

The Intersection of Down Syndrome and Alzheimer's Disease

Fact Sheet

The National Down Syndrome Society (NDSS) strongly supports the inclusion of the Down syndrome community in all efforts to address Alzheimer's disease. Below are key facts regarding the connection between Down syndrome and Alzheimer's disease.

- Down syndrome occurs when an individual has a **full or partial third copy of chromosome 21** instead of the typical two. Chromosome 21 carries the **amyloid precursor protein (APP) gene**, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's. Having an extra copy of chromosome 21 puts individuals with Down syndrome at a higher risk of developing Alzheimer's disease.
- Individuals with Down syndrome have a **higher than 90% lifetime risk** of developing Alzheimer's disease. Alzheimer's disease is the **number one cause of death** for individuals with Down syndrome.
- The average **age of onset** of the disease for individuals with Down syndrome is **58 years old**. For the general population, onset before age 65 is rare and suggests a form of early-onset Alzheimer's disease separate from typical Alzheimer's disease.
- The average **length of progression** from onset of symptoms to death for individuals with Down syndrome and Alzheimer's disease is **4.6 years**. For the general population, the average length of progression is 4 - 8 years with some individuals living as long as 20 years.
- **Diagnosis and treatment:**
 - Diagnostic criterion for diagnosing Alzheimer's disease often does not take into account the **unique traits and cognitive diversity** of individuals with intellectual and developmental disabilities, such as Down syndrome.
 - Individuals with Down syndrome have been historically **excluded from clinical trials and coverage** of new drugs and treatments.
- **Impact on caregiving:**
 - In contrast with the norm for the general population, individuals with Down syndrome and Alzheimer's disease are often cared for by their **aging parents**.
 - Aging caregivers may reach a point at which they can no longer provide this care, however, **institutional options are limited**. Many memory or long-term care centers will not accept individuals with Down syndrome due to the age of the individual and their dual diagnosis.
 - At times, siblings may step in to provide care but this often necessitates a move to a new state which can **impact vital government benefits** such as Medicaid and home and community-based services.

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