

DEMENTIA HEALTHCARE INITIATIVE ADVOCATING FOR A DEMENTIA-CAPABLE SYSTEM OF CARE

Overview – Capitalizing on Opportunity

In the current healthcare reform environment, institutions and entire systems of care are increasingly moving toward a coordinated, person- and family-centered, value-based approach. There are tremendous opportunities to improve the care for those with Alzheimer's Disease and Related Disorders (ADRD) and their caregivers. It is within this window of opportunity that we can take concrete steps toward building more dementia-capable, integrated systems of care.

High quality and cost-effective managed care for people with dementia is not only possible – it is already being achieved in demonstration projects across the country.^{1 2} By integrating health plans, medical and behavioral health providers, long-term services and supports (LTSS), community based organizations (CBOs), patients, and caregivers into a system of care, such projects have begun making improvements in the cost and quality of care for patients with complex and/or chronic conditions.^{3 4 5 6 7 8}

With a thoughtful, well-executed advocacy strategy in place, we can capitalize on this moment of opportunity to make meaningful and sustainable systems change within healthcare for those impacted by dementia. This document will help you make the greatest possible impact as you advocate for change with health plans and among health care providers.

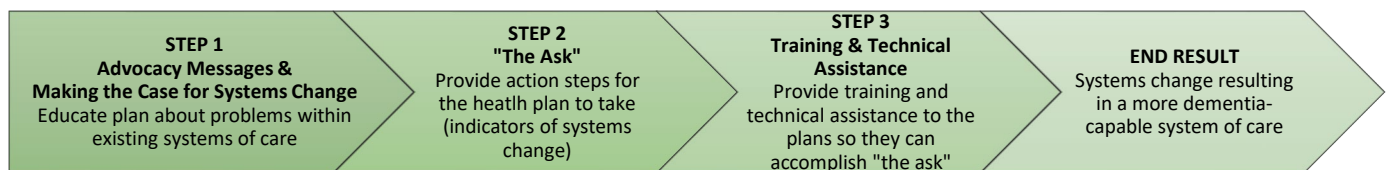
Dementia Healthcare Initiative Goals and Indicators of Systems Change

This initiative has three primary goals, each with corresponding indicators of systems change, to help health plans create a dementia-capable system of care. When speaking with health plan partners about goals, providing concrete examples of system change is invaluable.

Project Goals	Indicators of Systems Change to Achieve Project Goals
1. Better detection and care management of beneficiaries with dementia	<ul style="list-style-type: none"> • Health risk assessment/other assessments include cognitive impairment • Adopt a validated cognitive screening tool such as the AD8 • Integration of cognitive assessment into e-record • Protocol for diagnosis if screen is positive
2. Better partnerships between health systems and family/friend caregivers	<ul style="list-style-type: none"> • Identification of family/friend caregiver • Documentation of family/friend caregiver in e-record • Family/friend caregiver assessment adopted • Integration of family/friend caregiver education • Adoption of best practice care plans • Respite benefit provided by health plan • Workflow processes established for use of Dementia Care Specialist
3. Better partnerships with dementia-specific community-based organizations	<ul style="list-style-type: none"> • Provision of dementia-specific training programs and technical assistance • Provision of services & supports to patients and family/friend caregivers • Adoption of <i>ALZ Direct Connect</i>[®] referral program to connect to: <ul style="list-style-type: none"> ○ Support groups ○ Caregiver education ○ Early stage services ○ Care counseling ○ Engagement/activity programs

Getting Started with Advocacy

The goal of this advocacy messaging is to educate health plans about dementia, its impact on their service delivery system, and the changes they must make to better meet the needs of beneficiaries with dementia and their caregivers. Once the plans understand the impact and cost of *not* addressing this issue in a comprehensive way, advocates should make “the ask.” This means pushing the plans to integrate each of the indicators of systems change noted above into their health care delivery system. Project staff will need to provide training and technical assistance to health plan partners so they are able to implement and sustain these health system reforms.



In order to achieve goals, it is essential that advocates begin building relationships with healthcare and other relevant service providers along with state and federal agency partners as soon as possible. At every opportunity and interaction, you need to make the case for a dementia-capable system of care (see attached). Your case must combine their cost- and quality-conscious language to make plain why this change is necessary and what it can deliver.

When working with health plans, from the outset you should:

1. **Identify Advocates and Champions** – Individuals with the capability and inclination to advance the initiative are found within both the individual plans and the state health apparatus; work to identify them as soon as possible. Directors or Vice-Presidents of LTSS and Care Management, as well as Medical Directors, are good starting points. If someone has a personal connection to Alzheimer’s disease, they may be the natural champion at the plan or they may be able to connect you with a colleague who has decision-making authority.
2. **Craft Advocacy Messaging** – The messages that best resonate with health plans differ from those aimed at most other public interest advocacy targets; get familiar with plans’ focus on value, cost-control, and quality to craft your message accordingly, keeping in mind that the best strategy is to align your key dementia-related messages with your larger goals and expected outcomes. Repeat advocacy messages often and be clear and concise. (See advocacy messages below)

3. **Build Relationships** – Always be on the lookout for opportunities to engage and network with potential institutional advocates and champions in as many settings as possible; good options include health plan gatherings, stakeholder meetings, advisory groups, conferences, presentations, individual telephone conversations, and in-office meetings.
4. **Be an Assertive, Vocal Advocate** – Repeat your advocacy messages often and consistently with your institutional advocates and champions; ask to be put on meeting agendas, press your case before and after professional gatherings, and be persistent.
5. **Assess and Adjust** – The initial stages of the initiative call for flexibility and a willingness to actively consider what is and is not working well; regardless of your partners' potential preoccupations with implementation, remain consistent and persistent in your advocacy efforts.

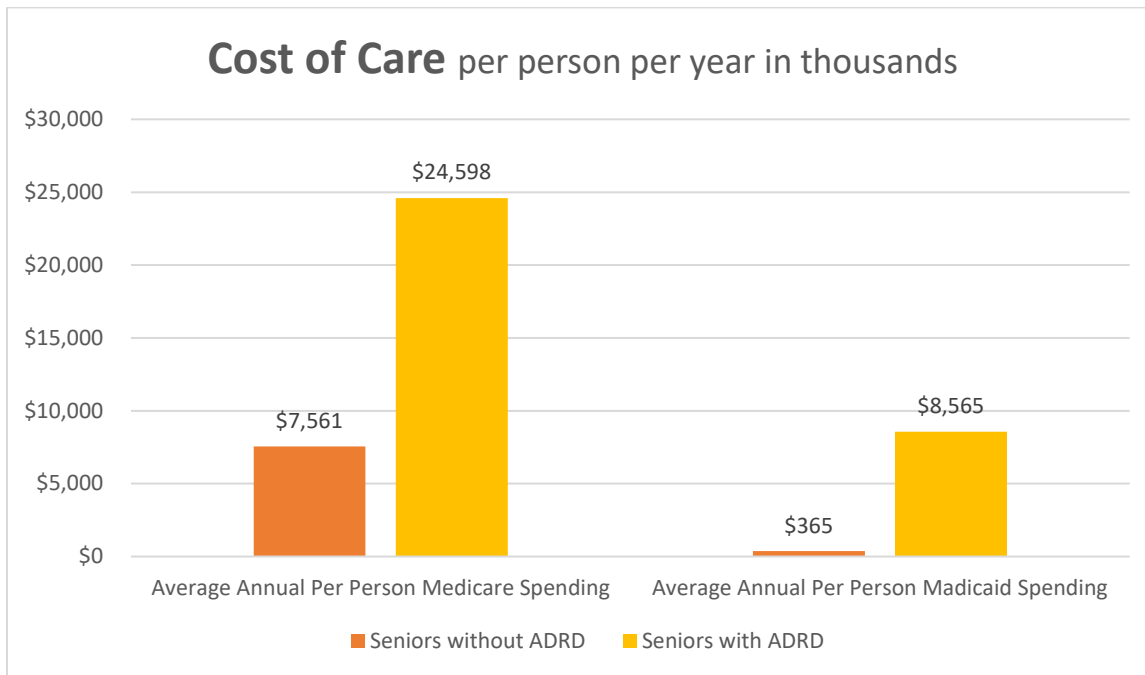
Advocacy Messages that Matter

There are several advocacy messages that should be used consistently throughout your advocacy efforts. These messages should be clear, concise, and poignant. Advocates should know the “canned” messages, but also have background knowledge and context associated with each message in the event that they are asked to share additional information. Below are the primary advocacy messages, and associated information related to each message, used in the Dementia Healthcare Initiative.

ADVOCACY STATEMENT #1: *Patients with dementia are expensive to health care insurers. They cost Medicare three times more than other beneficiaries in the same age group, primarily because of hospitalizations, and they cost Medicaid 23 times more, primarily because of nursing home placement.*

CONTEXT: The costs of care for people with dementia are high for all payers, including Medicare, Medicaid, and private insurers.^{9 10 11 12 13 14} This is due, in part, to the fact that dementia significantly increases the likelihood for hospitalization and length of hospital stays, compared to people with the same serious medical conditions, but without dementia.¹⁵ Dementia is also an independent risk factor for nursing home admission in community-dwelling older adults, even when controlling for numerous co-morbidities.¹⁶ In addition, many people with dementia have multiple coexisting conditions: 60% have hypertension, 26% have coronary heart disease, 25% have stroke, and 23% have diabetes.¹⁷

One study found that people with cognitive impairment and three additional chronic health conditions cost Medicare an average of \$50,000 per year.¹⁸ As a result, beneficiaries with moderate to severe cognitive impairment, as shown in the chart below, cost Medicare three times more than other beneficiaries in the same age group; this difference is driven primarily by hospitalizations. They cost Medicaid 23 times more than other enrollees of the same age, largely due to nursing home utilization.¹⁹



Alzheimer’s Association. 2019 Alzheimer’s Disease Facts and Figures. Alzheimer’s Dementia 2019;15(3):321-387.

ADVOCACY STATEMENT #2: *Only half of people with dementia receive a formal medical diagnosis, and of those classified, only about fifty percent have the diagnosis recorded in their medical record.*

CONTEXT: Lack of dementia diagnoses has serious implications for health plans and their members. Initially, many health plans may be reliant on medical record data such as historical claims data to determine the number of patients with dementia under their care. Given the fact noted above, their estimate will almost certainly be significantly lower than the actual number. While prevalence estimates for the general population of those 65 years and older is typically cited as being around 11%, for the dually-eligible population, the prevalence rate is more likely to be around 23%.^{20 21} This discrepancy likely reflects the complex health care needs of the dually eligible population and the fact that those with multiple chronic conditions, such as diabetes and hypertension, are at greater risk of developing dementia.

Second, without a diagnosis – let alone a documented diagnosis—effective care planning and care management cannot occur. Health plans cannot effectively convene interdisciplinary care teams and create care plans without knowing the conditions for which disease management is needed. When beneficiaries with dementia are diagnosed, their medical and LTSS care needs can be better managed, potentially resulting in reduced unnecessary hospitalizations and delayed nursing home placement.

ADVOCACY STATEMENT #3: *Family/friend caregivers are the backbone of our community-based long-term services and supports system.*

CONTEXT: An estimated 83% of the care for people with dementia is provided by family members in their own home.²² Those taking care of someone with ADRD provide billions of dollars of unpaid care annually in the United States. While aspects of such caregiving can be satisfying, these caregivers report experiencing considerable financial, emotional, and physical strain in the process. Despite the integral role of caregivers, they often remain unidentified by health care systems, their needs are not assessed, they are not provided with education and support, and they are not engaged in care planning processes. To improve care and lower costs, health plans need to identify caregivers, assess their needs, offer them education and support, and – finally – find opportunities to engage them in care planning and management.

Where We Go From Here

This type of advocacy requires repetition. At each stage of implementation and innovation, your growing relationship with healthcare partners and your advocacy messages remain crucial in moving toward a dementia-capable system of care. As the process advances, your advocacy approach should adapt accordingly and begin incorporating key indicators of system change.

For those struggling with ADRD, these coordinated care improvements mean improved person- and family-centered care via better screening for cognitive impairment, better-trained healthcare professionals, newly-developed systems to identify, assess, and support family/friend caregivers, new workflow processes to connect families with a trained Dementia Care Specialist, and adoption of a referral program that connects families to home and community-based services.

For plans and providers, these changes should mean greater access to specialized training, better coordinated care for individual patients, expanded patient-centered collaborations, and the promise of better long-term cost control that these reforms deliver. These reform-generated savings derive from avoiding unnecessary utilization of medical services, improved transitions across sites of care, and transition of beneficiaries from institutional care to lower-cost home and community-based services.

For more information and tools to improve dementia care in health care systems, visit: www.alzheimersla.org/professionals

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