

Insurance Planning and Predictive Testing

1. What types of insurance do I need to provide the most protection for myself and my family?

Insurance can be separated into two categories: health insurance and supplemental insurance.

Health insurance – helps cover the cost of medical expenses like doctor visits, medical testing, medical procedures, prescriptions, and hospitalizations.

Supplemental insurance is everything else. The two kinds of supplemental insurance that EVERYONE needs are disability and health insurance, life insurance is HIGHLY recommended if you want to safeguard loved ones (partner, kids, etc.) when you die, everything else is up to you:

Disability Insurance – covers up to 60% of salary if you cannot work due to illness or injury. Policies can last anywhere from one year until full retirement age (65 or 67)

Term Life – Term life policies last for a set number of years and are much cheaper than whole life policies. Term life policies typically last between 10 years and 30 years, and they don't have any complex tax implications or restrictions.

Whole Life – Whole life policies are a type of permanent life insurance that lasts your entire life. They are five to 15 times more expensive than term life but come with a cash value separate from the death benefit.

Accident Insurance - offers a payout if you experience injury or death due to an accident.

Hospital Insurance - helps cover the costs of a hospital stay for covered illness and injury, general hospitalizations, intensive care, and critical care.

Critical Care Insurance - provides a lump-sum cash benefit to help cover expenses associated with a qualifying serious illness. The list of covered conditions is very specific and does not often include Huntington's Disease.

Long-term Care Insurance - designed to cover long-term services and support, including personal and custodial care in your home, a community organization, or other facility.

Anyone with a family history of HD is usually not eligible for long-term care insurance unless they have a negative gene test.

Monthly insurance premiums can be very expensive and not everyone can afford additional insurance policies. Deciding what insurance policies are right for you/your family will depend on your specific needs, premium costs, and benefits provided.

2. Is my right to supplemental insurance protected if I have a genetic disease?

NO. Anyone at risk for or diagnosed with HD does not have a protected right to obtain supplemental insurance. The Genetic Information Nondiscrimination Act (GINA) only protects access to health insurance and your right to employment. GINA does not apply to Native American health insurance, the military, or employers with less than 15 employees.



3. When do I need to purchase supplemental insurance?

When it comes to HD, the earlier you purchase supplemental insurance, the better. Realistically, people at-risk for HD need to obtain supplemental insurance before predictive testing, even if testing is done anonymously.

Once someone gets a positive gene test, a clinical diagnosis, or starts to show symptoms of HD, they are no longer able to purchase supplemental insurance – their application will be denied. Most of the insurance listed above is highly recommended whether a person has HD or not.

4. Can I purchase supplemental insurance after testing positive if I test anonymously?

No. That would be fraud. If the insurance company discovered that you lied on your application, they would cancel your coverage, keep your premiums, and could pursue legal action.

5. Should I take advantage of employer-provided supplemental insurance?

1000% Yes. Employer-provided policies do not ask the same questions as private policies because they must be offered to all employees equally. This means employer policies are easier to get and are more cost effective. Most employers subsidize the cost of supplemental insurance benefits. The downside of employer-provided supplemental insurance is that the policies are tied to that specific job, so coverage will end if you leave the job, and you have more limited choices.

6. Can I opt into employer-provided supplemental insurance after I test positive?

Yes! Many employer-provided life and disability insurance policies waive pre-existing conditions as long as you pay into the policy for at least 12 months. You **always** need to read the policy terms first to confirm your HD or any other condition will be covered.

7. Where can I find information about supplemental insurance?

A good online resource is Policygenius.com. You can see all the different options, what they mean, and how they will impact premium costs. If you decide you want to purchase insurance, the best option is to work with an insurance broker.

8. What if I cannot afford supplemental insurance, what are my options?

If you cannot afford supplemental insurance, or do not want to pay into, there are other financial options. Some possibilities are investment accounts, high yield savings accounts (HIGHLY RECOMMEND), Health Saving Accounts, and 401ks/IRAs. Working with a financial planner is a good idea.

9. What can wait until after predictive testing?

Legal and financial planning should be done after testing. This includes things like setting up a will, trust, power of attorney, asset protection, and long-term financial planning.

For more information and resources about disability planning, please visit the HDSA Disability Program at www.HDSA.org/disability.

