

APPLYING FOR SHORT-TERM DISABILITY (STD), LONG-TERM DISABILITY (LTD) & SOCIAL SECURITY DISABILITY (SSD), USING THE COMPASSIONATE ALLOWANCE INITIATIVE (CAL) FOR FASTER PROCESSING

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How to Know When to Quit Working and File for SSD, STD and LTD

Honestly answering the questions below will help you to determine if it is time to quit work and apply for Disability now, or if your problems are being caused by other mitigating circumstances such as lack of sleep, (i.e.: because your wife just brought home your new baby); extra anxiety, (i.e.: because performance appraisals are coming up at work soon); being fatigued and not feeling well, (i.e.: because of having a cold or the flu); or any other stressful or tiring events in your life.

By saying and using “uncharacteristic” below, I am implying that the problems that you are experiencing at work now, are “uncharacteristic” of your past performance and achievements.

If you are not routinely experiencing any of these additional “stressors” in your life, and you have still answered the majority of the questions below “Yes,” then the problems you are experiencing at work are probably HD-related such as cognitive, emotional and behavioral symptoms.

- ◆ Have you gotten any “uncharacteristic” verbal warnings in the last 6 months to a year?
- ◆ Have you gotten any “uncharacteristic” written warnings in the last 6 months to a year?
- ◆ Has anyone confided in you at work that your job performance isn’t what it used to be, that you’re just not able to finish as much stuff at work now as you could before?
- ◆ Are you finding that it now requires you to “uncharacteristically” expend twice as much mental energy and concentration to complete your routine work-related responsibilities than it did before? For Example: “I just finished the report my boss wanted this afternoon and I am totally exhausted mentally.”
- ◆ Are you taking two to three times longer to “uncharacteristically” complete your routine work-related responsibilities than it was before? For Example: “I used to be able to finish my production report by Wednesday of each week but now it’s taking me until Friday for some reason.”
- ◆ Are you finding that you have an extremely “uncharacteristically” harder time focusing on your work-related responsibilities when you’re under a deadline or other routine work-related pressure?

- ◆ Are you having an “uncharacteristically” harder time routinely remembering how to do work-related responsibilities, even if you’ve done them for years and years? For Example: “I have done this job a million times before, why can’t I remember how to do it this time?”
- ◆ Are you “uncharacteristically” taking more time to complete your routine work-related responsibilities because of making silly errors that you would have never made before?
- ◆ Do you find yourself “uncharacteristically” forgetting meetings and other instructions from your boss and fellow employees routinely if you don’t write them down immediately?
- ◆ On a routine basis, are you “uncharacteristically” getting into trouble for being over budget or spending too much money?
- ◆ Do you “uncharacteristically” feel, on a routine basis now, that everyone at work is out to get you?
- ◆ Are you “uncharacteristically” getting into more arguments with your boss and fellow employees at work, on a regular basis now, and then find yourself trying to find ways to get even with them or prove them wrong?
- ◆ On a routine basis, do you sometimes “uncharacteristically” feel that it is okay to bend the rules regarding wearing safety equipment and following established safety guidelines and procedures; okay for you to not accurately report mistake you have made; or okay for you to speak in a “sexually flirting” way with other female employees?
- ◆ Do you find that you routinely have an “uncharacteristically” shorter fuse than before and routinely “blow up” and holler at others when things don’t go your way, or something unexpected happens?
- ◆ Do you find yourself routinely getting “uncharacteristically” irritated at little things fellow employees do, including your boss?
- ◆ When something happens at work that upsets you do you “uncharacteristically” find yourself routinely displaying a “search and destroy” attitude, rather than a “forgive and forget” attitude?
- ◆ Do you routinely find yourself “uncharacteristically” forgetting where you’ve saved your spreadsheets, PowerPoint presentations or Word documents that you worked on recently?

- ◆ Do you routinely find yourself “uncharacteristically” unable to do as much at work as you were previously able to?
- ◆ Do you routinely find yourself “uncharacteristically” thinking you deserve more money than you’re being paid at work so you have no problems taking a little extra money from the petty cash drawer routinely, or have no problems “padding” your expense report on a routine basis, so you can get the money you really deserve?
- ◆ Do you routinely find yourself “uncharacteristically” unable to make up our mind as to which decision to make on a routine basis? You used to be able to make snap decisions very quickly but now you can’t seem to make up your mind as you vacillate between what to do?
- ◆ Do you routinely find yourself “uncharacteristically” unable to keep up with daily quotas set for you, whether answering phone calls, making customer contact calls, or fabricating parts?
- ◆ Do you routinely find yourself “uncharacteristically” getting lost while driving to or from work, or forgetting where you are?
- ◆ Do you routinely find yourself “uncharacteristically” unable to listen to the car radio while on the way to work because it distracts your ability to focus on driving?
- ◆ Do you routinely find yourself “uncharacteristically” having lots of near misses or cutting people off while driving to work?
- ◆ Have you gotten any “uncharacteristic” warnings or tickets in the last 6 months to a year, from the local police or highway patrol, while driving to or from work?
- ◆ Do you routinely find yourself “uncharacteristically” making sexually leading comments to other female associates or the office staff?
- ◆ Has any female associate recently told you that what you recently said to them, or “innocently” did to them, could be considered “sexual harassment?”
- ◆ Do you routinely find yourself “uncharacteristically” wanting to take a nap at work because of being so mentally and physically exhausted or having to take a little nap as soon as you get home, before you do anything else?

- ◆ Do you routinely find yourself “uncharacteristically” thinking how sexually attractive other female employees are now, and fantasizing about having sex with them?
- ◆ Do you routinely find yourself “uncharacteristically” putting off talking to your employees, other colleagues, management, or customers because you’re afraid you won’t be able to answer their questions or follow their conversations?
- ◆ Do you routinely find yourself “uncharacteristically” avoiding people in general at work because you just “feel” like something is wrong with you but just can’t put your finger on it like before?
- ◆ Do you routinely find yourself “uncharacteristically” berating or “beating yourself up” for not remembering your computer password; for not remembering how to answer customer questions about the insurance you sell; or for not remembering statistical formulas and calculations for reports you’ve always done?
- ◆ Do you routinely find yourself “uncharacteristically” being unable to read whether-or-not you’ve upset someone at work because of something you’ve said or done?

14 Changes That Could Signal Concern In HD and Help You Decide If It’s Time to Quit Working and File for Disability

Here are “14 Changes That Could Signal Concern in HD” that I wrote several years ago. These can also be used to identify potential HD-related problems both at work and at home:

- 1) **Memory Loss that affects job or personal skills.** It is normal to forget an assignment, deadline or a colleague's name, especially when under stress. However, frequent forgetfulness or confusion at home or in the workplace over an extended period that is not typical of the person with HD may signal concern.
- 2) **Difficulty performing familiar tasks.** Busy people pause occasionally to think about what they are doing, or how to finish a project. However, concern is raised if tasks which used to be completed in two hours start taking all day, or if getting ready to go somewhere takes an hour instead of ten minutes.
- 3) **Problems with speech and language.** Everyone has trouble finding the right word sometimes, but a person with HD may forget simple words or substitute inappropriate

words, such as, "place the pie in the toilet," instead of saying "in the oven." Speaking may be slow, with pauses between words and responses.

4) **Disorientation to time and place.** Anyone may momentarily forget the day of the week or what is needed from the store. But persons with HD can easily become distracted and completely lose track of time and tasks. They may remain disoriented until it is brought to their attention. They may get lost driving home, to work, or even to a familiar store.

5) **Changes in mood or behavior.** Everyone experiences a broad range of emotions-its part of being human. However, persons with HD may exhibit rapid mood swings for no apparent reason. These moods may be uncharacteristic changes from their usual temperament. They may show reduced or inappropriate emotional responses to any given situation.

6) **Poor or decreased judgment.** Everyone has gotten upset when they received a traffic ticket. However, a person with HD who is stopped and falsely arrested for being drunk may become extremely angry and insult or even hit the policeman because of poor judgment or lack of consequential thinking.

7) **Problems with abstract thinking.** Balancing a checkbook can be challenging for anyone, but for someone with HD, recognizing numbers or performing calculations may be extremely difficult and stressful. Diminishing concentration, focus and sound decision-making may signal problems if they continue for no apparent reasons.

8) **Misplacing things.** We all misplace a wallet or keys from time to time. However, a person with HD may put items in inappropriate places and not remember doing so, such as placing a carton of milk in the cupboard or a wristwatch in the sugar bowl.

9) **Changes in personality.** Personalities often change with age. A person with HD may experience uncharacteristic changes in their personality. For example, someone who was generally easygoing may become angry, paranoid or fearful and someone who was outgoing may become withdrawn from social interaction.

10) **Loss of initiative.** It's normal to tire of housework, business activities or social obligations. But for most people, this feeling is brief and enthusiasm and interest return. The person with HD may become apathetic and become indifferent towards activities which used to bring them satisfaction and happiness.

11) **Depression.** Tragedy saddens us all but the person with HD may not recover- they may show increased irritability or crying and may express feelings of hopelessness or guilt. They may lose interest in ordinary activities, such as sex, and may even

experience disturbances in eating and/or sleeping patterns. Severely depressed individuals may even talk openly of suicide, saying things like, "I'm not needed anymore," or "Things would be better off without me."

12) **Loss of social inhibitions.** It is normal to change beliefs or values as you age. A person with HD may uncharacteristically start cussing, gambling, lying, cheating, stealing or being sexually promiscuous- things they would have never done before.

13) **Loss of visual-spatial coordination.** Anyone might misjudge a turn or hit a curb. However, a person with HD may lose the coordination or reflexes to avoid an accident, back out of a driveway, or shift the car. They may hit their elbows while walking through doorways or bump into a wall while simply walking down a hallway.

14) **Slowed comprehension.** Everyone occasionally misses the punch line of a joke but a person with HD may have poor or slowed comprehension so they cannot grasp the meaning of a story or conversation. There may also be slowed interpretations or misinterpretations of facial expressions, such as approval or disgust, causing inappropriate responses and misunderstandings.

NOTE: The changes noted above, subtle to severe, should be brought to someone's attention if they begin happening unexplainably or are not characteristic of your usual behavior or normal abilities. Since some of these warning signs are so personal, only you or someone close to you can help determine if they indicate areas for concern or are simply a result of mitigating circumstances of other stressors. Please understand that behavior that is considered normal for one person may not be considered "normal" for someone else.

You should also take advantage of your Therapist, Neurologist, or Psychiatrist, as they are usually very objective. Your spouse or family members can also help. In addition, a very close business associate/partner or employee can also help you to determine if your current performance is "uncharacteristic" of what you used to be able to do!

Understanding Potential Barriers and How To Overcome Them

Must Be Willing To "Come Out Of the Closet" and Be Tested

If your HD has been kept a secret, it is time to break the silence now, and follow these guidelines if you want to be approved for Social Security Disability (SSD) on the first submission. Not getting approved on the first submission could result in waiting an extra ten (10) or eleven (11) months, from the initial time you filed, to receive your first SSD payment, instead of in just 4-5 months (unless you proactively took out a short-term disability (STD) and long-term disability (LTD) policies at work). The longer you

have to wait for your first SSD check to come in means the longer you are unable to pay the bills, continue to eat out, and enjoy the quality of living you had before. It could also mean being required to see a Social Security Doctor, who knows nothing about HD, to verify that you are disabled because of HD; or possibly having to hire a costly lawyer to reapply for SSD benefits which will cost you thousands and thousands of dollars, unnecessarily.

Unawareness

If your loved one is suffering from “unawareness” and cannot tell that they are symptomatic enough to receive benefits (even after being repeatedly warned at work), and they do not see a need to file for SSD, please tell them that they will have more money to spend on their favorite things (ice cream and cookies, alcohol, cigarettes, movies, clothes, travelling to Hawaii, etc.) if they file. You can conduct the SSD interview for them. All you have to do is have them give the Social Security representative permission for you to do this.

You should make the call to SSD and tell the representative who answers that your spouse or loved one is unable to conduct this interview with them because of dementia, not being able to remember very well, or because they get confused easily and have a hard time understanding what you ask them because of their Huntington’s Disease. The representative will then ask to speak with your spouse, loved one, or family member to verify who they are. For verification, the Social Security representative will ask the person needing SSD their Social Security Number, Date of Birth, City and State where they were born, and their Mother’s maiden name. You should know enough about this person to be able to also answer general questions about their address, where they worked, etc., if necessary.

If, during the phone interview you are unable to answer any of the representative’s questions, just pause a minute and ask whomever you’re helping for the answer.

Refusal To Cooperate

In severe cases, where the person who needs to file for benefits refuses to cooperate or is combative, because they are already suffering from dementia, apathy, or unawareness, and have refused to give permission for me or their spouse, loved one, or family member to talk to the Social Security Representative for them, I have covertly “secured” all of the personal verification information beforehand (mentioned above), in addition to their address, information about their last job and why they are unable to work anymore, and pretended to be them on the phone.

If the person happened to be a woman, I would then ask a daughter, sister, aunt, or female friend to be them on the phone. This way, even those who refused to cooperate, were still able to receive these benefits that they desperately needed to improve their current quality of life. The next hurdle is intercepting the application SSD sends so you can fill it out and send it back in for the person.

Unable, Physically or Mentally, To Complete Forms

Some family members and social workers make the mistake of forgetting that Phds suffering from Dementia, Apathy, or Unawareness may not see the need to complete the paperwork and submit it or that they need to be “jump started” or helped to begin anything new. This means the paperwork will sit there, not be completed, and not be returned to SSD in a timely manner, thus forcing them to be denied. I know doing something for Phd breaks every rule that Social Workers have learned in school, about not doing the work for the person you are helping or they won't appreciate it or won't take ownership of it themselves. However, I can promise you that this methodology does not work well for those suffering from HD. I prefer to personally help them or complete their application myself and then submitting it right away.

A Humorous Example: I was helping Don get onto SSD and also the State of Arizona health care plan called AHCCCS. He did not have a birth certificate and you need an original to file for both. I asked him general questions on a visit to glean as much information as I could from him like where he was born, his Mother's maiden name and his Father's name. I also snooped through some of his bills, other paperwork lying around and his wallet to find out his Driver's License Number, Date of Birth, and Social Security Number. I then did two things, I called on his behalf “incognito” and asked them to send the Social Security Disability application paperwork and also went to the internet and Googled where to apply for his birth certificates from the state where he was born. After inputting all of the information that was required for him to receive his birth certificate, I then had it sent overnight via Federal Express.

The next day I was so pleased that everything had gone so smoothly until I called Don to enquire if he had received a package from Federal Express for me that day. He said “No” that he had heard a knock on the door that morning but that he didn't ever answer the door before 10 am! I then got in my car, rushed over to his apartment, and tried unsuccessfully to convince him to answer the door the next morning to receive my very important package (that contained *his* original birth certificate). I took the attempted delivery notice off his door in order to verify what time they would attempt redelivery the next day, and then returned to his apartment and waited for two hours until they redelivered his package.

I reveled in my success for about a week until I called him again to enquire if he had received the SSD application via mail. He said that he hadn't but I got suspicious, went there, and ended up fishing it out of the garbage can! After conducting the phone interview on his behalf “incognito” and also completing his SSD paperwork for him, the next challenge was to get him to a doctor to document that he couldn't work anymore. More on this topic later- getting him to go to the doctor cost me two of my best dinette chairs but it worked so I really didn't care! I know some of you are saying about now that I shouldn't have posed as Don, shouldn't have snooped around his apartment, etc. etc. but I honestly feel that sometimes, especially when sincerely trying to help those suffering from HD's Dementia and other symptoms, that the end does justify the means.

Wrongfully Believe SSD Is “Freebie” Program

Even though many have paid into the Social Security system all their lives, some Phds still feel reticent about receiving them because they incorrectly believe they are “free” and that goes against their religious or political beliefs. Please explain to them that SSD should be looked at like a savings account, long-term disability policy or life insurance policy that you make deposits into and pay premiums for while working and able to, and then when you are no longer able to work, because of disability, you can then legitimately take money out of your savings plan or receive the benefits that you have paid for all of your life!

Please explain to them that they will not be getting their SSD benefits for “free” or “nothing” because FICA has been deducted from each pay check the entire twenty, thirty or forty years they’ve been working. (“Under the Federal Insurance Contributions Act 12.4% of earned income up to an annual limit must be paid into Social Security, and an additional 2.9% must be paid into Medicare. If you’re a wage or salaried employee, you pay only half the FICA bill (6.2% for Social Security plus 1.45% for Medicare), and the tax is automatically withheld. Your employer contributes the other half... If you’re self-employed, however, you’re expected to cough up both the employee and the employer share of FICA. You are, however, permitted to deduct half of this self-employment tax as a business expense.”

<http://money.cnn.com/magazines/moneymag/money101/lesson18/index4.htm>

Sincerely Believe That They Are Still Capable of Working and Blame Problems On Everyone Else

Some see no need to file for SSD because they feel they are still capable of working, mostly because of unawareness, even though they’ve had unsuccessful results for several months to several years or disastrous results with getting hired and then terminated or laid off by four or five businesses. I explain to these Person’s with HD (Phds) that wouldn’t it be lots easier for them to just quit looking for a job, not work, and still get a paycheck?

Almost everyone in this situation who I have helped have seen the “light” and then agreed to file. I also assured them that they could still do odd jobs on the side for cash but would have this consistent check/deposit each month to count on. This way they could purchase a lot more and have a much higher quality of living!

General Guidelines

1. Complete and return everything Social Security sends you as quickly as possible. Any delays will slow up your approval process. Their instructions will say NOT to enclose any other information with their forms but do it anyway (see below for what to enclose) because you must educate them about HD.

2. It will then take several months for them to process your application and request information from every doctor you have seen, but don't worry because once approved, they will make your initial disability check retroactive back to your original date of your initial application.
3. Once you are approved, and if you are married and have children still living at home, you can immediately have Social Security Disability (SSD) take applications for your spouse and every child, under the age of 18, as they will also qualify for a small monthly disability check as part of your disability too.
4. On March 1st 2010, HD was been added to the "Compassionate Allowances" condition list! This should expedite the application process for Social Security Disability but unfortunately, every person I've talked to since then, when helping others file for SSD, hasn't known about it! However, be aware that HD is not listed under its own name, but is included under Mixed Dementias and this is a problem since most of the existing Guides or Literature about HD have little to nothing about Dementia in them yet. I highly recommend that you ask your Neurologist or Psychiatrist to put "dementia" as part of why you are disabled and cannot work.

HD Added to New Compassionate Allowance Conditions, Under Mixed Dementia (Effective March 1, 2010)

The following is taken from the SSA website: "Social Security has an obligation to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards.

Compassionate allowances are a way of quickly identifying diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal objective medical information. Compassionate allowances allow Social Security to quickly target the most obviously disabled individuals for allowances based on objective medical information that we can obtain quickly."

<http://www.ssa.gov/compassionateallowances/>



New Compassionate Allowance Conditions (effective March 1, 2010)

- 2 Amegakaryocytic Thrombocytopenia
- 3 Ataxia Spinocerebellar
- 4 Ataxia Telangiectasia
- 5 Batten Disease
- 6 Bilateral Retinoblastoma
- 7 Cri du Chat Syndrome
- 8 Degos Disease
- 9 Early-Onset Alzheimer's Disease
- 10 Edwards Syndrome
- 11 Fibrodysplasia Ossificans Progressiva
- 12 Fukuyama Congenital Muscular Dystrophy
- 13 Glutaric Acidemia Type II
- 14 Hemophagocytic Lymphohistiocytosis (HLH), Familial Type
- 15 Hurler Syndrome, Type IH
- 16 Hunter Syndrome, Type II
- 17 Idiopathic Pulmonary Fibrosis
- 18 Junctional Epidermolysis Bullosa, Lethal Type
- 19 Late Infantile Neuronal Ceroid Lipofuscinoses
- 20 Leigh's Disease
- 21 Maple Syrup Urine Disease
- 22 Merosin Deficient Congenital Muscular Dystrophy

23 Mixed Dementia

- 24 Mucosal Malignant Melanoma
- 25 Neonatal Adrenoleukodystrophy
- 26 Neuronal Ceroid Lipofuscinoses, Infantile Type
- 27 Niemann-Pick Type C
- 28 Patau Syndrome
- 29 Primary Progressive Aphasia
- 30 Progressive Multifocal Leukoencephalopathy
- 31 Sanfilippo Syndrome
- 32 Subacute Sclerosis Panencephalitis
- 33 Tay Sachs Disease
- 34 Thanatophoric Dysplasia, Type 1
- 35 Ullrich Congenital Muscular Dystrophy
- 36 Walker Warburg Syndrome
- 37 Wolman Disease
- 38 Zellweger Syndrome

POMS Section: DI 23022.015

Social Security Online

Effective Dates: 10/24/2008 - Present

Compassionate Allowance (CAL) DDS Instructions (DI 23022.015)

The CAL initiative is designed to quickly identify diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal, but sufficient, objective medical information. If the condition does not meet these strict criteria, it will not be designated as a CAL case.

All CAL-identified conditions are entered into the Predictive Model (PM) and are selected for CAL processing based **solely** on the claimant's allegations listed on the SSA-3368 (Disability Report—Adult) or SSA-3820—(Disability Report—Child).

Like Quick Disability Determinations (QDD), CAL cases will receive expedited processing within the context of the existing disability determination process.

CAL cases are similar to Terminal Illness (TERI) claims, although not all CAL cases involve terminal illness. For example, a person with a spinal cord injury could qualify as a compassionate allowance – even if he or she is expected to live for many years.

<http://policy.ssa.gov/poms.nsf/lnx/0423022015>

POMS Section: DI 23022.455

www.socialsecurity.gov

Effective Dates: 02/26/2010 - Present

Mixed Dementias (DI 23022.455)

MIXED DEMENTIAS	
ALTERNATE NAMES	Dementia due to multiple etiologies; Vascular dementia Alzheimer's disease (VaD); Parkinson's dementia; Diffuse Lewy- Body dementia; Frontotemporal dementia (Pick's disease); Huntington's dementia; Prion dementia; Progressive Supranuclear Palsy (PSP)

<http://policy.ssa.gov/poms.nsf/lnx/0423022455>

General Guidelines (Continued)

5. Some Person's with HD (Phds) quit working and stay home for several years and then decide to file for SSD. If you did this, DO NOT put the original day you quit working as SSD will not approve your application. Do not get "greedy" as SSD WILL NOT make your first check retroactive to 4 or 5 years ago, even if it was the correct time you quit working. You should pick a date from several months ago which is well after you have started establishing a paper trail documenting your HD-related "softer" symptoms and physical symptoms. You can simply state that you were having problems 4 or 5 years ago so you quit work then to see if that would help your symptoms but now you and your doctor have both decided that you are too symptomatic to ever return back to work again so you are filing for SSD claim now.

6. Using the same example in #5 above, it is also very important to note that there is a 10 year time limit from when you quit working to when you can file for Social Security Disability. If you wait over 10 years you will not be allowed to file and will lose all of the money you paid in while working for this important benefit!

7. You must also be younger than 65 years of age to qualify for SSD.

8. For those who have not tested or who have tested anonymously, unfortunately, you will have to come “out of the closet” and get tested so you can enclose your genetic test results with your initial application. You must also make sure your doctor also has a copy of your genetic test results. Part of coming “out of the closet” of anonymity also means that you must begin making a paper trail (meaning you will need to see your neurologist, psychologist, psychiatrist, therapist, Neuro-psychologist), preferably before you file for SSD so you will have a paper trail documenting your HD-affected behaviors, feelings, emotions, depression, any suicidal feelings, fears about your children being genetically discriminated against, anger at not being able to work or drive any more, and physical problems you have had in the recent past and are currently still experiencing.

Their names and addresses are the ones you will sign releases for authorizing SSD to contact in order to get your official medical information from. SSD will not accept any medical information that you send in pertaining to your personal medical records- it must receive this personal information from your current medical doctors or professionals.

9. Ideally, you will be working in conjunction with ALL of your medical professionals to determine when to go out on disability so please make them all aware that you are intending to do this and ask them if they will support your decision. It would also be appropriate to ask them if they have, or would put statements in your records that you are unable to hold a job because of the problems you’re having- and then they should be very specific in listing those problems.

10. If you are suffering primarily from the “softer” symptoms of HD- the behavioral, emotional and cognitive ones, I recommend that you see a Neuropsychologist first to take a Neuropsychological exam. The Neuropsychologist will interview you (where you can tell him, for example, how hard it is for you not to work, how depressed you’ve become, how you miss associating with your fellow workers, how hard it is on your spouse to be the only one earning a living now, how other family dynamics have changed, how hard it is on you to know that your children now have a 50/50 chance of inheriting this disease too, that you are having to take 2 to 3 naps each day to have strength or energy to do other things, etc.). In addition to the interview you will also be given a lengthy 5-6 hour Neuropsychological exam.

11. If you are scheduled to see the SSD doctor after you submitted your initial paperwork here are a few suggestions for both the person with HD (Phd) and their spouse/caregiver: For the Phd – You know that during each month you will have

“good” days and “bad” days, but your overall condition is one where you realistically can’t hold a full time job now. Because of this I encourage you not to prepare for any of these meetings with either the SSD doctor (or the Neuropsychologist). By this I mean don’t practice counting backwards from 100 by 7s, before seeing the doctor, but rather, simply respond naturally, without any prior preparation.

For the spouse/caregiver – Allow your Phd to dress as they do at home (and try not to be embarrassed) as this is more representative of how they actually are on a daily basis. Don’t help with their grooming or dressing on the day of their appointment and don’t “intervene,” “speak for,” or try to “calm” them during their interview as you normally would if your loved one get confused or emotional as this will allow the SSD doctor or Neuro-psychologist to see them how they really are and how they act and behave under different circumstances. Remembering not to do this you will allow the neurologist or examiner 1) to see the Phd as they really are on an everyday basis; 2) to get to hear their own responses, and 3) to watch them function using their own abilities, not yours!

12. If you are experiencing primarily the “softer” symptoms of HD, you should also begin seeing a psychiatrist, psychologist or a therapist. The psychiatrist will be the one to prescribe you medicine to alleviate your “softer” symptoms and the psychologist or therapist will keep you apprised if the medications are working. These medical professionals will begin establishing a paper trail documenting your symptoms and feelings (similar to those listed above for the neuro-psychologist) that will later help you qualify for SSD. These professionals will also be the ones to recommend a Neuro-psychologist if you need to take a neuro-psyche exam.

13. Being able to tell your loved one’s doctors or therapists (and having them record this) that they have not been able to drive now for 6 months, 2 years or 4 years, because of repeated accidents, near misses, inability to multi-task while driving, poor visual-spatial reaction time, etc. will drastically make them look more “disabled” than if they are still driving when you submit your SSD application. Are they disabled or not? See what I mean? Don’t inadvertently give the evaluators at SSD any doubt about whether-or-not your loved one is truly disabled.

14. CAUTION: If you don’t have a paper trail containing sufficient notes from doctors and other medical specialists that they think you’re disabled and SSD cannot make a decision from the medical records you’ve released to them, they will set an appointment for you to see one of their doctors. Believe me, you DO NOT want this to happen, however, if it does this is what I recommend: 1) ask if you can speak for your loved one because they have dementia (and are having trouble understanding questions and responding to them correctly) because of HD. You must also remember back to when your loved one was having some of their worst days and tell the doctor about these times. You can say things like: “Because of dementia my spouse can only remember to take his/her medications; bath, etc. when I prompt them.” or “They never remember to turn of the burners on the stove when finished cooking.” or “They can’t remember not to put metal containers in the microwave so you can’t allow them to cook anymore.”

When getting ready for this meeting please follow the same guidelines as discussed under the “For the spouse/caregiver” instructions above. If you are not approved on the first submission it will probably take several years to appeal your case, during which time you will have no Social Security Disability check coming in to defray costs and in fact, you will probably end up paying a lawyer to help you. Believe me, this will be more frustration than you want to deal with.

15. Some who are at-risk for HD may work for many years and then quit working for a number of years before applying for Social Security Disability. Here’s what one person’s “Your Social Security Statement” said when denying her SSD. She had worked 30 full years, from 1970 until 2000 and then got tested 6 years later for HD in 2006. She also filed for SSD but was denied it. Here’s why: “Disability- To get benefits if you become disabled right now, you need 35 credits of work, and 20 of these credits had to be earned in the last 10 years. Your record shows you do not have enough credits in the right time period.” Incredible that after working 30 years that she failed to qualify because of the stipulation that 20 credits must be earned in the last 10 years. Don’t fall into this same trap!

16. The same “Your Social Security Statement” also defines credits as follows: “To qualify for benefits, you earn ‘credits’ through your work – up to four each year. This year, for example, you earn one credit for each \$970 of wages or self-employment income. When you’ve earned \$3880, you’ve earned you four credits for the year...”

Feel free to e-mail Phillip Hardt at phardt1@cox.net or call him at 602-309-3118 to ask about specific issues or concerns you may have, and to get additional, more personal recommendations.

Establishing Your Paper Trail

DNA Analysis Report

Make sure that your Primary Care Physician (PCP), Neurologist and Psychiatrist all have copies of your DNA analysis report showing that you are carrying the HD gene and are predisposed to being clinically diagnosed with HD!

Neurologist and/or Psychiatrist Visits

You should have already proactively been seen by a Neurologist or Psychiatrist or already have a medical file with well established paper trail, including a copy of your DNA analysis report. Once you have decided that you are experiencing too many problems and it is just too hard emotionally and physically on you to continue working, make an appointment immediately with your current Neurologist or Psychiatrist. Tell them you are no longer able to work and ask them to add a note to your file stating that you are no longer able to work because of Dementia and Huntington's Disease. Make sure they also have a copy of your positive genetic test report in your medical file. Most Neurologists and Psychiatrists are scheduling months in the future so you must tell

them that you just quit your job and need to see them right away on an emergency basis. You can also ask them to be put on a cancellation list. When someone cancels because of being sick, you may get short notice to go in and take their appointment time and date.

As I mentioned in #12 above, if you are experiencing primarily the “softer” symptoms of HD, you should also begin seeing a psychiatrist, psychologist or a therapist. The psychiatrist will be the one to prescribe you medicine to alleviate your “softer” symptoms and the psychologist or therapist will keep you apprised if the medications are working. These medical professionals will begin establishing a paper trail documenting your symptoms and feelings (similar to those listed above for the Neuropsychologist) that will later help you qualify for SSD. These professionals will also be the ones to recommend a Neuropsychologist if you need to take a Neuropsychological exam.

Neuropsychologist Visit

If you are suffering primarily from the neuropsychiatric sequelae of HD’s “softer” symptoms, the Emotional, Cognitive and Behavioral ones, you still look okay enough physically, for anyone to believe that you cannot work because of being disabled. Because of this, you will need proof, through an objective exam, to prove that you are no longer able to work. This is exactly what a Neuropsychological Exam does- it documents how much HD is adversely affecting you work performance, punctuality, goal achievement, budget, memory, behavior, and actions and making them “uncharacteristic” from before you started symptoms. It will also estimate an approximate time when your mental, cognitive and behavioral symptoms started.

Initially, you, and your spouse can answer these questions by using the measuring stick called UNCHARACTERISTIC! Is the questionable behavior or actions of your loved one “uncharacteristic” of their prior work experience, expertise and education? By using uncharacteristic as the “measuring stick” to judge whether-or not current behavior or actions were different than prior behavior and actions is a great starting point.

Benefits of Testing

“The role of neuropsychology in dementia is not only helpful in verifying initial diagnoses, but it also helps to measure the rate of progression, provide indications on how deficits are changing over successive evaluations, and measure the efficacy of intervention therapies over repeated evaluations. It is helpful in research, providing sensitive tools for early detection and discrimination of deficits, and it helps provide powerful tools for clinical trials.

With respect to patient care, it can also help identify cognitive strengths and weaknesses and how deficits impact the activities of daily living. This can help us suggest to the family and the patient what he or she is still good at, how to remain productive, and what he or she should and should not try to do. For example, should the patient try to do finances, does he or she need a little help, or should that task be taken over by someone else? Neuropsychological testing also helps estimate the need for and extent of future care.

Neuropsychological testing, however, should not be used as a lone diagnostic tool; it is always most useful in conjunction with a multidisciplinary approach, including psychiatry, psychology, radiology, social work, or others that I have not mentioned.”

Penne Sims, Ph.D., “Neuropsychology of Mild Cognitive Impairment, Alzheimer's Disease, Dementia with Lewy Bodies, and Frontotemporal Dementia,” http://ci.columbia.edu/c1182/web/sect_6/c1182_s6_7.html

When I instructed one man, who was applying for STD/LTD and SSD because he was unable to work any longer, to immediately ask his Neurologist at Columbia University for a referral to get a Neuropsychological Exam, the Neurologist refused and stated that “You don’t need one yet- wait until you get rejected and then have one done!” This is obviously too little too late and luckily the Neurologist did finally give this Phd a referral. If you wait until you’re rejected before you request a referral to have a Neurological Exam done then you have already gone 4-5 months without pay. Now, will have to wait an additional 6-8 weeks to get an appointment, and then another 2-3 weeks for the results- and all without pay! See how it’s much smarter to just get one done to begin with, especially when you’re primarily struggling with the “softer” symptoms of HD, the emotional, behavioral and cognitive ones.

For a further explanation, please read: Phillip J. Hardt’s, “Using the Neuropsychological Exam and Other Tools to Help Those Struggling With the “Softer” Symptoms of Huntington’s Disease,” and Penne Sims, Ph.D., “Neuropsychology of Mild Cognitive Impairment, Alzheimer's Disease, Dementia with Lewy Bodies, and Frontotemporal Dementia,” at www.philliphardt.com.

Primary Care Physician Visit

You should also have already proactively been seen by a Primary Care Physician (PCP) or General Practitioner (GP) and already have a medical file and well established with initial paperwork, including a copy of your DNA analysis report. Once you have decided that you are experiencing too many problems and it is just too hard emotionally and physically on you to continue working, make an appointment immediately with your current PCP or GP. Tell them you are no longer able to work and ask them to add a note to your file stating that you are no longer able to work because of Dementia and Huntington's Disease. Make sure they also have a copy of your positive genetic test report in your medical file. You can usually get into to see your PCP or GP within a week. If there is a problem with scheduling, tell them that you just quit your job and need to see them right away on an emergency basis. You can also ask them to be put on a cancellation list. When someone cancels because of being sick, you may get short notice to go in and take their appointment time and date.

Social Security Disability (SSD) Is Not Enough for You or Your Family. It Is Imperative That It Be Supplemented with Short- and Long-Term Disability To Attain the Highest Quality of Living Possible For You and Your Family

I consider Social Security Disability (SSD) plan "B" because, unless you have a very high paying job, you will not take home much money from just SSD. I believe everyone should proactively consider taking out Short-Term Disability and Long-Term Disability while still working. The premiums can be expensive so please consider getting a job with an employer who offers them as a benefit and then the company will usually pay part of your premiums. If you already work for a company who offers STD and LTD insurance, please sign up for it during "open enrollment" so as to not raise any red flags that you may have a problem.

If you already have a low paying job or you haven't been in the workforce for a long time to build up your take home pay, you are only going to get about \$700 per month to live on. If you are just going to rely on it to live, it is going to be extremely hard. What if you could continue making exactly what you were while working full time the whole time you're disabled (until you turn 65). Imagine how much easier it would, and how much higher quality of living you and your family would be able to have if you did this? You can! It's insurance you can purchase for a very reasonable premium through your employer called Short-Term Disability (STD) and Long-Term Disability (LTD). In fact, many employers even supplement or pay part of these premiums for you. If you do not have this coverage now, please be proactive and take it out during the next open benefits enrollment period, (usually September through November of each year), that your employer has. Do not enquire about it during the rest so you don't raise any "red flags" of suspicion. I'm going to share my own personal example with you so you can see what a huge difference this makes:

I was the sole breadwinner for my little family, which consisted of my 8 children and a wife! That's 10 total if you're counting!

My monthly "net" salary, after taxes and other deductions were withheld, was:	\$3,000.
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After being able to no longer work and having to go out on disability the amount I get from Social Security Disability was:	\$1,499
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(I get a little higher amount now because of periodic Cost Of Living Allowance Increases (COLA))

Can you imagine going from living on \$3,000 per month to only \$1499? That's a 50% reduction!

STD also paid me \$3,000 per month for the 5 months I waited for my SSD to begin (\$15,000). Because I had proactively taken out STD and LTD while working, I was able

to continue paying the bills, buying groceries, and doing exactly as I was before I had to go out on disability.

If I had not had STD I would not have received anything for that 5 months and life would have been very tough at the Hardt house. You receive the full amount from STD (that you initially qualified for- in my instance \$3,000 per month) until you qualify for LTD.

Once you do this, you then get the full amount from LTD (that you initially qualified for- in my instance \$3,000 per month) until you qualify from SSD.

NOTE: Once you qualify for SSD, you need to let LTD know immediately as they will begin deducting the monthly amount you getting from SSD from their check. If you fail to notify them immediately, you WILL have to pay back the extra money they paid you when you were also getting a SSD payment.

The beauty is, you continue to get the same amount (that you initially qualified for- in my instance \$3,000 per month), it's just part is now coming from LTD and part is coming from SSD!

After being able to no longer work and having to go out on disability the amount I get from Long Term Disability was:

	\$ 952*
	\$1,499 (SSD)
TOTAL:	\$2,451*

*My total doesn't exactly add up to \$3,000 per month and here's why. After my wife divorced me, the 5 adopted children stayed with her. She received an additional \$550 per month for all of them, from SSD, under my disability benefit, until each of them turned 18. If you have underage children still living at home when you have to go out onto disability they get this extra amount. If you don't have any underage children still living at home when you go out on disability SSD will unfortunately not give you this extra amount.

This benefit is also calculated as if you were still married and still living at home also receiving the "benefit" of it. Since I was divorced LTD subtracted this amount from my benefit check. Because of this I claimed that it was part of my child support payments and the court accepted it. Had I still been married, instead of getting a \$952 monthly check from LTD I would have gotten \$1502 monthly check from them (\$952 + \$550)! \$1,499 monthly SSD benefit + \$1,502 monthly LTD benefit = \$3,001- exactly what I was taking home before!

SSD Only:

If you do not have STD and LTD and have to quit work because of HD symptoms and you immediately file for SSD, you will go without your regular monthly income for 4-6 months.

STD/LTD and SSD

In comparison, if you have STD and LTD and have to quit work because of HD symptoms, once you file for disability under STD, it will continue paying you a monthly check at approximately the 55% of your gross, which will be almost exactly what you were taking home while working full-time.

Can you see how having both STD and LTD will help you and your family tremendously?

More About Short-Term Disability (STD) and Long-Term Disability (LTD)

Once you decide that you are experiencing so many problems at work that it is too hard and too stressful for you to continue to work. Sometimes your situation at work is very precarious because you feel like you could be fired or demoted any moment because of all of the HD-related problems and symptoms you are experiencing.

You must decide to go out on STD and LTD before you get fired because once you are fired, you lose both of these benefits. If your boss or Human Relations (HR) calls you in to fire you, you MUST tell them right then that you are going out on STD and LTD and tell them that you do not accept being fired. Tell them you will contact them later with further details.

If they call you in and tell you that they are demoting you or transferring you to lesser responsibilities because of your problems, you MUST tell you are going out on STD and LTD because if they demote you to a lower pay rate and then you later go out on STD and LTD, they will only pay you 55% of the lower pay rate which will make it impossible to live on. You must go onto STD and LTD while at your current pay rate as this is what you and your family is living on. Taking home anything less will make it extremely hard to make ends meet.

Once management (your boss or HR) has initiated one of these scenarios, and you have told them that instead, you are going out on STD and LTD, you must immediately call the toll free number for STD and LTD and tell them that you are unable to work anymore and want to start disability the same day you're calling. If your employer initially won't agree to letting you go out on STD and LTD instead of being fired or demoted, explain to them that this is a win-win solution. You get to go out on STD and LTD because of your inability to work and your employer can hire someone to take your place as he doesn't have to carry you any longer on his payroll as an active employee. If your employer still refuses to assist you, just mention that you have no other option than to contact an advocacy expert and legal assistance to file a claim against him and the company as being in violation of the American's With Disabilities Act (ADA). Fortunately, most employers I have helped Phds talk to, have quickly seen the benefits of this win-win situation of allowing you go out on STD/LTD so they can hire a new worker. Realize that if your overall work performance has gotten to the point that your

company feels it has to take action against you, that your company being able to get you off their books (payroll) will probably be a relief to them, especially when they know that you are willing to go out onto STD and LTD and will be taken of financially.

Once you have used up all of your accrued vacation, sick day, and holiday pay hours, your employer should automatically make that time the start date for your STD. If they don't automatically put you out on STD you may have to call them to remind them to start it.

IMPORTANT: You should try to stick with the same employer too as once you reach tenure (10 years of service) most plans allow you to also continue your current medical, dental, vision, mental health plans as when you were a full-time employee. This will help you your family to live a much higher quality of life. If you only have SSD you will not qualify for any medical coverage (Medicare) until 2 years after being approved.

STD usually pays you for the first six (6) months after you have to quit working. During this initial six (6) months they will have you complete disability paperwork and will make appointments for you to see their own STD doctors to verify that you have Huntington's Disease. You must go to these doctor's appointments. Your spouse or a close family member should attend with you to add symptoms and problems you are having that you may omit and because you have problems remembering and get confused when having to answer questions.

They will have you sign a release to receive copies of all of your medical records. You should not have any medical records detailing that you have spoken to your PCP, Neurologist or Psychiatrist about Huntington's Disease. When you go into your appointment your spouse or close family member should go with you to add symptoms and problems you are having that you may omit and because you have problems remembering and get confused when having to answer questions. You should tell the STD doctor(s) that you don't know what is happening to you but someone mentioned that there might be Huntington's Disease in your family. If you have gotten tested anonymously you will then need to be tested again "in the open" so that the result of your DNA test becomes part of your medical records.

STD will continue paying your salary for six (6) months which is a little more than it will take to get approved for SSD, if you follow my guidelines implicitly, and if you call SSD right away, after contacting STD/LTD.

Once the STD doctors have approved you for disability you will then begin receiving the same amount from LTD. Once on LTD you may be required to have your Neurologist complete an annual "continuation of benefits" exam for you. I am putting the questions, yours may be similar, that you and your Neurologist will have to complete each time.

WARNING: Once you start receiving SSD you need to let STD/LTD immediately know how much you are getting and how much your children and wife are getting too as they will deduct the monthly amount you will be receiving from SSD from your LTD check. If you fail to notify LTD how much SSD you are receiving monthly, they will begin deducting this overpayment and this could result in you NOT receiving anything for several months.

Although SSD has a work program and you could conceivably earn up to a certain amount without jeopardizing your SSD, you should remember that you are applying for disability and this would send contradicting signals to everyone. In addition, any "legal" income you make will be reported to LTD and they will deduct whatever you have earned. The purpose of STD and LTD is to guarantee you the same amount of money while on disability that you were making while working full-time, not to give you more money than you were originally making.

You will still continue taking home the exact same amount, it's just part will be coming from SSD and part will be coming from LTD. (Please see my example in Figure 1 above).

General Questions for your Human Resource (HR) Department Regarding Your STD and LTD:

1) How long will my STD last before it converts to LTD? (Generally, STD lasts about 6 months while they send you to their doctors and gather pertinent medical information about you and HD from all of your existing doctors to verify you cannot work anymore.)

2) Will my STD wages remain level or will they decrease in 3-4 months?

(Generally, STD income will decrease after 4-5 months to encourage you to quickly comply with their requests to see their doctors.)

3) If you have any accrued sick or vacation time will they automatically start you on STD when these are used up or do you have to call in yourself to start the process?

4) What is the percentage of your current wages that LTD will pay you?

(Generally, this amount is 60%. Don't get scared. There is usually no taxes withheld from your LTD checks so the amount you actually take home will be almost exactly as much as what you were previously taking home!!)

5) Were my STD/LTD premiums paid pre-tax or post-tax? If they were post-tax then you will be liable to pay taxes on what you receive but most policies are pre-tax so there will be no taxes on your LTD checks.

FILING FOR DISABILITY

Instructions If You Have STD and LTD:

Contacting Short and Long-Term Disability and Social Security Disability, Using the Compassionate Allowance (CAL) Initiative for Faster Processing for SSD, to Start Your Disability Claims for Both

Here are the steps to take when you have proactively signed up for Short and Long-Term Disability (STD and LTD) and also Social Security Disability (SSD):

1. Once you have told your employer that you can no longer work you need to do the following:
 - a. Call your Short-Term Disability insurance company and notify them that you are unable to work anymore.
 - b. Call your Neurologist and/or Primary Care Physician (PCP) and make an appointment to see them immediately. Tell them you have quit work because it was too hard to go in each day.
 - c. Ask whoever can see you quicker, either your Neurologist or your PCP, to complete and sign a Work Release form for you stating that you are no longer to work and that you will be undergoing additional testing to determine what is the matter with you. You need to immediately give this to both your HR department at work and also to STD when they contact you back to make appointments for you to see their doctors.
 - d. Have your Neurologist order the DNA test for Huntington's Disease and also to refer you to a Neuropsychologist so you can take a Neuropsychological Exam, especially if you are primarily experiencing the "softer" symptoms of HD, the emotional, behavior and cognitive ones.
 - e. After you have talked with your Neurologist you should ask him to put a note in your medical record that you are unable to work any longer because of HD. (The letter at the very end of my answers to SSD's disability questions, by Dr. Dubinsky from KUMC, is an resource to ask your Neurologist or Psychiatrist to put into your medical file.)
 - f. If you are also seeing a therapist, be sure to contact them and tell them the same thing.

Note: When you call your Neurologist and/or PCP to make your emergency appointment they may schedule you two to three months in the future. Calendar this date and tell them this is an emergency because you're no longer able to work and have had to quit your full-time job to file for Short-Term Disability (STD). Simply ask them to put you on the doctor's cancellation list so you will be called early if anyone has to cancel. You should then hopefully get a call within a month. Be aware that the cancellation call will probably be in the morning for the same day appointment or in the

afternoon for an appointment the next morning. You must take these cancellations even though they are a little inconvenient. The sooner you see these doctors, the sooner your STD will be approved!

After filing for STD, read over all of instructions for how to file successfully for Social Security Disability (SSD). About 1 week after filing, follow the instructions in section 12 above and call Social Security to file for SSD. Please follow all of my guidelines to be approved the first time.

Social Security Disability (SSD) will also send you medical records releases to get copies of your medical records for disability eligibility determination. These are different than the ones you have already signed for Short-Term Disability (STD), that they will also use for disability eligibility determination. All forms you receive have got to be completed and returned to the appropriate source as soon as possible. Everyone knows that with HD you will have good days and bad days but please remember, when completing any forms, you need to answer the questions while remembering the worst days of your functioning, not your best. You should also follow this same guideline when meeting with any doctors too.

When STD sends you their disability application for you to complete, you must complete part of the application and then take the rest in to the doctor to complete and return to STD. Be sure to use the answers for SSD questions when you fill it out! Remember, you need to be as negative as possible, answering how things are on your worst days of functioning, not your best.

A representative from STD will contact you to schedule an appointment for you with one of their own Neurologists or Psychiatrists. This is one of the appointments you should not sleep the night before or dress up for. The sloppier you dress and sloppier your hair and everything else are the better!

When asked questions, you also need to remember your worst days of functioning when you answer them, not your best. Take your time in answering- pause a long time between every answer. Take the same information to your doctor's appointment as I recommend in section 12 for SSD. We have to educate everyone along the way about HD. Your spouse or close family member should drive you to your appointment as you should not be driving if you are disabled enough to be on STD and LTD. This doesn't mean that you still don't drive down to the corner grocery every now and then to get snacks but do not tell their doctors this. Your spouse or close family member should also ask if they can go in with you to the interview because of your "dementia," "confusion" and "memory loss" problems as they may need to answer some of the questions you get confused on and "redirect" some of your answers in case you are having a bad day and cannot remember correctly.

The day of your Neuropsychological exam you follow what I mentioned above in the preceding paragraph. You should also e-mail me or call me the week before so I can talk with you. This is imperative!

If you have not seen your primary care doctor yet, make an appointment with them and ask them to also put a note in your medical records that you are unable to work any more because of HD. Make sure your PCP also has a copy of your positive genetic DNA test in your file. What we are doing in each of these cases is establishing a "paper" trail that I explained the necessity of in my SSD instructions.

If you follow my instructions on how to file for STD and SSD you will NOT have the additional stress of having to see an additional Neurologist.

I strongly recommend that someone who doesn't have HD be asked to help you through this entire process. They should also be the one who completes your applications for you because of your dementia, confusion and loss of ability to understand and think clearly.

Don't worry, you'll do fine and remember, if you do have any questions or need additional help I will be there to assist you! I know that you are going to feel so much better after deciding to quit work and after completing your STD/LTD and SSD applications that you will wonder why you hesitated so long before doing it! Once you finally decide to quit you will find that many of the symptoms you have been experiencing will diminish too. Enjoy this time with your spouse, family and loved ones!

Please ask if you have ANY additional questions, either by calling me or e-mailing me.

Instructions If You Don't Have STD and LTD:

Contacting Social Security Disability, Using the Compassionate Allowance (CAL) Initiative for Faster Processing, to Start Your Disability Claim.

1. Call Social Security's national number: 1-800-772-1213 and request a phone interview with your local Social Security office. Tell them that you are filing a disability claim under the Compassionate Allowance (CAL) initiative. (If they haven't heard of it, or don't know what you're talking about, read them the information contained on my Compassionate Allowance page:



Compassionate Allowance Conditions

They will set up a date and time when someone from the local Social Security office will contact you for your interview. (The reason why I specify "phone interview" is because some of those with HD look okay physically and may not make a very good impression, as far as needing disability, if they go in person.) If they ask why you're requesting a phone interview tell them you can't drive anymore because of your cognitive symptoms. In my opinion, if you are still driving then you aren't disabled enough to apply.

2. The person taking your phone application will mail you an application packet, medical release forms, and a confirmation letter of the date and time for your phone interview.

3. You need to have your spouse or another family member or friend who knows you well there for the telephone interview. You should ask the SSD representative if your spouse, family member or friend, can do the interview for you because you get confused because of your Huntington's Disease and may forget important information. They will have you give them verbal authorization for them to talk with whomever else is there and then that person can give them the basic information they ask for.

Representative Payee

You should also tell the Social Security Representative on the phone that you wish to be the Representative Payee for your Spouse or family member. You will need a Representative Payee sooner or later and mentioning it during your initial and subsequent interview with Social Security will signal them that you are so disabled that you need someone else to manage your money for you. It doesn't matter if you are still able to do some money management things now as no one needs to know.

Attachments To Enclose With Your STD/LTD and SSD Disability Applications

I'm having you attach several brochures from HDSA, the non-profit organization for HD in the United States, one from the National Institutes of Health (Federal Government) and one from a major university (Kansas City) to increase credibility of the information you're sending. In addition, you need to attach a copy of the document showing your own DNA Analysis to prove you are actually carrying the HD gene.

Information from the following brochures and URLs should be printed out and the information **highlighted in yellow** and enclosed with your application for SSD: Include the following five informative sources:

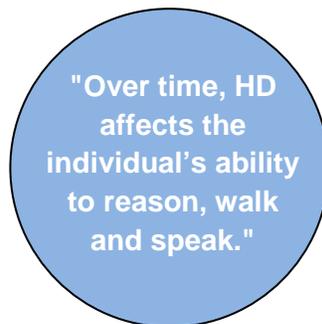
1. "Fast Facts About HD" To order one free copy from HDSA call 800-345-HDSA or ask you local chapter or affiliate for a copy. Here is the link to download it if you have a printer:

Fast Facts About HD

On this brochure, I would neatly highlight the following areas with a yellow Highlighter:

"Presently, there is no effective treatment or cure."

and



and

"Symptoms Include:

- Personality changes, mood swings and depression
- Forgetfulness and impaired judgment
- Unsteady gait and involuntary movements
- Slurred speech and difficulty in swallowing"

2. The second pamphlet is: "Huntington's Disease, A Guide For Families" To order one free copy from HDSA call 800-345-HDSA or ask you local chapter or affiliate for a copy. Here is the link to download it if you have a printer:

[Huntington's Disease, A Guide For Families](#)

Inside this brochure I would neatly highlight the following areas with a yellow Highlighter:

Pages 8-9 Movement Disorders

"Abnormal movements are the most visible symptoms of HD. Early signs of HD may include clumsiness, loss of balance and fidgeting. Problems with movements may include quick involuntary movements, known as chorea, twisting postures known as dystonia, and reduced speed and accuracy of fine movements. The movement disorders of HD are often accentuated with stress or excitement."

and

Pages 11-12 Cognitive Disorders

"HD causes more than movement disorders. It also affects the ability of the brain to understand, organize and retain information. Changes in cognition (the ability to think) can be an initial indicator of HD. HD progressively affects cognitive functions such as: organizing and prioritizing, controlling impulses, beginning and ending activities, creative thinking and problem solving. The person with HD may become forgetful, distracted or reckless."

and

Page 13 Emotional/Behavioral Disorders

"Among other things, HD causes progressive damage to the nerve cells in the brain that regulate thoughts and feelings. These unregulated emotions, caused by the disease, may cause mood swings and irritability. The patient may overreact to everyday events.

People with HD may say cruel things or behave aggressively because of the changes in their brains. It is important to know when it is the disease "talking" and not the patient."

Paperclip the pamphlet open to page 12 after you have highlighted everything noted above.

3. I would also print out the following web pages, making sure to include the information about where they are from to ensure credibility.

The first web page to click on and print out is:

[National Institute of Neurological Disorders and Stroke](#)

[National Institutes of Health](#)

Under, "What are the Major Effects of the Disease?" I would neatly highlight the following text with a **yellow Highlighter**:

"HD may affect the individual's judgment, memory, and other cognitive functions. Early signs might include having trouble driving, learning new things, remembering a fact, answering a question, or making a decision. Some may even display changes in handwriting. As the disease progresses, concentration on intellectual tasks becomes increasingly difficult."

"In some individuals, the disease may begin with uncontrolled movements in the fingers, feet, face, or trunk. These movements—which are

signs of chorea—often intensify when the person is anxious. HD can also begin with mild clumsiness or problems with balance. Some people develop choreic movements later, after the disease has progressed. They may stumble or appear uncoordinated. Chorea often creates serious problems with walking, increasing the likelihood of falls.”

“The disease can reach the point where speech is slurred and vital functions, such as swallowing, eating, speaking, and especially walking, continue to decline. Some individuals cannot recognize other family members. Many, however, remain aware of their environment and are able to express emotions.”

4. The second web page to click on and print out is:

[Kansas City Medical Center](#)

I would neatly highlight the following text with a **yellow Highlighter**:

“The clinical features of Huntington's disease can be thought of as a triad of emotional, cognitive and motor disturbances. Symptoms include chorea (dance-like involuntary movements), clumsiness, slurred speech, depression, irritability and apathy. Cognitive losses include intellectual speed, attention and short-term memory.

Huntington's disease affects people in different ways. One member of a family may have more trouble with clumsiness while another may have emotional outbursts. Moreover, symptoms of Huntington's disease in the same individual change over time.”

Your Own HD DNA Results Report

5. On your Diagnosis Service Report I would highlight the following text with a **yellow Highlighter**: "This individual possesses the Huntington's disease CAG mutation and therefore is predicted to be affected with or predisposed to developing the clinical symptoms associated with Huntington's disease." Please see my own DNA report below for an example.

Genetic Diagnostics, Inc.		One South Park # 100 Executive Plaza Worcester, Massachusetts 01602 (508) 334-4499 * (508) 738-2888	Page 1 of 1 Diagnosis Service Report <small>© 1997 Genetic Diagnostics, Inc. All Rights Reserved</small>
Order: Philip Ward		Requesting Physician:	
Date of Birth: 03/03/56	Sex: M	Book# (Genetic Diagnostics): 000000000	Request for: Smitiklin-Beecher Clinical LA
Specimen Type: Whole Blood		Address: Ahn - Lab Reference/Genetic Clin	Accession Number: 97000849
Test Category: Presymptomatic		7600 Tysons Avenue	Physician/Physician Assistant:
Test Requested: Huntington's Disease DNA Test		Van Nuys, CA 91405	Referral Number: WD1267090
		Additional Request by:	Specimen Collection Date: 01/08/97
			Accession Date: 01/10/97
			Report Date: 01/11/97
Interpretation: This individual possesses the Huntington's disease CAG mutation and therefore is predicted to be affected with or predisposed to developing the clinical symptoms associated with Huntington's disease.		Comments: This analysis identified an abnormal IT15 allele with greater than 36 CAG repeats (Huntington's disease full mutation) and a normal IT15 allele with less than 31 CAG repeats. Therefore, this individual is predicted to be affected with or predisposed to developing the clinical symptoms associated with Huntington's disease. Due to the current state of the technology, repeat sizes in large expansions are an estimate. This disease analysis, as performed here, is greater than 99% accurate.	
Technical Results: IT15 allele 1: 39 CAG repeats IT15 allele 2: 17 CAG repeats		Although individuals with an IT15 allele in the full mutation range are likely to develop symptoms associated with Huntington's disease, clinical prognosis and age onset and rate of progression cannot be predicted based on the CAG repeat size.	
Reference Range:		This is an autosomal dominant disorder; therefore, family members are at risk for possessing or inheriting this mutation. Genetic counseling for this individual and his/her family members is recommended.	
Reference Category	Number of CAG Repeats	References:	
Normal	Less than 31	1. Andrew, S.H. et al. <i>Human Mol. Genetics</i> 1994; 3: 67-67	
Intermediate	31-38	2. Goldberg, Y.P. et al. <i>Human Mol. Genetics</i> 1993; 2: 631-636	
Full Mutation	Greater than 38	*** FINAL REPORT ***	
Methods: Direct testing for the Huntington's disease mutation (abnormal expansion of the CAG tandem repeat in the IT15 gene) was performed by PCR amplification and/or Southern blot analysis of genomic DNA.		This test is performed pursuant to a PCR license agreement with Roche Molecular Systems, Inc.	

6. Once you have printed out all of the documents noted above and **highlighted the text that I've instructed you to in yellow**, please enclose all of these papers with your SSD application (even though they say not to add any other paperwork).

How to Effectively Answer Questions On Social Security's Disability Application Using Several Actual Applications. NOTE: You Can Also use Similar Answers to Complete your STD and LTD Application

Disability Report Adult - Form - SSA-3368-BK

Section I – Information About the Disabled Person

Questions A-I

Self explanatory

Section II – Your Illnesses, Injuries or Conditions and How They Affect You What are the illnesses, injuries or conditions that limit your ability to work?

Huntington's Disease is a degenerative brain disorder for which there is no cure. My symptoms have been cognitive (forgetting, inability to do two things at once, ability to comprehend is slowed and decreased, can't complete even simple tasks), mental and emotional (irritability, loss of social inhibitions, confusion, apathy, can't control my anger anymore and severe depression), physical (clumsiness, loose balance frequently, awkward gait, uncontrolled chorea movements all over my body). Symptoms will continue to get worse until I can't walk, talk or swallow any more.

How do your illnesses, injuries or conditions limit your ability to work?

Increasing forgetfulness and loss of short-term memory make it almost impossible to perform even routine tasks. Any stress caused by due-dates or schedules exasperates symptoms and makes my symptoms more exaggerated than they already are. Unabated emotions, especially irritability and loss of social inhibitions makes working with others extremely hard as I blow up easily and tell everyone exactly what's on my mind, and then don't care what I have said or who I have offended. Constant chorea movements and lack of balance control makes it impossible for me to type, hold things, or get things.

C, D, E F & G

Self-Explanatory

H If "yes," did your illnesses, injuries or conditions cause you to: (Check all that apply.)

- work fewer hours? (Explain below.)

- change your job duties? (Explain below.)
- make any job-related changes such as your attendance, help needed, or employers? (Explain below.)

All of the above. Huntington's Disease is an incurable, degenerative brain disorder and once symptoms start they continue to get worse and worse until you are afraid to do anything and lose the ability to do simple ordinary tasks. It continues to worsen almost daily.

I.

Self-Explanatory

J. Why did you stop working?

I stopped working because my disease has progressively gotten much worse and degenerated to the point where I can no longer control my emotions, think properly, remember things, or make good sound decisions. I get confused in once-familiar surroundings and fear, because of my lack of balance and severe chorea movements, that I will either hurt myself severely or do something that will hurt someone else.

Section III – Information About Your Work
Questions A-G

Self-Explanatory

Section IV – Information About Your Medical Records

Questions A-C, D1,2 and 3 and E1 and 2 and F

Self-Explanatory

Section V – Medications

Self-Explanatory

Section VI – Tests

Self-Explanatory (We will describe the genetic test under Section 9.)

Section VII – Education/Training Information

Self-Explanatory

Section VIII – Vocational Rehabilitation Information

A)

Self-Explanatory

B) Would you like to receive rehabilitation that could help you get back to work?

- Yes
- No

Check No and write in: Vocational Rehabilitation is not helpful when you have Huntington's Disease Dementia because ability to learn and remember new tasks is poor and because I am more slow and disorganized than before. My poor motor coordination, balance, and constant chorea prevents safe employment in manual labor.

Section IX – Remarks

Huntington's Disease is an incurable, degenerative brain disorder that affects every part of an individual's life. Characteristic features of HD include involuntary movements, dementia, and behavioral changes. Family members may first notice that the individual experiences mood swings or becomes uncharacteristically irritable, apathetic, passive, depressed, or angry. These symptoms may lessen as the disease progresses or, in some individuals, may continue and include hostile outbursts or deep bouts of depression. HD may affect the individual's judgment, memory, and other cognitive functions. Early signs might include having trouble driving, learning new things, remembering a fact, answering a question, or making a decision. Some may even display changes in handwriting. As the disease progresses, concentration on intellectual tasks becomes increasingly difficult. In some individuals, the disease may begin with uncontrolled movements in the fingers, feet, face, or trunk. These movements—which are signs of chorea—often intensify when the person is anxious. HD can also begin with mild clumsiness or problems with balance. Some people develop choreic movements later, after the disease has progressed. They may stumble or appear uncoordinated. Chorea often creates serious problems with walking, increasing the likelihood of falls. The disease can reach the point where speech is slurred and vital functions, such as swallowing, eating, speaking, and especially walking, continue to decline. Some individuals cannot recognize other family members. Many, however, remain aware of their environment and are able to express emotions.

Older Social Security Disability Application

Here are examples of how I would fill out the questions on a disability application, whether it be applying for LTD (Long Term Disability) or SSD (Social Security Disability), or another State sponsored disability program. Although YOUR individual symptoms may be slightly different, which will change your individual answers to each question, more importantly I hope you get the gist of how I've tried to answer the questions, using HD symptoms in your explanations. Once again, I'm not saying that this is the only way to do this, but hope it will help provide others who are starting this process with ideas. If you feel like you still need a little extra help, please e-mail me your symptoms or problems you've been experiencing at work or home, or the symptoms or problems your loved one is experiencing at work or home and I will be happy to help you out!

1-Describe your symptoms:

HD is a degenerative brain disorder for which there is no cure. My symptoms have been primarily cognitive (forgetting, inability to do two things at once, ability to comprehend is slowed, comprehension is decreased), mental and emotional (irritability, loss of social inhibitions, confusion, apathy, running red lights and don't care, can't focus on simple tasks, can't control my anger any more), physical (clumsiness, uncontrolled movements all over my body, loose balance frequently). See enclosures for additional information.

A. What brings on your symptoms or makes them worse?

Stress and fatigue aggravate symptoms

B. If you have pain where is it?

N/A for Huntington's Disease

C. How often do your symptoms occur like day or week?

Intermittently all the time.

D. Have your symptoms changed since you began having them?

They've become more noticeable to me and others and have progressively gotten worse.

E. How does your impairment affect your ability to complete routine activities or chores?

Increasing forgetfulness and loss of short-term memory make it extremely hard to perform routine tasks. Unabated emotions, especially irritability and loss of social

inhibitions, make working with others very hard. Loose temper too easily and don't care either.

2-Do you take medicine?

Yes

A. What kind?

Anti-Depressants to control depression and suicidal thoughts that are inherent with HD.

B. How often?

Daily. Will never be able to discontinue, only increase.

C. Does medicine help?

Currently, but from what I've read, will have to be increased continually.

D. Is there anything else you do to relieve your symptoms?

Nothing. There is no cure for Huntington's Disease and it is degenerative- my inability to perform normal, everyday things is getting harder and harder which really frustrates me. HD keeps getting worse until you die.

E. What do you do for exercise?

Water yard when balance is okay.

F. Describe what I do on an average day?

I get up late because of poor sleep, have to have breakfast fixed for me as I can't remember how to cook and because I drop things and burn things and burn myself. I need help getting dressed and must be told what to wear because I can't decide. I can't read because I get confused and if distracted I completely lose my train of thought. I watch TV mostly and am not able to remember some characters now or the plots. I like to go shopping with my spouse. They must drive because I've had too many accidents and near misses. I can't handle money any more so my spouse must pay for everything. I try not to walk very far of I fall because of balance, walking and chorea problems. I loved to garden but now I find myself falling flat on my face when I bend over to weed a row so I can't do this either. I used to go for short walks but now, because of my dementia, forgetfulness and confusion I get lost too easily, even in areas that were familiar in the past.. I used to cook most meals but now can't remember how to fix meals

and if I'm reading a mean, I get distracted and can't remember what I was doing if the phone rings, or if someone comes over. I must be reminded every morning and evening to take my medication or I won't remember. I have started choking when I eat my meals and this is very alarming to me. I need assistance getting into my Pajamas at night and must be reminded to brush my teeth too.

7-What activities are you NOT able to do now because of your symptoms that you were able to do in the past?

Afraid to do almost everything now as I have lost my self-confidence.
work/housework Burned self with grease because of clumsiness 3-4 times, got written up 3 times for being rude to customers, drop and spill things continually.
Recreation, personal care like grooming bathing, dressing I'm still able to do unassisted for now but much slower than before. Too confusing sometimes too.

8-Do your symptoms affect your ability to do these things **YES** or **NO**?

- *sitting*: uncontrollable muscle jerks and twitches make sitting difficult
- *standing*: intermittent loss of balance causes problems sometimes
- *walking*: is starting to be harder and I find myself focusing on each step
- *lifting/carrying*: afraid to lift or carry for fear I'll drop load if uncontrollable jerk happens
- *using your hands*: more clumsy now, cut self frequently, and drop things often
- *bending*: unaffected yet
- *kneeling, squatting*: harder when experiencing balance problems climbing - don't climb because I'm afraid of loosing balance while on a ladder
- *reaching forward*: loss of balance makes uncomfortable at times working or reaching overhead: loss of balance makes uncomfortable at times
- *hearing*: interpretation or comprehension of words is getting worse and must have others repeat things often
- speaking: already experiencing problems remembering words, no slurring yet, vulgar when I loose temper traveling to are from work: Have begun running red lights and will have to quit driving very soon.
- *reading the newspaper*: can't do any more because of loss of attention span
- *watching TV*: can't remember who is who or what's happening so isn't enjoyable any more
- *driving the car*: have already stopped driving because of repeated accidents and I'm afraid of killing others or family when running red lights
- *using the telephone*: takes long time to recognize voices and to recall numbers to dial. If people leave me messages I don't remember them later.
-

9-Your height:

INPUT YOUR HEIGHT HERE.

10-Names of 2 people we can call who know of your condition?

WOULD INCLUDE YOUR FAMILY DOCTOR, NEUROLOGIST, PSYCHOLOGIST, PSYCHIATRIST, OR OTHER FRIENDS.

11-Do you have any significant mental problems or emotional? If yes explain.

Those normally associated with HD, dementia, personality changes, drastic mood swings, loss of social inhibitions, cognitive decline, etc.

12-Do your mental emotional problems affect your day to day living or working? If yes explain.

Don't want to get up in morning, medication helps a little but makes sleepy and slower and dulls emotions

13-Have you ever received any mental or emotional treatment tell why if yes.

IF YOU'VE BEEN TO A PSYCHOLOGIST OR PSYCHIATRIST PUT THEM HERE, OTHERWISE PUT "NOT YET"

14-Do you think you need a mental or emotional evaluation in regard to YOUR disability benefits? If yes tell why.

Possibly, since cognitive and emotional symptoms are all part of HD.

15- Do you have a counselor?

PUT IN NAME OF YOUR PSYCHOLOGIST OR PSYCHIATRIST IF YOU'VE SEEN ONE REGARDING HD OR HD-RELATED SYMPTOMS.

16-Do you need another person help or need reminders or supervision in performing/completing the following activities? If yes, explain. **Yes** or No

- *bathing*: **Yes, don't see need to bath any more**
- *brushing your teeth*: **Yes, need help remembering to brush teeth**
- *fixing your hair shaving*: **Yes, Because of movements must use electric shaver because have cut myself before using razor**
- *selecting appropriate clothing*: **Yes, can't decide which clothes to wear**
- *cooking*: **Yes, keep forgetting to turn off burners and stove**
- *paying bills*: **Yes, have problems remembering when they're due or where I put them to be paid**
- *visiting*: **Don't visit because I can't drive anymore**

shopping/making change: **Slower than normal and not accurate at times**

- *riding the bus:* **Maybe, get confused often and may lose directions. Have gotten lost before in familiar surroundings and own neighborhood.**
- *taking care of children:* **No, all children are grown up**

17-Do you have difficulty keeping your mind or attention on a task/activity? If yes explain.

Yes, get distracted easily now, can't focus or remember well.

18-Do you have difficulty completing task? If yes, explain.

Same as 17 above.

19-Do you have problems making decisions? If yes, explain.

Yes, can't make up my mind or I act impulsively and do things I would have never done before.

20-What upsets you?

Change. Noise. Multiple instructions. Become frustrated not being able to perform as well as I did before. Can't control my emotions anymore.

21-When your daily routine changes how do you react?

I can't cope well and find myself unable to figure out what to do next.

22-When you have stress /or pressure how do you react?

My chorea movements increase and I become more animated and begin to slur my words and not think logically. I also lose my temper easier.

How often does it happen?

Depends on what "triggers" it during the day. Sometimes something small and sometimes something big. I try to avoid anything that would be stressful now like never using the freeway and never driving during rush hour, keeping radio off so there are no distractions, etc.

23-How do you get along with other people?

I have a very short fuse now and say exactly what's on my mind. Before I know I've done it I've told someone off. I am very aggressive now and don't care what others think or if I've hurt them with what I've said.

Another Disability Application: “Activities Of Daily Living Questionnaire To Claimant”

I. Self-Care Activities

1. Please describe what you do on an average day:

I get up, need help showering, grooming and dressing because of constant movements, loss of coordination and having to balance myself on something else continually. Can fix something simple to eat but eating requires extra time because of chorea movements. I'm afraid to use burners on stove because I've forgotten to turn them off for several hours before. I can't even clean a little any more because even small things tire me out too easily and must take constant breaks. Finishing tasks is hard because if the phone rings or I'm interrupted, I forget what I started to do before. I watch TV or listen to the radio. I can't read any more either because I can't focus and because of constant chorea movements. I can't drive any more so I just stay at home.

2. Do you need help taking care of your personal needs, bathing and grooming? _ Yes
_ No

If yes, what kind of help? Increasing forgetfulness and need for constant assistance accomplishing routine things such as showering, dressing, and grooming because of balance problems and constant chorea.

3. What is the most difficult self-care activity for you to do and why?

Every single self-care activity is extremely hard because of chorea, short-term memory loss, and balance problems.

4. Describe any change in your ability to do these self-care activities since your condition began and explain the cause for the change:

My ability to care for myself will only worsen as my degenerative brain disorder, Huntington's Disease continues to get worse.

5. Do you take any medications for your condition _ Yes _ No If yes, please list the names and how often you take them.

I take Zoloft, an antidepressant daily to control depression and suicidal thoughts that are inherent with Huntington's Disease. I will never be able to stop taking it, and will eventually end up increasing dosage as disease progresses.

II. Home Activities

1. Where do you live (house, apartment, mobile home) and who lives in the household with you?

I live with my husband/wife.

2. Do you plan and cook your own meals? _ Yes _ No If no, do you normally not cook, or are you unable because of your condition? How does it prevent you?

It is too confusing to plan meals ahead or to cook more than one thing at a time. I am too afraid that I will leave a burner on again and possibly burn the house down. I used to cook all the time and loved preparing meals for my family.

3. Do you do the household cleaning, clothes washing, yard work or any other work around the house. _ Yes _ No If no, why not? If yes, please describe what you do:

I cannot clean anymore because I knock things over or spill them because of my chorea and balance problems, and get too exhausted.

4. When you start a job, like washing dishes or cleaning a room, do you have trouble finishing the job _ Yes _ No If yes, what happens?

Yes, if I get interrupted or see something else in the room that catches my attention I lose focus and forget what I was doing and leave the job half done. I can't wash dishes or clean anymore because of my chorea movements and balance problems. Even when I try to help out I don't clean everything as well as I once did and although I realize this, I don't care now.

5. Do you do any shopping _ Yes _ No If yes, describe what you shop for, how often and how long it takes you to shop.

No, I haven't been able to drive for over 4 years now and must rely on others to take me with them. Can't do shopping any more because I don't have the strength or balance to any more. My chorea has knocked things on the floor and broken them before.

6. Please describe any changes in your ability to do these activities since your condition began and explain the cause for the changes.

Everything has gotten worse. There is no cure for Huntington's Disease and it is degenerative- my inability to perform normal, everyday things is getting harder and harder which really frustrates me. HD keeps getting worse until you die.

III. Social and Recreational Activities

1. Do you get along well with the people in your household _ Yes _ No Explain.

Unabated emotions, especially anger and irritability, when combined with loss of social inhibitions make me blow up and scream and yell and throw a temper tantrum at any little thing, or if I don't get my way. Everyone must walk on eggshells around me for fear of setting me off.

2. Do you get along well with other people in general. _ Yes _ No Explain.

I used to before becoming emotionally volatile and loosing my temper for any little reason. Others don't understand this disease and why I am like I am now. I guess it's scary to them.

3. How often do you visit with friends or relatives?

I don't visit very often because most of my friends quit coming by after my diagnosis. It's hard for them to take me declining and behaving uncharacteristic of the person they once knew. We make time to stay with relatives now but not for long as I don't want to be a burden to them and it's not as frequently as we used to.

4. Are you active in any religious club(s) or any other groups. _ Yes _ No How often do you go?

I cannot participate any more because of not being able to drive and being too much responsibility for someone else to come and pick me up. My speech is also unintelligible and I cannot initiate conversations. Others are afraid I'll fall and hurt myself.

5. What are your hobbies or pastimes (reading, handicrafts, hunting, biking, hiking, bowling, watching TV, etc.)?

I cannot do anything I loved to be before because of coordination and chorea-related problems. I can't focus long enough to read and don't enjoy it anymore because of terrible short-term memory, I can't remember what I just read about and this frustrates me.

6. Describe any changes in these social and recreational activities since your condition began and explain the cause for the change.

I have been unable to do any of my favorite things since progressing and I will loose even more as Huntington's Disease relentlessly progresses. Since I've also lost most of my self-confidence I'm even afraid to try anything either.

IV. Errands

1. Do you drive a car _ Yes _ No

I haven't been able to drive for over 4 years now.

2. Do you use the bus _ Yes _ No

No I cannot. I can't remember where I'm going and get lost easily. Can't walk to bus stop anyway.

3. Do you run errands by yourself (like going to the post office) _ Yes _ No

No, I cannot run any errands as I cannot get around by myself.

4. Do you manage your bills and other business matters _ Yes _ No

I am no longer able to stay focused long enough or even remember how to do most everyday things like paying bills anymore. Very frustrating.

5. Do you use the telephone book to find a number you do not know _ Yes _ No

Can't call out using a phone and can't use a phone book either.

If no to any of the above questions, please explain here.

Already explained with each question above.

1. Have any of these things changed since your condition began. _Yes _ No Why did they change?

I haven't been able to do anything listed above for over 4 years and as Huntington's Disease is degenerative and as more brain cells continue to die I will be unable to do more and more.

2. Have you tried to work since your disability began _ Yes _ No
What happened?

I haven't tried since everything is already too frightening and without any self-confidence I fear I would just feel worse and more frustrated about my inability to do what I used to do than I already do.

Sample Disability Letter

The ability to work and be productive is integral to our and others perception of ourselves. When a person has a disease or disability that prevents them from working as they used to be able to, they still should be able to work in a different fashion. In some countries the issue of disability is handled by the family taking over the support and care of the person who can no longer care for themselves or be employed. In other countries a significant governmental safety net is available to provide supportive and rehabilitative services. In some countries, such as the United States, the safety net is available (in late 1995) but only after some significant hurdles have been overcome to prove that the person in question is not able to care for themselves any longer.

The letter below has been slightly changed from the sample given in the back of the book by Neal Ranen from the Huntington's disease Clinic at The Johns Hopkins University.:

December 12, 1995

Enid Jones
1239 Springfield
Springfield, MO 12345
Re: Thomas Smith, KUMC No 1234567

Dear Ms. Jones;

This is to provide medical support of the disability application of Mr. Thomas Smith who has Huntington's disease.

Mr. Smith was seen in our Huntington's disease clinic for the first time on November 15, 1994 and was diagnosed as being affected with Huntington's disease (HD). Symptoms began in 1993. We have followed Mr. Smith since then and are confident of the diagnosis based upon clinical observations and his positive family history of relatives (father, uncle and his sister.) with Huntington's disease. MRI findings on September 19, 1995, included atrophy of the caudate nuclei and the cerebral cortex.

Huntington's disease is an inherited neurodegenerative disorder that is gradually progressive, ending in death from infection of general debilitation an average of 16 years after onset.

There are three characteristic clinical features: (1) loss of the ability to control bodily movements; (2) loss of ability to think and to act quickly, to learn and to remember and (3) apathy and severe depression, often resulting in suicidal behavior. Patients also exhibit poor social judgment and may be irritable and aggressive.

When last examined on December 15, 1995, Mr. Smith had abnormal eye movements, slow/dysarthric speech, poorly coordinated finger-thumb tapping, and rapid alternating movements, a wide-based gait with poor heel to toe walking, choreiform movements

and brisk deep tendon reflexes. He is at high risk for falling. The sensory examination, Romberg and cranial nerves are not affected in Huntington's disease.

Mr. Smith is slow and inaccurate with calculations, has poor recent memory, and at home cannot remember to carry out routine tasks such as: taking telephone messages, cooking or doing the laundry. His employer reports that he can no longer perform his duties on the assembly line. Frequently he made costly errors in filling customer orders when he was moved to a less demanding job in the factory. For these reasons, he cannot work there any longer. The patient last worked on July 26, 1995.

We do not routinely administer IQ tests to people with Huntington's disease for purposes of disability assessment. Although they decline, the IQ remains above 70 and does not adequately reflect the person's ability to work. This is because the person can perform some tasks when continually prompted, as is the case with IQ testing. However, people with Huntington's disease cannot perform even a simple sequence of tasks unprompted as would be the case at even a low job level.

Vocational Rehabilitation is not helpful to people with Huntington's disease, Their ability to learn new tasks is poor. They are slow and disorganized. Their poor motor coordination prevents their safe employment in manual labor.

Mr. Smith has suffered from depression associated with Huntington's disease since 1994. He is apathetic and irritable. These symptoms also interfere with his ability to work. In summary this 39 year old man was well until 1994 when Huntington's disease began. He has been unable to work since September 30, 1995 because frequent costly job related errors and the fact that he can no longer drive to work because of his Huntington's disease.

We hope that you will grant disability to the fatally ill individual. If you wish further information, please call us at (xxx) xxx-xxxx.

Sincerely yours,

Richard M. Dubinsky, MD
Associate Professor of Neurology
pc: Dept. of Medical Records, KUMC

cc: Mr. Thomas Smith
789 West 3rd Street
Kansas City, MO 65432

Please contact Phillip Hardt if you have ANY questions or need help completing your STD/LTD or SSD applications! Phil can be reached at: phardt1@cox.net or you can call him at 602-309-3118.

Revised 1-26-2012