## Alzheimer's Disease: Working Toward a Better Understanding



A Series by: Real World Health Care 2022

Alzheimer's disease is a leading cause of death in the United States and millions of Americans are affected by the disease.

**Alzheimer's Disease: Working Toward a Better Understanding** is a recently published series of articles that spotlights the organizations and efforts dedicated to helping patients and their caregivers cope with Alzheimer's and ensure they get the support they need.

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## 11 Myths About Alzheimer's Disease

Alzheimer's disease is a leading cause of death in the United States and millions of Americans are affected by the disease. It's important to distinguish the facts from the myths about Alzheimer's, especially when it comes to finding information online.

The following information about common myths surrounding Alzheimer's was originally published by the <u>National Institutes of Health's National Institute on Aging</u> (NIA), which leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. NIA is the primary Federal agency supporting and conducting Alzheimer's disease research. You can read the original 11 Myths About Alzheimer's Disease <u>here</u>.

### Myth #1: Alzheimer's disease and dementia are the same thing

People often use the terms Alzheimer's disease and dementia interchangeably, but there is a difference. Dementia refers to impaired memory, thinking, reasoning, and behavior, and Alzheimer's is just one type of dementia. The terms are likely confused because Alzheimer's is the most common cause of dementia and the most well-known. But there are other types of dementia, too, including <u>Lewy body</u> <u>dementia</u>, <u>frontotemporal dementia</u>, and <u>vascular dementia</u>. Learn more about <u>dementia and Alzheimer's disease</u>.

### Myth #2: I will develop Alzheimer's disease if my parent has it

If a parent or close relative has Alzheimer's disease, you may be worried about developing it as you get older. A person's chance of developing Alzheimer's is higher if they have certain genetic mutations or variations that can be passed down from a parent. However, just because a biological parent has Alzheimer's does not mean that their children will develop it.

Alzheimer's disease is complex, and scientists don't yet fully understand what causes it in most people. Research suggests that in most individuals, a host of factors beyond genetics play a role in the development and course of the disease. Environmental and lifestyle factors, such as exercise, diet, exposure to pollutants, and smoking may also affect a person's risk for Alzheimer's. Although we don't yet know how to prevent Alzheimer's, it's important to practice healthy behaviors throughout your lifetime, such as exercising regularly and eating a balanced diet. Learn more about Alzheimer's disease genetics.

### Myth #3: Only people in their 70s and older get Alzheimer's disease

While the greatest known risk factor for Alzheimer's is age, that does not mean that *only* older adults develop it. For most people with Alzheimer's, it's true that symptoms first appear in their mid-60s or beyond. However, some people experience symptoms earlier, even as young as their 30s. When a person develops Alzheimer's between their 30s and mid-60s, it's called early-onset Alzheimer's.

Early-onset Alzheimer's is rare — representing less than 10% of people with Alzheimer's. Developing Alzheimer's earlier in life can present specific challenges. People diagnosed at younger ages may be more likely to be raising children who are still at home or managing work and having to apply for disability than those who are diagnosed at older ages. Many people with <u>Down syndrome</u>, a genetic condition, will also develop Alzheimer's at an earlier age and may begin to show symptoms in their 40s. Learn more about the <u>causes of Alzheimer's disease</u>.

### Myth #4: Alzheimer's disease symptoms are normal as we get older

Many people become more forgetful as they age, and some forgetfulness, such as losing things from time to time, is normal. However, common <u>signs and symptoms</u> of Alzheimer's, such as making poor judgments and decisions a lot of the time, having problems recognizing friends and family, or losing track of the date or time of year are **not** a normal part of aging.

If you are worried about your memory or other possible Alzheimer's symptoms, <u>talk</u> <u>with your doctor</u>. The doctor may ask questions about your health history, perform assessments of your thinking and memory, and carry out medical tests to determine your diagnosis. Learn more about the <u>signs and symptoms of Alzheimer's</u> <u>disease</u>.

# Myth #5: There are no treatments available for people with Alzheimer's disease

There has been significant progress toward developing better treatments for people with Alzheimer's. Several medications are available that can help treat people with Alzheimer's disease. There are also coping strategies to help manage behavioral symptoms.

While there is currently no cure for Alzheimer's disease, thanks to scientific advances, research has never been more promising. In total, NIA is <u>funding more than 250 clinical trials</u> including both drug and nondrug interventions. These include testing treatments that target behavior and lifestyle factors as well as underlying causes of the disease. Learn more about how <u>Alzheimer's disease is treated</u> and where to find <u>Alzheimer's clinical trials</u>.

# Myth #6: I'm frequently forgetting things, it must be Alzheimer's disease

Even though memory problems are typically one of the first signs of Alzheimer's, not all memory problems mean a person has the disease. Some forgetfulness is normal as we age.

<u>Talk with your doctor</u> to determine whether the memory changes you're noticing are normal or may be a sign of something more serious. In some cases, <u>depression</u> or <u>medication side effects</u> can cause memory and other thinking problems. With

treatment, it may be possible to reverse some memory problems due to these reasons. Learn more about <u>what's normal memory loss and what's not</u>.

### Myth #7: You can buy supplements online to prevent or cure Alzheimer's disease

There are many websites and advertisements that promise certain supplements can effectively treat or cure diseases such as Alzheimer's. In some cases, these may seem reliable, offering advice on healthy aging and Alzheimer's to gain people's trust and promote their products. However, there is no scientific evidence backing these claims, and currently, no supplement has been proven to delay, prevent, treat, or cure Alzheimer's.

Talk with your doctor before taking any supplements or trying any other new treatments.

Find tips to help determine whether an <u>online health information article is reliable</u>.

### Myth #8: You can prevent Alzheimer's disease

There is no proven way to prevent Alzheimer's. However, there are steps you can take to help reduce your risk for this disease. A risk factor is something that may increase a person's chance of developing a disease. Some risk factors can be controlled, while others, such as the genes you inherit, cannot.

In general, leading a healthy lifestyle may help reduce risk factors that have been associated with Alzheimer's and other age-related health problems. These include:

- Controlling high blood pressure
- <u>Maintaining a healthy weight</u>
- Staying mentally and physically active
- Preventing head injury
- <u>Sleeping seven to nine hours</u> each night

Learn more about <u>reducing your risk for Alzheimer's disease</u> and <u>what we know</u> <u>about preventing Alzheimer's</u>.

# Myth #9: Doctors cannot definitively diagnose someone with Alzheimer's disease until after death

Before researchers developed <u>biomarker tests</u> in the early 2000s, the only sure way to know whether a person had Alzheimer's disease was through autopsy, a procedure that is performed after death. Now, lab and imaging tests are available to help a doctor or researcher see the biological signs of the disease in a living person. For example, it is now possible for doctors to order a blood test to measure levels of beta-amyloid, a protein that accumulates abnormally in people with Alzheimer's. Several other blood tests are in development. However, the availability of these tests is still limited. NIA-supported research teams continue to study options for faster, less-expensive, and less-invasive ways to diagnose Alzheimer's. Learn more about <u>biomarkers and Alzheimer's detection and research</u>.

# Myth #10: An at-home genetic test can tell me if I have (or will have) Alzheimer's disease

You may have heard about at-home genetic tests. These tests extract DNA from a person's saliva and provide reports of the genetic data. It's important to note that no genetic test can diagnose Alzheimer's disease. Genetic tests can identify certain rare mutations that cause early-onset Alzheimer's, as well as genetic variations that increase a person's risk for the disease. FDA has approved one of these tests for athome use. This test shows if a person carries a form of the *APOE* gene, APOE  $\epsilon$ 4. People with this variant are at an increased risk for Alzheimer's, but it does not mean that they will definitely develop the disease.

<u>Talk with your doctor</u> about these types of genetic tests. You also may want to schedule an appointment with a genetic counselor to help you consider whether a test is right for you and to understand the results. Learn more about <u>Alzheimer's disease genetics</u>.

### Myth #11: I'm not a scientist. I can't do anything to help fight Alzheimer's disease

Even if you are not a scientist, there are many ways that you can help advance Alzheimer's disease research! Volunteers participating in <u>clinical trials and studies</u> have led to meaningful advancements in the detection, diagnosis, and treatment of Alzheimer's. By joining a trial or study, you become a partner in helping researchers advance their knowledge toward effective diagnostics, treatments, and preventions. All types of volunteers are needed, including people living with dementia, caregivers, and healthy volunteers.

As a family member or friend of a person living with Alzheimer's, you can also help by offering support, such as learning <u>tips for communication</u> or <u>finding suitable</u> <u>activities</u>. You can also offer help by <u>supporting caregivers</u> of people with Alzheimer's or a related dementia. Learn more about <u>participating in Alzheimer's</u> <u>disease research</u> and <u>where to find a clinical trial</u>.

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

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# **Fighting for Equitable Representation in Alzheimer's Research**

Social determinants of health (SDOH) have long-term, far-reaching, and not always obvious ramifications in people's lives, including their risk for Alzheimer's disease and related dementias (ADRD). These disparities were made clear by a <u>2020 report</u> issued by <u>UsAgainstAlzheimer's</u> and the <u>Urban Institute</u>.

The report found that deep social inequities – in income, health insurance status, education and more – exist in U.S. counties highly impacted by Alzheimer's among Latinos and Blacks. According to the report, these SDOH are "under-recognized and under-appreciated in our national response to effectively treat and prevent Alzheimer's."

The effects of these SDOH are reflected in studies of <u>Alzheimer's prevalence rates</u>, which indicate that 18.6 percent of Blacks and 14 percent of Hispanics age 65 and older have Alzheimer's, compared with 10 percent of white older adults.

Racial disparities continue in diagnosing Alzheimer's. A recent National Institute on Aging (NIA) <u>study</u> found that, although Blacks are 1.5 to 2 times more likely than whites to develop Alzheimer's, they are 35 percent less likely to be diagnosed with the disease when participating in Alzheimer's research studies.

"These diagnosis disparities are only a small part of the story because there are so few Blacks and Latinos engaged in research," said Nancy Lynn, senior vice president, Strategic Partnerships, <u>BrightFocus Foundation</u>. "In fact, they currently make up less than 10 percent of all active participants in ADRD research studies and clinical trials."



Nancy Lynn, Bright Focus

### A Call for Inclusivity

Lynn estimates that by 2030, more than 40 percent of those with Alzheimer's will be Black and Latino. She said it is imperative for clinical trials to better represent these underserved communities moving forward. BrightFocus, which is currently managing a \$36 million global portfolio of over 150 Alzheimer's research projects, is working to narrow racial and ethnic disparities in Alzheimer's research. One way they are doing so is by removing obstacles minority researchers may face when applying for research grants. To help more researchers of color enter the Alzheimer's research pipeline, BrightFocus is providing travel fellowships for minority researchers to attend Alzheimer's research conferences and fast-track workshops. In addition to the travel fellowships, BrightFocus is reaching out to Historically Black Colleges and Universities (HBCUs) to make them aware of research grant opportunities.

"The best science and most novel ideas can come from anyone, anywhere, regardless of the researcher's nationality, ethnicity, race or gender," said Lynn, who noted that BrightFocus is working with a range of organizations in government, industry, academia, and local communities to address barriers to participation in clinical research.

### **Brain Info Live**

To help raise awareness in underrepresented communities about brain health, Alzheimer's, and the opportunity to participate in research trials, BrightFocus recently launched <u>Brain Info Live</u>SM, a series of free, entertaining, interactive online programs customized for diverse communities across the U.S. The Foundation is working with local community leaders and partners to tailor the information and resources in these live-streamed programs to various racial and ethnic cultures. The effort is designed to create a sustained dialogue about Alzheimer's and clinical trials – one that builds trust over time among community members, families, clinicians, researchers, and other health professionals.

"We need to recognize that frightening historic abuses by the medical establishment are not forgotten by communities of color," Lynn said. "To rebuild trust, we need to listen and validate those experiences. We need to *give back* first - information, services, time - before we ask these communities to participate in research. All people want to see themselves represented in the health care setting. Historically, however, most clinical trial recruitment outreach was done depicting white men in white coats standing in front of white boards."

To step away from this model, the *Brain Info Live* programs feature a local "cast" of individuals who reflect the race and ethnicity of others in their community. For example, one early <u>episode</u> targeted to the Boston area featured Mike Kincade of the Massachusetts Alzheimer's Disease Research Center, who is Black and active in local research diversity outreach, as well as Bernice Osborne, a Black woman who shared her experience as an Alzheimer's caregiver successively for both of her parents.

"We work closely with local organizations and community members to help us identify content and approaches that will really provide benefit to, interest, and motivate people from different neighborhoods," Lynn said. "There is no cookiecutter approach here, even among seemingly homogenous communities. It's clear, for example, that a Latino person who lives in Boston and comes from the Dominican Republic has different and unique cultural touchstones than a Latino of Mexican background living in San Diego or a Latino of Cuban background living in Miami."

Each *Brain Info Live* session features an "At the Movies" video segment, with clips from multi-lingual films and TV shows with Alzheimer's story lines that are relevant to the topic of the session.

"People learn and develop trust in messaging by being entertained, so the concept of 'edutainment' is central to our efforts and is much more appealing and retainable than a scientific lecture," Lynn said.

Initially launched in September 2021, *Brain Info Live* streams new episodes in various regions across the U.S. every three weeks. Prior episodes are archived for on-demand viewing. Future plans include live events and allowing partners, social services agencies and health care providers to "white-label" the programs for use in their own communities.

BrightFocus also hopes to use *Brain Info Live* as an entry point to on-the-ground efforts targeted to regions in which minorities face high burdens accessing Alzheimer's research opportunities and care. As an example, Lynn pointed to the Rio Grande Valley in Texas, where there is a high prevalence of the disease among Latinos, according to the <u>National Alzheimer's Disease Index</u><sup>™</sup>.

"Our goal is to offer long-term, sustained support to these communities, starting with programming through *Brain Info Live*, then moving to memory screenings, clinical trials at local clinics, and additional efforts to make access to care more equitable," Lynn concluded.

BrightFocus Foundation encourages community organizations, social services agencies and health care provider organizations to contact <u>Kait Halibozek</u> for information on how to bring *Brain Info Live* to their constituents.

## **Alzheimer's Association Calls for Diversity in Clinical Trial Participation**

Access to health care and the opportunity to achieve optimal health should not depend on where people live, their socioeconomic status, or their race and ethnicity, but as the COVID-19 pandemic has shown, that is not always the case.

COVID-related disparities served to shine a light on other areas of health disparities as well, including clinical trial diversity. In the case of Alzheimer's disease, for example, difficulties recruiting traditionally underrepresented groups has a

significant impact on researchers' ability to develop therapeutics and care models that work for people of all ethnic and racial backgrounds.

The <u>Alzheimer's Association</u> seeks to change that paradigm, with several initiatives designed to address obstacles, reach out to underserved communities and make clinical trial recruitment more equitable across diverse populations.

"Scientific discoveries should translate into improved health outcomes for all people, in all communities," said Carl V. Hill, PhD, MPH, Chief Equity, Diversity and Inclusion Officer, Alzheimer's Association. "Without representative participation in trials, it is impossible to get a complete understanding of how treatments will be safe and effective for everyone."



Carl Hill, Alzheimer's Association

### **Benefits of Clinical Trial Participation**

In addition to accelerating progress toward treatments, prevention and a cure for Alzheimer's, participating in clinical trials can translate into tangible benefits for individual patients, according to Dr. Hill. He noted that people involved in clinical trials tend to do somewhat better than people in a similar stage of their disease who are not enrolled in clinical trials, regardless of whether the experimental treatment works.

"Patients can get access to potential treatments before they are widely available," he explained. "They can take advantage of expert medical care at leading academic medical centers, often free of charge. Plus, they can take a more active role in their own health care through general health checkups that are often a regular component of trials." To help those living with Alzheimer's find a clinical trial for Alzheimer's and other dementia, the Alzheimer's Association launched <u>TrialMatch</u>, a free matching service to a continuously updated list of more than 700 studies, including drug and non-drug trials. Studies can be flagged with languages in which they are available, and users can filter studies by their preferred language.

### **Obstacles to Clinical Trial Participation**

Dr. Hill pointed to several obstacles keeping racial and ethnic minorities from being well represented in clinical trials, some of which have their genesis in long-standing mistrust of medical research.

"Black communities, for example, have passed-down memories of the heinous Tuskegee syphilis trial, forced sterilizations, and Baltimore's 1930s redlining initiative, the latter of which impacted health care access and outcomes for generations," he said. "Researchers and the health care system as a whole must therefore work on building trust before they can start to convince African Americans of the benefits of trial participation."

Even when unwarranted, fears over racism or discrimination from doctors and medical staff prompt some racial and ethnic minorities to delay seeking Alzheimer's care. A 2021 <u>study</u> found that more than one-third of Black Americans (36%), two-fifths of Native Americans (40%), and nearly one-fifth of Hispanic Americans (18%) and Asian Americans (19%) believes discrimination would be a barrier to receiving care. They are also less confident that they have access to health professionals who understand their ethnic and racial background and experiences, supporting the need for more diverse representation among health care providers.

Still other challenges to participating in Alzheimer's clinical trials are logistical in nature, including access to transportation, distance from clinical trial locations and ability to take time off from work or family duties.

"Researchers should receive funding from NIH and other sources to better understand how these local, logistical obstacles make it difficult to apply a one-sizefits-all solution," Dr. Hill said. "They also need to re-evaluate trial exclusion criteria, which have the potential to restrict the participation of those disproportionately affected by Alzheimer's or another dementia, like Latinos and African Americans."

### **Outreach Builds Awareness and Recruitment**

The Alzheimer's Association is leading two major clinical trials with a strong focus on diverse participation. The <u>New Ideas study</u> is recruiting 2,000 Latinos and 2,000 Blacks to investigate the impact of brain amyloid PET scan on clinical care outcomes, including diagnosis and treatment. The U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (<u>U.S. POINTER</u>) study is a two-year clinical trial studying the effects of multi-component lifestyle interventions on risk of cognitive decline in a diverse population.

"Together, these studies should provide valuable insight into how a patient's knowledge of their Alzheimer's hallmarks and risk factors affect how they manage their health," Dr. Hill said. "Will they take better care of their cardiovascular health? Will they go see their doctor more frequently? Research shows that when people can get their hypertension under control, progression from mild cognitive impairment to severe dementia slows down."

The two trials are actively recruiting, and the Alzheimer's Association is conducting community-based outreach through its 70+ chapters across the country, as well as through strategic partnerships with more than 20 national and countless local organizations, to get the word out in culturally relevant and appropriate formats.

Noting that partnerships at a national level translate into more effective community engagement, Dr. Hill said the Alzheimer's Association is working with the African Methodist Episcopal (AME) Church on a five-year program to disseminate free Alzheimer's and dementia-related information, resources and referrals to its two million members. It also is working with the National Association of Hispanic Nurses to develop culturally responsible and language appropriate content. A complete list of the Association's national partners can be <u>viewed here</u>.

"People are more likely to participate in clinical trials if they are invited by a trusted individual from their community," added Dr. Hill.

### **A Critical Moment**

Later this month, the Alzheimer's Association will host its <u>International Conference</u>, the most influential international meeting dedicated to advancing dementia science. This year, the Conference will have a special focus on health disparities and health equity, with a daylong workshop Addressing Dementia Risk Through Social Determinants of Health, co-sponsored with the CDC. The workshop will bring researchers and practitioners to increase understanding of how the conditions in which people live, learn, work and play affect dementia risks and outcomes.

"This is an exciting time in health equity research, but issues remain complex," Dr. Hill concluded. "We are at a critical moment in which more intentional inclusion in Alzheimer's and dementia research can help to change the course of a devastating disease and benefit generations to come."

# **Alzheimer's Disease: Better Care Starts with Trusted Information**

If you or someone you love has Alzheimer's disease, your search for treatments or a cure may lead you to consider a range of unproven remedies. To be clear, there are medications, treatments and strategies that can slow declines and help people with the disease have the highest possible quality of life. But there are also countless sham remedies with no scientific evidence of effectiveness and with little information provided about potentially harmful side effects or drug interactions.

<u>Jan Busby-Whitehead, MD, AGSF</u>, is the M. Andrew Greganti Distinguished Professor, Chief of the Division of Geriatric Medicine, and Director of the Center for Aging and Health at the University of North Carolina, Chapel Hill. She also serves as Board Chair for the <u>Health in Aging Foundation</u> (HiAF), a national non-profit

established in 1999 by the <u>American Geriatrics</u> <u>Society</u> (AGS) to bring the knowledge and expertise of geriatrics health care professionals to people as they age. She said that the HiAF was created, in part, to combat the vast amount of misinformation about Alzheimer's, dementia and other aging-related conditions. The HiAF's goal, she said, is to provide access to best practices and up-to-date clinical information.

"For years, we have seen vitamins, supplements and other purported Alzheimer's treatments advertised in the media and online," said Dr. Busby-Whitehead. "People who are searching for answers may be swayed by the advertisers' claims, but they should be careful to vet the information fully through a credible and trusted resource like their family doctor, a geriatrician, or an organization like the Health in Aging Foundation."



Jan Busby-Whitehead, American Geriatrics Society

#### **Geriatricians Provide Comprehensive Care for Complex Conditions**

According to Dr. Busby-Whitehead, geriatricians are a vital part of a total care team for people living with Alzheimer's disease. They can help patients and their caregivers separate fact from fiction when it comes to evidence-based Alzheimer's treatments and the limitations of <u>alternative remedies</u>.

Geriatricians are doctors who are specially trained and board-certified to evaluate and manage the unique health care needs and treatment preferences of people as they age. They are pioneers in advanced-illness care for older individuals, with a focus on championing interprofessional teams, eliciting personal care goals and treating patients as whole people. "Geriatricians provide comprehensive care for complex conditions, such as Alzheimer's disease," Dr. Busby-Whitehead said. "We treat the whole person, not just a single organ system or disease. We place the patient and their family at the center of the care we provide, and we pay special attention to the social and financial circumstances that can impact access to care and treatment compliance."

### **Education for Older Adults and Their Caregivers**

While the HiAF has a professional component that supports geriatrician trainees and recognizes achievements and leadership in geriatrics, it also operates a public education portal: <u>HealthinAging.org</u>, which provides older adults and caregivers with up-to-date information on health and aging, as well as access to a network of geriatrics health care professionals. All the tools on the site are regularly reviewed by geriatrics health care professionals and members of the AGS.

Not limited to Alzheimer's, the site provides comprehensive resources including:

• Information on <u>common diseases and disorders</u> that affect people as they age.

• Specific considerations for older adults and caregivers managing multiple health conditions.

- <u>Tip sheets</u> with guidance and information.
- <u>Ask the Expert</u> insights from health care professionals.

• A <u>What to Ask</u> series that provides practical questions and tips to direct conversations with health care professionals.

- A <u>Geriatrics Health Care Professional</u> locator to find a local geriatrics provider.
- A <u>Coronavirus</u> (COVID-19) information hub.

"After spending some time on HealthinAging.org, I could not believe the amount of information contained on it," said Amanda C., a caregiver from San Diego. "They have made a tremendous effort to distill technical and scientific information into a format and language that is easier to comprehend for most of us."

### **Understanding Different Types of Dementia**

As Real World Health Care continues our coverage of Alzheimer's Disease, we are grateful to the <u>National Institute on Aging</u> for this informative infographic. To learn more, visit <u>www.nia.nih.gov/health/what-is-dementia</u>.



Living with dementia can be challenging, but there are ways to manage it. To learn more about these types of dementia and other conditions that can cause dementia, visit www.nia.nih.gov/health/whati-s-dementia.

