Huntington’s Disease Disability Appeal Guide – Reconsideration & Administrative Law Hearing

Next Steps After a Disability Denial
If you are utilizing this Appeal Guide, you, a friend, or a family member has likely been denied disability. While a denial is very frustrating, and emotionally difficult, it should not be a discouraging sign. The Social Security disability process can be challenging, and takes a great deal of time and effort, but it is worth continuing the fight for disability and building the strongest case possible. This guide is here to help you through this process.

The purpose of this Appeal Guide is to help families and individuals with Huntington’s disease (HD) submit an online Social Security disability appeal at the Reconsideration and Administrative Hearing levels. This guide will explain:

- A step-by-step overview of what to expect when submitting an appeal;
- What information you will need to include with the appeal;
- How to thoroughly answer Social Security’s questions from the perspective of an individual with HD.

Huntington’s disease is a rare condition that is not well-known or understood, especially by Social Security. It is important to include information about what Huntington’s disease is, the common symptoms associated with HD, and how your HD impacts you on a daily basis when submitting a Social Security Disability application. It is important, and a good “best practice,” to provide as much information as possible when submitting a disability claim and working with Social Security. It is also important to complete the appeal from the perspective of a bad day – you have to be open and honest about what you CANNOT do, otherwise you might give Social Security the wrong impression.

You are not alone in this process. We are here to help.¹

¹ The material enclosed is provided for informational purposes only and does not constitute legal advice. We provide this information as a public service. Transmission of the information is not intended to create, and the receipt does not constitute, an attorney-client relationship between sender and receiver.
Disability Cycle

It is worth noting that Reconsideration, the first stage of appeal, is the most difficult level of the disability process to get an approval - only 4-10% of cases are approved at Reconsideration. It is very important to move forward and appeal to the Administrative Hearing level if your case is denied a second time. The Administrative law judge hearing level is your best chance for a disability approval, between 40-60%, so it is important to appear in person before a judge if you get to this stage.
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Disability Checklist

Before you start, make sure you have all of the information you need to complete the application:

**Request for Reconsideration:** Use to complete a level one (Reconsideration) appeal of a recently denied disability claim. *After completing this portion, the applicant will need to complete the Disability Report - Appeal (SSA-3441).*

- Information about applicant:
  - Applicant’s name, SSN, claim number (if different than SSN)
  - Mailing address and phone number of the applicant
- Information about claimant’s (applicant) representative - name, address, telephone number
- Issue being appealed needs to be disability

**Request for Hearing:** Use to complete a level two appeal of a recently denied Reconsideration claim (if applicable). *After completing this portion, the applicant will need to complete the Disability Report - Appeal (SSA-3441).*

- Information about applicant:
  - Applicant’s name, SSN, claim number (if different than SSN)
  - Mailing address and phone number of the applicant*
  - Indicate the reason the applicant does not agree with the SSA’s determination and why they would like to request a hearing before an administrative law judge (ALJ).
  - Confirm the applicant will appear in person at the hearing.

**Disability Report:** The applicant can provide updated information since the previously submitted disability report (initial or appeal).

- Information about applicant:
  - Applicant’s name (current and any prior), SSN, DOB
  - Mailing address and phone number of the applicant
- Third party contact information - name, relationship, daytime phone number, address
- Medical Condition(s):
  - Describe existing condition(s)
  - Describe changes to existing condition(s) since the initial application was submitted
  - Describe any new condition(s)
- Medical Treatment since the previously submitted disability report (initial or appeal):
  - Indicate any other names the applicant has used on medical records or educational records
  - Indicate the type (physical or mental) of condition(s) the applicant has seen a doctor for
    - *If the applicant only sees one doctor but has physical and mental symptoms, we recommend indicating both condition types.*
  - Name of provider/facility were the applicant was treated
    - *If applicant saw multiple providers at the same facility, list only the facility and name all the doctors.*

*For applicants experiencing memory loss, cognitive difficulty, carelessness, we recommend using the address or phone of a family member, social worker, or other trustworthy source that will be assisting during the applicant during the process.*
- Phone number of provider/facility
  *We recommend putting the medical record department phone number.*
- Mailing address of provider/facility
- First and last date of office visit and any upcoming appointments
- If seen in the emergency room or had an overnight stay, list 3 most recent visits for each
- Indicate the medical conditions the applicant was treated or evaluated for (these should match the conditions that were listed in the initial disability report and any new conditions)
- Indicate the type of treatment received (Ex: examination, medical testing, treatment plans, etc.)
- Provide information on tests the provider/facility completed, including dates of the test(s)
- If applicant saw anyone else (ex: prisons, social service agencies, etc.) for their condition(s), additional information will need to be provided.
- List of medications (prescription and non-prescription):
  - Name of prescribing doctor
  - Reason for taking the medicine
  - Side effects of the medication
    *If the applicant has not seen a provider since the prior disability report (initial or appeal) was completed, the applicant will need to provide the prescribing doctors name, city, and state.*
- Activities: describe any changes in the applicant’s daily activities or ability to care for their personal needs, since completing the prior disability report (initial or appeal). (Ex: dressing, bathing, tying shoes, fixing meals, etc.)
- Work and Education: if the applicant has worked or completed any educational training since completing the prior disability report (initial or appeal), additional information will need to be provided.
- Vocational Rehabilitation, Employment, or other support services: if the applicant has completed any of these since completing the prior disability report (initial or appeal), additional information will need to be provided.
- Remarks: include additional information about the applicant’s symptoms and limitations or explain an answer from another section in more detail.
Starting the Application

When you are ready to start your appeal, you can access the application here:
https://secure.ssa.gov/iApplsRe/start.

Look for the Green Boxes in the application guide to provide helpful tips.

Blue boxes tell you want information needs to be entered in the different appeal sections.

Red boxes indicate VERY important information.

Purple boxes provide details on how to answer questions, what information should be included in your answers, and examples to help make sure your application is completed as thoroughly as possible.
Disability Appeal

If the HD family member cannot complete the application/appeal on their own, it is very important for them to get assistance completing the application. The application is designed so someone else can complete the application on the disabled individual’s behalf.
The appeal does not have to be completed in one sitting. It is better to gather all of the information you need and take your time completing the appeal, even if it takes a few days. Save the reentry number in a safe place so you can get back into the appeal. To get back into the appeal, all you need is the re-entry number, the disabled individual’s Social Security number, and to confirm your identity.

Return to a Saved Appeal
Please enter the Reentry Number and the Social Security Number to continue where you left off.
If you lose or forget your reentry number, you will need to start a new appeal or the claimant can log into their my Social Security account, or create a new account, to check the status of their appeal and view their reentry number.

Applicant's Social Security Number (SSN):

On this screen, enter the reentry number and the applicant’s SSN to return to the application.

Disability Appeal

Please Confirm Your Identity
I am:

☐ Heath Cliff

☐ Someone else, helping Heath Cliff to appeal

On this screen, select who is completing the application.

On this screen, save the Re-entry number so you can return to the application. You can have a copy of the reentry number emailed to you.
There is very limited space provided in the application to indicate why you disagree with the determination (decision) made on your claim so you need to be as brief and specific as possible. When entering the reason why you disagree with the determination, it is important that you include the phrase “The previous denial of my claim should be reversed because I am disabled per Listing 11.17 for Adult Onset Huntington’s disease and I am unable to work.” This phrase will help Social Security correctly flag your case for HD and compassionate allowance. HD should be the primary diagnosis listed in this section, but it is important to include additional diagnoses if you have them, like depression and anxiety. You can find additional information about Social Security blue book Adult Listings here: https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm
Additional Contact

The additional contact should be a friend or family member that knows the HD family member well and sees them regularly. The additional contact can be the same person completing the disability appeal on the HD family member’s behalf, unless that person is an attorney. You want to include someone who is familiar with the HD family member’s symptoms and limitations and can describe how the HD family member struggles on a daily basis and what changes they have made to their life. Do not include a doctor here; there is a separate section for doctors, and only include a social worker if there are no other contact options.
Medical Conditions

On this screen, you will enter information about the changes in your medical conditions and your current HD symptoms.

Choose a date around the date listed on your denial letter. A specific date is not required, it is better to be general and list a month (March, June) or season (summer, fall), unless you are diagnosed with a new condition.

Even if the HD family member’s condition(s) has not changed much, or at all, ALWAYS check "YES" and include the symptoms and limitations they experience (chorea, involuntary movement, dropping objects, tripping, falling, memory loss, trouble concentrating, inability to multitask, trouble starting or finishing tasks, intellectual decline, trouble interacting with others, apathy, depression, anxiety, etc.). You do not want to leave any section of the application blank, especially a section that gives you the opportunity to describe what the HD family member experiences on a daily basis. Always remember talk about the HD family member’s symptoms from the perspective of a bad day.

New Conditions

Only check “YES” if you have actually been given a new diagnosis (ex: depression, anxiety, PTSD, sleep apnea, chronic pain syndrome, arthritis, etc.). All new SYMPTOMS should be included in the box above.
Medical Treatment

When completing this section of the application, you do not need to include every appointment the HD family member has attended since you provided that information in the initial application. Only include appointments that have taken place since you submitted the initial application.

Example: The HD family member began getting treatment for HD in July 2017. You submitted the initial application in January 2019, but the application was denied in May 2019 and you have until July 2019 to submit the appeal. When completing the appeal, you only need to include appointments that happened between January 2019 and July 2019, and any future appointments if they have been scheduled.

It is IMPERATIVE that you continue to get medical care while your application is pending. You never know if or when the one additional appointment can change the outcome of your disability application. Because HD is a progressive condition, every medical appointment matters.
Doctors and Hospitals

Disability Appeal

Doctors and Hospitals for Heath Cliff

Please tell us about anyone who has new or updated medical records about any of his physical or mental conditions (including emotional or learning problems).

<table>
<thead>
<tr>
<th>Status</th>
<th>Doctor or Healthcare Provider</th>
<th>City</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Click “Add Doctor” to add a doctor or healthcare provider.

Add Doctor

<table>
<thead>
<tr>
<th>Status</th>
<th>Hospital or Clinic</th>
<th>City</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Click “Add Hospital or Clinic” to add a hospital or clinic.

Add Hospital or Clinic

If you see more than one medical provider at the same Hospital/Clinic then only include the information for the Hospital/Clinic. You do not need to provide details about every medical provider if they all provide care at the same location.

Add as many doctors and hospitals/clinics as necessary. It is important to include ALL treating physicians, primary care physicians, physical therapists, counselors, etc., not just the neurologist that treats the Huntington’s Disease.

On this screen, add doctor and/or hospital information for any appointments, ER visits, or hospitalizations that have occurred between the date you submitted your initial application and the date you submit your appeal.
### Doctor or Healthcare Provider Details

**Name of Doctor or Healthcare Provider:**
- Title: [ ]
- First: [ ]
- Last: [ ]
- Suffix: [ ]

**Name of Practice or Medical Group:**

**Phone Number:**
- [ ] U.S.
- [ ] International
- 10-digit Number: [ ]
- Ext: [ ]

**Address:**
- **Country:**
  - United States or U.S. Territory [ ]
- **Street Address:**
  - Street Line 1: [ ]
  - Street Line 2: [ ]
- **City/Town:** [ ]
- **State/Territory:** [ ]
- **ZIP Code:** [ ]

**Patient ID Number, if known:**

### Treatment Dates with this Doctor or Healthcare Provider

Enter the closest date(s) Heath Cliff can remember. Examples: 6/2/2016, June 2015, Summer 2015.

**First Visit:** [ ]

**Last Visit:** [ ]

**Next Scheduled Appointment, if any:** [ ]

It is okay if you do not know the exact date, make your best guess.

These dates are the most important and need to be accurate so Social Security can collect your medical records.

### Medical Conditions Treated by this Doctor or Healthcare Provider

What medical conditions were treated or evaluated?
Examples: back injury, arthritis, diabetes, depression, blindness. (1000 characters maximum)

Only list conditions relevant to the physician:
- Neurologist = Adult Onset Huntington’s Disease (HD)
- Psychiatrist = depression, anxiety
- PCP = high blood pressure, depression, chronic pain, HD
- Physical therapist = motor symptoms from Adult Onset Huntington’s Disease

Characters remaining: 1000
Take your time when completing this section and make sure you include as much detail as possible. Also make sure to include your doctor’s up-to-date and accurate contact information (address, phone, and fax) otherwise Social Security may not be able to collect your medical records because they may not send the request to the right place.
On this screen, you will add any additional medical tests that did not fit in the Doctor/Healthcare provider section and confirm all the tests you have added are correct.

Test Details

- Test Type:
  - 

- Date(s) of Test:
Enter the closest date you can remember. Examples: 6/2/2015, June 2015, Summer 2015.

- Who ordered this test for Heath Cliff?
If this doctor’s or hospital’s name is not in the list, select “Other Doctor/Healthcare Provider” or “Other Hospital/Clinic”.

- Use the drop down menu to select the doctor or healthcare provider that ordered the test.

Tests for Heath Cliff

There is no limit to the number of tests you can add to your application.
"Add Medicine"

**Medicine Details**

- **Enter name of the medicine:** Enter only one medicine at a time. Look at the medicine container if necessary.
- **Why is [Name] taking this medicine?**
- **Describe any side effects experienced while taking this medicine:** Include physical or mental effects and allergic reactions. (1000 characters maximum)
- **Who recommended or prescribed this medicine?** If this doctor’s or hospital’s name is not in the list, select "Other Doctor/Healthcare Provider" or "Other Hospital/Clinic".

**Save**  
**Cancel**

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**Be sure to include ALL of your medications, not just medications you are taking for Adult Onset Huntington’s Disease. Again, Social Security looks at the combination of your impairments, medications, everything.**

**Verify the name and spelling of your medications when entering them into the application.**

**List the appropriate medical conditions when describing why you are taking the medication. It is important to use proper medical terminology to flag the right Social Security criteria, instead of indicating that you have shakes or movements, you should write that you have chorea secondary to Huntington’s disease.**

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**It is very important to include any and all side effects for your medications. Social Security takes side effects into consideration when making a disability determination and it can impact the outcome of your case, especially if you have severe side effects from your medications.**
On this screen, you will add any additional medications that did not fit in the Doctor/Healthcare provider section and confirm all the medications you have added are accurate and spelled correctly.

<table>
<thead>
<tr>
<th>Status</th>
<th>Name of Medicine</th>
<th>Prescribed by</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sortraline</td>
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</tr>
<tr>
<td></td>
<td>Lorazepam</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cyanocobalamin</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Dextroamphetamine-amp</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Ergocalciferol</td>
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<td></td>
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<tr>
<td></td>
<td>Fentanyl</td>
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<td></td>
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<tr>
<td></td>
<td>Fluticasone prop-salm</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>HYDROcodone-acetaminophen</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>TRUEPLUS INSULIN</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Levothyroxine</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Melatonin</td>
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</tr>
</tbody>
</table>

There is no limit to the number of medications you can add to your application.
On this screen, you will enter if anyone OTHER than a medical provider has medical evidence that is necessary for your case.

We need to know if anyone else has medical information about any of Heath Cliff's conditions or if he is scheduled to see anyone else.

This may include:
- workers' compensation
- vocational rehabilitation services
- insurance companies who have paid Heath Cliff disability benefits
- prisons and correctional facilities
- attorneys
- social service agencies
- welfare agencies
- school/education records

Since Heath Cliff last told us about his other medical information, does anyone have medical information about any of his physical or mental conditions (including emotional and learning problems) or is he scheduled to see anyone else?
- Yes
- No

Most people will not have information to submit in this category so it is okay to say “NO” and move on to the next section of the application. If the person applying for disability is between ages 18 and 22, it will be beneficial to include information about school/education records especially if the individual struggled in school and needed extra assistance or accommodations.
## Activities

**Activities for Heath Cliff**

*Since Heath Cliff last told us about his activities, has there been any change (for better or for worse) in his daily activities due to his physical or mental conditions? Examples of daily activities are household tasks, personal care, getting around, hobbies and interests, social activities, etc.*

- Yes  
- No

**Please describe the changes in his daily activities in detail:**

(1000 characters maximum)

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Like the Change in Conditions question above, ALWAYS check YES and include difficulties and limitations you experience every day (trouble dressing, unable to tie shoes, inability to cook, forgetting food on the stove, trouble with chores, taking naps, not able to drive, need reminders to bathe, need a shower bar or shower stool, can’t read and remember a book, cannot concentrate to watch a 30 minute tv show, etc.).
```

Characters remaining: 1000

If you need more space, continue in Remarks.

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You do not want to leave any section of the application blank, especially a section that gives you the opportunity to describe what you experience on a daily basis. Always remember to talk about your symptoms and limitations from the perspective of a bad day.
Employment and Related Activities

Work and Education

On this screen, you will enter information about your work status and education, if applicable.

**Work and Education for Heath Cliff**

Since Heath Cliff last told us about his work, has he worked or has his work changed?
- Yes
- No

Since Heath Cliff last told us about his education, has he completed or is he enrolled in any type of specialized job training, trade school, or vocational school?
- Yes
- No

Vocational Rehabilitation

On this screen, you will enter information about your vocational rehabilitation or other support services, if applicable.

**Vocational Rehabilitation, Employment, or Other Support Services for Heath Cliff**

We need to know about Heath Cliff’s participation in:
- an individual work plan with an employment network under the Ticket to Work Program
- an individualized plan for employment with a vocational rehabilitation agency or any other organization
- any program providing vocational rehabilitation, employment services, or other support services to help him go to work
- a Plan to Achieve Self-Support (PASS)
- an individualized education program (IEP) through an educational institution (if a student age 16-21)

Since Heath Cliff last told us about his vocational rehabilitation, has he participated, or is he participating, in one of these programs?
- Yes
- No

Most people will not have information to submit in these categories so it is okay to say “NO” and move on to the next section of the application if these questions do not apply to you.
Remarks

Additional Remarks for Heath Cliff

Please provide any additional information
Use this space to provide any information about the symptoms and limitations of Huntington’s Disease. This information could not be shown in earlier sections of this form. It is important to utilize this section.

Use ALL of the 2000 characters that Social Security has provided in this space. Reiterate that you are disabled due to Adult Onset Huntington’s Disease, provide information about what HD is, and describe why your HD keeps you from working:

"I should be deemed disabled per Adult Listing 11.17 for Adult Onset Huntington’s disease because I experience (physical/cognitive/behavioral – choose the combination that is relevant to you) symptoms from my HD that prevent me from working. HD is a neurocognitive degenerative disorder that impacts my ability to walk, talk, and reason. My symptoms of HD include (list all relevant symptoms). (Use the remaining space to provide details and examples of how your symptoms limit you – My memory is severely decline and I forget…; I have difficulty concentrating because…; I have trouble using my hands because…; I am tripping and falling more because…; etc.) Please flag my claim for CAL processing per DI 23022.923."

Characters remaining: 2000

It is very important to use this section and this space to discuss symptoms and limitations. You need to really stress why you or your loved one can no longer work as a result of Adult Onset Huntington’s Disease symptoms.
DO NOT FORGET TO ELECTRONICALLY SIGN THE MEDICAL RELEASE FORM SO SOCIAL SECURITY CAN REQUEST MEDICAL RECORDS ON YOUR BEHALF. Once you sign and submit the Medical Release Form, you will be taken to one last page where you can attach medical records and other relevant case documents (medical letters from a doctor, support letters from family and friends). Take this opportunity to attach any and all medical records that you have to make sure Social Security has all of the necessary evidence for your claim.
Questions?

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Email: abartlett@hdsa.org