

## Frequently Asked Questions

### **Social Security Administration (SSA) decision to add early-onset Alzheimer's disease to Compassionate Allowance Initiative**

#### **What is the Compassionate Allowance Initiative?**

Under this initiative, the Social Security Administration (SSA) finds individuals with certain diseases/conditions eligible for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits by the nature of the disease. While applicants still have to meet other SSDI criteria and/or SSI criteria, when it comes to the disability criterion, they are considered eligible by virtue of the disease and fast-tracked for a favorable decision about their eligibility for SSDI and SSI benefits. The SSA added early-onset Alzheimer's disease to the Compassionate Allowance Initiative effective Feb. 27, 2010.

#### **What is Social Security Disability Insurance (SSDI)?**

Social Security disability benefits (SSDI) are paid to individuals who have worked for enough years and have a condition that is so severe that they are not able to work. Administered by the SSA, SSDI makes monthly payments to eligible disabled individuals and is a significant benefit for individuals with early-onset (younger-onset) Alzheimer's disease. In addition to a monthly payment, it serves as entry to Medicare benefits for those under the age of 65. While there is a two-year wait for Medicare benefits, this wait period begins when the SSDI application is submitted. Family members (e.g., spouses and minor children) may also be eligible for benefits based on the applicant's work record.

#### **What is Supplemental Security Income (SSI)?**

Supplemental Security Income benefits (SSI) are paid each month to individuals who are aged, blind or disabled and have limited income and resources (assets). The "disability" criteria for SSI are the same as for SSDI benefits. Unlike SSDI, eligibility for SSI is not based on prior work experience. In addition, in most states, individuals who receive SSI are also automatically eligible for Medicaid (medical assistance) benefits.

#### **Who does this change to the Compassionate Allowance Initiative affect?**

It only affects individuals with early-onset (younger-onset) Alzheimer's disease and related dementias; generally, those individuals who are diagnosed with Alzheimer's and are under the age of 65. It does not affect individuals who are currently receiving full Social Security retirement benefits.

#### **Why is this important to individuals with early-onset Alzheimer's disease and related dementias?**

Social Security disability benefits are very important to those with early-onset (younger-onset) Alzheimer's and related dementias because these individuals are often initially denied benefits — but usually win on appeal. Those affected by early-onset Alzheimer's are often simultaneously faced with the enormous challenges that the disease presents, while also undergoing a long disability decision process that is financially and emotionally draining. Adding Alzheimer's disease to the list of "Compassionate Allowance" conditions simplifies and streamlines the SSDI/SSI application process, so that applicants can receive SSDI/SSI benefits in an expedited manner.

When applying for SSDI and/or SSI, the applicant must submit objective medical records that confirm that the applicant has been diagnosed with early-onset Alzheimer's disease.

**Is there a difference between early-onset and younger-onset Alzheimer's disease?**

**What is early-onset Alzheimer's?**

No, there is not a difference and the terms are used interchangeably. The term younger-onset/early-onset refers to Alzheimer's that occurs in a person under age 65. Younger-onset individuals may be employed or have children still living at home. Issues facing families include ensuring financial security; obtaining benefits and helping children cope with the disease. People who have younger-onset dementia may be in any stage of dementia — early, middle or late. Experts estimate that some 200,000 people in their 30s, 40s and 50s have Alzheimer's disease or a related dementia.

**Are there any “related dementias” currently on the Compassionate Allowance list?**

Yes. In addition to early-onset (younger-onset) Alzheimer's disease, there are four “related dementias” on the Compassionate Allowance list: frontotemporal dementia (FTD) or Pick's disease, Creutzfeldt-Jakob disease, mixed dementia and primary progressive aphasia. Again, this initiative only applies to individuals who are not receiving full Social Security retirement benefits and have these specific “related dementias.”

**How do I apply for SSDI or SSI?**

To apply for SSDI and/or SSI benefits, you must submit an application and other documents to your local SSA office. The Alzheimer's Association has prepared a checklist to assist individuals with the application process. Depending on your situation, you may be eligible for both SSDI and SSI.

In addition, the SSA has a wealth of information on its disability programs at [www.socialsecurity.gov](http://www.socialsecurity.gov), including a disability planner available at <http://www.socialsecurity.gov/dibplan/>.

**Should I apply for SSDI if I am receiving early retirement benefits from Social Security?**

Yes, if you are receiving early retirement benefits, you should apply for SSDI because your benefits should increase and you may become eligible for Medicare before you turn 65.

Additional information about the Compassionate Allowances Initiative can be found at <http://www.ssa.gov/compassionateallowances/>

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

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