

THE AGITATION BLINDSPOT IN ALZHEIMER'S CARE SURVEY

**HOW STIGMA, MISUNDERSTANDING & EMOTIONAL BURNOUT
ARE AFFECTING CAREGIVERS NATIONWIDE**



The Alliance for Aging Research's *Agitation Blindspot in Alzheimer's Care Survey* provides an overview of agitation in Alzheimer's dementia and describes results from two, distinct online national surveys conducted by Wakefield Research.

The first survey was conducted among **1,000 U.S. Alzheimer's caregivers** between April 21 and May 5, 2025, using an email invitation and an online survey.

The term "caregivers" was defined as unpaid or family caregivers who regularly provide care for someone with Alzheimer's disease.

The second survey was conducted among **1,000 nationally representative U.S. adults ages 18+**, between April 21 and May 5, 2025, using an email invitation and an online survey.

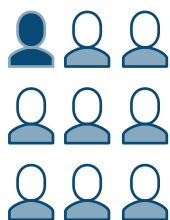
Results of any sample are subject to sampling variation. The magnitude of the variation is measurable and is affected by the number of interviews and the level of the percentages expressing the results.

For the interviews conducted in this study, the chances are 95 in 100 that a survey result does not vary, plus or minus, by more than 3.1 percentage points from the result that would be obtained if interviews had been conducted with all persons in the universe represented by the sample.

Funding for the survey and report was provided by:



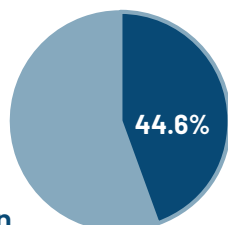
UNDERSTANDING AGITATION IN ALZHEIMER'S DEMENTIA



More than
7 million Americans—
1 in 9 people—
age 65 and older
are living with
Alzheimer's disease.¹

It is a reality many families are facing. In addition to memory loss and other cognitive symptoms, individuals with Alzheimer's disease can experience a range of neuropsychiatric symptoms, including mood disorders, psychosis, sleep disturbances, and agitation.²

About half (44.6%)
of people living
with Alzheimer's
dementia
show signs of
developing agitation in
Alzheimer's dementia.²



- Do not show signs of developing agitation in Alzheimer's dementia
- Show signs of developing agitation in Alzheimer's dementia

Yet many caregivers for people living with Alzheimer's dementia don't know that agitation in Alzheimer's dementia is a separate but related condition, distinctly different from cognitive decline (e.g., memory loss).³

Symptoms of agitation in Alzheimer's dementia may include:

Physical Restlessness²

Pacing
Aimless wandering
Repeated motions

Verbal Aggression²

Cursing
Screaming
Lashing out verbally

Physical Aggression²

Throwing things
Breaking things
Trying to hurt oneself or others

Disinhibition⁴

Saying things that are inappropriate
Undressing in public

¹Alzheimer's Association. Alzheimer's Disease Facts and Figures. Published: 2025. Last accessed: July 16, 2025. Available at: <https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf>

²Halpern R, Seare J, Tong J, Hartry A, Olaoye A, Aigbogun MS. Using electronic health records to estimate the prevalence of agitation in Alzheimer's disease/dementia. *Int J Geriatr Psychiatry*. 2019;34(3):420-431.

³Senanarong V, Cummings JL, Fairbanks L, et al. Agitation in Alzheimer's disease is a manifestation of frontal lobe dysfunction. *Dement Geriatr Cogn Disord*. 2004;17(1-2):14-20.

⁴Alzheimer's Society. Loss of inhibitions and dementia. Last accessed: March 20, 2025. Available at: <https://www.alzheimers.org.uk/about-dementia/stages-and-symptoms/dementia-symptoms/losing-inhibitions>



THE REALITY OF CAREGIVING

Family members and others who regularly provide care for someone living with symptoms of agitation in Alzheimer's dementia are under immense pressure and are struggling.

93%

OF CAREGIVERS OF PEOPLE LIVING WITH SYMPTOMS OF AGITATION in Alzheimer's dementia report feeling **overwhelmed or emotionally drained**.

49%

believe AGITATION IN ALZHEIMER'S DEMENTIA is even harder to deal with than **memory loss**.

This figure rises to

59%

AMONG THOSE WHO CARE FOR SOMEONE who experiences symptoms of agitation in Alzheimer's dementia on a **daily basis**.

Caring for someone living with symptoms of agitation in Alzheimer's dementia often requires significant time and emotional investment. These sacrifices can have lasting effects on **financial stability, personal lives, and mental health**.

Personal and Financial Tradeoffs



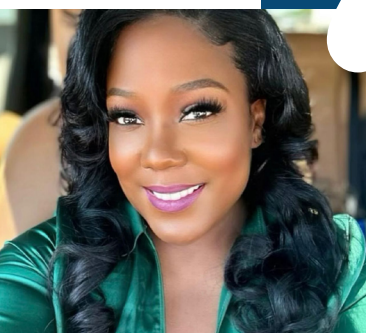
A **quarter (25%)** of caregivers of someone with symptoms of agitation in Alzheimer's dementia report having had to **quit their jobs or work fewer hours** to accommodate caregiving duties.



48% report having **difficulty sleeping**.



More than 1 in 5 (22%) note a **decline in their own physical health** as a result of caring for someone with symptoms of agitation in Alzheimer's dementia.



Caregiver Testimonial

"Caring for my mom through her agitation in Alzheimer's dementia has brought constant, unpredictable change that deeply affects both our lives. The emotional and practical toll has been heavy – the disease has changed my mom as a person, altered our daily routines and put our personal plans on pause. But it is an honor to care for my mom, just as she has done for me and our whole family all of our lives.

Without support from others, the ongoing challenges can feel overwhelming. If you know someone living with agitation in Alzheimer's dementia, checking in on their caregiver from time to time and offering up community support can make a world of difference."

- Lamia Scott*

Social Disconnection and Isolation

38%

of caregivers of people with symptoms of agitation in Alzheimer's dementia report feeling **isolated** or **alone**

41%

have experienced **increased tension** with other family members, which could lead to greater isolation.

64%

say they **lack time** for their own hobbies or interests.

53%

have had to **skip social outings** or events due to their caregiver role.

*Lamia Scott is a paid collaborator of Otsuka America Pharmaceutical, Inc. and Lundbeck.

BARRIERS TO SEEKING CARE

Although agitation in Alzheimer's dementia is common²—it's not commonly understood. Many people, including caregivers themselves, do not recognize all of the behaviors that can be signs of agitation in Alzheimer's dementia, nor do they feel equipped to address them.

This lack of awareness, combined with stigma, silence, and widespread misconceptions, can leave caregivers without the tools or confidence to navigate one of the most challenging aspects of Alzheimer's dementia.



2 in 5

**U.S. ADULTS SURVEYED (40%)
do not link agitation symptoms
to Alzheimer's disease.**

Misconceptions About Agitation

Only a third of all caregivers surveyed (36%) link physical aggression with Alzheimer's dementia, and even fewer (31%) associate disinhibition (e.g., saying inappropriate things or undressing in public) with the disease.



There's a misconception about how to manage agitation in Alzheimer's dementia, even among caregivers.

73%

OF CAREGIVERS BELIEVE THAT AGITATION IN ALZHEIMER'S dementia requires the same care approach as memory loss alone.

But agitation in Alzheimer's dementia is diagnosed and managed separately.^{5,6} If you are caring for someone showing signs of agitation in Alzheimer's dementia, talk to their doctor.

⁵ Jones, E., Aigbogun, M. S., Pike, J., Berry, M., Houle, C. R., & Husbands, J. (2021). Agitation in dementia: Real-world impact and burden on patients and the healthcare system. *Journal of Alzheimer's Disease*, 83(1), 89–101.

⁶ Koenig, A. M., Arnold, S. E., & Streim, J. E. (2016). Agitation and irritability in Alzheimer's disease: Evidenced-based treatments and the black box warning. *Current Psychiatry Reports*, 18(1), 3.

Silence and Stigma

Even when agitation is recognized, talking about it is difficult. This reluctance can be rooted in **guilt**, **fear of judgment**, or the **stigma** surrounding behavioral symptoms.

Nearly  **1/3** OF CAREGIVERS WHO CARE FOR SOMEONE EXPERIENCING SYMPTOMS OF AGITATION (32%) in Alzheimer's dementia have been **reluctant to discuss it with a healthcare professional** because they feel guilty or fear talking about the person they care for in this way.



Top Reasons for Staying Silent:

32% are concerned about being **misunderstood** or dismissed.

25% believe **nothing can be done** to address these symptoms.

22% feel **stigma** around agitation symptoms.

21% are **uncomfortable** talking about agitation symptoms in front of the person for whom they provide care.

For caregivers of people living with symptoms of agitation in Alzheimer's dementia, many are hesitant to discuss symptoms like:



Raising their voice, yelling, or screaming (35%)



Complaining or being negative (35%)



Repeatedly asking questions or requesting attention (34%)

IT'S OKAY TO ASK FOR HELP.

If you are a caregiver, and the person you care for is experiencing symptoms of agitation in Alzheimer's dementia—like pacing, wandering, shouting, repeated motions, throwing or breaking things²—**it's okay to ask for help.**

These symptoms are more common than many realize. You are not alone.

Don't wait to speak up for support.

Report the symptoms to their doctor and ask about ways to help manage these behaviors effectively.



To learn more about agitation in Alzheimer's dementia, visit AlzheimersAgitation.org.

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