

# How to File for Social Security Disability

## What you need to know

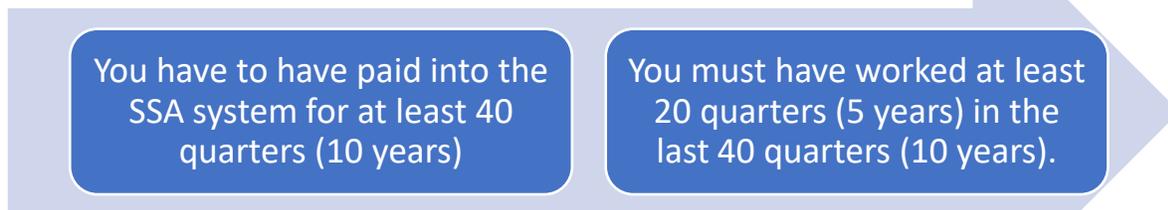
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As of 2012, Adult on-set Huntington's Disease (HD) and Juvenile Huntington's Disease (JHD) were both added to the Social Security Administration's Compassionate Allowance List (CAL). This means applications under the Social Security Disability Income (SSDI) or Supplemental Security Income (SSI) programs will be expedited for HD persons, however, don't apply too soon, you will need to ensure that there is enough medical evidence to meet the definition of disability under Social Security law.

### Ways to Apply:



### Eligibility:



### What you want to PROVE:

You have the disease by either medical & family history or genetic testing results, AND

Demonstrate how symptoms prevent you from working.  
*Symptoms can include movements, physical impairments/limitations, cognitive difficulties and behavioral & emotional symptoms.*

If you did not pay into the system for 40 quarters or have been self-employed or not working, you may be eligible for **Supplemental Security Income (SSI)**. Visit the **Social Security Website** for more information.



## What you will need for the application:

### Compassionate Allowance Listing Designation

When entering your disability state:

***“Huntington’s Disease with increasing limitations under DI 23022.923” OR “Juvenile Huntington’s Disease under DI 23022.923 or Early-Onset HD under DI 23022.923”***

When an application is flagged in the system as Compassionate Allowance, it should not ask lengthy questions about past employment history.

### Documentation

1. Medical
2. Employment
3. Personal and Family Observations

#### Medical Documentation

- Names, addresses and telephone numbers of doctors, hospitals, clinics, and institutions that treated you and dates of treatment.
- Medical records from General Practitioner/Primary Care Physician, Neurologist, Psychiatrist/Psychologist, Genetic Counselor, etc. that demonstrates that you have HD symptoms AND details what those symptoms are.
- Include a list of the medications you are taking

#### Employment Documentation

- Employment records that demonstrate a decline in performance or work place accommodations you had due to not meeting expectations. This can include: e-mails, formal disciplinary action or write ups.
- if only verbal meetings were held to discuss your work performance, you can include the date, time, staff/supervisors present and details of the discussion in your journal to submit with your application.
- work history over past 16 years: Company names, addresses and telephone numbers along with description of the kind of work you did

#### Personal and Family Documentation

Keep an “Activities of Daily Living” journal: describe how HD symptoms are preventing you from completing everyday tasks such as cooking, cleaning, paying bills, driving, managing medication, dressing, bathing, housekeeping, caring for children, etc.

- It may be best for FAMILY MEMBERS to keep the diary as they can often see subtle changes that may be happening.
- Keep the journal as matter of fact as possible and SUMMERIZE the symptoms/changes caused by HD.
- Submit the journal with your application.
- You will need to have your Social Security number for you, spouse and minor children for the application.



## Medical Disability Definition – as defined and evaluated by Social Security

***The inability to engage in any substantial gainful activity (SGA) because of medically determinable physical or mental impairment(s):***

That can be expected to result in death, OR

That has lasted or that we can expect to last for a continuous period of not less than 12 months.

**Medical Disability Evaluation Criteria:** The Social Security process for to determine disability involves 5 steps:

### Are you working?

If you are working and your Monthly INCOME cannot exceed the SGA level (around \$1200) you will likely not be considered disabled.

### Is your medical condition “severe”?

To qualify your impairment(s) must significantly limit your ability to do basic work activities (walking, sitting, seeing and remembering)

### Can you do any other type of work?

If unable to do your previous work SS evaluates your age, education, past work experience and transferable skills to determine if you can work in another type of job.

### Can you do the work you did previously?

SS is evaluating to determine if your impairment prevents you from performing the duties of your current/previous job.

### Is your medical condition in the list of disabling impairments?

HD is on the Compassionate Allowance List, see following page “Impairment Evaluation Criteria” for the specific details of what social security is looking for in the application.

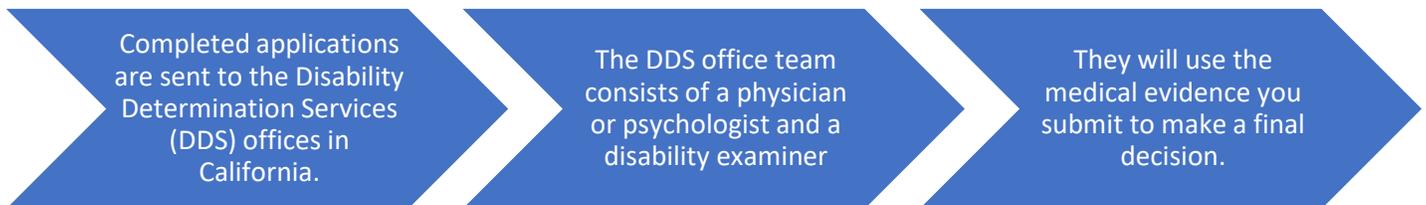


HD diagnosis is not enough to be considered disabled. Social Security is evaluating your functional ability as it relates to your ability to work and care for yourself.

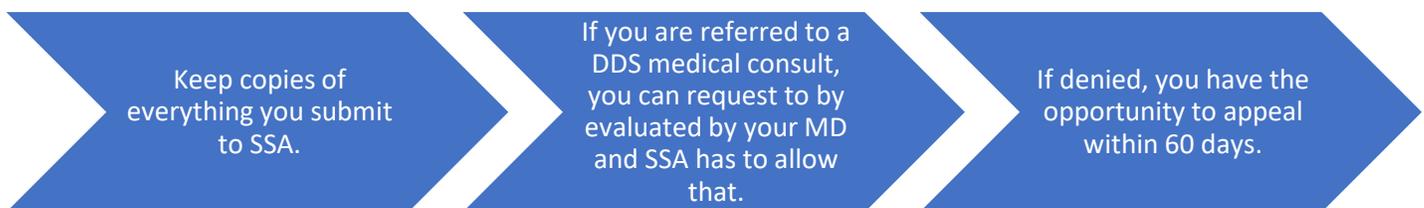
### Language Do's & Don'ts:

DO Say	DON'T SAY
<ul style="list-style-type: none"> <li>I am limited by balance from doing any work around dangerous machinery, etc</li> </ul>	<ul style="list-style-type: none"> <li>I can't work</li> </ul>
<ul style="list-style-type: none"> <li>I have troubles with fine motor making _____ difficult and unsafe.</li> </ul>	<ul style="list-style-type: none"> <li>I am totally disabled</li> </ul>
<ul style="list-style-type: none"> <li>As a result of HD symptoms I am experiencing impulsivity which is causing difficulties in getting along with co-workers and customers.</li> </ul>	<ul style="list-style-type: none"> <li>I should be awarded benefits</li> </ul>
<ul style="list-style-type: none"> <li>I am limited by cognitive decline and I am unable to learn new tasks and take on new responsibilities.</li> </ul>	<ul style="list-style-type: none"> <li><i>NONE of the "Don't Say" column tells the assessor what is happening with you and this information will cause the application to be denied.</i></li> </ul>

### Who decides if you are disabled?



### Submitting the Application and Approval/Denial:



### FOR MORE INFORMATION VISIT:

[HDSA.org](http://HDSA.org)

[Social Security Administration](#)

[Special Needs Alliance](#)

[Disability Rights California](#)



Evaluation Criteria from SSA please visit:

<https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>

Click on Sec 11.00, Neurological Disorders, and scroll down to 11.17

Excerpts from the Adult Listing, criteria for HD are outlined below



## Impairment Evaluation Criteria

Huntington's disease is on the Compassionate Allowance List and falls under the following section:

- Section 11.00 – Neurological Disorders
  - **11.17 Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration,**

When evaluating your disability claim, Social Security will be looking for evidence of the following impairment(s):

- Disorganization of motor function in two extremities (see 11.00D1), resulting in an extreme limitation (see 11.00D2) in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.
- OR
- Marked limitation (see 11.00G2) in physical functioning (see 11.00G3a), and in one of the following:
  1. Understanding, remembering, or applying information (see 11.00G3b(i)); or
  2. Interacting with others (see 11.00G3b(ii)); or
  3. Concentrating, persisting, or maintaining pace (see 11.00G3b(iii)); or
  4. Adapting or managing oneself (see 11.00G3b(iv)).



## Motor Functioning is defined as:

- What does SSA mean by disorganization of motor function? *From:*  
[https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11\\_17](https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11_17)
  - *Disorganization of motor function means interference, due to your neurological disorder, with movement of two extremities; i.e., the lower extremities, or upper extremities (including fingers, wrists, hands, arms, and shoulders). By two extremities we mean both lower extremities, and both upper extremities, or one upper extremity and one lower extremity. All listings in this body system include criteria for disorganization of motor function that results in an extreme limitation in your ability to:*
    1. *Stand up from a seated position; or*
    2. *Balance while standing or walking; or*
    3. *Use the upper extremities (including fingers, wrists, hands, arms, and shoulders).*
  - Need to demonstrate through your documentation the degree of interference with your ability to move and ambulate and/or interference with the use of fingers, hands and arms in your work environment and at home when taking care of yourself.



## Mental Functioning Changes is defined as:

How does SSA evaluate limitations in physical and mental functioning under these listings? Excerpts from: [https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11\\_17](https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11_17)

- *Marked Limitation in one of the four areas of mental functioning (see 11.00G3). The term "marked" does not require that you must be confined to bed, hospitalized, or in a nursing home.*
- *Marked limitation and physical functioning means that, due to the signs and symptoms of your neurological disorder, you are seriously limited in the ability to:*
  - *Independently initiate, sustain, and complete work-related physical activities.*
  - *you may have a marked limitation in your physical functioning when your neurological disease process causes persistent or intermittent symptoms that affect your abilities to independently initiate, sustain, and complete work-related activities, such as standing, balancing, walking, using both upper extremities for fine and gross movements, or results in limitations in using one upper and one lower extremity.*
  - *The persistent and intermittent symptoms must result in a serious limitation in your ability to do a task or activity on a sustained basis.*
  - *You need not be totally precluded from performing a function or activity to have a marked limitation, as long as the degree of limitation seriously limits your ability to independently initiate, sustain, and complete work-related physical activities.*
- *Marked limitation and mental functioning due to the signs and symptoms of your neurological disorder, you are seriously limited in the ability to function independently, appropriately, effectively, and on a sustained basis in work settings.*
  - *We do not define "marked" by a specific number of mental activities, such as: the number of activities that demonstrate your ability to understand, remember, and apply information; the number of tasks that demonstrate your ability to interact with others; a specific number of tasks that demonstrate you are able to concentrate, persist or maintain pace; or a specific number of tasks that demonstrate you are able to manage yourself.*
  - *You may have a marked limitation in your mental functioning when several activities or functions are impaired, or even when only one is impaired.*
  - *You need not be totally precluded from performing an activity to have a marked limitation, as long as the degree of limitation seriously limits your ability to function independently, appropriately, and effectively on a sustained basis, and complete work-related mental activities.*

- **Areas of physical and mental functioning.**
  - **Physical functioning.** *Examples of this criterion include specific motor abilities, such as independently initiating, sustaining, and completing the following activities: standing up from a seated position, balancing while standing or walking, or using both your upper extremities for fine and gross movements. Physical functioning may also include functions of the body that support motor abilities, such as the abilities to see, breathe, and swallow.*
  - **Mental functioning.**
    - **Understanding, remembering, or applying information.** *This area of mental functioning refers to the abilities to learn, recall, and use information to perform work activities. Examples include: understanding and learning terms, instructions, procedures; following one- or two-step oral instructions to carry out a task; describing work activity to someone else; asking and answering questions and providing explanations; recognizing a mistake and correcting it; identifying and solving problems; sequencing multi-step activities; and using reason and judgment to make work-related decisions. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.*
    - **Interacting with others.** *This area of mental functioning refers to the abilities to relate to and work with supervisors, co-workers, and the public. Examples include: cooperating with others; asking for help when needed; handling conflicts with others; stating your own point of view; initiating or sustaining conversation; understanding and responding to social cues (physical, verbal, emotional); responding to requests, suggestions, criticism, correction, and challenges; and keeping social interactions free of excessive irritability, sensitivity, argumentativeness, or suspiciousness. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.*
    - **Concentrating, persisting, or maintaining pace.** *This area of mental functioning refers to the abilities to focus attention on work activities and to stay on-task at a sustained rate. Examples include: initiating and performing a task that you understand and know how to do; working at an appropriate and consistent pace; completing tasks in a timely manner; ignoring or avoiding distractions while working; changing activities or work settings without being disruptive; working close to or with others without interrupting or distracting them; sustaining an ordinary routine and regular attendance at work; and working a full day without needing more than the allotted number or length of rest periods during the day. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.*

- *Adapting or managing oneself. This area of mental functioning refers to the abilities to regulate emotions, control behavior, and maintain well-being in a work setting. Examples include: responding to demands; adapting to changes; managing your psychologically based symptoms; distinguishing between acceptable and unacceptable work performance; setting realistic goals; making plans for yourself independently of others; maintaining personal hygiene and attire appropriate to a work setting; and being aware of normal hazards and taking appropriate precautions. These examples illustrate the nature of this area of mental functioning. We do not require documentation of all of the examples.*
- Make sure to demonstrate the change in mental functioning in the above areas with specific examples/incidents and/or any written documentation from an employer or medical professional that illustrates the decline in mental or physical functioning and the impact it has on the person's ability to meet employer expectations and perform the duties of their job.



Help and support is available check out:

[HDSA.org](https://www.hdsa.org)

[Social Security Administration](https://www.ssa.gov)

[Special Needs Alliance](https://www.specialneedsalliance.org)

[Disability Rights California](https://www.disabilityrightsca.org)

**Information shared in this document is from [www.ssa.gov](https://www.ssa.gov): Social Security Red Book and Social Security Blue Book, List of Impairments, as well as disability tips shared by Allison Bartlett, Esq, Manager of Disability Programs @ HDSA.**