



## Disability and Legal Preparation for Early-Mid Stage symptomatic HD

**Medical Care:** Medical care is essential for obtaining many of the disability and legal benefits that will be needed for a symptomatic HD individual. Medical evidence provided by regular medical care is the only fact based way to provide support for all disability claims.

- Receive regular medical care:
  - See your medical providers at least once per year
    - Primary care physician
    - Neurologist
  - Be honest with your medical providers about the severity of your symptoms
- Start care with relevant specialists:
  - Neurologist
  - Psychiatrist
  - Physical or occupational therapist
- Speak with your medical providers about disability:
  - You will not be approved for disability if you do not have support from your medical providers
  - Medical providers will need to complete disability forms

**Disability:** There are many disability options that provide financial protection in the event you have to stop working due to HD: Temporary State Disability, Short-Term Disability, Long-Term disability, Employer Funded Disability, and Social Security Disability. It is very important to figure out what benefits you are eligible for and to follow the application instructions. All of these disability programs require proof of HD in order to be awarded benefits

- Determine what disability benefits you are eligible to receive:
  - Temporary State Disability – only for California, Hawaii, New Jersey, and New York, and Rhode Island
  - Short Term Disability – provided by employer
  - Long-Term Disability – provided by employer or private policy
  - Employer Funded Disability – provided by employer or private policy
  - Social Security Disability – federal benefit available to most Americans

- Short Term Disability:
  - Ask Human Resources Department for a copy of the short-term disability benefits form
  - Complete the form
  - Ask employer to complete employer section of the form
  - Get medical verification from healthcare provider
  - Submit the form
- Long-Term Disability:
  - Read copy of policy to determine:
    - Timelines you are required to meet
    - What information must be submitted to prove claim
    - What “disabled” means for your specific insurance policy
  - Work with Human Resources Department or Insurance company directly to make sure claim is submitted correctly
  - Submit your claim promptly
    - Most claims only give you 60 days after your HD impacts your ability to work
  - Gather all necessary medical records to submit to insurance company
- Employer Provided Disability:
  - Read copy of policy to determine:
    - Timelines you are required to meet
    - What information must be submitted to prove claim
    - What “disabled” means for your specific insurance policy
  - Work with Human Resources Department or Insurance company directly to make sure claim is submitted correctly
  - Submit your claim promptly
  - Gather all necessary medical records to submit to insurance company
- Social Security Disability:
  - Gather information required for claim:
    - Social Security card or number
    - Proof of Age (birthdate or birth certificate)
    - Citizenship or alien status record (birth certificate, naturalization certificate, US passport)
    - Proof of Income
    - Medical Sources
    - Work History
  - Decide how to submit application:
    - Online – <https://www.ssa.gov/benefits/disability/>
    - Over the phone
    - In-person (not an option during COVID Pandemic)
  - Complete and submit application
  - Follow-up with Social Security regarding status of claim and verify that your medical records have been received
    - Find local Social Security office here: <https://secure.ssa.gov/ICON/main.jsp>

**Health Insurance:** Health insurance is essential for the continuation of medical care and for long-term care placement for HD individuals, when the time comes. Private disability insurance usually does not include health insurance and there is a 24 month waiting period for Medicare if you are approved for Social Security Disability Insurance (SSDI), so it is very important to plan for the waiting period and choose another health insurance option.

Health Insurance Options:

- Insurance through spouse
- COBRA
  - Continuation of employer provided insurance at full cost
  - Often very expensive
  - Lasts for 18 months with a possible 11 month extension if approved for SSDI -> covers full Medicare waiting period
- Private insurance
  - [www.Healtcare.gov](http://www.Healtcare.gov)
  - <https://www.policygenius.com/>
- Medicaid
  - Has been expanded in 39 states so many Americans can now qualify

Health Care Assistance Options:

- Low-income assistance program
  - Most major hospitals and health care systems offer low-income and uninsured financial assistance
- Community health centers
  - <https://www.healthcare.gov/community-health-centers/>
- Speak with medical providers about financial assistance options

**Legal Decision-Making Documents:** Legal decision-making documents give someone else, a person you choose, the right or the ability to make decisions for you because you are not able to make the decision. There are many reasons you may not be able to make a decision: out of the country, unconscious, incapacitated due to Huntington's disease or another medical condition.

Power of Attorney (POA):

- Must contain the date of execution
- Must be signed by the individual granting the POA
- Must be signed before a notary public and/or signed by two witnesses (state specific)
- Needs to name the person who you want to act on your behalf as your "agent"
- Needs to define what powers the person will have to act on your behalf, like handling financial and business transactions, which includes buying or selling a house
- <https://formswift.com/power-of-attorney>
- <https://powerofattorney.com/>

Healthcare Power of Attorney

- Must contain the date of execution
- Must be signed by the individual granting the POA
- Must be signed before a notary public and/or signed by two witnesses (state specific)

- Needs to name the person who you want to act on your behalf as your “agent”
- Needs to define what medical decisions the “agent” will be able to make on your behalf, for instance where you can get medical treatment, what medications you can take, or if you can get surgery.
- Advanced Directive/Living Will
  - Choose a medical decision maker
  - Decide what matters most in life
  - Choose what decisions your medical decision maker is able to make
  - Tell Others (physicians, family) about your wishes
  - Make sure to speak with your doctors and ask questions
  - <https://prepareforyourcare.org/welcome>