



Working together to improve health care quality, outcomes, and affordability in Washington State.

Alzheimer's Disease and Other Dementias Report and Recommendations

2017

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Executive Summary

The Dr. Robert Bree Collaborative was established in 2011 to provide a forum in which public and private health care stakeholders can work together to improve quality, health outcomes, and cost-effectiveness of care in Washington State. Alzheimer's disease and other dementias are a growing concern in Washington State and around the country. The complex symptoms including in memory, cognition, and social functioning are difficult for patients themselves, their family members and friends, and the health care system at large. In many cases no clear guidelines exist to support the patient through diagnosis and increase in symptoms. The Bree Collaborative elected to address this topic and convened a workgroup to develop recommendations that met from January 2017 to November 2017.

This Report and Recommendations has six focus areas developed in partnership with the Dementia Action Collaborative:

1. Diagnosis,
2. Ongoing care and support,
3. Advance care planning and palliative care,
4. Need for increased support and/or higher levels of care,
5. Preparing for potential hospitalization, and
6. Screening for delirium risk.

The goal of the recommendations are to support patients, their family members, and other caregivers across the disease process. The workgroup developed a roadmap for implementation starting on page 5 outlining the patient perspective for optimal care alongside operational details for each of the six areas walking through the current state, intermediate steps toward implementation of the recommendations, and a description of optimal care. Following this on page 12 are specific steps for stakeholder groups including: patients and family members, primary care practices and systems (including primary care providers), health plans, hospitals, skilled nursing facilities, and Washington State agencies to improve quality of dementia care, health outcomes of people with dementia and their caregivers, and affordability.

The remainder of this Report is meant to support these six focus areas including discussions of the evidence and best practices for diagnosis, how to best support patients and families through disease progression, linking these recommendations to earlier Bree Collaborative work around advance care planning and palliative care, and information on transitions of care and delirium. The Report also discusses other work within Washington State to facilitate high-quality dementia care including development of the Washington State Plan to Address Alzheimer's Disease and Other Dementias and ending with an inclusion of dementia-specific measures.

Dr. Robert Bree Collaborative Background

The Dr. Robert Bree Collaborative was established in 2011 by Washington State House Bill 1311 “...to provide a mechanism through which public and private health care stakeholders can work together to improve quality, health outcomes, and cost effectiveness of care in Washington State.” The Bree Collaborative was modeled after the Washington State Advanced Imaging Management (AIM) project and named in memory of Dr. Robert Bree, a pioneer in the imaging field and a key member of the AIM project.

Members are appointed by the Washington State Governor and include public health care purchasers for Washington State, private health care purchasers (employers and union trusts), health plans, physicians and other health care providers, hospitals, and quality improvement organizations. The Bree Collaborative is charged with identifying up to three health care services annually that have substantial variation in practice patterns, high utilization trends in Washington State, or patient safety issues. For each health care service, the Bree Collaborative identifies and recommends best-practice, evidence-based approaches that build upon existing efforts and quality improvement activities to decrease variation. In the bill, the legislature does not authorize agreements among competing health care providers or health carriers as to the price or specific level of reimbursement for health care services. Furthermore, it is not the intent of the legislature to mandate payment or coverage decisions by private health care purchasers or carriers.

See **Appendix A** for a list of current Bree Collaborative members.

Recommendations are sent to the Washington State Health Care Authority for review and approval. The Health Care Authority (HCA) oversees Washington State’s largest health care purchasers, Medicaid and the Public Employees Benefits Board Program, as well as other programs. The HCA uses the recommendations to guide state purchasing for these programs. The Bree Collaborative also strives to develop recommendations to improve patient health, health care service quality, and the affordability of health care for the private sector but does not have the authority to mandate implementation of recommendations.

For more information about the Bree Collaborative, please visit: www.breecollaborative.org.

Alzheimer’s disease and other dementias are a growing concern in Washington State and around the country. The complex symptoms including memory, cognition, and social functioning are difficult for patients themselves, their family members and friends, and the health care system at large. In many cases no clear guidelines exist to support the patient through diagnosis and increase in symptoms. The Bree Collaborative elected to address this topic and a workgroup convened to develop recommendations from January 2017 to November 2017.

See **Appendix B** for the Alzheimer’s Disease and Other Dementias workgroup charter and a list of members.

See **Appendix C** for results of the Guideline and Systematic Review Search Results.

Purpose Statement

The decline in memory and other cognitive functions and corresponding loss of independence because of dementia is a growing concern in our aging population. Age is the biggest risk factor for dementia with prevalence rates of 13.9% in those 71 and older increasing to 37.4% for those 90 and older.¹ The majority of cases, 69.9%, are due to Alzheimer's disease with vascular dementia (also known as post-stroke dementia) accounting for 17.4% and the remaining 12.7% due to a combination of Parkinson's dementia, normal-pressure hydrocephalus, frontal lobe dementia, alcoholic dementia, traumatic brain injury, Lewy body dementia, or being of unknown origin.¹ Hearing loss, associated with increasing age, is also associated with cognitive decline and increased risk of dementia.² Washington State has the third highest rate of death from Alzheimer's disease of any state and Alzheimer's is the third highest age-adjusted cause of death within the State overall.³ The number of people diagnosed with dementia is expected to increase 40% in next 10 years and 181% over the next 30 years.³

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) defines dementia as decline from previous level of performance in learning and memory, language, executive function, complex attention, perceptual-motor, and/or social cognition that interfere with independence in everyday activities absent another cause (e.g., depression, in the context of delirium).⁴ Dementia can impact ability to plan and carry out activities, manage work and personal finances, and take medications.⁵ Severe dementia is associated with greater prevalence of behavioral and psychological symptoms including agitation, anxiety, depression, delusions, and sleep or appetite changes.⁶ These behavioral and psychological symptoms are complex and can be the most difficult for family members and other caregivers.⁷ Dementia also can result in a higher risk of falls at home, hospitalizations, and risk of falls within a hospital setting.^{8,9} Dementia is associated with higher out of pocket expenses, that increase with the severity of the diagnosis, especially for hospital or nursing home care and prescription medications.^{8,9} Additionally, dementia is a terminal condition that lends itself well to palliative care services.

In many practices in Washington State, there are no guidelines to increase quality of care for diagnosis or care for patients with Alzheimer's disease and other dementias.¹⁰ This is costly to the health care system and overly burdensome to primary care clinicians, and patients, their caregivers, and the community.

The Bree Collaborative Alzheimer's Disease and Other Dementias Workgroup endorses and aims to build off the previous work within Washington State, specifically the [Washington State Plan to Address Alzheimer's Disease and Other Dementia](#). The workgroup aims to align care delivery with the existing evidence-based standard of care for each stage of disease and across health care settings for both for patients and their families and caregivers. The workgroup seeks to address the variation in quality of treatment across the state of Washington through implementation of these standards and build a health care system that is responsive to individual patient and family need as well as being equitable.

Recommendations

The Bree Collaborative Alzheimer's Disease and Other Dementias workgroup has developed recommendations in six areas: (1) diagnosis, (2) ongoing care and support, (3) advance care planning and palliative care, (4) need for increased support and/or higher levels of care, (5) preparing for potential hospitalization, and (6) screening for delirium risk. This recommendation is developed in partnership with the Dementia Action Collaborative and seeks to build off the work of the health and medical subcommittee. Alzheimer's disease and other dementias occur in all cultural and ethnic groups and must be addressed in a culturally-sensitive manner.

The workgroup defines dementia as outlined by the National Institute on Aging and the Alzheimer's Association including symptoms that:¹¹

- *“Interfere with the ability to function at work or at usual activities; and*
- *Represent a decline from previous levels of functioning and performing; and*
- *Are not explained by delirium or major psychiatric disorder;*
- *Cognitive impairment is detected and diagnosed through a combination of (1) history-taking from the patient and a knowledgeable informant and (2) an objective cognitive assessment, either a “bedside” mental status examination or neuropsychological testing. Neuropsychological testing should be performed when the routine history and bedside mental status examination cannot provide a confident diagnosis*
- *The cognitive or behavioral impairment involves a minimum of two of the following domains*
 - *Impaired ability to acquire and remember new information—symptoms include: repetitive questions or conversations, misplacing personal belongings, forgetting events or appointments, getting lost on a familiar route.*
 - *Impaired reasoning and handling of complex tasks, poor judgment—symptoms include: poor understanding of safety risks, inability to manage finances, poor decision-making ability, inability to plan complex or sequential activities.*
 - *Impaired visuospatial abilities—symptoms include: inability to recognize faces or common objects or to find objects in direct view despite good acuity, inability to operate simple implements, or orient clothing to the body.*
 - *Impaired language functions (speaking, reading, writing)—symptoms include: difficulty thinking of common words while speaking, hesitations; speech, spelling, and writing errors.*
 - *Changes in personality, behavior, or comportment— symptoms include: uncharacteristic mood fluctuations such as agitation, impaired motivation, initiative, apathy, loss of drive, social withdrawal, decreased interest in previous activities, loss of empathy, compulsive or obsessive behaviors, socially unacceptable behaviors.”*

We found it helpful to ground all six focus areas in the patient perspective to keep the patient at the center of care improvement. On the following pages we outline the patient perspective alongside operational details for each of the six areas walking through the current state, intermediate steps toward implementation of the recommendations, and a description of optimal care.

Following this on page 12 are specific steps for stakeholder groups including: patients and family members, primary care practices and systems (including primary care providers), health plans, hospitals, skilled nursing facilities, and Washington State agencies to improve quality of dementia care, health outcomes of people with dementia and their caregivers, and affordability.

Table 1: Recommendations for Optimal Alzheimer’s Disease and Other Dementia Care

	Focus Area	Patient Perspective	Operational Details
1	Diagnosis	<i>I or my family members have concerns about memory. My care team talks with me about my concerns and helps me understand the cause of any trouble with thinking ability. I know who to contact in case of urgent questions or situations and have thought about the type of care that I would want at different stages of the disease.</i>	<p>Current State: While some providers may routinely screen for or discuss cognitive issues with patients, in many cases issues with memory and cognition are only addressed if they are brought up by the patient or family member(s). Once brought up by the patient or family member, issues with memory or cognition may be adequately addressed by the provider. In some cases there may be no clinical follow-up. The provider may be unsure as to screening tools, how to utilize the Medicare Annual Wellness Visit, or next steps and may not feel comfortable discussing cognitive issues due to lack of training and lack of a system-wide protocol for addressing cognitive concerns. Primary care providers may diagnose dementia or may refer to a specialist (i.e., neurologist, geriatric psychiatrist) for diagnosis if one is available within the health care system. Specialty consultation may be unavailable.</p> <p>Intermediate Steps: Practices work to increase providers’ level of comfort and expertise in diagnosing and discussing a dementia diagnosis, increasing understanding that this diagnosis is within the primary care scope of practice. Clear guidelines are available on how to make the diagnosis using validated tools with the expectation that the provider will truthfully discuss the diagnosis with the patient and family and record the diagnosis in the medical record. Practices may pilot screening programs with select populations, reporting on lessons learned before implementing wider screening. Primary care providers involve a neurologist or other specialist as needed for consultation and support or for differential diagnosis.</p> <p>Optimal Care:</p> <ul style="list-style-type: none"> • The patient has an identified primary care provider. • Patient and family members receive coordinated care as part of an interdisciplinary team that has been trained in how to talk about cognitive impairment. This may include support staff in the primary care provider office, specialists such as neurology consultation, and community partners. • Family members or other caregivers are included in conversations and feel supported and heard. • Primary care providers are clear on the value of early detection and feel comfortable truthfully discussing cognitive issues, understanding the uncertainty that can accompany the diagnosis. Mild cognitive impairment (MCI) or dementia is detected at an early stage.

			<ul style="list-style-type: none"> • Hearing loss is assessed and appropriately addressed (e.g., hearing aids, personal amplifiers) as hearing loss can complicate identification and treatment. • Diagnosis follows a two-stage clear clinical protocol with initial screening through the Medicare Annual Wellness visit or other visit in which cognitive impairment is detected with a brief (<5 minutes), validated tool. Direct observation with consideration of information obtained by family members, friends, or others may also be used. <ul style="list-style-type: none"> ○ A positive finding is followed by additional evaluation and confirmation of the diagnosis, if needed. Diagnosis follows the Alzheimer’s Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition outlined in Appendix D and in a Clinical Provider Practice Tool outlined here. ○ The diagnosis conversation and any subsequent conversations follow the Alzheimer’s Association principles for a dignified diagnosis, listed in Appendix E, and includes an advance care planning conversation (see #4). HCPCS code G0505 (i.e., detailed structural assessment of dementia or Alzheimer’s disease performed by a clinician that cannot be done the same day as an office visit) can be billed for care planning services provided to individuals with cognitive impairment.
2	Ongoing Care and Support/Management	<i>Once I have a diagnosis, I and my family members feel hopeful that we/I can manage my cognitive diagnosis with my care team and family member(s).</i>	<p>Current State: Patients experience significant variability in the type and number of interventions and support offered after diagnosis and throughout the disease course. Patients and families are not consistently informed of treatment options, community services, or an answer to the question “I have a diagnosis, what do I do now?” and can feel lost. Providers may be unaware of the supports available in their community or there may be a lack of community support and providers are uncertain as to next steps.</p> <p>Intermediate Steps: The practice has a pilot pathway for interventions and supports to offer at different stages throughout the disease process that may not be used for all appropriate patients. Family and caregivers may be part of the initial conversation, but may not feel supported throughout the disease process.</p> <p>Optimal Care:</p> <ul style="list-style-type: none"> • Patients are often best supported by a care team framework. The care team may include providers outside of the practice (e.g., specialty care). Patients and family members are included as part of the care team with patient goals and values being

		<p>incorporated into the type of interventions offered as well as consideration for comorbid conditions.</p> <ul style="list-style-type: none"> • Primary care teams routinely assess complexities of supporting patients with dementia and the needs of family care partners for enhanced support. • Dementia care management services (e.g., home health, phone-support, enhanced outpatient management) are offered to patients or caregivers who have been determined to be high-risk. This high-risk group may include patients that have several medical comorbidities, complex medication regimens, behavioral/psychiatric symptoms, and/or history of frequent utilization of acute care services. Care management services to consider may include: comprehensive in-home assessment by trained health care professionals; collaborative goal-setting between clinicians, care partners and patients; close follow-up and coordination of medical and psychosocial services and routine assessment of needs. • Providers routinely consider a patient’s dementia diagnosis and comorbid conditions when making decisions to minimize unnecessary or harmful care. Providers appropriately treat conditions that can worsen symptoms or lead to poor outcomes, including depression and existing medical issues. • The care team is able to maximize functioning to meet patient and family needs at each stage of the disease. • Evidence-based interventions (e.g., exercise, diet modification) are suggested upon diagnosis and discussed during any follow-up visits. The care team assess and discusses with the patient and family how to reduce risk of falls, how to optimize function and mitigate confusion, how to manage medication(s), and how to address driving status and safety (outlined here). • The level of support offered depends on patient-factors including complexity, severity, level of caregiver support, and other factors. • Neuropsychiatric symptoms (e.g., agitation, psychosis) may be due to social, psychological, or environmental factors and management should be discussed using a shared-decision making approach. Non-pharmacologic approaches are best attempted first; pharmacologic therapies are not a first line therapy. • Patients and families are offered information about available community supports such as through the Alzheimer’s Association and local Area Agency on Aging programs. • Patient quality of life is maximized through a focus on individuals’ preserved capabilities and identities, access to services that prolong functioning (e.g., speech,
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			<p>occupational, physical therapies hearing aids or personal amplifiers), and continued engagement with social networks and enriching activities, through use of a strengths-based approach.</p> <ul style="list-style-type: none"> Caregivers are supported and providers assess and note caregiver knowledge, skills, capacity and possible distress at each visit. Caregivers are also connected with resources such as county Family Caregiver Support Programs, which facilitate access to respite care, and support groups, if available.
3	Advance Care Planning and Palliative Care	<p><i>I have had a meaningful conversation with my doctor, including my family member(s), about what I want for end-of-life care. We have written this down into an advance directive that is accessible by my care team and family. I feel confident that my goals of care will be followed. If I need it, I have access to and understand the need for palliative care.</i></p>	<p>Current State: Care given to patients at the end of life varies based on institutional protocol and is not necessarily aligned with patient goals of care. Family and other caregivers may feel burdened in making clinical decisions without having had previous conversations with the patient and feel overwhelmed and unsupported. Patient symptoms (e.g., pain) may not be well-managed or addressed. Non-value added care may be provided, such as mammograms or feeding tube placement in patients with advanced dementia.</p> <p>Intermediate Steps: Patient and family members have begun to have conversations about goals for care but may not have had these in a clinical setting and have not documented their goals in an advance directive or the advance directive is not accessible to the care team.</p> <p>Optimal Care:</p> <ul style="list-style-type: none"> Patients, providers, family, and other caregivers have had a comprehensive advance care planning conversation in a clinical setting that has been documented in an advance directive as early as possible to maximize the patient’s voice and input. This stipulates specific treatment preferences (if known and applicable to the situation), a durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making; a written personal statement that articulates the patient’s values and goals regarding end-of-life care; discussion of risks, benefits, and goals for a potential hospitalization; and Physician Orders for Life Sustaining Treatment (POLST). Providers routinely consider patient’s dementia diagnosis and issues of decision-making capacity when making decisions to minimize unnecessary or harmful care and discuss this with the patient and family. The care team has discussed when palliative care and/or hospice might be appropriate.

			<ul style="list-style-type: none"> The patient and family know who to contact if symptoms (e.g., pain) develop or worsen and feel confident in their care plan.
4	<p>Need for Increased Support and/or Higher Levels of Care</p>	<p><i>I and my family members have a plan if my cognitive decline and care is more than can be managed safely at home with my current supports.</i></p>	<p>Current State: For most patients and families there is little information about planning for possible transitions to higher levels of care. Providers and care teams may be unsure as to community supports available to patients and families and not know how to identify proactive steps to take (e.g., additional home support, residential care).</p> <p>Intermediate Steps: Initial conversations about the diagnosis include information about progression of cognitive decline and changes in functional abilities. Patients and family members are encouraged to start thinking about potential need for higher levels of care at home or in an alternative living situation. Patients and families are connected to community resources that provide education about these care options and understand how to manage behavioral symptoms as much as possible.</p> <p>Optimal Care:</p> <ul style="list-style-type: none"> Patients and family members understand that they may face decisions about the need for increased care, care transitions and/or increased stress and caregiver burden. Patients and families have these conversations early on in the disease, anticipating progression and have a plan if care needs are greater than can be safely managed at home with current supports, such as additional in-home care or services, respite care, or move to a residential facility. From the time of initial diagnosis, patients and family members are connected to community resources that can help plan for future and increasing care needs. Monitoring for progression of cognitive decline, emergence of behavioral symptoms, functional impairment (e.g., activities of daily living), and care-partner/family capacity is part of each primary care visit and communicated to the patient and family members. Planning includes consideration for caregiver stress and capacity, financial and insurance concerns (e.g., long term care coverage), health care considerations, and availability of local residential facilities, paid caregivers, and community resources (such as Meals on Wheels, volunteer chore services, etc.).

<p>5 Preparing for Potential Hospitalization</p>	<p><i>I and my family understand that I may need to receive care from a hospital and have planned ahead for a potential hospital visit. After leaving the hospital, I and my family know our next steps – whether that is continuing to live at home or receiving care at a residential facility – and have enough information to make a decision comfortably.</i></p>	<p>Current Care: Hospitalization or a visit to an emergency room may feel unexpected to patients and family members. Clinicians and hospital staff may be unaware of the dementia diagnosis or any patient communication issues and may be unprepared for preventing patient safety issues such as agitation, delirium or adverse reactions to medications. At discharge, patients and families may feel unsupported in managing symptoms at home or unsure about transitions to residential care or a rehabilitation facility.</p> <p>Intermediate Steps: Patients and families begin to have conversations about how to plan and prepare for a potential hospitalization. Hospitals have plans on how to incorporate relevant personal information (e.g., dementia diagnosis) into the electronic health record (EHR), procedures performed and care provided during the hospitalization (e.g., anesthesia and pain protocols), and how to communicate this diagnosis to staff. Discharge protocols identify family caregivers and take into consideration needs of patients with dementia and how to support patients either being discharged to home or to a residential care facility.</p> <p>Optimal Care:</p> <ul style="list-style-type: none"> • Patients and family members have had conversations early on in the disease process to address patient wishes for hospital visits and medical intervention including risks and benefits of hospitalization. This may include using a POLST. • Family and other caregivers understand red flags that may necessitate entry into an acute care setting and understand how to implement the previously developed care plan if the patient is unable to express his or her wishes. • All treating clinicians and other staff are aware of the dementia diagnosis and understand the patient’s communication ability, ability to hear, behavioral concerns (e.g., agitation, exit seeking, wandering), and other information that the patient may not be able to communicate (e.g., allergies, other reactions to medications, dietary preference). • At discharge, the patient and family members are supported whether the patient is going home, to their prior facility, or to a residential care facility. Discharge planners facilitate discharge to the most appropriate location given an assessment of the patient’s current status (which may have changed since hospitalization), care partner or facility’s ability to meet needs, and rehabilitation potential. • The hospital team communicates with the facility or caregiver discharge instructions, current medications, and follow-up appointment needs.
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<p>6 Screening for Delirium Risk</p>	<p><i>In a hospital, my care team asks me questions to see whether confusion and lack of independence will be an issue, especially after surgery. I understand what this might mean for me and my recovery.</i></p>	<p>Current Care: Screening for delirium or incorporation of a patient’s dementia diagnosis into the medical record is not a routine part of hospital care.</p> <p>Intermediate Steps: Practices and hospitals may develop a pilot project to incorporate screening for delirium into a specific pre-surgical care pathway (e.g., total joint replacement) with eventual plans to learn from implementation and spread the protocol to all admissions.</p> <p>Optimal Care:</p> <ul style="list-style-type: none"> • During hospitalization, all patients 65 years of age or older or with other identifiable risk factors are screened for risk of delirium. Results are incorporated into the medical record and the care team is aware of risk. • The patient as well as their family and other caregivers are made aware of the risk of delirium, what symptoms might look and feel like, and what delirium might mean for recovery. • Hospitals and providers implement care plans and protocols to minimize risk for delirium and have established plans to respond appropriately when it occurs.
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Diagnosis

- Talk to your health care providers about any concerns you might have about memory or thinking ability. Your care team should ask you a standard set of questions and may set up a follow-up appointment.
- Talk to your health care providers about any concerns you have about being able to hear. If you do have hearing impairment, talk about hearing aids or an assisted listening device (e.g., pocket talker).
 - Information on identifying symptoms of hearing loss:
www.hearingloss.org/content/symptoms-hearing-loss
 - Information on how to communicate with someone who has hearing loss:
www.agingcare.com/articles/hearing-loss-communication-techniques-144762.htm
- Make sure you can identify your primary care provider or family doctor.
- Review the resources developed by the Washington State Dementia Action Collaborative especially the [Dementia Road Map: A Guide for Family and Care Partners](#). This tool takes patients and caregivers in all stages of cognitive decline through action steps and questions from the early stages of being worried and wondering to late-stage dementia.
- During diagnosis we recommend that your health care provider follow the principles outlined in the Alzheimer's Association's Principles for a Dignified Diagnosis. You can see these principles that have been developed by patients here: www.alz.org/national/documents/brochure_dignified_diagnosis.pdf and also listed in **Appendix E** on page X.
- Ask your care team about local resources. Connect to others in your community who may be going through the same process. Some resources include:
 - The county's [Area Agency on Aging](#) provider (including referrals for family and caregiver support such as respite care facilities)
 - [African American Elders Program](#)
 - [Alzheimer's Association of Washington State](#)
 - [Alzheimer Society of Washington](#)
 - [American Association of Retired Persons](#) (AARP)
 - [American Automobile Association](#) (AAA) Senior Drivers
 - [Chinese Information and Service Center](#)
 - [Community Living Connections](#) including resources by [county](#)
 - [Hearing Loss Association of America - Washington State Association \(HLA-WA\)](#)
 - [Momentia Seattle](#)
 - [National Institute on Aging](#)
 - [Open Doors for Multicultural Families](#)
 - [Seattle Indian Health Board](#)
 - [Path with Art](#)
 - [Washington State Department of Social and Health Services - Office of the Deaf and Hard of Hearing](#)

Ongoing Care and Support/Management

- Talk with your care team about how to maintain quality of life and what this means to you and your family. Including concerns about:
 - Progression of cognitive decline
 - Managing other diagnoses that you might have (e.g., diabetes, high blood pressure, hearing loss)
 - Driving status and safety (outlined [here](#)).
 - Home safety and risk of falls
 - Feeling down or depressed
 - Confusion, agitation, aggression, and/or wandering
 - Sleep quality and sleep disturbance
 - Managing medications
 - Ability of your care partner/family to meet your care needs now and in the future
 - Whether palliative care or hospice might be appropriate
 - Any other concerns
- Consider lifestyle changes as recommended by your care team (e.g., cardiovascular exercise, mindful changes to diet).

Advance Care Planning. Think about the type of care you would want at the end of life. Have a conversation with your family members or other caregivers about what you would want. You should also have a conversation with your care team about your wishes, goals, and values for end-of-life care that includes caregivers and the individual designated as your durable power of attorney for health care.

- You should complete:
 - An advance directive that stipulates specific treatment preferences (if known and applicable to the situation),
 - A durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and
 - A written personal statement that articulates your values and goals regarding end-of-life care.
 - Physician Orders for Life-Sustaining Treatment (POLST)
- There are many resources out there to help people have this conversation including:
 - Alzheimer’s Association End-of-Life Decisions (specific to dementia): www.alz.org/national/documents/brochure_endoflifedecisions.pdf
 - Death Over Dinner: <http://deathoverdinner.org/>
 - The Conversation Project (specific to dementia): http://theconversationproject.org/wp-content/uploads/2016/05/TCP_StarterKit_Alzheimers.pdf
 - End of Life Washington – Alzheimer’s Disease/Dementia Mental Health Advance Directive: <http://endoflifewa.org/alzheimers-diseasedementia-advance-directive/>
 - Five Wishes: www.agingwithdignity.org
 - Honoring Choices Pacific Northwest: www.honoringchoicespnw.org
 - US National Library of Medicine Medline Plus: <https://medlineplus.gov/ency/patientinstructions/000472.htm>

Planning for Higher Care Needs and Hospitalizations

- Have conversations early on in disease progression about your wishes for hospital visits and medical intervention. Conversations should include risks and benefits of hospitalization and may include filling out a Physician Order for Life Sustaining Treatment also known as POLST. As part of these conversations, think about the type of care that you would not want (e.g., feeding tubes). Information from Choosing Wisely and Consumer Reports on feeding tubes can be found [here](#).
- Write down your wishes into a care plan with family and other caregivers. Talk about how family members or other caregivers should implement the care plan if you are unable to express your wishes.
- Be sure that you and your family or other caregivers understand red flags that may mean you need to go to the hospital and under what conditions you may not want to receive care in the hospital setting.
- Talk about the potential need for a higher level of care (e.g., more help at home) if care needs are greater than can be safely managed. Conversations should include financial as well as medical concerns.
- Connect to community resources or state resources that can help plan for future and increasing care needs including respite care.
- Discuss palliative care with your care team as well as whether or not hospice care might be appropriate.
- Pack an emergency bag that can help make a hospitalization less stressful. This “to go” bag might include:¹²
 - Copies of insurance cards
 - List of medical conditions, medications, and allergies
 - Your primary care provider’s name and contact information
 - Your advance directive or POLST order
 - Other personal information such as name and preferred language, need for glasses, dentures, or hearing aids.
 - Snacks or water
 - Incontinence briefs, if usually worn, moist wipes, and plastic bags
 - Comforting objects or music player with earphones
 - A change of clothing, toiletries, and personal medications for yourself
 - Pain medicine, such as ibuprofen, acetaminophen, or aspirin—a trip to the emergency room may take longer than you think, and stress can lead to a headache or other symptoms
 - A pad of paper and pen to write down information and directions given to you by hospital staff
 - A small amount of cash
 - A note on the outside of the emergency bag to remind you to take your cell phone and charger with you
- More information: www.nia.nih.gov/health/going-hospital-tips-dementia-caregivers and www.alz.org/cacentralcoast/documents/4-preparing_hospital_stays.pdf
- Caregiving can be stressful. Talk to your provider about your needs as a caregiver. More information here: www.alz.org/care/alzheimers-dementia-stress-check.asp

Review **Table 1**

Diagnosis

- Identify the patient’s primary care provider and be sure the patient and family members know who this is.
- Provide care as part of an interdisciplinary team where all members have been trained in how to talk about a dementia diagnosis that is tailored to the patient’s individual and cultural needs and goals of care including language. This may include support staff in primary care provider office, specialists such as neurology consultation, and community partners. The patient and family or other caregivers should be included as part of the care team and supported along with the patient.
- Assess for and appropriately address hearing loss (e.g., hearing aids, personal amplifiers). Hearing loss can complicate dementia identification and treatment.
- When talking to patients and family members, follow the Alzheimer’s Association’s Principles for a Dignified Diagnosis in **Appendix E**. Be truthful about any diagnosis. At the patient’s request, purposefully include family members or other caregivers in any conversation and work to be sure they feel supported and that their concerns are heard as well as those of the patient.
- Work with information technology, billing/coding and other practice resources to add the G0505 code to your electronic health record and learn how to use it. More information:
www.alz.org/documents_custom/the%20cognitive%20assessment%20toolkit%20copy_v1.pdf
 - Information on Medicare’s Cognitive Impairment Assessment and Care Planning Code, G0505 (Alzheimer’s Association Expert Task Force Recommendations and Tools for Implementation): www.alz.org/careplanning/downloads/cms-consensus.pdf
 - Information including tools and instructions on how to screen, assessment tools including NPI-Q, a Behavior Screen, Safety Assessment/Guide, Caregiver Profile/stress, End-of Life Checklist: <http://alz.org/careplanning/downloads/care-planning-toolkit.pdf>
 - General information: www.alz.org/careplanning/
- Institute a two-step process for diagnosis supported by a clear, clinical protocol. Support and train providers and staff on the value of early detection, how to comfortably talk about dementia, and on the uncertainty that can accompany the diagnosis. Refer to the [Position Paper from the Dementia Action Collaborative](#) for guidance.
 - **First Step:** Initial screening through the Medicare Annual Wellness visit (if Medicare) or other visit (Medicaid, private insurance). Follow steps as outlined in the Alzheimer’s Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition in **Appendix D**. Use a brief (<5 minutes), validated tool or direct observation with consideration of information obtained by family members, friends or others when screening.
 - **Second Step:** A positive finding results in a follow-up visit with additional evaluation and confirmation of the diagnosis, if needed. This follow-up visit may use HCPCS code G0505 (i.e., detailed structural assessment of dementia or Alzheimer’s disease performed by a clinician that cannot be done the same day as an office visit).¹³

- Include family members or other caregivers as identified by the patient in the conversation.
- Have an empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversation about wishes, goals, and values for end-of-life care. Include the caregivers and especially the individual designated as the durable power of attorney for health care in the conversation. Talk about the difference between an advance directive and POLST and situations in which each would be acceptable.

Document:

- An advance directive that stipulates specific treatment preferences (if known and applicable to the situation),
- A durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and
- A written personal statement that articulates the patient’s values and goals regarding end-of-life care.
- POLST, if appropriate.
- Diagnostics should include:
 - Additional testing to validate diagnosis (see the [Position Paper from the Dementia Action Collaborative](#))
 - Assessment of other treatable causes of cognitive impairment including:
 - Sleep apnea
 - Alcohol use (e.g., using the [Alcohol Use Disorders Identification Test \(AUDIT\)](#))
 - Depression (e.g., using the [Patient Health Questionnaire-9](#))
 - Overview of other medications that might impact cognition (e.g., benzodiazepines)
 - Laboratory testing to rule out treatable causes of cognitive impairment including a complete metabolic panel and other tests as clinically indicated.¹⁴
 - Additional dementia screening labs: (From <http://www.actonalz.org/sites/default/files/documents/ACT-Provider-ClinicalPracticeTool.pdf>)
 - Contingent labs (per patient history): RPR or MHA-TP, HIV, heavy metals (From www.actonalz.org/sites/default/files/documents/ACT-Provider-ClinicalPracticeTool.pdf)
 - Imaging (e.g., CT, MRI) may be appropriate in certain situations as clinically indicated.
- Assess activities of daily living and any patient, family, or other caregiver concerns.
 - Assess risk and quality of life
 - Inquire about driving status and safety (outlined [here](#)).

- Assess hearing loss if not already done.
 - Inquire about home safety and assess for risk of falls
 - Assess for depression and risk of suicide
 - Discuss how to mitigate confusion, agitation, aggression, and/or wandering
 - Assess for sleep quality and sleep disturbance
 - Review and manage medications
 - Caregiver stress, capacity, and support
- After diagnosis, connect patient and family to appropriate local and/or state/national sources of care and support:
 - The county's [Area Agency on Aging](#) provider (including referrals for family and caregiver support such as respite care facilities)
 - [African American Elders Program](#)
 - [Alzheimer's Association of Washington State](#)
 - [Alzheimer Society of Washington](#)
 - [American Association of Retired Persons](#) (AARP)
 - [American Automobile Association](#) (AAA) Senior Drivers
 - [Chinese Information and Service Center](#)
 - [Community Living Connections](#) including resources by [county](#)
 - [Momentia Seattle](#)
 - [National Institute on Aging](#)
 - [Open Doors for Multicultural Families](#)
 - [Seattle Indian Health Board](#)
 - [Path with Art](#)
- Provide a copy of or other access to the Washington State Dementia Action Collaborative's [Dementia Road Map: A Guide for Family and Care Partners](#)

Ongoing Care and Support/Management

- Incorporate the dementia diagnosis and consideration for the patient's cognitive function into shared decision making for routine medical care including into decisions about unnecessary or potentially harmful care (e.g., mammograms).
- Continue to include the patient and family or other caregivers as part of the care team.
 - Look for signs of caregiver distress. Support caregivers and assess and note caregiver knowledge, skills, capacity and possible distress at each visit. Connect caregivers with available resources.
- Identify the patient's goals of care and work to maximize function that meet patient and family needs at each stage of the disease.
- Work with health care team to appropriately treat conditions that can worsen symptoms or lead to poor outcomes, including depression and existing medical issues.
- Routinely assess complexities of managing patients with dementia and the needs of family care partners for enhanced support.
- Offer evidence-based dementia care management services (including home health, phone-support and enhanced outpatient management) to patients and caregivers who have been determined to be high-risk. This high-risk group may include patients that have several medical

comorbidities, complex medication regimens, behavioral/psychiatric symptoms, and/or history of frequent utilization of acute care services.

- Offer appropriate interventions. Level of support offered depends on patient-specific factors including complexity and severity of disease, comorbid health conditions, level of caregiver support, and other factors.
 - Educate family about the diagnosis and available treatment including the natural progression of dementia.
 - Talk about the benefit of cardiovascular exercise
 - Talk about the benefits of mindful changes to diet (e.g., increasing daily fruit and vegetable intake)
 - Discuss neuropsychiatric symptoms (e.g., agitation, psychosis) and management strategies using a shared-decision making approach appropriate to the patient. Manage with non-pharmacologic treatments first, consulting with behavioral health providers when possible.
 - Continue to offer information about available community supports.

Planning for Higher Care Needs and Hospitalizations

- Discuss possible red flags that may necessitate admission to an acute care setting as well as risks and benefits of hospitalization.
- Discuss how to plan and prepare for a potential inpatient stay including risks and benefits of a hospitalization and when the patient may want to be hospitalized and when they may not want care in a hospital setting.
- Monitoring for and communicate to the patient and family members about:
 - Progression of cognitive decline
 - Emergence of behavioral symptoms
 - Functional impairment (e.g., activities of daily living)
 - Care-partner/family capacity
- Talk with patients and family about the potential need for receiving additional in-home supports or transitioning to a higher level of care (e.g., residential care facility) if care needs are greater than can be safely managed. Planning should include consideration for caregiver capacity, financial and insurance concerns (e.g., long term care coverage), health care considerations, and availability of local residential facilities, paid caregivers, and community resources (e.g., Meals on Wheels, volunteer chore services).
- Be aware that delirium may be an issue after surgery. Talk about this risk with patients and family members.

Advance Care Planning and Palliative Care

- If not already done as part of the diagnostic process or completed earlier, have an empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversation about wishes, goals, and values for end-of-life care. Include the caregivers and especially the individual designated as the durable power of attorney for

health care in the conversation. Talk about the difference between an advance directive and POLST and situations in which each would be acceptable. Document:

- An advance directive that stipulates specific treatment preferences (if known and applicable to the situation),
- A durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and
- A written personal statement that articulates the patient's values and goals regarding end-of-life care.
- POLST, if appropriate.
- Discuss palliative care with the patient and family or other caregivers as well as whether or not hospice care might be appropriate.
- Ensure that the patient and family know who to contact if symptoms (e.g., pain) develop or worsen. Ask if the patient and family feel confident in their care plan and work to fill any gaps.

Residential Facilities

- Provide regular dementia-specific training for staff, including environmental and non-pharmacological interventions for neuropsychiatric symptoms.
- Educate health care providers and staff on:
 - Symptoms of hearing loss and how to communicate with persons who have hearing loss. Information on how to communicate with someone who has hearing loss: www.agingcare.com/articles/hearing-loss-communication-techniques-144762.htm
 - How to have empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversations. The difference between an advance directive and POLST, and patients for whom each would be acceptable.
 - How to refer patients to community-based advance care planning resources if appropriate.
 - Explaining the terms on an advance directive and POLST to family and friends at the end of a patient's life
 - Supporting the patient, family, and friends during a time of crisis.
- Work to promote discussions with residents about how to have conversations regarding personal goals of care and the type of care desired at the end of life with family members, friends, and health care providers; the importance of having an advance directive that includes a living will (also known as a health care directive), a durable power of attorney for health care, and a written personal statement about health care goals and values; and the difference between POLST and an advance directive.
- Enter advance directives and/or POLST into the patient's medical record once completed and communicate with the patient and his or her primary care provider as to whether the patient has advance directives and/or a POLST in his or her medical record.
- Promote awareness of the value of palliative care and hospice and encourage appropriate hospice referrals.

- Implement a quality improvement program to encourage greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation.
- Measure family satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies.
- Support patients as they navigate care between different health care facilities and systems including facilitation of information sharing and patient and family outreach during times of crisis.

Hospitals

- Educate staff about Alzheimer's disease and other dementias including on disease progression, care needs, communication, involving the family and other caregivers in decisions, and potential impact on hospitalization.
- Screen all at-risk (e.g., ≥ 65 years old) patients on admission for risk of delirium using a brief cognitive test (e.g., Confusion Assessment Method or CAM)
 - If delirium is detected, provide targeted, multimodal prevention strategies aligned with the NICE clinical guidelines. This should include the use of bedside tests daily in the first days after surgery (e.g., Confusion Assessment Method-Intensive Care Unit or CAM-ICU, Delirium Detection Score).
 - Incorporate results into the medical record and confirm care team is aware of results.
 - Talk to the patient and family about the risk for delirium after surgery, what symptoms might look and feel like, management strategies, and what delirium might mean for recovery.
- Be sure that all treating clinicians and other staff are aware of a patient's dementia diagnosis and hearing loss and understand the patient's communication ability, behavioral concerns (e.g., agitation, exit seeking, wandering), and other information that the patient may not be able to communicate (e.g., allergies, other reactions to medications, dietary preference).
- **Discharge**
 - Support the patient and family members whether the patient is being discharged to a home or to a residential care or rehabilitation facility.
 - Assess family and caregiver support and feasibility of providing care at home (e.g., activities of daily living) including connecting to any available community supports (e.g., in-home services). Local and/or state/national sources of care and support may include:
 - The county's [Area Agency on Aging](#) provider (including respite care referrals)
 - [Alzheimer's Association of Washington State](#)
 - [Alzheimer Society of Washington](#)
 - [American Association of Retired Persons](#) (AARP)
 - [American Automobile Association](#) (AAA) Senior Drivers
 - [Momentia Seattle](#)
 - [National Institute on Aging](#)
 - If the patient is being discharged to a residential facility, identify facilities with vacancies and help the patient and family make a decision (e.g., meetings their needs, is certified

- by Medicare, is reasonable distance, has training or services specific to patients with cognitive impairment).
 - Discuss factors like length of stay, cost, services to be conducted, and other patient questions.
 - The hospital team communicates with the facility or caregiver discharge instructions, current medications, and follow-up appointment needs.
- Educate health care providers and staff on:
 - How to have empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversations
 - How to be reimbursed for these conversations.
 - The difference between an advance directive and POLST, and patients for whom each would be acceptable.
 - How to refer patients to community-based advance care planning resources if appropriate.
 - Explaining the terms on an advance directive and POLST to family and friends at the end of a patient's life
 - Supporting the patient, family, and friends during a time of crisis.
- Review your facility's protocols around asking about and honoring advance directives to decrease barriers to patients' wishes being honored at the end of life.
- Enter advance directives and/or POLST into the patient's medical record once completed and communicate with the patient and his or her primary care provider as to whether the patient has advance directives and/or a POLST in his or her medical record.
- Promote awareness of the value of palliative care, hospice, encourage appropriate hospice referrals, and be sure to communicate any referrals back to the patient's primary care provider.
- Support patients as they navigate care between different health care facilities and systems including facilitation of information sharing and patient and family outreach during times of crisis.

Health Plans

- Increase member awareness of how to maintain overall heart and brain health with age, about the difference between age-related changes in memory and the warning signs of dementia, and about the benefits of timely diagnosis of Alzheimer's disease and other dementias.
- Encourage hospitals, nursing homes, and other applicable settings to implement a quality improvement program focused on greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation
- Measure patient and family satisfaction with dementia care with use of a survey tool similar to that used by hospice agencies.
- Develop inclusive and comprehensive benefits for patients with Alzheimer's disease or other dementia allowing them to receive care consistent with their wishes and goals even if not eligible for hospice (e.g., palliative care).
- Support patients as they navigate care between separate health care facilities and systems including facilitation of information sharing and patient and family outreach during crisis.

Employers

- Recognize that many employees may be serving as informal caregivers to their family members or others. Incorporate caregiver supports into employee assistance programs.
- Educate your employees about how to have conversations regarding personal goals of care and the type of care desired at the end of life with family members, friend, and health care providers; the importance of having an advance directive that includes a living will (also known as a health care directive), a durable power of attorney for health care, and a written personal statement about health care goals and values; and the difference between POLST and an advance directive.
- Promote employee wellness by increasing awareness of how to maintain overall heart and brain health with age, about the difference between age-related changes in memory and the warning signs of dementia, and about the benefits of timely diagnosis of Alzheimer’s disease and other dementias.

Washington State Health Care Authority

- Promote awareness and utilization of advance care planning at multiple levels of health care delivery systems.

Diagnosis

The workgroup recommends early detection of mild cognitive impairment (MCI) in order to better support the patient and family members but does not recommend population-level screening of older adults. Early detection supports patients and family members and allows patients and families to plan for future cognitive changes. The Dementia Action Collaborative has developed a clinical protocol for diagnosis, available [here](#).

The United States Preventive Services Task Force is currently [updating their recommendation](#) on screening for cognitive impairment in older adults. A previous review in 2013 found insufficient evidence to either recommend for or against population-level screening.¹⁵ While current data may be lacking to support comprehensive population-level screening, the workgroup's expert opinion agrees with the potential benefits of early detection and supports efforts in this area.

The Patient Protection and Affordable Care Act added an annual wellness visit as a new Medicare benefit in January 2011 requiring a health risk assessment and assessment of cognitive impairment (no specific tool is endorsed).¹⁶ The Alzheimer's Association convened a workgroup to guide adoption of this inclusion, reviewing available evidence on validated tools to assess cognitive impairmentⁱ and recommends using either the General Practitioner Assessment of Cognition (GPCOG), the Mini-Cog (repeating three unrelated words, performing clock drawing test, repeating the three unrelated words), or the Memory Impairment Screen (MIS) due to each being less than five minutes to administer,

Addressing Barriers

The workgroup understands that time is one of the most significant barriers to addressing patient and family concern about memory loss and a diagnosis. **Code G0505** was developed to reimburse separately for assessment and care plan development for Medicare beneficiaries with cognitive impairment. Find more information on background, implementation, and use from the Alzheimer's Association through the following links:

- www.alz.org/careplanning/downloads/cms-consensus.pdf
- <http://alz.org/careplanning/downloads/care-planning-toolkit.pdf>
- www.alz.org/careplanning/

validated, easily administered by non-clinical staff, and free from bias and need for payment for copyright.^{17,18,19} Our Report and Recommendations does not review the specificity and sensitivity of the various screening tests as that has been done elsewhere. The Alzheimer's Association developed a Medicare Annual Wellness Visit Algorithm for Assessment of Cognition, included in **Appendix D**. The workgroup endorses this algorithm as a best-practice clinical pathway and recommends this as the first step of a two-step process followed by further evaluation or formal cognitive testing with a longer instrument. Further evaluation can often be out of the scope of the annual

wellness visit and can be done on the same day or as a new visit that may include family members or caregivers not present at the annual wellness visit. This two-step process is supported by the Alzheimer's Association and is recommended due to being time-efficient.²⁰ This second diagnostic step

ⁱ The Alzheimer's Association reviewed: 7-Minute Screen, Abbreviated Mental Test, Blessed Orientation-Memory-Concentration Test (long and short), Cambridge Cognitive Examination, Clock Drawing Test, General Practitioner Assessment of Cognition, Mini-Cog, Memory Impairment Screen, Mini-Mental State Examination, Montreal Cognitive Assessment, Rowland Universal Dementia Assessment, Sweet Screening Instrument, The Short Portable Mental Status Questionnaire, Short Test of Mental Status, Time and Change Test

can be done by the primary care provider or through a referral within or outside of the practice (e.g., to a neurologist, neuropsychologist). Caregiver(s) or other family members should be present for this visit.

Ongoing Care and Support/Management

Patient self efficacy is important for positive patient outcomes. The workgroup recommends working to instill hope in those diagnosed with dementia and their family members and other caretakers. Many diseases (e.g., pain, hypertension) have been shown to have increased positive outcomes with a positive patient mindset, including Alzheimer's disease.²¹ The 2017 Lancet International Commission on Dementia, Prevention, Intervention, and Care focuses on nine modifiable risk factors (that contribute to about 35% of dementia cases) based on patient age: (1) early life: education to at least age 15; (2) mid-life: reducing hypertension, obesity, and hearing loss; and (3) later life: reducing depression, managing diabetes, increasing physical activity, smoking cessation, and increasing social contact.²² Intervening in these areas has been called a priority for public health.²³ The link between cerebrovascular disease and dementia risk is well established, and should be part of conversations about prevention.²⁴ The Lancet Commission also recommends individualized dementia care, supporting caregivers, end-of-life care planning, and planning for future care needs, among others.²⁵

Interventions

Pharmacologic treatment approved for Alzheimer's disease and recommended by the American Academy of Neurology, The American College of Physicians, the American Academy of Family Physicians, the American Psychiatric Association, and the American Geriatric Society include cholinesterase inhibitors or memantine for patients diagnosed with Alzheimer's disease after a discussion with the patient about risks and benefits.^{26,27} While clinical research into experimental drugs targeting the proteins associated with cognitive decline have recently not met with success, the most promising interventions include exercise and diet modification.²⁸

The Agency for Healthcare Research and Quality conducted a systematic review of interventions to prevent age-related cognitive decline, cognitive impairment, and clinical Alzheimer's type-dementia, completed March 2017.²⁹ Interventions under review included "*cognitive training, physical activity, nutraceuticals, diet, multimodal interventions, hormone therapy, vitamins, antihypertensive treatment, lipid lowering treatment, nonsteroidal anti-inflammatory drugs (NSAIDs), antidementia drugs, diabetes treatment, and other.*" Analysis found no high-strength evidence to delay or prevent cognitive decline, medium strength evidence that cognitive training has positive effects on adults with presumed normal cognition, and weak evidence for cognitive training on adults with clinical Alzheimer's disease or other dementias. Other interventions such as vitamins (e.g., vitamin E in women, B12 plus folic acid) were associated with positive outcomes (weak evidence) with a general trend toward efficacy for physical activity and vitamin B12 plus folic acid.

Other systematic reviews have focused on specific interventions and found more promising results. Exercise has been shown to be associated with a reduction in the risk of diagnosis with Alzheimer's disease and in some studies to be associated with improved cognition and balance after diagnosis.^{30,31} Specific diets high in vitamin E, B vitamins, and the n-3 fatty acid and low in saturated fat have also been associated with slowed cognitive decline.³² The Mediterranean–DASH Intervention for

Neurodegenerative Delay, based on the Dietary Approaches to Stop Hypertension diet, has been shown to be associated with slower rates of cognitive decline and lower incidence of Alzheimer's disease.^{33,34,35}

Other multimodal interventions, including the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) study that include a combination of nutritional guidance, exercise, cognitive training, social activity, and management of metabolic and vascular risk factors have been shown to be associated with a reduction in cognitive decline or maintenance of function.³⁶ These multimodal interventions are more difficult to adopt in the United States health care environment, but elements may be suited for widespread use.

Communication and shared-decision making, advance care planning and care goals, and keeping the patient at the center of care have been identified by other researchers as key goals for palliative care for patients with dementia.³⁷ However, inclusion of palliative care into guidelines for patients with dementia has significant gaps, with less attention to end of life care than to other areas, especially around grief.³⁸

Palliative Care and End of Life Care

This workgroup draws on the Bree Collaborative's previous work around end-of-life care. The Bree Collaborative convened a workgroup that met from January to November 2014. The workgroup's goal is that all Washingtonians be informed about their end-of-life options, communicate their preferences in actionable terms, and receive end-of-life care that is aligned with their wishes, goals, and values. The workgroup developed the following five focus areas corresponding to how an individual would ideally experience advance care planning for the end of life. These focus areas work to empower patients to voice their wishes and make sure that the care that all Washingtonians receive at the end of life is the care that they and their families want. The recommendations are highly aligned with this workgroup. Read the Report here: www.breecollaborative.org/wp-content/uploads/EOL-Care-Final-Report.pdf and see focus areas below:

1. Increase awareness of advance care planning, advance directives, and Physician Orders for Life Sustaining Treatment (POLST) in Washington State
2. Increase the number of people who participate in advance care planning in the clinical and community settings
3. Increase the number of people who record their wishes and goals for end-of-life care using documents that: accurately represent their values; are easily understandable by all readers including family members, friends, and health care providers; and can be acted upon in the health care setting
4. Increase the accessibility of completed advance directives and POLST for health systems and providers
5. Increase the likelihood that a patient's end-of-life care choices are honored

Transitions of Care

The workgroup framed transitions of care from a patient perspective, acknowledging that patients and family members will need to both think about (1) increasing needs for care and support at home, (2) transitions from the home into higher levels of care, and (3) that hospitalization may occur and the patient may then need to transition from the hospital to either the home or to a residential care facility. Adopted by the Bree Collaborative, November 15, 2017.

Care transitions can be stressful for the patient and family, and if not well managed can result in patient safety issues and poor care outcomes.³⁹ Health professionals report need for discharge planning for patients with dementia to routinely exceed supply with critical issues around communication with other care settings and around medication.⁴⁰ Patients admitted to the inpatient setting are often not assessed for dementia and staff can be untrained on how to safely manage patients with dementia.⁴¹ Guidelines for patients stress the importance of pre-planning for a potential hospital admission and for protocols that support patient assessment of dementia and planned next steps to mitigate behavioral concerns and patient safety issues (e.g., wandering).⁴²

Delirium

Delirium is an acute change in cognition and attention defined in the DSM-V as “*Disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (reduced orientation to the environment) [that] develops over a short period of time (usually hours to a few days), represents an acute change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.*”⁴³ Delirium is not due to a preexisting condition, but cognitive impairment is a risk factor as is depression and functional status, and can cause poor health outcomes, stress for family members and other caregivers, and can be underdiagnosed.⁴⁴ Delirium has been associated with an increased risk of death and risk of institutionalization, independent of baseline dementia.⁴⁵ As many as 52% (range 37-52%) of elderly patients undergoing cardiac surgery and 65% (25-65%) undergoing hip replacement have experienced delirium.⁴⁶

The National Institute for Health and Clinical Excellence (NICE) developed a Guideline for Prevention of Delirium including 13 clinical recommendations for hospitalized patients and for at-risk adults in long-term care settings, listed in **Appendix F**.⁴⁷ The workgroup endorses these clinical recommendations and recommends that at-risk patients be screened for delirium using a brief cognitive test (e.g., CAM) to allow for risk assessment of post-operative delirium and as a comparison to post-surgical testing. If delirium is detected, the workgroup recommends targeted, multimodal prevention strategies aligned with the NICE clinical guidelines. This should include the use of bedside tests daily in the first days after surgery (e.g., Confusion Assessment Method-Intensive Care Unit (CAM-ICU), Delirium Detection Score).⁴⁸ Family and other caregivers should be provided with education and appropriate coping skills to recognize and manage delirium.⁴⁹

Other Work in Washington State

Developing a Washington State Plan

Governor Jay Inslee convened a Washington State Aging Summit in 2013 with leaders from public and private sectors around the need for a Washington State-specific Alzheimer's disease state plan. The Legislature answered this charge in 2014 with Senate Bill 6124 that created a taskforce, the Alzheimer's Disease Working Group, to look at the needs of those with Alzheimer's disease and other dementias, services within Washington State to meet needs, and projecting future population-level needs and system capacity.⁵⁰ The Working Group released the Alzheimer's State Plan in January 2016 including:

- Goals – Broad visionary statements
- Strategies – High-level plans to achieve the goals
- Recommendations – Specific responses or actions

[Read the Washington State Plan to Address Alzheimer's Disease and Other Dementias](#)

Like the State Plan, this Report and Recommendations is based on a public-private framework, builds on previous work that is person and family-centered, and that takes a life-course approach. The Washington State Plan contains much more comprehensive epidemiological information than this Report and Recommendations. We encourage those interested in further information to consult the State Plan.

The Dementia Action Collaborative (DAC) formed in April 2016 to implement the State Plan through a focus on: (1) public awareness and community readiness, (2) long-term services and supports, and (3) health and medical best practices. A public-private partnership made up of 37 stakeholders representing those with dementia, family caregivers, medical providers, researchers, Legislators, Washington State Agency staff, and support organizations, the DAC prioritized recommendations that could be accomplished through heightened collaboration and within existing state resources, that could sustain momentum and awareness through partnerships. The Bree Collaborative was engaged as a partner in July of 2016 and selected Alzheimer's disease and Other Dementias as a topic around which to develop clinical recommendations. This builds from the health and medical subcommittee action item to convene an expert panel to identify and endorse evidence-based standards for diagnosis, treatment, supportive care, and advanced planning.

[Learn more about the Dementia Action Collaborative.](#)

Measurement

We encourage organizations to operationalize metrics as relevant to their organization. [Healthy People 2020](#) includes two Alzheimer’s disease and other dementias related metrics:

- Diagnosis awareness among persons with Alzheimer's disease and other dementias or their caregiver (percent, 65+ years)
- Preventable hospitalizations among persons with Alzheimer's disease and other dementias (percent, 65+ years)

The American Academy of Neurology proposes has proposed nine metrics to measure quality of care for those with Alzheimer’s disease and other dementias.⁵¹ Many of these measures are aligned with the focus areas of this set of recommendations.

Table 2: American Academy of Neurology Proposed Metrics for Those with Alzheimer’s Disease and Other Dementias

Title	Description
1. Disclosure of dementia diagnosis	Percentage of patients with a diagnosis of a qualifying dementing disorder or disease whose diagnosis has been disclosed to them and, if available, their primary caregiver
2. Education and support of caregivers for patients with dementia	Percentage of patients with dementia whose caregivers were provided with education on dementia disease management and health behavior changes and were referred to additional resources for support in the last 12 months
3. Functional status assessment for patients with dementia	Percentage of patients with dementia for whom an assessment of functional status was performed at least once in the last 12 months
4. Screening and management of behavioral and psychiatric symptoms associated with dementia (BPSD)	Percentage of patients with dementia for whom there was a documented screening for behavioral and psychiatric symptoms, including depression, and for whom, if screening positive, there was also documentation of recommendations for management in the last 12 months
5. Safety concern screening and follow-up for patients with dementia	Percentage of patients with dementia or their caregivers for whom there was a documented safety screening in 2 domains of risk, dangerousness to self or others and environmental risks, and for whom, if screening positive, there was documentation they were provided with recommendations for their mitigation, which may include referral to other resources, in the last 12 months
6. Driving screening and follow-up for patients with dementia	Percentage of patients with dementia for whom there was a documented screening for driving risks and for whom, if screening positive, there was also documentation they were informed of alternatives to driving in the last 12 months
7. Advance care planning and palliative care counseling for patients with dementia	Percentage of patients with dementia who have an advance care plan or surrogate decision-maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision-maker or provide an advance care plan and percentage of patients with dementia or their surrogate decision-maker who received comprehensive counseling regarding ongoing palliation and symptom management and end-of-life decisions within 2 years of initial diagnosis or assumption of care
8. Pain assessment and follow-up for patients with dementia	Percentage of patients with dementia who underwent documented screening for pain symptoms at every visit and if screening positive also had a documentation of a follow-up plan
9. Pharmacologic treatment of dementia	Percentage of patients with dementia or their caregivers with whom available guideline-appropriate pharmacologic treatment options and nonpharmacological behavior and lifestyle modifications were discussed at least once in the last 12-month period

Appendix A: Bree Collaborative Members

Member	Title	Organization
Susie Dade MS	Deputy Director	Washington Health Alliance
John Espinola MD, MPH	Executive Vice President, Health Care Services	Premera Blue Cross
Gary Franklin MD, MPH	Medical Director	Washington State Department of Labor and Industries
Stuart Freed MD	Chief Medical Officer	Confluence Health
Richard Goss MD	Medical Director	Harborview Medical Center – University of Washington
Jennifer Graves, RN, MS	Senior Vice President, Patient Safety	Washington State Hospital Association
Christopher Kodama MD	President, MultiCare Connected Care	MultiCare Health System
Daniel Lessler MD, MHA	Chief Medical Officer	Washington State Health Care Authority
Paula Lozano MD, MPH	Associate Medical Director, Research and Translation	Kaiser Permanente
Wm. Richard Ludwig MD	Chief Medical Officer, Accountable Care Organization	Providence Health and Services
Greg Marchand	Director, Benefits & Policy and Strategy	The Boeing Company
Robert Mecklenburg MD	Medical Director, Center for Health Care Solutions	Virginia Mason Medical Center
Kimberly Moore MD	Associate Chief Medical Officer	Franciscan Health System
Carl Olden MD	Family Physician	Pacific Crest Family Medicine, Yakima
Mary Kay O’Neill MD, MBA	Partner	Mercer
John Robinson MD, SM	Chief Medical Officer	First Choice Health
Terry Rogers MD (Vice Chair)	Chief Executive Officer	Foundation for Health Care Quality
Jeanne Rupert DO, PhD	Medical Director, Community Health Services	Public Health – Seattle and King County
Kerry Schaefer	Strategic Planner for Employee Health	King County
Bruce Smith MD	Medical Director	Regence Blue Shield
Lani Spencer RN, MHA	Vice President, Health Care Management Services	Amerigroup
Hugh Straley MD (Chair)	Retired	Medical Director, Group Health Cooperative; President, Group Health Physicians
Shawn West MD	Family Physician	Edmonds Family Medicine

Appendix B: Alzheimer's Disease and Other Dementias Workgroup Charter and Roster

Problem Statement

Washington State has the third highest rate of death from Alzheimer's disease of any state.¹ This is expected to increase 40% in next 10 years and 181% over the next 30 years.¹ In many practices in Washington State, there are no guidelines to increase quality of care for screening, diagnosis, or treatment of Alzheimer's disease and other dementias.² This is costly to the health care system and overly burdensome to primary care clinicians, and patients, their caregivers, and the community.

Aim

To align care delivery with existing evidence-based standard of care for diagnosis, treatment, supportive care, and advanced care planning within primary care for patients with Alzheimer's disease or other dementias and their families and caregivers while decreasing variation in quality of treatment across the state of Washington.

Purpose

To propose evidence-based recommendations to the full Bree Collaborative on:

- Aligning with the [Alzheimer's State Plan](#) and the Alzheimer's Disease Working Group.
- Diagnostic tools for Alzheimer's disease and other dementias.
- Offering supportive care to patients and their family and other caregivers including medication management and managing co-morbid conditions.
- Support with late-stage dementia and advance care planning.
- Referring to other resources such as counseling, senior day programs, or palliative care of those with dementia.
- Identifying other areas of focus.

Duties & Functions

The Alzheimer's Disease and Other Dementias workgroup will:

- Research evidence-based guidelines and best practices (emerging and established).
- Consult relevant professional associations and other stakeholder organizations and subject matter experts for feedback, as appropriate.
- Meet for approximately nine months, as needed.
- Provide updates at Bree Collaborative meetings.
- Post draft report(s) on the Bree Collaborative website for public comment prior to sending report to the Bree Collaborative for approval and adoption.
- Present findings and recommendations in a report.
- Recommend data-driven and practical implementation strategies.
- Create and oversee subsequent subgroups to help carry out the work, as needed.

¹ Alzheimer's Association. Alzheimer's Statistics Washington. Available: www.alz.org/documents_custom/facts_2016/statesheet_washington.pdf

² Washington State Department of Social and Health Services. Washington State Plan to Address Alzheimer's Disease and Other Dementias. January 1, 2016. Available: www.dshs.wa.gov/sites/default/files/SESA/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf

- Revise this charter as necessary based on scope of work.

Structure

The workgroup will consist of individuals confirmed by Bree Collaborative members or appointed by the chair of the Bree Collaborative or the workgroup chair.

The chair of the workgroup will be appointed by the chair of the Bree Collaborative.

The Bree Collaborative program director will staff and provide management and support services for the workgroup.

Less than the full workgroup may convene to: gather and discuss information; conduct research; analyze relevant issues and facts; or draft recommendations for the deliberation of the full workgroup. A quorum shall be a simple majority and shall be required to accept and approve recommendations to send to the Bree Collaborative.

Meetings

The workgroup will hold meetings as necessary. The program director will conduct meetings along with the chair, arrange for the recording of each meeting, and distribute meeting agendas and other materials prior to each meeting. Additional workgroup members to be added at the discretion of the chair.

Name	Title	Organization
Kristoffer Rhoads, PhD (Chair)	Primary Neuropsychologist, Memory and Brain Wellness Center	University of Washington Medical Center
Kimiko Domoto-Reilly, MD	Alzheimer's Research Center	University of Washington Medical Center
Richard Furlong, MD	Primary Care	Virginia Mason Medical Center
Barak Gaster, MD	Professor of Medicine	University of Washington Medical Center
Kelly Green, MSW	Social Worker	Evergreen Health
Debbie Hunter	Family Caregiver	
Nancy Isenberg, MD, MPH, FAAN	Neurologist, Clinical Associate Professor of Neurology, Center for Healthy Aging & Memory	Virginia Mason Medical Center
Arlene Johnson	Family Caregiver	
Kerry Jurges, MD	Primary Care	Confluence Health
Eric Larson, MD, MPH	Vice President for Research and Health Care Innovation	Kaiser Foundation Health Plan of Washington
Todd Larson	Family Caregiver	
Myriam Marquez	Patient Advocate	
Shirley Newell, MD	Chief Medical Officer	Aegis Living
Darrell Owens, DNP, ARNP	Clinic Chief, Director	University of Washington Outpatient Primary, Palliative and Supportive Care Program
Tatiana Sadak, PhD, ARNP	Psychiatric Nurse Practitioner	Associate Professor of Geriatric Mental Health, University of Washington School of Nursing
Bruce Smith, MD	Medical Director	Regence Blue Shield

Appendix C: Guideline and Systematic Review Search Results

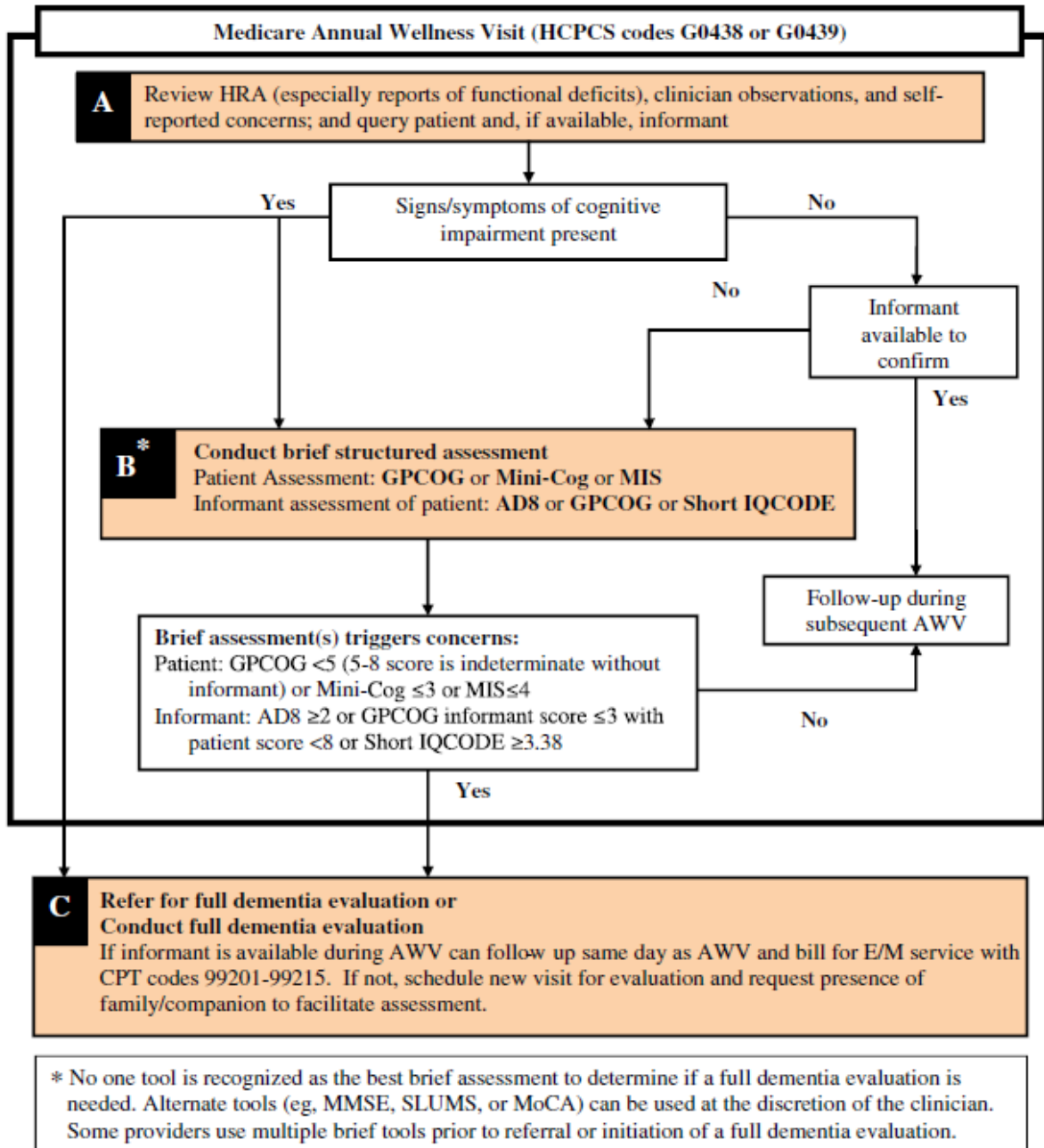
Source	Guidelines or Systematic Reviews
AHRQ: Research Findings and Reports	<p>(2017) Interventions to Prevent Age-Related Cognitive Decline, Mild Cognitive Impairment, and Clinical Alzheimer's-Type Dementia</p> <p>(2016) Non-pharmacologic Interventions for Agitation and Aggression in Dementia</p>
Cochrane Collection	<p>(2017) The use of vitamin E in the treatment of mild cognitive impairment and Alzheimer's disease (AD)</p> <p>(2017) Proteins in cerebrospinal fluids (CSF) for early prediction of developing Alzheimer's disease or other dementia in people with mild cognitive problems</p> <p>(2017) Is dance movement therapy an effective intervention for dementia? A review of the evidence</p> <p>(2016) Medicines for sleep problems in dementia</p> <p>(2016) Treatment of epilepsy for people with Alzheimer's disease</p> <p>(2016) Statin withdrawal in people with dementia</p> <p>(2016) Omega-3 fatty acids for the treatment of dementia</p> <p>(2016) Mini-Mental State Examination (MMSE) for the detection of dementia in people aged over 65</p> <p>(2016) Statins for the prevention of dementia</p> <p>(2015) Montreal Cognitive Assessment (MoCA) for the diagnosis of Alzheimer's disease and other dementias</p> <p>(2015) Rivastigmine for people with Alzheimer's disease</p> <p>(2015) Regional Cerebral Blood Flow SPECT for detection of Frontotemporal dementia in people with suspected dementia</p> <p>(2015) Dimebon for Alzheimer's disease</p> <p>(2015) Baseline scores of Mini-Mental State examination (MMSE) for early prediction of developing dementia in people with mild cognitive impairments (MCI)</p> <p>(2015) Cholinesterase inhibitors for rarer dementia associated with neurological conditions</p> <p>(2015) A brief cognitive screening test (Mini-Cog) for the assessment of possible dementia</p> <p>(2015) Dopamine transporter imaging for the diagnosis of dementia with Lewy bodies</p> <p>(2015) ¹⁸F-FDG PET scan for early prediction of developing Alzheimer's disease or other dementia in people with mild cognitive impairment (MCI)</p> <p>(2014) ¹¹C-PIB-PET scan for early prediction of developing Alzheimer's disease or other dementia in people with mild cognitive impairment (MCI)</p> <p>(2014) Statins for the treatment of Alzheimer's disease</p> <p>(2014) Proteins in blood and cerebrospinal fluids for early prediction of developing Alzheimer's disease or other dementia in people with cognitive problems</p> <p>(2014) There is no evidence that MPACs (PBT1 or PBT2) are of benefit in Alzheimer's dementia</p> <p>(2014) Management of faecal incontinence and constipation in adults with central nervous system diseases</p> <p>(2013) Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia</p> <p>(2013) Rivastigmine for vascular cognitive impairment</p>

	<p>(2013) Withdrawal of chronic antipsychotic drugs for behavioural and psychological symptoms in older people with dementia</p> <p>(2013) Cerebrolysin for vascular dementia</p> <p>(2012) No evidence from randomised controlled trials for or against the use of huperzine A in the treatment of people with mild cognitive impairment</p> <p>(2012) Anti-dementia drugs for people with memory problems but without dementia</p>
Specialty Society Guidelines (via Guideline Clearinghouse including Choosing Wisely)	<p>(2016) The American Psychiatric Association practice guideline on the use of antipsychotics to treat agitation or psychosis in patients with dementia.</p> <p>(2016) Canadian Task Force on Preventive Health Care Recommendations on screening for cognitive impairment in older adults.</p> <p>(2015) American Geriatrics Society American Geriatrics Society 2015 updated Beers Criteria for potentially inappropriate medication use in older adults.</p> <p>(2014 revised) American College of Radiology ACR Appropriateness Criteria® dementia and movement disorders.</p> <p>(2014 revised) U.S. Preventive Services Task Force Final Recommendation Statement Cognitive Impairment in Older Adults: Screening</p> <p>(2014) American Occupational Therapy Association, Inc. Occupational therapy practice guidelines for home modifications.</p> <p>(2013 revised) University of Iowa College of Nursing, John A. Hartford Foundation Center of Geriatric Nursing Excellence Bathing persons with dementia.</p> <p>(2013) Alzheimer's Association, Society of Nuclear Medicine and Molecular Imaging Appropriate use criteria for amyloid PET: a report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association.</p> <p>(2013) Alzheimer's Association Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting.</p> <p>(2012 revised) Hartford Institute for Geriatric Nursing Recognition and management of dementia.</p> <p>(2012 revised) American Medical Directors Association Dementia in the long term care setting.</p> <p>(2012 revised) Hartford Institute for Geriatric Nursing Assessing cognitive functioning. In: Evidence-based geriatric nursing protocols for best practice.</p> <p>(2012 revised) Hartford Institute for Geriatric Nursing Assessment and management of mealtime difficulties.</p> <p>(2012) Hartford Institute for Geriatric Nursing Managing oral hydration.</p>
Health Technology Assessment Program	<p>(2014) Functional neuroimaging for primary degenerative dementia or mild cognitive impairment <i>"Functional neuroimaging for primary degenerative dementia or mild cognitive impairment is not covered. Functional imaging technologies including: fludeoxyglucose (FDG) Positron Emission Tomography (PET), (11)C-dihydrotrabenazine (C-DTBZ) PET, Single Photon Emission Computed Tomography (SPECT), Functional Magnetic Resonance Imaging (fMRI) for the diagnosis of primary degenerative dementia or mild cognitive impairment."</i></p>
Center for Disease Control and Prevention	<p>Information: What is Alzheimer's Disease?</p> <p>Information: Healthy Brain Initiative</p>
National Institute on Aging	<p>Information: Alzheimer's Disease & Related Dementias</p>

Institute for Clinical and Economic Review	No relevant reviews.
BMJ Clinical Evidence Systematic Overview	(2012) Dementia (2007) Depression in adults: psychological treatments and care pathways
Veterans Administration Evidence-based Synthesis Program	(2011) A Systematic Evidence Review of Non-pharmacological Interventions for Behavioral Symptoms of Dementia (2010) A Systematic Evidence Review of Interventions for Non-professional Caregivers of Individuals with Dementia (2010) A Systematic Evidence Review of the Signs and Symptoms of Dementia and Brief Cognitive Tests Available in VA

Appendix D: Alzheimer’s Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition

Source: Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer’s Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimers Dement.* 2013 Mar;9(2):141-50.



Appendix E: Alzheimer's Association Principles for a Dignified Diagnosis

Source: Alzheimer's Association. Principles for a Dignified Diagnosis. Available: www.alz.org/national/documents/brochure_dignified_diagnosis.pdf

Talk to me, the person living with dementia, directly. I am the person living with the disease, and though those close to me will also be affected, I am the person who needs to know first.

Tell the truth. Even if you don't have all of the answers, be honest about what you do know and why you believe it to be so.

Test early. Helping me get an accurate diagnosis as soon as possible gives me more time to cope, live to my fullest potential and access information and resources.

Take my memory concerns seriously, regardless of my age. Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because of my age. At the same time, don't forget that the disease can also affect people in their 40s, 50s and 60s.

Deliver the diagnosis in plain but sensitive language. My diagnosis may be one of the most important things I ever hear. Please use language that I can understand and be sensitive to how this may make me feel.

Coordinate with other care providers. I may be seeing more than one doctor. It's important that you talk to my other care providers to ensure everyone has the information so that changes can be identified early and I won't have to repeat tests unnecessarily.

Explain the purpose of different tests and what you hope to learn. Testing can be very physically and emotionally challenging. It would help me to know the purpose of the test, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Give me tools for living with this disease. Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, what medical treatments are available, and what support and resources are offered through the Alzheimer's Association® and my community.

Work with me on a plan for living a quality life. Medication may help modify some of my neurological symptoms, but I am also interested in recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

Recognize that I am an individual and the way I experience this disease is unique. This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

Alzheimer's is a journey, not a destination. Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's disease.

Appendix F: NICE Guideline for Prevention of Delirium

Source: O'Mahony R, Murthy L, Akunne A, Young J; Guideline Development Group. Synopsis of the National Institute for Health and Clinical Excellence guideline for prevention of delirium. *Ann Intern Med.* 2011 Jun 7;154(11):746-51. Available [here](#).

1. Ensure that persons at risk for delirium are cared for by a team of health care professionals who are familiar with the person at risk. Avoid moving persons within and between wards or rooms unless absolutely necessary.
2. Give a tailored, multicomponent intervention package. Within 24 hours of hospitalization, assess persons at risk for clinical factors contributing to delirium. On the basis of the results of this assessment, provide a multicomponent intervention tailored to the person's individual needs and care setting.
3. The tailored, multicomponent intervention package should be delivered by a multidisciplinary team trained and competent in delirium prevention.
4. Address cognitive impairment or disorientation by providing appropriate lighting and clear signage, ensuring that a clock (consider providing a 24-hour clock in the critical care unit) and a calendar are easily visible to the person at risk; talking to the person to reorient them by explaining where they are, who they are, and what your role is; introducing cognitively stimulating activities (for example, reminiscence); and facilitating regular visits from family and friends.
5. Address dehydration and constipation by ensuring adequate fluid intake to prevent dehydration by encouraging the person to drink—consider offering subcutaneous or intravenous fluids, if necessary, and taking advice when managing fluid balance in persons with comorbid conditions (for example, heart failure or chronic kidney disease).
6. Assess for hypoxia and optimize oxygen saturation, if necessary, as clinically appropriate.
7. Address infection by looking for and treating infection, avoiding unnecessary catheterization, and implementing infection-control procedures in line with the NICE clinical guideline on infection control (13).
8. Address immobility or limited mobility through the following actions: Encourage persons to mobilize soon after surgery and walk (provide appropriate walking aids that are accessible at all times) and encourage all persons, including persons who are unable to walk, to carry out active, range-of-motion exercises.
9. Address pain by assessing for pain; looking for nonverbal signs of pain, particularly in persons with communication difficulties (for example, persons with learning difficulties or dementia or persons on a ventilator or who have a tracheostomy); and initiating and reviewing appropriate pain management in any person in whom pain is identified or suspected.
10. Carry out a medication review for persons receiving several drugs, taking into account both the type and the number of medications.
11. Address poor nutrition by following the advice given in the nutrition support in adults section in the NICE clinical guideline and ensuring that dentures fit properly in persons who have them.
12. Address sensory impairment by resolving any reversible cause of the impairment, such as impacted ear wax, and ensuring hearing and visual aids are available to and used by persons who need them, and check that such aids are in good working order.
13. Promote good sleep patterns and sleep hygiene by avoiding nursing or medical procedures during sleeping hours, if possible; scheduling medication rounds to avoid disturbing sleep; and reducing noise to a minimum during sleep periods.

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