

Welcome and Appreciation!



Massachusetts
Councils On Aging

Dementia Friendly Massachusetts (DFM)

*Dementia Friendly Massachusetts is a **state-wide, grassroots movement** comprised of organizations, individuals, and municipalities growing dementia friendly communities **to become more inclusive** and supportive of those living with dementia, their families, and care partners. Dementia Friendly Massachusetts is a member of Dementia Friendly America and is generously supported by Tufts Health Plan Foundation.*



Today's Goals



- Networking and Sharing Resources
- Seeing all of us in DFM
- Thinking regionally; acting locally
- Understanding resources for our efforts
- Considering next steps



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Agenda

- **Welcome: Emily Kearns, Dementia Friendly Massachusetts (DFM)**
- **Reframing Dementia: Language Matters**
- **Taking Stock: Participants Inventory - What we have done; what we want to do**
- **Brag 'n Borrow: Sharing our Wheel; no need to reinvent it**
- **Moving Forward Together: Dementia Friendly Massachusetts – Overview and Available Resources**
- **Next Steps: Getting Involved**
- **May Meetings: Resources Panel**
- **MCOA Grant – RFP Release (expected March 2018)**



DFM – Sharing a Dementia Language

“Words are very powerful – they can build you up or put you down. When you are speaking about dementia remember this.”

- Agnes Houston, person with dementia

- **Language changes needed:**
 - **Not “suffering” from dementia but living with challenges**
 - **Not “patients” when living in the community**
 - **Not “demented” but living with dementia**



Dementia is...

- ▶ **Dementia is – NOT a specific disease**
- ▶ **Dementia is - a general term for a decline in mental ability severe enough to interfere with daily life**
- ▶ **Memory loss is an example**
- ▶ **Alzheimer's is the most common type of dementia**
- ▶ **Some conditions creating dementia are reversible - thyroid problems and vitamin deficiencies**



Reframing Dementia: Inclusion and Accessibility

World Health Organization's Action Plan – April 2017

Dementia Action Alliance – First Annual Conference June 2017

- **Dementia as living with a disability – supported by cognitive ramps**
- **Dementia as a public health issue**
- **Culture change – disabilities rights movement**
 - **“nothing about me without me”**
 - **Inclusion, accessibility, being seen as a resource**
 - **People living with dementia, like all of us, need and deserve to live with purpose and choice**
 - **Ex. Mentoring and advocacy – Dementia Action Alliance**



Dementia Statements: developed by people with dementia and caregivers/care partners

- **We have the right to** be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- **We have the right to** continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- **We have the right to** an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.



Statements – Cont'd



- **We have the right to** be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- **We have the right to** know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

(Source: <https://www.dementiaaction.org.uk/nationaldementiadeclaration>)



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Listening to Learn

If you cannot think of how to resolve a situation, have the patience to ask and we will probably find a great solution together. I am still me, I am still capable, I just need help to find other ways to thrive in what is now a different looking and often difficult world to me.

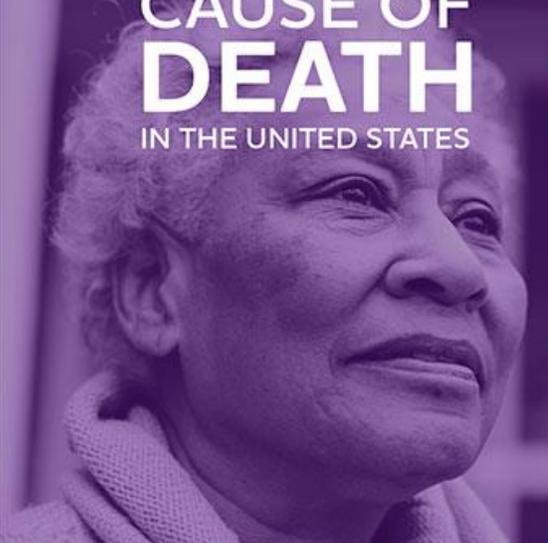
- Wayne Eaton



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(Source: https://www.dementiaaction.org.uk/case_studies/20321_how_to_be_dementia_friendly_-_wayne_eaton)

ALZHEIMER'S DISEASE IS THE
6TH LEADING
CAUSE OF
DEATH
IN THE UNITED STATES



MORE THAN
5 MILLION
AMERICANS ARE LIVING WITH ALZHEIMER'S

1 IN 3 SENIORS
DIES WITH ALZHEIMER'S
OR ANOTHER DEMENTIA



IN 2015, MORE
THAN 15 MILLION
CAREGIVERS
PROVIDED AN
ESTIMATED

18.1 BILLION
HOURS OF
UNPAID CARE

ALZHEIMER'S COSTS CAREGIVERS
MORE THAN THEIR TIME

FAMILY CAREGIVERS SPEND MORE THAN
\$5,000 A YEAR
CARING FOR SOMEONE WITH ALZHEIMER'S

FOR SOME FAMILIES THIS MEANS
MISSING A VACATION

BUT FOR OTHERS, IT MAY MEAN
GOING HUNGRY

EVERY
66 SECONDS

SOMEONE IN THE UNITED STATES
DEVELOPS THE DISEASE



IN 2016, ALZHEIMER'S AND OTHER
DEMENTIAS WILL COST THE NATION

\$236 BILLION

IT
KILLS
MORE
THAN

BREAST AND
PROSTATE CANCER
COMBINED

Massachusetts



- **Current: 120,000 individuals living w Alzheimer's**
- **2025: 150,000 will be living w Alzheimer's**
= a 25% increase



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Source: Alzheimer's Association and <https://www.dementiaaction.org.uk/nationaldementiadeclaration>

Prevalence: Whole-Community Impact



- **1 in 10 people age 65 and older has Alzheimer's Disease**
 - - Not including other causes of dementia
- **Of those living with Alzheimer's:**
 - 3 % are ages 65 – 74**
 - 17% are ages 75 – 84**
 - 32% are 85 and older (1 in 3)**



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Disparities – Implications for DFM Efforts



- **Older African Americans and Hispanics are more likely to live with Alzheimer's and other dementias**
- **African- Americans: twice as likely than older whites**
- **Hispanics – 1.5 times as likely than older whites**
- **NOTE: genetic factors don't seem to account for this difference in prevalence.**
- **Health, lifestyle, and socioeconomic risk factors matter**
- **Implications – Increased outreach and inclusion to support diverse communities needed**



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Taking Stock: Participants Inventory

What we have done; what we want to do



Reflection – Participant Survey



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Defining Dementia-Friendly

Dementia-friendly communities

- ▶ Help people with dementia feel included and supported in the places they work, live and play.
- ▶ Focus on stigma reduction and the inclusion of people with dementia.
- ▶ Ensure that people living with dementia feel supported by their community members whether they are at post offices, retail outlets, using transportation or enjoying hobbies out in the community.
- ▶ “Community” can mean a location like a neighborhood or city, but can also include groups of people with shared interests or features, such as professional groups, religious organizations or businesses....even your book club, a faith group or your business, a local coffee shop or grocery store.

Source: <http://www.alzheimer.ca/en/bc/About-dementia/Dementia-friendly%20communities/What%20is%20a%20dementia-friendly%20community>



Defining Age-Friendly



Age-Friendly Communities

- ▶ Encourage active ageing by optimizing opportunities for health, participation, and security in order to enhance quality of life as people age.
- ▶ Adapts its structures and services to be accessible to and inclusive of older people with varying needs and capabilities.

“ To understand the characteristics of an age-friendly city, it is essential to go to the source – older city dwellers.”

– WHO’s, Global Age-friendly Cities: A Guide

Source: <file:///C:/Users/emily/Documents/Documents/Dementia%20Friendly%20Communities/Age-%20vs%20Dementia-%20Friendly/global-age-friendly-cities-guide-english.pdf>



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Brag 'n Borrow—Sharing our wheel; no need to reinvent it

Inventory our efforts: what we have done !

- reporting out to one another - seeing strong communities
- reporting out to whole group - identifying regional strengths



Going Forward - *Stick 'ems*

- What more do we want to do?
- What do we need?



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Dementia Friendly Massachusetts

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Dementia
Friendly
America

dfamerica.org

Twitter
[@dfamerica_](https://twitter.com/dfamerica_)

Dementia Friendly – A Cross Sector Approach



1st Lap Successes: 3 Guideposts



Efficiency

- Aligned activities to reduce duplication and competition, and to more efficiently move toward our goal of a dementia friendly Massachusetts.

Scale

- Made “dementia friendly” a familiar term across the state and sectors

Inclusion

- Formed AECI Committee: “access, equity and cultural inclusion”
- Began making the voices of people living with dementia more central to this movement

*Example: Dementia- and Age- Friendly Alignment
= efficient, scalable, and inclusive*



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2nd Lap - Current Goals: Changing Lives, Systems, and Community Cultures

- ▶ Reducing dementia's stigma
- ▶ Increasing inclusive practices in social, civic, medical and commercial organizations – supporting cultural diversity and people living with dementia
- ▶ Improving caregiver/care partner health
- ▶ Increasing number of dementia-friendly communities
- ▶ Increasing persons living with dementia's experience of their community as dementia- friendly.



Key Activities



- **Educate and empower** municipal leaders who manage local aging services.
- **Advocate** for policies to improve the quality of life for older adults.
- **Collaborate** with partners to increase efficient capacity and ensure delivery of quality programming to advance healthy aging for older adults.



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Resources for Your Community: Technical Assistance, Trainings, and Workshops



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Dementia Friends is a global movement now underway in the US and 24 other countries. Volunteers are trained as Champions to lead hour-long information sessions that raise awareness, build empathy, and help everyone in a community identify simple personal actions that make a difference.

The program is currently available in English and Spanish. To learn about Dementia Friends Massachusetts, please visit www.dementiafriendsma.org or contact Beth Soltzberg at bsoltzberg@jfcsboston.org



Memory Cafés are welcoming social gatherings for people living with dementia, along with their family, friends and caregivers. Cafés are free of charge, and no one is asked their diagnosis.

Visit the Massachusetts Memory Café Directory at www.jfcsboston.org/MemoryCafeDirectory

A free Toolkit for starting a Memory Café is available at www.jfcsboston.org/MemoryCafeToolkit or in Spanish at www.jfcsboston.org/GuiaCafeDeMemoria

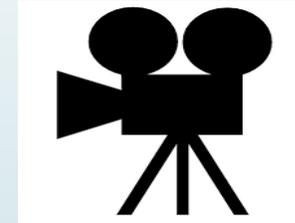


MA Executive Office of Elder Affairs (EOEA)



EOEA's Role in Dementia Friendly Massachusetts (DFM)

- Develops tools & resources with DFM partners to help facilitate dementia friendly activity.
- Produces and distributes DFM videos that increase awareness and inspire DFM involvement among high-risk populations.
- Identifies and disseminates advice and best practices from dementia friendly community leaders in other states and countries.



MA Executive Office of Elder Affairs (EOEA)



- Continuously works to enhance the dementia capability of the Commonwealth's system of home and community-based services and supports.



- Keeps the Executive Office of Health and Human Services, the Governor's Office, and other policy-makers abreast of dementia friendly activity across our state.

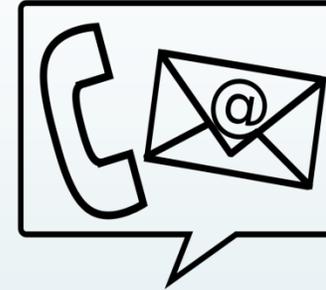


- Maintains a DFM website:

<https://www.mass.gov/dementia-friendly-massachusetts>



MA Executive Office of Elder Affairs (EOEA)



For more information, contact Pam MacLeod:

pam.macleod@state.ma.us

617-222-7435

What is the MHAC?

The **Massachusetts Healthy Aging Collaborative** is a network of leaders in community, health and wellness, government, advocacy, research, business, education, and philanthropy who have come together to advance healthy aging.

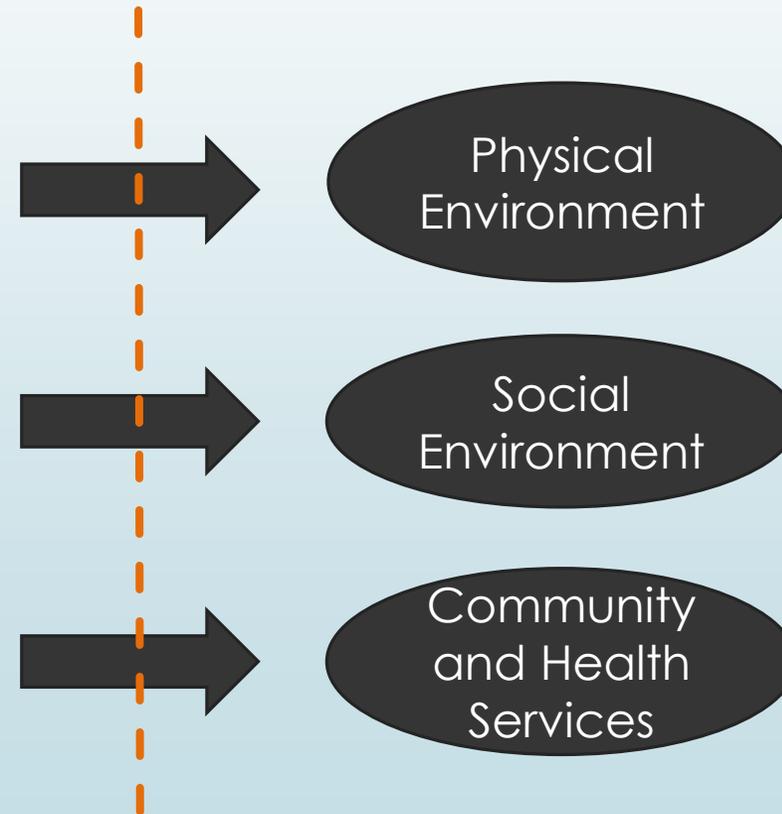
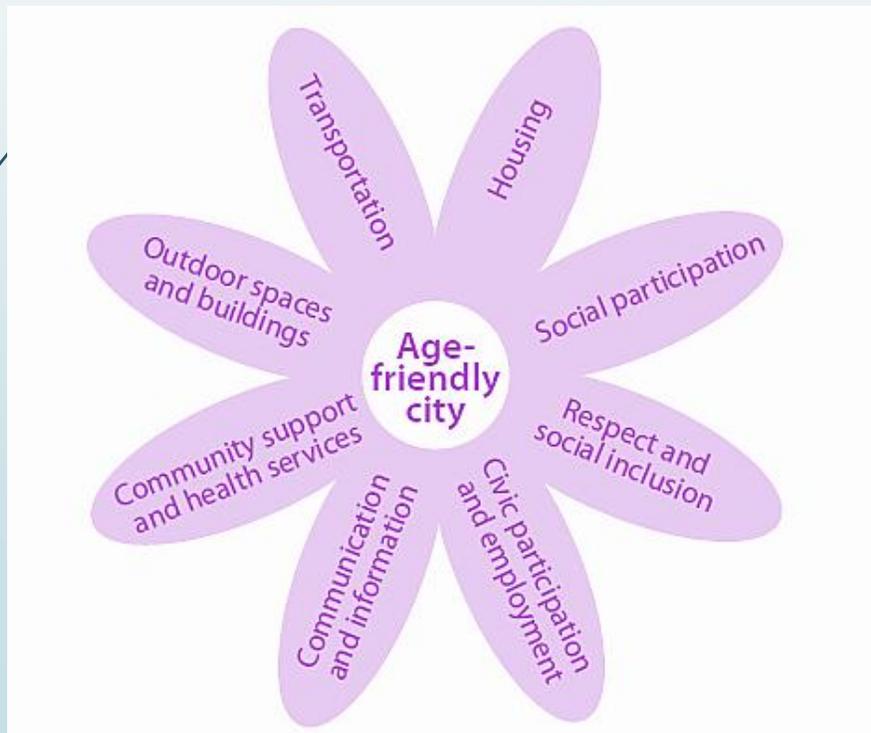
Focus: Advancing Age-Friendly and Dementia Friendly Communities

- 1) Building and supporting the Age-Friendly movement in Massachusetts
- 2) Deepen capacity-building work at the community level
- 3) Embed access, equity, and inclusivity in our approach and the Age-Friendly movement
- 4) Develop and communicate policy and advocacy platform



What is “Age-Friendly”?

- A continuous improvement process focusing on three areas:
 - *Physical environment*
 - *Social Environment*
 - *Community and health services*



Better Together Strategy

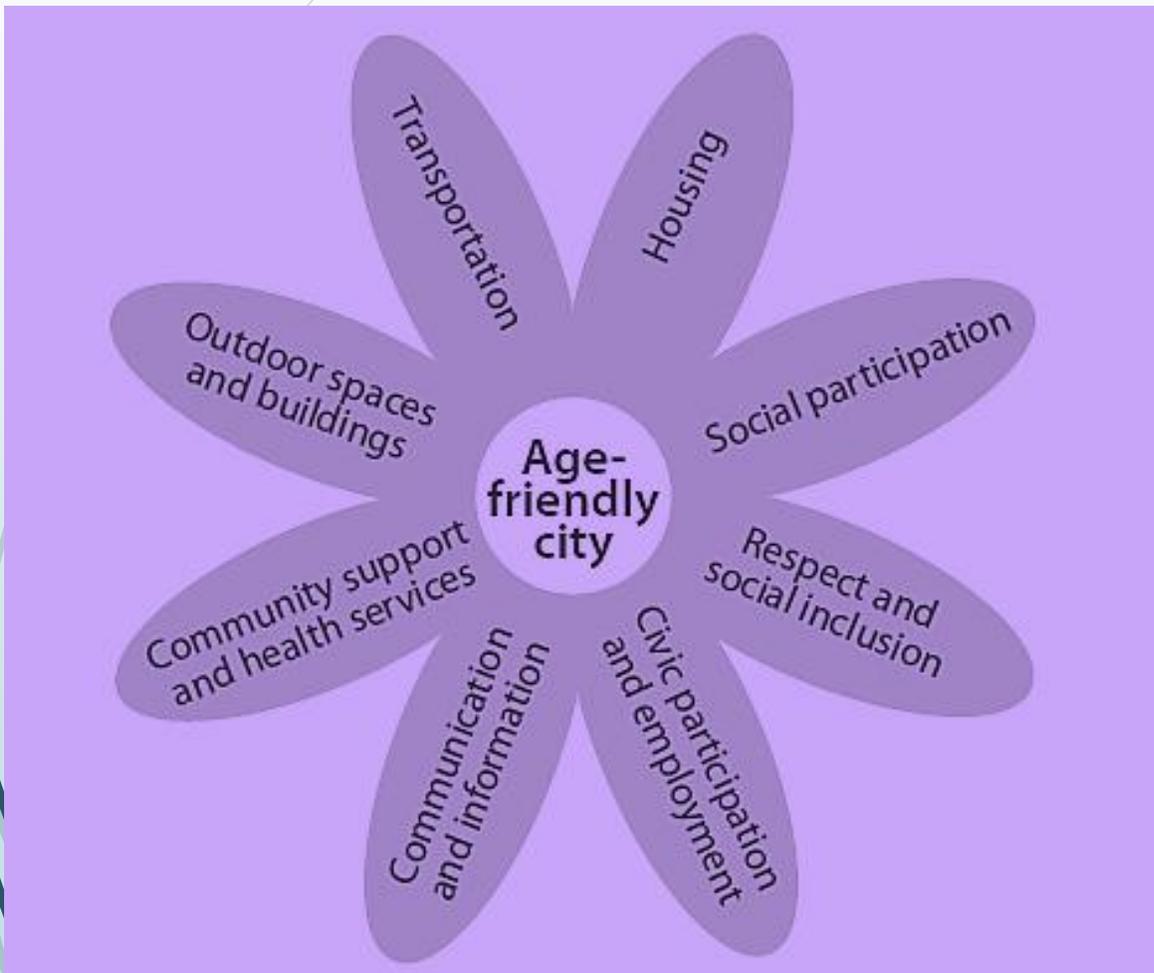
RESEARCH REPORT

MARCH 2016

Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities

Natalie Turner and Lydia Morken

Simplified “Better Together” Strategy



Age-Friendly Community efforts should...

- *Include people living with Dementia, caregivers, and service/support providers on task force*
- *Include a Dementia Friendly advisory group that can focus on raising awareness and working through sectors/domains in coordination with Age-Friendly*

Resources and Contact Info

- James Fuccione: James.Fuccione@mahealthyaging.org
 - 617-717-9493
- AARP: Better Together [Report and Framework](#)
- AARP: [Livability Index](#)
- [Dementia Friendly Massachusetts Toolkit](#)
- MHAC: [Age-Friendly Toolkits](#)
- MHAC: [Mass. Healthy Aging Community Profiles](#)
- MHAC: [Current Age/Dementia Friendly Communities in MA](#)
- N4A Report: [Making Your Community Livable for All Ages](#)
- WHO: [Checklist of essential features of age-friendly cities](#)
- **NEW!** [“What We Have and What We Need”](#) – Building an Age- and Dementia Friendly Commonwealth
- Tri-State Learning Collaborative: [Tools and Resources](#)

Alzheimer's Association

- **24/7 Hotline: 24/7 Helpline: 800.272.3900**
- **Support Groups for Caregivers/Care Partners**
- **Power and Purpose for People Living with Alzheimer's and Other Related Dementias**
- **Alz Meetups**
- **Trainings – all sectors including community small businesses and customer service**

Contact: Maura Moxley

- **Maura Moxley, Director of Community Engagement
Alzheimer's Association®, Massachusetts/New Hampshire Chapter**
- **Phone: 617.868.6718 x2067**
- **www.alz.org/MANH**

Next Steps = Get Involved!



- Join the DFM mailing list – receive newsletters, updates, and more
 - <https://mcoaonline.com/resources/dementia-friendly/sign-email-list/>
- Join your local DF leadership team and organize educational events and trainings
- Join or Convene a DFM sector leaders group and/or diversity leadership group – Do you know movers and shakers in a sector – banking, hospitality, medical, etc.?
- Become a Dementia Friend: <http://dementiafriendsma.org/>
- Join advocacy organizations including Dementia Action Alliance
 - <https://daanow.org/>
- Create and participate in innovative programs
 - *Memory Cafes*
 - *Music and Memory*
 - *Dementia Friendly Cruises*
 - *Dementia Friendly Fitness Programs – YMCAs*



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May Meetings and Beyond



- Rotating sites – increasing access for all communities
- Meeting the Resource Team – panelists
- Identifying Sector Champions
- Expanding Leadership to Represent Diverse Communities
- MCOA – RFP Release of ACL Grant Opportunities (March 2018 expected)



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MCOA – New Grant: Caregiver Respite and Social Services Project *(see handout and check MCOA website – expected March release)*

- **Managed by:** MCOA
- **Funding:** The Administration for Community Living (ACL), Administration on Aging funded the Massachusetts Councils on Aging (MCOA) for a 3 year project, ending 8-31-20.
- **Goal:** Improve the well-being of caregivers of people with dementia by increasing their social connections with others in their community as well as with experts who can help a caregiver manage their new duties and roles.



MCOA's New ACL Grant's Project Activities



- **Family Support Counselors:** Alzheimer's Association MA/NH Chapter develops a new volunteer corps of Family Support Counselors (FSC) and Community Engagement.
- **Respite Companions:** Build a corps of volunteer respite companions making regular weekly 2-3 hour in-home visits and/or social outings with a person living with dementia.
- **New Memory Cafes:** Start additional Memory Cafes to provide “soft respite” that caregivers desperately need to feel less socially isolated.



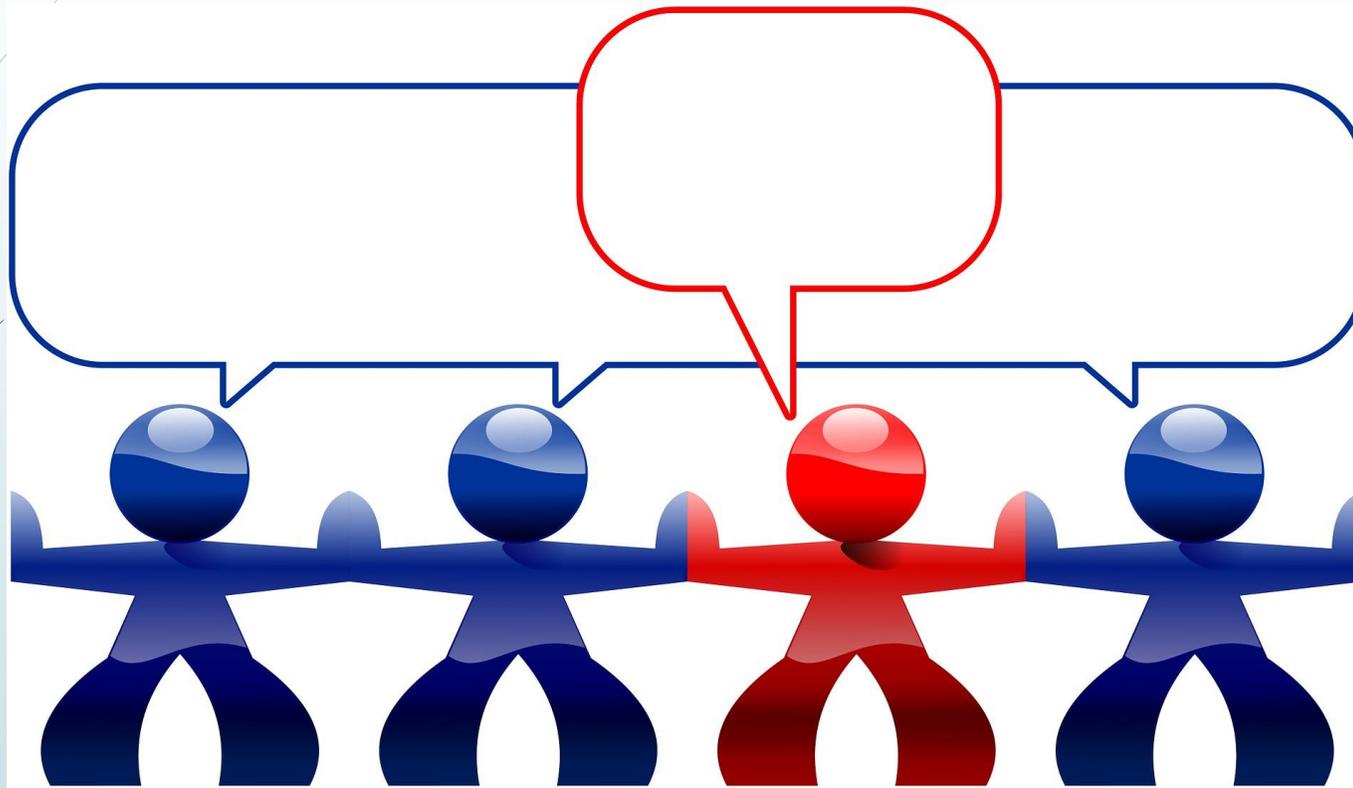
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Possibilities Made Real: Innovations in Programs Celebrating the Whole Individual

- ▶ [Music and Memory](#)
- ▶ [TimeSlips Storytelling](#)
- ▶ [Hip Hop](#)



Comments and Questions



Dementia Friendly Massachusetts



For More Information

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