

# Annual Report of the Alzheimer’s Advisory CouncilDate: April 2021

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## Introduction

The Massachusetts Alzheimer’s Advisory Council (Council) was established under Massachusetts General Laws, Chapter 6A, Section 16AA and Chapter 220 of the Acts of 2018 to advise the Executive Office of Health and Human Services (EOHHS) and the Legislature on Alzheimer’s disease policy. This report is in response to Section 16AA’s requirement that the Council submit its first annual report by no later than March 1, 2021. Section 16AA also directs the Council to develop a state plan on Alzheimer’s by March 1, 2021. In 2021, the Council, which began meeting on March 19, 2019, will continue to meet at least quarterly. In February 2021, the Council’s work culminated in the publishing of the *Massachusetts State Plan on Alzheimer’s Disease and Related Dementias, April 2021* (Alzheimer’s State Plan), which wasprovided to the legislature along with this annual report.[[1]](#footnote-1)

According to the National Institute on Aging, “Dementia is the loss of cognitive functioning (thinking, remembering, and reasoning) and behavioral abilities to such an extent that it interferes with a person's daily life and activities.”[[2]](#footnote-2) Although dementia has many causes, Alzheimer's disease is the most common cause and the vast majority of people who develop dementia are age 65 or older.[[3]](#footnote-3)

There are about 130,000 people in Massachusetts living with dementia[[4]](#footnote-4) supported by over 340,000 family caregivers.[[5]](#footnote-5) Because it is estimated that 50 percent of Americans living with dementia are undiagnosed,[[6]](#footnote-6) it is likely that there are at least 130,000 more residents living with this condition without a formal diagnosis. Furthermore, an estimated 40% of individuals diagnosed with Alzheimer’s Disease and Related Dementias (ADRD), or their caregivers, are unaware of the diagnosis.[[7]](#footnote-7)

The Alzheimer’s Advisory Council provides opportunities for policymakers to work with a wide range of stakeholders from across the state to pool their expertise and resources. It will continue to strive to ensure that the Commonwealth’s residents affected by dementia receive the support, services, and care they need to live healthy and meaningful lives.

## Alzheimer’s Advisory Council

The Secretary of the Executive Office of Health & Human Services serves as chair of the Council. On February 24th, 2020, the Secretary designated the Secretary of the Executive Office of Elder Affairs (EOEA) to serve as the Chair. This change enabled an advocate living with dementia to assume EOEA’s seat, changing his Council status from honorary member to voting member. This was an important step.

As shown in Appendix A, the 17-member Council is comprised of a diverse group of public health professionals, clinicians, healthcare providers, researchers, legislators, dementia advocates, and caregivers.

## Alzheimer’s Advisory Council Process

The Council convened nine public meetings between March 2019 and February 2021.[[8]](#footnote-8) It reviewed the experiences of people affected by dementia; reviewed the Commonwealth’s dementia policies, programs, and services; and identified priority areas to address. After a five-month hiatus due to the COVID-19 outbreak, seven workgroups led by Council members convened a series of meetings and presented to the Council their recommendations for Years 1-2 (Calendar Years 2021-2022). The seven workgroups are listed below in alphabetical order:

1. Caregiver Support and Public Awareness
2. Diagnosis and Services Navigation
3. Equitable Access and Care
4. Physical Infrastructure
5. Public Health Infrastructure
6. Quality of Care
7. Research

During its public meetings, the Council discussed and voted to approve or change each workgroup’s recommendations for Years 1-2. This work culminated in the development of the Alzheimer’s State Plan, April 2021, which comprises recommendations and implementation plans approved by the Council.

Although the Council’s focus was on Years 1-2, each workgroup developed recommended strategies for Years 3-4 and Year 5 and beyond. Those strategies will be presented to the Council during future meetings, refined, and finalized.

The diagram below illustrates the flow of the Council’s work.

**Alzheimer’s Advisory Council - Workflow**

|  |  |  |
| --- | --- | --- |
| **Timeframe** | **Activities** | **Outcome** |
| **March 2019 to December 2019** | * Listened to individuals and families affected by dementia
* Reviewed and discussed programs, services, challenges, and issues
 | **Gathered Information** |
| **January 2020 to February 2020** | * Identified seven workstreams
* Formulated preliminary goals by workstream
 | **Workstreams Identified** |
| **March 2020 to July 2020** | * Placed Council work "on hold" due to COVID-19 outbreak
 | **Five-month Hiatus** |
| **August 2020 to September 2020**  | * Identified Council members to lead workgroups and recruited stakeholders to participate
* Began forming and convening workgroups sequentially
 | **Workgroups Formed** |
| **October 2020 to February 9, 2021**  | * Workgroups identified and prioritized issues, and presented recommendations to Council
* Council discussed and voted to adopt strategies to include in Alzheimer's State Plan
 | **Alzheimer’s State Plan Finalized** |

## Summary of Goals and Recommendations, 2021-2022

The Council adopted the following goals and recommendations for Calendar Years 2021 and 2022 (i.e., Years 1 and 2). The Alzheimer’s State Plan includes additional information such as implementation plans for Years 1 and 2 and preliminary implementation plans for Years 3 and 4 and Year 5 and beyond. The Alzheimer’s State Plan also lists the individuals who participated in each of the workgroups.

| **Workgroup** | **Goals** | **Recommendations** |
| --- | --- | --- |
| **Caregiver Support and Public Awareness** | * Identify short-term approaches to improve awareness of the pathways to available supports and services for dementia caregivers and their care partners
* Compare and evaluate the experiences of caregivers of people living with dementia as they navigate the Commonwealth’s system of supports and services
 | * Make and distribute three videos (English, Portuguese, Spanish,) of caregivers talking about the help they got and how they got it
* Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website an overview of statewide pathways, services, and supports for people living with dementia and their caregivers
* Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner
 |
| **Diagnosis and Services Navigation** | * Increase the number of people living with dementia who are diagnosed, informed of their diagnosis, and able to effectively attain helpful information, services, and care planning
 | * Significantly increase the numbers of undiagnosed or cognitively impaired residents who are diagnosed with dementia and informed of their diagnosis
* Ensure that after a dementia diagnosis, individuals and their families have access to comprehensive information and care planning services
 |
| **Equitable Access and Care** | * Close gaps in equitable access to information, supports, services and care
 | * Close informational gap and address fragmentation of care access, care planning, and dementia services
 |
| **Physical Infrastructure** | * Identify and incorporate dementia-friendly physical infrastructure into age-friendly physical infrastructure work
 | * Raise awareness of the importance of age- and dementia-friendly design
* Incorporate age- and dementia-friendly scoring into all state-funded physical infrastructure projects
 |
| **Public Health Infrastructure** | * Respond to the CDC’s Notice of Funding Opportunity (NOFO) around implementing BOLD (Building Our Largest Dementia) Infrastructure
 | * Seek CDC funding to form a Public Health Workgroup to review the CDC’s Healthy Brain Initiative’s Road Map; engage stakeholders, review information; and present recommendations to the Alzheimer’s Advisory Council
 |
| **Quality of Care** | * Identify gaps in quality of care for people living with dementia in Massachusetts and strategies to close those gaps
 | * Develop a person-directed care plan framework and template
* Develop a plan that ensures that staff in primary care, long-term care and home-care settings across the state receive the training and support needed to build and retain interprofessional dementia care teams
 |
| **Research** | * Advance dementia research in Massachusetts
 | * Increase diversity of dementia research and researchers
 |

## Progress Made on Requirements of Chapter 220 of the Acts of 2018

As part of its deliberations, the Council reviewed the status of requirements in Massachusetts General Laws, Chapter 6A, Section 16AA from Chapter 220 of the Acts of 2018.

| **Requirement** | **Status**  |
| --- | --- |
| Creates permanent statewide advisory council and an integrated state plan to effectively address Alzheimer’s disease | The [Alzheimer’s Advisory Council](https://www.mass.gov/orgs/alzheimers-advisory-council) has been established and as required, provided the state legislature with the Alzheimer’s State Plan.  |
| Requires content about Alzheimer’s and related dementias be incorporated into physicians, physician’s assistants, registered nurses, and licensed practical nurses continuing education programs that are required for the granting or renewal of licensure | All licensees will have until November 7, 2022 to complete this one-time requirement. Approximately 63,392 out of 175,197 registered nurses, licensed practical nurses, and physician assistants licensees have completed the required training as of March 2021. Several organizations are offering CME courses that fulfill this requirement including the [Massachusetts Medical Society](http://www.massmed.org/ALZ/), [Massachusetts Health & Hospital Association](https://mhalink.thinkific.com/courses/alzheimer-s-and-related-dementias), [Massachusetts Nurses Association](https://www.massnurses.org/nursing-resources/continuing-education), and the [Alzheimer’s Association](https://training.alz.org/products/4043/?_ga=2.161701244.173323166.1597930398-1732199026.1547496008). |
| Requires doctors to share an Alzheimer’s diagnosis and treatment plan with a family member or legal personal representative within the existing framework of federal and state privacy laws | In 2021, the Alzheimer’s Association, MA/NH will work with leadership of the executive branch and the Board of Registration in Medicine to issue guidance.    |
| Requires hospitals that serve an adult population to have an operational plan in place for recognizing and managing individuals with dementia within three years of the laws’ enactment | This requirement is due October 1, 2021. Much of this work has been delayed due to hospitals responding to COVID-19. The Massachusetts Health & Hospital Association (MHA) led a workgroup to develop an action plan document including tools and resources. Their [report](https://www.mhalink.org/MHA/MyMHA/Communications/PressReleases/Content/2018/MHA_Press%20ReleaseAlzheimersRelatedDementiasGuidance.aspx) was published in 2018.  |
| Requires Elder Protective Services (EPS) caseworkers to be trained on Alzheimer’s disease | EOEA has developed and delivered comprehensive dementia training for EPS workers. All EPS workers in MA have completed the dementia training and new workers take the online training within their first month. |

## Assessment of Services and Care for People Living with Dementia

As part of its deliberations, the Council reviewed and discussed issues around the availability of, and access to services and supports for people living with dementia. When the Council first began convening, it reviewed and discussed the state supported programs (listed in Appendices A through D of this report). This information, along with knowledge gained from discussions with people living with dementia and caregivers, helped the Council to formulate preliminary recommendations which led to the formation of workgroups.

The workgroups began by examining access, availability, and quality of state-supported and other information, services, and care for people living with dementia and their caregivers. They identified gaps and prioritized areas of concern that led the workgroups to develop the goals and recommendations listed in this report.[[9]](#footnote-9) The implementation plans, responsible organizations, and other information included in the Alzheimer’s State Plan, April 2021 (the Plan) intend to close the gaps and address the challenges identified by the Council and its workgroups.[[10]](#footnote-10) For each recommendation, the workgroups identified expected outcomes for Years 1-2 (Calendar Years 2021 and 2022). The Council will monitor and evaluate progress made on those outcomes on an ongoing basis while the responsible organizations implement the strategies outlined in the Plan.

## Younger-Onset Alzheimer’s and Related Dementias

Alzheimer’s disease and related dementias (ADRD) are not just experienced by older adults. Younger-onset (also known as early-onset) ADRD affects people younger than age 65. About 5 percent of Americans diagnosed with ADRD have younger-onset dementia.[[11]](#footnote-11) Many people with younger-onset dementia are in their 40s and 50s. When they first experience dementia, many of these younger adults have children, careers, and caregiving responsibilities, making life for these individuals particularly challenging. The number of Massachusetts residents living with a diagnosis of younger-onset dementia is estimated at approximately 6,500 individuals.[[12]](#footnote-12)

The Council met with a panel of individuals living with younger-onset ADRD in Massachusetts and gathered information about their experiences with care providers, service providers, and others. Indicated below are quotes from the panel members. They not only reflect common experiences among the panel members, but also reflect similar issues experienced by older adults living with dementia:

*“Upon diagnosis, I was given test results and medication by my doctor, but no referrals to other resources or information”*

*“Education and recurring training for health professionals is very important”*

*“When someone gets a cancer diagnosis, they are connected with supports and counseling, but with a dementia diagnosis, they do not receive such resources”*

*“It’s important for those of us who have the disease to have support but it’s also important to support the family members who are dismayed and confused and are taking on the burden of managing the household”*

*“Navigating the system is still unbelievably challenging”*

There was a general feeling among individuals on the panel that there are services and supports available to older adults living with dementia that would be helpful yet unavailable to them due to their age. This issue needs further investigation due to the complexities of eligibility requirements for some programs, a lack of public knowledge about available resources and services, and the unique challenges faced by individuals within this age group.

Related to these issues is a common theme raised by Council members and their workgroups. Specifically, there is a general lack of knowledge about dementia services and supports among people of all ages as well as among health care providers. Stakeholders participating in the Council’s workgroups reported that programs that are helpful to individuals and their caregivers (regardless of age) are fragmented and difficult to navigate. Adding to the confusion, especially for individuals with younger-onset dementia, are differing eligibility requirements for different programs. Some of those requirements are based on age with age 60 being a common threshold.[[13]](#footnote-13)

The Alzheimer’s State Plan, April 2021 includes an action plan for addressing these issues. It is intended that following the implementation of the action plan, Massachusetts residents *of all ages* living with dementia will have a clear understanding of help available to them and how to get it. The action plan also includes a section entitled, “Equitable Access and Care,” which includes strategies to ensure that the needs of Massachusetts residents *within every underrepresented group[[14]](#footnote-14)* are considered as the specific recommendations within the Alzheimer’s State Plan are being implemented.

So as not to single out one underrepresented group more than any other, the Council will comply with the requirements associated with younger-onset dementia in MGL, Chapter 6A, Section 16AA(b)(2) by devising and implementing an approach that:

* defines equity for this population in a manner that is integrated within the context of equity and inclusion for all underrepresented groups,
* ensures that the needs and challenges faced by all underrepresented groups within the younger-onset population are understood, and
* views work associated with this uniquely diverse population as a valuable opportunity to build an approach to define and address equity and inclusion within and among all underrepresented groups affected by dementia.

## Unforeseen Positive Outcomes from the Council’s Work

The Council’s discussions inspired members and partnering organizations to take positive action outside of formal Council participation. Examples appear below.

* Pandemic constraints and procedures can be confusing to individuals living with ADRD. A team from EOEA and the Massachusetts Councils on Aging (MCOA) worked with the Alzheimer’s Association, MA/NH to develop and distribute a tip sheet on COVID-19 testing for caregivers of individuals living with dementia.[[15]](#footnote-15)
* As a partner in the Dementia Friendly Massachusetts movement, EOEA convened an informative and engaging discussion with attendees of a meeting of the Massachusetts Association of Regional Planning Agencies (MARPA). The discussion helped raise awareness among municipal and regional planners around the characteristics, importance, and benefits of incorporating age- and dementia friendly design into physical infrastructure such as streets and outdoor spaces, parks and recreational areas, and commercial and residential buildings.
* As a result of feedback received from caregivers who shared their experiences with the Council about somewhat confusing automated telephone messages at some of the Aging Services Access Points (ASAPs), EOEA reviewed the automated messages and immediately began working with the ASAPs to implement improvements.
* The process of applying for a CDC grant helped DPH understand the importance of including the caregiver module in the 2021 implementation of the Behavioral Risk Factor Surveillance System (BRFSS). EOEA will be funding the inclusion of this module for one year to gather data specific to Massachusetts, which will also enable the state to compare its information with other states.
* Motivated by Council discussions about caregiver stress, EOEA rolled out Alternate Site Day Program services with ASAP executive directors. These services are comprised of a minimum of 2 hours of day program-like support in the home provided by a home health aide, that includes support for activities of daily living (ADLs).

## Appendices

### Appendix A: Alzheimer’s Advisory Council Members

|  |  |
| --- | --- |
| **Alzheimer’s Advisory Council**  | **Seat** |
| **Secretary Elizabeth C. Chen, PhD, MBA, MPH** -Secretary, Executive Office of Elder Affairs and Chair of Alzheimer’s Advisory Council | Secretary, EOHHS  |
| **Susan Antkowiak** - Vice President of Programs & Services, Alzheimer’s Association, Massachusetts/New Hampshire (MA/NH) | State Alzheimer’s Organization |
| **Michael Belleville** -Dementia Advocate | Secretary, EOEA  |
| **Maura Brennan, MD** - Program Director, Baystate Health Geriatric Workforce Enhancement Program | Alzheimer’s Researcher 1 |
| **Andrew Budson, MD** - Chief of Cognitive & Behavioral Neurology, Associate Chief of Staff for Education and Director of the Center for Translational Cognitive Neuroscience at Veterans Affairs (VA) Boston Healthcare System, Associate Director for Research at Boston University Alzheimer’s Disease Center, Lecturer in Neurology at Harvard Medical School, Medical Director of the Boston Center for Memory  | Secretary, Veterans’ Services  |
| **Robin Callahan** - MassHealth (Retired) | Director, Office of Medicaid |
| **Representative Tricia Farley-Bouvier** - Vice Chair, Joint Committee on Elder Affairs | House Chair, Elder Affairs |
| **Jonathan Jackson, PhD** - Founder and Executive Director, Community Access, Recruitment, & Engagement Research Center, Massachusetts General Hospital, Instructor in Neurology at Harvard Medical School | Alzheimer’s Researcher 2 |
| **Senator Patricia Jehlen** - Co-chair, Joint Committee on Elder Affairs | Senate Chair, Elder Affairs |
| **Rhiana Kohl** - Caregiver | Alzheimer’s Patient Advocate 1 |
| **James Lavery** - Director, Bureau of Health Professions Licensure, Dept. of Public Health (DPH) | Commissioner, DPH |
| **Barbara Meehan -** Alzheimer’s Advocate/Former Caregiver | Alzheimer’s Caregiver 1 |
| **Hector Montesino** - President, Embrace Home Care Services | Alzheimer’s Patient Advocate 2 |
| **Bernice Osborne-Pollar** - Caregiver | Alzheimer’s Caregiver 2 |
| **Linda Pellegrini, MS, GNP-BC** - Geriatric Nurse Practitioner, UMass Memorial Medical Center | Health Care Provider 1 |
| **Heather Sawitsky** -Fox Hill Village Homeowners Corporation | Health Care Provider 2 |
| **James Wessler** –CEO, Alzheimer's Association, MA/NH and New England Regional Leader | State-basedAdvocacy Organization |

### Appendix B: State Supported Services for Individuals Living with Dementia[[16]](#footnote-16)

| **Service** | **Program** | **Description** | **Eligibility if** **< 60 years old** | **Eligibility if****≥ 60 years old** |
| --- | --- | --- | --- | --- |
| **Navigation and Counseling** | [***Massachusetts Family Caregiver Support Program***](https://www.mass.gov/family-caregiver-support-program) | Assist with navigation to resources and counseling, as well as some direct service assistance  | If diagnosed with **dementia** | Available to **all caregivers** of individual age 60 or over  |
| **Navigation and Counseling** | [***Options Counseling***](https://www.mass.gov/service-details/options-counseling-program) | Provides information about public and private long term services and supports; most counselors are designated Dementia Friends and have completed dementia training | If diagnosed with **dementia** | Available to all 60 and over |
| **Nutrition** | ***Congregate Meals*** | Addresses nutrition, food insecurity, chronic disease, and social isolation through congregate meals.[[17]](#footnote-17) Individuals do not have to be receiving state home care services to receive a meal through the nutrition program | People with disabilities who live in elder housing facilities where congregate meals are served – Includes a spouse at any age | Available to all age 60 and over and their spouses at any age |
| **Nutrition** | ***Home Delivered Meals*** | Addresses nutrition, food insecurity, chronic disease, and social isolation through home-delivered meals. Individuals do not have to be receiving state home care services to receive a meal through the nutrition program | Individuals with disabilities who live at home with their caregivers who are age 60 or older | Available to all age 60 and over  |
| **Elder Abuse Prevention** | ***Protective Services Program*** | Statewide system for receiving and investigating reports of elder abuse and for providing protective services to older adults | Not eligible | **Clinical** eligibility |
| **Elder Abuse Prevention** | ***Money Management*** | Assists those who have difficulty managing personal household budgets, paying bills, keeping track of banking records, intervening with creditors and handling other issues related to personal finances | Not eligible | **Income** and **clinical** eligibility |
| **Insurance Navigation and Support** | [***Serving the Health Insurance Needs of Everyone (SHINE)***](https://shinema.org/) | A state health insurance assistance program that provides free health insurance information, counseling and assistance to Massachusetts residents with Medicare and their caregivers  | If Medicare beneficiary | Available to all turning **65** and over |
| **Insurance Navigation and Support** | [***Prescription Advantage***](https://www.mass.gov/prescription-drug-assistance) | Provides supplemental assistance, based on income, for its members with Medicare prescription drug coverage, and primary prescription insurance coverage comparable to Medicare Part D and for those not eligible for Medicare | If meeting MassHealth **disability guidelines** and income **eligibility**  | Income eligibility for those **65** and over |
| **In-Home supports** | [***State Home Care Program***](https://www.mass.gov/in-home-services)*(See Appendix E for more information)* | Provides in-home and community supports and services, including personal care, companionship, meal preparation, laundry and assistance with activities of daily living and instrumental activities of daily living | If diagnosed with **dementia**, as well **clinical** **eligibility** | **Clinical** **eligibility** |
| **Evidence-Based Programs** | [***Savvy Caregiver Training***](https://www.mass.gov/news/training-for-families-caring-for-individuals-living-with-dementia) | A series of six evidence-based training sessions for family caregivers of persons with dementia  | If living with dementia | If living with dementia |

### Appendix C: Additional Services Available by Insurance Type

In addition to the state supported programs listed above, some services are covered by insurance. They vary depending on the type of insurance someone has.

**MassHealth**

**Eligibility**

Applicants must demonstrate MA residency, verified citizenship or immigration status, and [financial eligibility.](https://www.mass.gov/service-details/eligibility-for-health-care-benefits-for-masshealth-the-health-safety-net-and) Additional eligibility rules for **Long Term Services and Supports (LTSS)** include an asset test and clinical eligibility.

**MassHealth members living with Alzheimer’s disease and related dementias have access to a wide range of services:**

***Community-Based Long-Term Services and Supports (LTSS)***

Supports intended to enable individuals to live with independence and dignity in their communities. These services include: Adult Day Health, Adult Foster Care, Continuous Skilled Nursing, Day Habilitation, and the Personal Care Attendant (PCA)Program. *(See Appendix D**for more information)*

***Facility-Based Long-term Services and Supports (LTSS)***

Nursing Facility Services (>100 days), and Chronic Disease Rehabilitation Hospital Services (>100 days)

***Other Covered Services***

Durable Medical Equipment, Oxygen and Respiratory Therapy, Home Health Agency, Hospice Services, Therapy Services (Physical Therapy, Occupational Therapy, Speech Therapy)

**MassHealth members may be able to enroll in a special health plan or a home and community-based services (HCBS)** **waiver program. These programs are offer care coordination and case management services:**

* [**Senior Care Options (SCO)**](https://www.mass.gov/senior-care-options-sco)**:** For dual-eligible (MassHealth and Medicare) individuals over 65. SCO combines health services with social support services. SCO provides care coordination and specialized geriatric support services, along with respite care for families and caregivers.
* [**One Care**](https://www.mass.gov/one-care)**:** For dual-eligible (MassHealth and Medicare) individuals under age 65. One Care provides members with a care coordinator, one care plan, and prescription coverage through one plan.
* [**Program of All Inclusive Care for the Elderly (PACE)**](https://www.mass.gov/program-of-all-inclusive-care-for-the-elderly-pace)**:** For individuals 55 or older who meet the level of care for a nursing facility but prefer to remain in the community. PACE provides a wide range of medical, social, recreational, and wellness services to eligible participants.
* [**The Frail Elder Waiver**](https://www.mass.gov/info-details/frail-elder-waiver-information-for-applicants-and-participants) **(FEW):** For individuals age 60 and older who meet the level of care for a nursing facility but prefer to remain in the community. Services are based upon a Service Plan. Examples of services include Alzheimer’s/Dementia Coaching, chore, companion, home delivered meals, laundry, respite, and transportation.
* [**The Moving Forward Plan (MFP) Waivers**](https://www.mass.gov/info-details/moving-forward-plan-mfp-waivers#about-the-program-): For individuals living in a nursing facility or chronic disease, rehabilitation, or psychiatric hospital. MFP participants are eligible for supports and services designed to help them move back to their community. There are two versions of this waiver program:
	1. *MFP Residential Supports (MFP-RS): individual must need residential support services with staff supervision 24 hours a day, 7 days a week.*
	2. *MFP Community Living (MFP-CL): individual must be able to move to their own home or apartment or to the home of someone else and receive services in the community.*

**Medicare**

**Eligibility**

Individuals qualify for Medicare at age 65, or if they are under 65 and have been receiving Social Security disability benefits for at least 24 months (need not be consecutive).

**Specialty care options for individuals with Alzheimer’s disease and related dementias**

Medicare will pay for some, but not all, care costs associated with Alzheimer’s or dementia:[[18]](#footnote-18)

* Medicare covers inpatient hospital care and some of the doctors' fees and other medical items for people with Alzheimer's or dementia who are age 65 or older
* Medicare Part D covers many prescription drugs
* Medicare will pay for up to 100 days of skilled nursing home care under limited circumstances (custodial long-term nursing home care is not covered)
* Medicare will pay for hospice care delivered in the home, a nursing facility or an inpatient hospice facility for those with dementia who are determined to be near the end of life
* Medicare will pay for cognitive assessment and care planning services for individuals diagnosed with Alzheimer’s disease, other dementias, or mild cognitive impairment

**Commercial Coverage**

**Specialty care options for individuals with Alzheimer’s disease and related dementias**

Commercial plans in Massachusetts typically cover:

* Home health care
* Occupational Therapy (OT)
* Physical Therapy (PT)
* Speech Therapy (ST)
* Durable Medical Equipment (DME)

Additionally, some commercial insurance plans in Massachusetts have partnered with the [Alzheimer’s Association MA/NH chapter](https://www.alz.org/manh) to provide Dementia Care Consultants.

### Appendix D: MassHealth Community-Based Long Term Services and Supports

|  |  |  |
| --- | --- | --- |
| **Program** | **Description** | **Eligibility** |
| ***Adult Day Health (ADH)*** | Services for individuals with cognitive impairment and their caregiver; a day program providing nursing and therapeutic services and oversight, including therapy, nutrition, dietary counseling, case management, activities, and assistance with ADLs[[19]](#footnote-19) | Over the age of **60** or a diagnosis of **younger-onset Alzheimer's** and needs assistance with a minimum of **4 IADLs [[20]](#footnote-20)** |
| ***Adult Foster Care (AFC)*** | Designed to assist with ADLs and IADLs. Persons receiving AFC services live with an AFC caregiver, who is responsible for the person's care 24 hours a day. AFC service recipients also receive visits from a multidisciplinary team consisting of, at a minimum, a registered nurse and a care manager | Requires assistance with at least **1 ADL** |
| ***Continuous Skilled Nursing (CSN)*** | As nurse visit of more than 2 consecutivehours per visit provided to members in their home. Members who need CSN also receive care management | Requires medically necessary skilled need of **more than two continuous hours** per visit |
| [***Personal Care Attendant Program (PCA)***](https://www.mass.gov/masshealth-personal-care-attendant-pca-program) | A self-directed personal careprogram providing assistance with personal care needs (i.e., assistance withADLs and IADLs)  | Persons with **permanent** or **chronic disabilities** (including eligible individuals living with **dementia**) who require assistance with **2 or more ADLs** |
| ***Home Health Services*** | Provides nursing visits, home health aide services, and physical, speech, and occupational therapy to members in their homes and communities  | Requires a need for skilled nursing, therapy services, or assistance with ADLs |

### Appendix E: Executive Office of Elder Affairs (EOEA) Home Care Program

[**The Home Care Program**](https://www.mass.gov/in-home-services) provides care management and in-home support services to help older adults, people with disabilities, and people with Alzheimer’s Disease or related dementia successfully age in place within Massachusetts.

**Eligibility**

Eligibility for the Home Care Program is based on age, residence, and ability to carry out daily tasks including but not limited to, bathing, dressing and meal preparation. Care management and in-home services support adults 60 years and older or residents aged under 60 with Alzheimer’s disease who need respite services. Cost share amounts for support services through the Home Care program are determined based on income.

Applicants must be living at home within Massachusetts outside of an institutional or certified assisting living setting.

**Programs**

There are four versions of the home care program that are available to all Massachusetts residents, including those under 60 who are diagnosed with dementia, based on clinical and income eligibility.

1. ***Enhanced Community Options Program******(ECOP):*** Supports those who meet the clinical eligibility for nursing homes but who are ineligible for MassHealth Standard. The goal of the program is to delay or prevent nursing home placement with supports for Instrumental activities of daily living (IADLs) and activities of daily living (ADLs)
2. ***Home Care Basic:*** Supports individuals for their needs in ADLs and IADLs, enabling them to remain at home in the community
3. ***Home Care Over Income:*** Same as Home Care Basic, but these consumers pay a share of the cost of services based on income
4. ***Respite Over Income:*** Supports individuals for their needs in ADLs and IADLs, enabling them to remain at home in the community. These consumers pay an income-based percentage of the cost of services. This program is for individuals who have a caregiver.
5. ***Home Care Basic Waiver***: Supports individuals for their needs in ADLs and IADLs, enabling them to remain at home in the community, and who are eligible for MassHealth standard and the Frail Elder Waiver.
6. ***Choices***: Supports individuals for their needs in ADLs and IADLs, enabling them to remain at home in the community, and who are eligible for MassHealth standard and the Frail Elder Waiver.

**Services**

While enrolled in an EOEA home care program, a range of services are available to consumers, based on additional eligibility criteria. There are 49 home care services available, including:

|  |  |
| --- | --- |
| * *Adult Day Health Program*
* *Alzheimer’s Day Program*
* *Alzheimer’s/Dementia Coaching*
* *Enhanced Technology/Cellular Personal Emergency Response System (PERS)*
* *Grocery Shopping and Delivery*
* *Home Based Wandering Response Systems*
* *Medication Dispensing Systems*
* *Home Delivered Meals*
 | * *Homemaker (assists with IADLs)*
* *Personal Care*
* *Respite Care*
* *Supportive Day Program*
* *Supportive Home Care Aide*
* *Transportation*
* *Wanderer Locator*
* *Laundry Care*
 |

1. The Alzheimer’s State Plan, April 2021 is posted on the Council’s website: <https://www.mass.gov/orgs/alzheimers-advisory-council>. [↑](#footnote-ref-1)
2. National Institute on Aging: <https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis>. [↑](#footnote-ref-2)
3. In this report, the term “dementia” is used interchangeably with the term “Alzheimer’s disease and related dementias, also referred to as “ADRD.” [↑](#footnote-ref-3)
4. Liesi, H., Rush University Institute on Healthy Aging; based on data from the Chicago Health and Aging Project: Weuve, J., Hebert, L.E., Scherr, P.A., Evans, D.A., Prevalence of Alzheimer disease in U.S. states. *Epidemiology*2015;26(1): E4‐6. https://doi:10.1097/EDE.0000000000000199. PMID: 25437325. This number was similarly reflected in the *Massachusetts Healthy Aging Data Report Community Profiles* (2018), UMass Boston, Gerontology Institute. [↑](#footnote-ref-4)
5. Estimated by the Alzheimer’s Association using data from the 2009 Behavioral Risk Factor Surveillance System survey, U.S. Census Bureau, Centers for Medicare & Medicaid Services, National Alliance for Caregiving, AARP and U.S. Department of Labor. [↑](#footnote-ref-5)
6. Boustani, M., Peterson, B., Hanson, L., Harris, R., Lohr, K. N., & U.S. Preventive Services Task Force (2003). Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Annals of internal medicine*, *138*(11), 927–937. https://doi.org/10.7326/0003-4819-138-11-200306030-00015 [↑](#footnote-ref-6)
7. U.S. Dept. of Health and Human Services, Office of Disease Prevention and Health Promotion: Healthy People 2030 report states that [59.7 percent](https://health.gov/healthypeople/objectives-and-data/browse-objectives/dementias/increase-proportion-older-adults-dementia-or-their-caregivers-who-know-they-have-it-dia-01) of adults aged 65 years and over with diagnosed Alzheimer's disease and other dementias, or their caregiver, were aware of the diagnosis in 2013-15. Source of data: [Medicare Current Beneficiary Survey (MCBS), CMS](https://health.gov/healthypeople/objectives-and-data/data-sources-and-methods/data-sources/medicare-current-beneficiary-survey-mcbs). [↑](#footnote-ref-7)
8. To view meeting dates and materials, see the Council’s website: <https://www.mass.gov/orgs/alzheimers-advisory-council>. [↑](#footnote-ref-8)
9. For a list of the Council’s goals and recommendations, see the section of this report entitled, “Summary of Goals and Recommendations, 2021-2022.” [↑](#footnote-ref-9)
10. The Alzheimer’s State Plan, April 2021 is posted on the Council’s website: <https://www.mass.gov/orgs/alzheimers-advisory-council>. [↑](#footnote-ref-10)
11. Mendez. M.F, Early-onset Alzheimer Disease and Its Variants; *Continuum;* 2019 February; 25(1): 34–51. https//doi:10.1212/CON.0000000000000687

<https://www.alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset>. [↑](#footnote-ref-11)
12. This estimate is based on 5 percent of the 130,000 individuals living with ADRD diagnosis in MA and does not include the estimated 40 percent of people of all ages who are living with dementia without a formal diagnosis. [↑](#footnote-ref-12)
13. See Appendix B for a list of state supported services for individuals living with dementia along with age-related eligibility criteria. [↑](#footnote-ref-13)
14. Examples of other underrepresented groups include Asian immigrants (in order of number of people in MA: Chinese, Vietnamese, Khmer/Cambodian, Korean, Burmese); Black/African American (not Latinx); blind or vision impaired; Cape Verdean; immigrants and refugees, including other Black immigrant communities; individuals living in rural areas; individuals who are incarcerated; individuals with housing insecurity; individuals with intellectual and developmental disabilities (I/DD); Latinx, including Brazilian/Portuguese speaking; LGBTQ; Native Americans; people living alone with dementia; people with hearing loss/late deafened; and veterans. [↑](#footnote-ref-14)
15. To view the tip sheet, see: [COVID-19 Testing: Tips for Families with a Loved One Living with Dementia](https://www.alz.org/media/manh/documents/COVID-Tips-COVID-Testing-Final.pdf) [↑](#footnote-ref-15)
16. State supported **information and referral services** are available to adults of all ages living with dementia or other disabilities. Specifically, [MassOptions](https://www.massoptions.org/) and [Aging Services Access Points](https://www.mass.gov/location-details/aging-services-access-points-asaps-in-massachusetts) play an essential role in helping individuals navigate to services, programs, and resources that fit their unique needs. [↑](#footnote-ref-16)
17. During the pandemic, "grab and go" meals are made available for people of all ages. Some are state supported, and others are supported by community agencies, schools, and restaurants. [↑](#footnote-ref-17)
18. <https://www.alz.org/help-support/caregiving/financial-legal-planning/medicare> [↑](#footnote-ref-18)
19. **Activities of daily living (ADLs)**—Include bathing and showering, personal hygiene and grooming, dressing, toilet hygiene, functional mobility, and self-feeding [↑](#footnote-ref-19)
20. **Instrumental activities of daily living (IADLs)**—Include cleaning and maintaining a home, managing money, preparing meals, shopping for groceries and necessities, taking prescribed medications, and using the telephone [↑](#footnote-ref-20)