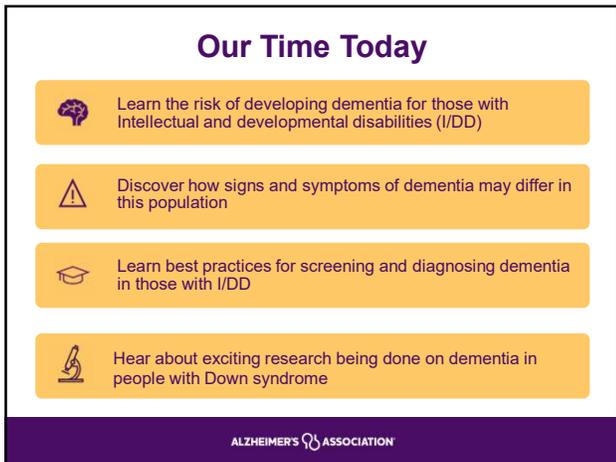
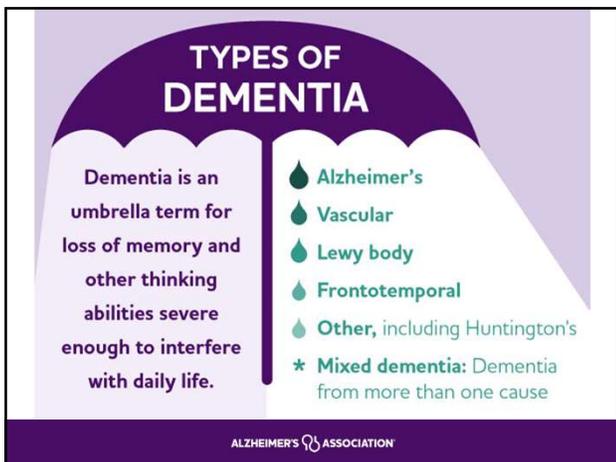


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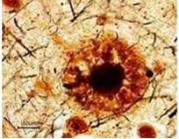
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3

The Hallmarks of Alzheimer's Disease

1 Plaques



Made up of beta amyloid

2 Tangles



Made up of Tau

3 Brain Cell Death



Healthy Brain Advanced Alzheimer's

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Alzheimer's Disease is a Continuum

Dementia due to Alzheimer's Disease

Asymptomatic

MCI* due to Alzheimer's Disease

Mild

Moderate

Severe

No symptoms but biological changes may be occurring in the brain **up to 20 years** before symptoms start

Symptoms of cognitive decline appear

Symptoms interfere with some daily activities

Symptoms interfere with many daily activities

Symptoms interfere with most/all daily activities

MCI = Mild Cognitive Impairment is an early stage of memory loss or other cognitive ability loss that **may** develop into dementia

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Intellectual/Developmental Disability



an umbrella term for differences usually present at birth and that uniquely affect the trajectory of the individual's physical intellectual and/or emotional development.

Types of I/DDs

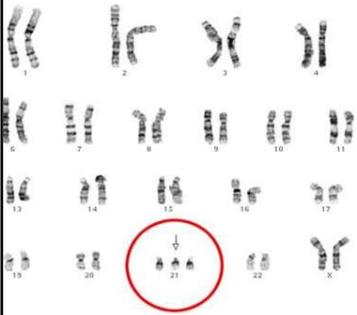
- Autism
- Down Syndrome
- Fetal Alcohol Syndrome
- Cerebral Palsy
- Fragile X

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What is Down Syndrome?

The most common genetic developmental disability

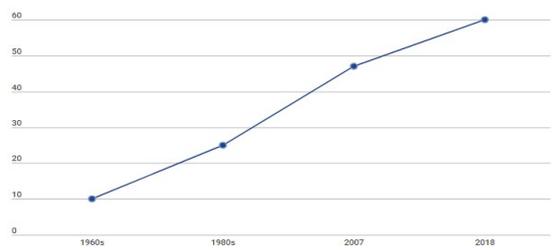


Approximately 400,000-600,000 people in the US are living with Down syndrome

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Life Expectancy for People with Down Syndrome



Source: Centers for Disease Control and Prevention and Global Down Syndrome Foundation
Graphic by Amanda Fahey and Halley Mensik/Cronkite News

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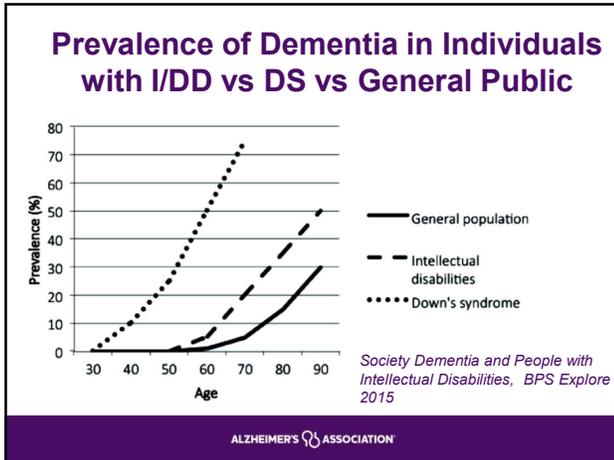
Aging in DS

- Premature aging
- Diagnostic Overshadowing
- Aging parents did not expect children with DS to live this long
- Siblings are the triple decker sandwich generation care givers



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Why would people with I/DD have higher risk for dementia?

<p>Higher rates of:</p> <ul style="list-style-type: none"> • Heart disease • Diabetes • Seizures • Depression/anxiety • Other chronic medical conditions • Anticholinergic medication use 	<p>Lower rates of:</p> <ul style="list-style-type: none"> • Baseline cognitive reserve • Educational attainment • Activity level
---	---

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Why do people with DS have higher risk for dementia?

<ul style="list-style-type: none"> • 21st chromosome is where amyloid precursor protein, the protein that clumps together to form the plaques of Alzheimer's disease, are made. 	<ul style="list-style-type: none"> • By age 40, nearly all people with Down syndrome have the brain pathology of Alzheimer's disease
--	---

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Rates of Dementia

General Population

Age	Percentage
40+	
65+	11%
85+	33%

Down Syndrome

Age	Percentage
By age 40	9%
By age 50	33%
60+	50%+
80+	

https://www.alz.org/documents_custom/2024-facts-and-figures.pdf

Ances, 2025 with data from the ABC- DS

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Signs of Dementia in People with Down Syndrome

- Social withdrawal/apathy
- Disorientation
- Loss of daily living skills
- Changes in personality
- Loss of speech
- Aggression
- Change in sleep patterns
- Changes in self-talk, adherence to routines
- Incontinence
- Unsteady gait
- Major weight change
- Forgetfulness
- **New-onset seizures**

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A Conceptualization



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Moving Backward in Time here



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Screening for Dementia

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What is a Screening?

- An instrument that permits the recording of select data that is associated with a condition or disease.

- **A positive screening is not a diagnosis, it simply tells us if more investigation is needed.**

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Why Screen for Dementia?

- Provides medical personnel organized information regarding changes
 - Some treatable/reversible conditions can mimic dementia, so noting changes early can help catch and treat these conditions.
- Can lead to earlier referral for and obtainment of a diagnosis
 - Can lead to more/different resources and supports
 - Helps caregivers know how to properly respond to behavior changes and plan for the future

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When to Screen for Dementia?

For people with Down syndrome:

For people with other I/DDs



Or when changes are first noticed

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Early Detection Screen for Dementia

- Developed by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
- Tool & manual available online in multiple languages at the-ntg.org



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NTG-EDSD: 4 Key Sections

- Demographics
- General ratings of health, mental health, and life stressors
- Domains of Possible Change
 - ADLs
 - Language and Communication
 - Sleep-Wake Change Patterns
 - Ambulation
 - Memory
 - Behavior and Affect
- Chronic Health Conditions

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Domains of Possible Change

NTG-EDSD - page 3

[Check column option as appropriate]

	Always been the same	Always but worse	New symptoms in past year	New or worse
Activities of Daily Living				
1. Dressing (e.g., putting on clothes)				
2. Eating (e.g., using knife and fork)				
3. Walking				
4. Bathing (e.g., showering, washing)				
5. Transferring (e.g., getting in and out of bed)				
6. Driving a car				
7. Shopping for groceries				
8. Managing finances (e.g., paying bills)				
9. Managing medications (e.g., taking pills)				
10. Managing household tasks (e.g., cleaning, laundry)				
11. Managing transportation (e.g., driving, walking)				
12. Managing personal care (e.g., grooming, dressing)				
13. Managing social activities (e.g., visiting friends, going to church)				
14. Managing other activities (e.g., hobbies, work)				
Language & Communication				
15. Understanding spoken language				
16. Understanding written language				
17. Expressing spoken language				
18. Expressing written language				
19. Understanding and using numbers				
20. Understanding and using words				
21. Understanding and using sentences				
22. Understanding and using paragraphs				
23. Understanding and using letters				
24. Understanding and using symbols				
25. Understanding and using colors				
26. Understanding and using shapes				
27. Understanding and using sizes				
28. Understanding and using weights				
29. Understanding and using lengths				
30. Understanding and using temperatures				
31. Understanding and using directions				
32. Understanding and using time				
33. Understanding and using dates				
34. Understanding and using months				
35. Understanding and using years				
36. Understanding and using seasons				
37. Understanding and using days of the week				
38. Understanding and using hours of the day				
39. Understanding and using minutes				
40. Understanding and using seconds				
41. Understanding and using fractions				
42. Understanding and using decimals				
43. Understanding and using percentages				
44. Understanding and using ratios				
45. Understanding and using proportions				
46. Understanding and using equations				
47. Understanding and using inequalities				
48. Understanding and using functions				
49. Understanding and using graphs				
50. Understanding and using tables				
51. Understanding and using charts				
52. Understanding and using diagrams				
53. Understanding and using maps				
54. Understanding and using globes				
55. Understanding and using compasses				
56. Understanding and using rulers				
57. Understanding and using protractors				
58. Understanding and using calculators				
59. Understanding and using computers				
60. Understanding and using smartphones				
61. Understanding and using tablets				
62. Understanding and using televisions				
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65. Understanding and using video cameras				
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71. Understanding and using smartwatches				
72. Understanding and using fitness trackers				
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Advantages of Using the NTG-EDSD

- Can be completed by anyone
- Establishes baseline
- Easily reviewed by a clinician



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An Alternate Way to Track Subjective Complaints

- Videotaping an activity or skill yearly starting at age 35 for DS or age 50 for other DDs and repeated annually to monitor for change in function.
- If a change is noticed, videotape the activity every 6 months.

*Note: this method works best if started **BEFORE** the individual begins to experience changes



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Advantages of Video Taping

Establishes a baseline

Individualized to the person

May be easier to see change then compared to now

Anyone can do it



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After Screening: Next Steps

Review the form and/or video recording. Are changes present?

No

Yes

Put in chart and re-screen annually

Make an appointment with an appropriate physician

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Please note...

A positive screening is not a diagnosis!!!

Not all memory and behavior changes are caused by dementia!

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Dementia Mimics

- Depression
- Delirium
- Medication side effects
- Thyroid problems
- Vitamin Deficiencies
- Urinary-tract infections
- Excessive alcohol consumption

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Diagnosing Dementia in People with I/DDs

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Diagnostic Difficulties

Limited incidence of self-reporting changes

Diagnostic overshadowing

Vulnerability to confounding diagnoses (delirium)

Pre-existing limitations in intellectual abilities

Lack of provider training

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Parts of a Comprehensive Diagnosis

🗨️ Subjective Complaints

🧠 Cognitive Testing

🩺 Medical history/screening

✅ Review of differential diagnoses

🏥 Medical Tests

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Subjective Complaints

- What the individual or others observe that make them concerned that dementia may be present

Multiple studies have confirmed that this is the single most important part of a diagnosis for someone with I/DD

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Cognitive Testing

There is no acceptable standard cognitive testing for dementia in this population.

However, inclusion of at least one standardized tool for cognitive assessment is recommended to track the individual's change over time.

Examples of things to track include:

- General orientation
- Reading/writing/math skills
- Naming abilities
- Basic motor skills
- General knowledge
- Language comprehension
- Recall of newly learned information.

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Medical History/Screening



- Physical and neurologic exam
- Other medical problems
- Current medications
- Diseases that run in the family
- Rule out differential diagnoses

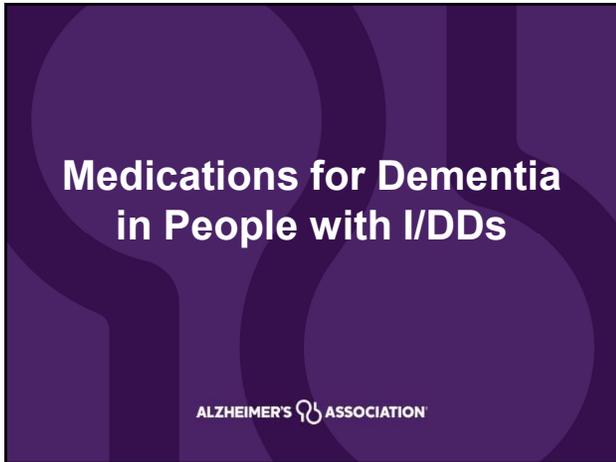
35

Other Testing

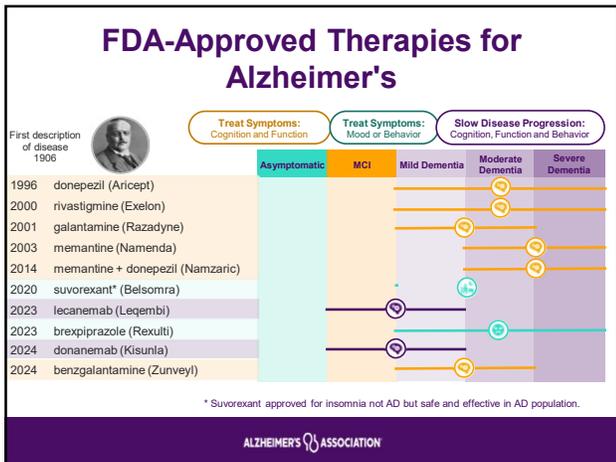
- Blood work
- MRI/CT
- Sleep Study
- Hearing Testing
- Vision Testing
- EEG



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Dementia Medications for People with I/DDs

- Studies for donepezil in adults with Down syndrome are mixed. Most studies have had a relatively small sample size and shown modest to no effect
- Study of memantine in adults with DS showed no improvement but also no increase in adverse side effects.
- Anti-amyloid medication prescribing guidelines specifically excluded people with DS as being eligible

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Ongoing Research on Dementia in People with I/DDs

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ABC-DS
Alzheimer Biomarker Consortium-Down Syndrome

Goal is to follow a cohort of adults with Down syndrome over time to identify early biomarkers that may herald the onset of Alzheimer's disease.

519 Participants enrolled and counting	265 Research project requests	946 Scans (381 MRIs; 277 Tau PETs; 288 Amyloid PETs)	133 Publications
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<https://abc-ds.org/>

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Trial-Ready Cohort-Down Syndrome (TRC-DS)

Bringing the latest discoveries in the Alzheimer's field to people with Down syndrome

TRC-DS
Trial-Ready Cohort-Down Syndrome

Routinely monitors study participants for any changes to their brain health or function over time through blood tests and brain imaging to eventually match them with applicable Alzheimer's disease clinical trials.

<https://www.trcds.org/>

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ALADDIN Study in DS-AD (Amyloid Lowering for Alzheimer's in Down syndrome with Donanemab Investigation)



- Phase 4 Trial starting summer 2025?:
- Can Donanemab reduce levels of amyloid in the brain?
 - Is safe and well-tolerated in participants with Down syndrome?

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ABATE Study

- Testing a vaccine that can potentially remove amyloid plaque build up in the brain before dementia is symptomatic in people with Down syndrome.
- Low and mid-dose cohorts showed no serious adverse events
- More results expected in 2026



<https://www.abate-study.com/>

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HERO Study



- Testing the safety and efficacy of a new medicine that is injected into the lower back, called ION269,
- Hopes to protect the brains of people with Down syndrome by telling them to produce less amyloid beta

<https://www.hero-study.com/>

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The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.



Our dual mission symbol represents the abstract forms of a human head and a beaker, emphasizing the people and the science behind our cause.

Care & Support Advocacy Education & Awareness Research Diversity, Equity & Inclusion

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Let's Stay in Touch!

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