

2019-2022 ROADMAP FOR CREATING A DEMENTIA CAPABLE MICHIGAN



Prepared by the

**MICHIGAN
DEMENTIA COALITION**

May 15, 2019



STATE OF MICHIGAN
OFFICE OF THE GOVERNOR
LANSING

GRETCHEN WHITMER
GOVERNOR

GARLIN GILCHRIST II
LT. GOVERNOR

May 13, 2019

Dear Michiganders:

Alzheimer's disease and other forms of dementia represent an emerging public health crisis for Michigan and the nation. Currently, an estimated 190,000 Michigan residents age 65 and older have Alzheimer's disease, a number projected to grow to 220,000 by 2025.

Every sector of our state is affected by this challenge. More than half a million Michigan family members are caring for a loved one with dementia, and they bear the greatest responsibility. But this impact is also felt by our employers, our healthcare systems, our state resources and economy, and every community in the state. The cost to Medicaid alone for people 65 and over with dementia in Michigan was \$1.37 billion in 2018. These costs are projected to increase to \$1.7 billion in 2025.

Addressing the impact of Alzheimer's and related dementia is crucial, and this newly completed *Roadmap for Creating a Dementia Capable Michigan* represents an important first step. The *Roadmap* aligns with national efforts led by the Centers for Disease Control and Prevention to prioritize brain health as an integral component of overall health, and identifies critical issues and opportunities, along with specific actions that can guide Michigan's efforts to address this serious public health challenge.

I commend the work the Michigan Dementia Coalition has done in the creation of the *Roadmap*. Led by the Alzheimer's Association Michigan Chapters, AARP Michigan, and the Michigan Alzheimer's Disease Research Center, the coalition consists of more than 65 organizations including healthcare systems, universities, state agencies, service providers and many others, making use of their combined knowledge, experience and resources.

I urge you to review the recommendations outlined in this document and join us in helping to implement the *Roadmap* and make Michigan a truly dementia capable state. Together, we can improve the quality of life for Michigan residents living with dementia and their families.

Sincerely,

Gretchen Whitmer
Governor of Michigan

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EXECUTIVE SUMMARY

Dementia is the general term for a loss of cognitive functioning and behavioral abilities that is severe enough to interfere with a person's daily life and activities. Alzheimer's is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies, frontotemporal dementia, and Huntington's disease. The impact of dementia on individuals, families, and Michigan's state budget is expected to grow significantly in the coming years.

An estimated 190,000 Michiganders age 65 and older have Alzheimer's dementia.¹ And because this figure does not include people under age 65, or with other types of dementia, or who are living with dementia that is undiagnosed, the actual number of Michigan residents living with dementia is even larger.

More than half a million family members in Michigan are caring for loved ones with Alzheimer's or other dementias,² and family members caring for a loved one with dementia experience nearly twice the out-of-pocket costs of those caring for an adult without dementia.³ The estimated cost in Michigan to Medicaid alone for people age 65 and older with dementia was over \$1.4 billion in 2018, and that number is currently projected to increase to \$1.7 billion in 2025.⁴

In late 2016 a committed group of organizations and individuals came together as the *Michigan Dementia Coalition* to identify opportunities to improve quality of life for Michigan residents with dementia and their families. Led by the Alzheimer's Association Michigan Chapters, AARP Michigan and the Michigan Alzheimer's Disease Research Center, our coalition now consists of approximately 65 organizations and over 120 individuals, including researchers from Michigan State University, University of Michigan and Wayne State University, as well as representatives from Michigan's Area Agencies on Aging, the Michigan Assisted Living Association, Rethinking Dementia: Accelerating Change, the Luella Hannan Memorial Foundation, Elder Law of Michigan, the Michigan Department of Health & Human Services and many other partners who work in various capacities with people living with dementia. Our vision is to make Michigan a **dementia capable state**.

This roadmap represents our combined efforts. It describes the current and projected future impact of dementia on individuals, families, state government and local communities in Michigan, and it describes four key goals and strategies to make Michigan a more dementia capable state by 2022:

- **People:** Promote the well-being and safety of people living with dementia at all ages and stages.
- **Partnerships:** Mobilize multisector partnerships to strengthen the service network.
- **Public Health:** Recognize and promote dementia as a public health priority.
- **Policies:** Enact policies that strengthen families, communities and the economy.

The members of the Michigan Dementia Coalition have pledged to continue working together to help connect individuals living with dementia and their families with resources, and to facilitate the sharing of successful models and best practices among practitioners and across communities.

We stand ready to offer our combined expertise and organizational resources and look forward to working with Michigan's policymakers, community leaders and other interested individuals and organizations to address the challenges and opportunities before us to make Michigan a dementia capable state.

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THE IMPACT OF DEMENTIA IN MICHIGAN

PREVALENCE

- An estimated **190,000 Michiganders** age 65 and older have Alzheimer's dementia, and by 2025 that number is currently projected to grow to 220,000.⁵ The total number of Michigan residents living with dementia is even larger because this estimate does not include people with other types of dementia, people under age 65, or people living with dementia that is undiagnosed.
- Alzheimer's disease is the most common type of dementia and represents **60-80%** of all cases.⁶ Other types include vascular dementia, dementia with Lewy bodies, frontotemporal dementia, and Huntington's disease.
- The percentage of people with Alzheimer's dementia increases with age. Three percent of people age 65-74 have Alzheimer's dementia, 17% of people age 75-84 have Alzheimer's dementia, and 32% of people age 85 and older have Alzheimer's dementia. Of people who have Alzheimer's dementia, **81% are age 75 or older.**⁷
- Almost **two-thirds** of Americans with Alzheimer's are **women.**⁸
- Based on Medicare data for those age 65 and older, Alzheimer's or another dementia had been diagnosed in 10.3% of non-Hispanic whites, 13.8% of African-Americans and 12.2% of Hispanics.⁹
- Older **African-Americans** are about **twice as likely** to have dementia as older whites.¹⁰ Studies indicate that Hispanics are about **one and one-half times** as likely to have dementia as non-Hispanics,¹¹ depending on the specific Hispanic ethnic group observed.¹²

COSTS TO FAMILIES

- An estimated **517,000 family caregivers** in Michigan are caring for loved ones with dementia. They provide an estimated 589 million hours of unpaid care annually to people living with dementia. The value of this unpaid care is over \$7 billion.¹³
- Family caregivers for an adult with dementia **spend more time per week** caring for their loved one than other caregivers (13.7 hours per week caregiving vs. 11.7 hours). For caregivers age 35 and older, three in ten spend 21 or more hours per week caregiving.¹⁴
- On average, Medicare beneficiaries age 65 and older with dementia paid nearly **\$11,000 out of pocket annually** for health care and long-term care services not covered by other sources.¹⁵
- Family caregivers caring for an adult with dementia reported nearly **twice the annual** out-of-pocket costs of those caring for someone who does not have dementia (\$10,697 vs. \$5,758).¹⁶
- From time of diagnosis, total lifetime **cost of care** for a person with dementia was **\$321,780** in 2015 dollars. Costs for a person with dementia over a lifetime were \$184,500 greater than for someone without dementia.¹⁷

COSTS TO TAXPAYERS

- The estimated **cost to Medicaid** for people age 65 and older with dementia in Michigan was over **\$1.4 billion** in 2018, and that number is projected to increase to \$1.7 billion in 2025.¹⁸
- Twenty-seven percent of older individuals living with dementia who have Medicare also have Medicaid coverage, compared with 11% of individuals without dementia. Average annual Medicaid payments per person for Medicare beneficiaries with dementia (\$8,399) were **23 times as great** as average annual Medicaid payments for Medicare beneficiaries without dementia (\$358).¹⁹
- **Medicare and Medicaid cover about two-thirds** of the total paid health care, long-term care, and hospice costs for people living with dementia. Total per-person health care and long-term care payments made in 2018 from all sources for Medicare beneficiaries with dementia were over three times as great as payments for other Medicare beneficiaries in the same age group (\$48,977 per person for those with dementia compared with \$13,976 per person for those without dementia).²⁰
- People with dementia have **twice as many hospital stays per year** as other older adults.²¹
- The share of long-term care services users who have dementia according to the Centers for Disease Control and Prevention:²²
 - Percent of adult day services center participants: 29.9% (2014)
 - Percent of residential care community residents: 39.6% (2014)
 - Percent of home health agency patients: 31.4% (2013)
 - Percent of hospice patients: 44.7% (2013)
 - Percent of nursing home residents: 50.4% (2014)

COSTS TO EMPLOYERS

- **65% of family caregivers** in Michigan, both current and former, provided care while working full- or part-time.²³
- Caregivers of loved ones with dementia report a greater impact on their work situation than other caregivers. They are more likely to need to leave work early, take paid and unpaid time off, work different hours, or take an additional job.²⁴
- Nationally, 15% of caregivers report they **quit their job** to provide care, 57% report losing work time to appointments and crises, and 16% had to take a leave of absence.²⁵
- 42% of U.S. workers have provided care for an aging relative or friend in the past five years. About **half** (49%) of the workforce expects to be providing eldercare **in the coming five years**.²⁶

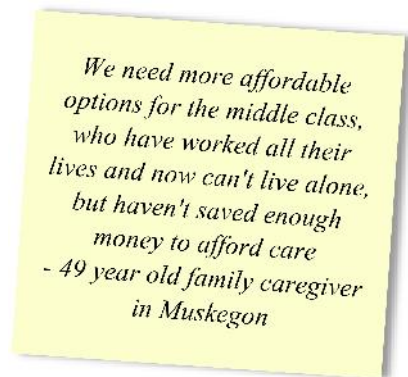
WHAT MICHIGAN RESIDENTS ARE SAYING

Dementia impacts individuals and families of all backgrounds and knows no political boundaries. Ninety-two percent of adults age 18 and over believe Alzheimer’s disease/dementia is a serious problem in our country today. Two-thirds (68%) of adults age 18 and over personally know someone who has had Alzheimer’s disease, dementia, or another condition causing cognitive decline.²⁷

In early 2017 the Michigan Dementia Coalition conducted an online survey of Michigan residents to gather input to help inform the coalition’s work. A total of 1,506 respondents completed a nine-question survey, 62% of whom described themselves as a spouse, partner, son, daughter or other relative of a person with dementia. About 14% described themselves as “Other,” but upon reviewing their responses we learned that many of them were also friends or family members of persons living with dementia, or they fit multiple categories. 10.3% described themselves as health care or social service providers; 2.5% were non-family caregivers of a person living with dementia; 1.7% were public employees or public officials; and 7.6% did not identify themselves. Approximately 2% of the respondents described themselves as a person living with dementia.

The biggest need identified was *Affordability of services*. Nearly 3 out of every 4 respondents (73.3%) identified the lack of affordability of services as one of the top three most pressing needs facing people living with dementia in Michigan and their families.

The next biggest need identified was *Information about the types of services available and how to use them*. Nearly two-thirds of respondents (65.5%) identified getting information about the services that are available as one of the top three most pressing needs facing people living with dementia and their families in Michigan.



*We need more affordable options for the middle class, who have worked all their lives and now can't live alone, but haven't saved enough money to afford care
- 49 year old family caregiver in Muskegon*

The survey’s respondents indicated that the service **most valuable** to them was ***Help applying for or accessing benefits***. The service rated **second most valuable** was ***In-home personal care services***. 77.3% of respondents said receiving help in applying for or accessing benefits was “very valuable” to them. 75.4% of respondents said receiving in-home personal care services was “very valuable” to them.

Other services that family caregivers in Michigan have indicated they value are ***respite care*** and ***training and resources*** for family caregivers.

AARP research in 2018 found that 89% of registered voters age 45 and over in Michigan support additional availability of respite care services, defined as short-term help from a home health aide or provided at an adult day program to give family caregivers a break. 77% of registered voters age 45 and over in Michigan believe it is extremely or very important to have more resources and training for family caregivers.²⁸



*Family members need help learning about available services, how to access them, how to choose safe options. I care for my mother and I have often felt at a loss looking for options.
- 63 year old family caregiver in Plymouth*

WHAT DOES IT MEAN TO BE DEMENTIA CAPABLE?



Dementia capable systems can be implemented at different levels, such as within a care system, business or organization, or within a community or state.²⁹ Dementia capable states and communities consider the impact of dementia across all aspects of the state or community, including services eligibility, information distribution and access, the role of family caregivers, safety, workforce training, and daily interactions for workers and other community members.^{30 31}

The Michigan Dementia Coalition's vision of a ***Dementia Capable Michigan*** is a state in which:

- People living with dementia are recognized as the real-life experts when it comes to living with dementia.
- Stigma is no longer a barrier to discussing, diagnosing and living with dementia.
- There is public awareness about brain health, dementia, risk factors and current research.
- Services for people living with dementia are available and easily accessible across the state, regardless of socioeconomic status or ethnic background.
- Individuals working in Michigan's health care and long-term care systems have the skills they need to provide timely, accurate diagnoses and high quality services to people living with dementia.
- Physical and social environments are adapted to include, enable and empower people living with dementia and their care partners.
- Local communities and agencies partner with families to promote the well-being and safety of people living with dementia at all ages and stages.
- Employers are equipped to support family caregivers and the aging workforce.
- Decision makers use a common dementia roadmap in determining policy and resource allocations.

In October 2018, the federal Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association released *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*, the third in their series of Healthy Brain Initiative "road maps" to advance cognitive health as an integral component of public health.³²

The CDC's *2018-2023 Road Map* describes 25 specific actions that state and local public health agencies and their partners can take to promote cognitive health, including educating and empowering the public, developing policies and mobilizing partnerships, assuring a competent workforce, and helping support family caregivers.



Many of the actions identified in the CDC's *2018-2023 Road Map* parallel the Michigan-specific needs and opportunities that the Michigan Dementia Coalition identified through our workgroup efforts over the past two years and that have been reflected in surveys of Michigan residents as cited elsewhere in this document.



To develop our **2019-2022 Roadmap for Creating a Dementia Capable Michigan**, the Steering Committee of the Michigan Dementia Coalition reviewed and compiled the findings and recommendations from our workgroups to identify **four key goals** along with strategies to create a dementia capable Michigan.

Those four goals and strategies are described further on the following pages.

FOUR GOALS WITH STRATEGIES TO CREATE A DEMENTIA CAPABLE MICHIGAN

PEOPLE

Promote the Well-Being and Safety of People Living with Dementia at all Ages and Stages

- Help people living with dementia and their families more readily connect with information and resources.
- Increase access to training, education and support for family caregivers and care partners of people living with dementia.
- Promote ways to help people stay safe at home and engaged in their community.
- Share tools and facilitate training for families, community members and others who may interact with people living with dementia to prevent abuse and financial exploitation.
- Ensure that services for people living with dementia are person-centered, affordable and accessible regardless of where people live.

PARTNERSHIPS

Mobilize Multisector Partnerships to Strengthen the Service Network

- Pursue practical opportunities to improve coordination across the continuum of care for people living with dementia.
- Identify and remove administrative barriers to collaboration.
- Ensure that individuals working in Michigan's health care and long-term care systems have the knowledge, skills and understanding needed to provide high quality dementia supports and services.
- Increase and strengthen the direct care workforce to reduce turnover and improve job satisfaction.

PUBLIC HEALTH

Recognize and Promote Dementia as a Public Health Priority

- Increase public awareness about brain health, dementia and risk factors.
- Promote early detection and diagnosis, and opportunities to participate in clinical research.
- Improve data collection regarding dementia in Michigan.
- Reduce disparities by providing underserved areas and underrepresented groups with equitable access to quality services.
- Increase participation of community stakeholders in public health decisions regarding dementia.

POLICIES

Enact Policies that Strengthen Families, Communities and the Economy

- Meet the current unmet need and prepare for increased future demand for home and community based services for people living with dementia.
- Increase access to and information about quality, affordable respite services for people living with dementia and their families.
- Meet the growing need for affordable, reliable transportation services for people living with dementia.
- Identify policy or regulatory changes to help prevent abuse and financial exploitation of people living with dementia.
- Incentivize professionals to specialize in geriatrics to better prepare for our state's increasingly older population.
- Engage and equip employers to prepare for a growing population of employees balancing work and family caregiver responsibilities due to dementia.

PROMOTE THE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AT ALL AGES AND STAGES

PEOPLE

Strategies

- Help people living with dementia and their families more readily connect with information and resources.
- Increase access to training, education and support for family caregivers and care partners of people living with dementia.
- Promote ways to help people stay safe at home and engaged in their community.
- Share tools and facilitate training for families, community members and others who may interact with people living with dementia to prevent abuse and financial exploitation.
- Ensure that services for people living with dementia are person-centered, affordable and accessible regardless of where people live.

More Information

Help people living with dementia and their families to more readily connect with information and resources.

While there is a lot of information available online about dementia, one of the top concerns voiced by families is that they don't know where to start or how to sort through all the information.³³ It can be hard to figure out which services are needed, which are actually available in their community, and whether they are likely to meet the eligibility standards for various services, such as the MI Choice Medicaid waiver program, Programs of All-Inclusive Care for the Elderly (PACE), veterans benefits, or services provided by their local Area Agency on Aging.

*It is hard to find out about organizations and places where to get help. I have talked to every organization that I think would help, and I am still flying by the seat of my pants.
- Robin, Dowagiac*

*It is just hard to find information out there about the types of services and when I do find them they are during the day while I am working so I cannot get my mother to them without taking time off work.
- Brenda, Royal Oak*

Local resource guides are available in some parts of the state, such as the comprehensive dementia-specific resource guide created by *Rethinking Dementia: Accelerating Change*, a community collaborative in Grand Rapids and west Michigan.³⁴ Still, respondents to the Michigan Dementia Coalition's 2017 survey expressed a desire for a "one-stop shop" for Michigan residents to more readily connect with dementia-specific resources and information wherever they live in the state.

In late 2018 the Alzheimer’s Association and AARP rolled out **CommunityResourceFinder.org**, a comprehensive online community resource tool that is searchable by zip code and powered by Carelike®. The updated database expands the previously available Alzheimer’s Association Community Resource Finder which launched in 2011 and receives about 37,000 monthly visits.

We are hopeful that this tool will become the one-stop shop that Michigan families have asked for, to help people anywhere in the state find local resources based on specific needs, such as payment options and specialized services. We invite Michigan providers of services for people living with dementia and their families to visit <https://provider.carelike.com/account/registerprovideralz> to set up and maintain a profile on this site to help the public learn more about their services and to ensure the information is kept up-to-date.

Additionally, AARP Michigan is currently working with other members of the Michigan Dementia Coalition to produce a Michigan-specific printed resource guide for family caregivers who are caring for a loved one with dementia based on the AARP Michigan Family Caregivers Resource Guide, which AARP produced for a general caregiver audience in 2016.³⁵ The Michigan Dementia Coalition expects to finalize and distribute this printed resource guide beginning in late 2019.



This is an area in which Michigan can continue to improve. So long as resources continue to be fragmented and families continue to feel lost, the **Michigan Dementia Coalition** will continue working, with community partners and organizations, to help people living with dementia and their families to more readily connect with the information they need.

Increase access to training, education and support for family caregivers and care partners of people living with dementia.

A wide range of training opportunities are available for family caregivers and care partners in Michigan, but many families are not aware of them or may be unable to access them. Nationwide, the majority of Area Agencies on Aging (AAAs) do not offer evidence-based caregiving training for family caregivers.³⁶ In Michigan, however, 12 of the state’s 16 Area Agencies on Aging provide the evidence-based *Savvy Caregiver* training to family caregivers of persons with dementia who are living at home through their six-week Creating Confident Caregivers® program. In 2017, those 12 Michigan AAAs provided 57 Creating Confident Caregivers programs in 34 counties, serving 448 caregivers with 4,300 hours of training.³⁷ The Alzheimer’s Association, Michigan Alzheimer’s Disease Center, AARP, the Institute of Gerontology at Wayne State University and other organizations also provide various opportunities for training including workshops for family caregivers.

CommunityResourceFinder.org *Provider Categories:*

- Adult Day Care Programs
- Area Agencies on Aging
- Assisted Living
- Dementia Diagnostic Center
- Early Stage Programs
- Elder Law Attorneys
- Geriatric Care Managers
- Geriatric Psychiatrists
- Geriatricians
- Home Care
- Home Health Care
- Hospice
- Hospitals
- Independent Living
- Neurologists
- Skilled Nursing Care
- Social Engagement Programs
- Support Groups
- Transportation

In 2017, the Michigan Health Endowment Fund provided a two-year grant to a consortium of faculty and staff from Michigan State University, University of Michigan and Wayne State University Institute of Gerontology to create the THRIVE Network: Educating Dementia Caregivers on Wellness and Self-care. THRIVE builds on the caregiver wellness initiative of the Michigan Alzheimer’s Disease Core Center and uses a network of virtual and in-person resources to connect family caregivers and care partners of people living with dementia to resources, support and education with an emphasis on self-care and wellness. THRIVE aims to make the pathway of family caregivers easier by fostering supportive connections and continuous learning, because how well a caregiver thrives directly impacts how the person in their care will thrive.³⁸



It is also important that family caregivers and care partners of people living with dementia have access to information about legal matters such as capacity issues, powers of attorney, financial planning and pitfalls to avoid when managing a loved one’s money. Elder Law of Michigan³⁹ operates several programs that provide legal advice, information and services free of charge to individuals and their family caregivers. A series of helpful guides for *Managing Someone Else’s Money in Michigan*⁴⁰ are available online through a collaboration led by the Sixty Plus, Inc. Elderlaw Clinic⁴¹ supported by a Prevent Elder and Vulnerable Adult Abuse, Exploitation, Neglect Today (PREVNT) Initiative grant through the Michigan Department of Health and Human Services Aging and Adult Services Agency. Caregivers may also want to consult a local elder law attorney for personalized planning, advice and assistance.⁴²

Too often families are simply not aware of the opportunities for training and resources that may be available to them. However, there are other practical barriers, too. While many options may exist in the more populous parts of the state, family caregivers in rural areas often lack access to education programs, support groups, or even online training if internet connections are unreliable. Additionally, attending in-person caregiver training can be difficult for caregivers who have limited transportation or respite options and their participation would require them to leave their loved one with dementia home alone.



The members of the **Michigan Dementia Coalition** look forward to continuing to work with state and community partners to overcome these barriers so more family caregivers can access the training and support they need.

Promote ways to help people stay safe at home and engaged in their community.

Preventing Falls. Many people living with early stages of dementia can safely function at an independent level without assistance from others. As dementia progresses, however, the risk of falling increases exponentially. Falls are the leading cause of hospitalization in people living with dementia. It is estimated that 60% of people living with dementia fall at least once each year.⁴³

Dementia causes a decrease in both physical and cognitive abilities, often leading to generalized weakness, gait changes, and balance/coordination impairments, as well as delayed processing and reaction times. Reduced physical activity also leads to a decrease in muscle mass and strength, deconditioning, increased fall risk, and a further reduction of physical activity.⁴⁴ Increasing or maintaining physical activity is crucial for people living with dementia, who have lower levels of physical activity and motor function compared to older people without dementia.

The AARP *Home Fit Guide*⁴⁵ describes many simple steps individuals and families can take in their homes to decrease the risk of falls, such as removing rugs, decluttering the floor to prevent tripping, and maintaining optimal lighting. Michigan’s Area Agencies on Aging also offer *A Matter of Balance* workshops which integrate strategies from multiple disciplines for decreasing the risk of falls. In addition, ensuring utilization of an assistive device such as a cane or walker will provide increased safety, confidence, and functional mobility while decreasing falls. Falls in people living with dementia are a complex event with multiple factors to consider, and reducing falls in people living with dementia requires a multi-disciplinary approach which evolves as the disease progresses.



Medication Safety. While medication errors and adverse drug events are common among older adults in general, studies have shown that people living with dementia are at even greater risk, with approximately 40% of their hospital admissions being due to drug related problems.⁴⁶ For one thing, as a person’s dementia progresses, they face an increased risk of failing to take their medications as prescribed. A person living with dementia who is prescribed multiple medications can also face dangerous drug interactions if there is a lack of coordination among their health care providers.

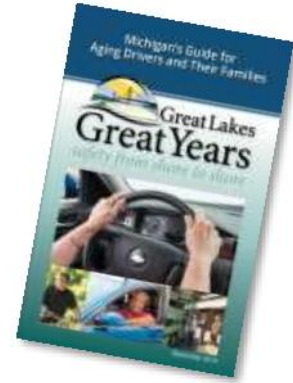
The Alzheimer's Association offers a tip sheet on medication safety for people living with dementia and their families which includes developing a routine, asking a physician or pharmacist to check for potential drug interactions, and inquiring about alternative forms of medications for patients with difficulty swallowing.⁴⁷



The **Michigan Dementia Coalition** also looks forward to working with health care providers and other stakeholders to identify opportunities to improve medication reconciliation for people living with dementia.

Driving. Being able to drive and control how you get around is important to the dignity, independence and emotional well-being of adults of all ages and conditions. People living with dementia who develop significant impairments in memory, reasoning, and judgment may be unable to continue driving safely. Losing the ability to drive can negatively impact people living with dementia, decreasing their participation in activities outside the home and increasing social isolation and depressive symptoms.⁴⁸

Resources such as *Michigan's Guide for Aging Drivers and Their Families*⁴⁹ can help people living with dementia and their families figure out how to prolong their independence while encouraging safe driving. In addition, driver rehabilitation specialists⁵⁰ can assess a person's driving ability and help people living with dementia and their families decide when it may be time to stop driving and start relying on other ways to get around instead, as described further in the **POLICIES** section regarding affordable, reliable transportation options, on page 27.



Staying Engaged in the Community. Going outdoors and getting out into the community, sometimes alone, is an important aspect of maintaining an active and independent lifestyle after a diagnosis of dementia.⁵¹



Options for people living with dementia to remain active and engaged in the community include memory cafés, dementia mentors⁵² and senior companion programs.⁵³

Memory cafés, a concept started in the Netherlands in the 1990s, offer a safe and comfortable space where people living with dementia and their care partners, friends and family can socialize, engage in activities such as games or listening to music, or enjoy a meal together. Memory cafes currently operate in Grand Rapids, Marquette, Ypsilanti and elsewhere in Michigan.^{54 55}

Staying Safe. People living with dementia may experience disorientation and are at greater risk of becoming lost.⁵⁶ Caregivers and others who work with people living with dementia often use the term “wandering” to describe this behavior.⁵⁷ In Michigan this can be particularly dangerous when it occurs in cold weather or in a rural area.

According to the Alzheimer's Association, 60% of individuals with Alzheimer's disease will at some point wander and become lost.⁵⁸ Wearable devices and other new assistive technologies offer promising opportunities to help people living with dementia stay safe and maintain a better quality of life. Many relatively new products and services make use of technology to help caregivers and communities locate persons living with dementia who may become lost, including *Life Tracker*, *Care Trak*⁵⁹, *AngelSense*⁶⁰ and *Safe Return*, a partnership between MedicAlert and the Alzheimer's Association. Nonetheless, it is important that the use of these sorts of devices be voluntary and protect the dignity and privacy of the individual living with dementia.



Moving forward, the **Michigan Dementia Coalition** hopes to facilitate information sharing about promising technologies and collaborative community models to help individuals living with dementia remain safe and engaged in their community.

Share tools and facilitate training for families, community members and others who may interact with people living with dementia to prevent abuse and financial exploitation.

Several high quality tools are available that individuals living with dementia and family caregivers can use to plan and protect themselves from fraud, and that professionals in the community can use to help prevent abuse and financial exploitation of people with diminished capacity due to dementia.

One potential way to help individuals and family caregivers protect themselves could be through the expansion of SAFE, a grant-funded program developed by Peter Lichtenberg at the Wayne State University Institute of Gerontology that is currently available to residents in the Metro Detroit area. SAFE offers resources like *Protecting Yourself From Financial Exploitation* and offers one-on-one assistance to recover from scams or identity theft.⁶¹ Another resource that individuals and family caregivers can use is the AARP Fraud Watch Network, which provides online resources and maintains a searchable map that shows active scams.⁶²



The **Michigan Dementia Coalition** also recommends expanding the adoption of training protocols for financial professionals regarding diminished capacity, including training on the use of the Lichtenberg Financial Decision Screening Scale⁶³, as well as promoting training on diminished capacity for legal professionals, housing counselors, discharge planners, and other professionals.

Ensure that services for people living with dementia are person-centered, affordable and accessible regardless of where people live.

In the online survey conducted by the Michigan Dementia Coalition in 2017, the biggest need respondents identified was *affordability of services*. Nearly 3 out of every 4 respondents (73.3%) identified the lack of affordability of services as one of the top three most pressing needs facing people living with dementia in Michigan and their families.⁶⁴ Family caregivers caring for an adult with dementia reported nearly twice the annual out-of-pocket costs of those caring for an adult without dementia (\$10,697 vs. \$5,758).⁶⁵ From time of diagnosis, total lifetime cost of care for a person with dementia was \$321,780 in 2015 dollars. Costs for a person with dementia over a lifetime were \$184,500 greater than for someone without dementia.⁶⁶

I have dementia and worry for my wife and assistance she may need. I also worry about the financial bind that could come about as my condition continues to deteriorate - if I need long term care I worry that she could lose our home, savings, etc.
- Response #86 (Anonymous)

Medicare and Medicaid cover about two-thirds of the total paid health care, long-term care, and hospice costs for people living with dementia. Total per-person health care and long-term care payments from all sources in 2018 for Medicare beneficiaries with dementia were over three times as great as payments for other Medicare beneficiaries in the same age group.⁶⁷ Twenty-seven percent of people with dementia who have Medicare also have Medicaid coverage, compared with 11% of people without dementia.⁶⁸ The estimated cost in Michigan to Medicaid for people age 65 and over with dementia was over \$1.4 billion in 2018, and that number is currently projected to increase to \$1.7 billion in 2025. Average annual Medicaid payments per person for Medicare beneficiaries with dementia (\$8,399) were 23 times as great as average annual Medicaid payments for Medicare beneficiaries without dementia (\$358).⁶⁹

Michigan needs to find ways to make services for people living with dementia more affordable for families, for state government, and for the health and long-term care systems generally. This is not an easy goal, but there are steps we can take in Michigan to help move our state closer to achieving it. Reducing preventable hospitalizations, supporting caregivers, ensuring access to safe transportation, delaying or preventing the need for institutionalization, and encouraging collaborative care models are examples of ways to save money while better meeting the needs of Michigan residents.

Delaying or preventing the need for individuals living with dementia to be placed in long-term care facilities is one way to reduce costs of care, while also better reflecting the preferences of families to stay together. Providing home and community-based services to help caregivers continue to care for their loved ones at home can delay or prevent the need for persons with dementia to be placed in nursing homes, which can save money for families and money for taxpayers. The average cost per year to stay in a semi-private room in a nursing home in Michigan is \$95,630.⁷⁰

*My dad has dementia. He worked for Ford Motor Co for 35 years and now his pension and social security are not enough to cover specialized treatment.
- Janis, Ann Arbor*

Research has found that high caregiver stress is a highly significant predictor of an older adult’s placement in a nursing home, especially when caring for someone with dementia.^{71 72 73} Family caregivers of persons living with dementia commonly experience more stress than those caring for adults who do not have dementia, in part because care needs are progressive, complex, and frequently unpredictable.⁷⁴ Increasing access to affordable respite care or access to in-home services – help with things like bathing, medications and preparing meals – can allow a family member to continue caring for their loved one safely at home.

Other potential ways to help families better afford the long-term care services that people living with dementia increasingly need as their condition progresses include:

- Tax credits for family caregivers;
- Promoting information about third-party reimbursement for various services; and
- Improving coordination among providers across the care continuum.



MOBILIZE MULTISECTOR PARTNERSHIPS TO STRENGTHEN THE SERVICE NETWORK

PARTNERSHIPS

Strategies

- Pursue practical opportunities to improve coordination across the continuum of care for people living with dementia.
- Identify and remove administrative barriers to collaboration.
- Ensure that individuals working in Michigan’s health care and long-term care systems have the knowledge, skills and understanding needed to provide high quality dementia supports and services.
- Increase and strengthen the direct care workforce to reduce turnover and improve job satisfaction.

More Information

Pursue practical opportunities to improve coordination across the continuum of care for people living with dementia.

One opportunity to strengthen the service network for people living with dementia lies with using care models that promote collaboration across multiple disciplines. Collaborative care models—models that include not only geriatricians, but also social workers, nurses, psychologists and medical assistants—have been shown to improve care coordination for patients with cognitive impairment and reduce health care costs associated with hospitalizations, emergency department visits and other outpatient visits.⁷⁵

Similarly, an inter-professional approach to care for patients with dementia can have an impact reducing re-hospitalizations. For example, the use of clinical pharmacists providing hospital follow-up calls for patients discharged from a Veterans Affairs hospital focusing on medication review and reconciliation led to significantly fewer 60-day hospital readmissions.⁷⁶

Embedding clinical professionals such as social workers and psychologists in hospital systems, emergency departments and primary care offices is another example of a best practice. And it is of foremost importance that any collaborative care model recognizes and includes the person living with dementia and their family caregiver or care partner as part of the care team.

Practical opportunities to help improve care coordination in Michigan include recognizing examples of quality and innovative programming that provide high quality care and support services for individuals living with dementia, or creating service-specific communication networks for providers to recognize and disseminate best-care practices among supportive service providers around the state.



As a first step, the **Michigan Dementia Coalition** is in the process of developing a multisector listserv for Michigan stakeholders in the field of dementia.

Identify and remove administrative barriers to collaboration.

Patients often look to their primary care physicians first for information and resources, but primary care practices may not have enough personnel or resources to share about the support services available in their community for people living with dementia and how to link their patients to them.

Additionally, Medicare reimbursement rates can serve as a disincentive for early diagnosis and treatment of patients with dementia due to the intensive nature of such care. Addressing these and other practical barriers to coordination has the potential both to improve patient care and help control total care costs for people living with dementia.

Potential avenues to reduce or remove administrative barriers to collaboration include:

- Pursuing changes to Medicare reimbursement policies to incentivize value-based, person-centered care for people living with dementia and other advanced illnesses; and
- Breaking down informational silos to promote and facilitate sharing among providers of records pertaining to the various medical, psychological, social and other services being provided to a person living with dementia.



Members of the **Michigan Dementia Coalition** look forward to working with policymakers, professional associations and other partners to identify and recommend potential incentives, payment models, or other evidence-based approaches to promote greater collaboration across the health care and long-term care delivery systems.

Ensure that individuals working in Michigan’s health care and long-term care systems have the knowledge, skills and understanding needed to provide high quality dementia supports and services.

People living with dementia and their families interact with healthcare professionals in many different settings from family doctors’ offices, adult day centers, nursing homes, dentists’ offices, and more. The licensed professionals who work in these healthcare settings are highly trained and skilled in their specific area of care, but do not necessarily receive training specific to dementia. In a dementia capable Michigan, providers across sectors would have basic competencies in dementia care to ensure access to safe, consistent, excellent care for every Michigan resident with dementia.

In a dementia capable state, curriculum in the health professions includes an emphasis on aging and the special considerations needed when working with older adults, and health care practitioners are familiar with what does and does not constitute normal aging.

In a dementia capable state, primary care providers have the tools and knowledge they need to:

- Evaluate memory and cognitive changes;
- Work with dementia patients and their families to create person-centered plans; and
- Help their patients and family members understand and manage potentially distressing behavioral expressions.

Beyond health care professionals, in a dementia capable Michigan ***individuals employed across the continuum*** of health care and long-term supports and services for people living with dementia would have the ability to do all of the following in an effective, compassionate, culturally sensitive and gender-sensitive manner:

- Provide person-centered dementia care.
- Communicate with individuals with dementia.
- Address distressing behaviors without the use of physical or chemical restraints.
- Address the individual's social needs.
- Address specific aspects of safety, such as the increased risk of falls or becoming lost.⁷⁷



The Administration on Aging/Administration for Community Living's *Training Resources Compendium for Dementia Care Providers and Volunteers* is one good resource that lists programs that meet minimum standards of quality and content.⁷⁸

Michigan is also fortunate to have a great number of dementia training opportunities available for health care and long-term care professionals. These opportunities range from conferences hosted by groups such as the Alzheimer's Association, Area Agencies on Aging and other non-profit organizations to specialized training or certificate programs through colleges and universities. While these opportunities exist, attendance among licensed professionals could be increased. In some areas of the state, nurses, nurse's aides and social workers have access to these training opportunities. In other parts of the state, opportunities are few and often come with barriers to participation such as cost or location of the training.



Members of the **Michigan Dementia Coalition** look forward to working with state licensing boards, professional associations and other partners to share information and resources about dementia-specific training and diagnostic tools for licensed health professionals, and develop pipelines for dementia assessment, diagnosis and care via continuing education. The **Michigan Dementia Coalition** will also continue to help identify ways to incentivize the adoption of dementia-specific training as a best practice across Michigan's health care and long-term care systems.

Increase and strengthen the direct care workforce to reduce turnover and improve job satisfaction.

More than 60% of persons diagnosed with dementia live in their own home or in the home of a family caregiver. Those who do reside outside of their home are typically cared for in long-term care facilities, adult foster care homes, or assisted living settings that are not exclusive to persons with dementia. In all these settings, many people living with dementia will eventually need the help of paid caregivers, also known as direct care workers.

Like many other states, Michigan is experiencing a direct care workforce crisis. Home and community based providers, along with facilities that provide supports and services to people living with dementia, are facing serious difficulty finding, hiring and retaining high quality direct care workers and personal care aides.

Demand already exceeds availability, and the need for home health aides and personal care aides is projected to grow 41% from 2016 to 2026, much faster than the average growth rate for all occupations.⁷⁹ The secondary challenge, after finding workers, is ensuring that workers are competent and equipped to deliver a level of care that is adequate and person-centered, and that they want to remain on the job. The high turnover rate among this workforce wreaks havoc with the continuity and quality of care and is expensive.

Michigan's IMPART Alliance—a coalition of researchers, personal care aides, clients and agencies—is currently working to develop solutions to the direct care worker shortage crisis in Michigan.⁸⁰ At the core of IMPART's efforts is a comprehensive, evidence-based personal care assistant training program called *Building Training...Building Quality*[™] that was developed through a federally-funded six-state demonstration project. Project findings show that a stable, well-trained direct care workforce is associated with higher worker and client satisfaction and better client health outcomes, including fewer falls and emergency department visits.⁸¹

Additionally, more needs to be done to expand the dementia-specific training that direct care workers receive, whether they work in institutional or in-home settings, particularly regarding behavioral and non-pharmacological treatment for distressing behavioral expressions. In 2008 the Michigan Dementia Coalition's Dementia Competencies Workgroup created a resource guide for direct care workers entitled *Knowledge and Skills Needed for Dementia Care: A Guide for Direct Care Workers in Everyday Language*,⁸² and additional training resources developed by a variety of sources can be found through the National Alzheimer's and Dementia Resource Center.⁸³



Members of the **Michigan Dementia Coalition** look forward to further discussions and opportunities to connect direct care workers and entities that employ them with resources to help Michigan's direct care workforce become more dementia capable.



RECOGNIZE AND PROMOTE DEMENTIA AS A PUBLIC HEALTH PRIORITY

PUBLIC HEALTH

Strategies

- Increase public awareness about brain health, dementia and risk factors.
- Promote early detection and diagnosis, and opportunities to participate in clinical research.
- Improve data collection regarding dementia in Michigan.
- Increase participation of community stakeholders in public health decisions regarding dementia.
- Reduce disparities by providing underserved areas and underrepresented groups with equitable access to quality services.

More Information

Increase public awareness about brain health, dementia and risk factors.

The Michigan Dementia Coalition proposes to work with the Michigan Department of Health and Human Services and other stakeholders to develop an updated public outreach plan regarding dementia that:

- Conveys key messages about dementia including that dementia is not a natural part of aging; that it is caused by diseases of the brain; that it is not just about memory loss; that it is possible to live well with dementia; and that there is more to a person living with dementia than just their dementia.⁸⁴
- Shares information about social determinants and lifestyle risks, and what people can do to achieve risk reduction as individuals, and as communities.
- Conveys the value of early detection and diagnosis and how it can make a positive difference in terms of planning, treatment options, and quality of life.
- Makes use of a wide variety of communication channels, recognizing that people from different age groups, abilities and backgrounds get their information in different ways and from different sources. To ensure the opportunity of “dementia literacy” for everyone, we need to ensure that information is accessible and understandable by people of all reading levels, levels of computer savvy, physical abilities, and racial, ethnic and cultural backgrounds.
- Provides targeted information and engagement for high-risk and underserved groups.
- Confronts the barrier of stigma. Stigma prevents people from talking honestly about dementia symptoms, both within the family and with others around them. Fear and stigma lead to delays in diagnosis, poorer outcomes, social isolation, and more.



Information in the field of dementia is constantly changing, so the **Michigan Dementia Coalition** will continue to facilitate the continued sharing of experiences, knowledge, ideas and best practices among practitioners, and with the public.

One way we plan to do so is by holding statewide dementia summits to bring Michigan practitioners, policymakers, community leaders and members of the public together each year to share up-to-date information about dementia, including best practices for providers of services and supports; state and local resources for people living with dementia and their families; current research happening at Michigan universities; how local communities can become more dementia capable; and roles for community partners.

Promote early detection and diagnosis, and opportunities to participate in clinical research.

According to the Alzheimer’s Association, 82% of older adults believe it’s important to have their thinking or memory checked, but only 16% receive regular cognitive assessments.⁸⁵ Similar research conducted by AARP found that relatively few adults (36%) have been asked questions about their cognition during a check-up with their doctor. A higher percentage (44%) of adults age 65 or older have been asked, although still fewer than half.⁸⁶

In a dementia capable Michigan, medical practitioners would routinely screen older adults for cognitive impairment.

Early diagnosis affords patients and their families time to adjust to their diagnosis and develop advanced care plans, arrange for support services, and make informed decisions related to employment, driving, housing, and finances. Understanding a loved one’s diagnosis can also help preserve or repair family relationships.



Several high quality tools are available to help practitioners and health systems with diagnosis and treatment for patients who present dementia symptoms. Two examples are the Gerontological Society of America *Kickstart-Assess-Evaluate-Refer* (GSA KAER) Toolkit, introduced in 2017 for primary care providers to help detect cognitive impairment,⁸⁷ and Dementia Friendly America’s *Clinical Provider Practice Tools*.⁸⁸



The **Michigan Dementia Coalition** looks forward to working with providers to share information and help facilitate the use of these and similar tools.

In a dementia capable state, information is also more readily available among both practitioners and the public regarding opportunities for individuals to participate in clinical research, as described further on page 31.

Improve data collection regarding dementia in Michigan.

An estimated 190,000 Michiganders age 65 and older have Alzheimer's dementia, and by 2025 this number is projected to grow to 220,000.⁸⁹ The total number of Michigan residents currently living with dementia is thought to be even larger than this estimate because it does not include people with other types of dementia, people under age 65, or people living with dementia that is undiagnosed.

We need more Michigan-specific data on dementia including incidence, prevalence, services most benefiting people living with dementia and their caregivers, and access barriers to those services.

Such information would help guide Michigan policymakers, communities, health care systems and service providers in planning for future needs and making resource allocation decisions.



Opportunities to improve data collection regarding dementia in Michigan could include:

- Incorporating dementia-specific questions in existing state-sponsored health survey efforts such as the Behavioral Risk Factor Surveillance System (BRFSS) or through additional research sponsored by the Michigan Alzheimer's Disease Research Center; and
- Establishing a state-level registry of people diagnosed with dementia based on health insurance charges, with information collected for epidemiological purposes only and without personal identifiers.

Reduce disparities by providing underserved areas and underrepresented groups with equitable access to quality services.

Michigan's ability to improve the health and health care of its aging population is hampered by the existence of health disparities among diverse groups of people based on race, ethnicity, gender, disability, geography, income and other characteristics.⁹⁰ Disparities are widely found in the social determinants of health in our state; that is, conditions in the environments in which people are born, live, work and age that affect their health and other quality-of-life factors.⁹¹ Variations in health, lifestyle and socioeconomic risk factors are believed to account for most of the differences in risk of dementia by race/ethnicity,⁹² although the need for more research in this area has been identified.⁹³

For example, older African-Americans are about twice as likely to have dementia as older whites,⁹⁴ and studies indicate that Hispanics are about one and one-half times as likely to have dementia as non-Hispanics,⁹⁵ depending on the specific Hispanic ethnic group observed.⁹⁶ Health conditions such as cardiovascular disease and diabetes, which are associated with an increased risk for dementia, are more

prevalent in African-American and Hispanic people.⁹⁷ Underrepresented ethnic groups also tend to have less access to information about dementia, less access to culturally appropriate care and services, and higher levels of stigma.

In Michigan, health disparities that start at birth and continue into adulthood affect the lives of millions of people of color, in particular.⁹⁸ Health and health care equity requires inclusiveness and knowledge-based empowerment of underserved and underrepresented communities. Opportunities to address health care disparities related to dementia and disparities in access to dementia-related supports and services include:

- Connecting people to research opportunities that strengthen culturally appropriate services;
- Establishing partnerships with health care providers and providers of dementia-related supports and services to identify and address barriers that affect equitable access;
- Encouraging and empowering communities to promote healthy living practices and supporting those efforts; and
- Encouraging funders to foster multi-sector collaborations to address social determinants of health.

Increase participation of community stakeholders in public health decisions regarding dementia.

In a dementia capable state, decision makers use a common dementia roadmap to determine policy and resource allocations, along with input from individuals, families and the communities of which they are a part. A dementia capable state encompasses local governments, faith-based organizations, businesses, multicultural community groups, first responders and other stakeholders partnering with families to promote the well-being and safety of people living with dementia at all ages and stages.

Ensuring the participation of community stakeholders will help advance the goals and strategies set forth in this *Roadmap* by allowing them to become shared visions and values, increasing the capacity of communities to shape outcomes, and fostering multi-sector collaboration.⁹⁹ Engagement of community stakeholders creates shared accountability and responsibility on issues, and helps mitigate challenges in communities with distrust of the system or different intergenerational priorities.¹⁰⁰

Opportunities to increase the participation of community stakeholders in making public health decisions regarding dementia include:

- Engaging faith-based organizations, businesses, and trusted community-based partners such as libraries and senior centers to facilitate a direct communication with the community; and
- Supporting local public-private sector engagement around known determinants of health that increase the risk of developing dementia.



ENACT POLICIES THAT STRENGTHEN FAMILIES, COMMUNITIES AND THE ECONOMY

POLICIES

Strategies

- Meet the current unmet need and prepare for increased future demand for home and community-based services for people living with dementia.
- Increase access to and information about quality, affordable respite services for people living with dementia and their families.
- Meet the growing need for affordable, reliable transportation services for people living with dementia.
- Identify policy or regulatory changes to help prevent abuse and financial exploitation of people living with dementia.
- Incentivize professionals to specialize in geriatrics to better prepare for our state’s increasingly older population.
- Engage and equip employers to prepare for a growing population of employees balancing work and family caregiver responsibilities due to dementia.

More Information

Meet the current unmet need and prepare for increased future demand for home and community-based services for people living with dementia.

In-Home Care. Michigan needs to do more to meet the current unmet need and prepare for increased future demand for home and community-based services for people living with dementia. Studies have shown time and again that people prefer to remain living in their homes if they need long-term care as they age. Similarly, families prefer that their loved ones remain living at home as long as they can do so safely. Nevertheless, people with dementia represent half of all nursing home residents in the United States.¹⁰¹

Demand continues to exceed the number of “slots” for home and community-based services under Michigan’s MI Choice Medicaid waiver program as administered by the Medical Services Administration of the Michigan Department of Health and Human Services (MDHHS). Similarly, waiting lists continue to exist in Michigan for the non-Medicaid in-home senior services administered by the Aging and Adult Services Agency (AASA) of the MDHHS and provided through Michigan’s regional Area Agencies on Aging.



These services, including home-delivered meals and personal care, help non-Medicaid and near-Medicaid eligible Michiganders avoid higher-cost forms of care. A recent study of individuals on wait lists for AASA in-home services found that within two years of being placed on a waitlist, those who received no help were five times more likely to be living in a nursing home and twice as likely to have received treatment from a hospital emergency room in the past 90 days.¹⁰² Rebalancing Michigan’s long term care system – that is, allowing a greater share of the people needing services to remain in their homes – can also save taxpayer dollars because Medicaid dollars can support nearly three people in home and community-based services for every one person in a nursing home.¹⁰³



Members of the **Michigan Dementia Coalition** will continue to work with policymakers and other stakeholders to ensure that resource allocations appropriately reflect the current and future need for home and community-based services for people living with dementia.

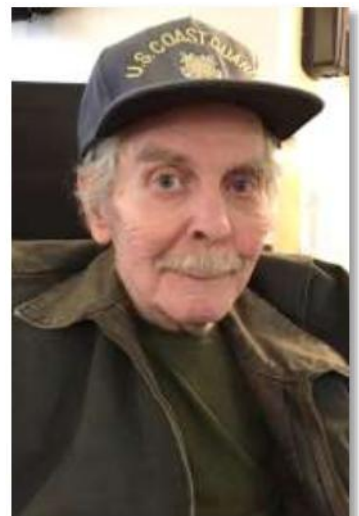
Increase access to and information about quality, affordable respite services for people living with dementia and their families.

Respite. Respite care services are short-term services provided for a person living with dementia to provide a break or “respite” from their regular routine with their family caregiver. Respite is available in a variety of forms: it can be provided outside the home, such as at an adult day center, or inside the home by having a personal care aide stay with the person with dementia while their family caregiver is out. Respite services can empower caregivers to keep providing care for their loved ones by giving them time to care for themselves, while also ensuring that the person with dementia is engaged and well cared for. Increasing access to affordable respite care and increasing awareness among family caregivers that respite care is available has the potential to improve quality of care for more people living with dementia by reducing family caregiver stress, which in turn helps prevent or delay costly and unnecessary out-of-home placements.^{104 105 106}

More Michigan residents with dementia and their family caregivers could benefit from respite care than currently use it, but barriers to access exist. First – and often – caregivers do not seek help. They may not recognize that they need it, may not know who can help them, or may not trust anyone else to do what they do. Second, many people cannot afford respite care because it may be available to them only on a private pay basis. Third, respite options are not always widely available or convenient to use, especially in rural areas.

Potential opportunities to improve affordability, quality and availability of respite programs in Michigan include:

- Exploring tax incentives to help offset the costs of adult day programs or other respite services;
- Working with insurance companies to include respite care as part of wellness or managed care programs; and
- Recognizing and publicizing quality and innovative respite program opportunities in communities.



There is also a particular need in Michigan to increase access to emergency respite care for individuals with dementia in situations in which their caregivers suddenly become unavailable, such as when a caregiver is sick or has a medical emergency and is hospitalized. The lack of emergency respite services too often leads to individuals with dementia being placed in institutional settings.

Meet the growing need for affordable, reliable transportation services for people living with dementia.

Transportation. Finding ways to meet the growing need for specialized transportation services for people living with dementia is an important aspect of becoming a dementia capable state. Cognitive impairment due to dementia can lead to deficits in reaction times and attention.¹⁰⁷ Studies suggest that drivers with dementia have an approximately two to five times greater risk of involvement in a crash compared with age-matched controls.¹⁰⁸ A complicating factor is that a person living with dementia may not recognize that their driving abilities have declined.¹⁰⁹ Nevertheless, giving up driving can be a deeply personal and emotional issue, particularly in a “car state” like Michigan. Driving cessation can have a significant negative impact on the lives of people living with dementia if it takes away their access to healthcare, to buy necessities, and to stay connected to family, friends and the community.

In a dementia capable state or community, people living with dementia are empowered to get to where they want and need to be, safely and for a reasonable cost. Potential opportunities to improve safe transportation options for Michigan residents living with dementia include:

- Providing training and opportunities for public transportation drivers to learn about their passengers who have dementia;
- Pursuing additional state and federal funding for dementia specific transportation services; and
- Potential collaborations with companies such as Uber or Lyft to provide safe and convenient door-to-door transportation.

Other exciting new possibilities are emerging thanks to innovations in automotive technology.



Members of the **Michigan Dementia Coalition** look forward to collaborating with people living with dementia, the mobility industry and other stakeholders to identify and test both short- and longer-term opportunities.



Identify policy or regulatory changes to help prevent abuse and financial exploitation of people living with dementia.

People living with dementia are at increased risk for elder abuse and exploitation. Reduced cognitive capacity and ability to problem solve and advocate for needs increases the likelihood of elder abuse and exploitation.¹¹⁰ Perpetrators often recognize cognitive deficits and may target persons they see as vulnerable. As their condition progresses, people living with dementia also become increasingly susceptible to self-neglect, as they may lose insight or the ability to safely perform “activities of daily living” such as medication management, handling finances, or their own personal care.¹¹¹ Additionally, misunderstood behaviors as a person’s dementia progresses, such as agitation or aggression, can result in even a well-meaning caregiver intentionally or unintentionally causing physical harm. The most predictable factors contributing to this are the stress and burden of caregiving, i.e. “caregiver burnout.”^{112 113}

Identifying specific policies that address the abuse or exploitation of people living with dementia is a complicated issue that encompasses fraud (by strangers, by fiduciaries, or by other trusted persons), capacity issues, duties to report (e.g. for social workers or financial institutions), and a wide range of family dynamics. It is also a difficult issue area in which to develop policy because it requires balancing individual freedom and a person’s right to self-determination with the policy goal of protecting vulnerable people from those who would harm or exploit them.

One way Michigan could do a better job preventing abuse and exploitation would be to address the existing inconsistencies in the definition of *vulnerability* and the application of protocols regarding vulnerability. Differing interpretations of who qualifies as “vulnerable” often become an impediment to assessment and intervention for both families and state agencies charged with preventing elder abuse.



We know that more can be done to protect people living with dementia from abuse and exploitation in our state. The **Michigan Dementia Coalition’s *Ending Abuse and Exploitation Workgroup*** is working to identify opportunities to improve collaboration regarding vulnerable adult protocols in Michigan and to promote training for professionals in various fields who encounter people living with dementia to help improve their interactions. Members of the **Michigan Dementia Coalition** are also currently pursuing research regarding the different definitions and interpretations of *vulnerable* across Michigan’s legal, medical, social service and public safety fields that will inform these discussions.

Incentivize professionals to specialize in geriatrics to better prepare for our state’s increasingly older population.

The vast majority of Michigan’s older adults will never have dementia, while some people develop dementia well before they turn 65. Nevertheless, age remains the largest risk factor for dementia: 3% of people age 65-74 have Alzheimer’s dementia, 17% of people age 75-84 have Alzheimer’s dementia, and 32% of people age 85 and older have Alzheimer’s dementia. 81% of the people who have Alzheimer’s dementia are age 75 or older.¹¹⁴

The year 2030 marks an important demographic turning point in U.S. history according to the U.S. Census Bureau's 2017 national population projections. By 2030, all baby boomers will be older than age 65, representing one out of every five U.S. residents.¹¹⁵ However, most curricula in the health professions still do not emphasize aspects of aging and the special considerations needed when working with older adults. To better prepare for our state's increasingly older population, Michigan needs to encourage more professionals to specialize in geriatrics and dementia care.

Potential opportunities to address Michigan's projected shortage of geriatrics professionals include:

- Creating financial incentives for physicians, nurse practitioners, nurses and social workers to specialize in geriatrics, such as student loan forgiveness through the Michigan State Loan Repayment Program¹¹⁶ which is funded by state, federal and local dollars;
- Doing more to introduce the field of geriatrics to health professions students by increasing the number of rotations for health professions students in places where people living with dementia are served such as geriatric outpatient practices, geriatric assessment centers, assisted living, adult day programs, and Programs of All-Inclusive Care for the Elderly (PACE); and
- Requiring licensed health professionals to receive training on the diagnosis, treatment and care of patients with cognitive impairment.



Engage and equip employers to prepare for a growing population of employees balancing work and family caregiver responsibilities.

Nearly two-thirds of family caregivers in Michigan report being employed either full- or part-time during the period they were providing care for their loved one.¹¹⁷ Caregivers for loved ones with dementia report an even greater impact on their work situation than other caregivers. They spend more time per week caring for their loved one than other caregivers,¹¹⁸ and are more likely to need to leave work early, take paid and unpaid time off, work different hours, or take an additional job.¹¹⁹

More employers are recognizing that family caregiving can have a negative impact on the workforce, increasing labor costs and lowering productivity.¹²⁰ A dementia capable Michigan engages and equips employers to realize a positive rate of return through strategies¹²¹ that help their employees balance caregiving responsibilities with their jobs.

LEADING THE WAY WITH RESEARCH

The dementia research community in the state of Michigan is vibrant, collaborative and leading the way to find ways to stop or slow the progression of dementia and improve quality of life for people living with it.

The *Michigan Alzheimer's Disease Research Center (MADRC)* is a collaborative effort funded by the National Institute on Aging within the National Institutes of Health (NIH). It brings together clinicians, researchers, aging experts, and other academic and service professionals from the University of Michigan, Michigan State University, and Wayne State University to:

- Provide state-of-the-art clinical services to diagnose and treat people in all stages of dementia.
- Conduct clinical trials to test whether novel drugs can slow the progression of disease.
- Conduct lifestyle intervention and memory training studies to help prevent the onset or progression of dementia.
- Advance research into the causes of Alzheimer's disease and related dementias in order to develop new therapies for clinical trials.
- Leverage brain imaging and blood samples to develop new biomarkers for dementia, which is critical for early diagnosis.
- Train the next generation of dementia researchers.
- Sponsor pilot funding to encourage innovative cross-university collaborations and attract NIH funding.
- Provide critical community outreach services to increase public awareness of dementia and dementia risk factors.
- Provide key resources for families to reduce caregiver and care partner burdens.
- Conduct studies and provide resources to prevent elder abuse, neglect, and legal fraud.



Michigan also boasts many active *translational research programs* studying Alzheimer's disease and related dementias outside of the MADRC. Several research groups at the University of Michigan, Michigan State University, Central Michigan University, Western Michigan University, and others are actively engaged in "translational research," which is a "bench-to-bedside" approach that focuses on using basic science insights for the development of treatment strategies for patients, including new drugs, devices and therapies.

Other researchers in Michigan are currently engaged in projects to identify gaps in services across communities or demographic groups, find ways to better address the needs of family caregivers, improve the built environment to make homes and communities safer for people with dementia, and more.

OPPORTUNITIES TO PARTICIPATE IN CLINICAL RESEARCH

Michigan residents may choose to participate in research studies via the MADRC at the University of Michigan, which conducts multiple ongoing research projects including drug studies, observational studies, lifestyle intervention studies, imaging studies, and caregiver studies. The MADRC is currently seeking research volunteers experiencing early signs of memory changes as well as healthy older adults. Most of these studies are conducted in Ann Arbor and Detroit. The best way to learn about MADRC research opportunities is to consult their website at <http://alzheimers.med.umich.edu/research/> or call 734-936-8803.

Michigan State University also conducts dementia studies for Michigan residents in the Lansing area. Current research includes drug treatment studies for dementia symptoms, studies to reduce agitation in persons living with dementia, and imaging studies. These studies are available to patient volunteers in varying stages of dementia as well as healthy volunteers. The best way to keep track of MSU clinical research in dementia is to consult their website at <https://neurology.msu.edu/CoGeNT/services/current-clinical-trials>.

Other regional sites that are conducting or planning clinical research in the future include:

In the Detroit area

Wayne State University:

<https://neurology.med.wayne.edu/dementia>

Quest Research Institute:

<http://www.questri.com/areas-of-research/alzheimers-diseasememory-loss/>

In the Grand Rapids area

The Alzheimer's Alliance:

<https://alzheimers.msu.edu/>

In the Kalamazoo/Battle Creek area

Bronson Neuroscience Center:

<https://www.bronsonhealth.com/locations/bronson-neuroscience-center/research/current-research-studies/>

Other ways to find opportunities to participate in clinical research include:

- *TrialMatch.alz.org*. This is a free clinical studies matching service that connects individuals with Alzheimer's, caregivers and healthy volunteers to current studies.
- *ClinicalTrials.gov*. This is a US National Library of Medicine database of privately and publicly funded clinical studies conducted around the world (use "Michigan" as a search term).

THE MICHIGAN DEMENTIA COALITION: PURPOSE, BACKGROUND AND NEXT STEPS

The Michigan Dementia Coalition currently consists of over 120 individuals from dementia-related fields and backgrounds, representing more than 65 organizations. Our purpose in working together as members of the Michigan Dementia Coalition is to make use of our combined knowledge, experience and resources to improve quality of life for people living with dementia and their families. Organizations and individuals have come together as the Michigan Dementia Coalition several times over the past three decades. However, the last time a Michigan Dementia Plan was published was in 2009, for the period 2009-2011.

Led by the Alzheimer's Association Michigan Chapters, AARP Michigan and the Michigan Alzheimer's Disease Research Center, the current Michigan Dementia Coalition came together beginning in late 2016 to identify current needs and opportunities for Michigan to become a more dementia capable state. From late 2016 to the present, more than 100 people from various dementia-related backgrounds have participated in meetings of the full coalition, workgroups, or both.

Based on feedback from the coalition's 2017 online survey, the following 6 Michigan Dementia Coalition Workgroups (*see Appendix A*) were organized and met in 2017 and 2018 to gather public and professional input, share best practices, and identify Michigan-specific opportunities for systemic improvement:

- Input Workgroup
- Education, Training, and Healthcare Service Delivery Workgroup
- Safety, Legal, and Financial Issues Workgroup
- Supportive Services Workgroup
- Public Awareness Workgroup
- Data Workgroup

On July 13 and August 10, 2018, the full coalition came together for two half-day work sessions to review and discuss the findings and recommendations of the six workgroups. Throughout the fall of 2018 our Steering Committee refined the findings and recommendations from our workgroups to create this roadmap.

Next Steps

The Michigan Dementia Coalition plans to continue building our coalition in 2019 as we work together to carry out next steps needed to achieve the vision set forth in this roadmap. The coalition has established the following initial committees for our work in 2019, and we welcome additional members to serve on any or all of them:



- *Steering Committee.* Provides leadership and strategic direction for the coalition. For more information or to participate, contact Lisa Dedden Cooper at lcooper@aarp.org.
- *Communications and Public Awareness Committee.* Develops materials and strategies for communicating with the public, communities, and other stakeholders about the work of the coalition, including online, in print, in person and through the media. For more information or to

participate, contact Jennifer Howard at jhoward@alz.org or Scott Counts at scott.counts@hc.msu.edu.

- *Public Policy and Legislative Advocacy Committee.* Develops legislative strategies to achieve the goals and objectives set forth in this Roadmap, coordinates with the Steering Committee to determine short and long-term priorities, and works with the broader coalition to activate partner organizations to advance these priorities. For more information or to participate, contact Jennifer Hunt at jahunt@alz.org.
- *Lived Experience Committee (Persons Living with Dementia).* Actively recruits, engages, and accommodates persons living with dementia to fully participate in all aspects of the MI Dementia Coalition. For more information or to participate, contact Brenda Roberts at broberts@miassistedliving.org.
- *Public Health and Cross Sector Collaboration Committee.* Raises awareness among the state’s multi-disciplinary stakeholders who impact healthy aging and brain health, and encourages collaboration between sectors by developing strategic relationships and creative solutions to address dementia as a significant public health issue. For more information or to participate, contact Alexis Travis at travisa1@michigan.gov.
- *Ending Abuse and Exploitation Committee.* Works across agencies and alongside local prevention coalitions to expand opportunities for improvement in recognizing and preventing abuse, exploitation and neglect for all persons impacted by dementia. For more information or to participate, contact Les Dubin at dubinles@med.umich.edu.

Additionally, our member organizations are committed to continuing to help connect individuals living with dementia and their families with resources, and to facilitate the sharing of successful models and best practices among practitioners and across communities.

We stand ready to offer our combined expertise and organizational resources and look forward to working with Michigan’s policymakers, community leaders and other interested individuals and organizations to address the challenges and opportunities before us to make Michigan a dementia capable state.



2017-2018 WORKGROUP PARTICIPANTS

STEERING COMMITTEE

Lisa Dedden Cooper, JD, AARP Michigan (Co-Chair)
Jennifer Lepard, Alzheimer's Association Greater Michigan Chapter (Co-Chair)
Scott Roberts, PhD, University of Michigan School of Public Health and MADRC (Co-Chair)
Melanie Baird, LMSW, Alzheimer's Association Greater Michigan Chapter
Scott Counts, PhD, Michigan State University Dept of Translational Science & Molecular Medicine
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Lisa Misenhimer, MSW, Rethinking Dementia: Accelerating Change
Keith Morris, JD, MPA, Elder Law of Michigan
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Phil Lewis, Michigan Department of Health & Human Services, Aging & Adult Services Agency
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PUBLIC AWARENESS WORKGROUP

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Gail Brusseau, LMSW, Lakeshore Regional Entity
Lisa Misenhimer, MSW, Rethinking Dementia Michigan
Ken and Barbara Johnson, Alzheimer's Association volunteers
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Scott Roberts, PhD, University of Michigan School of Public Health
Sherii Sherban, Scene Magazine and Senior Times Southcentral Michigan

SUPPORTIVE SERVICES WORKGROUP

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Anne Ellermets, MPA, Area Agency on Aging of Western Michigan
Anne O'Rear, Alzheimer's Association GMC
Bonnie Hogoboom, Region 3B Area Agency on Aging, CareWell Services
Brenda Stoneburner, Michigan Department of Health & Human Services
Carol Robinson, DNP, RN, CHPN, Making Choices Michigan
Carolyn Stramecki, MHSA, Honoring Health Care Choices - Michigan
Chris Simons, Clark Retirement Community
Chris Walekowski, Volunteer, Alzheimer's Assn Early Stage Programs & Memory Café
Courtney McCarary, Porter Hills
Craig Frazier, Capital Area Transportation Association
Debra Yamstein, Brown Center, JVS Human Services
Deedre Vriesman, MA, NHA, Samaritas Senior Living
Joan Konyndyk, Hope Network
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Julie Shaw, Aging Services and RSVP Program of Marquette County
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Karen Schelberg, Alzheimer's Association
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Kendrick Heinlein, Area Agency on Aging of Western Michigan
Kris Lindquist, Alger County Commission on Aging
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Meegan Joyce, The Rapid
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Sheryl Darroch, Alzheimer's Association Respite Services
Stacy McIntyre, Golden Horizons
Sue Davidson, Bethlehem Intergenerational Center, Director
Suzann Ogland-Hand, PhD, Neuropsychologist, Ogland-Hand Consulting
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Christopher Berry, JD, CELA, The Elder Care Firm
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Lisa Fisher, Michigan Department of Health & Human Services, Adult Protective Services
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Diane Bright, OTRL, AARP Executive Council
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INPUT WORKGROUP (2017 SURVEY)

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DATA WORKGROUP

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Leslie Dubin, LCSW, ACSW, University of Michigan School of Social Work

ENDNOTES

¹ 2019 *Alzheimer's Disease Facts and Figures*, Alzheimer's Association, *Alzheimers Dement* 2019;15(3):321-87, Table 4, page 20. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>

² 2019 *Alzheimer's Disease Facts and Figures*, Table 8, page 36.
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³ *Family Caregiving and Out-of-Pocket Costs: 2016 Report*, page 7.
https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf

⁴ 2019 *Alzheimer's Disease Facts and Figures*, Table 15, page 52.
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⁵ 2019 *Alzheimer's Disease Facts and Figures*, Table 4, page 20.

⁶ 2019 *Alzheimer's Disease Facts & Figures*, Table 2, pages 9-10.

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¹² Mehta, K. M., & Yeo, G. W. (2017). *Systematic review of dementia prevalence and incidence in United States race/ethnicity populations*. *Alzheimers Dement* 2017; 13(1):72-83.

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- ¹⁴ *Caring For People With Dementia: Caregivers' Experiences*, page 6. (Nov 2018).
https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2018/caring-people-dementia-survey.doi.10.26419-2Fres.00262.001.pdf
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From unpublished tabulations based on data from the Medicare Current Beneficiary Survey for 2011. Prepared under contract by Avalere Health, March 2016.
- ¹⁶ *Family Caregiving and Out-of-Pocket Costs: 2016 Report*, page 7.
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These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice, as well as state-by-state Medicaid spending, for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Hebert et al³⁰ and included in this report (5.5 million in 2018),^{A2} rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (the Centers for Medicare and Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.
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- ²¹ *2019 Alzheimer's Disease Facts and Figures*, page 44.
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- ²³ *2018 AARP Survey of Registered Voters Age 45 and Older*. Conducted for AARP Research by American Directions Group. 1,000 registered voters, age 45 and older. The statewide sample was drawn from an age-targeted list of residents who are registered to vote in Michigan. Telephone (both landline and cell) surveys were conducted from April 9 - April 26, 2018.
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https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2018/caring-people-dementia-survey.doi.10.26419-2Fres.00262.001.pdf
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http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf. The data used in this analysis come from the *Caregiving in the U.S.* 2015 study, jointly conducted by the National Alliance for Caregiving and AARP Public Policy Institute.
- ²⁶ Reinhard, S., Levine, C., & Samis, S., *Home Alone: Family Caregivers Providing Complex Chronic Care*, AARP Public Policy Institute (2012). https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

²⁷ *2018 AARP Alzheimer's Disease and Dementia Awareness Poll*. A telephone omnibus survey conducted by AARP Research fielded May 8-12, 2018, among a nationally representative sample of 1,004 Americans age 18+. Random digit dialing was used with 60% landline and 40% cell phone. Margin of error for the national sample is +/- 3.1.

²⁸ *2018 AARP Survey of Registered Voters Age 45 and Older*. Conducted for AARP Research by American Directions Group. 1,000 registered voters, age 45 and older. The statewide sample was drawn from an age-targeted list of residents who are registered to vote in Michigan. Telephone (both landline and cell) surveys were conducted from April 9 - April 26, 2018.

²⁹ *A Public Health Approach to Alzheimer's and Other Dementias, Module 4: Dementia Capable Systems and Dementia Friendly Communities*. <https://www.cdc.gov/aging/aginginfo/pdfs/ALZ-Module4-Dementia-Capable-Systems-Dementia-Friendly-Communities.pdf>

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³² *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Alzheimer's Association and Centers for Disease Control and Prevention. Chicago, IL: Alzheimer's Association (2018). <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>

³³ In a review conducted by the MDC Public Awareness Workgroup in 2017, we identified over a dozen websites with dementia-related resources for Michigan residents from government and non-profit sources alone, each providing useful but piecemeal information.

³⁴ <https://rethinkingdementiami.org/resourceguide>

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³⁶ *Process Evaluation of the Older Americans Act Title III-E-National Family Caregiver Support Program: Final Report*, by the Lewin Group, https://www.acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf, as cited on Page 4 of *From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia* (<https://www.aarp.org/content/dam/aarp/ppi/2017/08/from-research-to-standard-practice.pdf>)

³⁷ *Michigan Aging Information System FY 2017 NAPIS Client and Service Report*, page 27. https://www.michigan.gov/documents/osa/FY_2017_NAPIS_Report_Final_June_2018_626969_7.pdf

³⁸ <https://www.canr.msu.edu/thrivenetworkmi/index>

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⁴⁰ <https://protectmymoneymi.org>

⁴¹ <https://www.cooley.edu/academics/experiential-learning/sixty-plus>

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⁴³ Iaboni, A et. al. *A Palliative Approach to Falls in Advanced Dementia*. American Journal of Geriatric Psychiatry, vol. 26, no. 4 (April 2018): 407-415. ClinicalKey. Web. 25 April 2018.

⁴⁴ Zieschang, T et al, *Falls and Physical Activity in Persons with Mild to Moderate Dementia Participating in an Intensive Motor Training*. Alzheimer Disease and Associated Disorders, vol. 31, no. 4 (October-December 2017): 307-314. PubMed. Web. 25 April 2018.

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⁴⁸ American Geriatrics Society. (2015). *Clinician's guide to assessing and counseling older drivers* (3rd ed.). Retrieved from <https://geriatricscareonline.org/toc/clinicians-guide-to-assessing-and-counseling-olderdrivers-3rd-edition/B022>

⁴⁹ https://www.michigan.gov/documents/mdot/MDOT_OlderDriverGuide_455323_7.pdf

⁵⁰ To search for rehabilitation specialists in your area, visit www.aota.org/olderdriver. Under "Driving & Community Mobility," click the button marked "Search for a Driver Rehabilitation Specialist."

⁵¹ <https://alzheimer.ca/en/bc/Living-with-dementia/I-have-dementia/Disorientation-and-getting-lost>

⁵² <https://www.dementiamentors.org/home.html>

⁵³ <https://www.nationalservice.gov/programs/senior-corps/senior-corps-programs/senior-companions>

⁵⁴ <http://alzheimerscafe.com/public.html.alzheimerscafe.com/Welcome.html>

⁵⁵ <http://www.memorycafedirectory.com/memory-cafes-in-michigan/>

⁵⁶ <https://www.alz.org/help-support/caregiving/stages-behaviors/wandering>

⁵⁷ There is debate over use of the term "wandering." Some advocates and people living with dementia feel it perpetuates a stigma surrounding dementia, and discounts that an individual may have a reason or unmet need that led to the situation in which they got lost.

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⁵⁹ www.caretrak.com

⁶⁰ www.angelsense.com/protect/dementia

⁶¹ <https://iog.wayne.edu/outreach/success-after-financial-exploitation--safe->

⁶² <https://action.aarp.org/site/SPageNavigator/FraudMap.html?cmp=RDRCT-ADV-FRAUD-050916>

⁶³ Lichtenberg, P., Ficker, L., Rahman-Filipiak, A., Tatro R., Farrell, C., Speir, J., Mall, S., Simasko, P., Collens, H. & Jackman Jr, J., *The Lichtenberg Financial Decision Screening Scale (LFDSS): A new tool for assessing financial decision making and preventing financial exploitation*, Journal of Elder Abuse & Neglect, 28:3, 134 (2016) https://iog.wayne.edu/research/lfdss_online_publication-jean_2016.pdf

⁶⁴ *2017 Michigan Dementia Coalition Online Survey*. Developed by the Input Workgroup of the Michigan Dementia Coalition and fielded January 20-February 20, 2017, via Convio Luminare. A total of 1,506 respondents completed the nine-question survey.

⁶⁵ *Family Caregiving and Out-of-Pocket Costs: 2016 Report, page 7*. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf

⁶⁶ *Societal and Family Lifetime Cost of Dementia: Implications for Policy*, Eric Jutkowitz et al (Aug 2017) <https://onlinelibrary.wiley.com/doi/abs/10.1111/jgs.15043>

⁶⁷ *2019 Alzheimer's Disease Facts and Figures*, page 43.

⁶⁸ *2019 Alzheimer's Disease Facts and Figures*, page 43.

These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice, as well as state-by-state Medicaid spending, for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition

of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Hebert et al³⁰ and included in this report (5.5 million in 2018),^{A2} rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (the Centers for Medicare and Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.

⁶⁹ 2019 Alzheimer's Disease Facts and Figures, page 43.

⁷⁰ Genworth 2017 Cost of Care Survey, conducted by CareScout[®], June 2017. <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

⁷¹ Spillman, BC and Long, SK, *Does High Caregiver Stress Lead to Nursing Home Entry?* Washington, DC: Urban Institute (2007)

⁷² Yaffe, K. et al, *Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia*, Journal of the American Medical Association 287:2090–97 (2002).

⁷³ Gaugler, J. et al, *Predictors of Nursing Home Admission for Persons with Dementia*, Medical Care 47:191–98. (2009)

⁷⁴ Feinberg, L., *From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia*. AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2017/08/from-research-to-standard-practice.pdf>

⁷⁵ 2019 Alzheimer's Disease Facts and Figures, pages 56. Citing:

French DD, LaMantia MA, Livin LR, Hecceg D, Alder CA, Boustani MA. *Healthy Aging Brain Center improved care coordination and produced net savings*. Health Aff 2014; 33(4):613-8.

For example, an interprofessional memory care clinic was shown to reduce per-person health care costs by \$3,474 in 2012 dollars (\$3,974 in 2017 dollars) over a year for individuals with memory problems compared with others whose care was overseen by a primary care provider only. More than half of the cost savings was attributed to lower inpatient hospital costs. The program was relatively low cost per person, with an average annual cost of \$618 (\$707 in 2017 dollars) — a nearly 6-to-1 return on investment.

⁷⁶ Paquin A, Salow M, Rudolph J., *Pharmacists calls to older adults with cognitive difficulties after discharge in a tertiary Veterans Affairs Medical Center: a quality improvement program*. Journal of the American Geriatrics Society. 2015;63:571-77.

⁷⁷ *Dementia Training Factsheet*, Alzheimer's Impact Movement, June 2017. http://act.alz.org/site/DocServer/2013_Dementia_Training.pdf?docID=49067

⁷⁸ *2016 Training Resources Compendium for Dementia Care Providers and Volunteers*. Prepared for Erin Long, Administration on Aging Administration for Community Living. Prepared by Elizabeth Gould & Patty Yuen, RTI International. This list of resources is not exhaustive, but each resource was selected and reviewed by the National Alzheimer's and Dementia Resource Center staff. <https://nadrc.acl.gov/sites/default/files/uploads/docs/2016%20Provider%20Training%20Resources%20compendium.pdf>

⁷⁹ Bureau of Labor Statistics, U.S. Department of Labor, Occupational Outlook Handbook, Home Health Aides and Personal Care Aides (accessed October 30, 2018) <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>

⁸⁰ <https://www.impartalliance.org/>

⁸¹ Luz, C. and Hanson K., *Filling the Care Gap: Personal Home Care Worker Training Improves Job Skills, Status, and Satisfaction*. Home Health Care Management & Practice. 2015:1-8.

⁸² <https://phinational.org/wp-content/uploads/legacy/clearinghouse/DemCompGuide-EverydayLang.pdf>

⁸³ <https://nadrc.acl.gov/guides-and-presentations>

⁸⁴ The five key Dementia Friends[®] messages as set forth at <https://dementiafriendsusa.org/what-dementia-are>: 1) Dementia is not a normal part of aging. Not everyone who grows old will develop dementia. 2) Dementia is caused by diseases of the brain. The

most common is Alzheimer's. 3) Dementia is not just about having memory problems. It can affect thinking, communication and doing everyday tasks. 4) It is possible to have a good quality of life with dementia. 5) There's more to the person than the dementia. People with dementia are a valuable part of the community.

⁸⁵ 2019 *Alzheimer's Disease Facts and Figures*, page 62.

⁸⁶ 2018 AARP *Alzheimer's Disease and Dementia Awareness Poll*. A telephone omnibus survey conducted by AARP Research fielded May 8-12, 2018, among a nationally representative sample of 1,004 Americans age 18+. Random digit dialing was used with 60% landline and 40% cell phone. Margin of error for the national sample is +/- 3.1.

⁸⁷ <https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf>

⁸⁸ <http://www.dfamerica.org/provider-tools/>

⁸⁹ 2019 *Alzheimer's Disease Facts and Figures*, *Alzheimers Dement* 2018;14(3):367-429, Table 4, page 20.

⁹⁰ *Disrupting Disparities: A Continuum of Care for Michiganders 50 and Older*, AARP Michigan with Western Michigan University College of Health & Human Services, page 8 (2018). <https://s18672.pcdn.co/wp-content/uploads/2018/10/AARP-Report-Disrupting-Disparities.pdf>

⁹¹ *The Color of Health*, Health Equity Alliance and Calhoun County Public Health Department (2013).

⁹² 2019 *Alzheimer's Disease Facts and Figures*, page 21. Citing:
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⁹³ *Alzheimer's disease-related dementias: Research Challenges and Opportunities*. ADRD Report and Memorandum 2013. Conference and Recommendations Report to the NINDS Council. https://www.ninds.nih.gov/sites/default/files/ADRD_2013_Report-and-Memorandum_508comp_0.pdf

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⁹⁹ *Communities in Action: Pathways to Health Equity*, National Academies of Sciences, Engineering, and Medicine (2017). <https://www.ncbi.nlm.nih.gov/pubmed/28418632>

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