

**Montana Alzheimer's / Dementia Work Group  
2015 Town Hall Meetings  
Analysis Report**

**July 1, 2015**

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*"I didn't know where to go. My kids said "It's you or her." They meant that one of us, my wife or me, was going to have to go (to a facility), my wife because of her symptoms or me because of my fatigue. There's a saying, "A drowning man always takes someone with them."*

*– Conrad Town Meeting*

*Participant*

## **I. Introduction**

This document is intended for use by the members of the Montana Alzheimer's / Dementia Work Group as they choose what to include as recommendations and courses of action in Montana's Alzheimer's Action Plan: Addressing the Current and Future Needs of People with Alzheimer's Disease and Related Dementias. All edits are welcome!

Thirteen Town Hall Meetings were held in May and June, 2015 in eleven communities. They were hosted in the urban areas of Missoula, Kalispell, Billings, Great Falls and Bozeman, and the rural towns of Dillon, Lewistown, Miles City, Glasgow, and Conrad. A Town Meeting was also conducted in Helena at the Annual Governor's Conference on Aging in May. A total of 275 people attended the meetings.

The audience that was actively recruited was members of households experiencing the diseases. Local services providers were instrumental in recruiting their attendance, and it is appreciated. Service providers were also in attendance, and of course, they also had personal stories to relay about the diseases as well as their professional points of view.

Conversations took place around the following three open-ended questions, and it was emphasized that there were no wrong answers and all thoughts and suggestions were welcome:

1. What is helping you and your family or community deal well with these diseases? What is an asset? What's going well? Who and what kinds of services are in place that help you?
2. What needs, gaps, worries and issues do you experience? What is making this tough to manage for you and your family or households you are aware of?
3. What do you recommend? What changes and improvements should the Montana Alzheimer's / Dementia Work Group focus on and include in their State Alzheimer's Action Plan?

In addition to the conversations, each Town Hall ended with the participants 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.

Two documents accompany this report for anyone interested. They consist of the raw data the points in this Report are drawn from: the transcribed notes of the facilitated conversations, and the transcribed final priority points from each meeting's participants.

There are also other data, facts, and statistics to consider. A two-page survey was handed out at each Town Hall Meeting. This information is being entered as this Report is being written, and will be worth a concentrated study as well.

The outline used below follows the subjects consistently found in State Alzheimer's Disease Plans across the country. They are the goal statements and convey the actions planned, the projects undertaken, and the efforts focused on. Following the outline is a list of the priority subjects of interest to the Town Hall attendees. It will be of as much interest as the findings tied to the goal statements, if not more.

All of the points and recommendations made here are from the participants' perceptions. There may be errors in what they report, but their awareness and opinions were what was invited and sought. Some subjects such as growing the capacity of the health care system, brain health, and data collection did not come up.

Finally, in addition to many of the Work Group members, we had some other notable attendees:

- ✎ Senator Roger Webb in Billings who is a member of the Children, Families, Health and Human Services Legislative Interim Committee,
- ✎ Representative Kathleen Williams from Bozeman,
- ✎ Virginia Loranger from U.S. Senator Jon Tester's office in Missoula attended the Kalispell meeting,
- ✎ In Great Falls *Great Falls Tribune* reporter, Briana Wipf, which resulted in a headline story about the Work Group's plans and the Montana's Alzheimer's Action Plan: Addressing the Current and Future Needs of People with Alzheimer's Disease and Related Dementias document we are writing, and
- ✎ In Billings, *Billings Gazette* reporter Pat Ballinger.

## II. Findings correlated with typical State Plan goal / subject areas

### 1. Public awareness: Increase public awareness of Alzheimer's disease among the public.

#### Assets:

- People are hungry for information. A good handful of books, movies, and websites were highly recommended between attendees.

#### Gaps/Needs/Challenges:

- People don't know where to start when the disease is first suspected in a loved one or friend. The logical first steps for basic information are an unknown.
- People are deeply afraid of their own futures; they don't know the warning signs.
- Not everyone has access to or interest in the internet. This cannot be the only source of resources for the public.

#### Recommendations:

- Weekly newspaper columns, especially in the weekly, rural town papers.
- Pass along the recommended best books, movies, and websites.
- “Get ready to be old” classes or seminars hosted by churches perhaps.

### 2. Early detection and diagnosis: Encourage increased detection and diagnosis of Alzheimer's disease.

#### Assets:

- Some people want to know if dementia is in their future.

#### Gaps/Needs/Challenges:

- It is perceived that doctors don't want to be direct and announce the presence of the disease.

#### Recommendations:

- Encourage doctors to regularly use the screening tools and to be as direct as possible with their patients.
- Encourage patients to ask for the screening tools to be administered.
- Encourage doctors to suggest to patients that they bring in family members for announcements about dementia.
- Publicize the warning signs and the behaviors to not worry about.

3. Care and case management: Improve the individual health care that those with Alzheimer's disease receive.

Assets:

- People appreciate and trust their doctors.
- Where the few navigators / case managers exist (Billings and Kalispell) they are lauded.

Gaps/Needs/Challenges:

- What case management? Patients leave doctor's offices with no resources, recommendations, or supports.

Recommendations:

- The idea of a navigator case manager who is in regular contact and follow the person receiving services and their family felt like a miracle whenever it was mentioned.

4. Quality of care: Improve the quality of the health care system in serving people with Alzheimer's.

N/A

5. Health care system capacity: Expand the capacity of the health care system to meet the growing number and need of those with Alzheimer's.

Assets: N/A

Gaps/Needs/Challenges: N/A

Recommendations:

- With the explosion of the affected population anticipated and recognized, it is recommended we do everything we can to recruit neurologists, Gerontologists, Gerontology nurses and Nurse Practitioners, and ensure General Practitioners are up-to-speed.

6. Training: Better equip health care professionals and others to deal with individuals with Alzheimer's.

Assets:

- Hospital staff (from the social workers to the marketing staff, administration, and front desk welcomers and intake people) want the training and see the value of it, hospital-wide.
- Dementia-friendly communities were understood to be a good concept, where lots of people in the town or city are trained to identify, interact with and enjoy the company of people with dementia.
- A coffee shop in Missoula held a one-day event to welcome people with dementia and their loved ones.

Gaps/Needs/Challenges:

- There are no dementia friendly community initiatives in Montana to our knowledge, where lots of people are trained in how to identify, interact and enjoy the company of people with dementia.
- Law enforcement, emergency room, and EMTs personnel are perceived to be uncomfortable in working with people with dementia.

– Health care directives are described as having no value; when push comes to shove, they are all too frequently ignored.

Recommendations:

- Because of the issue of health care directives being ignored, orient and train on health care directives including about the “do not resuscitate” orders.
- Pursue the concept, trainings, and adoption of Dementia Friendly Communities.
- Law enforcement, emergency room, and EMT staffs need training on dementia, to spot it in patients and the best practices of how to deal with people with it.

7. Workforce development: Increase the number of health care professionals that will be necessary to treat the growing aging and Alzheimer’s populations.

Assets:

- A number of people attended the Town Hall Meetings to offer their own time, as a volunteer to families needing respite or household chores done or whatever gap needed filling.
- There was awareness of the low rate of pay provided to a lot of the health care workers who interact on a daily basis with people with dementia.

Gaps/Needs/Challenges:

- There isn’t any existing system to coordinate volunteers with households needing them, or awareness of them where they do exist.
- There are very few people in hospital settings who are specialists on these diseases, or that at least this is the perception. There are no Gerontologist in even some of our large cities, Bozeman for instance.

Recommendations:

- Create a system and/or publicize any that already exist (Senior Companion?) to coordinate volunteers with households that need hands-on help. Integral to this potential service is training about the diseases, which wasn’t envisioned to be lengthy or in-depth but more of an orientation about what to expect.
- Recruit Gerontologists and other aging specialists and pay them more to incentivize their moves to Montana.
- Make training about dementia a pre-requisite for employment at assisted living and nursing home facilities.

8. Home and community-based services: Improve services provided in the home and community to delay and decrease the need for institutional care.

Assets:

- Some communities have comprehensive, in-print directories of senior services that are updated every year or two. Some of them post the document on-line.
- Some people have a wonderful support people of family, friends, their church and neighbors.
- In some towns and cities, in-home care is readily available by trained personnel and trusted organizations.

Gaps/Needs/Challenges:

- None of the directories of senior services provided had more than one entry naming Alzheimer's or dementia services. Some had none. People have an extremely inadequate understanding of where to go, who to ask, what service providers to contact. It is truly mind boggling for some people, and significantly contributes to the stress of the situation.
- Even the phone books were brought up. It's not clear what to look under for help with dementia or questions about it.
- Some caregivers are alone in their responsibilities to provide care for their loved one. Some are completely worn out and don't know where to turn for all the tasks that were at one time shared with a spouse or parent – the lawn, grocery shopping, housework, bills, etc. It's not clear who to call to arrange for outside help in these areas.
- The same applies to in-home care assistance; what companies or programs have staff that can be hired? At least initially, there is a big gap in people's awareness of who facilitates such staffing.
- Then the cost of in-home care becomes a significant issue. One person explained that a \$30 an hour, trained service provider is really necessary, but even \$8 an hour was going to be impossible – and what level of competency do you get for \$8 an hour, she also asked.

Suggestions:

- In the yellow pages of phone books there needs to be the categories of dementia and Alzheimer's, with all related service providers and organizations under them.
- Subsidize family members or caregivers to stay home and care for a person with the diseases. The math makes such more sense; the cost savings is potentially enormous versus moving a person to a care facility.
- Ensure each community has a provider service or organization who facilitates in-home care.

9. Long-term care: Improve long-term care, including assisted living, for those with Alzheimer's disease.

N/A

10. Caregivers: Assist unpaid Alzheimer's caregivers.

Assets:

- Support groups are highly praised. They provide ideas, comfort, resources, and respite, particularly in some of the larger cities (Billings, Bozeman, Missoula, Great Falls) where there are sometimes four to six held every month, and at least one in some smaller towns (Glasgow).
- Some communities have directories of senior service that are updated every year or two. Some of them post the document on-line.

Gaps/Needs/Challenges:

- Support groups come and go; they are frequently hosted by a facility and a specific person who, when they move on or have to cease hosting them, are not replaced. Even in big cities like Helena, there are no known support groups taking place. Rural towns have the same experience.

Suggestions:

- Support groups both affiliated with facilities and those that are independent are requested. Though the participants thought it was unintended, newcomers don't feel welcome at support groups hosted by a facility. It is assumed that the support group is solely for the family members of the residents. Make it known if it's otherwise.
- In communities where multiple support groups could be held, an AA model was mentioned and confirmed as a good idea in the subsequent Town Hall meetings. Ideally there are several support group meetings each month or even week, and as a caregiver is able, they can "drop in" to any and / or even all of them.
- In the yellow pages of phone books there needs to be the categories of dementia and Alzheimer's.
- Pay people to care for their own loved ones, especially if it means leaving employment to do so.
- Allow family members paid leave time to periodically provide attention or meet the needs of their loved one.

11. Research: Increase research on Alzheimer's disease.

Assets:

NA

Gaps/Needs/Challenges:

- Eight people used the word "cure" and 10 people used the word "research" in their priority statement at the end of the meeting, so it is seen as serious need.

Recommendations:

- In Great Falls, where the McLaughlin Center is housed, there were approximately a half dozen staff and interns present at our Town Meeting. They suggested in their priority statement notes the following: early detection methods and drug therapies; better treatment options and possible cures; alternative therapy research to manage and alleviate symptoms; earlier diagnosis; and earlier treatments to keep cognitive abilities and quality of life longer.

12. Brain health: Promote activities that will maintain and improve brain health.

Recommendations:

- Only one person in one community mentioned the importance of keeping our brains alert, active and functional.

13. Data collection: Create a better system of data collection regarding Alzheimer's disease and its public health burden.

N/A

14. Safety: Improve public safety and addressing the safety-related needs of those with Alzheimer's.

Assets:

- In small towns, neighbors look out for each other's loved ones. If someone with dementia is seen too far from home, a family member is called.
- Some people carry notes that say "I have Parkinsons Disease. I am not drunk." or wear a bracelet that says "If found, please call my loved ones" and their contact information.
- The Summit community center in Kalispell has a test they administer at a person's request to help determine whether he or she should continue driving.

Gaps/Needs/Challenges:

- Fear about the wandering of a loved one with dementia is significant.
- Technology exists that allows people to be tracked by Sheriff's Departments, but families are reticent about having to call unnecessarily.
- Law enforcement personnel, as well as other first responders, are not always aware of a person's cognitive status, and when they are it is perceived they are uncomfortable.
- Doctors don't like being made responsible for announcing, "No more driving for you," even at the request of family members.

Recommendations:

- Research and make known what kinds of GPS, cell-phone, or other monitoring system would allow family members/caretakers to know the whereabouts of the individual.
- Standardize and institutionalize a means of drawing attention to a person's dementia status for law enforcement and first responders to look for – a bracelet, a necklace, or a wallet card.
- Replicate the program at the Summit in Kalispell to help people make the decision to quit driving.

15. Legal issues: Address legal protections for, and legal issues faced by, individuals with Alzheimer's.

Assets:

- Some households had good modeling by their parents about how to prepare for later in life decisions, health planning, legal planning, and asset management. Some people have taken classes on the subject of aging preparedness, and learned everything they need to have in order well before they age – or to help their parents with their actions and decisions.
- MontGuides are universally appreciated. Some senior centers and Offices on Aging have them prominently displayed, keep the racks full, and highly recommend them to the guests.
- AARP and the Department of Public Health and Human Services, Aging Services Division, host a lawyer-provided (John McCrae) day-long training on long-term care planning including all the subjects just mentioned.
- The Department of Public Health and Human Services, Aging Services Division, prints the *Montana Legal Guide to Long-Term Care Planning*. It is updated annually, and in the last edition, 3,000 copies were printed. It is quite comprehensive, and they print other relevant documents as well.
- There are approximately 8,000 AARP members in Montana, and they receive the AARP magazine and newsletter that each month covers these issues.

Gaps/Needs/Challenges:

- A lot of households know little to nothing about how to go about planning for old age, from financial and legal issues to health care directives.
- Health care directives are ignored. In almost every meeting, a story was told about the hospital staff contradicting what was meant to be a “do not resuscitate” order, and the resulting trauma.
- There is one trainer of the AARP-hosted day-long training, and it is provided only every other year in the urban centers.

Recommendations:

- Implement universal use of POLST and other end-of-life planning tools and directives. Help people understand what Power of Attorney, estate planning, living trusts, advance directives, and Guardianship and Conservatorship are about. Educate the younger members of the family about them, and encourage the conversations with the older generations about them. Make training on all these more accessible, more frequent, and more well-known and understood.
- Get the MontGuides into more people's hands. In most of the senior centers, community centers, and hospitals where the Town Hall meetings were held, they were not visible.
- Distribute the DPHHS Aging Services Division, *Montana Legal Guide to Long-Term Care Planning* more widely.

16. State government structure: Improve how government evaluates and adopts policies to help people with Alzheimer's disease and their families.

Assets:

Gaps/Needs/Challenges:

- The subjects of Medicaid and Medicare were hot ones. They are universally misunderstood, confusing, and irritating. The process of application feels terribly slow and painful.
- CHIP counselors, specialists in the subjects of Medicare and Medicaid, are not a well-known community asset, they aren't widely publicized, and in small towns, they may be 100 miles away.

Recommendations:

- More CHIP counselors are needed, and their availability in person and on the phone better publicized.

### III. Conversation priority themes

#### 1. Caregivers are on fire.

The desire to keep people experiencing ADRD in their homes is of paramount importance. It is what people want for themselves and their loved ones. It is very hard to accomplish successfully. Caregivers are on fire. At every single meeting, there was crying by caregivers. They collectively and desperately need:

##### a. Support groups

Every attendee who had attended one gained so much. The desired model is the presence of several in communities that can support them, the same time, place and date each month to which people can drop in as they have time (and coverage at home). Alcoholics Anonymous is to be emulated: Anyone can attend at any time, no reservation is required, bring whomever you would like to, we are always here for you. Also, for those offered at care facilities, let it be known (repeatedly) that anyone may join the group.

*“I want to hear, and I want to say to others, “How else can I help you?” A support group would be so good. I learned three years into the experience what I wished I had learned early on.”*  
– Conrad

*“I would go to support group meetings if they were offered. And my dad would use respite services if they were available. Are they?”*  
– Miles City

*“Please, more support groups, we need one in every community. Support groups need an educational component, not the same thing over and over. Provide presenters. I need someone to talk to.”*  
– Lewistown

*“Support groups need to also be available at night for people who work.”* – Missoula

##### b. Care navigators / case managers

When diagnosed, people leave the doctors' offices with nothing, truly nothing. (There are a few exceptions in some of the big cities, but it was a ubiquitous issue.) There are no resource lists handed to patients and families, there are no instructions about the best care practices, there are no long-term care planning resources offered. Every household needed and wanted someone to regularly communicate with, who would insure follow-through takes place, and needs are met. Navigators or case managers can provide the antidote to the feelings of isolation and despair.

*“Who in our community can help families understand their insurance – and re-assure them?”*  
– Lewistown

*“There are six financial planners in town, but where to find services is an adventure!”*  
– Miles City

"What existing services are there? None. I've heard discussions by two assisted living and one long term care center about the possibility of adult day care, but it is not currently in place. Home health and hospice used to be able to people admitted to the hospital allow the family some respite, but the doctors don't allow it anymore." – Dillon

d. Longer-term respite, a weekend or more, or everyday care

"Where are all the people today? Respite care is terribly needed." – Lewistown

– Kalispell

unbearable, the repeated questions."  
activity and he won't just sit. I don't drink, but I'm thinking about taking it up. It's can think about something else. I want to take him somewhere where there will be an of town for a week. Here is where the key is. Come over and take a rest." At least you have help in the house, I take a nap at the neighbor's house. People tell me "I am out need adult day care, so I can be home alone. I can't ever get anything done. When I asks the same questions over and over. I don't know how much more I can handle. I am at my wits end. I start thinking "I can handle this," then I feel it's so overwhelming. He ("My husband has) had it for five years. Physically I can handle it, but emotionally, I am

"I am really disappointed there is little or no assistance available at Senior Centers, a place to bring someone who needs watching for a few hours or a half day. We need a Coordination Center for people in this situation." – Bozeman

c. Short-term respite, a few hours  
Women in particular, but men as well, need to take a nap, to go exercise, to have coffee with a friend – and realize it takes a toll on them to forego all these normal activities. They want both opportunities for this kind of respite – in the home and the option of at a trusted care setting. Regardless of place, the staff involved have to be competent and trained. In small towns, it came up twice that volunteers could be trained to fill this niche, including by a gal who attended with that very purpose in mind, to volunteer her time.

"There are a couple of support groups. They are really good for older people, the sharing, the suggestions for each other, the comradeship is really good." – Missoula

"We need a local, professional with training, like a social worker who when a person is diagnosed, a kind gentle soul will help evaluate and get them on track early. A Community Alzheimer's Specialist." – Lewistown

– Miles City

"A nurse navigator for Alzheimer's / Dementia like we do for breast cancer makes so much sense. When my dad had dementia, my sisters' and my goal was to keep my mother alive."

- e. Volunteers are willing to be respite providers.

*(My priority suggestion is to coordinate) “volunteers trading respite caregiving.”*  
– Bozeman

*“I like the idea of a care-giver cooperative, where caregivers essentially take turns caring for each other’s loved ones. In terms of easily accessible grassroots types of organization, it is feasible and do-able.”*  
– Bozeman

- f. Basic sources of trusted, best practice information

*“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.”*  
– Bozeman

*(We need) “education, someone to call when presented with unexpected situations, similar to a crisis hotline for the newly diagnosed and caregivers.”*  
– Billings

- g. Services in the home, paid caretaking

*“Nothing is good. It’s a challenge especially for the main caretaker, me. I’m still working and I am encouraging my mom to get help in the home so she can get off the time clock, even to just go up and hide in her sewing room. What’s going well? That’s a stupid question.”*  
– Kalispell

*(My priority suggestion is) “better home care support to keep people in their homes as long possible.”*  
– Billings

## 2. Guilt versus social acceptance

### a. Respite

The guilt associated with even taking a respite break, let alone admitting someone to long-term care of some kind is overwhelming. Address the attitude and acceptance of people’s choices in these areas.

*“I put my husband in a nursing home, and perhaps I did it earlier than I needed to. The guilt was unbelievable. I had a lot of support, though, to do so. People told me it would be harder later. I go to see him and find him alone, with no nurses around or activity going on. Maybe the bad stuff, like him spending time with feces in his pants, wouldn’t have happened. I don’t know.”*  
– Billings

b. I can do this!

The Montana attitude of self-reliance and independence that says “I should be able to handle this” and “My parents were able take care of *their* parents” is getting in the way of self-care and even the safety of the person with the disease. People are worn out, and we need to make it a social norm that it’s acceptable to access help, rest, and the services of facilities.

*“I am a nurse. I feel like this community needs a day care. When we just went to Tallahassee, Florida to see a friend whose husband takes her to an adult day care facility, but not frequently enough. He is in total denial, and is getting no rest, none whatsoever! He is only in his 70s, a retired college professor and research scientist. He never gets out of the house and he won’t ask for help. He needs to know it’s okay to ask for and accept help.”*

– Dillon

*“My pride was the toughest.”*

– Glasgow

3. System changes are needed

a. Medicaid process reform stood out as a high priority.

*“We need more waiver beds now!”*

– Bozeman

*(I recommend as the priority) “more waiver slots through Medicaid, and pay for families until their loved one can move into a facility.”*

– Bozeman

*“Fix the Medicaid waiver program so there are more slots to allow people to go to memory care assisted living instead of having to go to a skilled care (facility), which is more expensive.”*

- Kalispell

*“Services need to be affordable for people who don’t make enough for care, but make too much for assistance.”*

– Missoula

*“Help families with the finances and don’t put them in the Poor House. Not everyone is on Medicaid. Find a better way of assessing assets.”*

– Miles City

*“The most distressing to me is folks living at home and the dementia is getting worse. They can’t get into a nursing home without a waiver. The Medicaid piece is the first one that helps people move into a skilled community. The average cost is \$45,000 for a memory care unit, but they end up in a skilled nursing home that costs \$95,000 a year.”*

– Bozeman

*“Medicaid and Medicare are a jungle. ... getting through the paperwork – and then you get to the bottom and the answer is “no” because you saved for retirement. I’m totally happy with the care. I worked for a nursing home for 90 women! Finding something affordable is a whole new learning experience. With cancer, you have all sorts of options for treatment and information – and it’s covered! The affordability is a nightmare.”*

– Bozeman

*“What’s the difference between Medicaid and Medicaid waivers? We don’t know what to do. We don’t know who to ask?”*

– Lewistown

- b. Create a tax credit for caregivers and a stipend for full-time caregivers.
- c. Increase the funding to Area Agencies on Aging to allow them to become the go-to source for ADRD information, referrals, counseling, support groups, classes, etc. And, importantly, provide them with a budget to publicize these services because it was quite clear that knowing where to go for what feels like a maze.

*“We need more information. I was a maintenance man at a nursing home for 30+ years, and all of a sudden it smacked me in teeth: We don’t know enough about aging and Alzheimer’s.”*

– Bozeman

*“Better publicize all the services!”*

– Missoula

- d. Caretaker leave

*“Caretaker leave needs to exist at workplaces, so employees can take off time for doctors’ appointments and care for their family member.”*

– Lewistown

#### 4. Prepare to Age!

##### a. Seminars

People appreciate what they learned from their parents, if they were lucky enough to have organized, responsible, future-focused parents who knew to put things in place so their adult children experienced less of a burden. For those who didn’t have that kinds of parenting history, it’s a confusing maze of what to do. The classes or seminars offered by the AARP and DPHHS Office on Aging or something similar would be most welcomed. Churches were mentioned as potential hosts because of the credibility they transfer to such a learning experience.

##### b. Publications and other resources

There are many fine publications and smaller lessons to be learned, in addition to a full blown class of some kind. Very few people were aware of them, but would like them to be made more available.

c. Final wishes, advanced directives, POLST Forms, living wills, guardianship... some people are familiar with, and a lot are still a worry. Are we missing any? People need counseling and education on these subjects for their aging parents and request it, as well for themselves. Also, at almost every Town Meeting someone relayed a story of an advanced directive being ignored, and people want to be taught how best to deal with this kind of situation.

#### 5. Health care providers need help

##### a. Training

It is felt that training in a lot of nursing homes and assisted living facilities need to be stepped up to include information about ADRD. It was keenly suggested that training on the diseases be a pre-requisite to working in such care settings.

*“My mom got kicked out of three nursing homes for being violent.” – Conrad*

b. Doctors are not saying the “A” word out loud.

Doctors are perceived to be reticent about announcing the diagnosis. Families told us about begging doctors to share the diagnosis with them, and the doctors refusing.

*“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.”*  
– Missoula

c. Doctors need to help connect patients with someone, some resource, something!

It is requested that doctors provide some resources at the time diagnosis is made, to assist the family in at least the initial connections to care and other resources. It was acknowledged and appreciated wherever it did take place, but agonizing in the situations where nothing, instead, was offered.

*“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.”*  
– Billings

*“Doctors need to provide community resources like sending us to Caregiving for Caretakers – or at least one person in town, a social worker, to get started. We feel we are in left field.”*  
– Lewistown

*“My sister’s fiancé was just diagnosed at age 65. She has no idea what to do. She needs legal help, and they aren’t married! The doc needs training on who people should turn to for resources. No referrals were made!”*  
– Missoula

*“I request doctors make more referrals to neural psychologists.”*  
– Missoula

d. Doctors need to be able to speak to and with the families. Some won’t at all because of patient confidentiality, so it was suggested that the doctors ask for the patient’s permission to include the families early on in the stages of the disease.

*“My dad was diagnosed at a pretty young age, but at the same time, an extremely late diagnosis. This resulted in a very limited window of time to prepare. Doctors are hesitant in telling people they have it. There is no solution; the only one is to die.”*  
– Bozeman

e. Facilities need expert advice on dementia from the outside.

*“We have a crying need for gerontology nurses to go into the facilities.”*  
– Missoula

*“Emergency room personnel need to be both trained themselves and to learn when to call in experts. Law enforcement, as well.”*  
– Missoula

6. Mainstream education about the disease; it is widespread

- a. Common knowledge would help people be kinder, help people prepare for it in their families and themselves, and more effectively recognize it in people around them.

*“It’s just flat getting the word out. My daughter said, “Is it really as bad as the movie Still Alice portrays?” There is no quick fix. The younger generation has no clue that it ends with death, the lack of resources, where it goes, and what to expect.” – Bozeman*

*“What is the stigma about? People are afraid. Every family in the United States is affected – grandparents, parents and siblings.” – Bozeman*

*“I think my husband had it for over 20 years, in hindsight. He was an optometrist, and then he became very unhappy with the profession. We went to Arizona to be with his brother and ran a hotel for 8 years. How is one diagnosed?” – Conrad*

*“How many of us are aware of the different stages? A few of us only.” – Miles City*

*“I kept it private, kept it in. It can be bad and depressing. If the public knew about it, then people know and would be more compassionate about it.” – Glasgow*

*“Provide education in grade school and high school health classes to teach tolerance of people with ADRD. It’s so prevalent. Use guest speakers at assemblies. Cover how to communicate with people with the diseases.” – Miles City*

- b. Improved knowledge will reduce the fear and the stigma attached to the disease.

*“Part of the resistance is, if they accept it (as happening to a loved one), they have the realization that it can happen to them to. When a bad situation is happening, there is an unconscious tendency to think it will rub off.” – Glasgow*

*“Provide tapes, CDs, and videos on this subject at the Library.” – Miles City*

*“The general public is woefully ignorant and avoid learning much about it. It’s the stigma.” – Missoula*

*“All the efforts of awareness are about the cure, not helping people who are currently experiencing it. There is huge fear and isolation. It contributes to an unfortunate culture. We need to better understand how to live with the disease – a bigger focus on caring.” – Missoula*

7. Rural areas have nursing homes, a few assisted living facilities, and not much more.

- a. The rural areas suffer; there are just fewer services to access.

*“Somehow, get the services and support to the rural towns!” – Conrad*

*“Education for physicians, nurses, families and friends that is accessible to rural Montana.”*  
– Glasgow

*“Billings is blessed with services. In rural communities, there is nothing. The people experiencing these diseases have to move, and it’s criminal that people have to move away from their home communities.”*  
– Billings

- b. The volunteer respite worker idea came up as a strong suggestion in rural towns.

*“I came today to see if I could volunteer.”*  
– Conrad

- c. Finally, the resistance to asking for help in rural areas is pronounced.

*“Do one-on-mentoring, a buddy system, like they do in AA with a sponsor. It’s hard to ask for help. Our rural, small, agricultural towns with strong, private people say “We did this on our own, what would I learn at a meeting?” and “Why can’t I be enough?”*  
– Miles City

#### 8. Adults with no children or whose children/family live far away

- a. A director of an Area Agency on Aging said this is her biggest worry – personally and about the senior population.

*“My good friends and I have talked about this for years. We have no children. Who the heck is going to take care of us?! We need to figure this out – and sooner, rather than later!”*  
– Helena

- b. A model of appointed guardians similar to the CASA, Court Appointed Special Advocates, that works with children, was recommended for adults and seniors who have dementia.

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