

## Additional Resources

### Screening Tool - NTG-EDSD

Get the tool and learn how to use it.  
[the-ntg.org/ntg-edsd](https://the-ntg.org/ntg-edsd)

### Adult Down Syndrome Center

Filter by “Alzheimer’s and Dementia.”  
[adscresources.advocatehealth.com](https://adscresources.advocatehealth.com)

### NTG Publications Library

Filter by “Dementia Care.”  
[the-ntg.org/publications-1](https://the-ntg.org/publications-1)

### National Down Syndrome Society

[ndss.org/resources/alzheimers](https://ndss.org/resources/alzheimers)

### Project ECHO (Clinicians Only)

Discuss your case with expert providers.  
[dsmig-usa.org/project-echo](https://dsmig-usa.org/project-echo)

### IDD-TRANSFORM

Get more information about these questions and access additional resources.  
[med.stanford.edu/idd-transform/resources.html](https://med.stanford.edu/idd-transform/resources.html)

Scan to learn  
more about  
Down syndrome  
& Alzheimer’s.



People with Down syndrome can develop Alzheimer’s earlier than the general population, but rarely before age 40.



It’s estimated that more than 50% of people with Down syndrome will develop Alzheimer’s disease by the age of 60.



Experts recommend baseline screenings starting around age 35 so that any changes in cognition or abilities can be monitored.



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# Understanding Down Syndrome & Alzheimer’s: A Guide for Caregivers and Clinicians

# Caring for Loved Ones with Down Syndrome & Alzheimer's

## What is Alzheimer's disease?

Alzheimer's is a brain disease that leads to dementia and impacts a person's memory, thinking skills, and ability to do simple tasks.

## What are the symptoms of Alzheimer's in people with Down syndrome?

- Behavioral changes
- Decline in abilities
- Difficulty walking
- Memory loss and confusion
- Difficulty with communication
- Changes in sleep patterns
- Change in body functions (e.g., incontinence and difficulty swallowing)
- Onset of seizures

## What is the connection between Alzheimer's and Down syndrome?

People with Down syndrome develop Alzheimer's more often and at earlier ages than the general population.

## How can I be alert to Alzheimer's?

When the person is in their mid-30's, screen them for any unusual changes using a free tool called the NTG-EDSD. Fill it out yearly and share it with your doctor. Use it to track changes, which could be symptoms of Alzheimer's but may be related to some other treatable condition.

## How is Alzheimer's diagnosed?

If screenings show changes in your loved one, your doctor will start by ruling out other conditions. Then they may refer you to a specialist (e.g, neurologist, geriatrician) for additional testing and an official diagnosis.

## What treatments exist for Alzheimer's?

Currently, there is no cure. There are medications that may manage some behavioral symptoms and others that may treat the disease while it's still mild. There may be options to enroll in clinical trials. Ask your doctor for more information.

## What if my doctor doesn't understand the risk of Alzheimer's for people with Down Syndrome?

Not all doctors receive special training in this area, so show them this brochure to help guide your next discussion.

## What should I do once we've received a diagnosis for Alzheimer's?

Alzheimer's will progress, so you'll need a plan to move forward. You may consider seeking professional help to assist with legal, financial, and advanced care planning. You may also benefit from joining a support group as you navigate this new reality.

More information is on the [IDD-TRANSFORM website](#). **Scan the QR code on the reverse of this page to learn more.**

# Addressing Alzheimer's Disease in Patients with Down Syndrome

## Advise caregivers to begin screening loved ones who are in their mid-30's.

Not all screening tools are appropriate for people with Down syndrome. Ask them to use the NTG-EDSD annually, keep records of the results, and bring them to wellness visits.

## Track notable changes or concerns.

New or worsening symptoms may be unrelated to Alzheimer's, or they may reflect disease progression.

## Rule out other conditions.

Cognitive decline occurs for reasons other than dementia (e.g., depression, sleep apnea, hypothyroidism). Conduct needed evaluations and make referrals to pursue a differential diagnosis.

## Consult additional clinician resources.

Read evaluation and management guidelines. Attend a Project ECHO session to seek expert input about the care of people with Down syndrome. Scan the QR code on the reverse of this page for more information.

## Remember to be kind.

This is an extremely sensitive topic for your patients and their caregivers.