Baystate Health | UMass Chan Medical School

NAVIGATING SOCIAL AND HEALTH CARE NEEDS FOR PEOPLE LIVING WITH DEMENTIA IN UNDERSERVED COMMUNITIES

Izckra Speight CHW, Beth Edelberg-Cardillo SW
Rebecca Symmons RN, Alina Sibley NP

Geriatrics House Calls, Division of Geriatrics and Palliative Care

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FYI:2024 Alzheimer's Stats

- Did you know that 5%-6% of all cases of ALZ. Disease are diagnosed as early onset, typically aged 45-60. Dementia has been diagnosed in people in their 30's, 40's and 50's. The youngest being 19!

Racial Disparity in Eldercare

Literature Review: Racial Disparity

- *NIH: Many factors contribute to the limited diagnosis of dementia in resource-poor areas. Three major obstacles (1) low health literacy (2) limited access to health care, and (3) the stigma associated with dementia.
- American Geriatrics Society: Trust is the confidence that the clinician has the relevant experience and will be devoted to the patient's well-being.
- Lack of sensitivity to, and respect for, cultural differences may compromise the end-of-life care for minority patients.

Literature Review

- *Attending health care appointments and participating in social activities are important for older adults, but these activities are often limited by transportation barriers.
- Frailty and living in an area with cracked or broken sidewalks were both associated with lower odds of public transportation use.
- *JAGS: In a study with a sample of insured Latinos, Limited English Proficiency (LEP)was significantly associated with the lack of a regular source of care, long waits, and difficulty getting information and advice by telephone.

Literature Review cont.

Did You Know?

The office of Social Security reports:

Every day 10,000 Baby Boomers turn age 65 in the USA. Are we prepared as a nation to provide care? For those who are or will be diagnosed with dementia? And Underserved?

Case Study Mr. J

85 yo Spanish speaking gentleman, resides in the community . He lives in a one-bedroom apartment subsidized by the housing authority. Daughter is his primary caregiver and health care proxy. Past medical history of diabetes, hypertension, depression, anxiety, and incontinence.

Mr. J dependent on ADLs and IADLs. His diabetes has been hard to control. Daughter reports he often demands high sugar at night. On multiple prescription medications, which daughter manages. He has had increased confusion, frequently repeating statements, talking to family members who are no longer living. In addition, he has missed several appointments at the clinic over past 6 months. Patient's carepartner reports he has had frequent falls, has been found wandering outside wearing only a brief.

For past 7 years his daughter has resided with him. She provides 24hr care and is currently sleeping on a mattress on the kitchen floor. Has been living with him unauthorized Therefore the patient is currently facing eviction. Her goal is to move her dad into a 2-bedroom apartment. She needs to complete DPOA however is unsure of her last address which was in the Dominican republic. Daughter does not speak English. To further complicate patient does not have an insurance with wrap around options. Dtr does not have access to computer. Neither patient dtr have any formal education.

Case Study Mr. J

BARRIERS

- No wrap around insurance coverage
- Language
- Health illiteracy
- No dementia diagnosis
- Financial
- No DPOA
- Caregiver lacks knowledge/resources to establish support
- Polypharmacy
- Little to no formal education

POSSIBLE SOLUTIONS

- Offer senior care or adult care options for wrap around support
- Provide documents in patients language, connect to an interpreter
- Educate patient/caregiver to manage chronic illness and geri syndromes
- Refer patient to geriatrician or neuropsych, complete cognitive testing, minicog, AD8, MMSE, provide diagnosis if appropriate, provide community support resources
- Refer to complete DPOA
- Establish connections between caregiver and community programs such as AAA's

Case Study Mr. J

CURRENT STATUS:

- NP completed cognitive testing, diagnosed Mr. J with vascular dementia.
- RN provided education re: diabetes management, coordinated nutrition consult with local AAA. Worked with caregiver to improve health literacy by providing education material printed simple and concise with photos for examples.
  - Safety adjustments made to prevent/discourage wandering. A safe return bracelet was ordered. Alarms placed on doors and windows. Patient now supervised 24/7
- SW worked together with CHW. Connection with notary for DPOA was made
  - Housing authority contacted; appeals submitted. However, they are moving forward with eviction.
  - Daughter is encouraged to apply for section 8 housing as well as other state and federal housing options.

Roles of the Interdisciplinary Team

Nurse Practitioner

- Team lead for Geri Pall House Calls program
- Geriatric assessments: 4 M's/Geri syndrome's and education (What Matters, Mentation, Medications, & Mobility) and f/u
- Recommendations re 4 M's care
- Collaboration amongst providers

Nurse

- Advanced Directives
- Med Recs/polypharmacy
- Screenings/Cognitive Testing
- Education 4 M's/Geri syndromes
- Collaboration with clinic RNs/ACO/other agencies

Community Health Workers (2)

- Program education
- Case management
- Community Resources/Referrals
- Community liaison
- Falls Education/Brain/body education
- IT/Hardware logistics

Social Workers (2)

- Difficult family dynamics/dementia or other
- Dementia with behaviors/safety concerns
- Education Brain/body health/habilitation
- High caregiver burden
- Social isolation
- Dementia Support Groups
- Complicated GOCC

MD

- Supports team with complex cases as needed
- Supportive role in IPT meetings
- Grant Administrator

Typical concerns/referrals

- Memory concerns
- Dementia confirmation
- Dementia with difficult behaviors
- Caregiver Burden
- Polypharmacy
- Multiple hospitalizations/no shows
- Recurrent falls
- Goals of Care

What We See

- Untimely diagnosis
- Lack of involved care-partner
- No shows, poor f/u
- Difficulty navigating complicated system
- Medication non-adherence
- Lack of insurance, transportation, social engagement
- Increased falls, mood changes, confusion, hospitalizations

Barriers

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- Cognitive changes
- Low educational attainment
- Cultural/language barriers
- Financial limitations
- Mobility changes/transportation access
- Sandwich generation

Systemic Barriers

- Structural racism/classism (conscious/unconscious)
- Fragmentation of care
- Lack of interpretation services
- Poor access to transportation services
- Lack of education about dementia for providers
- Lack of teams to take care of PLwD & families

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Navigating Barriers

What Can You Do?

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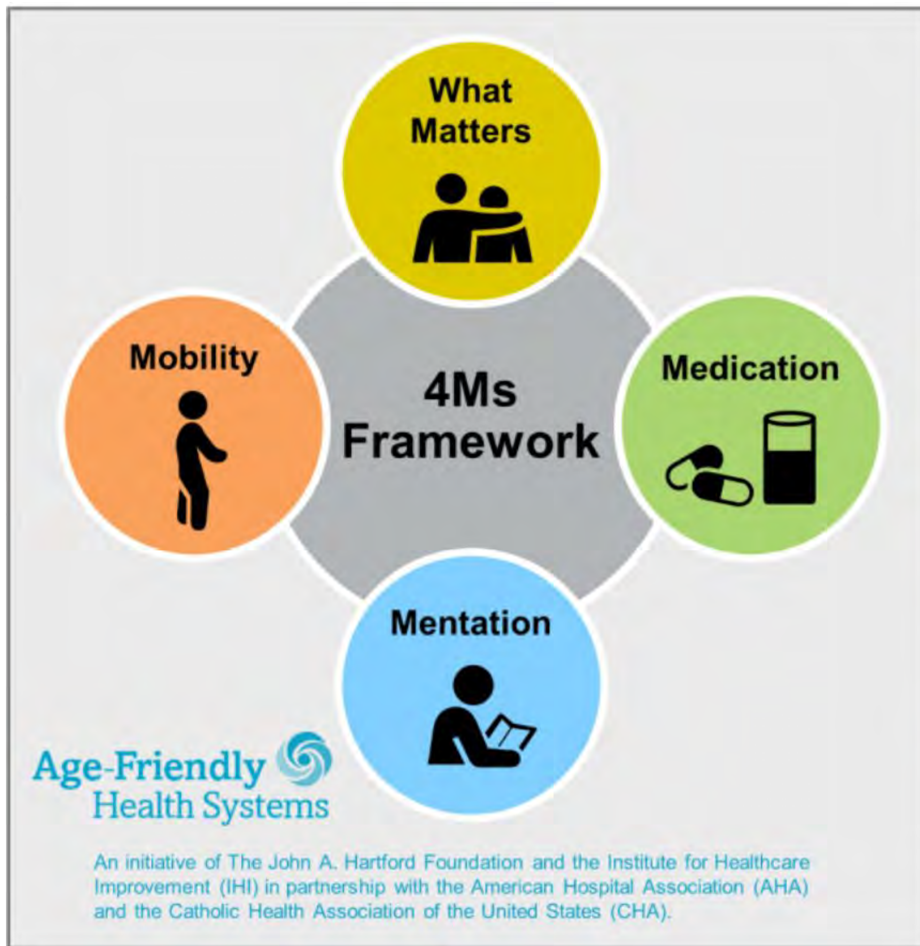
Age-Friendly Care



What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation

Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end of life care, and across settings of care

What Matters

Determine and document What Matters Most

- Meant to be ongoing conversations
- What are their goals
- Involve family/HCP

Complete advanced directives WITH education to patient and care partner, include:

✔ ***HCP*** *(How to Choose a HCP/How to Be a HCP)* *https://theconversationproject.org/get-started*

✔ ***Goals of care conversations*** *(tools: Conversation Starter kit, Serious Conversations)* *https://theconversationproject.org/get-started*

✔ ***Durable Power of Attorney*** *(DPOA vs POA)*

✔ ***MOLST***

✔ ***Funeral planning if appropriate*** https://www.homefuneralalliance.org/

Medications

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation

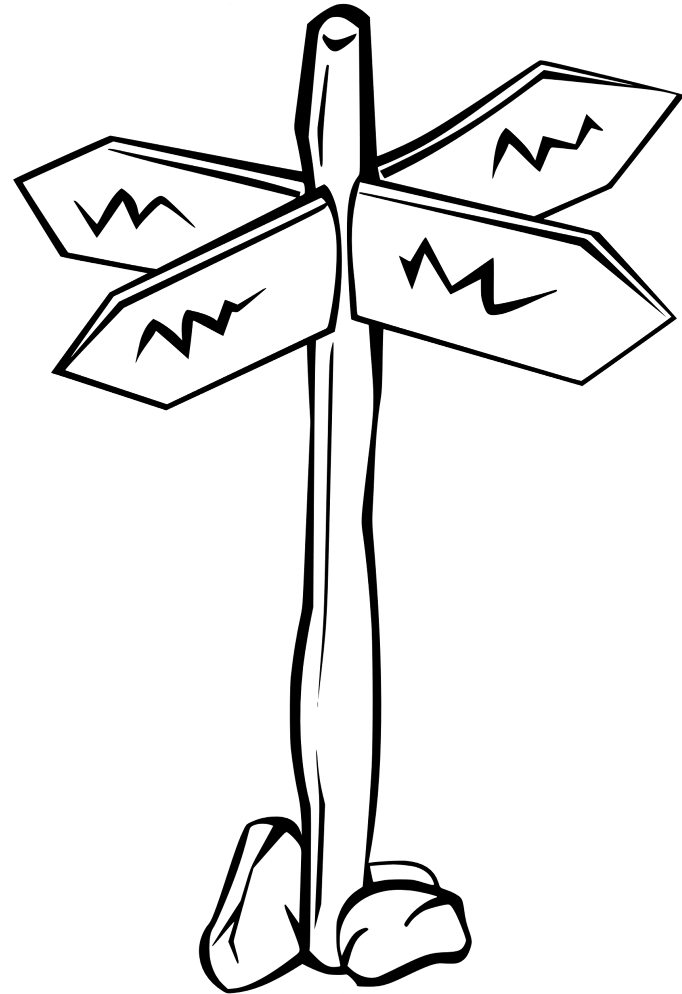
Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

Navigating Barriers cont.

- Engage family members early, educate about age-friendly care, encourage communication with pcp
- Provide handouts in appropriate language on brain body health, warning signs of dementia
- Refer to existing support services/organizations



The Home Visit

Medication Reconciliation in Home

- Requires sensitivity
- Clearer picture of health management
- Uncovers social concerns leading to health complications
- Vulnerability may lead to withheld information

Take a Look Inside

- Discuss what matters to patient/caregiver
- Gathering information
- Reviewing current system
- No judgment
- Assess health literacy
- Build trust

Gathering the Details

- Review active med list with patient/caregiver
- Any over the counter (OTC)
- Any herbal remedies
- Smoking/alcohol/drugs
- Storage
- organization

AGS Beers Criteria

Tables:

- Medications to Avoid
- Health Condition Considerations
- Drug Interactions
- Harmful Side Effects
- Renal (kidney) Impairment

Examples:

- Analgesics (meperidine)
- Antibiotics (ciprofloxacin with warfarin)
- Antihistamines (brompheniramine)
- Antipsychotics (any)
- Anxiolytics (benzodiazepines)
- Cardiac medications (disopyramide)
- Diabetes medications (chlorpropamide) Gastrointestinal medications (H2-blockers for delirium)
- And more

Storage & Management

How:

- Original rx bottles
- Weekly med box prefilled by self or caregiver
- Multi-packing system
- Electronic med management system

Other concerns:

- Complete a pill count
- Review dates obtained from pharmacy
- Assess patient/ caregiver knowledge of medication

Medication Management Options

Medication Side Effects/Safety Concerns

- Dizziness/imbalance
- Falls
- Overdose
- Low blood pressure
- Withdrawal
- Somnolence
- Kidney failure
- Liver failure
- Heart failure
- Confusion
- Insomnia
- Aggression

Communication

WHO

- Patient
- Care partner
- Care team
  - PCA
  - Case manager
  - Primary care doctor
  - Social worker
  - Community health worker
  - Visiting nurse

WHEN

- Visit to the clinic
- New diagnosis
- Visit to urgent care/emergency room
- Hospitalization
- Following outpatient procedure
- Any change in patient's health status

Normal Aging vs. Dementia

While some mild changes in cognition are considered a normal part of the aging process, dementia is not.

- Normal age-related declines are subtle.
- Affects the speed of thinking and attentional control.
- Abnormal aging declines in cognition are more severe.
- Thinking abilities, such as rapid forgetting or difficulties navigating, solving common problems, expressing oneself in conversation or behaving outside of social rules are affected.
- Abnormal aging may include the motor system resulting in excessive tripping, falls or tremors or hallucinations. (Lewy Body Disease)

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms.

What is “Habilitation Therapy” OR “Showing Families/Caregivers of PLwD How to Bring Joy into the Home”?

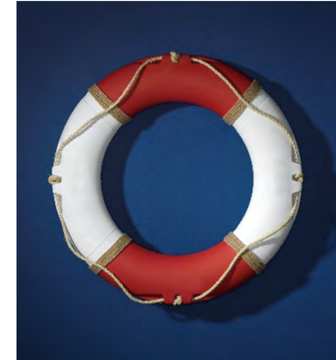
- Created by Paul Raia, PhD and Joanne Koenig, 1996
- Comprehensive behavioral approach to caring for people with dementia.
- Creates and maintains positive emotional states through the course of each day.
- Capabilities, independence and morale are consistently engaged to produce a state of psychological well-being.
- Difficult symptoms can be reduced or eliminated.
- May reduce the need for anti-psychotic medication.

The Bottom Line: Go with the Flow

- Does it matter if your mom thinks it's Tuesday when it's Friday? NO
- What does matter is thinking its summer when its winter and wearing a t shirt and no jacket to go outdoors.
- It only matters when it matters!!!!
- Your mom loved playing UNO, she no longer knows how to play but asks to play with you.
- Does it matter if she can't play? NO
- Go by her rules and it's a win-win.

What’s a Fiblet?

- When mom says “ I can’t go out because I’m waiting for dad to get home”. Reality is dad passed away 10 years ago
- Fiblet: Mom, dad went to the dentist, he’ll call when he’s coming back. He said to go without him.
- Fiblets are not lies, they are lifesavers!
- Do not think that you are lying to your loved one, you are lying to the disease.



Social Domain

- Structured activities are the engine of the social domain.
- PLwD who spend significant amounts of time doing “nothing” experience more psychiatric symptoms such as anxiety, depression, paranoia, delusions and hallucinations
- Time should be filled with opportunities for reminiscing and fun, not to just pass the time

Make Life Purposeful & Enjoyable

- Importance of activities
- Music/Dance
- Games
- Photo albums
- Arts and crafts
- Gardening
- Cooking/Prep
- Walks
- Take a drive
- Grandkid visits

Communication

- Approach
- Body language (smile)
- Eliminate the word “NO”
- Distraction redirect

Communication Domain

- This domain is the MOST critical in terms of eliciting positive emotions.
- One can never change behavior with words alone, instead strategize the approach to the person or to the environment.
  - Increase use of body language; encourage the use of gestures, demonstrations, signs, and pictures.

Functional Domain

- Case Study: Mr. J had great difficulty with his morning showers, being combative and angry. High caregiver stress.

Spend 5 minutes to save 20 rule

- Strategize: What relaxes Mr. J?
  - Examples: Play music Mr. J enjoys, have conversations on weather, religion, family, etc.
  - Now start the shower in a relaxed manner

Ask the Question?
Are Basic Needs Being Met?

- Hungry
- Thirsty
- Tired
- Pain/Sick/UTI
- Over/Under stimulated

Unmet Basic Needs Can Bring Behavioral Challenges

- Unmet needs (Behaviors are a form of communication) What is the PLWD trying to tell you? (i.e. Need to use bathroom, hungry, stomachache, bored, tired, jealous, frustrated, overwhelmed, pain, and dehydration)
- Other behaviors can be caused by: Delusions, hallucinations, paranoia, or misunderstood events.

Social Worker/Home Visit

- Background information
- Psycho-social history
- Safety Assessment:
- Driving? Should they be re-tested?
- Wandering/gotten lost?
- Firearms in home?
- Does the person smoke?/Smoke Alarms
- Does the person live alone? Life Line in Place?
- Who manages bills?
- Scams?

Social Worker Role

- Stove safety: Does the person know to turn off stove, history of smoke alarms going off, burnt food?
- Are there alarms in the home?
- Are there cameras in home, esp. if living alone
- Does the person know what to do in emergency, call 911?
- Personal hygiene?
- Socialization-Isolation/depression

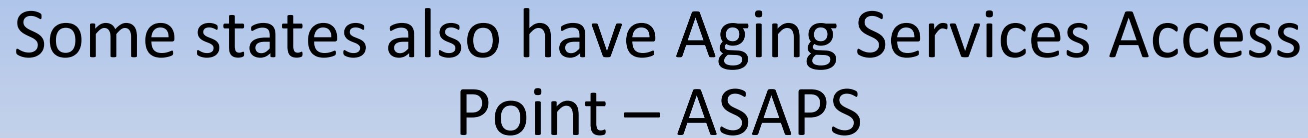
Social Work Role

- Are housing needs met? Accessibility?
- Do you need a HCP, DPOA, or guardianship?
- Educate, educate, educate!

Assessment of Needs

- Transportation
- Housing
- Social Isolation
- Caregiver Supports
- Mental health and Behavioral Health
- Health Care
- **CASEMANAGEMENT**

Where to start?



Senior Centers or Councils on Aging

Insurance

Medicare + Medicaid

Medicaid Wavers - Frail Elder Waver

Refer to financial counselors at hospitals or community health centers

Refer to programs offered Office of Elder Affairs like SHINE o SHIP that supports patients with enrollment to insurance

Medicaid Benefits

- Benefits:
  - Pays for Adult Day Health Programs
  - Pays for Lifeline
  - Pays for Medicare B premium based on your income
  - Pays Medicare D plan premium and lowers plan co-pays
  - Acts as a secondary insurance to Medicare eliminating the need for a Medicare supplement.

Medicaid Waivers

Also known as Home and Community Based waiver

Must be 60 or older

Must be an AAA/ASAP client (some exceptions: PACE and SCO programs can waiver their program participants)

Must meet clinical eligibility: frail enough to need nursing home care

Must meet Medicaid income and asset guideline

If married, eligibility is determined by looking at the frail spouse's income only, as if they were "divorced" financially.

AAA/ASAP

- Homemaking – State Home Care Program
- PCA services – Personal Care Management Program
- Adult Day Programs
- Nutrition Programs/Meals on Wheels
- Family Caregiver Support
- Adult Foster Care Program
- Long-Term Care and Assisted Living
- Ombudsman Programs
- Adult Protective Services
- Money Management Program
- Congregate & Supportive Housing
- Referrals to ALF, etc.

Medicaid Community Programs

They offer wrap around services with coordinated care

SCO (Senior Care Organization) is like an HMO for dual eligible consumers 65 or older. SCO's typically offer expanded benefits, over and above what Medicaid consumers would otherwise get.

PACE (Program of All Inclusive Care for Elders) is also like an HMO, consumers must stay in network. Consumers need to be 55 or older and frail enough to need nursing home care.

One Care, a program for 64 and younger dual eligible, operates much like a SCO. Consumers are automatically enrolled and must "opt out" if they do not want to participate in the plan they have been assigned.

Safety and Lifestyle Issues

- Medications
- Finances
- Driving
- Cooking
- Wandering
- Falls

https://www.alz.org/careplanning/downloads/safety-assess-checklist.pdf

Safety

MEDICATIONS – Family, Medminders, Multipacking

FALLS - Fall prevention interventions

WANDERING - Door and bed alarms

COOKING - Memory aids (911 Sign), stove shut off devices – FIREAVERT

DRIVING - Driving assessments

Falls

- CDC STEADI
- Home safety assessment program
- DMEs
- Personal Emergency Response Systems – Lifeline
- Home Modification Programs
- PT/OT referrals

Wandering

- **MedicAlert/Safe Return Bracelet**
- Waiver program
- Form HERE Sponsored Membership
  - Enrollment: $55
  - Service: $35/year

- **GPS tracking devices, electronic search and rescue technology.**

Safety Assessment - Driving

Is patient still driving?

- Ask family members to drive with older adult.
- AARP driving self-assessment tool.
- Local hospital programs.
- Discuss with medical. provider and request RMV medical evaluation form, if concerned.

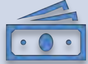
Transportation Services

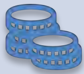
Many local Senior Centers have transportation options available. Please contact your local town center or call your AAA.

Public transportations often offers Senior Van Services or Paratransit Services for people with disabilities. Call your local transit authority.

Private organizations offer transportation services.

Finances


Don’t ignore the financial responsibility!


Bill paying - Money management program at AAA

Designate Durable Power of Attorney - most bills (credit card agencies/cable/electricity, etc)

Representative Payee - social security

Authorized Representative - insurances

Alzheimer's Association

- **Care Consultation -** personalized to the needs of individuals and families, and available at no cost to families.

- **Dementia Care Coordination (DCC)**

  in MA and New Hampshire –

  HIPAA compliant online referral forr

https://hipaa.jotform.com/ALZ_DCC/referralform

Alzheimer's Association Helpline

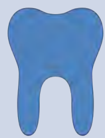
- 1(800) 272-3900. (live chat and online form av.)
- Available 365 days 24/7
- Specialists and master's-level clinicians
- More than 200 languages
- Anyone with questions about caring for someone with memory problems.
- Habilitation therapy support

Veterans Benefits Advisor

- Located in each Town Hall
  - scroll to the bottom of website to search by zip code

Misc

Eye Care America/ Prevent blindness. Free services. Link here



Dental - Community clinics, sliding scale

Health Care for the Homeless - clinic.

Immigrations - Catholic Charities Agencies

Legal Services - Local bar associations

Acknowledgment/Summary

Our team: NP, RN , SW and CHW's that serve the underserved elderly.

- Supported by grant
- Replication difficult

However…

- Available resources: case manager, SW, admissions/discharge worker
- Local Area Agencies on Aging (AAA or ASAPs), veterans administration, Alzheimer's Association, boards of health have trained staff for underserved elderly
- Tools and resources provided to further assist you in fostering further community education and collaboration
- Essential element for healthier older adult communities

Resources

- Alzheimer's Association (Helpline, Dementia Care Coordination, Support groups, Educational webinars:1-800-272-3900 or alz.org)
- Careblazers.com (great you tube videos, free or join for comprehensive program) https://www.youtube.com/dementiacareblazers
- https://www.aao.org/eyecare-america
- https://www.alz.org/help-support/resources/helpline
- https://www.catholiccharitiesusa.org/what-we-do/immigration-services/
- https://www.cdc.gov/steadi/patient.html
- https://www.gsssi.org/files/content/Bid%20Specifications/AAA%20Plan%20FINAL.pdf
- Frail Elder Waiver (FEW) | Mass.gov
- https://www.fireavert.com/
- https://www.mass.gov/info-details/aging-services-network#aging-services-access-points-(asaps)-and-area-agencies-on-aging-(aaas)-
- https://www.mass.gov/info-details/masshealth-members-and-benefits
- https://www.medicalert.org/medical-id/medical-ids-bracelets/?categories=bracelets
- https://ftds.phhp.ufl.edu/us/Fitness-to-Drive Screening Measure Online
- https://www.mass.gov/rmv Medical Evaluation Form

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