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Department of Public Health



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1. Executive Summary

The goals of the Alzheimer's and Related Dementias Acute Care Advisory Committee were to identify and communicate the challenges and opportunities for providing optimal care to persons with dementia in acute care settings; to provide options for hospitals to improve the quality of



care for the patient and the caregiver/provider experience; and to offer strategies to improve the cost effectiveness of care.

The presence of dementia interacts with all other diagnoses and medications that appear in the acute care setting, placing patients with dementia

at greater risk for adverse events than other patients. Therefore, special attention is required for the identification and management of dementia in patients experiencing acute illness. (See 3.4 for unique risks for persons with dementia in the acute care setting.)

These recommendations are grouped into four categories: Emergency Department (ED), Inpatient, Education and Training, and Quality Measures. The report is designed to mirror the patient and caregiver journey from arriving at an acute care facility through the ED, inpatient stay, and discharge.

The Committee made a series of recommendations with three top priorities:



- 1. Hospitals should have an operational plan in place, available to the public and Department of Public Health upon request, to identify dementia and/or delirium in the ED and/or inpatient settings and to create a specialized care plan in the event that delirium, dementia, or both are detected. This operational plan should include, but is not limited to, the following: a) recognition of dementia and/or delirium; b) screening procedures; c) management and treatment in all relevant departments; d) development of a dementia-friendly environment; e) transfer or discharge procedures; and f) an annual hospital self-assessment. Hospitals should review the plan with their Patient and Family Advisory Council prior to implementation.
- 2. Pursuant to the CARE Act, hospitals should develop a process to ensure that designated caregivers are involved in hospital processes, specifically transfer and discharge planning, when an individual has dementia.
- 3. Hospitals should also develop Quality Assurance Performance Improvement (QAPI) measures and processes, available to the public and Department upon request, that outline the hospital's operational plan effectiveness and include how clinical and relevant non-clinical staff receive routine training in the care of individuals with Alzheimer's and related dementias and their caregivers.

This report sheds light on a topic that merits attention. It is intended to drive future discussion and inform comprehensive strategy at the hospital and state level about best practices to identify dementia and/or delirium and adjust care plans accordingly. The report includes recommendations pertaining to care in the ED; care in the inpatient setting; education and training for hospital staff; processes to support designated caregivers pursuant to the CARE Act; and quality measures. The recommendations are grounded in evidence and developed with existing programs and supports in mind in order to promote widespread adoption.

The *caregiver perspective* vignettes included in this report give voice to the experiences of actual caregivers and are compiled from stories sent to us from caregivers around the Commonwealth. They highlight the importance of incorporating caregivers into the conversation.

The Committee's recommendations are intended not only to improve the patient and caregiver experience in the acute care setting, but also to increase acute care quality and cost-effectiveness. The recommendations presented include ways to streamline the care delivery process by promoting early identification of dementia and/or delivery, the development of care plans that



take patients' cognitive status into consideration, inclusion of caregivers in care plan development and discharge planning, and discussion of advance care planning options.

Research has shown that improving care for persons with dementia is cost effective. A recent study found that dementia's "societal costs" amount to



between \$41,000 to \$56,000 per case per year, including the estimated cost of informal care, formal care, and medical care.¹ When focusing on the last five years of life, dementia has been shown to be substantially more costly than other conditions — for decedents with dementia, average health care spending in the last years of life (including health insurance costs, out-of-pocket costs, and informal care costs) amounted to around \$287,000 per decedent, while average health care spending was around \$183,000 per decedent for other causes of death.²

The Alzheimer's and Related Dementias Acute Care Advisory Committee is pleased to contribute recommendations to the ongoing discussion about how to provide optimal acute care to persons with dementia. The Committee proposes that, within the next three years, the top three recommendations become the standard of care in all Massachusetts hospitals serving an adult population. The Committee further recommends that after three years, this standard of care will be an expectation of all Massachusetts hospitals serving an adult population and will be incorporated into future survey and Quality Assurance Performance Improvement (QAPI) processes.

¹ Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary Costs of Dementia in the United States. The *New England Journal of Medicine*. 2013;368(14):1326-1334. Doi: 10.1056/NEJMsa1204629.

² Keley AS, McGarry K, Gorges R, Skinner JS. The Burden of Health Care Costs in the Last 5 Years of Life. *Annals of Internal Medicine*. 2015;163(10):729-736. Doi: 10.7326/M15-0381.



2. Introduction

Caregiver Perspective:

During the years I took care of my parents with Alzheimer's, I did not always have positive experiences at the ED or the hospital. I found that sometimes the staff was not trained to help a person with dementia. I had to have the records with me and explain that my father had Alzheimer's. I did have 'angels' along the way to help me make difficult decisions, like the head of nursing at the nursing home where my mom was staying. But hospitals and EDs could do a lot more.

The Alzheimer's and Related Dementias Acute Care Advisory Committee developed recommendations to address dementia-capable acute care in Massachusetts. These recommendations recognize that dementia-capable acute care is vital for both quality and cost-effectiveness of care.

The Committee was convened pursuant to Chapter 228 of the Acts of 2014. Approved and enacted into law on August 5, 2014, the legislation reads:

AN ACT RELATIVE TO THE MASSACHUSETTS ALZHEIMER'S AND RELATED DEMENTIAS ACUTE CARE ADVISORY COMMITTEE

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same as follows:

SECTION 1. (a) The department of public health shall convene an Alzheimer's and related dementias acute care advisory committee. The committee shall consist of the secretary of health and human services or a designee; the secretary of elder affairs or a designee; the commissioner of public health or a designee; the secretary of veterans affairs or a designee; the office of Medicaid or a designee; 2 Alzheimer patient advocates; 2 Alzheimer caregivers; 2 health care providers from acute care settings; 2 researchers with Alzheimer-related expertise in basic, translational, clinical or drug development science; 2 representatives of the Massachusetts/New Hampshire chapter of the National Alzheimer's Association; and 2 representatives of the



Massachusetts Hospital Association.

(b) The committee shall meet within 90 days of the effective date of this act and a minimum of 3 times.

SECTION 2. (a) The committee shall: (i) craft a strategy to address dementia-capable care in all acute care settings in the Commonwealth; (ii) be responsible for presentation of strategy to the general court and all pertinent state agencies and departments and participate in implementing the strategy; (iii) help to ensure that acute care settings are dementia-capable with Alzheimer's and related dementias; (iv) coordinate with federal government bodies to integrate and inform dementia-capable care in acute care settings; and (v) provide information and coordination of Alzheimer's and related dementia care in acute care settings across all state agencies.

(b) The committee shall advise the general court on Alzheimer's and related dementia policy in acute care settings and make a written report to the general court, the governor and all other pertinent state agencies within 9 months of the committee's first meeting.

The Committee was composed of the following individuals representing the organizations outlined in the statute:

Name	Organization
Susan Antkowiak	Alzheimer's Association, Massachusetts/New Hampshire Chapter
	Representative of the Massachusetts/New Hampshire Chapter of the National Alzheimer's Association
Sanford Auerbach	Boston Medical Center
	Researcher with Alzheimer-related expertise in basic,
	translational, clinical, or drug development science
Sandra Bellantonio	Berkshire Health Systems
	Health care provider from acute care setting
Alice Bonner	Executive Office of Elder Affairs (co-chair)
	Secretary of Health and Human Services Designee
Mary DeRoo	Executive Office of Elder Affairs
	Secretary of Elder Affairs Designee



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Eric Donovan	Massachusetts Department of Veterans' Services
	Secretary of Veterans Affairs Designee
Alan Holbrook	Family Caregiver
	Alzheimer caregiver
Lewis Lipsitz	Beth Israel Deaconess Medical Center and Hebrew SeniorLife
	Representative of the Massachusetts Health & Hospital
	Association
Low of the Modelh area	Massachusetta Conorol Hagnital Physician Organization
Lynette Matthews	Massachusetts General Hospital Physician Organization
	<i>Representative of the Massachusetts Health & Hospital</i> <i>Association</i>
	Association
Ellyn McSweeney	Family Caregiver
	Alzheimer caregiver
Barbara Moscowitz	Massachusetts General Hospital
	Health care provider from acute care setting
Linda Pellegrini	University of Massachusetts Memorial Hospital
	Alzheimer patient advocate
Daniel Press	Beth Israel Deaconess Medical Center
	<i>Researcher with Alzheimer-related expertise in basic,</i> <i>translational, clinical, or drug development science</i>
	translational, clinical, of arug development science
Steve Sauter	MassHealth
	Office of Medicaid designee
Nina Silverstein	University of Massachusetts Boston
	Alzheimer patient advocate
Lindsey Tucker	Massachusetts Department of Public Health (co-chair)
	Commissioner of Public Health Designee
T 117 1	
James Wessler	Alzheimer's Association, Massachusetts/New Hampshire Chapter
	Representative of the Massachusetts/New Hampshire Chapter of
	the National Alzheimer's Association



The Committee met five times between December 7, 2016, and June 19, 2017.

The Committee's charge aligns with other current Massachusetts initiatives affecting persons with dementia, their family members, and caregivers. For example, the Dementia Friendly Massachusetts Initiative, launched through a partnership between the Massachusetts Executive Office of Elder Affairs, Jewish Family & Children's Services and other partners, is working to bring individuals and organizations together with the goal of "[enabling] people living with dementia and those who care about them to live full, engaged lives."³

Regarding caregivers, the Caregiver Advise, Record, Enable (CARE) Act was enacted into law in December 2016.⁴ The CARE Act allows a hospitalized patient to designate a caregiver, whose information will be documented in the patient's medical record and who will be granted access to the patient's health information and discharge plan.⁵

2.1. Organization of Report and Recommendations

This report is organized to follow the flow of an individual with dementia and his or her caregiver(s) chronologically, from the time that they arrive in acute care, usually through the Emergency Department (ED); possibly in observation status, inpatient stay, and discharge. The critical role of formal (paid) and informal caregivers (often referred to as family caregivers or care partners) is threaded throughout the various sections of the report.

In presenting these recommendations, the Alzheimer's and Related Dementias Acute Care Advisory Committee recognizes that hospitals and their EDs vary widely; therefore, implementation of these recommendations will also vary.

2.2. Clarification of Terms

³ Dementia Friendly Massachusetts Initiative. Mass.gov. http://www.mass.gov/elders/civicengagement/dementia-friendly-massachusetts-initiative.html. Accessed June 10, 2017.

⁴ Bill H.3911: An Act Authorizing The Disclosure of Medical Information to Certain Designated Caregivers. Malegislature.gov. https://malegislature.gov/Bills/189/House/H3911. Accessed June 10, 2017.

⁵ Commonwealth of Massachusetts House No. 3911. An Act establishing the caregiver advise, record, and enable (CARE) act. The One Hundred and Eighty-Ninth General Court (2015-2016). Filed on December 18, 2015.



For the purposes of this report, the Committee determined that "acute care" will be defined as care delivered in a hospital setting, both inpatient and emergency department (ED). For the purposes of this report, the ED setting also includes patients admitted for observation status. This report does not include long-term acute care hospitals (LTACs), rehabilitation hospitals, or other non-acute hospitals.

The phrase "cognitive impairment" may refer to a wide range of conditions, including progressive illnesses such as Alzheimer's disease, transient conditions such as delirium, and other conditions that alter cognitive function but are not necessarily related to age or dementia (such as an acute brain injury). The charge of this committee is to develop recommendations to improve the acute care experience for patients with Alzheimer's and related dementias and their caregivers; thus, in the context of this report, "cognitive impairment" refers to dementia and/or delirium (persons with dementia are especially vulnerable to developing delirium - see 3.2.) However, the recommendations presented in this report have the potential to benefit people with other forms of cognitive impairment as well.

This report uses the term "caregiver" to refer to any person, paid or unpaid, who assists a person with dementia in any way, including family members, paid home care workers, friends, neighbors, partners. In this report, "caregiver" or "family caregiver" does not include professional hospital staff.

2.3. Acknowledgements

The Alzheimer's and Related Dementias Acute Care Advisory Committee benefitted from presentations from experts, who provided background on topics ranging from delirium to advance care planning. The Committee would like to thank:

- **Chad Darling, MD** Associate Professor, Department of Emergency Medicine at University of Massachusetts Medical School
- **Maura Kennedy, MD** Immediate Past President of the Academy of Geriatric Emergency Medicine and Assistant Professor of Emergency Medicine at Harvard University



- Sherman Lohnes, JD Director for the Division of Health Care Facility Licensure and Certification at Bureau of Health Care Safety and Quality, Massachusetts Department of Public Health
- Katie Maslow, MSW Fellow at Gerontological Society of America
- Melissa Mattison, MD Chief of Hospital Medicine at Massachusetts General Hospital and Assistant Professor of Medicine at Harvard Medical School
- Beth Scheffler, BSN, APRN Complaint Unit Manager, Division of Health Care Facility Licensure and Certification at Bureau of Health Care Safety and Quality, Massachusetts Department of Public Health
- Harriet Warshaw Executive Director at The Conversation Project

The Department of Public Health and the Executive Office of Elder Affairs are deeply indebted to the dedicated members of the Alzheimer's and Related Dementias Acute Care Advisory Committee, who devoted many hours to developing the recommendations in this report. We are also grateful for the skillful drafting of this report by our dedicated colleague and intern, Marina Renton, and to Darrell Villaruz, program manager, Bureau of Health Care Safety and Quality, Department of Public Health, for his expert facilitation and overall staff support of this project.



3. Background

3.1. Dementia

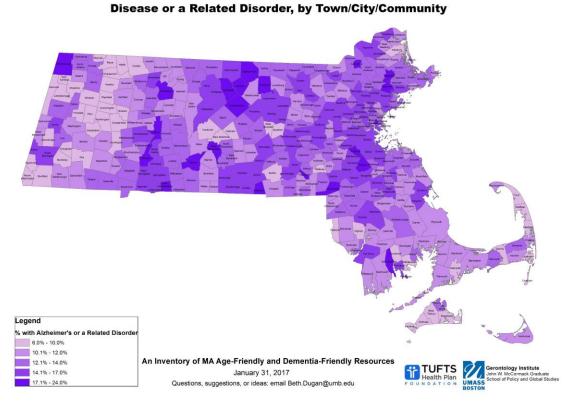
3.1.a. Definitions

Alzheimer's Disease and Related Dementias (ADRD): According to the U.S. Department of Health & Human Services, ADRD are "debilitating conditions that impair memory, thought processes, and functioning, primarily among older adults."⁶



⁶ What is Alzheimer's Disease and Related Dementias. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. https://aspe.hhs.gov/what-alzheimers-disease-and-related-dementias. October 6, 2015. Accessed May 29, 2017.





Percentage of Medicare Beneficiaries > Age 65 with Alzheimer's

Courtesy of UMass Boston Gerontology Institute. The above map illustrates the prevalence of Alzheimer's disease and related dementias (e.g. those described below) in Massachusetts elders across the state.

3.1.b. Types

There are several forms of dementia. The most common (60-80 percent of cases, according to the Alzheimer's Association) is **Alzheimer's disease**, a progressive illness that causes global cognitive decline and memory impairment associated with the buildup of amyloid plaques in the brain, neuro-fibrillary tangles, and other neuro-degenerative changes.⁷ Approximately 120,000 Massachusetts residents aged 65 and older have Alzheimer's disease as of 2017, and that number

⁷ Types of Dementia. Alzheimer's Association. http://www.alz.org/dementia/types-of-dementia.asp. Accessed February 25, 2017.



is projected to rise to 150,000 by 2025.⁸ Alzheimer's disease is the sixth leading cause of death in Massachusetts.⁹ In 2016 alone, the Alzheimer's Association estimates that 333,000 caregivers delivered 380,000,000 hours of unpaid care.¹⁰

Dementia also has early-onset forms that affect adults younger than 65. For example, early-onset Alzheimer's disease can affect people in their 40s and 50s and accounts for up to five percent of

Spotlight on Early-Onset Dementia

Dementia is not solely a disease of the elderly; it can affect adults in their 40s and 50s, posing unique challenges. Younger adults may have less common forms of dementia, such as frontotemporal dementia (FTD). Health care professionals should consider the possibility that younger adults accessing hospital care for other reasons could have dementia or delirium; if suspected, staff should follow guidelines for identification, screening, management (including communication), care planning, and discharge planning. Alzheimer's disease cases in the United States, or around 200,000 people.¹¹

Vascular dementia is caused by damage to large blood vessels, causing a stroke with resultant cognitive deficits, or to smaller blood vessels (arterioles),¹² leading to more gradual cognitive decline.¹³ Vascular dementia also frequently co-occurs with Alzheimer's disease, leading to

⁸ Alzheimer's Statistics Massachusetts. Alzheimer's Association.

http://www.alz.org/documents_custom/facts_2017/statesheet_massachusetts.pdf. Accessed June 10, 2017.

⁹ Ibid.

¹⁰ Ibid.

¹¹ Younger/Early Onset Alzheimer's & Dementia. Alzheimer's Association.

http://www.alz.org/alzheimers_disease_early_onset.asp. Accessed February 25, 2017.

¹² Vascular Dementia: Types of Vascular Dementia. Alzheimer's Society.

https://www.alzheimers.org.uk/info/20007/types_of_dementia/5/vascular_dementia/3. Accessed June 10, 2017.

¹³ Vascular Dementia: Symptoms. Alzheimer's Society.

https://www.alzheimers.org.uk/info/20007/types_of_dementia/5/vascular_dementia/4. Accessed June 10, 2017.



greater cognitive deficits than would be expected by either condition alone.¹⁴ Through these and other mechanisms, it contributes to dementia in up to approximately 20 percent of cases.¹⁵

Dementia with Lewy Bodies

(**DLB**), a progressive disease characterized by the presence of abnormalities composed of alphasynuclein protein in the brain, accounts for 10 to 25 percent of dementia cases.¹⁶ Some DLB symptoms, such as general stiffness or difficulties with balance, overlap with symptoms of Parkinson's disease. DLB and Parkinson's Disease Dementia share symptoms and overlap in their effects on the brain. Prominent symptoms may



include confusion, fluctuations in thinking, reasoning or personality; visual hallucinations, delusions, and memory loss.¹⁷

The term **Frontotemporal Dementia (FTD)** covers a set of degenerative disorders resulting from nerve cell loss in the frontal or temporal lobes of the brain.¹⁸ Frontotemporal disorders may lead to changes in behavior and personality, language ability, and motor skills.¹⁹

¹⁴ Vascular Dementia. Alzheimer's Association. http://www.alz.org/dementia/vascular-dementia-symptoms.asp. Accessed February 25, 2017.

¹⁵ Vascular Dementia. WebMD. http://www.webmd.com/stroke/guide/vascular-dementia. Accessed May 18, 2017.

¹⁶ Dementia with Lewy Bodies. Alzheimer's Association.

http://www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp. Accessed February 25, 2017.

¹⁷ Ibid.

¹⁸ Frontotemporal Dementia (FTD). Alzheimer's Association.

http://www.alz.org/dementia/fronto-temporal-dementia-ftd-symptoms.asp. Accessed February 25, 2017.



Less common forms of dementia include alcohol-related brain damage (either directly from toxic effects of alcohol or through thiamine deficiency in Wernicke-Korsakoff Syndrome),²⁰ normal pressure hydrocephalus (affects cognition, alertness, balance/gait, and continence due to fluid buildup in the brain),²¹ Huntington's disease (genetic and progressive condition that leads to cognitive decline, mood changes, and involuntary movements),²² and Chronic Traumatic Encephalopathy (from repeated sub-concussive brain injuries).²³



¹⁹ Frontotemporal Disorders: Information for Patients, Families, and Caregivers. National Institute on Aging. https://www.nia.nih.gov/alzheimers/publication/frontotemporaldisorders/types-frontotemporal-disorders. Published February 2017. Updated March 24, 2017. June 10, 2017.

²⁰ What is alcohol-related brain damage? Alzheimer's Society.

https://www.alzheimers.org.uk/download/downloads/id/1765/factsheet_what_is_alcohol-related_brain_damage.pdf. Published October 2015. Accessed June 10, 2017.

²¹ Normal Pressure Hydrocephalus (NPH). Alzheimer's Association.

http://www.alz.org/dementia/normal-pressure-hydrocephalus-nph.asp. Accessed June 10, 2017. ²² Huntington's Disease. Alzheimer's Association. http://www.alz.org/dementia/huntingtons-disease-symptoms.asp. Accessed June 10, 2017.

²³ Frequently Asked Questions about Chronic Traumatic Encephalopathy. Boston University CTE Center. http://www.bu.edu/cte/about/frequently-asked-questions/. Accessed June 10, 2017.



3.1.c. Progression

Cognitive impairment in persons with dementia progresses through a number of stages. In the early stages of dementia, a person may continue to be largely independent,²⁴ while in the later stages of dementia a person's cognitive deficits and need for special care typically become more apparent.²⁵ A person in the earlier stages may not report changes in thinking or memory to health system professionals; therefore, it may be difficult to detect early dementia in primary or acute care settings. The Committee recommended including content in trainings on the importance of interventions for persons in the early stages of dementia whose symptoms might not be easily recognizable.

3.2. Delirium

A significant concern in hospital care, particularly care for persons with dementia, is the development and treatment of delirium. Delirium is distinct from dementia, although it is more common in hospitalized patients who have a diagnosis of dementia than in those without.²⁶ It is important to be able to distinguish between the two conditions. Delirium is a temporary condition (lasting anywhere from days to months) that causes acute confusion and persistent symptoms and can lead to adverse long-term outcomes.²⁷ Delirium is common, affecting up to a third of hospital patients over 70.²⁸ Delirium can be caused by a range of events, including infection, medications, dehydration, sleep-wake cycle disturbance, anesthesia and others.²⁹ The

²⁴ The Early Stages of Dementia. Alzheimer's Society.

https://www.alzheimers.org.uk/info/20073/how_dementia_progresses/203/the_early_stages_of_d ementia. Accessed February 25, 2017.

²⁵ The later stages of dementia. Alzheimer's Society.

https://www.alzheimers.org.uk/info/20073/how_dementia_progresses/103/the_later_stages_of_d ementia. Accessed February 25, 2017.

²⁶ Elie M, Cole MG, Primeau FJ, Bellavance F. Delirium Risk Factors in Elderly Hospitalized Patients. *Journal of General Internal Medicine*. 1998;13(3):204-212. doi:10.1046/j.1525-1497.1998.00047.x.

 ²⁷ Collier R. Hospital-induced delirium hits hard. *CMAJ*: Canadian Medical Association Journal. 2012;184(1):23-24. doi:10.1503/cmaj.109-4069.
 ²⁸ Ibid

²⁹ Siddiqi N, Harrison JK, Clegg A, Teale EA, Young J, Taylor J, Simpkins SA. Interventions for preventing delirium in hospitalised non-ICU patients. *Cochrane Database of Systematic Reviews* 2016, Issue 3. Art. No.: CD005563. DOI: 10.1002/14651858.CD005563.pub3.



alertness of patients with delirium (their level of consciousness) tends to fluctuate, requiring frequent monitoring to detect the presence of delirium.³⁰

Delirium can present in two ways: as hyperactive or hypoactive.³¹ With hyperactive delirium, a patient may become agitated; with hypoactive delirium (the more common form), a patient may become quiet or lethargic.³² Because a patient is less active when suffering from hypoactive delirium, the condition is often overlooked; thus, it is important that healthcare professionals be educated about recognizing and evaluating for both types of delirium.³³

Delirium is preventable. A recent Cochrane Review of the literature found that multi-component interventions, addressing multiple risk factors for delirium (e.g. by including individualized care planning, checklists/protocols, and reorientation), are effective in delirium prevention.³⁴

Pharmacological interventions for dementia or delirium should be approached with caution. A recent systematic review and meta-analysis found that "antipsychotic pharmacotherapy does not improve outcomes when used for prevention or treatment of delirium in hospitalized adult patients. Antipsychotics were not associated with improvements [in] short-term mortality, severity or duration of delirium, and length of ICU and hospital stay."³⁵ Despite limited evidence of the effectiveness of antipsychotic drugs in the treatment of dementia and prevention or management of delirium, they are commonly prescribed,³⁶ with potential negative consequences. A 2016 study found that, of patients discharged from the hospital on antipsychotics, 65% of those readmitted to the hospital were still taking the same antipsychotics, indicating that being

³⁰ Collier, 2012.

 ³¹ Kennedy M. Presentation at Second Meeting of the Alzheimer's and Related Dementias Acute Care Advisory Committee. http://www.mass.gov/dph/alzdementia. February 3, 2017.
 ³² Ibid.

³³ Ibid.

 $^{^{34}}$ Ib1d.

³⁴₂₅ Siddiqi et al., 2016.

³⁵ Neufeld KJ, Yue J, Robinson TN, Inouye SK, Needham DM. Antipsychotic Medication for Prevention and Treatment of Delirium in Hospitalized Adults: A Systematic Review and Meta-Analysis. *Journal of the American Geriatrics Society*. 2016:64(4);705-714. DOI:10.1111/jgs.14076.

³⁶ Loh KP, Ramdass S, Garb JL, Thim M, Brennan MJ, Lindenauer PK, Lagu T. Long-term Outcomes of Elders Discharged on Antipsychotics. *Journal of Hospital Medicine*. 2016:11(8);550-555. DOI:10.1002/jhm.2585.



started on antipsychotics in the acute care setting may result in long-term use.³⁷ A randomized controlled trial of patients receiving palliative care published in the January 2017 issue of *JAMA Internal Medicine* produced further evidence to suggest that individualized management of delirium without antipsychotic medication is most often preferable, as antipsychotics are not as effective as other strategies with fewer or no side effects.³⁸ Given the frequency with which antipsychotic medication programs regarding both dementia and delirium management may be indicated.

3.3. Potential Unintended Negative Consequences

The Committee's recommendations should be taken with care to avoid potential unintended consequences, such as misdiagnosis, stigmatization, loss of autonomy and independence, declaration of incompetence, and ensuing actions that may be taken following such a declaration. This report does not address all of the complexities associated with determining decisional capacity in patients visiting the Emergency Department or inpatient setting.

Labeling someone "cognitively impaired" or adding a diagnosis of dementia may begin a cascade of events leading to a patient being evaluated for his or her ability to consent to treatment and live independently; it could even lead to a determination that a guardian or other substitute decision-maker is needed. While this may be a helpful course of action for patients with dementia who were previously undiagnosed, cognitive impairment in older adults may be due to temporary confusion or acute delirium and therefore transient, related to medications, infection, dehydration, or other conditions or circumstances. Therefore, training for health care professionals must include how to distinguish dementia from delirium, the potential for the two conditions to co-exist, and the importance of sharing uncertainty about the diagnosis with the patient, family, and other members of the health care team. Patients with suspected cognitive impairment and an unclear diagnosis should be reassessed frequently since their condition may change over the course of a hospitalization and after discharge.

³⁷ Ibid.

³⁸ Agar MR, Lawlor PG, Quinn S, Draper B, Caplan GA, Rowett D, Sanderson C, Hardy J, Le B, Eckermann S, McCaffrey N, Devilee L, Fazekas B, Hill M, Currow DC. Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative Care: A Randomzied Clinical Trial. *JAMA Internal Medicine*. 2017;177(1):34-42. DOI:10.1001/jamainternmed.2016/7491.



3.4. Dementia and Acute Care Utilization

Persons with dementia are more likely to be seen in the ED when compared to persons with

similar medical conditions who do not have dementia. They also have higher utilization rates of nursing facilities, hospitals, and home health care, as well as more care transitions.³⁹

Individuals with dementia face unique risks while hospitalized and post-discharge that merit special attention. A 2012 study of patients aged 65 and older found that persons with dementia were at increased risk for hospitalization.⁴⁰ The study authors suggested several evidence-based reasons why dementia might be linked with increased hospitalizations, including:

• There is a greater likelihood that someone with dementia will have or will develop comorbid conditions that require hospitalization;

Spotlight on Particular Risks for Persons with Dementia in the Hospital

- Delirium
- Falls
- Development of incontinence
- Indwelling urinary catheters
- Pressure ulcers
- Untreated pain
- Agitation behaviors (e.g. aggression, yelling)
- Physical restraints
- Functional decline
- Insertion of feeding tubes

Source: Maslow K, Mezey M. Adverse Health Events in Hospitalized Patients with Dementia. AJN, *American Journal of Nursing*. 2008;108(1):1.

- Dementia complicates the day-to-day management of chronic conditions by the patient or caregiver and contributes to difficulty identifying and expressing new symptoms of comorbid conditions;
- A change in situation (e.g. living situation or caregiver change) might disrupt the day-today care for a person with dementia; and

³⁹ Callahan CM, Arling G, Tu W, et al. Transitions in Care among Older Adults with and without Dementia. *Journal of the American Geriatrics Society*. 2012;60(5):813-820. doi:10.1111/j.1532-5415.2012.03905.x.

⁴⁰ Phelan EA, Borson S, Grothaus L, Balch S, Larson EB. Association Between Incident Dementia and Risk of Hospitalization. *JAMA*. 2012;307(2):165-172. doi:10.1001/jama.2011.1964.



• An individual with dementia may become more acutely ill and require hospitalization as compared to someone with the same condition who does not have dementia.⁴¹

Furthermore, individuals with dementia are at higher risk of developing superimposed delirium, which not only increases the risk of hospitalization but also increases the risk of complications and a prolonged length of stay during hospitalization.

One risk factor for hospitalization — difficulty communicating symptoms or a change in condition — is a particular point of concern when a person has dementia. Communication challenges that lead to hospitalization may persist during a hospitalization and could prolong an inpatient stay, if dementia is not identified and the unique needs of the person and caregivers are not addressed.

Persons with dementia also tend to have higher acute care utilization costs. A 2000 study, using data from 1996-1997, reported that patients with dementia had a hospital stay of approximately four days longer than patients without dementia.⁴² The cost of care per person at the time of that study was about \$4,000 higher for



patients with dementia.⁴³ Alternatives such as hospital-at-home⁴⁴ and similar programs that enable individuals with dementia to be cared for in a familiar setting with their usual caregivers

⁴¹ Ibid.

 ⁴² Lyketsos CG, Sheppard J-ME, Rabins PV. Dementia in elderly persons in a general hospital.
 American Journal of Psychiatry. 2000;157(5):704–707. doi:10.1176/appi.ajp.157.5.704.
 ⁴³ Ibid.

⁴⁴ Leff, Bruce. Why I Believe in Hospital at Home. NEJM Catalyst. http://catalyst.nejm.org/whyi-believe-in-hospital-at-home/. Published February 5, 2017. Accessed April 13, 2017.





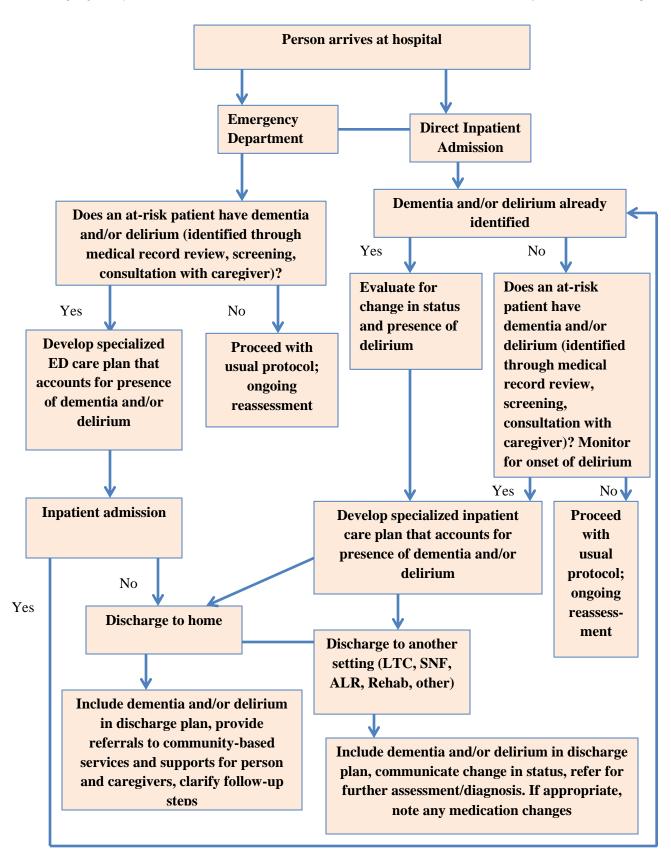
may improve outcomes, lower health care costs, and minimize unnecessary or avoidable hospital care.

Various causes of cognitive impairment, including dementia and delirium, may be identified during a hospitalization through the use of screening tools. Many screening tools are inexpensive and relatively quick to

administer. Several commonly used tools are described in Table 2 in section 9.1.

Patient Flow of a Person with Dementia through the Acute Care System

This diagram serves as a visual representation of the movement of a patient through the acute care system and highlights key moments at which delirium and/or dementia status should be assessed and folded into the care plan.





4. Emergency Department Recommendations

Summary of Recommendations: Massachusetts hospitals should prepare an Emergency Department (ED) operational plan for the recognition and management of patients with dementia and/or delirium. This plan should be reviewed by the hospital's Patient and Family Advisory Council and should include but not be limited to: a) recognition of dementia and/or delirium; b) screening procedures; c) management and treatment; d) developing a dementia-friendly environment; and e) transfer or discharge procedures.

Caregiver Perspective:

My experience bringing my parent with dementia to the ED has been challenging at times. Once, we had to wait for four hours. My mom was very anxious and very cold. I had to run around to try to find someone to give us a blanket. My mom was also incontinent, and it was challenging to bring her to the bathroom. Once they called us in, I had to do a little 'teach-in' in a subtle way, as I was uncomfortable talking about my mom in front of her.

A short time after I brought my mom to the ED, I saw an announcement in its newsletter that the hospital was having a professional summit for staff to talk about dementia and were inviting caregivers to share their experiences at the hospital. I was so happy to know that the hospital was recognizing a need and doing something about it.

4.1. Recognition of Dementia and/or Delirium

Recognition of dementia and/or delirium can take place at several points in a patient's experience moving through the ED: in the waiting room, both during registration and while waiting to be seen; during the history or examination; and in the admission or discharge process. The Committee has the following recommendations:

4.1.a. Prior History

- 1. Consult with family members/other informants to obtain prior history and current status.
- 2. Review patient's medical records, including any relevant notes from EMS/transport team.



3. Observe patient behavior in the ED; look for warning signs of possible cognitive impairment, with or without behavioral manifestations of distress or difficulty communicating.

4.1.b. Screening

1. Screen all appropriate patients for dementia and delirium. EDs should establish a simple threshold requiring screening for both dementia and delirium. The objective of screening at this point is to identify cognitive impairment for the purposes of determining ED treatment protocols and appropriateness of interventions.

The Committee does not recommend mandating the use of particular screening tools. A summary of available tools and their effectiveness is provided in 9.1.

The Committee recognizes that each hospital has certain unique characteristics. Therefore, the appropriate dementia and delirium screening thresholds should be determined by individual hospital teams based on their patient population and available services.

As the ED is not an environment conducive to a complete diagnostic evaluation, this section of the report emphasizes screening for and identification of cognitive impairment and referral for further diagnostic assessment and evaluation.

4.2. Management and Treatment

- 1. Dementia and/or delirium should be captured prominently in the ED medical record, following a similar protocol to those identifying a patient at risk for falls.
- 2. Cognitive status should be integrated into treatment decisions. Emergency clinicians should try to avoid uncomfortable or unnecessary procedures that may provoke or worsen delirium, or, in a patient who already has delirium, may require potentially dangerous sedating drugs or restraints to obtain reliable results. (For example, sedating a delirious person with late-stage dementia for a head CT scan when he or she would not be a candidate for aggressive intervention.)
- 3. EDs should establish protocols for pain identification and management in individuals with dementia and/or delirium.



4. EDs should establish protocols that include family members/caregivers in development and implementation of treatment plans.

4.3. ED Environment

- 1. EDs should identify quiet areas (when possible) where a patient with dementia and/or delirium can be placed and accompanied by a caregiver or care attendant (staff member or volunteer). These quiet areas should be available to caregivers while their care partner is going through the admission process, in order to limit caregiver anxiety.
- 2. EDs should encourage the use of trained volunteers to assist/support patients with dementia and/or delirium and their caregivers.

4.4. Advance Care Planning



The ED is not the ideal setting for advance care planning discussions. A discussion of advance care planning options (e.g., end-of-life wishes, advance directives) should take place in the outpatient setting with an individual's primary care provider (PCP) as soon as possible after a diagnosis of dementia is made or suspected. However, sometimes

advance care planning conversations will take place in the ED in order to develop a treatment plan consistent with the patient's wishes, assuming the individual does not have a health care proxy or living will on file. The Committee has the following recommendations relative to advance care planning:



- 1. ED physicians should increase their involvement in advance care planning discussions to promote identification of goals of care, wishes, and preferences as early as possible and to guide treatment plans.
- 2. Resources, such as The Conversation Project's Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia,⁴⁵ Massachusetts Medical Orders for Life Sustaining Treatment (MOLST),⁴⁶ and Honoring Choices Massachusetts,⁴⁷ should be made available to staff and caregivers to facilitate advance care planning decisions. All of these resources are available for free online (see footnotes 45-47).

4.5. Transfer or Discharge

The decision to admit or discharge, and to what setting, should take into account the patient's goals of care, prognosis, comfort, as well as family/caregiver availability and capability.

The following recommendations consider transfer or discharge practices from the ED for three scenarios.

4.5.a. Transport to Hospital

1. Transport by EMS or private ambulance can be frightening and overwhelming for individuals with dementia and their caregivers. Taking the time to reassure caregivers and explain what is going to happen, to answer questions and address caregiver concerns is essential and may influence care in the ED. Information gathered by transport professionals from family members or formal care providers about individual preferences and behavior triggers as well as adaptive devices may be critical to ED staff and should be communicated during the initial transfer.

http://www.honoringchoicesmass.com/about/about-us/. Accessed May 17, 2017.

⁴⁵ Your Conversation Starter Kit: For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia. The Conversation Project.

http://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf. Accessed April 14, 2017.

⁴⁶ Basic Information About MOLST. MOLST. http://molst-ma.org/basic-informaton-about-molst-0. Accessed May 17, 2017.

⁴⁷ About Us. Honoring Choices Massachusetts.



4.5.b. Inpatient Admission

- 1. Prominently identify best available information on patient's cognitive status in his/her medical record.
- 2. Communicate information on cognitive status to post-acute care provider (e.g., MD/NP/PA, social worker, behavioral health specialist) in warm handover (person to person communication) to ensure hospital treatment plans are aligned with post-acute care plan and patient/family goals, wishes, and preferences.
- 3. Make resources available to families or friends directly caring for a patient in the ED who will now be admitted by providing a packet of materials, which may include:
 - a. One-page fact sheet on recognizing signs of dementia and/or delirium and steps to obtaining a complete diagnosis
 - b. Template for a one-page overview (e.g., "This is Me" profile (see 5.2)) sharing caregiver's knowledge of the patient with hospital staff.⁴⁸
 - c. One-page listing of community resources, including organizations such as the Alzheimer's Association, Aging Service Access Points (ASAPs), and other local or statewide resources.

4.5.c. Discharge to Home

- 1. Incorporate dementia and/or delirium into discharge plan.
- 2. Include caregivers in plan development.
- 3. Establish a direct referral to a program such as the Alzheimer's Association's Dementia Care Coordination program or direct referral to a local ASAP or Council on Aging for patients and caregivers to ensure that families are directly connected to support via established organizations. Information about this referral program should be provided and reinforced to families or caregivers at the time of hospital discharge.

⁴⁸ This Is Me – support tool to enable person-centered care. Alzheimer's Society.
https://www.alzheimers.org.uk/info/20113/publications_about_living_with_dementia/415/this_is_me. Accessed April 14, 2017.



- 4. Provide patients and caregivers with information for further support, training, and appropriate referrals at the time of ED discharge. This information may include:
 - a. One-page checklist of resources and best practices for dementia care, including recommended follow-up steps
 - b. Information about the hospital's referral program to community-based resources
- 5. Provide a one-page checklist of individualized, person-centered dementia care planning follow-up steps. Include accommodations for common situations, such as supportive transportation options and driving evaluation follow-up, issues with wandering, need for caregiver respite, legal and financial planning, etc.
- 6. Communicate information on the patient's cognitive status during the hospitalization or ED visit to the patient's PCP (e.g., via the discharge summary or telephone call if appropriate) as well as designated responsible party (if applicable) for further evaluation/management.
- 7. Clearly identify at discharge any medication changes that could influence cognitive status.

4.5.d. Discharge to Referring Institution (e.g. Nursing Home, Skilled Nursing Facility, Rehabilitation facility, Rest Home, Assisted Living Residence (Traditional or Special Care/Memory Care Unit))

- 1. Identify dementia and/or delirium, including updated/current status and communicate to referring institution.
- 2. Incorporate status update/new issues related to cognitive status (e.g., super-imposed delirium) into discharge plan/recommendations and communicate information on cognitive status to post-acute care provider (e.g., MD/NP/PA, social worker, behavioral health specialist) in warm handover (person to person communication) to ensure hospital treatment plans are aligned with post-acute care plan and patient/family goals, wishes, and preferences.
- 3. Refer and/or make recommendations for further assessment/diagnosis if appropriate.
- 4. Clearly identify any medication changes that could influence cognitive status.



Caregiver Perspective:

I took my mother to the doctor not thinking she would end up in the ED. The doctor was very concerned about my mother's elevated lab tests. I arrived at the hospital very worried about my mother, who kept saying she was fine and wanted to go home. The staff at the ED were wonderful and supportive, especially the doctor in charge, who talked to my mom in a calming voice and also tried to calm me down. The doctor told me that they understood what I was going through and offered me a glass of water. I felt very supported by the doctor and staff at the ED and very much appreciated the way everyone handled the situation.

5. Inpatient

Summary of Recommendations: Hospitals should have an operational plan in place to identify dementia and/or delirium and to create a specialized care plan in the event that delirium, dementia, or both are detected. This plan should be reviewed by the hospital's Patient and Family Advisory Committee and include but not be limited to: a) recognition of dementia and/or delirium; b) screening procedures; c) management and treatment in all departments; d) developing a dementia-friendly environment; and e) transfer or discharge procedures.

5.1. Recognition of Dementia and/or Delirium

- 1. Persons with dementia and/or delirium in the inpatient setting should be identified through the admission process. A summary of effective screening tools is included in 9.1.
 - a. Selected screening tools should be incorporated into an electronic medical record, if applicable.
- 2. A positive screen for dementia and/or delirium should trigger the development of an individualized care plan addressing a patient's specific needs, including but not limited to delirium prevention and management, behaviors, sleep, nutrition, mobility, and patient and caregiver education. Conducting a screening for the purposes of identifying dementia and/or delirium does not constitute a comprehensive or definitive diagnostic assessment.



5.2. Management and Treatment

- 1. Care planning should promote caregiver involvement and education, and caregivers should participate in treatment and transition decisions. Methods to promote caregiver involvement may include the following:
 - a. A "Welcome letter" in the patient's room outlining hospital protocol for visitors and providing useful contacts.
 - b. A "This is Me" or similar type of patient profile. This document can be completed by patients and caregivers and includes information about the patient's preferences, background, and triggers that may lead to manifestations of distress or challenges in communicating with the patient (e.g., hearing or vision impairment, valued routines).⁴⁹
 - c. Flexibility with regard to hospital visiting policies, such as liberalizing visiting hours and allowing caregivers to stay in a patient's room overnight.
 - d. Referrals to programs such as the Alzheimer's Association's Dementia Care Coordination program or direct referral to a local ASAP or Council on Aging for patients and caregivers to ensure that families are directly connected to support via established organizations and other community-based resources. (See 4.5.c for a more detailed recommendation to establish a direct referral program with the aim of ensuring that caregivers are directly connected to support via established organizations.)

5.3. Inpatient Environment

- 1. Hospitals should work towards developing a dementia-friendly environment and integrating dementia and/or delirium into treatment decisions. Sample improvements include the following:
 - a. Modifying the physical environment through methods such as inclusion of largefaced clocks, signage, attention to specific lighting patterns and intensity, room placement (e.g., bed next to window or near nurse's station).
 - b. Color-coding via signage in the patient's room, bracelet or notation on the medical record and any transfer/requisition forms to identify at-risk patients.

⁴⁹ This Is Me: This leaflet will help you support me in an unfamiliar place. Alzheimer's Society and Royal College of Nursing.

https://www.alzheimers.org.uk/download/downloads/id/3423/this_is_me.pdf. Accessed June 8, 2017.



- c. Designating quiet areas and safe walking spaces.
- d. Providing opportunities for a person who is restless to walk safely and ensuring that there is a "lost person protocol" addressing finding patients and notifying appropriate authorities and relatives.⁵⁰
- e. Ensuring that the patient is physically active as soon after admission as possible, based on medical orders and not requiring a physical therapy evaluation unless indicated.
- f. Utilizing dementia volunteers. For example, the Hospital Elder Life Program (HELP) utilizes trained volunteers.⁵¹

The use of dementia volunteers presents an opportunity for future study. Factors to consider include the cost of building a corps of volunteers (recruitment, training, resources) and the specific role description for volunteers.

5.4. Advance Care Planning

A discussion of advance care



planning options (e.g., end-of-life wishes, advance directives) should take place in the outpatient setting with an individual's PCP as soon as possible after a diagnosis of dementia is made or suspected. While the inpatient setting is not always ideal for advance care planning discussions, in some cases advance care planning discussions are necessary in order to develop an appropriate treatment and discharge plan, should the patient not already have advance directives in place. The Committee has the following recommendations related to advance care planning:

⁵⁰ Silverstein NM, Flaherty G. Wandering in Hospitalized Older Adults. ConsultGeri.
 https://consultgeri.org/try-this/dementia/issue-d6.pdf. Updated 2012. Accessed June 11, 2017.
 ⁵¹ What does HELP provide? Hospital Elder Life Program.

http://www.hospitalelderlifeprogram.org/about/what-we-do/. Accessed June 11, 2017.



- 1. Physicians in acute care settings should increase their involvement in advance care planning discussions to promote identification of goals of care, wishes, and preferences as early as possible and to guide appropriateness of treatment plans.
- 2. Resources, such as The Conversation Project's Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia, Massachusetts Medical Orders for Life Sustaining Treatment (MOLST), and Honoring Choices Massachusetts, should be made available to staff and caregivers to facilitate advance care planning

decisions. All of these resources are available for free online (see footnotes 45-47).

5.5. Transfer or Discharge

The decision to discharge and to what setting should take into account the patient's goals of care, prognosis, comfort, and family/caregiver availability and capability.



5.5.a. Discharge to Home

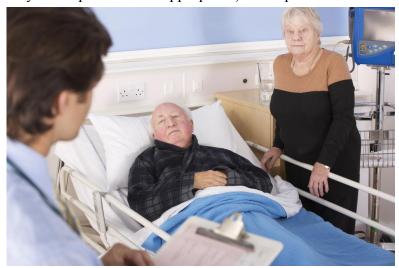
- 1. Incorporate dementia and/or delirium into discharge plan.
- 2. Include caregivers in discharge plan development.
- 3. Establish a direct referral to a program such as the Alzheimer's Association's Dementia Care Coordination program or direct referral to their local ASAP or Council on Aging for patients and care partners to ensure that families are directly connected to support via established organizations. Information about this referral program should be provided and reinforced to families or other caregivers at the time of hospital discharge.



- 4. Provide patients and caregivers information for further support, training, and appropriate referrals, including scheduled follow-up appointments, upon a patient's discharge from the hospital.
- 5. Provide a one-page checklist of individualized, person-centered dementia care planning follow-up steps. This checklist should include accommodations for common situations, such as supportive transportation options and driving evaluation follow-up, wandering and other safety issues, need for caregiver respite, legal and financial planning, etc.
- 6. Communicate information on the patient's cognitive status during the hospitalization (e.g., via the discharge summary or telephone call if appropriate) to the patient's PCP as

well as designated responsible party (if applicable) for further evaluation/management.

 Clearly identify at discharge any medication changes that could influence cognitive status.



5.5.b. Discharge to a Referring Institution (e.g. Nursing Home, Skilled Nursing Facility, Rehabilitation facility, Rest Home, Assisted Living Residence (Traditional or Special Care/Memory Care Unit))

- 1. Identify dementia and/or delirium and any status updates (e.g. super-imposed delirium); and communicate information on cognitive status to referring provider (e.g., MD/NP/PA, social worker, behavioral health specialist) in a warm handover (person to person communication).
- 2. Incorporate status update/new issues related to cognitive status into discharge treatment plan/recommendations and communicate directly with post-acute care provider to ensure hospital treatment plans are aligned with post-acute care plan and patient/family goals, wishes, and preferences.



- 3. Refer and/or make recommendation/referral for further assessment/diagnosis if appropriate.
- 4. Clearly identify any medication changes that could influence cognitive status.

5.5.c. Transfer to another unit or floor within the hospital

- 1. Information on a patient's cognitive status, recent changes or updates, and/or presence of delirium should be communicated by nurse-to-nurse report or other method when patients are transferred from one unit to another within the institution.
- 2. Information from caregivers and hospital staff regarding baseline status, behavioral manifestations of distress, environmental or other triggers, successful interventions (what soothes the patient or is effective in distracting him/her, activity preferences, mobility, medication changes) should be included in transfer information.



6. Education and Training

Caregiver Perspective:

I decided to take my husband to the ED after he fell. It was too late in the evening to go to Urgent Care, and our daughter was worried about him. The triage nurse saw us right away and put us in a designated place by the nurses' station. We had to wait almost four hours to be seen, but the staff was very helpful. The hospital staff would not release him home until they could see him walk with the brace, but he was too tired and couldn't even sit up. We had to stay until the next day. When he was still too exhausted, the hospital staff ended up sending him to rehab. I wish that hospital staff could receive more training to listen to advice of family members about whether a person with dementia would be better off receiving therapy at home.

Symptoms of dementia are often complicated by comorbid illness and new environments that pose special challenges to those with cognitive impairment, their families, and hospital staff. Hospitals should prepare personnel with the skills and education they need to prevent or alleviate unnecessary challenges.

The committee recommends that hospitals implement the following practices relating to education and training of hospital personnel and caregivers:

- 1. Hospitals should provide culturally sensitive education on delirium and dementia to all personnel, volunteers, and students who may encounter patients with dementia and/or delirium and/or their caregivers. Suggested components include:
 - a. Mandatory participation for all personnel, volunteers, and students who may encounter patients with dementia and/or delirium and/or their caregivers. Participating groups may include but are not limited to: hospitalists, attendings, house staff, admitting staff, nursing, social work/case management/discharge planning, therapy, pastoral care, imaging/laboratory/radiology, reception, transportation, environmental services, and dietary.
 - b. Education and training should also be offered to those involved in transporting someone with dementia to the hospital.



- c. Education and training should be provided upon hire and routinely, as part of ongoing training, which may be part of annual continuing medical or nursing education requirements. It should include guidelines for recognizing dementia and/or delirium when a patient may be in the early stages and not displaying easily recognizable symptoms.
- d. Education and training may be provided via the established methodology utilized by individual hospitals (e.g., online, classroom, combination). For example, see the "Try This" series outlined in 9.2.
- e. Training materials should be made available in multiple locations and multiple departments, so that they are easily available and accessible to all staff.
- f. Include caregiver training in care planning and discharge planning.
- 2. Hospital surveyors should receive training specific to the recognition, screening, management, and treatment of dementia and/or delirium.



Caregiver Perspective:

After my father was already diagnosed with Alzheimer's, he had to go to the hospital due to a urinary tract infection. The staff wanted to keep him overnight with an antibiotic IV. They told me that, in order to keep him overnight, he would need to be either restrained or sedated since they didn't have enough staff to be with him all the time. I had to stay overnight to take care of my father and help him with the confusion of being in a different place.

7. Quality Measures

The Committee recommends the following quality measures be adopted. These measures apply to both the ED and the inpatient experience.

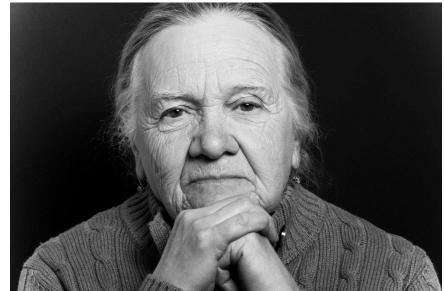
- 1. The hospital should ensure that a process is in place to identify patients with dementia and/or delirium.
 - a. The Committee does not specify what clinical assessment should be used to make these diagnoses and communicate them to staff, as long as the diagnosis is recognized and communicated to ensure that patients can be properly treated.
- 2. The hospital (including inpatient floor and observation unit) should have a discharge plan in place that addresses care coordination and caregiver needs.
 - a. The Committee recommends using a modification of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) questionnaire, which asks whether the patient or, in this case, the caregiver understood how to manage the health needs of the patient when they left the hospital. Data on the responses to this question are included in Centers for Medicare and Medicaid Services' Hospital Compare.
 - b. The Committee also suggests adding a question specific to dementia, such as, "Did the caregiver understand how to manage the acute care needs of a patient with dementia after his or her discharge from the hospital?" and/or "Does the caregiver understand his or her expanded caregiving role, including access to resources and support?"



- 3. The hospital or ED should have a method of identifying new prescriptions written for contraindicated medications (for example, medications from the Beers List that includes medications generally contraindicated in patients older than age 75⁵²) who were seen in the hospital or ED.
 - a. This could be reported as a number and percentage of all patients over age 75 seen in the ED or hospital and considered a marker of poor quality if it exceeds the 75th percentile for other EDs or hospitals in a given region of the U.S. Such medications would include anticholinergics and antipsychotics. The Committee recommends measuring this in all elderly patients instead of only patients with dementia because it can predispose any elderly patient to delirium and its adverse

consequences.

- 4. The hospital or ED should have a reporting structure in place to ensure that evidence of a "goals of care" discussion is included in the medical record for any elderly patient (>75 years of age) who may be at risk of developing Alzheimer's or related dementia.
 - a. This binary (yes/no) question could also be reported as a percentage of all elderly patients and



considered a marker of poor quality if it did not occur in at least 75% of these patients. The "goals of care" discussion would help guide all clinical decisions and practices for patients with dementia in the hospital or ED and is therefore a better quality indicator than any particular process of care.

⁵² American Geriatrics Society 2015 Beers Criteria Update Expert Panel. Geriatrics Society 2015 Updated Beers Criteria for Inappropriate Medication Use in Older Adults. *Journal of the American Geriatrics Society*. 2015:63(11);2227-2246.Doi: 10.1111/jgs.13702.



8. Conclusion

8.1. High-Priority Recommendations

The Committee's top three recommendations are:

- 1. Hospitals should have an operational plan in place, available to the public and Department of Public Health upon request, to identify dementia and/or delirium in the ED and/or inpatient settings and to create a specialized care plan in the event that delirium, dementia, or both are detected. This operational plan should include, but is not limited to, the following: a) recognition of dementia and/or delirium; b) screening procedures; c) management and treatment in all relevant departments; d) development of a dementia-friendly environment; e) transfer or discharge procedures; and f) an annual hospital self-assessment. Hospitals should review the plan with their Patient and Family Advisory Council prior to implementation.
- 2. Pursuant to the CARE Act, hospitals should develop a process to ensure that designated caregivers are involved in hospital processes, specifically transfer and discharge planning, when an individual has dementia.
- 3. Hospitals should also develop Quality Assurance Performance Improvement (QAPI) measures and processes, available to the public and Department upon request, that outline the hospital's operational plan effectiveness and include how clinical and relevant non-clinical staff receive routine training in the care of individuals with Alzheimer's and related dementias and their caregivers.

The Committee proposes that, within the next three years, the top three recommendations become the standard of care in all Massachusetts hospitals serving an adult population. The Committee further recommends that after three years, this standard of care will be an expectation of all Massachusetts hospitals serving an adult population and will be incorporated into future survey and Quality Assurance Performance Improvement (QAPI) processes.

The Committee urges hospitals to begin to adopt these high-priority recommendations in order to create a dementia-capable health system within the Commonwealth of Massachusetts.



Table 1: Summary of Recommendations and Suggested Implementation Steps

Setting of	Category	Description	
Care (ED or			
Inpatient)			
ED, Inpatient	Overall	Hospitals should have an operational plan in place, available to the public and Department of Public Health upon request, to identify dementia and/or delirium in the ED and/or inpatient settings and to create a specialized care plan in the event that delirium, dementia, or both are detected. This operational plan should include, but is not limited to, the following: a) recognition of dementia and/or delirium; b) screening procedures; c) management and treatment in all relevant departments; d) development of a dementia-friendly environment; e) transfer or discharge procedures; and f) an annual hospital self-assessment. Hospitals should review the plan with their Patient and Family Advisory Council prior to implementation.	
ED, Inpatient	Overall	Pursuant to the CARE Act, hospitals should develop a process to ensure that designated caregivers are involved in hospital processes, specifically transfer an discharge planning, when an individual has dementia.	
ED, Inpatient	Overall	Hospitals should also develop Quality Assurance Performance Improvement (QAPI) measures and processes, available to the Department upon request, that outline the hospital's operational plan effectiveness and include how clinical and relevant non- clinical staff receive routine training in the care of individuals with Alzheimer's and related dementias and their caregivers.	
ED	Recognition of Dementia and/or Delirium	Consult with family members/other informants to obtain patient's prior history and current status.	
ED	Recognition of Dementia and/or Delirium	Review patient's medical records, including any relevant notes from EMS/transport team.	
ED	Recognition of Dementia and/or Delirium	Observe patient behavior; look for warning signs of possible cognitive impairment, with or without behavioral manifestations of distress or difficulty communicating.	
ED	Recognition of Dementia and/or Delirium	Screen all appropriate patients for dementia and delirium. EDs should establish a simple threshold that would require screening for both dementia and delirium. The objective of screening at this point is to identify cognitive impairment for the purposes of determining ED treatment protocols and appropriateness of interventions.	
ED	Management and Treatment	Capture dementia and/or delirium prominently in the ED medical record, following a similar protocol to those identifying a patient at risk for falls.	
ED	Management and Treatment	Integrate cognitive status into treatment decisions. Emergency clinicians should try to avoid uncomfortable or unnecessary procedures that may provoke or worsen delirium, or, in a patient who already has delirium, may require potentially dangerous sedating drugs or restraints to obtain reliable results.	
ED	Management and Treatment	Establish protocols for pain identification and management in individuals with dementia and/or delirium.	
ED	Management and Treatment	Establish protocols that include family members/caregivers in development and implementation of treatment plans.	
ED	Environment	Identify quiet areas where a patient with dementia and/or delirium can be placed and	



H O		
		accompanied by a caregiver or care attendant (staff member or volunteer). These quiet areas should be available to caregivers while their care partner is going through the admission process, in order to limit caregiver anxiety.
ED	Environment	Encourage the use of trained volunteers to assist/support patients with dementia and/or delirium and their caregivers.
ED	Transport to Hospital	Take the time to reassure caregivers and explain what is going to happen, answer questions and address caregiver concerns. Information gathered by transport professionals from family members or formal care providers about individual preferences and behavior triggers as well as adaptive devices may be critical to ED staff and should be communicated during the initial transfer.
ED	Transfer to Inpatient	Prominently identify best available information on patient's cognitive status in his/her medical record.
ED	Transfer to Inpatient	Communicate information on cognitive status to post-acute care provider (e.g., MD/NP/PA, social worker, behavioral health specialist) in warm handover (person to person communication) to ensure hospital treatment plans are aligned with post-acute care plan and patient/family goals, wishes, and preferences.
ED	Transfer to Inpatient	Make resources available to family and friends directly caring for patient being admitted by providing a packet of materials about dementia and/or delirium, resources, and ways to advocate for patient.
Inpatient	Recognition of Dementia and/or Delirium	Identify persons with dementia and/or delirium in the inpatient setting through the admission process.
Inpatient	Recognition of Dementia and/or Delirium	Positive screen for dementia and/or delirium should trigger development of individualized care plan. Care plan should address the patient's specific needs, including but not limited to delirium prevention and management, behaviors, sleep, nutrition, mobility, and patient and caregiver education. Conducting a screening for the purposes of identifying dementia and/or delirium does not constitute a comprehensive or definitive diagnostic assessment.
Inpatient	Management and Treatment	Care planning should promote caregiver involvement and education, and caregivers should participate in treatment and transition decisions. Methods to promote caregiver involvement may include: providing an outline of hospital protocol for visitors and useful contacts, filling out a "This is Me" or similar patient profile, having flexibility with regard to hospital visiting policies, and making referrals to dementia caregiver consultation and other community-based resources.
Inpatient	Environment	Work towards developing a dementia-friendly environment, including by modifying the physical environment, allowing quiet and safe spaces and opportunities for a restless person to walk, and utilizing dementia volunteers. See 5.3 for full details.
Inpatient	Transfer to Another Unit or Floor Within the Hospital	Communicate information on patient's cognitive status, recent changes or updates, and/or presence of delirium via nurse-to-nurse report or other method.
Inpatient	Transfer to Another Unit or Floor Within the Hospital	Include information from caregivers and hospital staff regarding baseline status, behavioral manifestations of distress, environmental or other triggers, and successful interventions in transfer information.
ED, Inpatient	Discharge to Home	Incorporate dementia and/or delirium into discharge plan.
ED, Inpatient	Discharge to Home	Include caregivers in discharge plan development.
ED, Inpatient	Discharge to Home	Establish a direct referral to a program such as the Alzheimer's Association's Dementia Care Coordination program or direct referral to a local Aging Service



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		Access Point (ASAP) or Council on Aging for patients and caregivers to ensure that families are directly connected to support via established organizations. Information about this referral program should be provided and reinforced to families or caregivers at time of discharge.
ED, Inpatient	Discharge to Home	Provide patients and caregivers with information for further support, training, and appropriate referrals at time of discharge. This information may include: information on resources and best practices for dementia care, including recommended follow-up steps; and information about the hospital's referral program to community-based resources.
ED, Inpatient	Discharge to Home	Provide a one-page checklist of individualized, person-centered dementia care planning follow-up steps, including accommodations for common situations, such as supportive transportation options and driving evaluation follow-up, issues with wandering, need for caregiver respite, legal and financial planning, etc.
ED, Inpatient	Discharge to Home	Communicate information on patient's cognitive status during hospitalization or ED visit to patient's primary care provider (e.g., via the discharge summary or telephone call if appropriate) as well as designated responsible party (if applicable) for further evaluation/management.
ED, Inpatient	Discharge to Home	Clearly identify at discharge any medication changes that could influence cognitive status.
ED, Inpatient	Discharge to Referring Institution	Identify dementia and/or delirium, including updated/current status and communicate to referring institution.
ED, Inpatient	Discharge to Referring Institution	Incorporate status update/new issues related to cognitive status (e.g., super-imposed delirium) into discharge plan/recommendations and communicate information on cognitive status to post-acute care provider (e.g., MD/NP/PA, social worker, behavioral health specialist) in warm handover (person to person communication) to ensure hospital treatment plans are aligned with post-acute care plan and patient/family goals, wishes, and preferences.
ED, Inpatient	Discharge to Referring Institution	Refer and/or make recommendations for further assessment/diagnosis if appropriate.
ED, Inpatient	Discharge to Referring Institution	Clearly identify any medication changes that could influence cognitive status.
ED, Inpatient	Education and Training	Hospitals should provide culturally sensitive education on delirium and dementia to all personnel, volunteers, and students who may encounter patients with dementia and/or delirium and/or their caregivers.
ED, Inpatient	Education and Training	Mandatory participation for all personnel, volunteers and students who may encounter patients with dementia and/or delirium.
ED, Inpatient	Education and Training	Education and training should be offered to those involved in transporting someone with dementia to the hospital.
ED, Inpatient	Education and Training	Education and training should be provided upon hire and routinely, as part of ongoing training, which may be part of annual continuing medical or nursing education requirements. It should include guidelines for recognizing dementia and/or delirium when a patient may be in the early stages and not displaying easily recognizable symptoms.
ED, Inpatient	Education and Training	Education and training may be provided via the established methodology utilized by individual hospitals (e.g., online, classroom, combination).
ED, Inpatient	Education and Training	Training materials should be made available in multiple locations and multiple departments, so that they are easily available and accessible to all staff.



ED, Inpatient	Education and	Include caregiver training in care planning and discharge planning.
	Training	
ED, Inpatient	Education and	Hospital surveyors should receive training specific to the recognition, screening,
-	Training	management, and treatment of dementia and/or delirium.
ED, Inpatient	Advance Care	Increase physician involvement in advance care planning discussions to promote
-	Planning	identification of goals of care, wishes, and preferences as early as possible and to
		guide treatment plans.
ED, Inpatient	Advance Care	Make resources, such as The Conversation Project's Starter Kit for Families and
_	Planning	Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia,
	-	Massachusetts Medical Orders for Life Sustaining Treatment (MOLST), and
		Honoring Choices Massachusetts, available to staff and caregivers to facilitate
		advance care planning decisions.
ED, Inpatient	Quality Measures	Ensure a process is in place to identify patients with dementia and/or delirium.
ED, Inpatient	Quality Measures	Ensure a discharge plan is in place that addresses care coordination and caregiver
_		needs.
ED, Inpatient	Quality Measures	Implement a method of identifying new prescriptions written for contraindicated
		medications from the Beer's List in patients older than age 75 who were seen in the
		hospital or ED.
ED, Inpatient	Quality Measures	Have a reporting structure in place to ensure that evidence of a "goals of care"
_	-	discussion is included in the medical record for any elderly patient (>75 years of age)
		who may be at risk of developing Alzheimer's or related dementia.

8.2. Dissemination of Recommendations

In addition to being presented to the General Court, the committee recommends that this report be disseminated to key stakeholders statewide as well as to relevant national organizations. Organizations that may receive a presentation or webinar on the report include but are not limited to:

- Health care organizations;
- Professional organizations;
- Community organizations that provide care and/or support to persons with dementia and their caregivers; and
- Advocacy organizations.





This report will also be made accessible online, through the Department of Public Health, Executive Office of Elder Affairs, Massachusetts Health & Hospital Association, and Alzheimer's Association websites.

The recommendations presented in this report should inform development of best practices for hospitals in their care planning for persons with dementia. The recommendations could also be incorporated into continuing medical education programs, such as ones offered by the Alzheimer's Association and the Massachusetts Medical Society.

Improving acute care for persons with dementia and their caregivers presents an opportunity for all of us to continue to move Massachusetts forward toward becoming a dementia-inclusive Commonwealth. In addition, it has the potential to reduce hospital costs, improve patient and caregiver satisfaction, and promote an age-friendly health system for all.



9. Appendices

9.1. Dementia and Delirium Screening Tools

Tool Name	Description	Completed by Whom?	Length/Time to Administer	Reliability
AD8: The Washington University Dementia Screening Test (also known as "Eight-item Interview to Differentiate Aging and Dementia") ⁵³	Screening test that is able to identify early stages of multiple types of dementia. Questions ask person taking survey to report whether there has been a change "in the last several years caused by cognitive (thinking and memory) problems."	Patient or informant	Eight questions; Three minutes to administer	Sensitivity > 84%; Specificity > 80%; Reliably distinguishes individuals with dementia from individuals without dementia; Sensitive to early cognitive changes; Distinguishes between cognitively impaired persons and persons without dementia: Positive predictive value > 85%, negative predictive value > 70%
Confusion Assessment Method (CAM and CAM- ICU) ⁵⁴	Identifies whether or not delirium is present; does not identify severity of delirium. Should not be used to see if there has been a change in delirium status. CAM-ICU: for mechanically ventilated patients. Test includes four features: acute onset or fluctuating course; inattention; disorganized thinking; altered level of consciousness.	Clinician. No psychiatric training required, but clinician should be trained to give and score the screening tool.	Designed to quickly evaluate delirium status	CAM and CAM-ICU: Sensitivity: 94-100%, Specificity: 89-95%.
Informant	Long form has 26 questions,	Informant	16 questions	Short form has a correlation

Table 2: Dementia/Delirium Screening Tools: An Overview

⁵³ Galvin JE, Zweig Y, Greenberg SA. The AD8: The Washington University Dementia Screening Test ("Eight-item Interview to Differentiate Aging and Dementia"). ConsultGeri. https://consultgeri.org/try-this/dementia/issue-d14.pdf. Published 2013. Accessed February 26, 2017.

⁵⁴ Waszynski CM and Greenberg SA. The Confusion Assessment Method (CAM). ConsultGeri. https://consultgeri.org/try-this/general-assessment/issue-13.pdf. Published 2003. Updated 2012. Accessed June 11, 2017.



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Questionnaire on Cognitive Decline in the Elderly – Short Form (IQCODE-SF) ⁵⁵	and short form has 16 questions. Questionnaire assesses for cognitive decline.			of .98 with longer one. From review of the tool: "[Questionnaire] validly reflects past cognitive decline, performs at least as well at screening as conventional cognitive screening tests, predicts incident dementia, and correlates with a wide range of cognitive tests. The disadvantage of the IQCODE is that it is affected by informant characteristics such as depression and anxiety in the informant and the quality of the relationship between the informant and the subject." Could be used together with other brief cognitive tests for dementia.
Mini-Cog ³⁶	Tool designed to distinguish patients with dementia from those without (not valid for mild cognitive impairment). It identifies patients who should receive additional evaluation. Patients asked to memorize three words and draw a clock. Effective in use with older adults with different linguistic, cultural, and literacy backgrounds.	Patient	3 minutes; can be used in all health care settings	Sensitivity: 76-99%; Specificity: 89-93% (95% confidence interval)
Mini-Mental State Examination (MMSE) ⁵⁷	Covers the following: orientation, memory, attention, ability to name, ability to follow written and	Clinician	11 questions; 5-10 minutes	Found to be valid and reliable

⁵⁵ Jorm AF. The informant questionnaire on cognitive decline in the elderly (IQCODE): A review. *International Psychogeriatrics*. 2004;16(3):275-293. doi:10.1017/S1041610204000390.
 ⁵⁶ Carolan Doerflinger DM. Mental Status Assessment of Older Adults: The Mini-Cog. ConsultGeri. https://consultgeri.org/try-this/general-assessment/issue-3.1. Accessed February 26, 2017.

⁵⁷ Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975;12(3):189–



	spoken commands, ability to			
	write a sentence, ability to			
	copy a complex polygon			
Montreal	Screening for mild cognitive	Clinician	10 minutes;	Sensitivity: 90-96%;
Cognitive	impairment and early		used in wide	Specificity: 87% (95%
Assessment	Alzheimer's disease. Screens		range of	confidence interval);
$(MoCA)^{58}$	the following areas: attention		clinical	Detected 100% of
	and concentration; executive		settings	Alzheimer's disease at 87%
	function; memory; language		_	specificity
	visuoconstructional skills			
	conceptual thinking;			
	calculations; orientation			

198. doi:10.1016/0022-3956(75)90026-6.

⁵⁸ Carolan Doerflinger DM, Greenberg SA, Boltz M. Mental Status Assessment in Older Adults: Montreal Cognitive Assessment: MoCA Version 7.1 (Original Version). ConsultGeri. https://consultgeri.org/try-this/general-assessment/issue-3.2.pdf. Updated 2012. Accessed February 26, 2017.



9.2. Environmental Scan of Existing Programs, Tools and Resources

What is this?	Program/Docu ment Title	Description	Research Results	Where Implemented	More Information
Existing Programs in Hospitals: Comprehensive Program, including Tools, Trainings, policies for system redesign for geriatric patients. Nursing focus but interprofessional	NICHE (Nurses Improving Care for Healthsystem Elders) program + "Try This" Series	Offers training, resources, project management, clinical protocols, with the goal of improving healthcare for older adults in healthcare settings. "Try This" series: series of training modules on best practices in nursing care for older adults. Has a series specific to older adults with dementia	Reports of effectiveness published online, including a report specifically on dementia. Discusses four NICHE sites that have implemented quality improvement projects related dementia. One site (Saint Mary's Health Care) saw a decrease in length of stay by .74 days, greater confidence providing care for patients with behavioral disturbances among nurses (Intervention: development of a nurse driven dementia pathway addressing causes of behavioral disturbances that lead to behavior changes.)	More than 700 NICHE sites around the world. More than a dozen in Massachusetts.	http://www.nicheprogram.org NICHE Hospitals Report. Best Practice Conducted in NICHE Hospitals: Dementia. NICHE. https://s3.amazonaws.com/2015 niche/NICHE+Hospitals+Repor t+Dementia.pdf. Accessed June 12, 2017.
Existing Programs in Hospitals: Comprehensive	Tailored Activity Program for Hospitals (TAP- H)	11 sessions in 3 phases during hospitalization. Phases: Assessment and activity planning; activity	Evaluation Results: "Responses suggest a predominantly high engagement level with	Not in wide use yet. TAP program has been	Gitlin LN, Marx KA, Alonzi D, Kvedar T, Moody J, Trahan M, Van Haitsma K. Feasibility of the Tailored Activity Program



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	program focused on behavioral interventions during hospitalization for individuals with dementia. Person-centered, interprofessional with OT focus. Includes program design, trainings, system redesign for dementia	(2016)	implementation and staff training; generalization. Program is unique in focus on assessing what a patient can do and using patient interests to determine appropriate activities.	positive behavioral outcomes." "Providing patients with activities matching interests and capabilities compared to standard activity resulted in greater pleasure and less anger and anxiety." Tailoring increased positive and reduced negative behaviors. Limitations: small sample size, wide variation of behaviors. Staff ended up endorsing program "As TAP-H effectively engages patients, does no harm, yields positive behavioral and affective responses, and can be integrated within hospital payment mechanisms, we believe there is sufficient	implemented in the U.S. and abroad, including in hospitals	for Hospitalized (TAP-H) Patients With Behavioral Symptoms. <i>Gerontologist</i> . 2016;00(00):1-10. Doi: 10.1093/geront/gnw052.
				responses, and can be integrated within hospital		
-	Existing Programs in	University of California, San	Has published a set of guidelines on the UCSF	N/A	University of California San	http://memory.ucsf.edu/caregivi ng/hospitalization



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Hospitals: Comprehensive program with trainings, guidelines, resources. Uses trained volunteers. Family education tools.	Francisco Partner With Me (PWM) Project	Memory and Aging center website with tips and resources for hospitalization of a patient with dementia (e.g. pre- hospitalization checklist for patients with memory impairment, guide to hospital visits for patients with memory loss). Project consists of a DVD and education packet for caregivers as well as a questionnaire and patient- specific care plan for the hospital stay. PWM program makes use of trained volunteers who collect information about patient's routines to develop a care plan.		Francisco Medical Center	
Existing Programs in Hospitals: Comprehensive Program for delirium prevention	Hospital Elder Life Program (HELP)	Designed to help prevent delirium among hospitalized older adults. Services delivered by program staff and/or volunteers and include daily visitation, therapeutic activities, daily exercise, relaxation and sleep promotion, hearing and vision adaptations, assistance and company during meals, geriatric interdisciplinary care,	Various studies have found that the program prevents delirium, improves quality, prevents functional and cognitive decline, decreases hospital length of stay, reduces nursing home placement, decreases rate of hospital falls, and decreases sitter use.	>200 HELP sites globally	http://www.hospitalelderlifepro gram.org



		provider education, assistance with transition out of hospital.			
Existing Programs in Hospitals: Comprehensive Program	Acute Care for the Elderly (ACE) Unit	Acute care unit designed with needs of elderly in mind. Generally lower nurse-to- patient ratios, focus on physical environment and nursing. Goals include maintaining patient's function level prior to admission, and reducing, for example, falls, delirium, functional decline, use of restraints. Enhanced staff training in geriatrics and dementia.	2012 study found that ACE units are cost-effective: shorter length of stay resulting in about \$1,000 saved per patient (Barnes et al.). 2012 systematic review and meta-analysis found that ACE unit was associated with fewer falls, less delirium, less functional decline from two weeks prior to admission, shorter length of hospital stay, fewer discharges to a nursing home, lower costs, more discharges to home. No differences in functional decline between baseline hospital admission status and discharge, mortality, or hospital readmissions (Fox et al.).	About 200 units around the country	 Barnes DE, Palmer RM, Kresevic DM, Fortinsky RH, Kowal J, Chren M, Landefeld CS. Acute Care for Elders Units Produced Shorter Hospital Stays at Lower Cost While Maintaining Patients' Functional Status. <i>Health</i> <i>Affairs</i>. 2012;31(6):1227-1236. Doi: 10.1377/hlthaff.2012.0142 Fox MT, Persaud M, Maimets I, O'Brien K, Brooks D, Tregunno D, Schraa E. Effectiveness of acute geriatric unit care using acute care for elders components: a systematic review and meta- analysis. <i>Journal of the</i> <i>American Geriatric Society</i>. 2012;60(12):2237-2245. Doi: 10.1111/jgs.12028. Gorman A. Hospital Units Tailored To Older Patients Can Help Prevent Decline. NPR. http://www.npr.org/sections/he alth-



Fristing	The Asias Davis			Eskenazi	shots/2016/08/09/486608559/h ospital-units-tailored-to-older- patients-can-help-prevent- decline. Published August 9, 2016. Accessed June 12, 2017.
Existing Programs in Hospitals: Comprehensive program including trainings, care management, including care transitions and in outpatient setting.	The Aging Brain Care Model, Indiana (2016)	Implementation project in Indiana made possible by Center for Medicare and Medicaid Innovation. Care management for elderly dementia and depression patients at Eskenazi Health in Indianapolis and Indiana University Health - Arnett. Hospitalization-specific: If individual is hospitalized, Care coordinator provides relevant information (e.g. symptoms, medications) to hospital. After discharge, care coordinator visits home within 3 days to "reconcile medications and [coordinate] any postdischarge care plan" (LaMantia et al.)	Evaluation recently published. Key findings: "Indiana's program achieves effective disease management for patients with dementia and depression using a workforce consisting primarily of LHWs [lay health workers]." "small but significant decrease in ED visits for program participants relative to matched comparison patients" "leadership is working towards licensure and broader distribution of program materials" (Second Annual Report: HCIA Disease-Specific Evaluation)	Health, Indianapolis; Indiana University Health - Arnett	 Cananan CM, Sachs GA, Lamantia MA, Unroe KT, Arling G, Boustani MA. Redesigning systems of care for older adults with Alzheimer's disease. <i>Health Affairs</i>. 2014;33(4):626-632. Doi: 10.1377/hlthaff.2013.1260. NORC at the University of Chicago. Second Annual Report: HCIA Disease-Specific Evaluation. Centers for Medicare & Medicaid Services. https://downloads.cms.gov/files /cmmi/hcia-diseasespecific- secondevalrpt.pdf. Updated March 2016. Accessed June 11, 2017. LaMantia MA, Alder CA, Callahan CM, Gao S, French DD, Austrom MG, Boustany K, Livin L, Bynagari B, Boustani
					MA. The Aging Brain Care Medical Home: Preliminary



					Data. Journal of the American Geriatrics Society. 2015;63(6):1209-1213. Doi:10.1111/jgs.13447.
Discontinued programs mentioned in Katie Maslow's presentation: trainings, policies, systems changes	Multiple programs	Cabrini Hospital, New York City, NY: separate hospital unit for patients with dementia; extensive staff training and mentoring; apparently positive results; unit closed when hospital plans changed Providence Milwaukie Hospital, Portland, OR: NICHE hospital; detection of cognitive impairment/dementia; extensive staff training; involvement of families; New Standard of Care dementia guidelines; activity kits for patients; program reduced as a result of high-level administrative commitment and hospital-wide staffing issues Mission Hospitals, Asheville, NC: full-time coordinator for "dementia-responsive care" hired in 2002; dementia consultation for staff; information and support for families; initial coordinator left in 2015, program ended along with all other geriatric programs	Evaluation of Providence Milwaukie Hospital program as of 2002, 2003: "These evaluation findings present a mixed picture. On the positive side, there was increased recognition of dementia and depression and increased use of dementia-related interventions Yet, there was little evidence that the tools for further assessment and care planning (the MMSE, GDS, and SOC) were being usedOctober 2003 audit demonstrates a significant increase in use of the MMSE. However, the data also demonstrate lack of attention to the established criteria for patient selection and minimal use of the SOC for patients identified with dementia." North Memorial Hospital Together We Improve Care	See description	Silverstein NM, Maslow K. Improving Hospital Care for Persons with Dementia. New York, NY: Springer Publishing Company, Inc.; 2006.



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			North Memorial Hospital, Robbinsdale, MN: detection of cognitive impairment/dementia; nursing protocols for dementia care; dementia consultation for staff; information and support for families; unclear status of program, staff lead has left	of Elders (TWICE) program found effective in reducing delirium/delirium risk factors in early 2000s. Hospital was in beginning stages of implementing an organizational approach; no outcomes at time of publication of <i>Improving</i> <i>Hospital Care for Persons</i> <i>with Dementia</i> .		
	Emergency Room: Program	Milford Regional Medical Center, Milford, MA (2015)	Operational since October 2015 renovation of Emergency Department. L-shaped section of the ED with 8-10 beds that can all be monitored by a staff member. Used by individuals with behavioral health needs (e.g. substance abuse, dementia, mental health disorders) once patients are cleared to be there by a physician	N/A	Milford Regional Hospital, Milford, MA	
	Emergency Room: National Guidelines	Geriatric Emergency Department Guidelines (2013)	Goal: provide a standardized set of realistic guidelines to improve care of older adults in the ED. Guidelines specifically related to delirium and dementia: Comprehensively evaluate geriatric adults presenting with delirium,	Recommendations include: Any geriatric patient admitted should be assessed for delirium risk factors. Patients presenting with agitated delirium should be managed safely. A therapeutic environment		American College of Emergency Physicians, The American Geriatrics Society, Emergency Nurses Association, Society for Academic Emergency Medicine. Geriatric Emergency Department Guidelines.



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		encephalopathy, or an altered mental status with goal of coordinating care and directing interventions towards undoing delirium. Limit use of chemical and physical restraints.	should be provided whenever possible. Performance improvement measures: "physical restraint utilization hours/days; use of benzodiazepines in geriatric patients with agitated delirium; utilization rates of orientation techniques"		https://www.acep.org/geriEDgu idelines/. Last updated 2013. Accessed June 13, 2017.
Recommendatio s/Tools for Dementia Screening: Recommendatio s on screening guidelines	Cognitive Impairment in Older Adults: An	Systematic review that addresses the following questions: "1) Does screening for cognitive impairment in community-dwelling older adults improve decision making, patient, family/caregiver, or societal outcomes?; 2) What is the test performance of screening instruments to detect dementia or mild cognitive impairment (MCI) in community-dwelling older adult primary care patients?; 3) What are the harms of screening for cognitive impairment?; 4) Do interventions for early dementia or MCI in older adults improve decision making, patient, family/caregiver or societal	"Currently, there is no trial evidence that addresses whether screening for cognitive impairment or early diagnosis of cognitive impairment improves patient, caregiver/family, or clinician decision making or improves important patient, caregiver, or societal outcomes." Harms of screening for cognitive impairment are not well studied. "AChEIs, memantine, complex caregiver interventions, and cognitive stimulation all have evidence to support their use	N/A	Lin JS, O'Conor E, Rossom R, Perdue LA, Burda BU, Thompson M, Eckstrom E. Screening for Cognitive Impairment in Older Adults: An Evidence Update for the U.S. Preventive Services Task Force. Evidence Report No. 107. AHRQ Publication No. 14-05198-EF-1. Rockville, MD: Agency for Healthcare Research and Quality; 2013.



outcomes?; and 5) What are the	in mild to moderate	
harms of interventions for	dementia. However, the	
cognitive impairment?"	average effects of benefits	
	observed in trials for these	
	medications and caregiver	
	interventions are generally	
	small and in people with	
	moderate (as opposed to	
	mild) dementia." Plus, side	
	effects of AChEIs are	
	common, and complex	
	caregiver interventions have	
	limited availability.	
	Limited and imprecise	
	evidence (although	
	promising) for benefits of	
	cognitive stimulation in	
	people with MCI and mild	
	dementia.	
	Screening for MCI:	
	Inconsistent definition of	
	MCI, instruments have	
	lower sensitivity than those	
	for dementia.	
	Little evidence for any	
	pharmacologic or	
	nonpharmacological	
	interventions for MCI.	



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Measure Sets on Dementia: Resource, Quality Measures	Dementia Performance Measurement Set (2011)	Developed by work group composed of members of the American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, and Physician Consortium for Performance Improvement. Goal: "identify and define quality measures focused on improving outcomes for patients with dementia."	Categories of recommended process measures: Measures addressing underuse of effective services (evaluation and treatment strategies); measures addressing safety; measures addressing underuse of patient-centered care strategies.	N/A	American Academy of Neurology, American Geriatrics Society, American Medial Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement. Dementia Performance Measurement Set. American Medical Association; 2011.
Measure Sets on Dementia: Resource, Quality Measures	Evaluation Measures Resources, RTI International (2016)	Goal: "help providers of dementia-related services identify appropriate and well- researched measures in support of their program evaluation plans."	Measures for providers: Dementia Attitudes Scale (no special permissions required), Alzheimer's Disease Knowledge Scale (permission required), Knowledge about Memory Loss and Care Test (permission required)	N/A	Hughes S, Gould E, Wiener J, Maslow K; RTI International. Evaluation Measures Resources. RTI Project Number 0212050.035.002.001.001; 2016.
Existing Training	Alzheimer's Association, St. Louis Chapter: Dementia Friendly Hospital	Training program for hospital staff members, designed to help ensure the needs of hospitalized persons with dementia are met. Five modules: Introduction, Medical Overview, Approaches	Effectiveness has been evaluated in a study with 540 participants at 4 community hospitals. Evaluation consisted of a pre-test, post-test, and 120-		Hospital Initiative. Alzheimer's Association. http://www.alz.org/stl/in_my_c ommunity_62183.asp. Accessed June 13, 2017.



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	Initiative (~2010)	to Communication and Behavior, Dementia Friendly Care, Connecting the Caregiver	day delayed post-test. Assessments evaluated knowledge, confidence, and practice parameters. Program well received. Program demonstrates "the feasibility of training hospital staff about dementia and its impact on patient outcomes. At baseline, there was low knowledge and confidence in the ability to care for dementia patients. Training had an immediate impact on knowledge, confidence and attitudes with lasting impact in 3 of 4 hospitals."	Galvin JE, Kuntemeier B, Al- Hammadi N, Germino J, Murphy-White M, McGillick J. "DEMENTIA-FRIENDLY HOSPITALS: CARE NOT CRISIS" AN EDCUATIONAL PROGRAM DESIGNED TO IMPROVE THE CARE OF THE HOSPITALIZED PATIENT WITH DEMENTIA. <i>Alzheimer disease and</i> <i>associated disorders</i> . 2010;24(4):372-379. doi:10.1097/WAD.0b013e3181 e9f829.
Existing Resource	Dementia Friendly Hospitals, Dementia Friendly America (2016)	Guidelines for communicating with persons with dementia, promoting person-centered care and care continuity, and creating a dementia-friendly physical environment.	N/A	Dementia Friendly Hospitals. Dementia Friendly America. https://static1.squarespace.com/ static/559c4229e4b0482682e8d f9b/t/57c892a79de4bb44f29931 ba/1472762535831/DFA- SectorGuide-Hospital.pdf. Updated August 24, 2016. Accessed June 13, 2017.
International Resources	Dementia Care in the Acute	Identifies the following strategies to improve dementia	N/A	Alzheimer's Australia. Dementia Care in the Acute



Hospital Setting:	care in hospitals: identify and		Hospital Setting: Issues and
Issues and	manage dementia (e.g. through		Strategies. Alzheimer's
Strategies,	pre-admission form asking		Australia, Inc.
Alzheimer's	about cognitive impairment,		https://www.fightdementia.org.
Australia (2014)	required screenings); involve		au/files/Alzheimers_Australia_
	caregivers; communicate		Numbered_Publication_40.PDF
	effectively; provide alternative		. Published June 2014.
	care to antipsychotic drugs;		Accessed June 13, 2017.
	create an appropriate physical		
	environment (keep patients		
	oriented, relaxed); reduce		
	avoidable hospitalization.		
	-		
	The report also identifies		
	existing programs in Australia		
	that address some of these		
	strategies.		
	_		



9.3. Resource List

Background Literature:

2016-09-15-Demetia-Care. CMS.gov Centers for Medicare & Medicaid Services. https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events-Items/2016-09-15-Demetia-

Care.html?DLPage=1&DLEntries=10&DLSort=0&DLSortDir=descending. Published September 27, 2016. Accessed April 18, 2017.

ACEP. Geriatric Emergency Department Guidelines // ACEP. https://www.acep.org/geriedguidelines/. Accessed April 18, 2017.

Acute Hospitalization & Alzheimer's Disease: A Special Kind of Care.

Adult-Gerontology Acute Care and Primary Care NP Competencies. American Association of Colleges of Nursing. http://c.ymcdn.com/sites/www.nonpf.org/resource/resmgr/files/NP_competencies_2.pdf. Published 2016. Accessed April 18, 2017.

Agar M. et al., Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative Care: A Randomized Clinical Trial. *Journal of American Medical Association - Internal Medicine*. 2017.

Age-Friendly Health Systems: How Do We Get There? *Health Affairs*. http://healthaffairs.org/blog/2016/11/03/age-friendly-health-systems-how-do-we-get-there/. Accessed April 18, 2017.

Amella E, Lawrence J. Eating and Feeding Issues in Older Adults with Dementia: Part 1: Assessment. *The Hartford Institute for Geriatric Nursing*, New York University, College of Nursing. 2007.

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