

STATE OF AGING IN CENTRAL INDIANA

Living in in the Community with Dementia



Thanks to our partners



Speakers



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Key Findings

1. There are approximately **110,000 Hoosiers** aged 65 and older living with Alzheimer's disease, the most common cause of dementia.
2. An overwhelming majority of people living with dementia reside in the community with **only 1 in 5 in assisted living** or nursing home settings.
3. People living with dementia **usually receive help from family or other unpaid caregivers** who often experience both reward and high levels of stress related to their caregiving roles.

Key Findings

4. 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.
5. 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.
6. 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.

Quote

“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

Dementia is Not Normal Aging

- Dementia is a progressive loss of cognitive ability that interferes with daily life.
- The most common cause of dementia is Alzheimer's disease.
- Dementia is not a part of normal aging.
- **Signs of dementia vs. age-related changes:**
 1. Forgetting recent information vs. sometimes forgetting a name
 2. Difficulty completing daily tasks vs. needing help with technology
 3. Losing things vs. occasionally misplacing things
 4. Changes in mood or personality vs. irritable if routine is disrupted

Dementia is Often Unrecognized

- Families often attribute dementia symptoms to “old age”.
- Mild to moderate dementia is often unrecognized by physicians.
- People with dementia often have multiple chronic diseases including hypertension, diabetes, and heart disease.
- Dementia complicates disease management and medical care.
- Lack of recognition of dementia may explain higher hospitalization and readmission rates in people with dementia.

Dementia Symptoms Need Evaluation

- Evaluation of dementia symptoms is crucial to determine the cause(s).
- Dementia symptoms may be due to side effects of medications, depression, alcoholism, thyroid disorders, and vitamin deficiencies.
- **Early diagnosis of Alzheimer's disease has many benefits:**
 1. Avoidance of medications that may make symptoms worse
 2. Provision of counseling and caregiver support
 3. Access to specialty care and social services
 4. Opportunity for advance care planning

Quote

“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

Alzheimer's Disease

- Among those diagnosed with dementia, 70% have Alzheimer's disease.
- Alzheimer's disease is the leading cause of disability and poor health in those 65 and older; and fifth leading cause of death in older adults.
- There are approximately 110,000 Hoosiers aged 65 and older living with Alzheimer's disease.
- Older age is the biggest risk factor for Alzheimer's disease, however, people with Down Syndrome develop Alzheimer's at an earlier age.
- Other risk factors include smoking, obesity and diabetes.

Alzheimer's/Dementia Prevalence in Central Indiana

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

■ Percent of group with Alzheimer's/Dementia

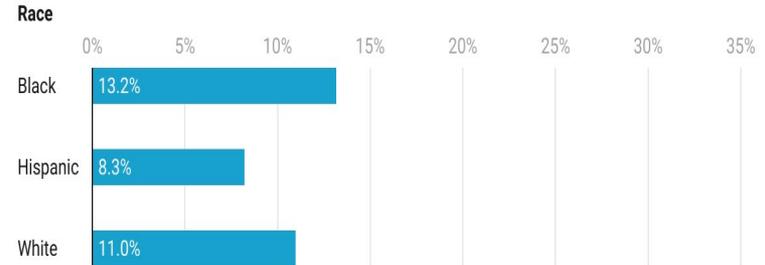
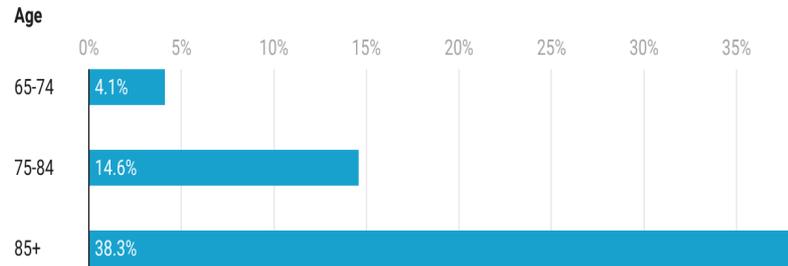


Chart: The Polis Center at IUPUI • Source: Centers for Medicare & Medicaid Services • Created with Datawrapper

Help from Unpaid Caregivers

- The overwhelming majority of people with dementia reside in the community with only 1 in 5 in assisted living or nursing home settings.
- Of those living in the community, 30% live alone and 70% live with others.
- Although often times not self-identifying as “caregivers”, over 90% of people with dementia receive help from family members, friends, or other unpaid caregivers.
- Most family caregivers provide care for four or more years.

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 activities, anxiety, and wandering.
- ✓ Addressing family issues and decision-making around care supports and living arrangements.
- ✓ Finding and coordinating support services (e.g., personal care and adult day programs).
- ✓ Hiring and supervising others who assist with care.
- ✓ Helping with medications and doctor's appointments.

Adapted from Table 7, Page 38, 2021 Alzheimer's Disease Facts and Figures

Caregiver Satisfaction and Stress

- **Caregivers frequently report a sense of satisfaction about caregiving:**
 - ✓ Positive feelings about family togetherness
 - ✓ Satisfaction of helping others
- **Caregivers also frequently report high levels of stress:**
 - ✓ More and more support is needed over time, e.g., daily to round-the-clock
 - ✓ Tasks can be personal and intrusive, e.g., help with bathing and incontinence
 - ✓ May encounter challenging behaviors, e.g., agitation and sleep disturbances
 - ✓ Often feel inadequate, lacking necessary information and skills
- **Despite reporting greater care demands, Black caregivers more often than White report positive aspects of caregiving.**

Quote

“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

Community Resources

Alzheimer's Association

- **Greater Indiana Chapter - Premier Resource for Help and Support**

Area Agencies on Aging

- **CICOA Aging & In-Home Solutions - Central Indiana**

Information on Home and Community Services:

- ✓ Non-medical personal care (e.g., bathing and dressing)
- ✓ Housekeeping, meal preparation, and shopping assistance
- ✓ Home delivered meals and transportation
- ✓ Home safety modifications
- ✓ Caregiver support services

Team-Based Dementia Care Programs

- **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.**

Sandra Eskenazi Center for Brain Care Innovation

- ✓ Geriatricians, social workers, nurses, and community health workers/care coaches
- ✓ Specialize in dementia care - compliment and support primary care
- ✓ Caregiver Stress Prevention Bundle: Counseling/Education, Crisis Plans, Caregiver Time Off, and Support Group Involvement
- **Shown to reduce dementia symptoms and caregiver stress**
- **Also prevents avoidable emergency department visits and hospitalizations**

Dementia Friends Indiana

Mission: DFI 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 living with dementia.

Quote: "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



Indiana's Dementia Strategic Plan

- The Indiana General Assembly during the 2021 legislative session established Indiana's Dementia Strategic Plan and Annual Report
- Indiana 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.
- Initial recommendations were developed by the Indiana Dementia Care Advisory Group and include:
 - ✓ New dedicated state staff position - Dementia Coordinator
 - ✓ Cross agency collaboration between Indiana FSSA, Indiana Department of Health, and Indiana Department of Homeland Security
 - ✓ Required training in dementia care for staff of Area Agencies on Aging, home health and personal care agencies, and first responders

Mission:

The Alzheimer's Association leads the way to **end Alzheimer's and all other dementia** — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Strategic objectives



Increasing concern and awareness.



Advancing public policy.



Enhancing care and support.



Accelerating research.



Growing revenue support of the mission.



Embracing diversity and inclusion.

Greater Indiana Chapter



- 21 staff serving 73 Indiana counties
- Network of 400+ volunteers deliver education and support, advocate, raise funds and connect Hoosiers to services
- Reach 6,000 Hoosiers per year with care and support services
- Advocating for 110,000 Hoosiers living with Alzheimer's disease and 215,000 caregivers

Care & Support Services / Resources

- 24/7 Helpline / Care Consultation
- Education
- Support Groups
- Early Stage Social Engagement
- Caregiver center at alz.org/care
- All programs offered free of charge

alzheimer's  association®

24/7 HELPLINE:

800.272.3900





The Alzheimer's Association is here
all day, every day for people facing
Alzheimer's disease through our free



24/7 Helpline **800.272.3900**



website **alz.org**



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The Alzheimer's Association
offers free **online** and
in-person education sessions
for those living with the
disease and their caregivers.

[alz.org/education](https://www.alz.org/education)



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The Polis Center

Local, State and National Collaborations

- **Central Indiana's leadership in Alzheimer's and dementia research**
 - Alzheimer's Association funding and collaboration
 - 30+-year partnership with Indiana Alzheimer's Disease Research Center
 - Collaborative for Aging Research and Engagement (CARE)
- **Advancing public policy in Indiana and nationwide**
 - Indiana Dementia Strategic Plan (2021)
 - Current legislative priorities include dementia-specific training for Home Health Aides
- **Collaborating with health systems and providers to maximize quality care**
- **Volunteerism and community partners**

Questions?

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Check out the State of Aging in Central Indiana

<https://centralindiana.stateofaging.org/>