

Social Security Disability Insurance and young onset dementia: A guide for employers and employees



What is Social Security Disability Insurance?

Social Security Disability Insurance (SSDI) is a payroll tax-funded, federal insurance program managed by the Social Security Administration (SSA). SSDI provides a monthly benefit for people who have worked in the past and paid Social Security taxes. SSDI benefits are only granted after a determination process, whereby the applicant must prove that they are disabled.

Who is eligible for SSDI?

Employees who have worked in jobs covered by Social Security and have a medical condition that meets Social Security's definition of a disability are eligible for SSDI. An employee with young onset dementia will be considered disabled if the employee cannot perform at the same working capacity as the employee did before the illness, and Social Security decides that the employee cannot adjust to other work because of a medical condition(s). The employee's disability must also be expected to last for at least one year or to result in death.

How do I apply for Social Security Disability Insurance?

An employee with young onset dementia may apply for SSDI benefits on their own or may hire a disability or SSDI representative to assist them in applying for or appealing a claim. Most SSDI applicants – about 90 percent according to the SSA – have a disability representative for their appeal. Typically, there are two primary types of paid SSDI representatives. There are companies with trained specialists experienced in handling SSDI applications and appeals. There also are law firms that specialize in disability related cases.

Employees with young onset dementia can apply for Social Security Disability Insurance online through the Social Security Administration website. The website has a wealth of information about the subject and we encourage you to visit the site and familiarize yourself with the process. *(See helpful resources at the end of this document for links to specific organizations you may find useful)*

You can also call the Social Security Administration's toll-free number, 1-800-772-1213, to make an appointment to apply for benefits by telephone or in person. If you are deaf or hard of hearing, you can call the Social Security Administration TTY at 1-800-325-0778.

How long does it take to get Social Security Disability Insurance?

The Social Security Administration requires a five month waiting period before providing Social Security Disability Insurance benefits. The five month waiting period ensures that during the early months of disability, the Social Security Administration does not pay benefits to persons who do not have long-term disabilities. Therefore, Social Security disability benefits will be paid beginning with the sixth full month after the date that their disability began. This is only an estimate, in practice filings can take up to eight months to complete. The appeals process for denied filings can likewise take 90 days to well over a year to get a hearing, depending on caseloads and persons are not entitled to benefits for any month in the waiting period.

Several types of dementia, including those commonly experienced by employees with young onset dementia, qualify for Social Security Disability Insurance under Compassionate Allowance.

What is Compassionate Allowance and what conditions qualify for Compassionate Allowance?

Compassionate allowances allow Social Security to quickly target the most obviously disabled individuals for allowances based on objective medical information that can be quickly obtained (see below). To help ease the situation for those who are clearly disabled because of illness, the Social Security Administration (SSA) maintains a list of conditions and diseases that are assumed to be disabling conditions that meet Social Security's standards for disability. Called "compassionate allowances," these disabling or life-threatening conditions qualify a person for an automatic approval for disability benefits. The Compassionate Allowance initiative significantly speeds up the process so that people with these conditions can get the benefits they need as soon as possible, often within days of filing for disability benefits. The original list of 50 qualifying conditions was expanded in February, 2010 to include 38 others including young onset Alzheimer's disease.

What young onset dementia conditions qualify for Compassionate Allowance?

The following conditions are on the Social Security Administration list of conditions that qualify for Compassionate Allowance. Also included are the diagnostic tests required to prove the employee with young onset dementia has the specific condition:

Early-Onset Alzheimer's Disease (AD) is the diagnosis of AD for a person younger than age 65 years. AD is a degenerative, irreversible brain disease that usually affects older people and causes dementia characterized by the gradual loss of previously attained cognitive abilities, including memory, language, judgment, and ability to function. Physiological changes in the brain include the rampant growth of two abnormal structures, amyloid plaques and neurofibrillary tangles, which interrupt normal brain activity. The onset of AD is subtle; memory impairment is frequently its

earliest manifestation, quickly followed by learning and language impairments. Because people with early-onset AD are often in the work force it is not uncommon for the disease to first manifest as a decline or loss in their ability to perform work related activities. Depression is also a common early symptom.

Diagnostic testing:

The diagnosis of early-onset AD is based on the combination of clinical and family history; neurological, cognitive, or neuropsychological examination; and neuroimaging. Pertinent clinical information includes history of onset and description of cognitive and functional impairments at home and at work. Currently, there is no specific clinical or laboratory diagnostic test for early-onset (or late-onset) AD and at present, the diagnosis can only be confirmed by brain biopsy or postmortem examination of the brain. A decline in Mini-Mental Status Examination (MMSE) scores over time is a likely indicator of possible dementia. Neuroimaging, such as computerized tomography (CT) or magnetic resonance imaging (MRI) is useful to demonstrate changes in the brain and to exclude other causes of dementia.

Mixed Dementia is dementia caused by multiple etiologies including; Vascular dementia, Alzheimer's disease, Parkinson's dementia, Diffuse Lewy-body dementia, Frontotemporal dementia (Pick's disease), Huntington's dementia; Prion dementia; Progressive Supranuclear Palsy (PSP). Mixed dementias are conditions with more than one etiology for the dementia. The combination of the Vascular dementia and Alzheimer's disease is the most common form. Mixed dementias are characterized by progressive and persistent intellectual decline compromising at least two spheres of cognition (i.e. memory, language, orientation, attention, executive abilities, etc). These individuals may also have motor and gait impairment, affective disturbances and sleep disturbances.

Diagnostic tests may include:

The diagnoses of mixed dementias are based on a clinical history of cognitive decline, neurologic and cognitive/neuropsychologic examination, and neuroimaging. Pertinent clinical information includes history of onset and description of cognitive and functional impairments at home and at work. History of a previous stroke(s) adds to the likelihood of the diagnosis, but is not required. Currently, there is no specific clinical or laboratory test for the diagnosis of Alzheimer's disease and its diagnosis can only be confirmed by brain biopsy or postmortem examination of the brain. Neuroimaging, i.e. computerized tomography (CT) or magnetic resonance imaging (MRI) is useful to demonstrate vascular lesions such as infarcts and lacunes, and to exclude other causes of dementia, some of which may be treatable.

Primary Progressive Aphasia (PPA) is a type of dementia characterized by slow erosion of language (aphasia) over a two year period. It affects the language and semantic functioning (semantic dementia) and eventually progresses to amnesia. People with primary progressive aphasia may have trouble naming objects or may misuse word endings, verb tenses, conjunctions and pronouns. Primary progressive aphasia is a type of frontotemporal dementia, a group of related disorders in the frontal or temporal lobes of the brain. Most people with primary progressive aphasia maintain ability to take care of themselves, pursue hobbies, and, in some instances, remain employed.

Diagnostic tests may include:

- Clinical exam,
- Speech/language evaluation that examines word retrieval, sentence formulation, and auditory comprehension skills,

- MRI or CT scan of the brain demonstrating atrophy of the brain language areas or of the frontal and temporal lobes.

Frontotemporal Dementia (FTD), Pick's Disease-Type A, is a syndrome associated with shrinking of the frontal and temporal anterior lobes of the brain. The presence of abnormalities in the nerve cells of the brain, called Pick bodies, distinguishes frontal lobe dementia from other types of dementia. The symptoms associated with Frontotemporal Dementia express themselves either through changes in behavior or problems with language. People experiencing Pick's type symptoms associated with behavior will have the greatest challenges with employment. Pick's disease generally occurs between the ages of forty and sixty years of age.

Diagnostic tests may include:

- Physical exam, clinical assessment and blood tests
- Neurological exam that checks awareness and responsiveness, vital signs, reflexes, sensory responses and coordination
- Neuropsychological testing, which assesses memory, ability to reason and judge, problem-solving skills and language skills. Brain imagining, such as MRI and CT, may demonstrate shrinkage of the frontal and temporal lobes and also help exclude other causes of dementia such as strokes and brain tumors. PET and SPEC tomography testing may be used to evaluate brain activity.

Creutzfeldt-Jakob Disease (CJD) is a rare, rapidly progressive, fatal brain disorder primarily characterized by mental deterioration, although motor problems can be significant in many cases. CJD belongs to a group of human and animal diseases known as transmissible spongiform encephalopathies (TSE) or prion diseases. Typically, onset of symptoms occurs at about age 60 and runs a rapid course. There are four major categories of CJD: sporadic CJD, hereditary CJD, acquired or iatrogenic CJD and variant CJD. Sporadic CJD is the most common form of the disease and accounts for 85% of cases. The cause of sporadic CJD is unknown, but it is believed that a normal cellular protein undergoes a spontaneous change in conformation that results in the disease. Hereditary or familial CJD is a very uncommon disease and the consequence of a mutation in the gene that encodes the prior protein. About 5 to 10 percent of CJD cases are hereditary. Acquired or Iatrogenic CJD is also very rare accounting for less than 1 percent of cases and results from the accidental transmission during medical interventions. Variant CJD was first reported in 1996. It is believed to be the result of eating meat from cattle with bovine spongiform encephalopathy (mad cow disease).

Diagnostic testing:

The diagnosis of CJD is suspected when there are typical clinical symptoms such as rapidly progressing dementia with myoclonus (twitching). Currently, there is no single diagnostic test for CJD except for brain biopsy. The first concern is to rule out treatable forms of dementia such as encephalitis or chronic meningitis. Common investigations include:

- Electroencephalography,
- MRI of the brain,
- Cerebrospinal fluid analysis
- Tonsil biopsy is helpful in the diagnosis of variant CJD, but less so in other forms of the disease.

Helpful resources:

Social Security Administration: Link to online disability application

<http://www.socialsecurity.gov/applyfordisability/>

Disability Rights Wisconsin

www.disabilityrightswi.org

State Bar of Wisconsin

www.wisbar.org

Coalition of Wisconsin Aging Groups, Elder Law Section

www.cwag.org

The Alzheimer's & Dementia Alliance of Wisconsin

<http://www.alzwisc.org>

Your local Aging and Disability Resource Center

http://www.dhs.wisconsin.gov/lc/lc_adrc/

The Alzheimer's Association

<http://www.alz.org>

Employment Resources Inc

www.eri-wi.org

*For further information please contact the Alzheimer's & Dementia Alliance at 608-232-3400
or toll free at 888-308-6251*