

Alzheimer's Disease in People With Down Syndrome

FACT SHEET

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People with Down syndrome are living longer than ever before. Yet growing older can bring new health challenges, including Alzheimer's disease.

The Connection Between Down Syndrome and Alzheimer's Disease

Many but not all people with Down syndrome develop Alzheimer's disease — the most common cause of dementia — when they get older. Alzheimer's is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out simple tasks. Estimates suggest that 50% or more

of people with Down syndrome will develop dementia due to Alzheimer's as they age.

People with Down syndrome are born with an extra copy of chromosome 21, which carries a gene that produces a specific protein called amyloid precursor protein (APP). Too much APP protein leads to a buildup of protein clumps called beta-amyloid plaques in the brain. The presence of beta-amyloid plaques is one of the hallmarks of Alzheimer's. By age 40, most people with Down syndrome have these plaques, along with other protein deposits, called tau tangles, which cause problems with how brain cells function and increase the risk of developing this disease. However, not all people with these brain plaques will develop the symptoms of Alzheimer's.

Alzheimer's Disease Symptoms

People with Down syndrome can begin to show symptoms of Alzheimer's in their 40s. But, like in all people with Alzheimer's, changes in the brains of people with Down syndrome that lead to these symptoms are thought to begin at least 10 years earlier. These brain changes include the buildup of plaques and tangles, the loss of connections between nerve cells, the death of nerve cells, and the shrinking of brain tissue (called atrophy).

The risk for Alzheimer's disease in people with Down syndrome increases with age, so it's important to watch for certain changes in behavior, such as:

- Increased confusion
- Short-term memory problems (for example, asking the same questions over and over)
- Reduction in or loss of ability to do everyday activities

Other possible symptoms of Alzheimer's dementia in people with Down syndrome are:

- Problems with coordination and walking
- Reduced ability to pay attention
- Behavior and personality changes, such as restlessness and being less social
- Changes in sleep
- Decreased fine motor control
- Difficulty finding one's way around familiar areas

Changes in behavior and function may vary based on a person's abilities before symptoms of dementia were apparent. Still, if you notice any of the changes listed above, contact a health care provider to find out more.

Note that not all dementia symptoms are caused by Alzheimer's, which currently has no cure, and no medications have been approved to treat this disease in people with Down syndrome. Medication side effects, depression, thyroid disease, and other conditions that can be treated and reversed may also cause dementia symptoms.

Down Syndrome and Alzheimer's Research

Alzheimer's can last several years or more. Symptoms get worse over time and eventually result in death. Scientists are working hard to understand why some people with Down syndrome develop this dementia while others do not. They want to know how Alzheimer's begins and progresses so they can develop drugs or other treatments that can stop, delay, or even prevent the disease process.

Research in this area includes:

- Basic studies to improve understanding of the genetic and biological causes of brain abnormalities that lead to Alzheimer's
- Observational research to measure cognitive changes in people over time
- Studies of biomarkers (biological signs of disease), brain scans, and other tests that may help diagnose Alzheimer's — even before symptoms appear — and show brain changes as people with Down syndrome age
- Clinical trials to test treatments for dementia in adults with Down syndrome

Clinical trials are the best way to find out if a treatment is safe and effective in people.

Scientists are hopeful that research on Alzheimer's and Down syndrome will not only help those with both conditions but may also lead to effective treatments for all people with Alzheimer's.

Participating in Research

New treatments, tests, and other discoveries would not be possible without volunteers who participate in clinical studies and trials. By volunteering, people can help others, possibly test new treatments, and access support and resources.

Volunteers and their caregivers should consider a study's risks as well as its benefits. For example, a new drug being tested may have potential side effects. Researchers must follow federal and international rules to ensure that all participants are safe and that their personal information remains confidential. Study staff can explain safety and other issues and answer questions as you decide whether to participate in a research study or clinical trial.

Not every clinical trial or study is right for every person. Studies have specific requirements that people must meet to participate. For example, studies may require participants to be a certain age, have a certain diagnosis, or have a specific genetic makeup. These requirements help ensure that the results of a study are reliable and useful. If you are not eligible for a specific study, there may be other opportunities.

Family members and other caregivers play an important role for adults with Down syndrome who participate in clinical research. They may be asked to accompany the person to study visits, answer health questions about him or her, or provide consent or permission for the person with Down syndrome to take part in the study. Family members and caregivers may also be eligible to participate in studies themselves.

"Informed consent" is a process in which researchers explain the study in detail, describe all the possible risks and benefits of the study, and clarify participants' rights.

Those who decide to participate sign a written agreement stating they understand the risks and benefits and agree to participate in the study. If a person cannot provide this consent, a legally authorized representative, such as a family member or caregiver, may give permission. The person with Down syndrome would also need to agree, called assent, to be in the study.

There are many ways to learn about research opportunities:

- Learn about the Alzheimer's Biomarkers Consortium-Down Syndrome (ABC-DS) and how to participate at www.nia.nih.gov/alzheimers/clinical-trials/alzheimers-biomarkers-consortium-down-syndrome.
- Learn about the Alzheimer's Clinical Trials Consortium-Down Syndrome (ACTC-DS) and how to participate at www.actc-ds.org.
- Join DS-Connect: The Down Syndrome Registry, a voluntary, confidential, online registry from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, part of the National Institutes of Health (NIH). You, your legally authorized representative, or your guardian can submit information about your health and, if desired, choose to be contacted about research opportunities. Visit <https://dsconnect.nih.gov> or email DSConnect@nih.gov for more information and to sign up.
- Learn about the INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) project at www.nih.gov/include-project.
- Search NIA's Alzheimer's disease Clinical Trials Finder at www.alzheimers.gov.
- Visit NIH's "Clinical Research Trials and You," which includes a list of questions to consider before participating in a clinical trial at www.nih.gov/health-information/nih-clinical-research-trials-you.

For More Information

Alzheimer's and related Dementias Education and Referral (ADEAR) Center

800-438-4380 (toll-free)

adear@nia.nih.gov

www.alzheimers.gov

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and health professionals on Alzheimer's disease and related dementias, including information on caregiving, clinical trials, and research. Staff members answer inquiries by phone, email, and in writing and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and related dementias, find clinical trials, and sign up for email updates.

Down Syndrome and Alzheimer's Disease

Alzheimer's Association

www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome

National Down Syndrome Society Publications

www.ndss.org/about-down-syndrome/publications

- Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers
- Aging and Down Syndrome: A Health & Well-Being Guidebook



National Institutes of Health

NIH Publication No. 20-AG-8021 | November 2020

National Down Syndrome Society Resources

www.ndss.org/resources/alzheimers

Medical Care of Adults With Down Syndrome: A Clinical Guideline

<https://pubmed.ncbi.nlm.nih.gov/33079159>

Down Syndrome Research and Resources

Down Syndrome: Condition and Research Overview

www.nichd.nih.gov/health/topics/downsyndrome

DS-Connect: The Down Syndrome Registry

<https://dsconnect.nih.gov>

INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome) Project

www.nih.gov/include-project

Global Down Syndrome Foundation

www.globaldownsyndrome.org

National Down Syndrome Congress

www.ndscenter.org

LuMind IDSC Foundation

www.lumindidsc.org

Other Alzheimer's Resources

Alzheimer's Association

800-272-3900 | www.alz.org

Alzheimer's Foundation of America

866-232-8484 | <https://alzfdn.org>

National Institute on Aging

Eunice Kennedy Shriver National Institute of Child Health and Human Development

National Institutes of Health

NIH...Turning Discovery Into Health®

U.S. Department of Health and Human Services