

Brain Health and Alzheimer's Disease Resources

AARP

What African Americans Say About Brain Health

<https://www.aarp.org/health/brain-health/info-2017/aarp-survey-black-brain-health-fd.html>

National Institutes on Aging

What are the signs of Alzheimer's disease?

<https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease>

Alzheimer's Stats

- One in three seniors dies with Alzheimer's disease or another dementia
- About two-thirds of people with Alzheimer's disease are women
- 5 million+ Americans are living with Alzheimer's disease; nearly 14 million will have the disease in 2050*
- African Americans and American Indians are up to twice as likely, and Hispanics are about 1.5 times more times likely, to develop Alzheimer's disease as non-Hispanic whites
- 3 in 5 people with Down syndrome get dementia by age 55
- Memory loss is just one symptom of Alzheimer's disease — early warning signs of the disease also include personality changes, confusion with time or place, difficulty completing familiar tasks, and trouble with numbers and problem-solving**
- Scientists at the UW are studying a range of factors that may contribute to Alzheimer's disease risk, including genetics, overall health, military status, socioeconomic status, gender, and race
- Advanced brain imaging allows scientists to detect early brain changes associated with Alzheimer's disease up to two decades before a person experiences symptoms of the disease
- Science consistently shows us that a healthy lifestyle – blood pressure control, physical activity, healthy sleep, and following the Mediterranean diet – is good for the brain and may slow the effects of Alzheimer's disease

Alzheimer's Association

Serving African American Families: Home and Community-Based Services for People with Dementia and their Caregivers

https://www.alz.org/national/documents/aoagrant_kts_aa.pdf

Behavioral changes from each stage of the disease <https://www.alz.org/help-support/caregiving/stages-behaviors>

African Americans and Alzheimer's Disease: A Silent Epidemic

<https://www.alz.org/media/Documents/african-americans-silent-epidemic-r.pdf>

The Alzheimer's Association has identified an emerging public health crisis among African Americans — the Silent Epidemic of Alzheimer's Disease. This report brings together for the first time an accumulating body of evidence about the scope and nature of Alzheimer's disease in African- Americans. Each study is important on its own, but only when put together does the magnitude of the crisis become clear.

Among the findings from research highlighted in this report :

- Alzheimer's disease is more prevalent among African Americans than among whites — with estimates ranging from 14% to almost 100% higher;
- There is a greater familial risk of Alzheimer's in African-Americans; and
- Genetic and environmental factors may work differently to cause Alzheimer's disease in African Americans.

Scientists are at a vital juncture in research. Advances in genetics and imaging, combined with our increased understanding of the mechanisms of Alzheimer's, provide immense opportunities to examine the disease in African Americans in ways that would not have been possible even five years ago. Without additional investment in Alzheimer's research targeted to all populations, but especially to African Americans, there is a danger that research will be stopped in its tracks.

Call-to-Action

This report lays out a plan of action that will require an unprecedented mobilization of public and private resources on three fronts:

- First, to accelerate the research to understand Alzheimer's in African Americans and to develop effective methods to manage and prevent disease.
- Second, to increase awareness of Alzheimer's among African Americans, to expand their participation in research, and to get services and treatments to those who are affected by the disease.
- Third, to develop and expand affordable, culturally appropriate services, including assessment, diagnosis, and care.

Black Leaders for Brain Health – University of Wisconsin, Alzheimer's Disease Research Center

<https://www.adrc.wisc.edu/black-leaders-brain-health>

The overarching mission of the Black Leaders for Brain Health is to guide the science of the Wisconsin Alzheimer's Disease Research Center endeavoring to meet the following goals and objectives:

1. Ensure discoveries are directed toward enriching the lives of Blacks affected by Alzheimer's disease and related dementias (ADRD) — enrich their quality of life, educationally, sharing scientific findings, and informing the process of discovery
2. Hold researchers and their staff accountable to meet medical ethical standards in their treatment of Black study participants, emphasizing professional, transparent, culturally humble, and respectful interactions with participants
3. Provide a voice and perspective, so that views of people affected by the science are reflected in scientific endeavors — across all phases of research, including the beginning stages of planning a research project, conducting studies, as well as the dissemination of findings
4. Inform researchers about required cultural competence to guide and improve research projects and research teams

National Alzheimer's Project Act

The National Plan, which originated in 2012, establishes five ambitious goals to both prevent future cases of Alzheimer's disease and related dementias (AD/ADRD) and to better meet the needs of the millions of American families currently facing this disease.

- Prevent and Effectively Treat Alzheimer's Disease by 2025.
- Optimize Care Quality and Efficiency.
- Expand Support for People with Alzheimer's Disease and Their Families.
- Enhance Public Awareness and Engagement.
- Track Progress and Drive Improvement.

Journal of Applied Gerontology

Insights from African American Older Adults on Brain Health Research Engagement: "Need to See the Need"

<https://journals.sagepub.com/doi/full/10.1177/0733464820902002>

Research Participation Findings (see full report for breakdown of "barriers and solutions")

The discussion of brain health research among AAs highlighted several barriers to participation and corresponding strategies for addressing the identified barriers and encouraging engagement. The barriers and solutions were in the areas of (a) mistrust, (b) avoidance and fear of acknowledging problems, and (c) seeing the risks of research, but not the need.

Resources

Eldercare Locator

800-577-1116 / eldercare.acl.gov

National Council on Aging

571-527-3900 / www.ncoa.org

Texas Health & Human Services (Aging)

www.hhs.texas.gov

Family Caregiver Alliance

800-445-8106 / www.caregiver.org