

# Understanding Alzheimer's Genes

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Know your family history

From the National Institute on Aging





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A person's genes can affect how likely they are to develop Alzheimer's disease.

# Introduction

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**Alzheimer's disease** is an illness of the brain. It breaks down connections among brain cells and causes these cells to die. Over time, this affects how well a person can remember, think clearly, and use good judgment. Alzheimer's begins slowly and gets worse over time.

Many people wonder if Alzheimer's runs in the family. Your chance of having the disease may be higher if you have certain genes passed down from a parent. However, having a parent with Alzheimer's does not always mean that you will develop it.

## This booklet will help you learn:

- what genes are
- how genes relate to Alzheimer's disease
- what it means if you have a family history of Alzheimer's

## Tips about using this booklet

Use the Table of Contents to help you find things quickly. Some medical terms, such as **genes**, are in bold. You can find how to say these words and what they mean in the "Words to know" section on page 19.

# Daniel's story



My mom cares for her mother who has Alzheimer's. I like to spend time with my grandmother and have seen how she has changed over time. We just learned that Aunt Adele, my mom's sister, also is showing signs of memory problems and possible Alzheimer's. It makes me wonder if my mom will get the disease, and if I'll get it someday, too.

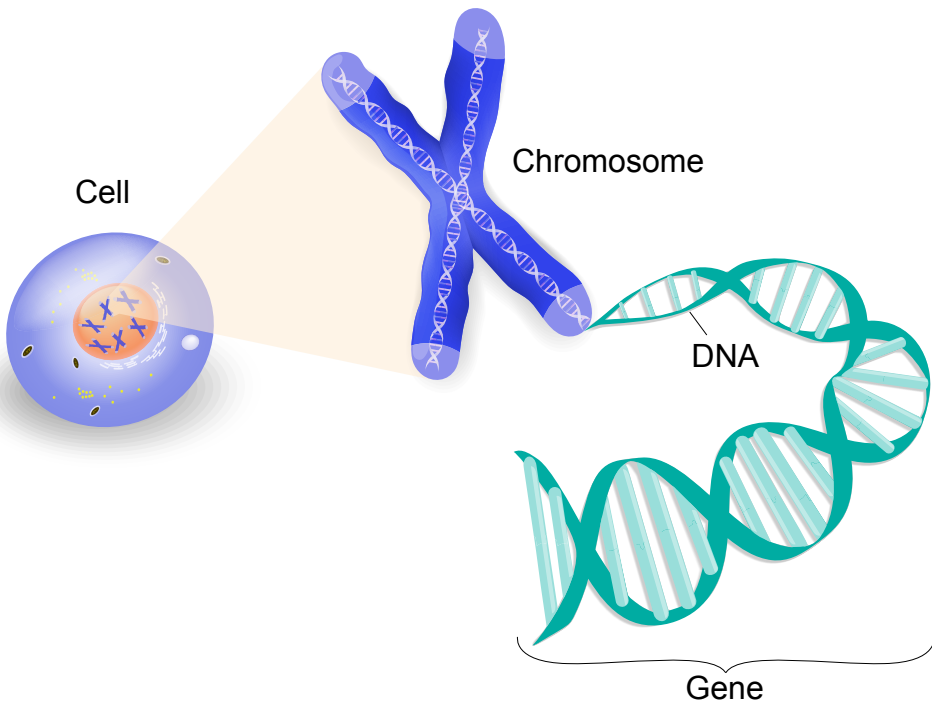
I decided to ask my doctor about my chance of getting Alzheimer's. He said he can't tell for sure who will get the disease but suggested some steps to stay healthy overall. Two steps I can take now are to eat right and exercise often.

# What are genes?

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**Genes** are found in every cell in every person's body (except red blood cells). They are passed down from a person's birth parents. They carry information that defines traits such as eye color and height.

Genes also play a role in keeping the body's cells healthy. Problems with genes—even small changes to a gene—can cause diseases like Alzheimer's disease.



Each human cell contains the instructions a cell needs to do its job. These instructions are made up of DNA, which is packed tightly into structures called chromosomes. Each chromosome has thousands of segments called genes. Parents pass down genes to their children.

# Do genes cause Alzheimer's disease?

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Alzheimer's is a complex disease. Doctors and scientists don't know yet exactly what causes it. But we do know that a person's genes can affect how likely they are to develop the disease. Having certain genes is a **risk factor** for Alzheimer's.

A risk factor is something that increases the chance of getting a disease. For example, smoking is a risk factor for cancer. High blood pressure is a risk factor for stroke.

Risk factors can include:

- genes passed down from a parent to a child
- a person's health habits, like eating unhealthy food or being inactive
- something in a person's surroundings, like in the air or water

Genetic risk factors are changes or differences in genes that can influence the chance of getting a disease. These risk factors are the reason some diseases run in families.

There are two types of Alzheimer's disease—late-onset and early-onset. They have different genetic risk factors.

## Late-onset Alzheimer's

Most people with Alzheimer's first show signs of the disease when they are in their mid-60s or later. The risk for late-onset Alzheimer's increases as a person gets older.

The causes of late-onset Alzheimer's are not fully known. They likely involve a mix of genes, lifestyle, and environment.

A gene called APOE (pronounced **ay-po-ee**) is often involved in Alzheimer's. Genes can have multiple forms. One form of APOE, called APOE  $\epsilon 4$  (pronounced **ay-po ee-for**), increases the risk for late-onset Alzheimer's. But, not everyone with APOE  $\epsilon 4$  will develop Alzheimer's. Also, people without this gene form can still develop the disease.



The causes of late-onset Alzheimer's likely involve genes, lifestyle, and environment.

# Early-onset Alzheimer’s

Early-onset Alzheimer’s is another type of the disease. People with this type start to show signs between age 30 and age 60. It is very rare.

Most people with early-onset Alzheimer’s have **familial Alzheimer’s disease**, or FAD. Some types of FAD are caused by a permanent change in one or more genes. The genetic change is passed down from a parent to a child.

Some people with early-onset Alzheimer’s do not have FAD. The reason they get the disease is not known.

Some differences between late-onset and early-onset Alzheimer’s disease	
Late-onset Alzheimer’s	Early-onset Alzheimer’s
Signs first appear in the mid-60s	Signs first appear between age 30 and age 60
Most common type	Very rare
May involve a gene called APOE ε4	Usually caused by gene changes passed down from parent to child

## Down syndrome and Alzheimer's disease

Many, but not all, people with Down syndrome develop Alzheimer's disease as they get older. People with Down syndrome are born with an extra copy of chromosome 21. This chromosome carries a gene that increases the risk of Alzheimer's. This type of Alzheimer's is not passed down from a parent to a child.

Learn more about Alzheimer's disease in people with Down syndrome at [www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome](http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-people-down-syndrome).



Many people with Down syndrome develop Alzheimer's disease as they get older.

# Sharon's story



I forgot to pay the rent for 2 months and recently lost my glasses. Sometimes, I can't come up with the right word when talking with others. I could tell my husband was starting to worry, and so was I.

I decided it was time to see my doctor. Some of my relatives have had Alzheimer's disease. My father started having memory problems when he was in his 60s. I'm in my 60s now.

The doctor asked me about my health and my family's health history. He said that many things, like depression or a bad reaction to medicine, can cause memory problems. He ordered some tests to help rule out Alzheimer's disease.

# If someone in my family has had Alzheimer's, will I have it, too?

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Many people worry about developing Alzheimer's disease, especially if a family member has had it.

Having a family history of the disease does not mean for sure that you'll have it, too. But, it may mean you are more likely to develop it.

## Late-onset Alzheimer's

No one can yet predict if you will develop late-onset Alzheimer's, even if it runs in your family. Late-onset Alzheimer's disease has been linked to APOE  $\epsilon$ 4. But, having this gene form does not always mean a person will develop the disease.

## Early-onset Alzheimer's

Familial Alzheimer's disease, or FAD—the most common type of early-onset Alzheimer's—is inherited. If a parent has a gene for FAD, there is a 50/50 chance that a child will inherit the gene. If the gene is passed down, the child will usually—but not always—have FAD. Doctors and scientists don't yet know if other types of early-onset Alzheimer's can be passed down.

# How can I know if I'm at increased risk for Alzheimer's disease?

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Families have many things in common, including their genes, environment, and lifestyle. Together, these things may offer clues to diseases, like Alzheimer's, that can run in a family.

## Late-onset Alzheimer's

There is no test yet to predict if someone will get late-onset Alzheimer's. If you are worried about changes in your memory or other problems with your thinking, talk with your doctor. Let him or her know if one or more close relatives has had the disease. Your doctor can suggest ways to stay healthy and watch for changes in your memory and thinking.

## Early-onset Alzheimer's

There is a test to learn if you have the gene changes that cause familial Alzheimer's disease, or FAD.

If you have a family history of FAD, talk with your doctor about getting tested. It's your choice to get tested or not.

Your doctor may suggest meeting first with a genetic counselor. This type of counselor helps people learn the risk of getting genetic conditions. They also help people make decisions about testing and what comes next.



## Create a family health history

A family health history can help you and your doctor know if Alzheimer's disease runs in your family. It lists health facts about a person and close relatives. It is a written record of:

- a family's health conditions
- lifestyle habits like smoking and exercise
- where and how family members grew up

Your family health history can show patterns of disease and risk factors. Try to include health facts about three generations—grandparents, parents, and children.

To learn how to create a family health history, visit NIH Senior Health at **[www.nihseniorhealth.gov/creatingafamilyhealthhistory](http://www.nihseniorhealth.gov/creatingafamilyhealthhistory)**.

# What can I do if I'm at increased risk for Alzheimer's disease?

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No medicine or other treatment is currently known to prevent or delay Alzheimer's disease. But, you can take steps to keep your brain and body as healthy as possible.

These steps include:

- ☐ Exercise regularly.
- ☐ Eat a healthy diet that is rich in fruits and vegetables.
- ☐ Spend time with family and friends.
- ☐ Keep your mind active.
- ☐ Control type 2 diabetes.
- ☐ Keep blood pressure and cholesterol at healthy levels.
- ☐ Maintain a healthy weight.
- ☐ Stop smoking.
- ☐ Get help for depression.
- ☐ Avoid drinking a lot of alcohol.
- ☐ Get plenty of sleep.

Talk with your doctor if you or someone close to you sees changes in your memory or thinking.



## Learn about clinical trials and studies

Joining a **clinical trial** or other research study is a way to help fight Alzheimer's disease. Some studies need people with a family history of Alzheimer's, and some seek families with early-onset Alzheimer's, or FAD. Other studies need healthy people with no history of the disease.

To find out more about clinical trials and studies:

- Call the Alzheimer's Disease Education and Referral (ADEAR) Center at **1-800-438-4380**. It's a free call.
- Visit the ADEAR Center website at **[www.nia.nih.gov/alzheimers/volunteer](http://www.nia.nih.gov/alzheimers/volunteer)**.
- Contact an Alzheimer's Disease Research Center. All Centers are listed at **[www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers](http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers)**.
- See "NIH Clinical Research Trials and You" at **[www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)**.

# Althea's story



My dad and his brother found out in their 70s that they had Alzheimer's. It seems to run in our family.

My dad's doctor suggested he join a clinical trial to test a new medicine. My dad agreed to join the trial. He wants to help find answers so others won't have to suffer from this disease in the future.

I was inspired to volunteer for research, too. I signed up for the Alzheimer's Prevention Registry, GeneMatch, and the Brain Health Registry. That way, I can be called on to take part in future studies. I want to do everything I can to help fight this disease.

# What do I need to know?

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- Genes are passed down from a person's birth parents. They carry information that determines a person's traits. They also play a role in keeping a body's cells healthy.
- Small changes or differences in a gene can lead to some diseases, such as Alzheimer's.
- A family history of Alzheimer's may mean a person is more likely to develop the disease. But, it does not mean he or she will get Alzheimer's for sure.
- People can take steps to keep their brains and bodies as healthy as possible.
- Joining a clinical trial or signing up for a registry is a way to help fight Alzheimer's disease.

**Talk with your doctor if you or someone close to you has changes in memory or thinking.** Your doctor can help find out what might be causing the problems. Many things that cause memory or thinking problems can be treated.



# Where can I get more information?

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Contact the following groups to learn more about Alzheimer's disease. They can give you information about Alzheimer's disease, support groups, and services. They can also help you find research centers and clinical trials and studies.

## Alzheimer's Disease Education and Referral (ADEAR) Center

Phone: 1-800-438-4380

Email: [adear@nia.nih.gov](mailto:adear@nia.nih.gov)

Website: [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)

The ADEAR Center provides information on:

- diagnosing Alzheimer's disease
- treating Alzheimer's symptoms
- caring for the person with the disease
- meeting the needs of caregivers
- finding long-term care for the person with Alzheimer's
- taking part in Alzheimer's disease research

ADEAR staff can refer you to local and national resources. The Center is a service of the National Institute on Aging, part of the Federal Government's National Institutes of Health (NIH).

## **Alzheimer's Association**

Phone: **1-800-272-3900**

Email: **info@alz.org**

Website: **www.alz.org**

The Alzheimer's Association is a nonprofit organization offering information and support services to people with Alzheimer's disease and their caregivers and families. The Alzheimer's Association also sponsors research. Call or visit its website to find out where to get help in your area. You can also sign up with TrialMatch to get information on research studies that might be right for you.

## **Alzheimer's Foundation of America**

Phone: **1-866-232-8484**

Email: **info@alzfdn.org**

Website: **www.alzfdn.org**

This foundation serves people with dementia and their caregivers and families. Services include a toll-free hotline, publications, and online resources.

## **NIH Senior Health**

Website: **www.nihseniorhealth.gov**

This senior-friendly website from the National Institute on Aging and the National Library of Medicine at NIH has health and wellness information for older adults. Topics include Alzheimer's disease and how to create a family health history.

# Alzheimer's Research Resources

## Alzheimer's Prevention Registry

Phone: 1-888-786-7259

Email: [info@endALZnow.org](mailto:info@endALZnow.org)

Website: [www.endalznow.org](http://www.endalznow.org)

The Alzheimer's Prevention Registry unites researchers with people interested in taking part in Alzheimer's studies.

## Brain Health Registry

Email: [info@brainhealthregistry.org](mailto:info@brainhealthregistry.org)

Website: [www.brainhealthregistry.org](http://www.brainhealthregistry.org)

This registry includes people age 18 and older who are interested in promoting healthy brain function through prevention of brain diseases, disorders, and injuries.

## Dominantly Inherited Alzheimer Network (DIAN)

Phone: 1-844-342-6397

Website: [www.dian-info.org](http://www.dian-info.org)

This international partnership seeks adult volunteers for research to understand a rare form of Alzheimer's disease caused by a specific gene mutation.

## GeneMatch

Phone: 1-888-786-7259

Email: [info@endALZnow.org](mailto:info@endALZnow.org)

Website: [www.endalznow.org/genematch](http://www.endalznow.org/genematch)

Part of the Alzheimer's Prevention Registry, GeneMatch identifies healthy volunteers age 55 to 75 who want to take part in Alzheimer's research based in part on their genetic background.

# Words to know

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## Alzheimer's disease

(pronounced **Allz**-high-merz duh-**zeez**)

A disease that damages communication among brain cells and causes nerve cells in the brain to die. These changes make it hard for a person to remember things, think clearly, and use good judgment. The symptoms begin slowly and get worse over time.

## Familial Alzheimer's disease (FAD)

(pronounced fuh-**mil**-ee-ul **Allz**-high-merz duh-**zeez**)

A type of early-onset Alzheimer's disease. It is caused by a permanent change in one or more genes passed down from a parent to a child.

## Clinical trial

(pronounced **klin**-uh-kuhl **try**-uhl)

A research study to find out if a new treatment is safe and effective. Healthy people and people with Alzheimer's disease can choose to take part in clinical trials.

## Genes

(pronounced **jeenz**)

Structures in a body's cells that are passed down (inherited) from a person's birth parents. They carry information that determines a person's traits and keep the body's cells healthy.

## Risk factor

(pronounced risk **fak**-tur)

Anything that increases the chance of developing a disease. Risk factors can be related to a person's genes, lifestyle, and environment. A genetic risk factor is a change or difference in a gene that raises a person's risk of getting a disease.



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