



Disability and Legal Preparation for Late-Stage symptomatic HD

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. **If you have reached late-stage HD and have not already applied for disability then your options will likely be limited to only Supplemental Security Income and you will need to meet the strict financial criteria and have less than \$2,000 in resource as an individual or \$3,000 as a married couple.**

- Social Security Disability - Supplemental Security Income:
 - 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
 - Earned income
 - Spouse's income
 - Value of Assets and Resources
 - Checking and Savings accounts
 - Personal property
 - Cars
 - Life insurance policy
 - Retirement account
 - Money set aside for burial expenses (up to \$1500)
 - Medical Sources
 - Work History
 - Decide how to submit application:
 - Online – <https://www.ssa.gov/benefits/disability/> (not available for all SSI applications)
 - 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. Most health insurance does not cover long term care costs so it is necessary to plan accordingly for long term care.

Health Insurance Options:

- Insurance through spouse
 - DOES NOT COVER LONG TERM CARE
- Private insurance
 - www.Healtcare.gov
 - <https://www.policygenius.com/>
 - DOES NOT COVER LONG TERM CARE
- Medicaid
 - Has been expanded in 39 states so many Americans can now qualify
 - States where Medicaid has not expanded will require a finding of disability to be eligible, meaning you must apply for SSI
 - Covers Long Term Care
- Medicare
 - Must be 65+ or you have been found disabled through SSDI
 - DOES NOT COVER LONG TERM CARE

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

Long-Term Care: Long-Term Care (LTC) describes the medical and non-medical care that is provided over an extended period of time to people who have a chronic illness or disability. Individuals with Huntington’s disease often need LTC as the disease progresses. LTC also refers to a specific kind of care, which includes nursing homes, skilled nursing facilities, and assisted living facilities. LTC is very costly and it can be very difficult to get placed into a LTC facility if the proper insurance is not in place. What needs to be done prior to placement in Long-term Care?

Financial Planning:

- Assets should be moved out of HD individual’s name, including house
 - Help with Medicaid eligibility
 - House can be taken by Medicaid to cover care expenses
- Divorce may be necessary to get essential benefits
- Review LTC payment options
 - Out of pocket

- Medicaid
 - LTC insurance (not an option after HD diagnosis)
- Possible loss of financial benefits (SSI, caregiver payments) when individual is moved to LTC
- Research care facilities
 - What care does the facility provide?
 - How will they manage your loved one?
 - What is the staffing ratio?
 - What do they know about HD?
- Acknowledge that transition to LTC may be difficult.
 - Be prepared to advocate for your loved one
 - Make sure your loved one's wishes are known
- Legal Decision-Making Documents need to be in place:
 - Durable Power of Attorney
 - Advanced directive/Living will
 - Medical decision maker/healthcare proxy
 - Outline medical wishes

Legal Decision-Making Documents: Legal decision-making documents give someone else 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. Most legal decision-making documents require that the individual still have mental capacity – the ability to make decisions and care for themselves – in order for the legal document to be effective. With HD, you need to put legal documents in place as soon as you start to show symptoms to make sure your legal wishes are followed. Many late-stage HD individuals lack mental capacity so the only available legal option is Guardianship/Conservatorship, which means they will have no say in the process.

- 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>
- Guardianship/Conservatorship
 - Request for guardianship must be submitted to your state court
 - Fill out the guardianship forms specific to your state
 - A doctor will need to complete a medical form, with medical evidence, to support the need for guardianship
 - The court will set a hearing to determine if guardianship is necessary
 - Court will appoint an attorney to represent the family member with HD
 - Judge will decide if request for guardianship is reasonable and necessary