



How to File for Social Security Disability

What you need to know

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Information shared in this document is from the Social Security Disability Evaluation and Social Security Red Book. In addition specific tips and language suggestions were gathered from 2014 HDSA National Convention Workshop: Assessing Disability -- "When It's time to apply for Social Security Disability Insurance", by Art Spencer.

Ways to File:

- On-line at www.ssa.gov
- Telephone at 1-800-772-1213
- In person at your local Social Security Office (see website for closest office to you)

The Process of Applying for Benefits

- 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.
- 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.

Eligibility

- You have to have paid into the SSA system for at least 40 quarters (10 years)
- You must have worked at least 20 quarters (5 years) in the last 40 quarters (10 years).
- 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), please visit www.ssa.gov or your local Social Security Branch for more information about the SSI program.

What you have to PROVE:

- You need to prove that you have the disease by either medical & family history or genetic testing results, AND
- Demonstrate how the HD symptoms prohibit your ability to work and meet employer expectations.
 - Symptoms can include: movement disorders, cognitive difficulties and behavioral and emotional symptoms.

Compassionate Allowance Listing Designation:

- To ensure your application is flagged as Compassionate Allowance you must use the “right” words:
 - When entering your disability state:
 - “Huntington’s Disease with increasing limitations”
 - “Juvenile Huntington’s Disease or Early-Onset HD”
- When an application is flagged in the system as Compassionate Allowance, it should not ask lengthy questions about past employment history.

Documentation needed to Complete Application and PROVE disability:**Medical Documentation**

- Names, addresses and telephone numbers of doctors, hospitals, clinics, and institutions that treated you and dates of treatment.
- Any medical documentation from your General Practitioner/Primary Care Physician, Neurologist, Psychiatrist/Psychologist, Genetic Counselor and etc. that demonstrates that you have HD symptoms AND details what those symptoms are.
- Ask your MD to discuss in the medical notes how the symptoms are preventing you from working and/or completing activities of daily living.
- Names and prescribed dosage of all medications you are taking
 - Have medicine bottles available to pull information from

Personal and Family Documentation

- Keep an “Activities of Daily Living” journal:
 - Describe how the 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.
 - See “Impairment Evaluation Criteria” for more detail about what Social Security considers when determining disability.
- 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.
- Social Security number for yourself, spouse and minor children.

Employment Documentation

- If you have any employment records that demonstrate a decline in performance or change in your work responsibilities due to not meeting expectations make sure to get copies and submit with your application.
 - 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.
 - Summary of work history over past 16 years
 - Company names, addresses and telephone numbers
 - Description of the kind of work you did

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:

1. Are you working?
 - a. If you are working and your substantial gainful activity (SGA) is at or exceeds the SGA level you will likely not be considered disabled.
 - b. If you are not working, steps 2-5 are considered.
2. Is your medical condition “severe”?
 - a. To qualify your impairment(s) must significantly limit your ability to do basic work activities (walking, sitting, seeing and remembering)
3. Is your medical condition in the list of disabling impairments?
 - a. HD is on the Compassionate Allowance List, and falls under Neurological Impairments, Degenerative Disease not listed elsewhere (11.17)
 - **See attached page titled “Impairment Evaluation Criteria” for the specific details of what social security is looking for in the application and documentation to validate your disability).
4. Can you do the work you did previously?
 - a. Social Security is evaluating to determine if your impairment prevents you from performing the duties of your current/previous job.
5. Can you do any other type of work?

- a. If unable to do your previous work they evaluate your age, education, past work experience and transferable skills to determine if you can work in another type of job and have substantial gainful employment.

Impairment Evaluation Criteria

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

- Section 11.00 – Neurological
 - 11.17 Degenerative Disease not listed elsewhere

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

- Disorganization of Motor Functioning described in section 11.04B and/or
- Organic Mental Disorders: changes in cognitive (thinking) abilities and affect (mood/behavior) changes described in section 12.02.

*****For evaluation purposes a 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’t’s:

DO Say	DON’T SAY
<ul style="list-style-type: none"> • I am limited by balance from doing any work around dangerous machinery, etc 	<ul style="list-style-type: none"> • I can’t work
<ul style="list-style-type: none"> • I have troubles with fine motor making ____ difficult and unsafe. 	<ul style="list-style-type: none"> • I am totally disabled
<ul style="list-style-type: none"> • Due to HD I am experiencing impulsivity which is causing difficulties in getting along with co-workers and customers. 	<ul style="list-style-type: none"> • I should be awarded benefits
<ul style="list-style-type: none"> • I am limited by cognitive decline and I am unable to learn new tasks and take on new responsibilities. 	<ul style="list-style-type: none"> • <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>

Motor Functioning is defined as:

- Social Security Listing of Impairments Category 11.04 Central Nervous System Vascular Accident
 - “Significant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movements, or gait and station.”
 - Paresis, paralysis
 - Tremor or other involuntary movements (chorea)
 - Ataxia

- 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.

Cognitive and Affect Changes is defined as:

- Social Security Listing of Impairments 12.02 Organic Mental Disorders
 - “Psychological or behavioral abnormalities associated with dysfunction of the brain.”
 - Need to demonstrate through your documentation persistence of at least one of the following:
 - *Disorientation to time and place*
 - *Memory impairment*
 - Short term—inability to learn new information
 - Long term—inability to remember information that was known sometime in past.
 - *Perceptual or thinking disturbances*
 - Hallucinations
 - Delusions
 - *Change in personality*
 - *Disturbance in mood*
 - *Emotional instability or impairment in impulse control*
 - Explosive temper outbursts
 - Sudden crying
 - Need to demonstrate through your documentation persistence of at least two of the following:
 - *“marked” is measuring the degree of limitation. It means more than moderate limitation but less than extreme.*
 - *Marked restriction of activities of daily living*
 - Cleaning, shopping, cooking, taking public transportation, paying bills, maintaining your home, grooming, bathing, dressing or using telephones.
 - Do you need someone to supervise or assist you when attempting a task(s)?
 - Do you get distracted or forget to complete task(s)?
 - *Marked difficulties in maintaining social functioning*
 - Refers to your capacity to interact independently, appropriately, effectively and on a sustained basis with other individuals.
 - Ability to get along with others (family, friends, neighbors, grocery store staff, landlords, bus drivers, etc.
 - Do you have a history of: getting into verbal arguments with people; fighting; fear of strangers; avoiding personal relationships or social isolation?

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- What is your ability to cooperate with others, show consideration and/or awareness for others feelings?
- *Marked difficulties in maintaining concentration, persistence, or pace*
 - Refers to the ability to sustain focused attention and concentration long enough to permit the timely and appropriate completion of tasks commonly found in work settings.
 - Best observed in work settings
 - Do you often forget to do something after being asked?
 - Do you find it difficult to concentrate for long periods of time when completing more challenging tasks?
 - Are you requiring more assistance and supervision to complete tasks you once completed independently?
- *Repeated episodes of decompensation, each of extended duration*
 - Exacerbations or temporary increases in symptoms or signs accompanied by a loss of adaptive functioning, as manifested by difficulties in performing activities of daily living, maintaining social relationships, maintaining concentration, persistence or pace.
 - As a result of your impairment(s) do you find yourself needing more treatment and/or placement in a less stressful situation?
 - Are you requiring a more structured psychological support system (hospitalizations, placement in board and care or other highly structured setting)?
 - Extended duration is defined as 3 episodes within 1 year (avg of once every 4 months) and each episode lasting 2 weeks or more.

Who decides if you are disabled?

- Completed applications are sent to the Disability Determination Services (DDS) offices in California.
 - The DDS office will decide if your medical condition is considered a disability under the Social Security law.
 - The DDS office team consists of a physician or psychologist and a disability examiner
 - This team will consider all the facts in your case and decide if you are disabled.
 - They will use medical evidence from your doctors and from hospitals, clinics, or institutions where you were examined or treated.

Submitting the Application and Approval/Denial:

- Keep copies of everything you submit to SSA.
- If SSA refers you for a DDS consult/Medical Relations Officer or Professional Relations Officer, you can request to have the evaluation completed by your MD and SSA has to comply and allow your doctor to complete the evaluation.

- For additional assistance with submitting or reviewing your application, Caring Voice Coalition (non-profit agency) has lawyers and advocates that can review applications and provide recommendations on how to make the claim stronger and more likely to be approved.
- If denied, you have the opportunity to appeal within 60 days. At that time you should contact Caring Voice Coalition for additional support for the appeal process.

Additional Resources:

- Caring Voice Coalition: <http://www.caringvoice.org/2014/04/understanding-your-disability/>
- Social Security Administration: <http://www.ssa.gov/disabilityssi/>