

# Understanding the Impact of Alzheimer's Disease





Alzheimer's disease is the sixth leading cause of death in the United States.



Care for Alzheimer's disease and other forms of dementia will reach **\$305 billion in 2020**. 60 to 80%

Alzheimer's disease is the most common form of dementia, accounting for **60-80% of dementia cases** in older adults.

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# **Key Takeaways:**

- According to the Centers for Disease Control and Prevention (CDC), by 2060 the number of Alzheimer's disease diagnoses is expected to reach 14 million more than doubling current cases.
- Between 2015 and 2060 the largest increase in diagnoses of Alzheimer's disease and related dementias will occur in the Hispanic and African American populations.
- Across all races, women are two times more likely to be diagnosed with Alzheimer's disease primarily because women have longer life expectancy.

# Introduction

Alzheimer's disease is named for Dr. Alois Alzheimer, a German psychiatrist who first discovered the microscopic plaques and tangles in the brain that are now known as hallmarks of the disease.<sup>1</sup> Alzheimer's disease is a progressive brain disorder that affects more than 5 million Americans and is the 6th leading cause of death.<sup>2</sup> The cost of Alzheimer's disease and other dementias is expected to reach \$305 billion in 2020, not including the estimated \$244 billion in unpaid care provided by family and friends.<sup>3</sup>

Alzheimer's disease and dementia are often conflated. While Alzheimer's disease is a type of dementia, it is important to understand that Alzheimer's is a specific disease with unique markers and methods of diagnosis. Dementia, however, is a syndrome and broadly describes several disorders whose symptoms involve memory loss and decline in reasoning.<sup>4</sup> Alzheimer's disease is the most common cause of dementia, accounting for 60-80% of dementia cases in older adults.<sup>5</sup> In addition to Alzheimer's disease, other types of dementia include frontotemporal disorders and Lewy body dementia. It is common for people to have a combination of two or more types of dementia, known as mixed dementia. For example, it is possible for a person to be diagnosed with both Alzheimer's disease and vascular dementia.<sup>6</sup> Other conditions can cause dementia-like symptoms, which can create challenges for appropriate diagnosis.

# Alzheimer's Disease Demographics

Most people with Alzheimer's disease 65 or older; however, approximately 200,000 Americans under the age of 65 are diagnosed with early-onset Alzheimer's disease.<sup>7</sup> For people with early onset Alzheimer's disease, signs appear between the mid-30s and mid-60s.<sup>8</sup>

While growing older does not cause Alzheimer's disease, age is the leading risk factor. For people over the age of 65, the risk of Alzheimer's doubles every five years.

A family history of Alzheimer's disease is another strong risk factor. Those who have a parent or sibling with Alzheimer's disease are at greater risk, especially if more than one family member is diagnosed.

While age and family history are out of our individual control, research shows that head injuries and heart disease are linked with Alzheimer's and vascular dementia.<sup>9</sup> Some medical conditions can cause symptoms that resemble dementia. Side effects of medications, depression or other emotional problems, vitamin deficiencies, and excessive alcohol consumption can all cause dementia-like symptoms that can be resolved once the condition is treated.<sup>10</sup> Healthy aging, protecting the brain, and taking steps toward good heart health can be key factors in avoiding an Alzheimer's or dementia diagnosis.

# Alzheimer's Disease and Minority Populations

According to the Centers for Disease Control and Prevention (CDC), by 2060 the number of Alzheimer's disease diagnoses is expected to reach 14 million—more than twice the current level . Between 2015 and 2060 the largest increase in diagnoses of Alzheimer's disease and related dementias will occur in the Hispanic and African American populations. Hispanics are estimated to see an increase of seven times the current rate of disease and diagnoses among African Americans are expected to quadruple.<sup>11</sup> Alzheimer's disease is the sixth leading cause of death in the United States but is the fourth leading

- 1 https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet
- 2 https://www.alz.org/media/Documents/alzheimers-facts-and-figures-infographic.pdf
- 3 <u>https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf</u>
- 4 https://www.aarp.org/health/dementia/info-2018/difference-between-dementia-alzheimers.html

- 6 <u>https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis</u>
- 7 https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s

- 10 <u>https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis</u>
- 11 <u>https://www.cdc.gov/aging/publications/features/Alz-Greater-Risk.html</u>

<sup>5 &</sup>lt;u>https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s</u>

<sup>8</sup> https://www.nia.nih.gov/health/what-causes-alzheimers-disease

<sup>9</sup> https://www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors

cause of death for older African Americans. For Hispanics, the average age when symptoms appear is nearly seven years earlier than for their white counterparts. While Hispanics are more likely to experience Alzheimer's disease, they are less likely to be accurately diagnosed.<sup>12</sup> Across all races, women are two times more likely to be diagnosed with Alzheimer's disease primarily because women have longer life expectancy.<sup>13</sup>

# **Diagnosing Alzheimer's Disease** and Dementias

Getting a definitive diagnosis of Alzheimer's disease or related dementias can be difficult for individuals and their families. In fact, Alzheimer's disease can only be definitively diagnosed after death through examination of brain tissue.<sup>14</sup> To diagnose Alzheimer's disease and other dementias, doctors look at a host of evidence including overall health, use of medications, memory tests, and diagnostic tools such as computer tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET).

In 2011, the National Institutes of Health and the Alzheimer's Association updated the clinical diagnostic criteria for Alzheimer's disease. The current guidelines describe 3 stages of Alzheimer's disease:

- Preclinical—Brain changes, including amyloid buildup and other nerve cell changes, may already be in progress, but significant clinical symptoms are not yet evident.
- Mild cognitive impairment (MCI)—A stage marked by symptoms of memory and/or other thinking problems that are greater than normal for a person's age and education, but that do not interfere with his or her independence. People with MCI may or may not progress to Alzheimer's dementia.
- Alzheimer's dementia-The final stage of the disease in which symptoms of Alzheimer's, such as memory loss, word-finding difficulties, and visual/spatial problems, are significant enough to impair a person's ability to function independently.<sup>15</sup>

# **Covering the Costs of Alzheimer's** and Other Dementias

In 2020, the cost of providing care to individuals with Alzheimer's disease and other related dementias is expected to reach \$305 billion. Unpaid caregivers add an additional \$244 billion to the cost of care. The majority of costs (51%, or \$155 billion) related to Alzheimer's disease and other dementias are covered by Medicare. A Medicare beneficiary with Alzheimer's disease or other dementia costs more than three times someone without Alzheimer's disease or other dementias. Because Medicare does not pay for nursing home or other longterm care services, individuals who are low income often rely on Medicaid to cover those costs. In 2019, Medicaid paid 17% of the costs, or \$51 billion. Individual costs for care can be expensive between health insurance premiums and deductibles. In 2020 the out-of-pocket expense for individuals is expected to reach \$66 billion, or 22% of the annual expenditure, with philanthropy and other sources of financial assistance making up the remaining 11%.<sup>16</sup>

# **Alzheimer's and Other Dementias Caregivers**

Caregivers assist individuals with activities of daily living (ADLs) such as bathing and dressing as well as instrumental activities of daily living (IADLs) such as paying bills or arranging a calendar. In the United States most older adults-83%-receive assistance from family, friends, or other unpaid caregivers. Almost half of all unpaid caregivers in the United States are providing care to a person with Alzheimer's disease or other dementia.<sup>17</sup>

# The Impact of COVID-19 on **Alzheimer's Disease and Other Dementias**

The COVID-19 pandemic has placed an added strain on those living with Alzheimer's disease, as well as medical personnel and caregivers. For Alzheimer's disease and dementia patients residing in congregate care facilities, COVID-19 has presented significant risks due to the challenges of limited space to ensure social distancing.<sup>18</sup>

https://www.endalznow.org/storage/documents/Cor/alzheimers%20disease%20facts\_figures\_factsheet\_updated\_aug.pdf 12

<sup>13</sup> https://alz-journals.onlinelibrary.wiley.com/doi/abs/10.1016/j.jalz.2018.06.3063

<sup>14</sup> https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet

<sup>15</sup> https://www.nia.nih.gov/health/alzheimers-disease-diagnostic-guidelines

<sup>16</sup> https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

<sup>17</sup> https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

<sup>18</sup> 

 $<sup>\</sup>label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:https://www.jhsph.edu/covid-19/articles/covid-19-guidance-on-protecting-individuals-residing-in-long-term-care-facilities.html \label{eq:html:protecting-individuals-residing-individua$ 

Additionally, people with Alzheimer's disease and dementia have experienced atypical COVID-19 symptoms, making a diagnosis challenging. For people with dementia, COVID-19 symptoms often include increased agitation and increased confusion, in addition to physical symptoms. Masks and other personal protective equipment used to keep patients and providers safe have also added to patient confusion and frustration.<sup>19</sup>

# **Federal Efforts**

The Federal government has funded a variety of research efforts aimed at improving the outcomes for dementia patients and their caregivers.

The <u>National Institute on Aging</u> is the primary Federal agency working on Alzheimer's disease and is one of 27 Institutes and Centers under the umbrella of the <u>National Institutes of Health</u>. The <u>Alzheimer's and related</u> <u>Dementias Education and Referral Center</u> (ADEAR) was created by Congress in 1990 and is a service of the NIA . The goal of ADEAR is to provide current, comprehensive, and unbiased information related to Alzheimer's disease and other dementias.

The National Alzheimer's and Dementia Resource Center

(NADRC) is funded by the Administration on Aging (AoA) within the Administration for Community Living (ACL). The NADRC provides expert technical assistance to AoA, ACL and Alzheimer's disease grantees as well as educational webinars and collaborative learning groups.

On January 4, 2011, President Obama signed the National Alzheimer's Project Act (NAPA) into law. NAPA instructed the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project, the goals of which include:

- Creating and maintaining an integrated national plan to overcome Alzheimer's disease
- Coordinating Alzheimer's disease research and services across all federal agencies
- Accelerating the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease
- Improving early diagnosis and coordination of care and treatment of Alzheimer's disease

- Improving outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease
- Coordinating with international bodies to fight Alzheimer's globally.

The law also requires the HHS Secretary to work with a newly established Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) to create and maintain a national plan to overcome Alzheimer's disease. The Obama Administration also announced a \$156 million investment to tackle Alzheimer's disease in 2012.<sup>20</sup>

To deliver on the goals of NAPA, HHS worked with the U.S. Department of Veterans Affairs (VA), the National Science Foundation (NSF), and the U.S. Department of Defense (DoD) to convene an Interagency Group on Alzheimer's disease and Related Dementias. The full Interagency Group is made up of representatives from 12 agencies and is designed<sup>21</sup> to carry out and execute NAPA's goals. The Interagency Group has so far held two summits, one in 2017 and in 2020. America's Health Insurance Plans (AHIP) played a key role in providing the research recommendations offered by health insurance providers for the 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, .

# Challenges

## Appropriate diagnosis

Diagnosing Alzheimer's disease and related dementias is a long and complex process with the only definitive diagnosis being available after death when brain tissue can be examined. Doctors can perform multiple diagnostic tests and gather subjective information from the patient and their family, but appropriate diagnosis takes time as well as thorough and honest reporting on a patient's condition.<sup>22</sup>

### Lack of a Cure

There is currently no cure for Alzheimer's disease or dementia. The lack of curative therapies leaves patients and family members fearing a diagnosis and overwhelmed by the possibility of living many years with cognitive challenges.

<sup>19</sup> https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html

<sup>20</sup> https://aspe.hhs.gov/system/files/pdf/105066/cmtach-JP1.pdf

<sup>21</sup> Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of the Assistant Secretary for Health (OASH), National Institute on Aging (NIA), Centers for Medicare & Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), Administration on Aging (AoA), Health Resources and Services Administration (HRSA), Agency for Healthcare Research and Quality (AHRQ), Substance Abuse and Mental Health Services Administration (SAMHSA), Food and Drug Administration (FDA), Indian Health Service (IHS), and Administration for Children and Families (ACF)

<sup>22</sup> https://www.nia.nih.gov/health/how-alzheimers-disease-diagnosed

### **Clinical Trial Limitations**

Alzheimer's trials cost more per patient than trials in most other therapeutic areas, due to the substantial amount of testing required for each patient. Patient screening and testing accounts for 50–70% of the total per-patient expense. In addition to the cost of running a trial, there are additional challenges with awareness and finding the right patient population. Approximately 99% of potential participants either do not consider or are never referred to a clinical trial. Awareness of the disease, proper diagnostic and assessment tools for providers, minority recruitment, and knowledge of trials are critical to the success of clinical trials. Alzheimer's clinical trials typically lack diversity among participants in terms of varied ethnicities, sexual and gender identities, or educational backgrounds.<sup>23</sup>

### **Expense**

Alzheimer's disease and other dementias come with direct and indirect costs. Direct costs include nursing home, home health, and other long term care expenses. Indirect costs include changes to quality of life for the patient and caregiver as well as costs incurred by the caregiver. Medicare and Medicaid cover the majority of costs related to Alzheimer's disease and dementia, but approximately 22% of costs, or \$66 billion, are out-of-pocket costs for patients. With the cost of care expected to rise to more than \$1 trillion by 2050, the cost to patients will continue to be significant.<sup>24</sup>

### Caregiving

A national poll showed that 45% of caregivers for an Alzheimer's disease or dementia patient report positive feelings about their caregiving experience. Caregivers also report significant challenges, including stress, depression, physical strain, employer complications, and negative health impacts, despite an appreciation for the time shared with a loved one.<sup>25</sup> Family caregivers often receive little training to care for their loved one and have few backup care or respite options.

# Health Insurance Provider Research Recommendations<sup>26</sup>

AHIP was asked to co-lead the Payer Stakeholder Group at the 2020 Summit and develop recommendations concerning how payers make coverage and related decisions for Medicare Advantage members living with dementia and their care partners. Together the full Stakeholder Group developed a list of questions to pose to health insurance providers representing Medicare Advantage (MA), including duals special needs (D-SNP) and Medicare-Medicaid (MMP) plans and Medicaid Managed Care plans, including those that deliver managed long term services and supports (MLTSS) The blinded interviews were conducted by <u>Health and Aging</u> Policy Fellows.

The Payer Stakeholder Group was able to offer nine recommendations:

- Research and analysis should be conducted to increase understanding about how various types of payer organizations make decisions about the dementia-related care, services and supports they will provide and the kinds of research findings that would help them make these decisions.
- Identify methods to effectively engage payer organizations in research related to dementia-related care, services, and supports.
- Conduct further research on health professional education for identification, detection/screening, treatment and management of dementia and related behaviors.
- Conduct further research on how best to educate and support care partners of individuals living with dementia to prevent care partner burnout.
- Conduct further research on the benefits of earlier advance care planning with individuals who are living with dementia and their care partners.
- Conduct further research on the impact of addressing social determinants of health on quality of life and other health outcomes for individuals living with dementia and their care partners.
- Conduct further research on earlier cognitive and functional assessment, including studies to determine whether earlier assessments lead to differences in health outcomes, disease trajectory, or care partner stress/burden.

26 https://aspe.hhs.gov/system/files/pdf/263841/PayerRecom20.pdf

<sup>23</sup> https://healthpolicy.usc.edu/article/due-to-complex-barriers-the-overwhelming-majority-of-alzheimers-patients-do-not-participate-in-clinical-trials/

<sup>24</sup> https://www.ajmc.com/view/economic-burden-of-alzheimer-disease-and-managed-care-considerations

<sup>25</sup> https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

- Conduct further research on what services state Medicaid programs offer to individuals with dementia and their care partners and how those programs make decisions regarding coverage.
- Conduct further research on how employers make coverage decisions for their retirees living with dementia and employees who are dementia care partners.

The full report, including details on each recommendation can be found <u>here</u>.

# **How Health Plans Are Helping**

### Anthem

Anthem affiliate CareMore is taking a deep dive approach to caring for individuals diagnosed with Alzheimer's disease and other dementias. CareMore approaches care delivery from a personal perspective and has the goal of providing the same level of care to their patients as they would to their loved ones. When CareMore decided to reevaluate their Alzheimer's disease and other dementias programs, one of the first steps was to reach out to CareMore staff with loved ones living with Alzheimer's disease or another form of dementia. The goal was to learn what changes could be made to improve the experience for patients and family members from the diagnosis to ongoing treatment and supportive services.

CareMore has always had a clinically holistic approach to Alzheimer's disease and other dementias. With strong case management, ongoing chronic disease management, and extensive partnerships to ensure a patient's social service needs were met, CareMore built a successful program that started with multi-step classes to learn about the disease and continued with consistent support from primary care, pharmacy, psychology, and case management services. As the model evolves, CareMore's partnerships with providers of social services will remain, but will take an enhanced approach to operationalize the clinical aspect of care for patients with Alzheimer's disease and other dementias. In creating this new approach, CareMore has recognized the unique medical, social, and psychiatric needs of patients and the need for appropriate response.

### Centene

Centene Corporation is a diversified, multi-national healthcare enterprise that provides a portfolio of services to government-sponsored and commercial healthcare programs, focusing on under-insured and uninsured individuals. With the largest MLTSS program in the United States, Centene brings its nationwide expertise and commitment to meet the needs of members with Alzheimer's disease and related dementias. Centene's subsidiary, Superior HealthPlan (Superior), in Texas serves nearly 140,000 members through STAR+PLUS, a Medicaid managed care program for people who have disabilities or are 65 or older. To respond to the needs of members living with memory and cognitive challenges, Centene and Superior partnered with The Johns Hopkins University (JHU) School of Medicine to pilot an evidence-based dementia care coordination program called Maximizing Independence (MIND) at Home<sup>™</sup>.

MIND at Home<sup>™</sup> is an innovative, comprehensive, homebased care coordination intervention created and tested at Johns Hopkins University for people with Alzheimer's disease or related dementias who are cared for in their own homes by family caregivers. The program is designed to systematically assess and help address unmet needs that may be barriers to persons with dementia remaining in their home, while maintaining their health and wellbeing and that of their caregiver.

This well-researched model has been shown to extend the time that a person with dementia remains at home by an average of nine months over the course of two years before transition to assisted living, admission to a nursing facility, or death. Results have also shown improved quality of life and quality of care, as well as substantially reduced family caregiver burden. A number of positive trends have been demonstrated by ongoing studies, including reductions in Medicaid expenditures for dual eligible participants. Further research is underway to verify these trends.

The goals of the Superior HealthPlan MIND at Home™ pilot are to explore the feasibility of adapting the academic model for use in a community-based setting for Medicaid beneficiaries, and to evaluate the impact of the collaborative model on member satisfaction, health outcomes, and potentially avoidable health care utilization. Adaptation of the MIND at Home™ model included building assessments and care plan templates in Superior's digital documentation platform, creating informational and marketing materials, and completing a training and delivery infrastructure for Superior spanning engagement of Care Managers and Community Health Workers, who act as frontline Memory Care Coordinators. Home-based, in-person visits, and telephonic Memory Care Coordinator visits are bolstered with weekly telecollaborative clinics via a hub-and-spoke telehealth platform that supports community-based providers for improved care based on the ECHO telementoring model. The pilot is currently tracking a set of metrics to determine whether MIND at Home<sup>™</sup> is associated with reduced acute care and emergency department utilization, expansion of the use of respite care, delay in transition out of the home, and impact on Superior members' health, care needs, quality of life, and service satisfaction compared to similar long-term services and supports (LTSS) for members receiving the current standard of care. The pilot study will last 18 months, with longitudinal comparative analysis occurring at 6, 12, and 18 months.

The MIND at Home<sup>™</sup> pilot launched in August of 2019. It is available to members who have a diagnosis of Alzheimer's disease or related dementia, are living at home in the community or a community-based setting, and wish to participate in the program. Initial results indicate the program is reducing emergency department and other high cost healthcare utilization, and high levels of satisfaction have been measured among members, caregivers, and staff. If successfully validated within the Superior STAR+PLUS population, the MIND at Home<sup>™</sup> program may be rolled out into other Superior product lines, as well as other Centene health plans. This pilot, and others like it, illustrate Centene's commitment to MLTSS and working with older adults and people with disabilities.

### HealthPartners

HealthPartners is a Minnesota-based integrated health care organization providing health care services and health insurance across multiple lines of business. Founded in 1957, HealthPartners is the largest consumer governed nonprofit health care organization in the nation. HealthPartners offers two Medicaid programs for older adults, Minnesota Senior Care Plus (MSC+) and Minnesota Senior Health Options (MSHO), a fully integrated dual eligible special needs plan (FIDE-SNP).

HealthPartners serves a very diverse population in their MSC+ and MSHO programs, with about half of the membership identifying as white with over 70 languages spoken among membership. HealthPartners MSHO and MSC+ membership also tends to be older with the average age being 77. HealthPartners recognized that only one in four individuals with Alzheimer's disease and related dementia (ADRD) have been appropriately diagnosed and only half of those with a diagnosis have it recorded in their medical file. There is also clear evidence that patients and families with dementia struggle with navigating the health care system. Individuals with dementia also have much higher risks of poor outcomes with hospitalizations and transitions, especially if they are not clearly diagnosed or if that information is not visible in the medical record. In developing the Dementia Care Model, different HealthPartners team members had firsthand experience serving as a caregiver during a parent's Alzheimer's disease journey and, therefore, had a great deal of insight into the emotional and physical burden that goes along with caring for someone with this unique condition. They also were able to emphasize attention to the importance of social supports for the enrollee and the caregiver. Much of the Dementia Care Model focus is on supporting caregivers.

In addition to HealthPartners providing extensive training to their MSHO and MSC+ Care Coordinators about dementia in terms of diagnosis and disease trajectory, HealthPartners offers and has developed some unique benefits to offer to enrollees to help with challenges related to cognitive decline. They became the first health insurance provider in the country to offer animatronic cats as a covered Medicare benefit, which has been proven to reduce stress and offer comfort during times of confusion or restlessness. As another supplemental benefit unique to HealthPartners, they offer iPads that are equipped with applications designed to keep people connected to their loved ones, thinking games, and organizational and communication tools for caregivers.

Elderly Waiver services that some MSHO and MSC+ enrollees (and caregivers) may benefit from are adult day programs, transportation, respite, Meals on Wheels, and assisted living. HealthPartners is able to offer many of these benefits to all MSHO members with ADRD who do not meet eligibility criteria for Elderly Waiver by offering them through Medicare as a Supplemental Benefit. HealthPartners also makes a variety of benefits available to all caregivers of MSHO members with dementia, including psychotherapy, training and education, caregiver coaching and counseling, Family Memory Care, and transportation for the caregiver to and from the aforementioned benefits.

A final, but critically important, aspect of the HealthPartners Dementia Care Model is outreach to the community to ensure the approach, programming, and materials are culturally sensitive. HealthPartners has partnered with key community based organizations (CBOs) to jointly facilitate focus groups of older adults from different communities asking for feedback. Focus groups are asked about how seniors in that community are talking about dementia, memory loss, the role of spirituality, awareness and acceptance of Alzheimer's and other dementias, where they find information about accessing care, what services are most helpful, and other topics. The goal is to gather information from focus groups and create intentional, culturally responsive programming and materials in the appropriate languages that will have the greatest impact for each community. HealthPartners has identified 5 diverse communities' they are working with in the initial phase of this work. A focus group with the Hmong community has already taken place, while the remaining groups have been delayed due to COVID-19.

### **SCAN Health Plan**

SCAN Health Plan was formed over 40 years ago when a group of senior activists in Long Beach, California got together, determined to improve access to the care and services they needed so they could stay as independent as possible. They brought together experts in medicine, gerontology, psychology, and social services and formed the not-for-profit Senior Care Action Network, now known as SCAN. Today SCAN has several lines of business to serve older Americans, including a fully integrated dual eligible special needs plan (FIDE-SNP), serving approximately 15,000 enrollees in southern California. SCAN's mission has been Keeping Seniors Healthy and Independent, a mission that has been important to all enrollees, especially those living with Alzheimer's disease and other dementias.

In partnership with leading experts at the University of California, Los Angeles, SCAN developed a memory program designed to identify enrollees with any form of dementia and provide need-specific supports. SCAN has created teams of social workers and community health workers who are trained in motivational interviewing as well as pharmacists to ensure appropriate medication use. As part of the Memory Care program, SCAN has tailored benefits to best suit the needs of individuals living with dementia and their caregivers. Benefits can include home modifications, meals, and respite for caregivers. The team also focuses on key areas including advanced care planning, medications, fall prevention, and supporting follow up care with their treating physicians.

In addition to physical health and safety needs, SCAN identifies social support needs through the health risk assessment (HRA) process. When an enrollee has a need that is not covered through SCAN-provided benefits, social workers utilize Aunt Bertha software to locate additional resources and provide a warm handoff to the available community-based resources. SCAN also partners with community-based organizations such as local Alzheimer's Association offices. Finally, to support the local municipalities' goals of being "age friendly," SCAN has developed a Trading Ages curriculum, using virtual reality technology to train the office staff of their provider network how to care for an aging population. While Trading Ages is not specific to the Alzheimer's disease and dementias populations, it does teach office staff about challenges that occur during the aging process as well as many geriatric syndromes. Trading Ages has also been used to train firefighters how to respond effectively to a 911 call from a senior. SCAN joined forces with the City of Long Beach's Fire Department to provide their hallmark Trading Ages senior sensitivity training to more than 400 first responders over the course of 21 sessions in November and December 2019. Fire Chief Espino responded to the training stating, "We always try to connect with the people we are serving in any situation. With Trading Ages, our emergency response teams are coming away with important insight into some of the challenges seniors face, which will enable us to respond with even greater empathy."

For more than 40 years, SCAN has kept true to the mission of Keeping Seniors Healthy and Independent. As new challenges arise, SCAN continues to develop sustainable responses that serve enrollees and the communities where SCAN operates.

# **Conclusion**

Alzheimer's disease and other dementias are complicated to appropriately diagnose and present many challenges for patients and their caregivers. It is essential, though, to pursue research that improves the rate of diagnosis and the options for care. People live with Alzheimer's disease and other dementias, on average, for ten years post diagnosis.<sup>27</sup> Health insurance providers are actively working on programs and opportunities that allow individuals to continue to live life, on their terms, for as long as possible. While there is currently no cure for Alzheimer's disease or other dementias, patients can continue happy and fulfilling lives for many years. Health insurance providers will continue to remain committed to the safety and health of millions of Americans, ensuring that they have access to the affordable, high-quality care they need and deserve.

### 27 https://www.dementiacarecentral.com/aboutdementia/life-expectancy-calculator/