

Advisory Council on Alzheimer's Disease and All Other Dementias



**Executive Office of Elder Affairs
Elizabeth Chen, Secretary**

**November 1, 2022
3:00-5:00 pm
Video Conference**



Agenda



1. Welcome, Logistics, Introductions *(20 min)*
2. Screening and Diagnosis: Presentation & Discussion *(35 min)*
3. Care Planning: Presentation & Discussion *(20 min)*
4. Younger-Onset Dementia and Equity Analysis Workgroup: Presentation, Discussion, Vote *(20 min)*
5. Physical Infrastructure: Presentation & Discussion *(15 min)*
6. Next Steps and Vote to Adjourn *(10 min)*

Alzheimer's Advisory Council Meeting

November 1, 2022



Workstream: Diagnosis & Services Navigation

Diagnosis Implementation Team

Status and Discussion

Workstream Leads

Representative Tricia Farley-Bouvier
James Wessler

Diagnosis Implementation Team Lead

James Wessler



Implementation Team Members



**James Wessler (Diagnosis
Implementation Team Lead)**

Council Member

Chief Executive Officer, Alzheimer's
Association, MA/NH Chapter, and New
England Regional Leader

Kathryn C. Burns, MHA

Chief Executive Officer
Greater Lynn Senior Services, Inc.

Hollis D. Day, MD, MS

Chief of Geriatric Medicine, Boston
Medical Center and Associate
Professor of Medicine, Boston
University School of Medicine

James Lavery

Council Member

Director, Bureau of Health Professions Licensure
Massachusetts Department of Public Health

Liz McCarthy

Health Systems Director
Alzheimer's Association, New England Region

Rebecca Starr, MD, AGSF

Medical Director, Geriatrics
Cooley Dickinson HealthCare

Hagen Yang, MD

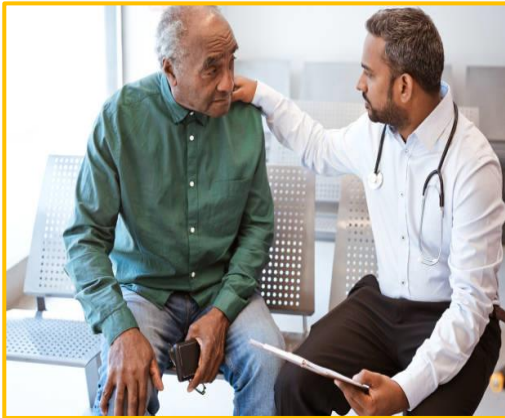
Neurologist
Atrius Health
Braintree - Harvard Vanguard



State Plan Recommendation



Recommendation around diagnosis as described in the Alzheimer's State Plan:



Recommendation

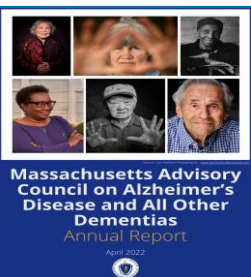
Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis



Council's Annual Report, April 2022



Four Focus Areas Indicated as “Next Steps” in the Council’s Annual Report, April 2021:



1. Develop and pilot a primary care screening workflow

2. Collaborate with MHA to develop a roadmap on how to create and implement a dementia operations plan

3. Develop a guide with BORIM to help physicians initiate diagnosis conversations

4. Examine how ASAPs identify home care clients with undiagnosed dementia; identify opportunities to ensure appropriate screening, care, and support



Challenges, Solutions, Next Steps



1. *Identify primary care practices to pilot a dementia screening workflow; assess effectiveness; develop implementation tool for practices to replicate*

Challenges:

- Unrealistic dependence on PCPs, many demands, time constraints
- Patients have up to a one-year wait at our major hospitals' dementia diagnostic centers for a full diagnostic evaluation (unless part of a clinical study)

Solution:

- Implement innovative approaches to relieve PCP burden around diagnosis and screening workflow; i.e., alternate payment models

Next Steps: Assess approaches to expand capacity statewide.

Approaches:

- Hub & Spoke model (*Disseminate screening/diagnosis beyond larger medical centers*)
 - Ex: [Georgia Memory Net](#)
- Care Ecosystem & Utilizing Community Health Workers
 - Ex: [Care Ecosystem at UCSF](#)
 - Ex: [Initiative at Cooley Dickinson](#)
- Better utilization of [Annual Wellness Visits](#) (Medicare Advantage)



Accomplishments & Next Steps



2. Collaborate with MHA to develop a brief user-friendly roadmap for development and implementation of a dementia operations plan

ACCOMPLISHMENTS

- ✓ Roadmap successfully launched in October 2022
- ✓ Over 300 attended webinar where roadmap was presented and discussed

NEXT STEPS

- Alzheimer's Association will work with MHA to develop a toolkit to potentially:
 - include detailed options for screening and training;
 - share sample plans to help hospitals learn from each other; and
 - educate families/consumers on how to advocate for a loved one.



Challenges, Solutions, Next Steps



3. Develop a guide with BORIM to help physicians initiate diagnosis conversations

CHALLENGES

- Physicians may be unclear about what to say to patients (with borderline scores)
- Lack of clarity regarding next steps, even with a clear screen. Confusion over emerging treatments
- Time constraints at PCP practices may result in rushed conversations and confusion among patients and families

SOLUTION

- Develop clear, concise, time-saving guidance that explains how to attain informed consent; takes the guesswork out of how to initiate diagnosis conversations; engages family care partners; and directs patients to resources and support
- Develop Practice Guidelines as new treatments are approved (Alz Assn)

NEXT STEPS

- Some of our workgroup members are working to draft this guidance for review by EOEa
- BORIM and EOEa have agreed to work together to include guidance as an addendum to BORIM's dementia diagnosis-related guidance released in November 2021



Challenges, Solutions, Next Steps



4. **Examine ASAP processes used to identify home care consumers with undiagnosed dementia. Identify opportunities to enhance education and advocacy for appropriate healthcare, treatment, and care**

CHALLENGES

- Current ASAP processes may reveal untapped opportunities to identify home care consumers living with undiagnosed dementia

SOLUTION

- Identify the untapped opportunities

NEXT STEPS

- Together with EOEA , we will convene a team to identify, examine, and seize opportunities in the home care program to advocate for appropriate screening, diagnosis, care, support and treatment



Diagnosis Discussion (20 min)



Questions

- **How would you propose we assess approaches to expand the Commonwealth's capacity to screen and diagnose for dementia?**

Examples of approaches:

- **Implementing a “Hub & Spoke” model (organizing and funding?)**
- **Can we work with insurers, particularly Medicare Advantage plans?**
- **Can we use Community Health Workers for screening such as spreading the approach used at Cooley Dickinson Hospital to other regions of the state?**
- **As new treatments are approved, how do we ensure equal access to all Massachusetts residents, who are appropriate for specific therapies?**

- **Are there other potential approaches you would recommend we examine, pilot, or implement?**



Person-Directed Care Planning



Care Planning Implementation Team Status and Discussion

November 1, 2022

Workgroup Leads

Linda Pellegrini, MS, GNP-BC, Geriatric Nurse Practitioner,
UMass Memorial Medical Center

Susan Antkowiak, Vice President of Programs & Services,
Alzheimer's Association, MA/NH Chapter



Person-Directed Care Planning



Our team's charge as described by the Council in the State Plan:

Develop a person-directed care plan framework and template





Care Planning Implementation Team



Linda Pellegrini, MS, GNP-BC

Council Member & Workstream Co-lead
Care Planning Implementation Team Co-lead
Geriatric Nurse Practitioner
UMass Memorial Medical Center

Susan Antkowiak

Council Member
Care Planning Implementation Team Co-lead
Vice President of Programs & Services
Alzheimer's Association

Mike Belleville

Council Member
Dementia Advocate

Deb Dowd-Foley

Caregiver Specialist
Elder Services of Worcester Area, Inc.

Laurie Herndon, MSN, GNP, BC (on sabbatical)

Project Director
Hinda and Arthur Marcus Institute for Aging
Research, Hebrew SeniorLife

Judy Johanson

Dementia Advocate
Mass. Alzheimer's Disease Research Center, MGH

Aaron Madow

Graduate Student (MPH candidate)
University of Massachusetts

Gad A. Marshall, MD

Medical Director of Clinical Trials at Center for
Alzheimer Research and Treatment,
Brigham and Women's Hospital (BWH); Associate
Neurologist at BWH; Assistant in Neurology at
Massachusetts General Hospital; Associate
Professor of Neurology at Harvard Medical School



Care Planning Implementation Status



Updates and Accomplishments

- Conducted two focus group sessions with family caregivers
 - Special thanks to:
 - Barb Meehan, Advisory Council Member
 - Deb Dowd Foley, Caregiver Specialist, Elder Services of Worcester Area, Inc.
 - Yung Phan, Multicultural & Senior Services Coordinator, Worcester Elder Affairs
 - Alzheimer's Association
- Sessions were held via Zoom, recorded with permission, minutes were taken, facilitated by Alzheimer's Association staff
- Questions provided in advance:
 - What was the experience of communicating with your doctor or healthcare provider about concerns regarding your loved one? Please share a positive experience or a negative experience. What types of things would you have expected from your doctor when discussing the diagnosis of your loved one?
 - What are the most important things you want a doctor or healthcare provider to know about your loved one?

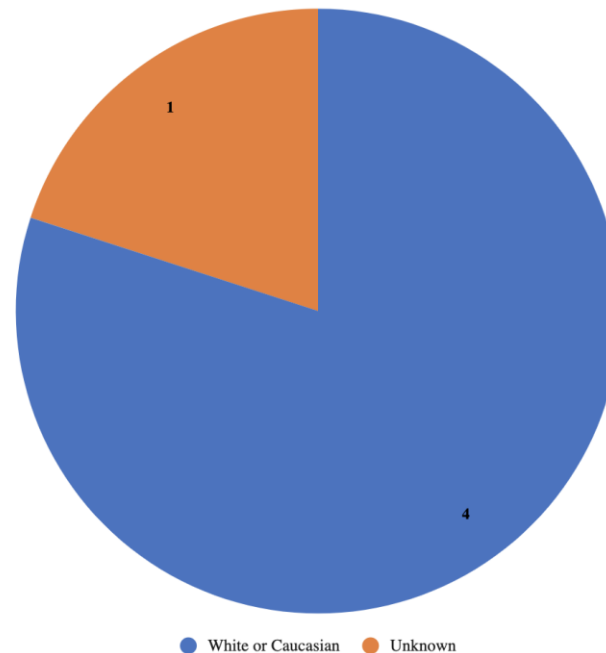


Care Planning Implementation Status



Updates and Accomplishments (Continued)

- Participant demographics: race/ethnicity of people living with dementia



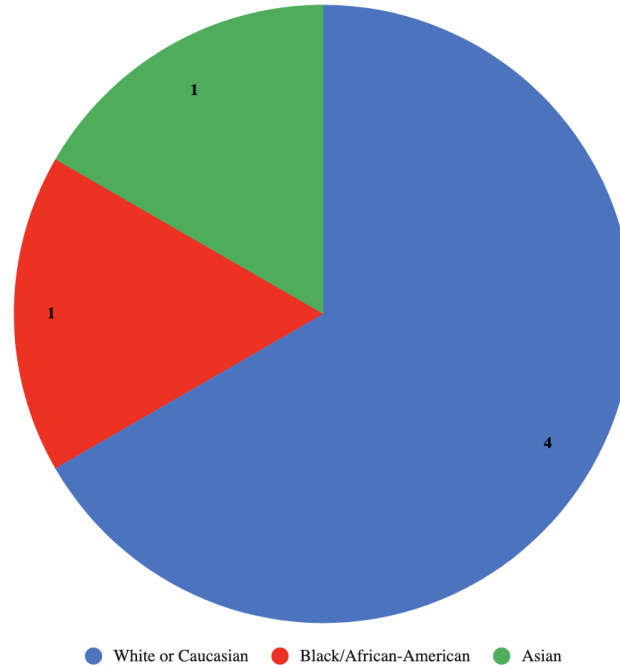


Care Planning Implementation Status



Updates and Accomplishments (Continued)

- Participant demographics: race/ethnicity of caregivers



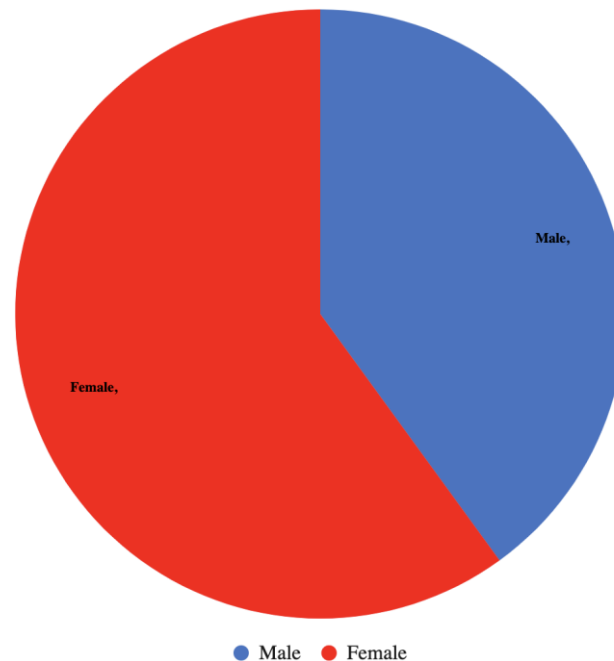


Care Planning Implementation Status



Updates and Accomplishments (Continued)

- Participant demographics: gender of people living with dementia



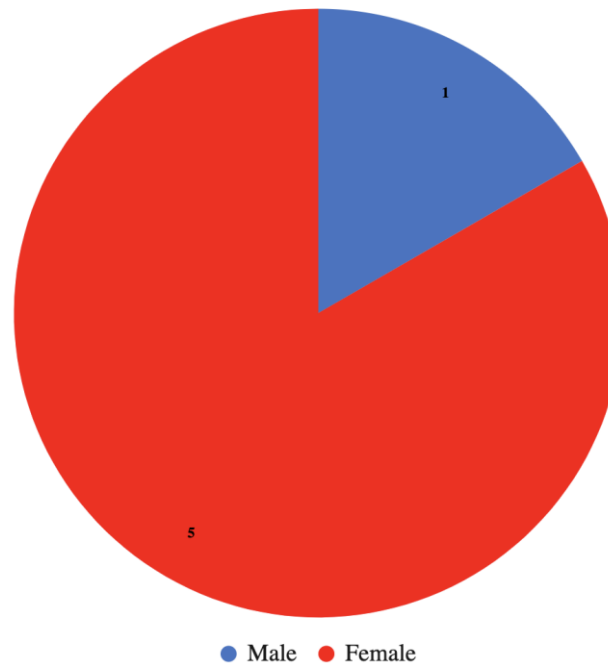


Care Planning Implementation Status



Updates and Accomplishments (Continued)

- Participant demographics: gender of caregivers



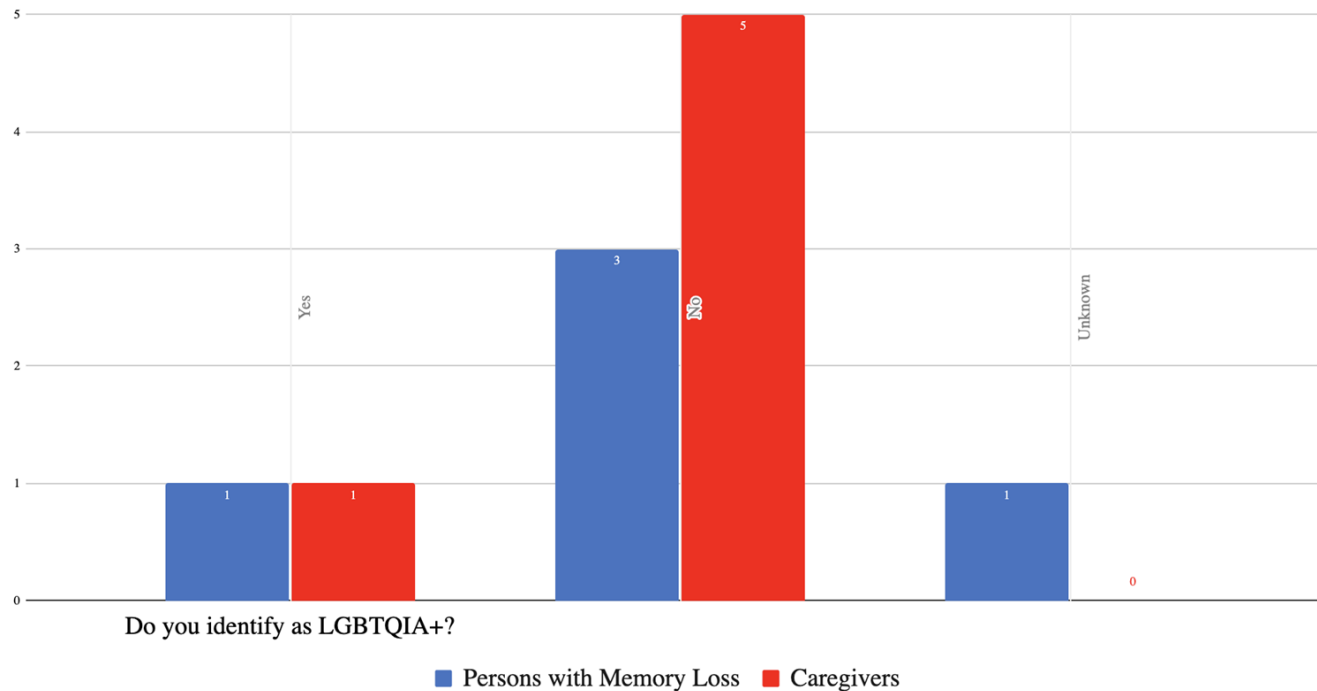


Care Planning Implementation Status



Updates and Accomplishments (Continued)

- Participant demographics: LGBTQ+ individuals in both groups



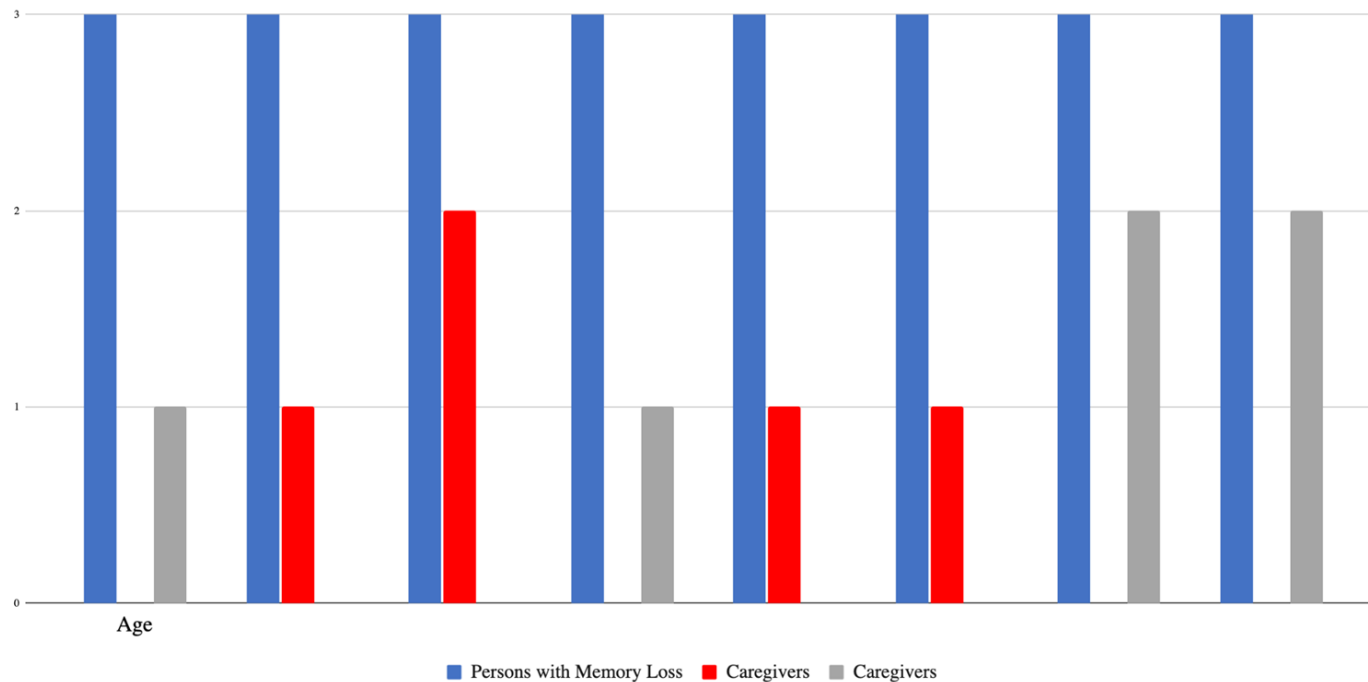


Care Planning Implementation Status



Updates and Accomplishments (Continued)

- Participant demographics: age of both groups





Care Planning Implementation Status



Updates and Accomplishments (*Continued*)

Themes from focus group sessions with people living with dementia:

Question: What was the experience of communicating with your doctor or healthcare provider about concerns regarding your loved one?

- Delay in getting the diagnosis and difficulty of the diagnostic process
 - complaints of memory problems not being taken seriously
 - difficulty getting an appointment with a neurologist
 - diagnostic process was brutal, traumatic, debilitating
 - focus was on physical exam and medications, NOT how the person was doing
 - care and support were not available during the process
 - some were told, “Go home and get your affairs in order”, “see you in 6 months”, no guidance was offered
 - not knowing what to expect
- Positive experiences
 - when the person had a long-standing relationship with the PCP - felt like they know them as a person
 - Referral to Dementia Care Coordination program - “the call made a huge difference”
 - Health care provider offered support that was positive and affirming
 - offered positive suggestions
 - recommended exercise, intellectual stimulation, social stimulation



Care Planning Implementation Status



Updates and Accomplishments (*Continued*)

Themes from focus group sessions with people living with dementia (continued):

Question: What are the most important things you want a doctor or healthcare provider to know about your loved one?

- need for care and support
- “get to know me as a person, not as a person with Alzheimer’s disease
- how to find acceptance and still live your best life
- how to tell other people
- what can you do to delay progression and maintain some control
- “Told my doctor up front my strengths, things that were important to me like writing and meeting friends”
- advocate for yourself
- early diagnosis is important so you can state what you want and make decisions for yourself
- need better overall care management and integration



Care Planning Implementation Status



Updates and Accomplishments (*Continued*)

Themes from focus group sessions with caregivers:

Question: What was the experience of communicating with your doctor or healthcare provider about concerns regarding your loved one?

- Communication
 - believe the caregiver when they say there is a problem
 - lack of guidance, care coordination and navigation, especially between the PCP and specialists
 - “people are rushed”, “system is flawed”
 - “I feel like an orchestra conductor, but I do not know anything about music”
 - “I was not prepared for how much I would have to advocate”
 - importance of asking the caregiver how they are doing



Care Planning Implementation Status



Updates and Accomplishments (*Continued*)

Themes from focus group sessions with caregivers (continued):

Question: What are the most important things you want a doctor or healthcare provider to know about your loved one?

- “who the person is”, “they are not their illness”, “help me to help her live the life she was living”
- listen to the caregivers - acknowledge who they are in the process
- trying to navigate the resources on your own can be daunting
- referral to a memory center was a life saver
- there should be cultural considerations



Care Planning Implementation Status



Updates and Accomplishments (*Continued*)

Themes from focus group session with Vietnamese caregiver with interpreter:

- lack of care coordination with specialists
- lack of explanations to family regarding medications, care
- no instructions after hospitalization, guidance or communication - “had to figure it out ourselves”
- daughter found ways to deal with mother’s outbursts by trial and error
- had a Vietnamese speaking counselor for a year, insurance changed, and new counselor did not speak Vietnamese, could not access an interpreter
- sister sent herbal medication from Vietnam that was helpful
- wishes her mother had a program to go to where she could socialize with others who spoke Vietnamese



Care Planning Implementation Status



Next Steps

- Meet with work group members
 - Discuss themes of sessions of people living with dementia and of those with caregivers
 - Consider value of creating new tool or using existing tools to help people living with dementia have improved communication, express their preferences and goals to health providers
 - Explore opportunities for directing tools to families and providers

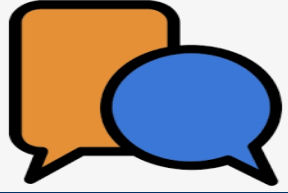


Care Planning Challenges and Solutions



Challenges

- Recruiting a diverse representation of participants
- Ensuring practitioners/providers value and utilize the input and experiences of the patient/person living with dementia
- Identifying best opportunities to provide tools to people living with dementia, caregivers and health providers



DISCUSSION (15 min)



Discussion

1. How can focus group data inform other work groups?
2. How do we promote the partnership between practitioners and their patient/person living with dementia to utilize the person-driven model of care planning?



Younger-Onset Dementia and Equity Analysis Workgroup



Recommendations & Implementation Plan

Workgroup Lead: Rhiana Kohl, PhD, Council Member

Presenter: Mike Belleville, Council Member and
Dementia Advocate



Workgroup Members



Younger-Onset Dementia & Equity Analysis Workgroup of the Council's Equitable Access & Care Workstream:

Rhiana Kohl, PhD, Council Member (Workgroup Lead)

Mike Belleville, Council Member & Dementia Advocate

Kathy Devine, Prescription Advantage Program Manager - EOEa

Chelsea Gordon, Director of Public Policy & Advocacy, Alzheimer's Association, MA/NH Chapter

Judy Johanson, Dementia Advocate - Mass. Alzheimer's Disease Research Center, MGH

Tracy Lungelow, Caregiver

Joe Montminy, Dementia Advocate

Paul Mathew, MD, Caregiver

Barbara Meehan, Council Member & Dementia Advocate/Formal Caregiver



Goal, Challenges, Recommendations



Goal

Address unmet needs and close gaps in equality, equity, and inclusion for people living with younger-onset dementia and the people who care for them

Challenges for Individuals Affected by Younger-Onset Dementia

1. Lack of **awareness** and **access** to the services, supports, and resources available to them
2. Unmet needs due to the differing nature of their challenges and their age compared with older adults

Recommendations

For people affected by younger-onset dementia and the medical community:

(1) Improve Awareness

Currently Available
Services, Supports, and
Resources

(2) Improve Access



Implementation Strategies, Years 1-3



Beginning in Year 1 (Calendar Year 2023)

1. Conduct comprehensive analysis, clarifying age-related eligibility of services and supports available to younger onset population
 - Examine resources available from aging services agencies, other government agencies, and the Alzheimer's Association
2. Design and develop a younger-onset section within EOEA's dementia website that clearly specifies available resources
3. Ensure that resources are identified and included in the new dementia webpages around:
 - Mental health support (therapy, support, and support groups)
 - Financial planning and management (help around making the right choices; protecting assets; and planning for the future)



Implementation Strategies, Years 1-3



Soon after today's meeting...

Ask the following teams to review and address a list of considerations developed by our workgroup, which are associated with these issues:

1. *Diagnosis and Services Navigation Workstream* - PCPs may not consider or may dismiss a young person's experiences with dementia symptoms.
2. *Care Planning Workgroup* - Although activities that promote wellbeing/living a good life/social engagement are beneficial, not everyone is aware of opportunities and how critical they are to maintaining a positive quality of life.
3. *Research Workstream* - People living with younger-onset dementia lack opportunities to participate in clinical trials.



Implementation Strategies, Years 1-3



Beginning in Year 2 (Calendar Year 2024)

1. Implement a communications plan that ensures that stakeholders¹ gain a better understanding of available resources
2. Implement a variety of communication approaches

For example:

- Launch the new younger-onset dementia webpages by disseminating the link
 - Convene informational sessions and webinars
3. Determine if available mental health and financial planning and management resources meet identified needs; and if not, recommend solutions

1. Stakeholders include Aging Services Access Points, the medical community, and individuals affected by younger-onset dementia



Looking to the Future



Years 3 and Beyond

- Work will continue beyond Years 1 and 2; and any new recommendations will be presented at future Council meetings
- The Council will likely continue to examine other unmet needs and new recommendations and implementation strategies

Potential examples:

- Specialized services tailored for people affected by younger-onset dementia
- Services for children of a parent living with younger-onset dementia



Organizations and Resources



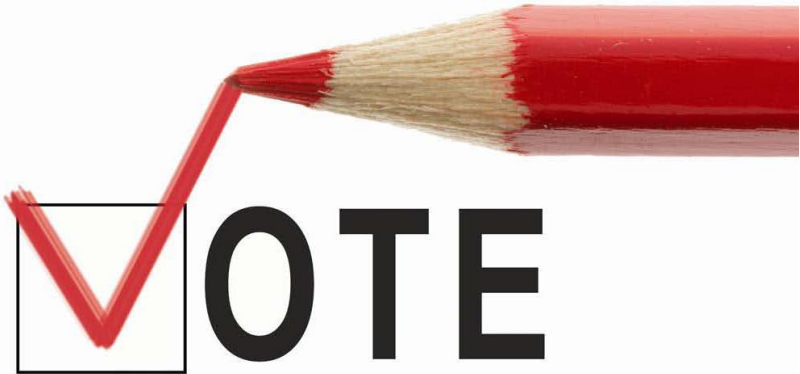
Responsible Organizations (no incremental costs)

- MA Executive Office of Elder Affairs (EOEA)

Resources

1. Lists of state supported services for people affected by younger-onset dementia prepared by our workgroup
2. Resources available from the Alzheimer's Association
3. Information from other organizations such as the federal government and dementia-related organizations

**Vote to Adopt or Amend
Recommendations & Implementation Plan**



Age and Dementia Friendly Physical Infrastructure



Implementation of Recommendations

Status and Discussion

November 1, 2021

Workstream Lead

Secretary Elizabeth Chen, EOEA

Implementation Team Co-leads

Patty Sullivan, Program Director
Dementia Friendly MA
MA Councils on Aging

James Fuccione, Senior Director
MA Healthy Aging Collaborative



Implementation Team Members



Implementation Team Co-Leads

Patty Sullivan, MS

Program Director
Dementia Friendly MA
MA Councils on Aging

James Fuccione, MPA

Senior Director
MA Healthy Aging Collaborative

Pam MacLeod, MBA, PMP

Senior Project Director
MA Executive Office of Elder Affairs

Maureen Mullaney, BS, MA

Transportation and GIS Program
Manager II
Franklin Regional Council of
Governments

Sandra Martin, MEP, MPH

Senior Planner and Health Agent
Berkshire Public Health Alliance
Public Health Program at Berkshire
Regional Planning Commission

Ruth Neeman, AIA

Principal, Director of Senior
Environments Studio
LWDA

Molly McKenna, MSW LCSW

Programs Development Manager
2Life Communities

Philippe Saad, AIA, LEED AP

Principal
Dimella Shaffer

Sanja Stegich, Intern



Age and Dementia Friendly Physical Infrastructure



Our charge as described in the Alzheimer's State Plan:



Recommendation #1 (Raise Awareness for Community Planning)

Raise awareness of the importance of age- and dementia-friendly design

Develop Age and Dementia-Friendly Design Considerations

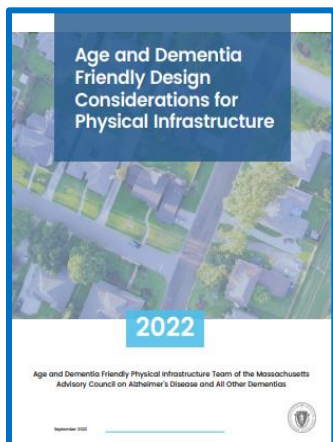


Recommendation #2 (Incorporate Scoring into Public Projects)

Incorporate age- and dementia-friendly scoring or explicit preference into all state-funded physical infrastructure projects



Updates and Accomplishments



Age and Dementia Friendly Design Considerations for Physical Infrastructure

- ✓ Developed a guide to rethinking how we plan, design, build, renovate, and maintain the Commonwealth's built environment with a special focus on our residents' needs as they age
- ✓ Developed an extensive Distribution Plan for the guide
- ✓ Delivered multiple presentations about the guide (Boston Society for Architecture, MCOA, Leading Age National, MHAC, Mass Trails) and many others are in the pipeline



- Continue to distribute the guide to architects, planners, and the aging services community more broadly
- Distribute to communities/COAs that received earmarks in the State Budget for the construction and /or maintenance of facilities
- Continue to work to incorporate dementia friendly elements in future versions of state procurement RFPs and/or add the following language:
 - “Preference in this competition will be given to proposals that reflect the needs of older adults including those living with dementia.”



Challenges and Solutions

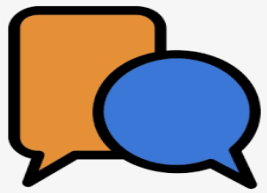


Challenges

- Design Criteria- Technical Specifications vs Design Considerations
- Communicating the importance/benefits of including such criteria in the procurement process
- Reaching the long-term goal of having *many* of the state's procurement processes reflect the needs of older adults and all people living with dementia

Solutions

- Continue to build partnerships with the design, planning, and procurement communities to establish a common language and meaning of age and dementia friendly design



DISCUSSION (7 min)



We are seeking your advice on:

- Upcoming state-funded procurements
- Hospitals or other public-facing settings where plans are underway for renovations or new construction



Next Steps & Vote to Adjourn



Next Steps



- 1. Draft the Council's next annual report**
- 2. Review and vote on the report at next Council meeting on February 7, 2023**
- 3. Submit the annual report (due on March 1, 2023)**



Vote to Adjourn