



Financial and Legal Preparation for Prodromal/Pre-symptomatic HD

Financial Planning & Insurance: Financial planning allows you to get a comprehensive picture of your current finances, set financial goals, and help you achieve your financial goals in the future. Insurance helps you cover the cost of medical care and other benefits you may need. Financial planning and obtaining the right insurance are important whether you are single, in a relationship, or have a family because they are necessary to ensure you are able to access and pay for proper medical care and long-term care in the future.

- Make sure you are paying into a disability/retirement program:
 - Social Security disability/retirement
 - Private State disability/retirement
 - Private teacher disability/retirement
 - General private disability/retirement (TIAA, Mutual of America, etc.)
- Review and sign up for employer provided benefits if they are available:
 - Health Insurance
 - Short term disability
 - Long-term disability
 - Life Insurance
 - Legal Shield – can opt into this benefit for a year to get a will drafted then stop
- What to Look for in Employer Benefits:
 - Health Insurance:
 - Exclusions that would limit your ability to get the care you need
 - Long-term disability:
 - Exclusions pertaining to genetic conditions
 - Timeframe limitations based on when you get diagnosed (will the policy cover you if you have already been diagnosed)
 - How long you pay into the policy before you can use it
 - Life Insurance:
 - Medical record requirements
 - Family history requirements

Asset/Resource Protection: Assets/resources can be anything of value owned by individuals or organizations, and they can be categorized in different ways. Personal assets usually include cash and cash equivalents; real estate and land; personal property such as cars, boats, and jewelry; retirement and investments. Asset/resource protection is particularly important if you have a spouse or family that will need to help provide for your care when your HD progresses. It is also important if you have a spouse, family, or family member that you want to guarantee will get your assets after you die.

- Determine what asset protection options will work best for you and your family:
 - Special Needs Trust - trust is meant for a dependent who receives government benefits, such as Social Security disability benefits
 - Medicaid Asset Protection Trust - Enables someone who would otherwise be ineligible for Medicaid to become Medicaid eligible
 - Income Trust - trust that can be helpful to Medicaid applicants in states that have a set income limit for qualifying for Medicaid
 - ABLE Account - tax-advantage savings accounts for individuals with disabilities that began before age 26 and does not count towards Supplemental Security Income (SSI) or Medicaid
 - Caregiver Agreement - a contract typically between a family member who agrees to provide caregiver services for a disabled or aging relative and the person receiving care that compensates the family member for the care provided
- Speak with a specialized attorney:
 - Elder Law Attorney - should be able to cover most of the necessary legal and asset protection options
 - Estate Planning Attorney - usually only assist with wills and trusts
 - Special Needs Trust Attorney – if you need a specialized trust it is important to work with an attorney that specializes in that area (trusts are very complicated)
- Create a Will:
 - 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

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.
- 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