

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of more than 10,000 people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. Personal insights and preferences are turned into data and validate the collective experience of living with this disease and caring for a loved one. We call it the "science of us."



The Pulse of the Community

What Matters Most:

The mission of the A-LIST is to use survey results to make life better for the broader Alzheimer's and dementia community. UsAgainstAlzheimer's makes sure policymakers, researchers, healthcare providers, drug developers, insurers and others who serve this community understand and consider A-LIST member insights about the Alzheimer's and dementia journey when making decisions that affect those living with the disease and caregivers.

Survey: Paying for Alzheimer's Drugs

The Centers for Medicare and Medicaid Services (CMS) recently announced its decision to deny Medicare coverage of the FDA-approved Alzheimer's treatments except for patients who participate in highly restrictive clinical trials. The CMS ruling extends to an entire class of drugs known as anti-amyloids that are intended to treat Alzheimer's disease in its early stages.

CMS officials said they will evaluate new drugs in this same class separately and will cover them if they're deemed effective for patients, though the agency has not clarified exactly what that process will be. Read more about Medicare's final decision [here](#).

Patient & Caregiver Opinions

Shortly after CMS announced its draft of this decision in January, we asked A-LIST members what's important to you when it comes to Medicare coverage for drugs to treat Alzheimer's disease. You can read the complete survey results [here](#).

The survey asked: "Are you aware of a recent proposal by Medicare related to covering new Alzheimer's drugs?" Two thirds of respondents were unaware (43%) or unsure (20%) of the CMS decision.

The survey also asked: "Given what you know, should Medicare cover the cost of FDA-approved drugs to treat Alzheimer's?" 74% of respondents said Medicare should cover the cost of new Alzheimer's disease treatments.

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Of those who said they were aware of the Medicare draft decision, 27% felt positive, 30% were neutral, and 43% negative about it.

Several respondents accurately described a portion of the decision. For example, one person living with Mild Cognitive Impairment (MCI) or dementia wrote, “Medicare is only covering Aduhelm and other drugs in the same class if you are in a study.”

Tradeoffs when taking a new drug for Alzheimer’s

Some new drugs for serious diseases like Alzheimer’s are approved through the FDA’s Accelerated Approval Program because they are reasonably likely to have an effect, while confirmatory studies continue to take place.

Survey participants were asked if they would want access to a drug for themselves or a loved one if their doctor thought it might work, even if it might have bad side effects.

- Of 54 diagnosed individuals, 41% said Yes, 19% said No, and Unsure 41%
- 243 current and former caregivers were split between Yes (41%), No (17%), and Unsure (42%)

Understanding Alzheimer’s Disease

Survey respondents were asked what they want Medicare officials to understand about Alzheimer’s when making decisions about paying for drugs to treat the disease. Here is what some caregivers wrote:

- “Anything that can either slow down or help cope with memory loss would be a real benefit for millions of people.”
- “It is a ravaging disease that turned my highly intelligent, college professor husband into a shadow of himself. No family, rich or poor, should have to endure that.”
- “It is the most devastating disease out there. You lose a piece of your loved one every day. Absolutely horrendous for the family. I would rather my mom had had cancer than Alzheimer’s.”
- “AD is one of the most cruel diseases, slowly



WHAT SURVEY RESPONDENTS WANT MEDICARE OFFICIALS TO UNDERSTAND ABOUT ALZHEIMER’S:

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stealing every bit of dignity before ultimately killing its victims. Families need hope, need to slow disease progression, extend quality of life and independence, preserve dignity, and increase years spent with their loved ones. No different than cancer drugs, drugs for heart disease, HIV, etc... AD drugs should be treated in the same manner.”

- “The disease is an unimaginable horror. Patients live in stark terror most of the time, and families bear an unbearable burden.”
- A person with dementia wrote, “Without a cure or a way to stop progression, we (persons living with dementia-related illness) will die! Plain and simple!!!”

Following the release of CMS’ final decision, UsA2 released [this statement](#) from Chairman George Vradenburg, saying in part, “In an unprecedented move, the agency formalized its plan to deny Medicare coverage to Alzheimer’s patients to FDA-approved Alzheimer’s treatments, something it has never done with any other patient group.”

For additional background on the Medicare decision and what it means, read this [New York Times article](#), [Medicare Officially Limits Coverage of Aduhelm to Patients in Clinical Trials](#).

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