



# MASSACHUSETTS ALZHEIMER'S DISEASE AND RELATED DISORDERS STATE PLAN RECOMMENDATIONS TWO-YEAR PROGRESS REPORT

OCTOBER 2014

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In February 2012, Massachusetts released a set of Alzheimer's Disease and Related Disorders State Plan Recommendations. The recommendations were commissioned by Governor Deval Patrick and prepared by a work group consisting of leaders from the Massachusetts Executive Office of Elder Affairs (EOEA), the Alzheimer's Association, Massachusetts/New Hampshire Chapter, individuals with dementia, family and professional caregivers, and a wide array of state and municipal agencies concerned with promoting public health and safety.

EOEA and the Alzheimer's Association have organized implementation of the plan around its five major recommendations:

1. Improve **access to services** and information for people with Alzheimer's;
2. Improve and expand support and education for **family caregivers**;
3. Develop an infrastructure for enhanced **quality of services** within the medical community;
4. Improve public awareness surrounding risk factors and **risk reduction** for Alzheimer's disease; and
5. Create a set of statewide recommendations for guidelines and minimum standards surrounding **quality of care** in all care settings.

Implementation of the plan is being overseen by EOEA's Assistant Secretary for Programs and Operations and the Alzheimer's Association's Vice President of Programs and Services. The following is a summary of the activity Massachusetts has taken to implement these recommendations.

## RECOMMENDATION 1:

### Improve access to services and information for people with Alzheimer's

**GOAL:** *Reduce barriers that prevent access to existing medical and social services for all affected by Alzheimer's, and encourage access to non-traditional services (e.g. art/music therapy).*

A primary barrier to access is lack of diagnosis. Massachusetts has addressed this barrier by administering an annual dementia screening to all EOEA Home Care Program consumers. Consumers whose screening indicates possible dementia are encouraged to follow up with their primary care provider for further screening and diagnosis, and are referred to supportive services from the Alzheimer's Association and other community organizations. The consumer's primary care provider is also sent a letter alerting them of the consumer's performance on the dementia screening and encouraging them to reach out to the consumer. An analysis of consumer data indicates that consumers receive an increase in Home Care Program services following a low score on the dementia screening.

Since January 2014, the Massachusetts Home and Community Based Services Medicaid Waiver has been covering Occupational Therapy and Habilitation Therapy, two services identified by EOEA as particularly useful to people with Alzheimer's disease and their family caregivers. EOEA distributed an Informational Memorandum in December 2012 to all Aging Service Access Point executive directors detailing the benefits of Occupational Therapy which, prior to coverage under the Waiver, had been underwritten for consumers with Alzheimer's through federal grant funding.

**GOAL:** *Increase availability of information to consumers with Alzheimer's, family caregivers and professional staff about available supportive dementia care services and long term care programs.*

Since 2011, EOEA, in partnership with the Alzheimer's Association, Massachusetts/New Hampshire Chapter, has provided fifteen trainings in Habilitation Therapy to over 350 professional caregivers representing all twenty-seven Aging Service Access Points and over 100 home care provider agencies. The trainings include a detailed discussion of strategies for providing effective treatment to consumers with Alzheimer's disease and related disorders, as well as an overview of available services and interventions that can help families live with the disease.

Since 2012, The Alzheimer's Association has increased the amount of training and education with professionals in the community to include training for attorneys, occupational therapists, physical therapists, medical professionals, nursing facility staff and nursing facility surveyors.



**GOAL:** *Increase availability of information to consumers with Alzheimer's, family caregivers and professional staff about available supportive dementia care services and long term care programs.*

On September 13, 2013, the Commonwealth of Massachusetts became the first state government to join the Alzheimer's Workplace Alliance, a national coalition of businesses and agencies with a commitment to promote Alzheimer's awareness in their communities and among their employees. The Commonwealth will now connect its employees with information on the early signs of Alzheimer's and with services, which will help people with dementia and their caregivers manage the disease. The Alzheimer's Association is currently coordinating with the Director of Human Resources for the Commonwealth and has completed two trainings reaching 30 senior human resource managers and 95 additional human resource staff.

**GOAL:** *Assess and address availability of transportation to services for individuals who are unable to drive*

Not yet achieved.

## **RECOMMENDATION 2: Improve and expand support and education for Family Caregivers**

**GOAL:** *Enhance respite care opportunities for families coping with Alzheimer's disease and related dementias.*

EOEA's Family Caregiver Program Director is a member of the Massachusetts Lifespan Respite Coalition, a statewide, volunteer collaboration representing family and professional caregivers of consumers of all ages with a broad range of disabilities. The Coalition seeks to promote respite through recruitment and training of volunteers as well as promotion of public and private reimbursement for respite care. The Family Caregiver Director is currently exploring private funding options to develop a corps of volunteers to provide in-home respite for caregivers of people with Alzheimer's disease.

**GOAL:** *Expand methods of education and support for caregivers and persons with memory impairment.*

EOEA and the Alzheimer's Association have distributed over 6,000 Alzheimer's Caregiver Guides and 1,800 Late-Stage Alzheimer's Caregiver Guides to the twenty-seven regional Family Caregiver Program Directors. The guides are also available online, along with a guide for Early Stage Alzheimer's Caregivers. A link to the guides is prominently displayed on EOEA's consumer information page.

EOEA and the Alzheimer's Association have also partnered with Massachusetts' Councils on Aging to increase the availability of Alzheimer's support groups throughout the state by promoting training for support group leaders. A set of well-attended trainings took place at two Councils on Aging in 2013, leading to the launching of eleven new support groups.

### **RECOMMENDATION 3:**

## **Develop an infrastructure for enhanced quality of services within the medical community**

**GOAL:** *Enhance quality of life for people with Alzheimer's by coordinating care at the primary care level.*

The Alzheimer's Association has created a database of over 3,000 physicians and other professionals who work with families coping with Alzheimer's and related dementias. These individuals receive information for their practices and patients on services, programs and other topics germane to Alzheimer's.

EOEA and the Alzheimer's Association have begun work on a pilot to improve communication among consumers, physicians' offices, and home care staff. As part of this pilot, EOEA and the Alzheimer's Association have revised the notification letter that is sent, with the consumer's consent, to her/his physician following a low score on the dementia screening tool now being administered by the Aging Service Access Points.

The Alzheimer's Association has also expanded their Dementia Care Coordination program to cover more than 50 referring physicians and partnered with Tufts Health Plan to expand care coordination for their subscribers with Alzheimer's disease.

**GOAL:** *Utilize the federal mandate for an Annual Wellness Visit for Medicare recipients to improve diagnosis and quality of care for people with Alzheimer's.*

The Alzheimer's Association published recommendations for utilizing the Annual Wellness Visit in the January 2013 issue of the journal *Alzheimer's and Dementia*. The local chapter's Medical and Scientific Committee has been promoting these recommendations for the past year, and is now developing strategies to further disseminate the information to primary care providers.

**GOAL:** *Implement a continuing education track for physicians and other clinicians in all appropriate provider settings about Alzheimer's and safety issues.*

The Alzheimer's Association is in the beginning stage of developing a CME-eligible curriculum for physicians on dementia, risk management and driving.

**RECOMMENDATION 4:**  
**Improve public awareness surrounding risk factors and risk reduction for Alzheimer's disease**

**GOAL:** *Complete a full statewide rollout of Silver Alert.*

EOEA has convened a Silver Alert Work Group, which includes representatives of the Alzheimer's Association, the Massachusetts State Police Fusion Center and the Massachusetts Association of Chiefs of Police. The purpose of the work group is to improve the capacity of Massachusetts' Silver Alert program to effectively identify individuals with dementia who have become lost and return them safely to their homes. A pilot partnership between select municipal police departments, councils on aging and aging service access points is being launched in order to develop strategies to improve the ability of police officers to search for and approach individuals who have wandered and, once returned home, connect them with services that can reduce risk of future wandering.

**GOAL:** *Develop a public awareness campaign to promote a healthy lifestyle in relation to risk reduction for Alzheimer's.*

Not yet implemented.

**GOAL:** *Reduce risk and level of harm created by economic abuse of people with Alzheimer's disease.*

EOEA has developed a web-based training for financial planners on fraud and financial abuse of consumers with dementia. Two trainings were presented in November 2013 and February 2014, attended by over 150 financial planners. An in person training, facilitated by EOEA and Alzheimer's Association staff and reaching 25 financial planners, took place in June 2014.

**GOAL:** *Develop an initiative to improve home safety issues for families affected by Alzheimer's disease.*

EOEA has worked with University of Southern New Hampshire faculty and the Alzheimer's Association to develop a training curriculum and set of recommendations for home care staff for improved safety assessment for homes with a family member who has dementia. The first training was held in October 2014, and was attended by 30 nurse managers, program managers, case management supervisors, quality supervisors and family caregiver specialists.

**RECOMMENDATION 5:**

**Create a set of statewide recommendations, guidelines and minimum standards surrounding quality of care in all care settings**

***GOAL:** Develop and establish required curricula with minimum of hours of training on dementia for all staff in all relevant care settings.*

The 2012 Act Providing for Dementia-Specific Training for Certain Employees of Long-Term Care Facilities (MGL Ch. 111, S. 71c) authorizes the Massachusetts Department of Public Health (DPH), in consultation with the Alzheimer's Association, Massachusetts/New Hampshire Chapter and representatives from the nursing home provider community, to develop regulations to establish minimum standards for dementia special care units to ensure safety and quality of services including dementia-specific training for all direct care workers, activities directors and supervisors of direct care workers in both traditional nursing homes and dementia special care units. DPH regulations were finalized in February 2014 that require 8 hours of initial training for workers in Alzheimer's-specialized units, and 4 hours of training each year thereafter.

***GOAL:** Improve opportunities for purposeful living throughout the day and evening to all persons, in all care settings in the state.*

MGL Ch. 111, S. 71c authorizes DPH, in consultation with the Alzheimer's Association, Massachusetts/New Hampshire Chapter and representatives from the nursing home provider community, to develop minimum standards for quality of activities programs in dementia special care units that provide dementia-specific activities. DPH now requires that all Alzheimer's units have at least one therapeutic activities director dedicated to the dementia unit to ensure meaningful and appropriate activities for residents.

***GOAL:** Develop a set of best practices for all care settings regarding environmental design for people with dementia.*

MGL Ch. 111, S. 71c authorizes DPH, in consultation with the Alzheimer's Disease and Related Disorders Association, Massachusetts/New Hampshire Chapter and representatives from the nursing home provider community, to develop guidelines for dementia special care unit physical design including, but not limited, to anti-wandering methods and promoting a therapeutic environment.

## **FUTURE PLANS**

EOEA, in partnership with the Alzheimer's Association, Massachusetts Chapter, is currently planning the following activity to address the state plan recommendations:

### **ACCESS TO SERVICES**

The Alzheimer's Association is now developing a campaign to increase awareness about Early Stage Alzheimer's Disease, including Younger Onset Alzheimer's, defined as that affecting adults aged 59 and under. The campaign will include paid and earned public service announcements that seek to increase awareness, reduce stigma and inspire people to access appropriate diagnosis, support and care. The campaign will allow Massachusetts to create a more positive message about Alzheimer's, emphasizing the importance of securing help early and becoming part of the solution. The campaign will be augmented with a program that focuses on providing individuals with Early Stage Alzheimer's disease an opportunity for community engagement, education, and support.

The Alzheimer's Association is also expanding the number of phone based support groups for family members in rural areas or whose caregiving duties prevent them from joining in-person support groups.

### **FAMILY CAREGIVERS**

EOEA and Alzheimer's Association staff are now reviewing free and low-cost on-line trainings as a potential tool to help homebound caregivers manage their responsibilities. Based on the review, EOEA will compile a guide to these trainings and distribute it throughout the health and aging service network.

### **QUALITY OF MEDICAL SERVICES**

The Alzheimer's Association Medical and Scientific Committee, a volunteer advisory board consisting of some of Massachusetts's most renowned physicians and researchers, has advised on the content for an on-line landing page for physicians, which will include vital information about services available to and being utilized by consumers. The Alzheimer's Association is in the process of developing the page, and pairing it with an app for physicians which will assist with the diagnosis and management of patients with Alzheimer's

### **RISK REDUCTION**

EOEA will work with state and local police to expand the Silver Alert enrollment project beyond the current twelve police departments piloting the program.

The Alzheimer's Association is currently collaborating with the Massachusetts Department of Public Safety and Security 911 Division to develop a training for police dispatchers surrounding





dementia and Silver Alert. Once this training is being implemented, EOEA will examine effective ways to reach and train patrol officers.

### ***QUALITY OF CARE***

EOEA and the Alzheimer's Association are in discussion to develop a series of trainings for professionals who have regular direct contact with people with Alzheimer's disease, but do not provide direct care. These include van drivers, home delivered meal staff, and administrative and custodial staff at aging service providers. The training will include an overview of the disease and general communication strategies to foster positive interaction with people with dementia.

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This progress has been the result of close collaboration between public, private and non-profit organizations across the aging, public health and public safety service and advocacy networks. To complete this work, continued partnership between state and private entities will be critical. The Alzheimer's Association hopes to continue to work with EOEA and other state agencies to develop strategies to address unmet goal recommendations, and welcomes input from state leadership in how best to fulfill those goals and identify resources to do so.