

# **Advisory Council on Alzheimer's Disease and All Other Dementias**



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

**June 21, 2022  
3:00-5:00 pm  
Video Conference**



# Agenda



1. Welcome, Logistics, Introductions *(10 min)*
2. Care Planning Team: Updates and Discussion *(30 min)*
3. Update on Equitable Access & Care Workstream *(10 min)*
4. Why Diversity, Equity, and Inclusion (DEI) Matter *(60 min)*
  - Panel of Individuals with Lived Experience
5. Next Steps and Vote to Adjourn *(10 min)*



# Person-Directed Care Planning



## Care Planning Implementation Team Status and Discussion

**June 21, 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

- Intern acquired - Aaron Madow, Public Health Graduate Student, University of Massachusetts.
- Committee member, Laurie Herndon, on 6-month sabbatical
- Convened two focus groups for people living with dementia.
- Created focus group resources including fliers, emails for potential participants, phone screening protocol, scripts, and discussion questions.
- Participants were recruited from Mass General Brigham and Alzheimer's Association (Early Stage Support Group and Early Stage Advisory Council).



# Care Planning Implementation Status



## Updates and Accomplishments (Continued)

- Phone or Zoom interviews were conducted with nine interested participants.
- Some interested participants did not attend. One interested participant withdrew.
- Three individuals participated in one session while two individuals participated in a second session.
- Alzheimer's Association staff facilitated focus group discussions. Meeting minutes were documented, and the sessions were recorded with the participants' verbal consent. Participants were advised the recordings would be viewed by the workgroup members and not shared or used for any other purpose.





# Care Planning Implementation Status



## Updates and Accomplishments (*Continued*)

- Discussion questions were shared in advance with participants, allowing them the opportunity to think about their experiences. Questions included:
  - *What was your experience of communicating with your doctor or healthcare provider about your concerns? Please share a positive experience or a negative experience. What types of things would you have expected from your doctor when discussing your diagnosis?*
  - *What are the most important things you want a doctor or healthcare provider to know about you?*
- Focus group facilitators were provided with discussion questions and suggested follow-up questions to support open discussion.





# Care Planning Implementation Status



## Next Steps

- Recruit caregivers or care partners of someone living with Alzheimer's or other dementia to participate in focus groups in early Fall
- Review information from all focus group sessions with workgroup members to inform next steps
- Make decision if using an existing tool or create a new template



# Care Planning Challenges and Solutions



## Challenges

- Recruiting a diverse representation of participants
  - *limited pool of individuals living with dementia from which to recruit*
  - *achieved diversity with gender and different forms of dementia but no apparent diversity with race or ethnicity*
- Engaging unsupported individuals
- Funding a third-party convener of stakeholders to develop the template
- Ensuring practitioners/providers value and utilize the input and experiences of the patient/person living with dementia

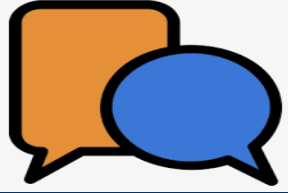


# Care Planning Challenges and Solutions



## Solutions

- Engage Advisory Council members to broaden recruitment efforts, elevating opportunity to ensure greater diversity of participants
- Collaborate with other workgroups to support reciprocal relationship between the person living with dementia and their practitioner/provider
  - Equitable Access & Care
    - ensure outcome meets the needs of diverse populations
  - Public Awareness
    - consider public awareness campaign highlighting the value of a reciprocal relationship between the person living with dementia and their practitioner/providers
  - Initial Diagnosis & Services Navigation
    - ensure the value of a reciprocal relationship between the person living with dementia and their practitioner/providers is part of provider education



## CARE PLANNG DISCUSSION (15 min)



### Discussion

1. How can the Advisory Council leverage relationships to help us recruit participants more accurately reflecting the diversity of our communities?
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?



# Advisory Council on Alzheimer's Disease and All Other Dementias, June 2022



## Update on Equitable Access & Care Workstream *(10 min)*



# Why Diversity, Equity, and Inclusion Matter



## Panel of Individuals with Lived Experience (60 min)

- Everyone on today's panel has been affected by dementia
  - Today, they will share their stories around cultural understanding (or lack of thereof) experienced anywhere; for example, among:
    - healthcare professionals, dementia care professionals, elder service agencies
    - senior centers, service providers, neighbors, friends, family, etc.
- 
- **Clint Kershaw**
  - **Valderez Oliveira**
  - **Pastor Tirsa Ramirez**



# Next Steps & Vote to Adjourn



**Next Meeting:**  
August 18, 2022  
3:00 to 5:00 pm

**Location: TBD**

**Vote to Adjourn**

