

# LIVING IN THE COMMUNITY WITH DEMENTIA

## STATE OF AGING IN CENTRAL INDIANA | RESEARCH BRIEF



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This research brief discusses the many challenges faced by the growing number of older people living with dementia (PLWD) in the community; and several promising initiatives that aim to better support PLWD and their caregivers.

Key findings include:

- An overwhelming majority of people living with dementia reside in the community with only 1 in 5 in assisted living or nursing home settings.
- Families often wrongly attribute dementia symptoms in their loved one to “old age”; and unless screening tests are performed, many physicians will miss the diagnosis.
- PLWD usually receive help from family or other unpaid caregivers who often experience both reward and high levels of stress related to their caregiving roles.
- Team-based dementia care programs developed by Indiana scientists are helping to ease the stress of caregiving and improve health outcomes of Hoosiers living with dementia.
- Dementia Friends Indiana is an inspirational movement seeking to reduce the stigma associated with the disease and create environments that are welcoming and conducive for those living with dementia.

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Dementia is a progressive loss of memory and cognitive ability severe enough to interfere with daily life. Among those diagnosed with dementia, 70% have Alzheimer's disease.<sup>1</sup> Other less common causes of dementia include vascular dementia (most commonly from multiple strokes and often coexisting with Alzheimer's disease), Lewy body disease, and Parkinson's disease. Alzheimer's disease is a type of brain disease that becomes worse with time. Typically, memory and language are impacted at first, often accompanied by changes in behavior, and in later stages problems arise with basic activities such as eating and walking.

Alzheimer's disease is the leading cause of disability and poor health in those 65 and older, and the fifth-leading cause of death in older adults.<sup>1</sup> It is estimated that there were approximately 110,000 Hoosiers ages 65 and older with Alzheimer's disease in 2020; and by 2025 this number is expected to increase by 18.2% to 130,000. Much of the increase is due to the aging of the population, however, smoking, obesity, and diabetes also increase risk for dementia.<sup>1</sup>

Older age is the greatest risk factor for Alzheimer's disease (35% of people ages 85 and older have Alzheimer's disease), however, people with Down Syndrome develop Alzheimer's at an earlier age (30% in their 50s have Alzheimer's disease).<sup>1,2</sup> There are more women living with dementia than men, but this is most likely simply due to women living longer than men on average. Nationally, older Blacks are about twice as likely and older Hispanics about one and one-half as likely to have dementia as older Whites. The higher prevalence of dementia in Blacks and Hispanics compared with Whites is thought to be primarily due to disparities in health conditions (e.g., cardiovascular disease and diabetes), socioeconomics, and life experiences rather than genetic factors.<sup>1</sup>

Signs of dementia include memory loss and changes in behavior or abilities that interfere with daily life.<sup>4</sup> Although normal aging may lead to forgetting names and occasional memory lapses, dementia is not due to old age. It is thus crucial for an older adult with cognitive symptoms to be evaluated by a physician to determine a specific cause of the symptoms. Importantly, dementia-like symptoms may also be due to side effects of medications, depression, alcoholism, a brain tumor, thyroid disorders, and certain vitamin deficiencies.

About half of Americans believe memory loss or cognitive decline is "a normal part of aging" rather than being an indicator of disease.<sup>1</sup> Furthermore, mild to moderate dementia is unrecognized by physicians in as many as 4 out of 5 PLWD.<sup>5</sup> Many people with dementia also have multiple chronic diseases, such as hypertension, diabetes, and coronary artery disease, and the dementia complicates caregiving and medical care for these conditions.<sup>6</sup> The lack of recognition of dementia by health care professionals and appropriate adjustments in medical care for PLWD may in part explain the higher hospitalization rates and numbers of care transitions in PLWD compared to older adults without dementia.<sup>7</sup> Due to

# 2020 Alzheimer's/Dementia Prevalence among Medicare Beneficiaries Age 65+ in Central Indiana.

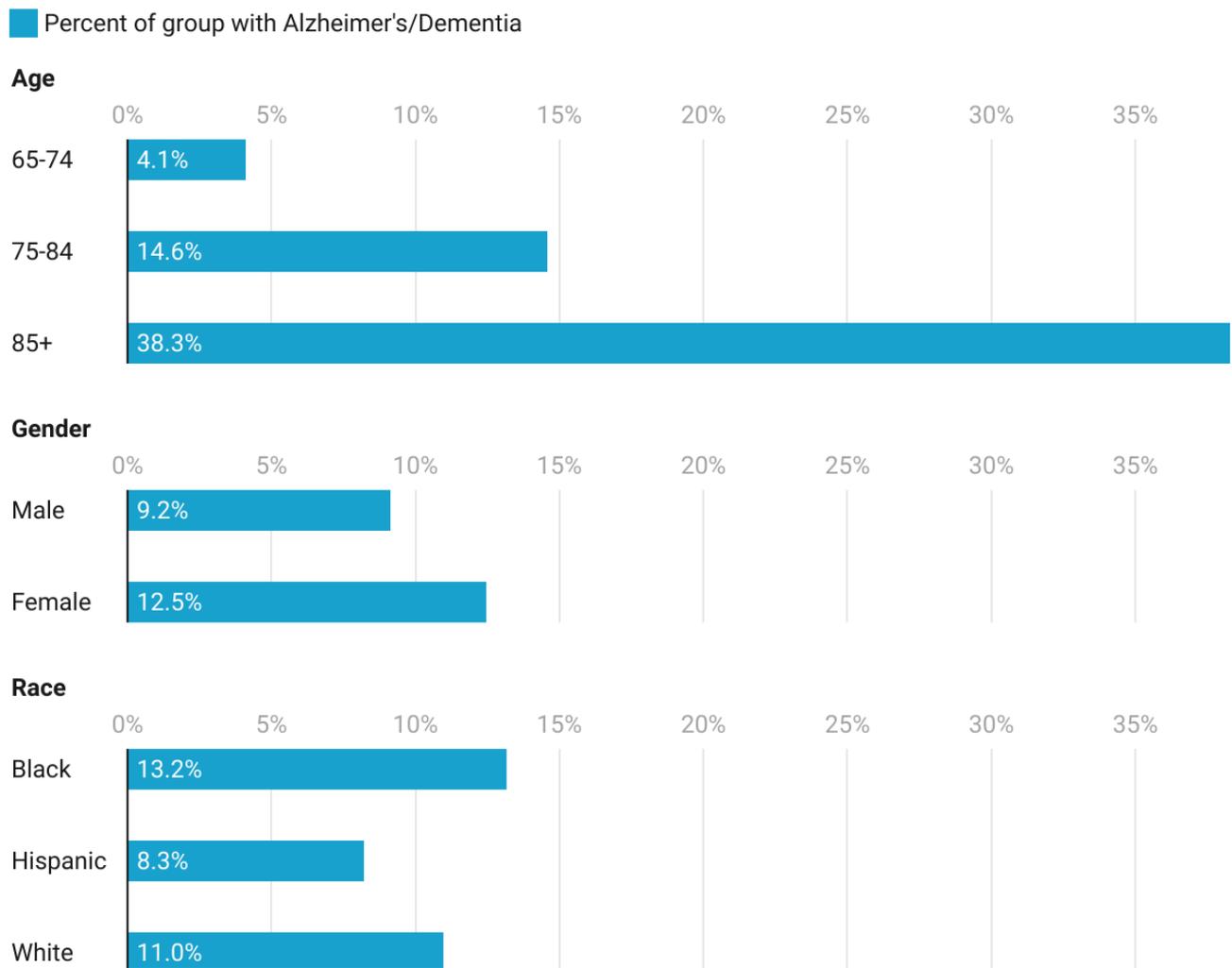


FIGURE 1: Centers for Medicare & Medicaid Services

their cognitive impairment, PLWD are likely not able to follow through on treatment plans or take medications as prescribed.

Although there is no current treatment to cure Alzheimer's disease, early diagnosis has many benefits including timely provision of counseling and caregiver support, avoidance of medications that may worsen cognitive symptoms, access to specialty care and social services, and the opportunity for advance care planning. For these reasons, it is recommended physicians screen patients for cognitive impairment, such as during the Medicare Annual Wellness Visit.<sup>5</sup>

## DENIAL BY FAMILY MEMBERS

*“Some family members are just in denial. They deny Mom has a problem at all. My job is coming alongside the main caregiver who sees the day-to-day changes...other family members often don’t see the full picture because they are not around it all the time. Some people hear the word dementia, but don’t know a lot about it. They all react differently. Some join the journey; others fight it because they don’t want it to be real.”*  
Dementia Care Coach

Most PLWD live in the community (81%) including some who are at the end of life. Only one in five live in either assisted living (6%) or nursing home (13%) settings.<sup>3</sup> Of those living in the community with dementia, 30% live alone and 70% live with others, typically spouses or other family members.<sup>3</sup> Although frequently not self-identifying as “caregivers,” over 90% of PLWD receive help from family members, friends, or other unpaid caregivers. Caregiving often includes helping with daily activities (e.g., bathing, dressing, meal preparation and transportation), providing emotional support and activities to promote engagement, managing medications, and coordinating paid in-home support services and health care.<sup>1</sup> Most family caregivers of PLWD in the community provide care for four or more years.<sup>1</sup>

### Common Dementia Caregiving Tasks

- Providing emotional support and a sense of security
- Helping with household activities such as shopping and meal preparation
- Assisting with personal activities such as bathing and dressing
- Managing behavioral symptoms such as repetitive activity, anxiety, agitation, and wandering
- Addressing family issues and decision-making around care supports and living arrangements
- Finding and coordinating support services such as in-home personal care and adult day programs
- Hiring and supervising others who assist with care
- Helping with medications and doctor’s appointments

FIGURE 2: Adapted from Table 7, Page 38, 2021 Alzheimer’s Disease Facts and Figures<sup>1</sup>

## CAREGIVER EXPERIENCE

Although caregivers of PLWD often report a sense of satisfaction about caregiving, they also frequently report higher emotional stress and are more likely to experience depression and anxiety and report poorer health than non-caregivers.<sup>1</sup> Work related changes such as cutting back on hours are also common in caregivers of PLWD.<sup>1</sup> When compared to White caregivers, Black, Hispanic, and Asian caregivers report greater care demands, less outside help/formal service use, and greater depression.<sup>1</sup> Despite this finding, Black caregivers more often than White caregivers report positive aspects of caregiving.<sup>1</sup>

*“There was never going back. It was never ‘oh, maybe this will get better next week, or we will go back.’ It’s more like ‘this is our new season.’ ... and there was never any notification it was coming. Like, I don’t remember the last time I had a coherent conversation with her, because that kind of dwindled away. I don’t remember the last time she said my name, because I didn’t know it was going to be the last time.” Family Caregiver*

The Alzheimer’s Association Greater Indiana Chapter is the premier resource for help and support for PLWD and those caring for someone with Alzheimer’s or other dementias.<sup>8</sup> Additionally, home- and community-based services (HCBS) to support PLWD and their caregivers can be accessed through Indiana’s Aging and Disability Resources Centers and Area Agencies on Aging – CICOA Aging & In-Home Solutions (CICOA) for Central Indiana residents.<sup>10</sup> This includes Indiana’s Community and Home Options to Institutional Care for the Elderly and Disabled program (CHOICE) and the Medicaid Aged and Disabled Waiver program.<sup>7</sup>

## CHRONIC CONDITIONS

*“Unfortunately, people living with dementia usually have other chronic conditions that require medication, and a person to be able to express what they are feeling... They do not have a good memory, so they can’t remember to take the medication and they don’t have good communication, so they can’t express the symptoms from other co-morbid conditions. Suddenly you are not just dealing with the cognitive, functional, and psychological disability and caregiver stress, but also chronic conditions that get out of control and that lead to hospitalizations.” Geriatrician/Dementia Specialist*

The Sandra Eskenazi Center for Brain Care Innovation (SECBCI) in collaboration with CICOA and the Alzheimer’s Association developed and evaluated a team-based approach to dementia care which includes geriatricians, social workers, nurses, and community health workers to improve the health of both the PLWD and their family caregivers.<sup>11</sup> The SECBCI care model is unique to Indiana and has been shown to reduce

dementia symptoms and caregiver stress while also preventing avoidable emergency department visits and hospitalizations.<sup>12</sup>

Dementia Friends Indiana, a statewide movement led by CICOA, “seeks to advance education and awareness of dementia, reduce the stigma associated with the disease, and create community environments that are welcoming and conducive for those with dementia.”<sup>13</sup> Several organizations and businesses in Central Indiana have been certified as “Dementia Friendly” and thousands of Hoosiers have become a “Dementia Friend”.

*“This has been one of the highlights of my professional career and even in my personal life. It’s been amazing to see our staff embrace this initiative and be more empathetic and caring to this patient population” Clinical Manager/Dementia Friend and Champion*



FIGURE 3: Dementia Friends Indiana

The Indiana General Assembly during the 2021 legislative session established Indiana’s Dementia Strategic Plan and Annual Report.<sup>14</sup> Under Indiana Code, the Family and Social Services Administration (FSSA) Division of Aging is required to develop a dementia strategic plan to identify and significantly reduce the prevalence of dementia in Indiana. The initial 2021 Dementia Strategic Plan and Annual Report was developed based on work and recommendations of the Indiana Dementia Care Advisory Group consisting of members representing more than two dozen organizational and agency partners dedicated to improving HCBS for PLWD and their caregivers.<sup>15</sup>



## Endnotes

- 1 2021 Alzheimer's Disease Facts and Figures. <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- 2 State of Aging in Central Indiana, Chapter: Health Outcomes, April 2021. <https://centralindiana.stateofaging.org/report-data/health-outcomes/>
- 3 Michael Lepore et al., "Living Arrangements of People with Alzheimer's Disease and Related Dementias: Implications for Services and Supports," Issue Brief, October 2017. <https://aspe.hhs.gov/sites/default/files/private/pdf/257966/LivingArran.pdf>
- 4 10 Warning Signs of Alzheimer's Disease, Early Detection Matters, Alzheimer's Association. <https://www.alz.org/national/documents/tenwarnsigns.pdf>
- 5 Cyndy B. Cordell et al., "Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment During the Medicare Annual Wellness Visit in a Primary Care Setting," *Alzheimer's & Dementia* 9 (2013) 141-150.
- 6 Cathy C. Schubert et al., "Comorbidity Profile of Dementia Patient in Primary Care: Are They Sicker?," *Journal of the American Geriatrics Society* 54 (2006) 104-109.
- 7 State of Aging in Central Indiana, Chapter: Health Care, April 2021. <https://centralindiana.stateofaging.org/report-data/health-care/>
- 8 Alzheimer's Association Greater Indiana Chapter <https://www.alz.org/indiana>
- 9 CICOA Aging & In-Home Solutions <https://cicoa.org>
- 10 State of Aging in Central Indiana, Chapter: Aging in Place, April 2021. <https://centralindiana.stateofaging.org/report-data/aging-in-place/>
- 11 Sandra Eskenazi Center for Brain Care Innovation <https://www.eskenazihealth.edu/health-services/brain-center>
- 12 Malaz Boustani et al., "A Profile in Population Health Management: The Sandra Eskenazi Center for Brain Care Innovation," *GENERATIONS – Journal of the American Society on Aging* (Spring 2019):68-72.
- 13 Dementia Friends Indiana. <https://www.dementiafriendsindiana.org/>
- 14 House Enrolled Act No. 1177. <https://legiscan.com/IN/text/HB1177/id/1997529>
- 15 Dementia Strategic Plan and Annual Report: State Fiscal Year 2021, Indiana Family and Social Services Administration. <http://iga.in.gov/legislative/2022/publications/agency/reports/fs-sa/#document-d726cd15>