

2022 MISSOURI

ALZHEIMER'S

STATE PLAN TASK FORCE

REPORT AND RECOMMENDATIONS





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MIKE KEHOE
LIEUTENANT GOVERNOR
STATE OF MISSOURI

Governor Parson, Senators, and Representatives,

By way of this letter I submit the work-product of the Alzheimer's State Task Force in accordance with RSMo 191.116. This report represents the combined efforts of a broad spectrum of Missourians with expertise relating to Alzheimer's and other dementia related diseases ranging from clinical to personal.

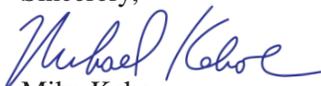
Alzheimer's and dementia related diseases either touch, or will touch, the lives of almost every Missourian. These diseases pose very unique challenges for physicians, care-givers, first-responders and others. Missouri, like other states, is trying to understand how it can adopt and implement policies and procedures to facilitate faster diagnoses, increase access to care, assist family member and care providers, and support innovative research and treatment.

I am under no illusion this report contains all the answers to this complex issue. On the contrary, I am certain it does not. Similarly, I am certain the task force, while composed of a broad mix of members who bring professional and individual expertise on the topic, cannot cover every perspective. Accordingly, I ask you consider this report for what it is: part of an on-going effort to facilitate diagnosis, treatment and care for individuals with Alzheimer's and dementia related diseases.

In effort to effect policy and legislative discussions, the Task Force endeavored to distill a tremendous amount of information into a series of recommendations for consideration. These recommendations are not all-inclusive, but rather represent the priority steps the Task Force believes the state should consider in its efforts. Each of these recommendations are made in view of your responsibility as Chief Executive and as legislators who must ultimately determine the right and priority use of limited resources.

On behalf of the Task Force, I wish to express our sincere gratitude to each of you for authorizing this important effort and for understanding the need to aggressively and effectively implement strategies in support of those with Alzheimer's and other dementia related diseases. I also thank you in advance for your consideration of these recommendations and for your efforts in the upcoming session.

Sincerely,


Mike Kehoe

EXECUTIVE SUMMARY

Alzheimer's disease and related dementias are a national crisis, affecting Americans across all walks of life and all regions of Missouri and the country. According to the Alzheimer's Association, 120,000 Missourians are currently diagnosed with Alzheimer's disease. Caring for those with Alzheimer's and related dementias cost the country approximately \$321 billion in 2021, with an estimated increase of up to \$1 trillion by 2050. In 2019, an estimated one in three seniors died from Alzheimer's or a related dementia. In Missouri, the most recent available data (2019) revealed 2,782 deaths from Alzheimer's and related dementias, an increase of 153.8% since 2000.

The members of the Task Force include representation from state government composed of the Lieutenant Governor, the state departments of Health & Senior Services, Social Services, and Mental Health, the Missouri

The Missouri Alzheimer's State Plan Task Force was commissioned by the 101st General Assembly to:

1. **Assess the current and future impact of Alzheimer's disease on Missourians.**
2. **Examine existing services and resources for persons with Alzheimer's and their caregivers.**
3. **Develop recommendations to respond to the public health crisis of Alzheimer's in Missouri.**
4. **Ensure all populations at higher risk are consulted.**
5. **Identify opportunities for the state to partner with federal government entities.**
6. **Provide information and coordination across all state agencies regarding Alzheimer's.**
7. **Examine dementia-specific training requirements across health care, adult protective services workers, law enforcement, and all other areas in which staff are involved with the delivery of care to those with Alzheimer's disease and other dementias.**
8. **Develop strategies to increase the diagnostic rate of Alzheimer's disease in Missouri.**

Division of Workforce Development, the Missouri Veterans Commission, the House of Representatives and State Senate, professionals working with persons with Alzheimer's, family caregivers and a person living with Alzheimer's disease or related dementias.

Upon completion of reviewing current services and resources related to Alzheimer's and other dementias and hearing the needs of Missourians through 8 community forums, the Alzheimer's State Plan Task Force fully supports the priority recommendations listed below. It is well documented that underrepresented and under-resourced communities are disproportionately impacted by Alzheimer's and dementia, and yet are less likely to be diagnosed; less likely to be recruited to participate in health research, and less likely to have access to care and support services. Successful implementation of these recommendations will require culturally-tailored approaches to benefit all residents of Missouri.

The task force has identified four focus areas with strategies for the State of Missouri to address and respond to the escalating public health crisis regarding Alzheimer's. This plan lays out the recommendations to enable the state of Missouri to meet the needs voiced during the town halls.

→ **Focus Area 1:**

Advance Risk Reduction, Early Detection and Timely Diagnosis

→ **Focus Area 2**

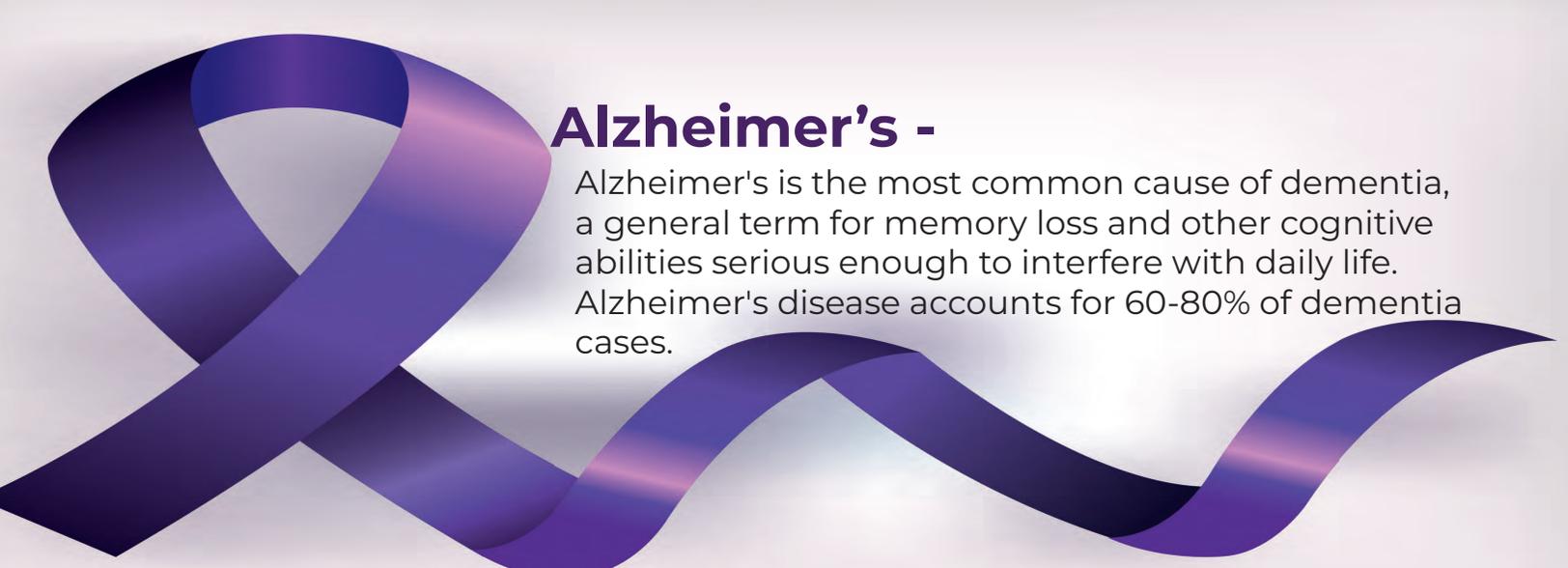
Increase Access to Care, Support, and Treatment

→ **Focus Area 3:**

Improve Quality of Care

→ **Focus Area 4**

Ensure a Coordinated Statewide Response



Alzheimer's -

Alzheimer's is the most common cause of dementia, a general term for memory loss and other cognitive abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 60-80% of dementia cases.

MISSOURI ALZHEIMER'S STATE PLAN TASK FORCE MEMBERSHIP

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Chairman

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Individual with Alzheimer's

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CATHERINE ROEHL

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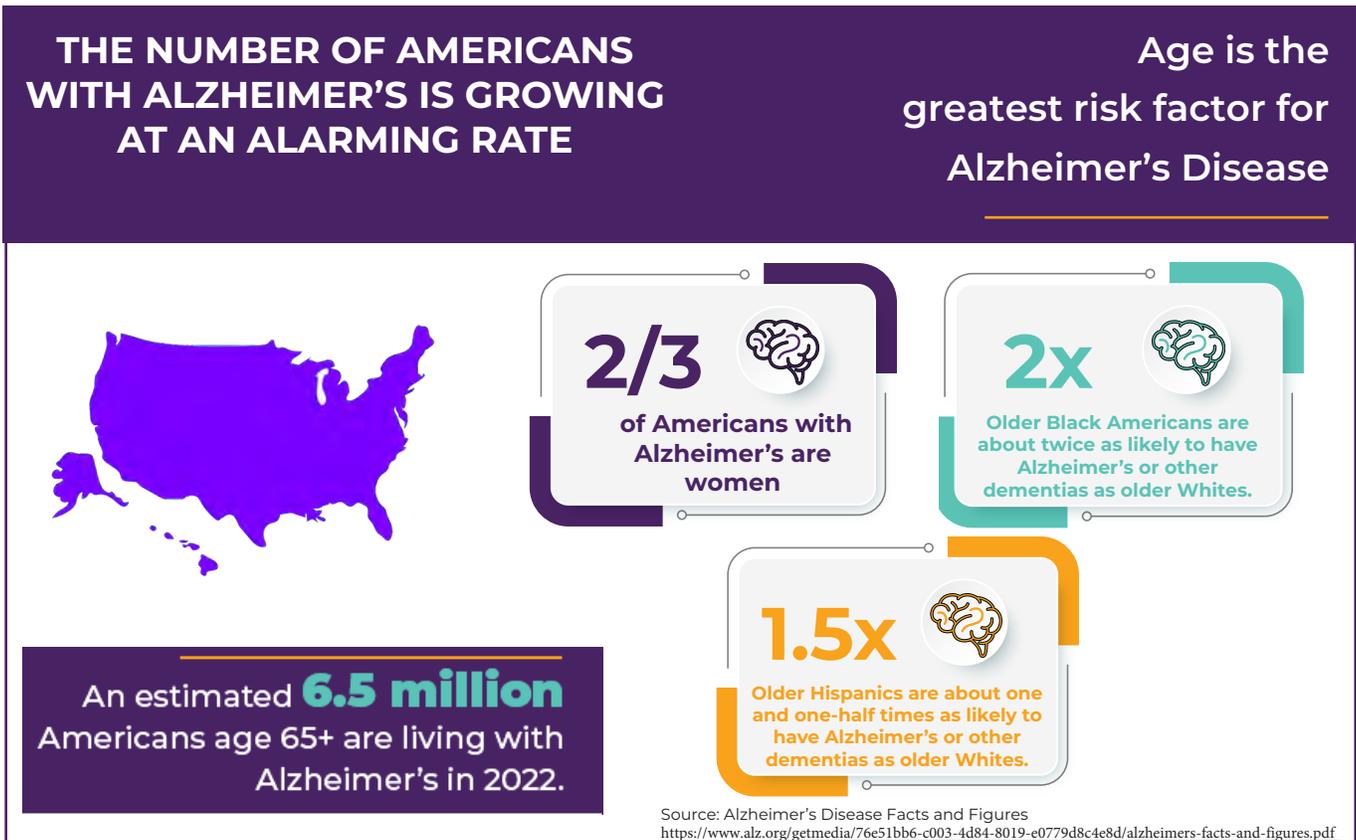
RECOMMENDATIONS TO ADDRESS ALZHEIMER'S IN MISSOURI

For the members of the task force, gathering input from persons living with Alzheimer's disease, family caregivers and stakeholders from across the state was a critically important part of the planning process. In the fall and winter of 2022, the Alzheimer's Association coordinated seven in-person town-hall-style community forums and one virtual town hall community forum. The voices of those who spoke at the community forums and those who completed surveys are considered throughout this plan. The five most common issues identified by those at the community forums include:

1. Limited public knowledge about Alzheimer's and other dementias.
2. A greater need for respite services and resources for caregivers.
3. Financial coverage of respite services and long-term care options.
4. Difficulty receiving a diagnosis, especially in rural areas.
5. Limited knowledge within the health care system of the resources and how to provide care for people with Alzheimer's or other dementias.

Additional issues communicated by those who attended the community forums or completed surveys can be found in Appendix A.

It is well documented that underrepresented and under-resourced communities are disproportionately impacted by Alzheimer's and dementia, and yet are less likely to be diagnosed; less likely to be recruited to participate in health research; and less likely to have access to care and support services. Successful implementation of these recommendations will require culturally tailored approaches to benefit all residents of Missouri.



Goal:

Expand access to resources to reduce stigma and increase early detection and diagnosis of dementia.

Justification

Early detection allows for the best opportunity to receive better medical care, enhance health outcomes and plan for future needs. Early detection and diagnosis will save money. Diagnosing the US population during the preclinical Alzheimer's disease and mild cognitive impairment stages could save as much as \$7.9 trillion in health and long-term care expenditures. Evidence shows that only about half of people with Alzheimer's have been diagnosed. Despite early detection and diagnosis illustrating many benefits and cost savings, Missouri residents in all areas, especially those that are in areas that are historically marginalized, rural communities, or areas that with residents who live at or below the federal poverty line, report difficulties obtaining an early and accurate diagnosis. A survey of health care providers in 2018 indicated a few common reasons/barriers to diagnosis:

- Lack of diagnostic training.
- Time constraints and lack of support.
- Communication difficulties and fear of causing stress
- Lack of treatments.
- Stigma¹.

Recommendations:

- The State of Missouri should fund an Alzheimer's public health campaign to educate the public about the early signs of cognitive impairment, the value of early detection and diagnosis, and discussing changes in memory and thinking with health care professionals.
- The State of Missouri should fund an Alzheimer's public health campaign specifically targeting medical professionals to increase their knowledge of dementia and the availability of dementia-specific training by working with state licensure boards.
- The State of Missouri should designate Alzheimer's disease as a public health issue and implement the State Alzheimer's Plan and the Centers for Disease Control and Prevention's Healthy Brain Initiative.

¹Alzheimer's Association. (2018). 2018 Alzheimer's Disease Facts and Figures. <https://www.alz.org/media/homeoffice/facts%20and%20figures/facts-and-figures.pdf> (accessed 12/12/2022)

Goal:

Increase funding for Alzheimer's respite grants in the state budget.

Justification:

More than 80% of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers - and nearly half of families caring for an older adult are caring for someone with dementia. In 2021, more than 11 million family members and friends of persons living with Alzheimer's provided more than 16 billion hours of unpaid care valued at nearly \$272 billion.²

The heavy burden of caring for someone with Alzheimer's affects the health and well-being of the caregivers themselves. For the last decade, funding in the state budget for Alzheimer's Respite Grants has been static at \$450,000. The number of Missourians living with Alzheimer's has grown by 10,000 in that time.

Recommendations:

- The State of Missouri should increase FY23 funding for Alzheimer's Respite grants to \$1,000,000 and by \$500,000 in subsequent budget years to reach \$3,000,000.

Goal:

Utilize community health workers (CHWs) to assist with providing dementia care.

Justification:

Many people experiencing cognitive impairment symptoms go unnoticed by health care professionals, in part, because they see their patients on an infrequent basis. Community Health Workers (CHWs) are representative of the communities they serve. Moreover, CHWs who see patients regularly are able to accurately speak to changes in cognitive health they witness overtime. Equipping them with the necessary information to confidently make referrals for further medical testing or care services will ensure that more Alzheimer's and dementia patients will have increased access to support services and receive better care.

Recommendations:

- The State of Missouri should ensure dementia competent training programs are made available for CHWs. This extends to being able to identify dementia symptoms in patients with comorbid health conditions and assess when a referral for further action is necessary. CHWs should also be given adequate resources regarding home and community based services so they can refer patients experiencing cognitive impairment to local care and support. Opportunities should be provided to increase the CHW workforce to include individuals from underrepresented and under-resourced communities.
- The State of Missouri should examine opportunities to fund the use of CHWs in providing services across the health care system.

²Alzheimer's Association. (2022). 2022 Alzheimer's disease Facts and Figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf> (accessed 12/12/2022)

INCREASE ACCESS TO CARE, SUPPORT AND TREATMENT CONTINUED

Goal:

Ensure state Medicaid programs provide appropriate coverage for approved drug and clinical treatments for persons living with dementia.

Justification:

With several promising new treatments, there is hope for the Alzheimer's and dementia community. People living with the disease have the right to make informed choices and access any approved treatment that is the right fit for their care and treatment plan. These benefits will only be realized if all patients have access to newly FDA-approved treatments.

Recommendations:

- The State of Missouri should examine existing MO HealthNet programs for gaps in service that limit the ability to utilize home and community-based services, respite, adult day services and other programs.
- The State of Missouri should establish a Medicaid billing code physicians can utilize when providing care planning services to those living with dementia and their caregivers, comparable to that of the Medicare billing code.
- The State of Missouri should ensure Medicaid coverage for future dementia treatments is aligned with the clinical standards established by the FDA for an approved treatment.

IMPROVE QUALITY CARE

Goal:

Improve residential and home and community based service provider licensure requirements for dementia care through culturally appropriate evidence and acuity-based models.

Justification:

During the Community Forums held around the state, many of those who attended spoke of wanting to ensure their loved ones received the highest standard of care. The case was also made that the level of care in Memory Care Units and Memory care facilities vary widely across the state.

Recommendations:

- The State of Missouri should examine evidence-based and acuity-based staffing methods as a condition of licensure in all settings.
- The State of Missouri should utilize quality care indicators related to cognitive assessments, diagnosis, diagnosis disclosure, staging, antipsychotics use, direct care staffing ratios, preventable hospitalizations, and other care and safety needs for use in state reimbursement rates.
- The State of Missouri should require transparency in the sharing of this information with the general public.

Goal:

Increase dementia competency of health care providers, first responders and caregivers to deliver person-centered care through dementia-specific and culturally competent training.

Justification:

As the disease progresses, individuals are unable to complete activities of daily living. Over time, people with Alzheimer's will lose the ability to use words and may communicate their needs through behavior. Often these disruptive behaviors will lead to interactions with first responders, as six in 10 people with dementia will wander. When individuals with dementia are lost, they may show signs of anxiety, fear or hostility – all of which can escalate to more aggressive behaviors.

Recommendations:

- The State of Missouri should implement minimum standards of evidence-based dementia training for all those who serve individuals with dementia. This should include medical professionals and first responders, and should also ensure continuing education requirements. The State of Missouri should monitor training programs, evaluate their effectiveness and ensure compliance with those requirements.
- The State of Missouri should leverage already existing technology and readily available resources (Area Agencies on Aging, libraries, senior centers, culturally tailored service providers, etc.) to aid in the distribution of person-centered, culturally appropriate, evidence-based training content.

Goal:

Accelerate workforce development in dementia care professions.

Justification:

Missouri residents cited long wait times between appointments and referrals, a general lack of care providers and specialists, and limited options in long-term care facilities at all community forums. The lack of resources in many communities led to the local care providers and facilities being over-extended. The growth of the workforce within dementia care professions would result in increased access to care, as well as improving the quality of available resources for all residents.

Recommendations:

- The State of Missouri should partner with institutions of higher learning to ensure dementia care professions are included within education systems to increase awareness of these jobs and the quality of care provided.
- The State of Missouri should utilize geographic-based grants, tax credits or other programs to incentivize those in dementia care professions to provide services in rural communities and additional locations identified as needing workforce growth.

Goal:

Create a statewide crisis response system that supports the unique behavioral needs of persons living with dementia.

Justification:

Care for persons with dementia can be challenging, especially when the person displays risky behaviors. Expanding the capacity for crisis response and stabilization, clarifying procedures for emergency protective placement and services and improving long-term care options can promote a thoughtful response that will benefit individuals and their caregivers.

Recommendations:

- The State of Missouri should expand the capacity for crisis response and stabilization by promoting dementia capability in the existing crisis response system, including mobile crisis units, law enforcement and other first responders.
- The State of Missouri should encourage the development of coordinated local and regional crisis intervention systems.
- The State of Missouri should enact a structure to review transfers and discharges of persons with Alzheimer's disease and related dementias, which includes an updated procedure, notification and appeals process.

Goal:

Establish and fund a full-time state agency position to coordinate the state's response to dementia.

Justification:

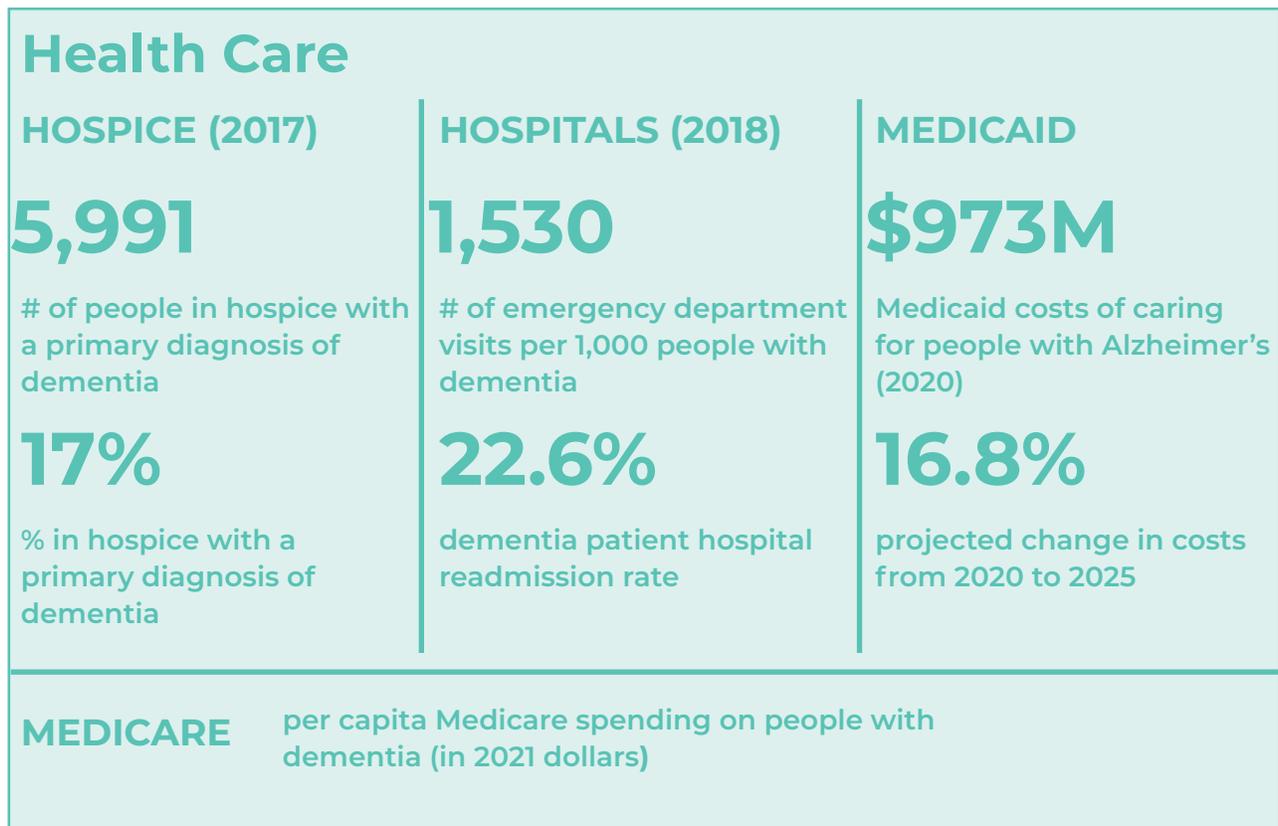
State plans assess current needs, identify gaps in services and recommend strategies and policies to better serve persons living with dementia and their families. Effective implementation of the recommendations can reduce the long-term impact of the disease on state budgets and improve the lives of people with dementia and their caregivers.

Recommendations:

- The State of Missouri should establish a State Dementia Services Coordinator within the Public Health Division of the Department of Health and Senior Services. A State Dementia Services Coordinator may:
 - Establish and maintain relationships with State agencies and community organizations in order to meet community needs and prevent duplication of services.
 - Increase awareness of and facilitate access to quality, coordinated care for people with dementia.
 - Help develop a roadmap of best practices to connect those in need to services.
 - Evaluate the implementation of the State recommendations in meeting goals as set by the State Task Force.
 - Explore the logistics of a centrally located resource where individuals can access information across the continuum of care.

BACKGROUND ON ALZHEIMER'S AND RELATED DEMENTIAS

Alzheimer's disease poses a grave and growing challenge to the State of Missouri and our nation. Many experts recognize that Alzheimer's will significantly affect the lives of millions of Americans who either live with this disease or care for someone who does. Less familiar are the economic consequences that Alzheimer's disease, with its cumulative costs, will impose on the State of Missouri and our country. The figure below documents the cost to Missouri due to health care for individuals with Alzheimer's disease.

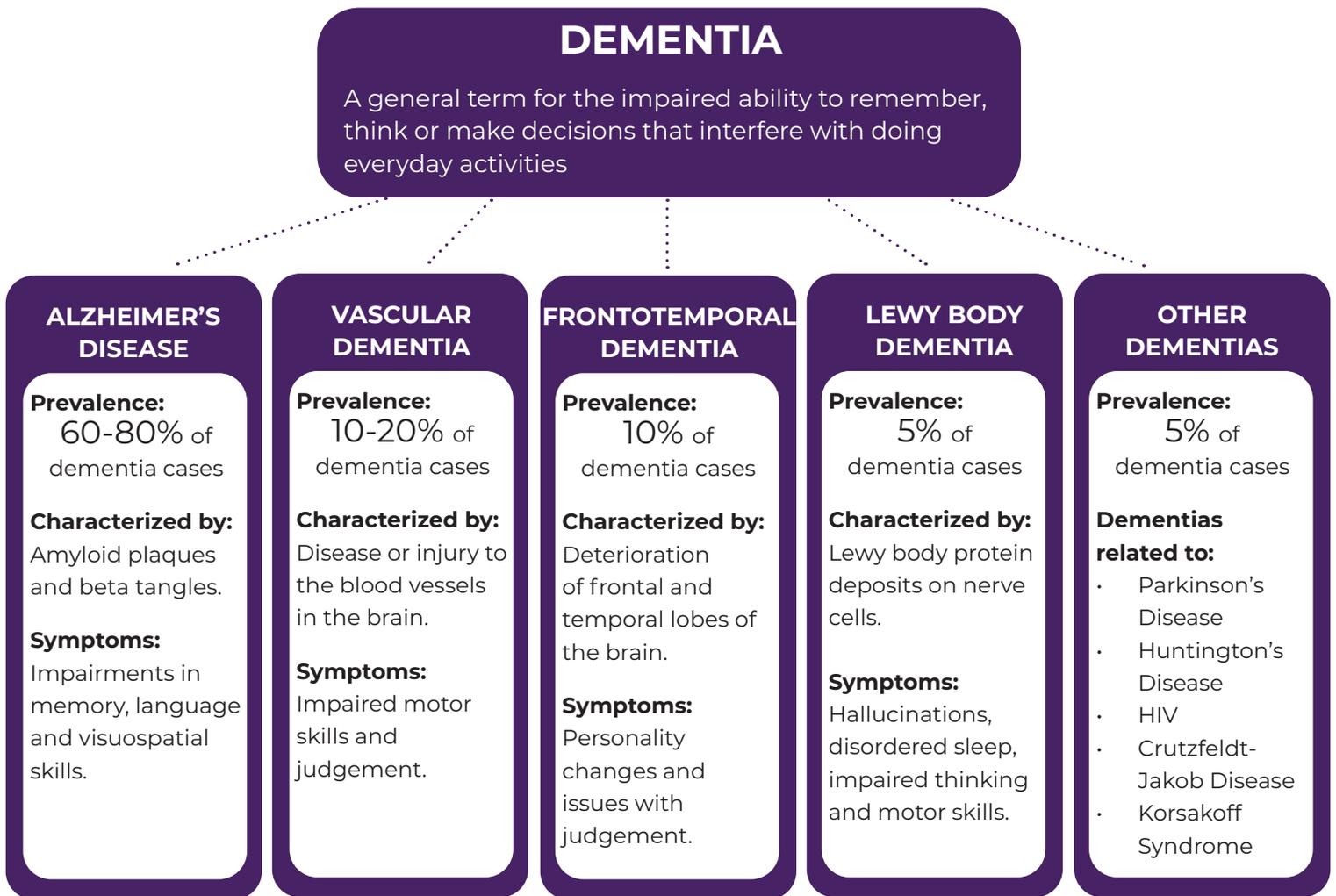


More than 120,000 individuals in Missouri are currently living with Alzheimer's or related dementia. With the aging of the baby boomer population, that number will escalate to more than 130,000 by 2025.

OVERVIEW OF ALZHEIMER'S DISEASE

Alzheimer's disease is a brain disorder named after German physician Alois Alzheimer who first described it in 1906. Scientists have learned a great deal about Alzheimer's disease in the century since Dr. Alzheimer first drew attention to it. Today we know that Alzheimer's disease:

- Is a progressive and fatal brain disease. Alzheimer's destroys brain cells, causing memory loss and problems with thinking and behavior severe enough to affect work, lifelong hobbies or social life. Alzheimer's disease gets worse over time and is fatal. Today Alzheimer's is the fifth-leading cause of death in the United States.
- Has no current cure. But treatments for symptoms, combined with the right services and support, can make life better for the millions of Americans living with Alzheimer's disease.
- Is the most common form of dementia, which is a general term for memory loss and other intellectual disabilities serious enough to interfere with daily life. Alzheimer's disease accounts for 60 to 80 percent of dementia cases.



Risk Factors for Alzheimer's Disease

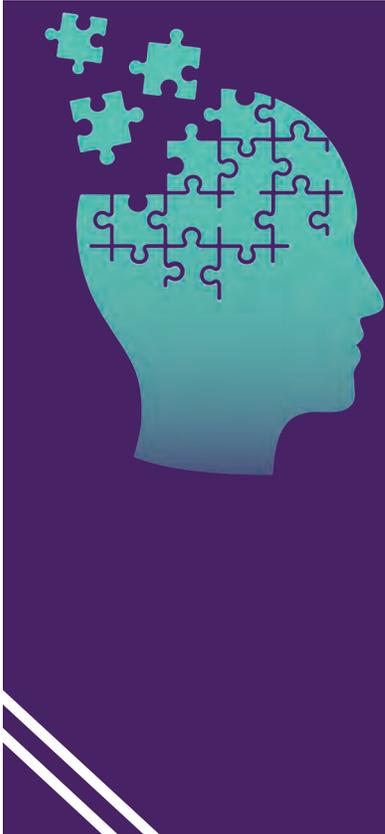
Although the cause, or causes of Alzheimer's disease are not yet fully understood, most experts agree that Alzheimer's, like other common chronic conditions, most likely develops as a result of multiple factors rather than a single cause. Most Americans with Alzheimer's disease are aged 65 or older, although individuals younger than age 65 can also develop the disease. The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging.

A small percentage of Alzheimer's disease, less than 1 percent, is caused by rare genetic variations found in a small number of families worldwide. In these inherited forms of Alzheimer's, the disease tends to develop before age 65, sometimes in individuals as young as 30.

A genetic risk factor in Alzheimer's developing at age 65 or older is Apo lipoprotein E-e4 (ApoE-e4). ApoE-e4 is one of three common forms of the ApoE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the ApoE gene from each of his or her parents. Those who inherit one ApoE-e4 gene have an increased risk of developing Alzheimer's disease. Those who inherit two ApoE-e4 genes have an even higher risk. However, inheriting one or two copies of the gene does not guarantee that the individual will develop Alzheimer's disease.

Warning Signs of Alzheimer's

In addition to the risk factors above, knowing the warning signs of Alzheimer's disease is important for early diagnosis.



WARNING SIGNS OF ALZHEIMER'S

- Memory loss that disrupts daily life.
- Challenges in planning or problem solving.
- Difficulty completing familiar tasks at home, at work or at leisure.
- Confusion with time or place.
- Trouble understanding visual images and spatial relationships.
- New problems with words in speaking or writing.
- Misplacing things in losing the ability to retrace steps.
- Decreased or poor judgement.
- Withdrawal from work or social activities.
- Changes in mood and personality.

Treatment of Alzheimer's Disease

The U.S. Food and Drug Administration (FDA) has approved four drugs that treat the symptoms of Alzheimer's disease. The cholinesterase inhibitor family of drugs boosts brain levels of acetylcholine. The three are Galantamine (Razadyne®), Rivastigmine (Exelon®) and Donepezil (Aricept®). Another option, Memantine (Namenda®), is the only drug approved by the FDA for moderate to severe stages of Alzheimer's disease.³ In 2021, the FDA gave accelerated approval to Aducanumab (Aduhelm™) which reduces amyloid plaques and may change disease progression. Aducanumab is an anti-amyloid antibody intravenous (IV) infusion therapy. Currently, there are approximately 143 additional drugs in the Alzheimer's disease drug development pipeline.⁴

Prevention of Alzheimer's Disease

A growing body of evidence suggests that the health of the brain, one of the body's most highly vascular organs, is closely linked to the overall health of the heart and blood vessels. According to the Alzheimer's Association's article *Can Alzheimer's Disease Be Prevented*, "Though research is still evolving, evidence is strong that people can reduce their risk by making key lifestyle changes, including participating in regular activity and maintaining good heart health."⁵ Additionally, the article states that regular physical exercise may be a beneficial strategy to lower the risk of Alzheimer's and vascular dementia as it may directly benefit brain cells by increasing blood and oxygen flow in the brain. Because of its known cardiovascular benefits, a medically approved exercise program is a valuable part of any overall wellness plan heart-healthy eating, including limiting the intake of sugar and saturated fats and eating plenty of fruits, vegetables, and whole grains may also help protect the brain.

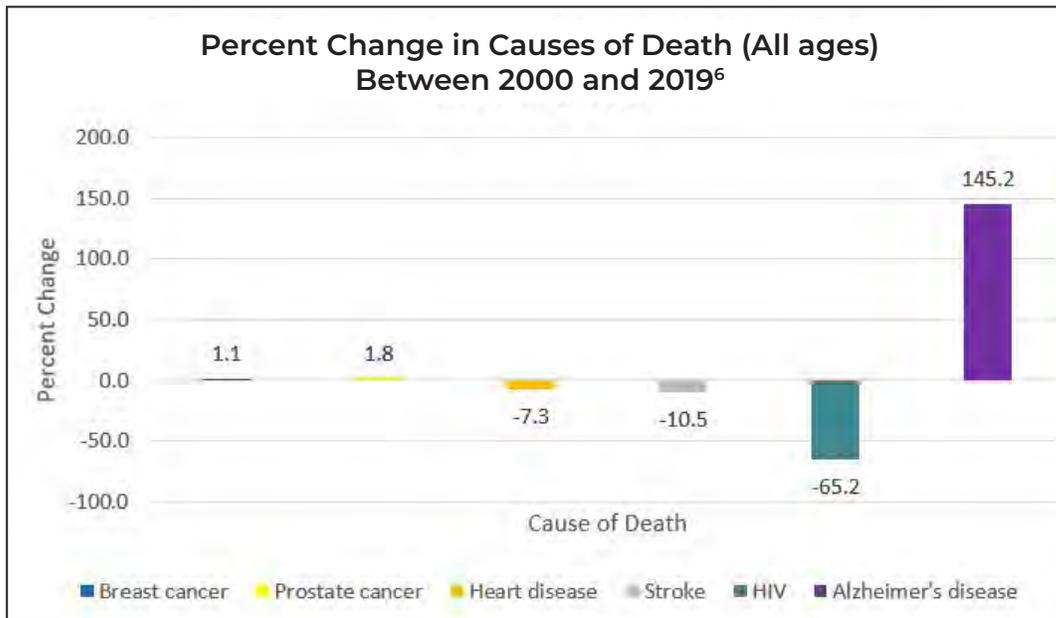
Key Facts about Alzheimer's Disease and Related Dementia

- An estimated 6 million Americans of all ages have Alzheimer's disease.
- Without a means of prevention, better treatment, or cure, Alzheimer's is projected to cost the nation nearly \$1 trillion by 2050.
- More women than men have dementia, primarily because women live longer on average than men, increasing the time during which women could develop Alzheimer's or other dementia.
- Alzheimer's disease is the fifth-leading cause of death across all ages in the U.S. Deaths from Alzheimer's have increased 145% since 2000.
- Over 11 million Americans provided more than 16 billion hours of unpaid care for people with Alzheimer's or other dementias at an estimated value of nearly \$272 billion.

³Stanford Medicine. Medications for Alzheimer's disease. <https://stanfordhealthcare.org/medical-conditions/brain-and-nerves/alzheimers-disease/treatments/medications.html> (accessed 12/6/2022)

⁴Cummings, J.; Lee, G.; Nahed, P.; Kambar, N.; Zhong, K.; Fonseca, J.; Taghva, K. (2022, May 4). Alzheimer's disease drug development pipeline: 2022. <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/trc2.12295> (accessed 12/6/2022)

⁵Alzheimer's Association. Can Alzheimer's Disease be Prevented? https://www.alz.org/alzheimers-dementia/research_progress/prevention (accessed 12/6/2022)



SUBJECTIVE COGNITIVE DECLINE

2019–2020 Behavioral Risk Factor Surveillance System (BRFSS) Data from adults in 46 States, Puerto Rico, and the District of Columbia: People Aged 45 Years and Older

1 in 10 people aged 45 years and older are experiencing Subjective Cognitive Decline

SCD is self-reported MEMORY PROBLEMS that have been GETTING WORSE over the past year.

83% of people with SCD have at least one chronic condition. SCD might make the condition more difficult to manage

41% of people with SCD had to give up day-to-day activities

one in three people with SCD say it interfered with social activities, work, or volunteering

less than half of people with SCD have discussed their symptoms with a healthcare provider

35% of people with SCD need help with household tasks

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

alzheimer's association

cdc.gov/aging
alz.org/publichealth

CDC does not endorse private products, services, or enterprises. CS 303070-A July 2022

⁶ Alzheimer's Association. (2022) <https://www.alz.org/getmedia/76e51bb6-c003-4d84-8019-e0779d8c4e8d/alzheimers-facts-and-figures.pdf>

SUPPORTING PERSONS WITH ALZHEIMER'S AND RELATED DEMENTIAS IN MISSOURI

Early Stage Alzheimer's Disease

Increasingly, persons are being diagnosed earlier in the disease process. Receiving an early diagnosis enables individuals to actively participate in making decisions about their current and future needs. There is also a better chance of benefiting from treatment. In recent years, services and resources originally designed only for caregivers have expanded to also address the needs of persons with early-stage Alzheimer's.

Younger-Onset Alzheimer's

Alzheimer's is considered to be younger-onset if the individual is age 65 or younger when symptoms first appear. About five to six percent of people with Alzheimer's develop symptoms before age 65. Although we do not have statistics for Missouri, nationally there are an estimated 300,000 to 360,000 people with younger-onset Alzheimer's.⁷

Family Caregiving

Alzheimer's disease does not just affect the person with the disease, but it has a profound impact on families as well. In Missouri, more than 194,000 family members and friends provide more than 292 million hours of unpaid care, a contribution to the state valued at almost \$4.9 billion.

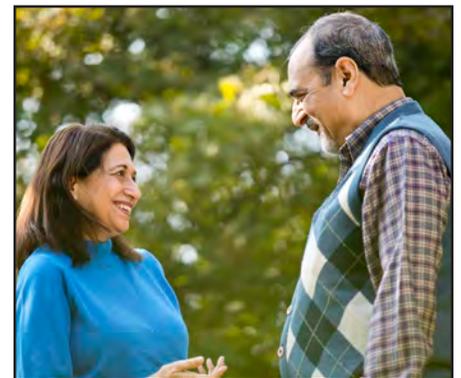
Caring for a person with Alzheimer's or related dementia is often very difficult. As a result, many unpaid caregivers experience high levels of emotional stress and depression. As heard repeatedly at the community forums, the stress of caregiving impacts the health, employment, income and financial security of many caregivers.

RESOURCES FOR PERSONS WITH ALZHEIMER'S AND THEIR CAREGIVERS

In Missouri, there are an array of services for individuals with Alzheimer's and related dementias and their caregivers. At the community forums, individuals spoke of the value of support groups, care consultations, helplines and respite. They also talked about their frustrations with knowing how and when to access services, the difficulty of getting an appropriate diagnosis and the need for resources in rural communities.

Services available across the state include (See Appendix B for Matrix of Services in Missouri):

- Consultations, service navigation and geriatric case management.
- Support groups.
- Information and assistance.
- Education and training.
- Legal and financial advice.
- Respite assistance.



⁷Mayo Clinic. (2022, April 29). Young-onset Alzheimer's: When symptoms begin before age 65. <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers/art-20048356#:~:text=About%205%25%20to%206%25%20of,onset%20form%20of%20the%20disease> (accessed 12/8/2022)

Respite Care Assistance

Caregivers often express that what they need most to continue caring for a person with dementia at home, is rest or a break from caregiving. According to the Centers for Disease Control and Prevention (CDC), “Caregivers of people with Alzheimer’s and related dementias provide care for a longer duration than caregivers of people with other types of conditions (79% versus 66%). More than half (57%) of family caregivers of people with Alzheimer’s and related dementias provide care for four years or more. More than six in ten (63%) Alzheimer’s caregivers expect to continue having care responsibilities for the next 5 years compared with less than half of caregivers of people without dementia (49%).”⁸

The CDC also warns, “The demands of caregiving can limit a caregiver’s ability to take care of themselves. Family caregivers of people with Alzheimer’s and related dementias are at greater risk for anxiety, depression and poorer quality of life than caregivers of people with other conditions.”⁶

In Missouri, respite assistance programs are available from the Area Agencies on Aging, the U.S. Department of Veteran Affairs Caregiver Support Program, a Department of Health and Senior Services general revenue funded program contracted with the Missouri Rural Health Association, and Medicaid Home and Community-Based Services through the Department of Health and Senior Services. Unfortunately, the non-Medicaid programs often have waiting lists and the amount of available assistance is minimal. Even with these limitations individuals stressed at community forums the importance of these programs and the need for additional funding.

Long-Term Care Services

According to the CDC, the majority (80%) of people with Alzheimer’s disease and related dementias are receiving care in their homes.⁹ As the disease progresses, they require additional assistance. Many access paid services at home, in the community or in a residential care setting. Often individuals utilize more than one setting over the long course of the disease.

In Missouri, home and community services available across the state include personal care assistance, homemaker/chore, home-delivered meals, respite, transportation, home health, adult day programs and hospice.

Licensed residential care options include residential care facilities (RCF and RCFII), assisted living facilities (ALF and ALF**), intermediate care facilities (ICF), and skilled nursing facilities (SNF). Only ALF**, ICF, and SNF can care for individuals that need more than minimal assistance to evacuate the facility, including those with Alzheimer’s.

Memory Care Units operate either as a facility serving only persons with dementia or as a unit within a long-term care facility. Memory Care Units are required to disclose to the state and make available to the public information about the dementia-specific services they offer. Currently, there are approximately 319 Memory Care Units across the state with approximately 9,015 memory care unit beds.¹⁰



⁸Centers for Disease Control and Prevention. (2019, October 30). Caregiving for a Person with Alzheimer’s Disease or a Related Dementia. <https://www.cdc.gov/caregiving/about/index.html> (accessed 12/6/2022)

⁹Centers for Disease Control and Prevention. What is known about caregiving for a person with Alzheimer’s disease or another form of dementia? (2019, October 30) [https://www.cdc.gov/aging/caregiving/alzheimer.htm#:~:text=The%20majority%20\(80%25\)%20of,receiving%20care%20in%20their%20homes.](https://www.cdc.gov/aging/caregiving/alzheimer.htm#:~:text=The%20majority%20(80%25)%20of,receiving%20care%20in%20their%20homes.) (accessed 12/6/2022)

¹⁰Missouri Department of Health and Senior Services. Licensing and Certification. <https://health.mo.gov/seniors/nursinghomes/licensecert.php> (accessed 12/7/2022)

Private Pay Costs

For Missourians who have to pay for care out of pocket, the financial burden of Alzheimer's and related dementias can be an additional stressor. Private pay rates for care have steadily grown, with rates during COVID growing exponentially due to worker shortages in the home care industry. According to the 13th Annual Edition of the HCP Benchmarking Report, in 2021, the average rate for personal care or companion/homemaker services in the central U.S. was \$22.25 per hour. 24-hour live-in care has seen an increase of 11.7% over the past five years, resulting in an average cost of \$313 per day in our area of the U.S. Home care rates in 2021 averaged \$29.00 per hour.

Medicaid Costs

Given the high average private pay cost of long-term care services, many people cannot afford to pay for services for the duration of the disease. Medicaid plays a critically important role when a person's private resources are exhausted. MO HealthNet, Missouri's Medicaid program, covers the cost of home and community services as well as care in a nursing home. Missouri Medicaid paid \$973 million for the cost of care of individuals with Alzheimer's.¹¹

Home and community-based services available to all MO HealthNet participants include personal care, adult day health care, and home health. Other home and community-based services are available under the Aged and Disabled waiver (respite, homemaker, chore, and home-delivered meals), the Independent Living Waiver (expanded personal care, specialized medical equipment & supplies, and environmental accessibility adaptation), and the developmental disabilities waivers (respite, expanded personal care, therapies, habilitation, crisis intervention, community transition, communication skills instruction, environmental accessibility adaptations, and specialized medical equipment & supplies).

Access to home and community-based waiver services varies by age, cognitive abilities, geographic location, and available funding. Vital respite services which relieve a caregiver are limited to individuals aged 65 and older, disabled individuals aged 63-64, and individuals who have a developmental disability. The Independent Living Waiver requires the participant to hire and manage their direct care workers, which may not be an option for most individuals with cognitive impairments. The wide array of services under the developmental disabilities waivers may be limited to services provided only in a specific county or based on available funding, which results in waiting lists for access to waiver services.

Most recently, the Structured Family Caregiving Waiver (SFCW) was implemented and is available to participants with a diagnosis of Alzheimer's disease or a related disorder. This waiver allows a live-in caregiver to provide homemaker, attendant care, medication oversight and transportation services.



¹¹Alzheimer's Association. Missouri Alzheimer's Statistics. (2022) <https://www.alz.org/media/Documents/missouri-alzheimers-facts-figures-2022.pdf>. (accessed 12/6/2022)

Long-Term Care Insurance

Private long-term care insurance is an option for those who have the foresight and purchase policies before developing dementia. Based on data from the National Health Expenditure Account, it is estimated that private insurance represented only 9% (\$38.5 billion) of long-term services and support spending in 2019. However, when policies are purchased before individuals develop the disease, long-term care insurance plays a significant role in paying for the care of people with dementia.

The Missouri Long-Term Care Partnership Program was launched in 2008 to promote the purchase of long-term care insurance. The partnership policy makes it easier to qualify for Medicaid if you have exhausted the benefits of your long-term care insurance policy. For example, a consumer with a \$200,000 coverage limit on his long-term care policy might exhaust the benefits after three years in a nursing home. If that consumer needs continued care, he may need to turn to Medicaid. For every dollar that a long-term care partnership insurance policy pays out in benefits, a dollar of personal assets can be protected if you apply for Medicaid. In other words, if your long-term care partnership policy paid out \$200,000 for your long-term care, an additional \$200,000 of your assets would be disregarded when determining your Medicaid eligibility.¹²

SUMMARY



The task force considered the voices of stakeholders who attended in-person and virtual community forums to develop the recommendations in this plan. The task force believes that the recommendations contained herein will advance the State of Missouri in the fight against Alzheimer's and related dementias. The recommendations should be used to address the four focus areas identified by the task force:

Focus Area 1: Advance Risk Reduction, Early Detection and Timely Diagnosis.

Focus Area 2: Increase Access to Care, Support, and Treatment.

Focus Area 3: Improve Quality of Care.

Focus Area 4: Ensure a Coordinated Statewide Response.

¹²Missouri Department of Insurance. Frequently Asked Questions for Partnerships. <https://insurance.mo.gov/consumer-faqs/partnership-policies-faqs>

OVERVIEW OF COMMUNITY FORUM RESPONSES (APPENDIX A)

The task force gained input from persons living with Alzheimer's disease or other dementias, family caregivers, and other stakeholders through a series of eight community forums that were hosted across Missouri. Seven of the eight forums were in-person, held in Jefferson City, Hannibal, Springfield, North Saint Louis, Jackson, Kansas City and St. Joseph, while the eighth was held virtually via Zoom. These town hall style community forums and corresponding surveys allowed constituents to provide feedback about what services they felt could be improved upon and needed further development based on personal experiences within their communities.

The task force heard from 104 individuals that participated voluntarily from both rural and urban communities. Common themes were heard between the forums, but it is acknowledged that the full experiences of Missourians related to Alzheimer's and dementia may not have been captured. Across the eight community forums, there were five overarching themes that the common issues and concerns participants voiced fell into:

1. Limited public knowledge about Alzheimer's and other dementias.
2. Greater need for respite services and resources for caregivers.
3. Financial coverage of respite services and long-term care.
4. Difficulty receiving an Alzheimer's diagnosis.
5. Limited knowledge within the health care system of Alzheimer's resources and how to provide the most appropriate care.

Limited Public Knowledge about Alzheimer's and Other Dementias

Forum participants were asked to identify where they saw gaps in public knowledge about Alzheimer's disease and other dementias. The most common response to this question was that the average person, especially those that have not personally been touched by the disease, has little information about what dementia is or the resources that are available to support families after a diagnosis. This has resulted in a continuation of stigma and misconceptions about the disease and led to the dismissal of those living with it by others. Many participants expressed that increasing the public's base knowledge of Alzheimer's and other dementias could lead to better experiences for those living with the disease when interacting with others in social situations, enable better care and treatment, as well as reduce stigma to aid in earlier diagnosis and risk reduction.

A Greater Need for Respite Services and Resources for Caregivers

Many individuals who are acting as a caregiver for a family member or loved one who is living with Alzheimer's or other dementias need more respite services. Often, the caregiver is unable to leave their family member by themselves, making it difficult to grocery shop, attend social events, support groups, or partake in other resources that are offered in person. There are existing respite services that many caregivers utilize, however, it was commonly mentioned that in rural areas, there are limited options within driving distance. The cost of certain respite services can also be a financial burden on families if they are unable to receive coverage for it. Participants stated that increased education and respite resources for caregivers would enable better in-home care of those living with dementia, as well as allow caregivers to maintain their health.

Financial Coverage of Respite Services and Long-Term Care Options

Across the eight community forums, many individuals expressed concern over the financial burden that long-term care options provided, as well as a few of the respite services. The majority of caregivers and/or people living with dementia the task force heard from were covered by Medicare, but not all of them qualified for Medicaid. Several people commented on this regarding certain respite services that required Medicaid eligibility to receive financial assistance. Most felt that there was a large group of people in the gap between not being Medicaid eligible, and being able to afford the cost of long-term care options or short-term respite services.

Difficulty Receiving an Alzheimer's Diagnosis

A commonly reported issue within health care systems visited by those that attended the community forums was a lack of resources and doctors that were able to accurately diagnose Alzheimer's and other dementias. Especially in rural areas, many people reported only having one or two neurologists within a feasible driving distance, leading to a 3-9 month wait time between receiving a referral and getting an appointment. Another commonly reported challenge with receiving a diagnosis was that doctors did not always examine all of the circumstances surrounding a person living with dementia's symptoms, leading to them basing their diagnosis decision on a small sample of time when symptoms could be observed by family members outside the concentrated period. Many had difficulty receiving second opinions in these scenarios due to the limited number of neurologists and physicians available.

Limited Knowledge Within the Health Care System of Alzheimer's Resources and How to Provide the Most Appropriate Care

As mentioned when talking about public knowledge and education regarding Alzheimer's and dementia, community forum participants stated that the misconceptions and stigma stemming from a lack of information contributed to difficulties experienced when attempting to receive a diagnosis. A commonly reported experience was that physicians, especially in rural areas, contributed dementia symptoms to normal parts of the aging process or alternative health conditions. Forum participants also noted that they did not receive the next steps regarding care and treatment from physicians once they did receive a diagnosis. Often, they located resources on their own, or through the assistance of friends, family, and a variety of media types. It was mentioned at all of the forums that providing dementia training to all those within health care and other professions that interact with people living with the disease would lead to better care and treatment procedures, as well as connect more families to resources.



Evaluating memory: What you can expect

It's important to visit a doctor and get evaluated when you or a family member or friend is facing memory loss concerns. Knowing what to expect can ease anxiety and help you prepare for necessary tests.

MATRIX OF SERVICES (APPENDIX B)

Type of Service	Availability	Funding Sources
Early Intervention and Counseling	Generally available	<ul style="list-style-type: none"> • Older American Act • Charitable donations • Private pay
Care Consultations, Service Navigation and Geriatric Case Management	Generally available	<ul style="list-style-type: none"> • Older American Act • Charitable donations • Private pay
Support Groups	Generally available	<ul style="list-style-type: none"> • Charitable donations • Private pay
Information and Assistance/Referral	Generally available Alzheimer's Association; 211 system; Area Agencies on Aging	<ul style="list-style-type: none"> • Charitable donations • Older Americans Act
Education/Training	Generally available however limited in rural communities (or by phone only)	<ul style="list-style-type: none"> • Older Americans Act • General Revenue- Alzheimer's grants • Charitable donations • Private pay
Legal/Financial Advice	Generally available for private pay; age, level of care and financial restrictions for publicly funded services	<ul style="list-style-type: none"> • Older American Act • Private pay • Legal services

**NOW IS THE BEST
TIME TO TALK
ABOUT ALZHEIMER'S
TOGETHER**



Home and Community-Based Services - Services may also be available in an institutional setting

Type of Services	Availability	Funding Sources
Respite	Generally available for private pay; age, level of care, and financial restrictions for publicly funded services	<ul style="list-style-type: none"> • MO HealthNet*** • Older Americans Act • General Revenue-Alzheimer's grants • Charitable donations • VA Benefits • Private pay
Personal Care/Homemaker/Chore	Generally available for private pay; age, level of care and financial restrictions for publicly funded services Generally available	<ul style="list-style-type: none"> • MO HealthNet* • Older Americans Act • Private pay • VA benefits
Home-delivered Meals	Generally available for private pay; age, level of care and financial restrictions for publicly funded services	<ul style="list-style-type: none"> • MO HealthNet** • Older Americans Act • Private pay
Adult Day Health Services	Generally available for private pay; age, level of care and financial restrictions for publicly funded services	<ul style="list-style-type: none"> • MO HealthNet* • Older Americans Act • Private pay
Transportation	Public transportation is available statewide; but individualized or specialty transportation is limited in the rural areas	<ul style="list-style-type: none"> • MO HealthNet • Older Americans Act • Public transit funding • Private pay
Personal Emergency Response System	Generally available for private pay; age, level of care and financial restrictions for publicly funded services	<ul style="list-style-type: none"> • Older Americans Act • Charitable donations • Private pay
Hospice Care	Available only if the person has a terminal illness with the prognosis that life expectancy is six months or less and they elect hospice services	<ul style="list-style-type: none"> • Medicare • MO HealthNet • Charitable donations • Private pay
Home Modifications	Generally available; Missouri Home Modification	<ul style="list-style-type: none"> • Private pay • Grants/loans • Older Americans Act • MO HealthNet****
Home Health	Generally available	<ul style="list-style-type: none"> • MO HealthNet • Medicare • Private pay • Private insurance • VA benefits

*MO HealthNet – Public funding available for MO HealthNet participants; restricted to those 18 years of age or older for adult day health care.

**MO HealthNet – Public funding available through the Home and Community-Based Services (HCBS) Aged & Disabled Waiver; restricted to those 63 years of age or older and subject to income and asset limits.

***MO HealthNet – Public funding available through the HCBS Aged & Disabled Waiver and the developmental disabilities waivers (DD); available to 63-64-year-olds who are disabled, 65+-year-olds, and individuals with developmental disabilities (regardless of age) if they are not on a waiting list for one of the DD waivers.

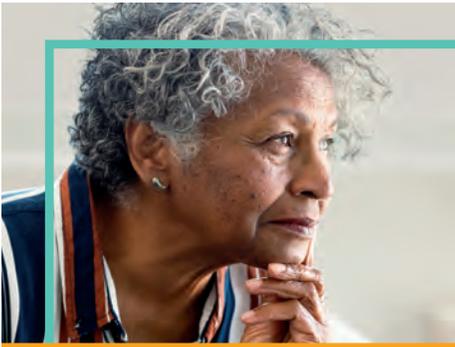
****MO HealthNet - Public funding available through the HCBS Independent Living Waiver (limit of \$5,000 every five years), the Developmental Disabilities (DD) Comprehensive, Community Support, and Prevention Waivers (limit of \$7,500 per year) is available to 18-64-year-olds who are disabled and capable of self-directing their services, and for individuals with developmental disabilities (regardless of age) if they are not on a waiting list for one of the DD waivers.

Licensed Residential/Institutional Services

Type of Services	Availability	Funding Sources
Residential Care Facility (RCF) -24-hour care and services including assistance with medications and care during short-term illnesses or recuperation	176 facilities with a capacity for approximately 4,225 individuals ¹³	<ul style="list-style-type: none"> • MO HealthNet • Cash grants • Private pay • LTC insurance • VA benefits
Residential Care Facility II (RCFII) - provides additional services including supervision of diets and assistance with personal care.	127 facilities with a capacity for approximately 4,600 individuals ¹³	<ul style="list-style-type: none"> • MO HealthNet • Cash grants • Private pay • LTC insurance • VA benefits
Assisted Living Facility – option 1 - 24-hour care and services including assistance with medications and personal care. Services are based on the abilities, desires, and functional needs of the individual and are delivered in a home-like setting.	74 facilities with a capacity for approximately 3,050 individuals ¹³	<ul style="list-style-type: none"> • MO HealthNet • Cash grants • Private pay • LTC insurance • VA benefits
Assisted Living Facility – option 2 - Similar to ALF option 1, an ALF option 2 may accept or continue to care for people with cognitive or physical impairments requiring additional assistance to evacuate in an emergency.	255 facilities with a capacity for approximately 16,100 individuals ¹³	<ul style="list-style-type: none"> • MO HealthNet • Cash grants • Private pay • LTC insurance • VA benefits
Intermediate Care Facility (ICF) - 24-hour personal care, health, and nursing care services under the daily supervision of a licensed nurse and the direction of a licensed physician.	21 facilities with a capacity for approximately 1,280 individuals ¹³	<ul style="list-style-type: none"> • MO HealthNet • Cash grants • Private pay • LTC insurance • VA benefits
Skilled Nursing Facility (SNF) - 24-hour care including skilled nursing care and treatment services commonly performed by or under the supervision of a registered professional nurse (RN).	511 facilities with a capacity of approximately 54,700 individuals ¹³	<ul style="list-style-type: none"> • MO HealthNet • Cash grants • Private pay • LTC insurance • VA benefits
Specialty Geriatric Psych In-patient Units – in-patient geriatric mental health services	48 psychiatric in-patient facilities with a capacity for approximately 2,140 individuals; Irregular distribution across the state and not all of the psychiatric units specialize in geriatric mental health. ¹⁴	<ul style="list-style-type: none"> • Medicare • MO HealthNet • Private pay • Some private insurance
Memory Care Units - SCUs are in long-term care facilities and provide environments, programs, and staff specifically designed for the care needs of Individuals with Alzheimer’s Disease.	319 facilities across the state ¹³	<ul style="list-style-type: none"> • MO HealthNet • Medicare (very limited/SNF only) • Private pay • LTC insurance • VA benefits
Housing/apartments with services	Not readily available in rural areas	<ul style="list-style-type: none"> • Private pay • HUD/RHA subsidies

¹³Missouri Department of Health and Senior Services. Licensing and Certification. <https://health.mo.gov/seniors/nursinghomes/licensecert.php> (accessed 12/8/2022)

¹⁴Missouri Department of Health and Senior Services. Licensed Psych Beds in Missouri. <https://health.mo.gov/safety/healthservregs/pdf/MOlicPsychBeds.pdf> (accessed 12/9/2022)



2022 Alzheimer's Disease Facts and Figures



seniors dies with Alzheimer's or another dementia

Over **11 million** Americans

provide unpaid care for people with Alzheimer's or other dementias



These caregivers provided more than **16 billion** hours valued at nearly

\$272 billion

More than **6 million**

Americans are living with Alzheimer's



In 2020, COVID-19 contributed to a

17% increase

in Alzheimer's and dementia deaths

In 2022, Alzheimer's and other dementias will cost the nation

\$321 billion

By 2050, these costs could rise to nearly

\$1 trillion

Between 2000 and 2019, deaths from heart disease have **decreased 7.3%**

while deaths from Alzheimer's disease have **increased 145%**

It kills more than **breast cancer and prostate cancer**

combined

More than **80%** of Americans know little or are not familiar with **mild cognitive impairment (MCI)**, which can be an early stage of Alzheimer's.

MISSOURI ALZHEIMER'S STATISTICS (APPENDIX D)



Missouri Alzheimer's Statistics



Prevalence

NUMBER OF PEOPLE
AGED 65 AND OLDER
WITH ALZHEIMER'S

Year	TOTAL
2020	120,000
2025	130,000

ESTIMATED % CHANGE

8.3%



Workforce

91

of geriatricians

211.0%

% increase needed to meet
the demand in 2050

74,380

of home health and
personal care aides

31%

% increase needed to meet
demand in 2028



Caregiving (2021)

194,000

Number of Caregivers

\$4,868,000,000

Total Value of Unpaid Care

35.8%

% of caregivers
with depression

292,000,000

Total Hours of Unpaid Care

64.1%

% of caregivers
with chronic
health conditions

13.3%

% of caregivers
in poor physical
health



Health Care

HOSPICE (2017)

5,991

of people in hospice
with a primary diagnosis
of dementia

17%

% in hospice with a primary
diagnosis of dementia

HOSPITALS (2018)

1,530

of emergency department
visits per 1,000 people
with dementia

22.6%

dementia patient hospital
readmission rate

MEDICAID

\$973M

Medicaid costs of caring
for people with Alzheimer's
(2020)

16.8%

projected change in costs
from 2020 to 2025

MEDICARE

\$25,366

per capita Medicare spending on people
with dementia (in 2021 dollars)



Mortality

OF DEATHS FROM ALZHEIMER'S DISEASE (2019)

2,782

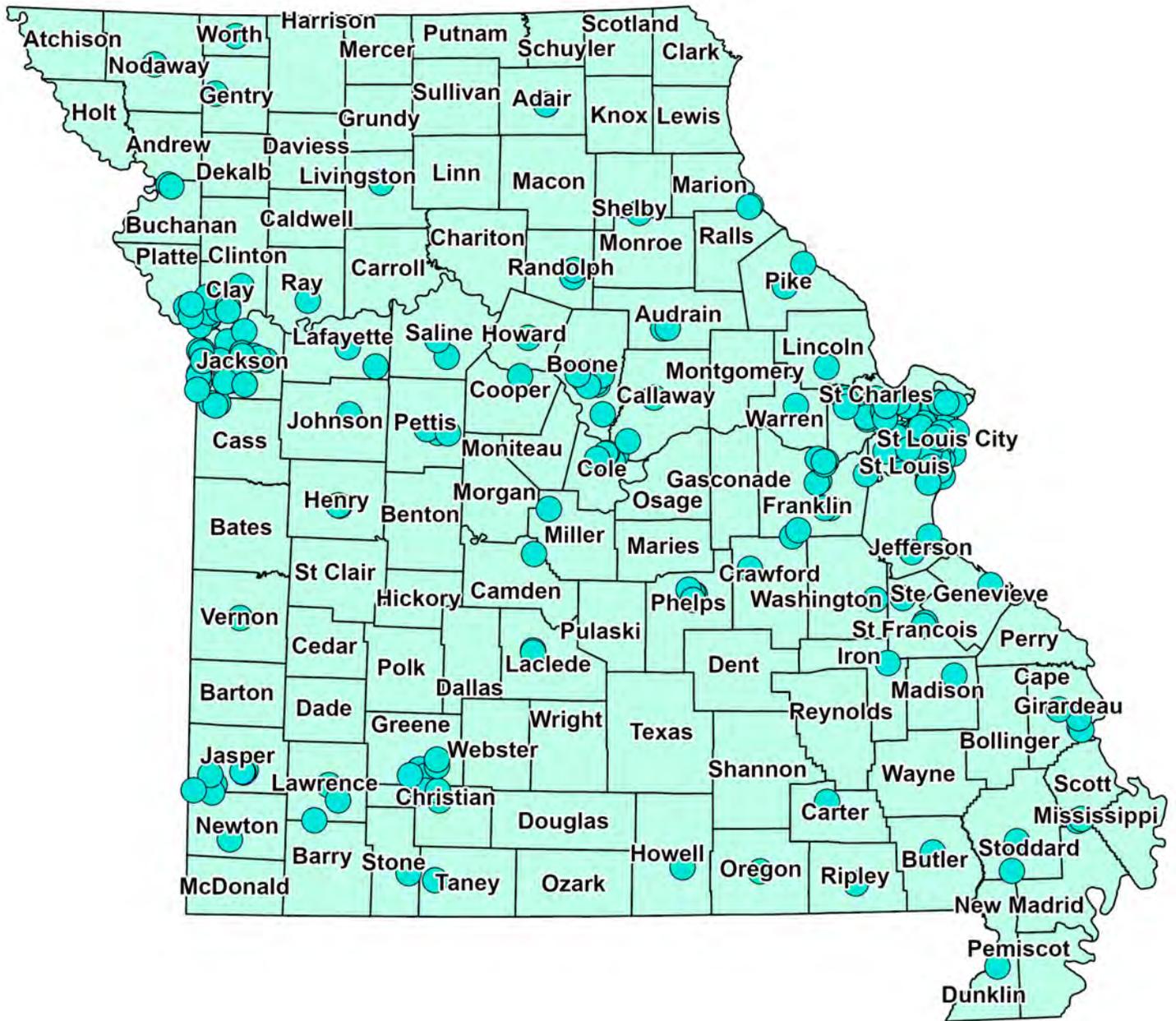
153.8% increase in
Alzheimer's deaths since 2000

More than **6 million Americans** are living with Alzheimer's, and over **11 million** provide their unpaid care. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$321 billion** in 2022, increasing to nearly **\$1 trillion** (in today's dollars) by mid-century.

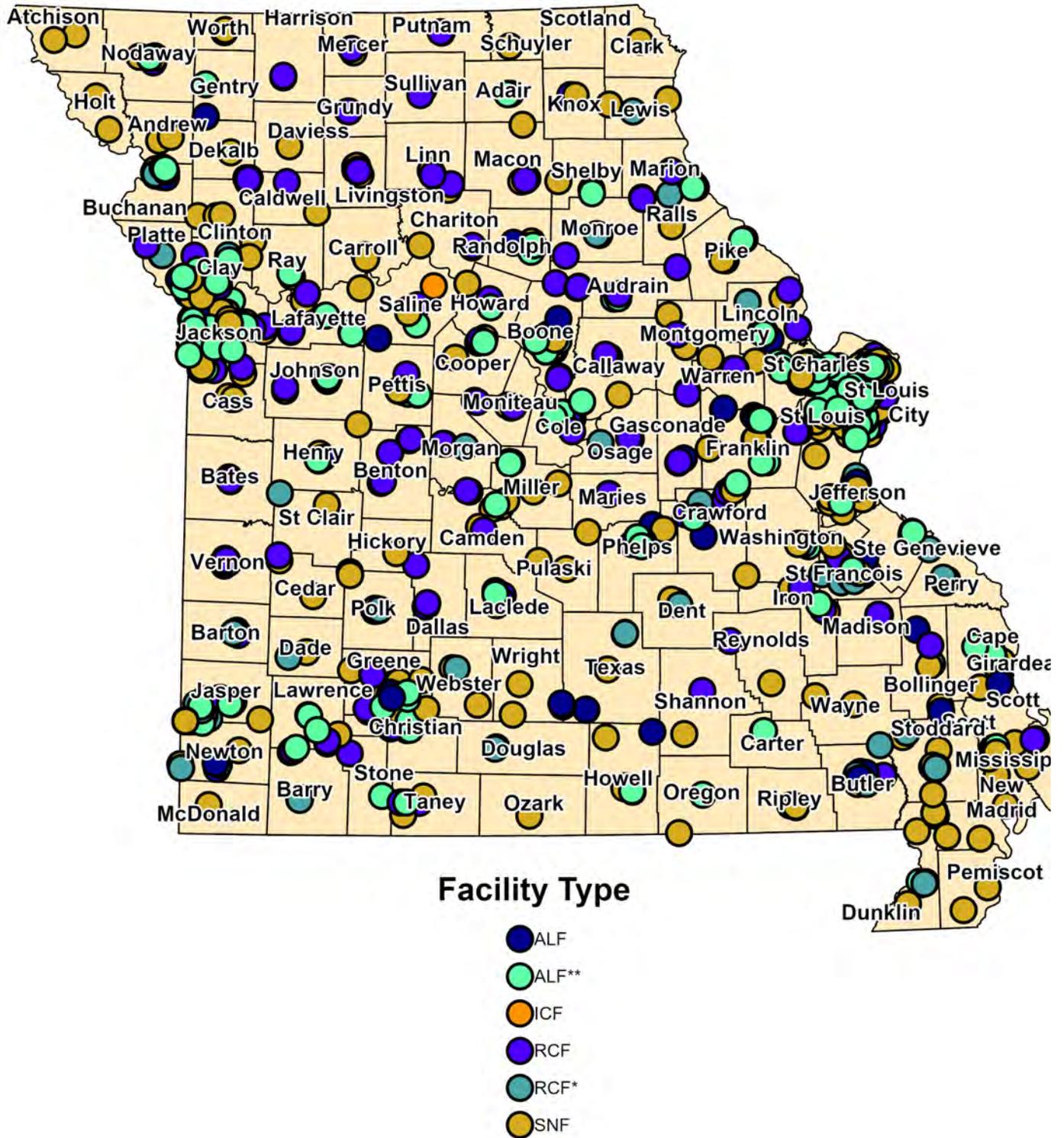
For more information, view the **2022 Alzheimer's Disease Facts and Figures** report at alz.org/facts.
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MISSOURI ASSISTED LIVING FACILITIES** (APPENDIX F)

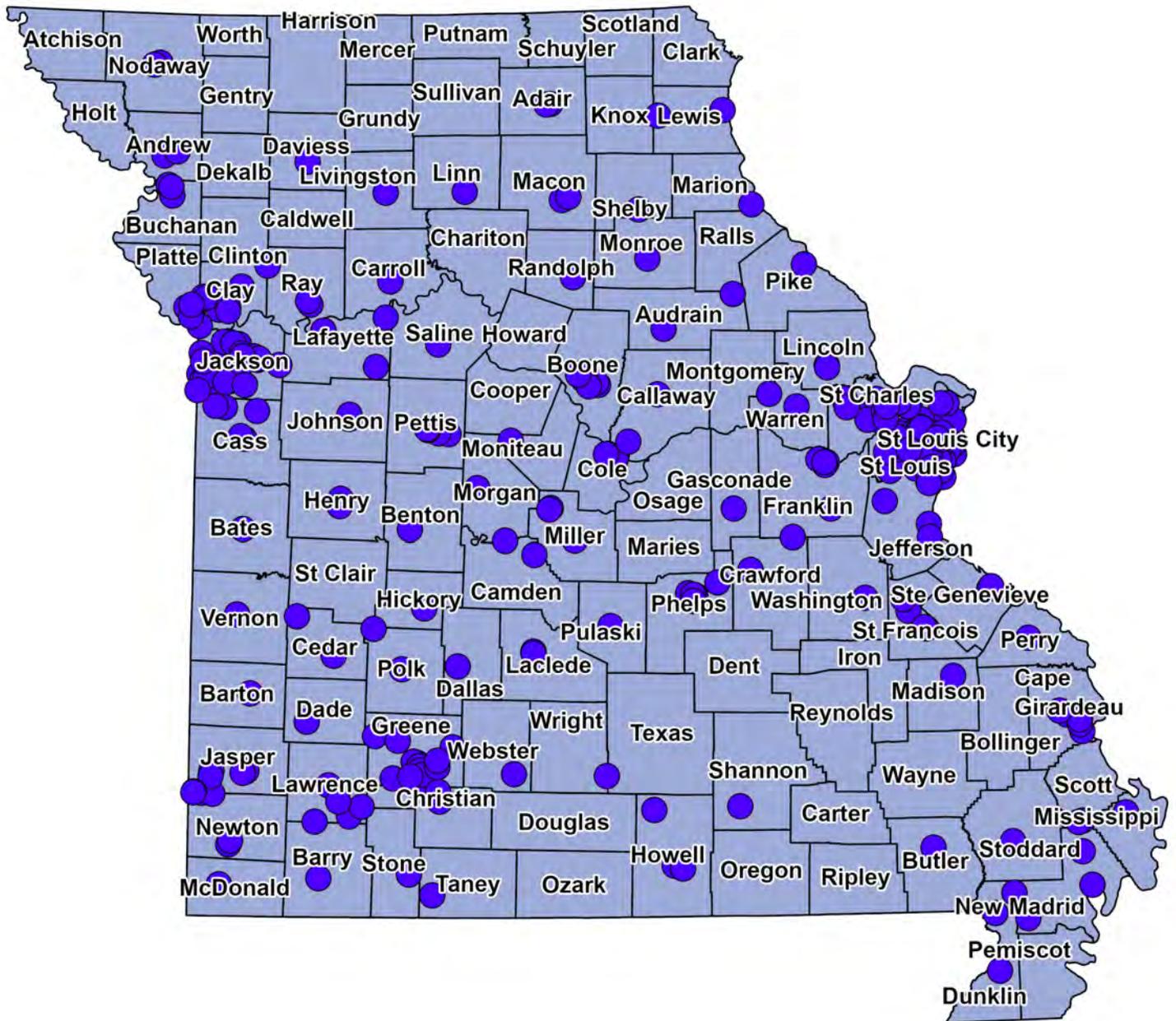


MISSOURI LONG TERM CARE FACILITIES COMBINED (APPENDIX G)

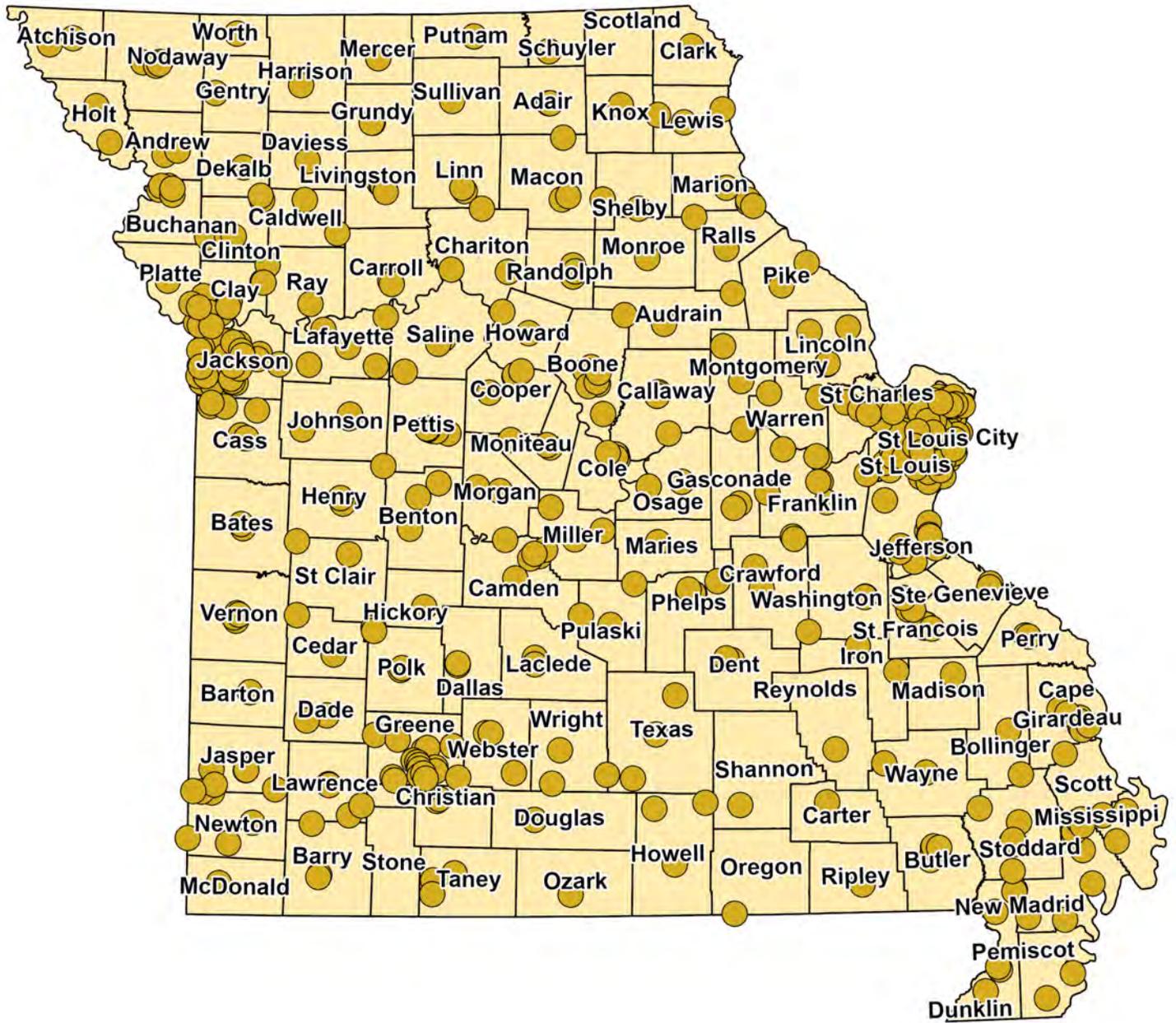


Some facilities at this map scale may be overlapping.

MISSOURI ALZHEIMER'S SPECIAL CARE UNITS (APPENDIX H)



MISSOURI SKILLED NURSING FACILITIES (APPENDIX I)





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