



# Patient Voices on Alzheimer's and Other Dementias Report

What 1,000 older adults had  
to say about prevention,  
detection, and care



# Introduction

As the number of older adults around the globe increases, so do projected cases of Alzheimer's and other dementias. According to the World Health Organization, an estimated 55 million people are living with dementia today, and that number is expected to more than double to 139 million by 2050.<sup>1</sup>

But as we face what may seem to be an insurmountable problem, there is good news. First, a growing body of research points to the powerful role prevention can play when it comes to dementia. Research estimates that up to 40% of dementia cases are preventable by addressing modifiable risk factors<sup>2</sup> — things like following a healthy diet; getting regular physical activity; avoiding smoking and excessive alcohol consumption; managing chronic health conditions; staying socially active; and more. Not only do these factors help prevent future dementia, but there's also growing evidence that interventions — such as moderate aerobic exercise<sup>3</sup> — can even help stall further decline in those with existing mild cognitive impairment (MCI).

Second, the pharmaceutical treatment landscape for Alzheimer's is evolving in front of us. As of this report publication, the FDA has granted accelerated approval for Leqembi, a disease modifying treatment for early Alzheimer's disease, and a healthy pipeline of drugs in development — 142 agents in 172 trials<sup>4</sup> — stands to further expand treatment options in the years ahead.

Of course, to treat early Alzheimer's disease — whether via medication, lifestyle interventions, or both — healthcare providers must first identify that a patient has cognitive impairment, and do so during an early phase of the

disease. And, as with virtually all health concerns, early identification and treatment of cognitive disorders will require provider and patient partnership to be successful. This partnership will be particularly important for primary care providers (PCPs) who often serve as a patient's first touchpoint when facing a new health concern. Understanding the disposition of older adults towards early detection of dementia — knowledge of symptoms, awareness of modifiable risk factors, openness to testing, and receptivity to treatment — will be critical to advancing early detection and improving treatment outcomes.

## Methodology

The survey was conducted for Linus Health by Wakefield Research among 1,000 nationally representative US adults 65 and older between January 12th and February 8th, 2023, via web and telephone interviewing. Data has been weighted to ensure an accurate representation of US adults ages 65+. Adults diagnosed with dementia were not surveyed.

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- 1 Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. License: CC BY-NC-SA 3.0 IGO.
  - 2 Livingston, G. (2020, August 8). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet Commissions*, 396(10248), 413-446.
  - 3 Baker, L. D. (2022, December 20). Topline Results of EXERT: Can Exercise Slow Cognitive Decline in MCI? *Alzheimer's & Dementia the Journal of the Alzheimer's Association*, 18(S11).
  - 4 Cummings, J. (2022, May 4). Alzheimer's disease drug development pipeline: 2022. *Alzheimer's & Dementia Translational Research & Clinical Interventions*, 8(1), online.

# Key findings

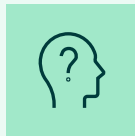
Results from a survey of 1,000 US adults over 65, focused on individuals without dementia.



## Unspoken concerns

Dementia is top of mind for older adults, but rarely discussed with their PCPs.

- ▶▶ 81% have some degree of concern they'll develop Alzheimer's or other dementias
- ▶▶ Only 12% report regularly discussing cognitive health with their PCP



## Myths & knowledge gaps

Older adults need more education on the basics of Alzheimer's and other dementias.

- ▶▶ Only 22% feel confident that they know the signs and symptoms of cognitive impairment
- ▶▶ Nearly half don't know that depression, anxiety, and social isolation are possible symptoms of cognitive impairment



## Risk factors & prevention

Many older adults are still unaware of the power of prevention.

- ▶▶ Almost 1 in 4 believe that dementia is genetic and there's nothing anyone can do about it
- ▶▶ Less than half are aware of the role alcohol consumption, sleep, and social connection play in cognitive health



## Demand for early detection

Older adults are nearly unanimous in their desire for early detection.

- ▶▶ 92% would prefer to know about Alzheimer's and other dementias early on, even before symptoms occur
- ▶▶ 70% cite the chance to intervene — with medications and/or lifestyle — as a motivating factor for early detection



## Care preferences vs. realities

Older adults want to get ahead of dementia, but healthcare practices lag behind.

- ▶▶ 75% would like to learn more about how to reduce their risk of dementia from their PCP
- ▶▶ Only 23% have ever had a formal cognitive assessment



## Emerging drug treatments

Older adults are paying attention and plan to take action once treatments are available.

- ▶▶ 6 out of 10 plan to reach out to a provider for more information
- ▶▶ More than 2 in 5 are likely to request testing for early Alzheimer's



# Unspoken concerns

Dementia is top of mind for older adults, but rarely discussed with their PCPs.

Alzheimer's and other dementias represents a worrisome topic for older adults — 81% of those surveyed have at least some concern that they may one day develop Alzheimer's or another form of dementia.

In fact, weighing this concern against other age-related health issues — like heart disease, ALS, and cancer — Alzheimer's and other dementias ranked as the *most* concerning possible diagnosis among older adults with almost 30% identifying it as their top concern.

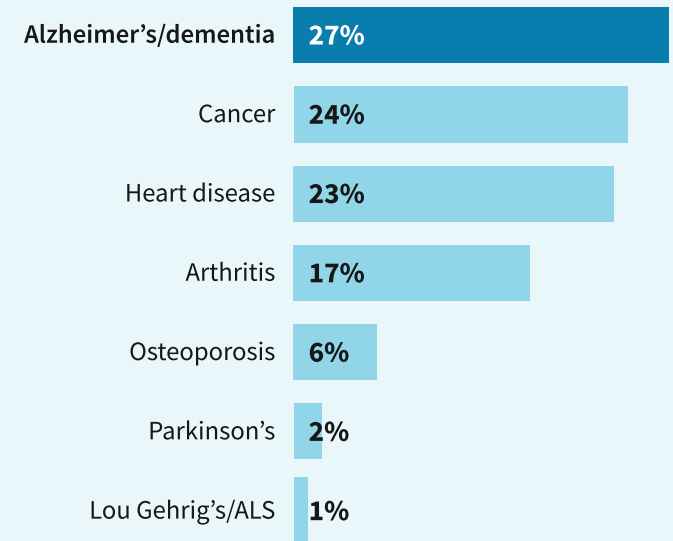
And while older adults may worry about cognitive issues, talking about their concerns with their PCP is another story. Though the majority of older adults report seeing their PCP an average of three times per year, only 12% say they regularly discuss cognitive health with their PCP.\*

Furthermore, the majority (68%) report that they rarely or never bring up questions or concerns about their cognitive health with their PCP.\*

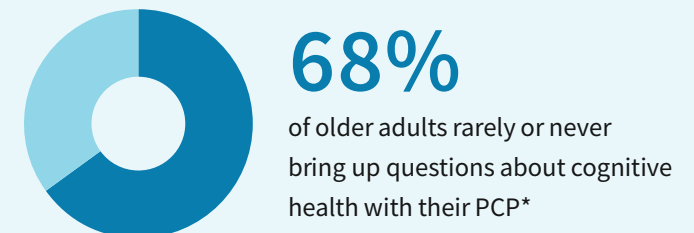
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\*Among the 97% of respondents who reported having a PCP.

## LEADING AGE-RELATED HEALTH CONCERNS AMONG OLDER ADULTS

*Select the top 3 health diagnoses associated with aging that concern you the most.*



*How often do you bring up questions or concerns about your cognitive health with your primary healthcare provider during visits?*





# Myths & knowledge gaps

Older adults need more education on the basics of Alzheimer's and other dementias.

While campaigns to fight misinformation about Alzheimer's and other dementias have made great progress, myths about cognitive decline remain persistent. Nearly 1 in 5 older adults believe that dementia is a normal part of aging.

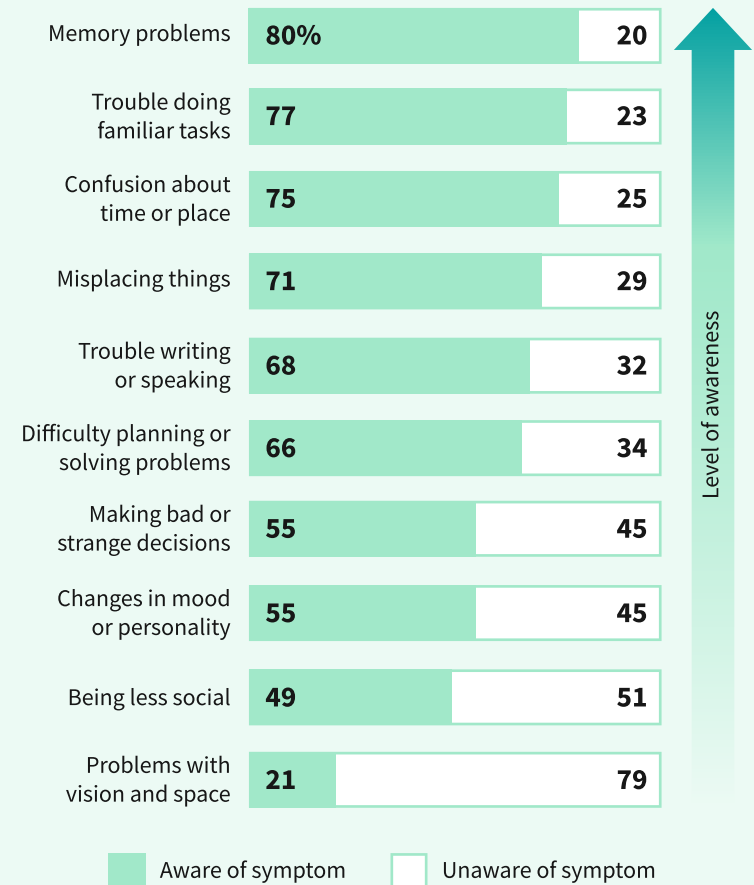
And when it comes to identifying early cognitive concerns, few trust their own abilities to do this. Only 22% report a high level of confidence that they know the signs and symptoms of cognitive impairment. Even among those that do feel confident or somewhat confident (61%) about their knowledge of early signs, there's evidence that respondents tend to overestimate this (see chart, right).

When asked to choose from a list of signs and symptoms of possible impairment, the respondents' ability to identify them was mixed, with some much easier to spot than others (see chart, right). Most notably, though neuropsychiatric symptoms are exceedingly common in those with cognitive impairment (present in up to 85% cases<sup>5</sup>), nearly half of respondents failed to recognize personality or mood changes, depression, anxiety and social isolation as possible symptoms.

5 Martin, E. (2020, April 14). Neuropsychiatric Symptoms in Mild Cognitive Impairment: A Literature Review. Dementia and Geriatric Cognitive Disorders, 49(2), 146-155. <https://doi.org/10.1159/000507078>

## SYMPTOMS OF COGNITIVE IMPAIRMENT: KNOWLEDGE GAPS

*Which of the following, if any, do you think are signs of cognitive impairment or early dementia?*





# Risk factors & prevention

Many older adults are still unaware of the power of prevention.

While the role of prevention in cognitive health may be well known among many in the healthcare community, older adults still hold an outdated understanding of the nature of dementia. In fact, **almost 1 in 4 believe that dementia is genetic and there's not much anyone can do about it.**

When asked to choose from a list of possible strategies for preventing dementia, respondents' knowledge of lifestyle and dementia risk was mixed, with some activities more well-known than others (see chart, right). But overall, **fewer than half are aware of the role that sleep, alcohol, and social connection play in cognitive health.**

Encouragingly, the direct link between healthy habits in day to day life and reducing dementia risk has a motivational impact on older adults, **with 95% indicating a willingness to make one or more changes to their lifestyle if they knew they were proven to support brain health,** with taking part in challenging mental activities (85%), increasing physical activity (74%), eating healthier foods (70%) and getting more sleep (59%) as the most likely actions respondents would take.

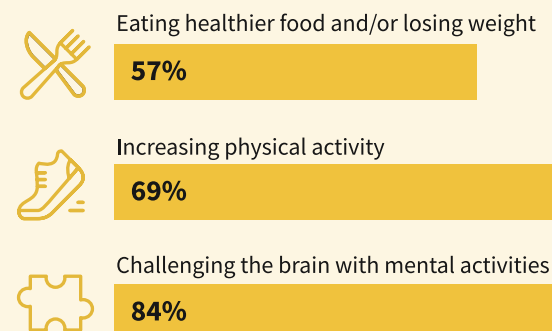
## LIFESTYLE INTERVENTIONS: KNOWLEDGE GAPS

*Which of the following, if any, do you think could specifically lower someone's chances of developing Alzheimer's or other forms of dementia?*

### Low awareness (<50%)



### High awareness (>50%)







# Demand for early detection

Older adults are nearly unanimous in their desire for early detection.

When asked about potential timing of detection, the vast majority of older adults surveyed — 92% — said they would prefer to know about Alzheimer’s and other dementias early on, even before symptoms occur, if possible. The majority of respondents (58%) go as far as saying they “strongly agree” with the notion that they would want to know prior to symptoms arising.

Those who indicate a preference for early detection point to multiple reasons for valuing this level of care and the opportunities it would provide, with the ability to plan for long term healthcare needs (73%), begin treatment with pharmaceuticals (71%), and make lifestyle changes to protect their brain health (70%) topping the list of reasons they would want to know early (see chart, right). On the intervention side, 52% also indicated an interest in joining clinical trials.\*

The survey findings also indicate the impact early detection would have on other types of planning and prioritizing for the future, with over half of respondents sharing that knowing about Alzheimer’s and other dementias early would impact their financial planning (53%) and how they prioritize life plans and spend their time (51%).\*

\*Among the 92% of respondents who had a preference for early detection.

## WHY OLDER ADULTS VALUE EARLY DETECTION

*Which of the following best describes why you would want to know if you have signs Alzheimer's or another form of dementia early on?\**



**73%**

Plan ahead for my long-term healthcare needs



**71%**

Begin treatment with any new or approved drugs



**70%**

Make lifestyle changes to protect my brain health



**53%**

Review and assess my finances for the long-term



**52%**

Join clinical trials that are testing new treatments



**51%**

Reprioritize life plans, like spending more time traveling



**47%**

Make changes to where I live or plan to live



## Care preferences vs. realities

Older adults want to get ahead of dementia, but healthcare practices lag behind.

Older adults are eager to be more proactive about cognitive health overall (as well as to take action, see pg. 8). However, the survey findings indicate that both conversations about cognitive health and formal cognitive assessments are not currently standard parts of preventive care today.

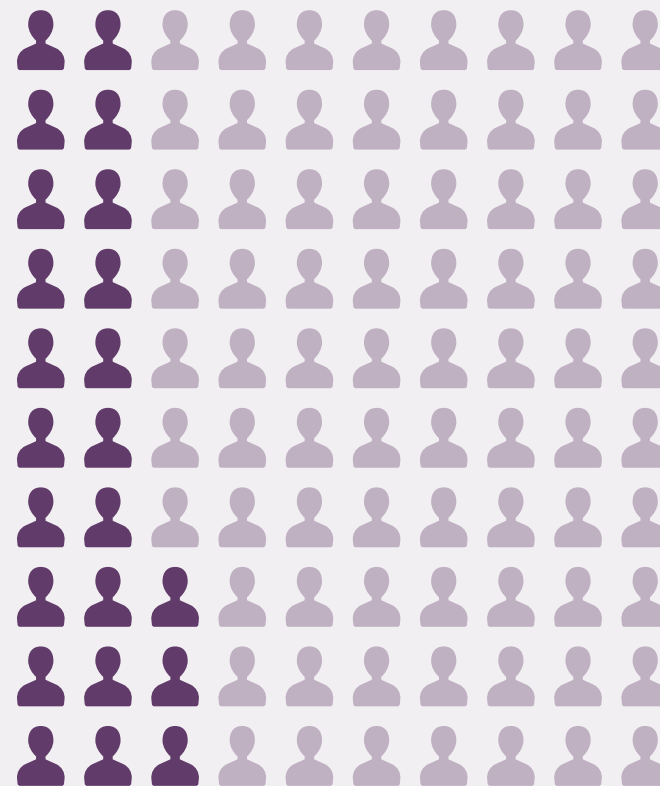
Survey responses reveal opportunities to both enhance cognitive healthcare delivery and facilitate proactive dementia prevention strategies in primary care. For example, only 16% of older adults report that their PCP has recommended lifestyle changes to support their cognitive health in the past few years. Correspondingly, the majority — 75% — say they would like more information from their PCPs on ways to reduce their risk of dementia.\*

Progressing from prevention to detection, despite the nearly universal appeal of early detection, overall testing rates are low. In fact, only 23% of respondents report that they have ever had a cognitive assessment. These low rates of assessment combined with symptom knowledge gaps among patients (see pg. 7) contribute to a high overall risk of signs of cognitive impairment going unnoticed during critical early stages.

\*Among the 97% of respondents who reported having a PCP.

### PERCENTAGE OF OLDER ADULTS WHO HAVE HAD A FORMAL COGNITIVE ASSESSMENT

*Have you ever had a cognitive assessment?*



# only 23%

of older adults have had a cognitive assessment



# Emerging drug treatments

Older adults are paying attention and plan to take action once new drugs are available.

When it comes to new treatments for Alzheimer's, word travels fast. Just weeks after the FDA's accelerated approval of a drug to treat early Alzheimer's disease in January, over 40% of older adults surveyed had already heard of the drug.<sup>6</sup>

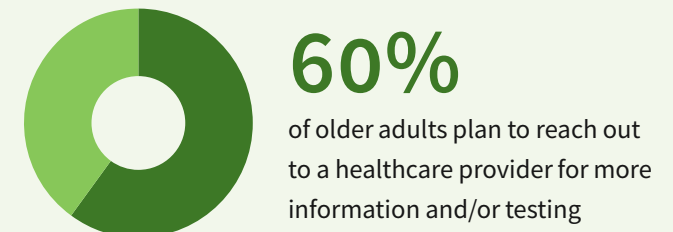
Beyond knowledge, many plan to take action once treatment is available. Even among this survey population of older adults without dementia, more than 6 out of 10 said they would reach out to a healthcare provider for more information or testing if they heard of a new drug for Alzheimer's being approved. In fact, almost 30% of respondents say they would definitely or very likely reach out to a provider to be tested for Alzheimer's even if they didn't have any symptoms (see chart, right). And, over half plan to do research online.

In general, there's widespread desire for early intervention and treatment. If diagnosed, nearly 9 out of 10 older adults indicate interest in taking a medication to potentially slow Alzheimer's, with a majority (58%) reporting they would absolutely do so.

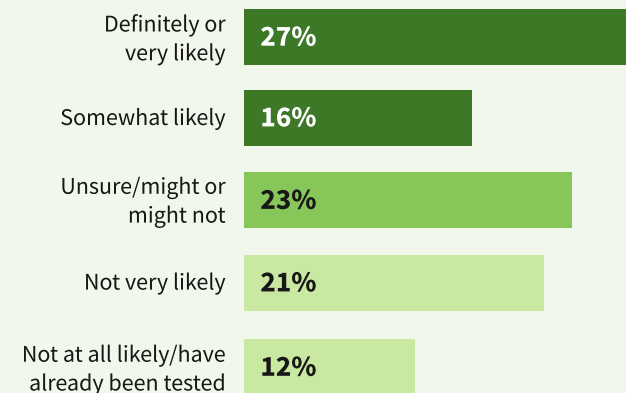
<sup>6</sup> The FDA announced accelerated approval of a new drug treatment of early Alzheimer's disease on January 6, 2023. This survey was fielded in the weeks immediately following (January 12 — February 8, 2023).

## WHAT OLDER ADULTS WOULD DO IF THEY HEARD OF A NEW DRUG BEING APPROVED FOR EARLY ALZHEIMER'S

*If you heard about a new drug being approved to treat early Alzheimer's disease, what would you do?*



*Even if you didn't have any symptoms, how likely would you be to ask a healthcare provider to test you for early Alzheimer's disease if a new medication were available?*



# Survey implications

As with all people, older adults live within networks — families, friends, providers, health plans, public health entities, cities, advocacy groups, religious communities, etc. This survey identifies trends within dementia prevention and care that have a wide variety of possible implications for all.



## Unspoken concerns

Dementia is top of mind for older adults, but rarely discussed with their PCPs.

- ▶▶ Proactive conversation about cognitive health can help connect concern about dementia with support and information
- ▶▶ PCPs need additional resources to be able to expand cognitive care during routine visits



## Knowledge gaps

Older adults need more education on the basics of Alzheimer's and other dementias.

- ▶▶ Efforts to dispel common myths around dementia (e.g. it's a normal part of aging) are important
- ▶▶ Older adults would benefit from additional education on signs symptoms of early cognitive impairment



## Risk factors & prevention

Many older adults are still unaware of the power of prevention.

- » Emerging science around prevention strategies isn't yet common knowledge among older adults
- » Older adults would benefit from additional education on modifiable risk factors and related lifestyle interventions



## Demand for early detection

Older adults are nearly unanimous in their desire for early detection.

- » Concerns around the negative impact of informing patients of a diagnosis (e.g. emotional distress) are largely unfounded — older adults **do** want to know
- » Knowing of a cognitive concern early delivers meaningful benefits to patients, opening a critical window for planning and intervention



## Care preferences vs. realities

Older adults want to get ahead of dementia, but healthcare practices lag behind.

- » Policy changes and additional resources are likely needed to increase cognitive assessment rates in primary care settings
- » More efficient tools — like digital cognitive assessments — can facilitate more widespread testing in primary care



## Emerging drug treatments

Older adults are paying attention and plan to take action once treatments are available.

- » Large numbers of older adults plan to reach out to a healthcare provider for information or testing once new treatments are available
- » Health systems can prepare for this rising demand by mapping out care pathways and workflows that anticipate the changes ahead



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