

ADWG Storyline/recommendation table as of Wednesday, October 24, 2018

Story Line #1: What can the State do to support stable, safe residential facilities and family homes for citizens living with Alzheimer’s Disease?

Home. A place of safety when we feel most vulnerable. Where we are cared for, accepted and celebrated for who we are. When Alzheimer’s Disease and other dementias begin to rob us of our abilities, our need for care and acceptance increases while the abilities of our informal network of caregivers are stretched, often adding to the suffering of our family unit. Eventually, our families look for various support services that can come to us to ease the burden and keep us safe and otherwise healthy in our homes. Finally, the support we need progresses to the point where residential institutions often become necessary for everyone involved.

When we hear widespread reports of safety and billing transparency issues in various kinds of residential institutions as well as home services program, we have a right to be deeply concerned. We expect the state to assure all residential facilities and services are stable, safe and affordable. We don’t want any institution caring for people it is not equipped to care for! The following are recommendations the State can act on to assure any residence - no matter the location or type - will continue live up to our expectations of “home”.

<p>1. Clearly define Minnesota’s dementia care standards across residential settings</p> <p>(The state) should develop and adopt consistent baseline standards of person-centered care practices for individuals living with dementia in long-term care facilities of all types. While our nursing homes at least have federal minimum standards for person-centered care that address issues related to care planning, (staff training?), therapeutic activities and physical environments, housing with services and assisted living facilities are only required to disclose their philosophy and practice guidelines with no enforcement by government on meeting those self-disclosed standards.</p>	<p>2. Establish a license for assisted living facilities</p> <p>MDH must establish a license for Assisted Living settings that is consistent with the standards of care for persons with dementia in a meaningful way and that is aligned with regulations in other settings.</p>	<p>3. Review, strengthen, and expand rights of vulnerable adults in long-term care settings</p> <p>DHS and MDH should review, strengthen and expand the rights of vulnerable adults living in long-term care settings and their families, including enhancing criminal and civil enforcement for consumers and staff when there are violations of the Home Care and Health Care Bill of Rights.</p>	<p><i>Recommendation candidate:</i></p> <p>4. Include son- or daughter-in-law in Minnesota Medical Leave Act statutes’ definition of designated caregiver.</p> <p>In-laws are not included under the Family Medical Leave Act despite a rather expansive definition of parent, e.g. foster, in loco parentis, etc.). Following states such as California, Connecticut, and New Jersey, the Minnesota Legislature should amend Minnesota statutes to expand the definition of “family” under the federal Family Medical Leave Act to include parent-in-law.</p>
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Story Line #2: What can the state do to ensure support throughout Alzheimer’s disease progression?

Alzheimer’s disease is a chronic condition that can last more than a decade. With increasingly refined techniques/assessments to diagnose Alzheimer’s at an early stage, more people will be knowingly living with the disease when symptoms might be mild or non-existent. As the disease

gradually develops, it will greatly affect those living with Alzheimer’s dementia in terms of memory, problem-solving, relationships, and movement. During each stage, people living with the disease have unique needs for support.

5. More information and counseling along the entire care continuum.

The [legislature should direct the Minnesota Department of Human Services] to reevaluate the long-term care counseling process and the information provided through Senior Linkage Line. Information should be provided in more consumer-friendly formats that will help in patient and family decision-making and general understanding of long-term care living options in our state.

6. Enhance upstream interventions and incentivize ADAD treatment.

Reform health systems in Minnesota to enhance upstream interventions for ADAD and incentivize the treatment of ADAD as a chronic disease by keeping up-to-date an authoritative link on the MDH Website.

7. Improve regional networks of medical and community support

The Minnesota Legislature should provide funding for development of a Minnesota state-wide network of community dementia resource centers. This could be through providing grants for specific communities working on this or through direct support through supervision by the University of Minnesota medical school or School of Public Health, similar to what is currently done in Wisconsin.

Story line #3: What can the state do to ensure that dementia-related data collection supports innovation in care and treatment?

Careful analysis of accurate data from multiple vantage points should be foundational to all decisions, be they medical, familial, or legislative. This analysis tells us what is so that we can create a story about what could be. A data-rich state government can shine a light on underserved populations, stimulate medical and care provider innovation, and encourage promising service partnerships. Minnesota’s dementia-related data is inadequate at a time when we need it to be extraordinary.

8. Install recommendation tracking system

Designate an entity within the state to monitor the state’s actions to accomplish these recommendations to end the reliance on external work group reviews and make it a part of the state’s larger strategic plan for health and aging services.

9. Improve overall quality, collection and accessibility of state’s dementia-related data

Require more individual and coordinated efforts by DHS and MDH to improve dementia-related data available to all those involved in efforts that will positively impact the realities of this disease.

10. Synchronize quality indicators

(Allow MDH to?) obtain Minnesota-based health care system and community data in order to develop and implement programs and/or policies designed improve care and foster a nurturing, supportive environment for persons with dementia and their caregivers.

Story line #4: What can the state do to strengthen medical support?

All Minnesotans benefit from a medical community that is prepared, educated, and supported to diagnose, treat, and care for people with Alzheimer’s and related dementias [as well as their caregivers?]. This means providing support along the continuum of the disease, which can last over a decade. We need doctors who can be honest about someone’s current and future capabilities and risks, and who can support family members and caregivers to understand what to expect when living with and caring for someone affected by the disease. Minnesota needs doctors who can speak our language and recognize our values. We all want to be treated with dignity and respect regardless of our background.

<p>11. Training of Health Care Professionals at Minnesota State Veterans Homes</p> <p>The Minnesota Department of Veterans Affairs (MDVA) through its Minnesota State Veterans Homes (SVH) should partner with higher education institutions and other governmental organizations to help create a workforce prepared to provide long term care services, including dementia care. The SVH are committed to providing comprehensive dementia training for the purpose of improved quality of care, enhanced person-centered care and resident satisfaction. This could be accomplished through comprehensive training of medical, dental, nursing, behavioral health and other health care professional trainees.</p>	<p><i>(Henriet will explain why it made sense to split this concern into two recommendations on Monday)</i></p> <p>12. Make training at nursing facilities eligible for MERC funding</p> <p>The legislature should revise Minnesota Statute 62J.692 to remove the exclusion of training in nursing facilities from receiving Medical Education and Research Costs (MERC) grants distributed by the Department of Health.</p> <p>13. Increase funding for training at sites that serve populations with high prevalence of dementia</p> <p>The legislature should provide additional funding for training at sites that serve populations with high prevalence of dementia, such as nursing homes, adult day service providers, and home health agencies, either by amending funding formulas for Medical Education and Research Costs (MERC) grants to include such sites or through additional funds.</p>	<p><i>Recommendation candidate:</i></p> <p>14. Prioritize and incentivize outcomes reporting on Alzheimer’s disease</p> <p>The state, including the legislature and state agencies, should prioritize outcomes reporting on Alzheimer’s disease, including but not limited to number of screenings/assessments, number of people diagnosed with ADAD/Alzheimer’s disease, and number and type of referrals.</p>	<p><i>Recommendation candidate:</i></p> <p>15. Healthcare licensing board to require training on cognitive impairment</p> <p>Encourage the licensing boards of healthcare professionals practicing in the state (physicians, physician assistants, nurse practitioners, nurses, social workers, psychologists, etc.) to require training in the detection, management and care of patients with cognitive impairment in order to fulfill annual/biannual continuing education requirements.</p>	<p><i>Recommendation candidate:</i></p> <p>16. Increase care providers’ use of ACT on Alzheimer’s Practice guidelines</p> <p>Promote dissemination and routine use of ACT on Alzheimer’s practice guidelines for the detection and management of cognitive impairment and dementia in primary and specialty care within all health systems throughout the state.</p>
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Story line # 5 What can the state do to encourage a reduction in the risks face by citizens living with Alzheimer’s disease?

While researchers currently agree there is no evidence that Alzheimer’s disease is preventable, Minnesotans impacted by Alzheimer’s disease and other dementias do face other significant and preventable risks such as financial exploitation, consumer fraud, and driving. To protect and keep everyone safe, we need standards and guidance around these issues, especially as the number of people living with Alzheimer’s disease and other dementias increases.

17. Structured coordination of messaging and awareness campaigns

Including:

- Designating an entity to collaboratively develop statewide language that is evidence-based or a promising practices and allows for local customization for cultural traditions and understanding.
- Empowering the designee to develop a strategy to implement shared language across stakeholders in Minnesota
- Community communication, messaging, and access to valid resources needs to be available in multiple formats to ensure every community member can access regardless of computer capabilities, e.g. local newspapers, PSAs on radio, tribal newspapers, religious communications

Recommendation candidate:

18. Guidance for physicians around risks and safety of patients living with Alzheimer’s disease.

Direct the Department of Public Services [and other relevant agencies, such as MDH] to continue to develop and implement standards for driving and Alzheimer’s disease and other dementias.

Cultural Responsiveness – Guiding Values

19. We expect the State to support the highest level of wellbeing and personhood for the individual with dementia living in community, family home, and residence. Therefore, we expect the state to:

Authenticity:

- Accept people where they’re at – individual, family, provider, etc. We’re all responsible to play an active role in the work of health equity and cultural responsiveness.
- Encourage providers and those in positions of power to be open to not only hear and learn about different needs but positively address concerns expressed showing that they have sought and fully heard the voice of the client/patient/caregiver

Assets-based approach to equity and diversity:

- Recognize there are many variations of families and caregiving can look different. A patient isn’t one person – it’s whatever their family structure is. Consider the needs of families and caregivers who may have different cultural norms and values related to dementia/Alzheimer’s, as well as families where the care structure isn’t a husband/wife team.
- Work with communities that have different norms around how they view Elder’s and Alzheimer’s. An equitable solution may mean that different groups need different things, rather than a one-size fits all approach.