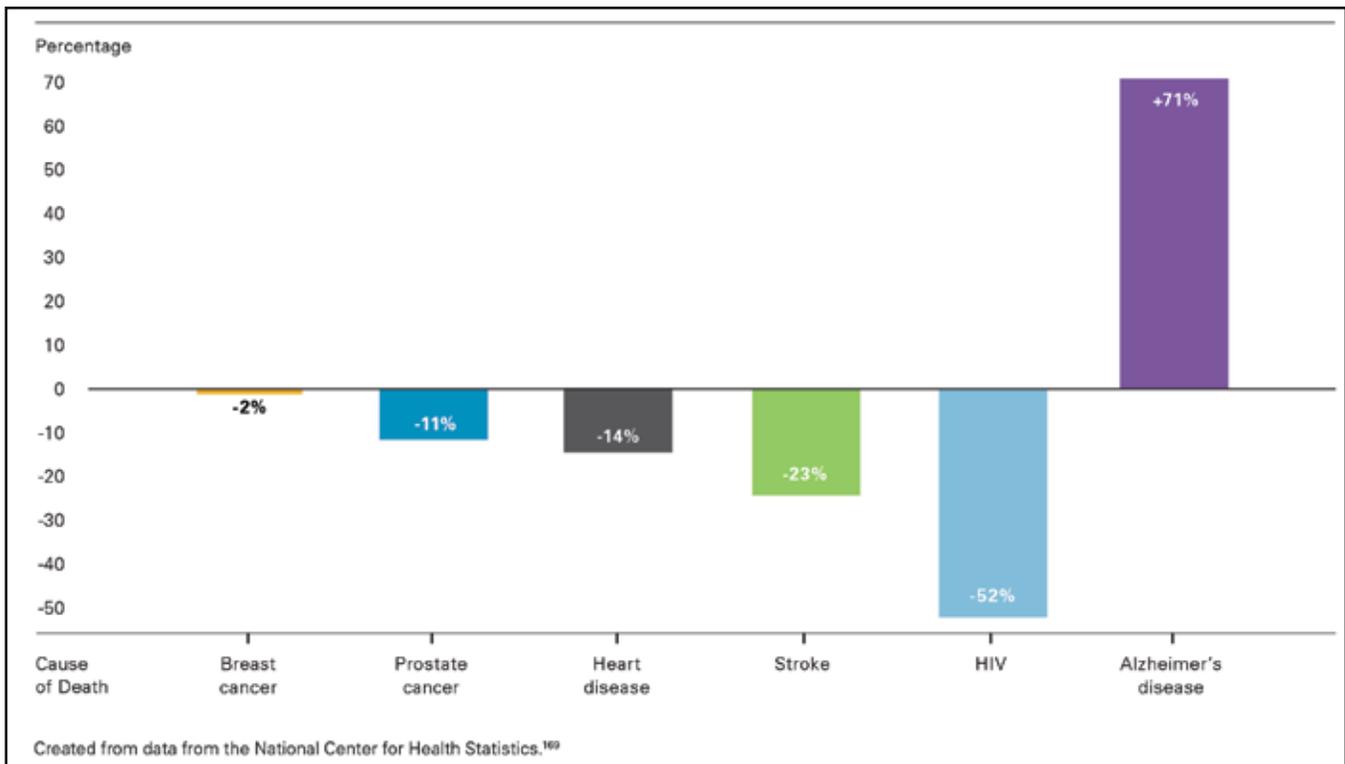
- In 2000, Montana ranked 14th in the nation in percentage of adults 65 and older. By 2025, Montana could rank as high as 3rd in the nation—with the 65 and older population accounting for at least 25% of the population of Montana.⁴
- Some Montana counties will experience over 100% growth in the 65 and 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}

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.

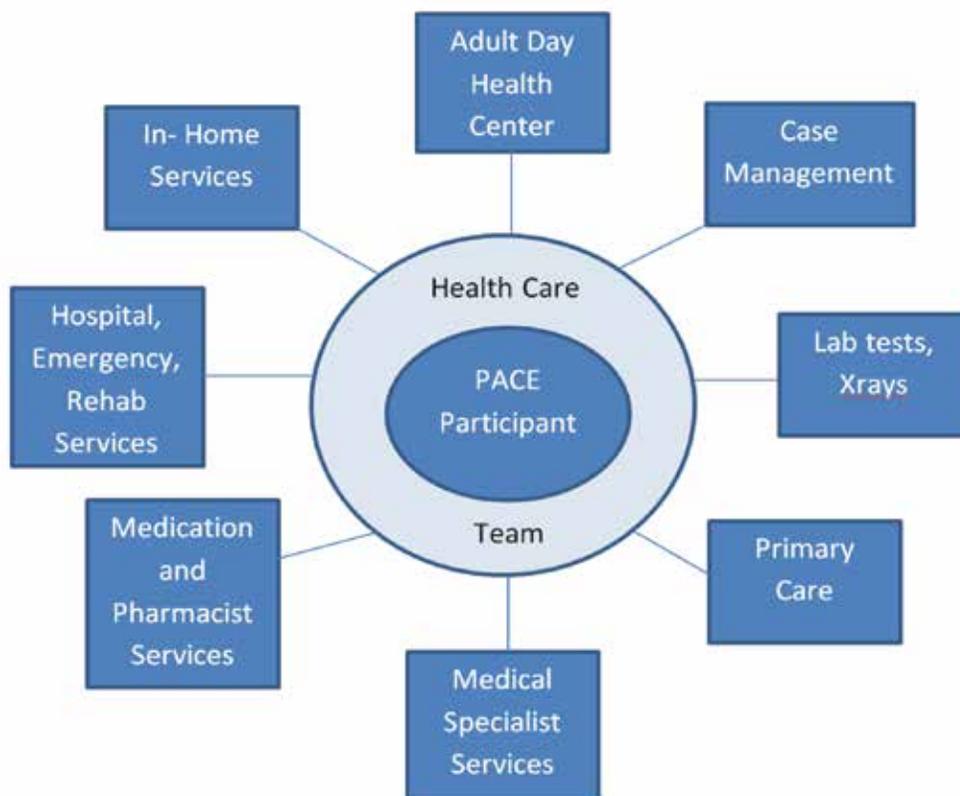
These teams treat individuals proactively, rather than reactionary based on a crisis or change in condition. Multidisciplinary team construction is dictated by available resources including time, availability, finances, and location.²²

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

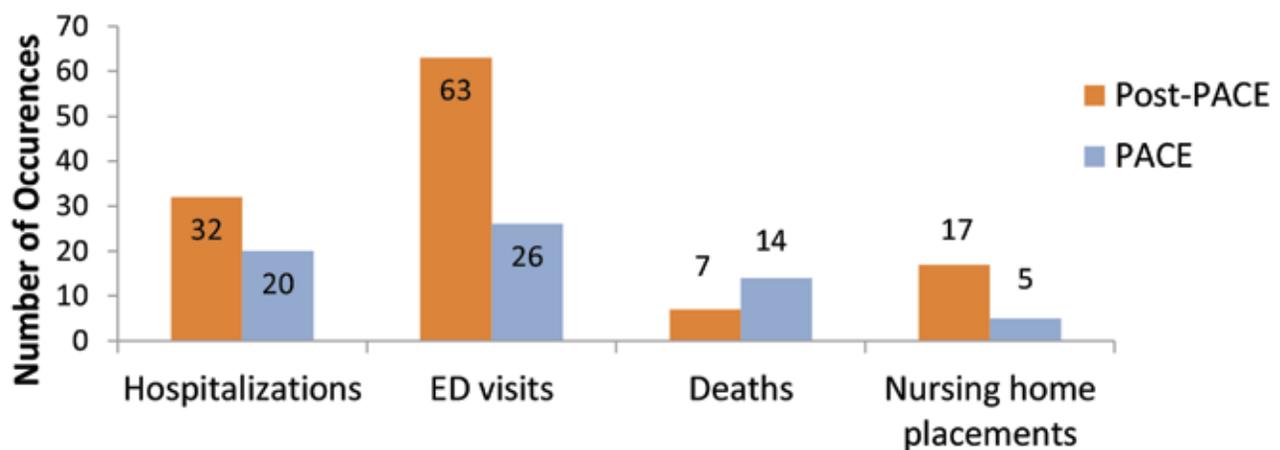


Montana participated in a PACE program from 2009 through 2011, at which point the state discontinued funding the program because there was not the population numbers to support the model in a frontier state like Montana.

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 risk 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