

We Are HDSA!



Huntington's Disease
Society of America

Support Group Newsletter • www.hdsa.org • (800) 345-HDSA • Issue 1, February 2013



Long Term Care Insurance

By Stacey K. Barton, MSW, LCSW

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What is Long Term Care Insurance?

Long Term Care (LTC) insurance assists with paying for nursing home, assisted living and in some cases in-home care and home modifications such as wheelchair ramps.

LTC is expensive. The average cost of a semi-private room in a nursing home in the United States is \$198/day and the average cost of a home health aide is \$21/hour (US Department of Health and Human Services, 2011, based on 2009 data). These numbers are averages. In the state of Hawaii, a semi-private nursing home will run, on average, \$316 per day! Because most people cannot afford to pay for this on their own, it is important to have an understanding of LTC insurance.

Most people mistakenly believe that Medicare will pay for LTC. This is only true in acute, short term cases following a hospitalization. It does not cover the more routine "custodial" care, which is what is typically required for people with HD. Medicaid does cover long-term care but is only available to those who meet certain income requirements (or become impoverished in the process of paying for LTC). It also greatly limits your choices of what facilities you can consider and will not in any significant way pay for in-home care or home modifications.

LTC insurance provides you with choice over the providers of your care because for the purpose of paying for care, you are considered a "private pay" consumer. This allows you to choose who will be your provider of care or services, as long as they are licensed companies.

LTC insurance can be very complex. There are additional riders available to account for inflation, in-home care, and other variables. You will have choices about the amount of coverage, the elimination period (see below for definitions), and other factors that affect the cost of the premium. In most cases, you will have to submit to a physical. There may be exceptions to this, such as if you are purchasing LTC

insurance upon starting a new job at a company that offers this benefit. You can inquire about what the underwriting process entails. This can be important for those who are gene positive but not yet symptomatic. It is much better to purchase this insurance before you complete testing and/or diagnosis.

It is important to choose a company with a strong financial standing that will be there in the future if you need to tap into this care. Many strong, stable companies have gotten out of the LTC insurance business. Most are honoring their current policies, but you would hate to pay on a policy for decades only to learn the company has gone bankrupt once you need to file a claim.

As with other types of insurance, it is important once you purchase a policy that you do not let it lapse by missing a payment. If this happens, you will be subject to reapplying and thus to any preexisting and exclusionary conditions.

How much does LTC insurance cost?

This varies based on your age and the type of benefits you are purchasing. That said, the average cost across all ages is over \$2,200 per year.

I have heard that it can be very difficult to get LTC insurance once you are diagnosed with HD.

This is true. Keep in mind that the underwriters likely don't really understand HD, so the distinction between being "gene positive" and "being diagnosed" is probably not clear to them. The Genetic Information Non-Discrimination Act (GINA) does not apply to LTC insurance so it is legally acceptable for them to deny you based upon your genetic risk, your gene status, or your disease state. For more information on GINA, please visit the HDSA GINA toolkit, found at www.hdsa.org/gina.

According to the National Association of Insurance Commissioners, "A long-term care insurance policy usually defines a pre-existing condition as one for which you received medical advice or treatment or had symptoms within a certain

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SSA Compassionate Allowance

As of December 1, HD and Juvenile HD both qualify for SSA's Compassionate Allowance Program. HD families applying for Social Security Disability benefits will now potentially receive a decision on their claim in a matter of weeks instead of months or years. HDSA's Online Disability Toolkit can be found at www.hdsa.org/disability and contains information about the application process. If an individual has been denied Disability, they should contact Jane Kogan at jkogan@hdsa.org.

Advocacy Opportunity: Health Insurance Exchanges & Essential Health Benefits

Right now, states are in the process of implementing their health insurance exchanges, either as an independent exchange or in partnership with the Federal Government. States that have chosen not to implement a health insurance exchange will have an exchange set up by the Federal Government. It is critical that HDSA advocates continue to participate in the process. Particularly, insurance exchanges should offer meaningful mental health parity, consistent coverage, and adequate prescription drug benefits. Go to www.hdsa.org/ehb to download a letter you can personalize and find the contacts for your state.

HDSA Advocacy & Education on Twitter

Follow [@JaneHDSA](https://twitter.com/JaneHDSA) to get HDSA Advocacy and Education updates on Twitter

period before you applied for the policy. Some companies look further back in time than others. Many companies will sell a policy to someone with a pre-existing condition. However, the company may not pay benefits for long-term care related to that condition for a period after the policy goes into effect, usually six months. Some companies have longer pre-existing condition periods or none at all."

What if I am at-risk and the application asks about a family history of HD?

You have to be honest on the forms but do not need to give them any more information than they request. If you are not truthful on the application and this comes out later, this is fraudulent and your benefits could be denied.

If you would like more information about finding Long Term Care insurance in your area, please contact your local social worker. You can find your local social worker information at www.hdsa.org/sw or by calling the HDSA National Helpline at **(888) HDSA-506**.

LTC Insurance Concepts:

Daily benefit amount: The maximum daily expense the insurance will pay.

Benefit period/Lifetime benefit maximum: Total amount of time or money that you can receive as benefits. This is often 2-5 years, but lifetime coverage may be available.

Inflation Protection: Allows the amount of your benefit to rise with inflation over time. This is important because of the costs of care are climbing rapidly, but if your benefit amount is static you may see a shortfall between your insurance benefit and the cost of care.

Elimination period: The number of days you have to pay for care before the policy kicks in.

Long Term Care Insurance

By Lisa Kjer, MSW, HDSA Center of Excellence Social Worker, UC Davis Medical Center, HDSA Northern California Chapter Social Worker

LTC Policies are designed to pay a daily rate for care. That daily rate can be applied to any of the services below. The daily rate you receive will depend on the extensiveness of the LTC policy purchased. Available policies will vary by company and by state.

- A semi-private room in a nursing home
- A private room in a nursing home
- Care in an Assisted Living Facility (for a one-bedroom unit)
- A Home Health Aide
- Homemaker services
- An Adult Day Health Care Center

Resources for information on LTC Insurance

National Clearinghouse for Long Term Care Information:
www.longtermcare.gov

Federal Citizen Information Center Guide to LTC Insurance:
www.pueblo.gsa.gov/cic_text/health/ltc/guide.htm#cover

National Association of Insurance Commissioners:
www.naic.org/index_ltc_section.htm

HDSA Annual Convention

Register now online for the HDSA Annual Convention in Jacksonville, FL at www.hdsa.org/convention.



We Are HDSA!

Did you know *We Are HDSA!* is available via e-mail? By signing up for an electronic version of *We Are HDSA!*, we not only reduce our costs but we also provide you with an easy way to share the newsletter with your friends and family. Thank you for being part of our efforts to become more environmentally and fiscally responsible.

HDSA E-mail List

Want to get more information about HDSA events and activities? Visit the HDSA website at www.hdsa.org to sign up!

Clinical Trials:

Want more information about your local clinical and observational trials, including the sites for ENROLL-HD? Visit www.hdsa.org/clinicaltrials to find clinical and observational trials nearest you. Sign up at www.hdtrials.org to find out about new opportunities to participate in clinical and observational trials.

What should I tell my adult children about my Huntington's disease?

Kit McFarlane, MSW, HDSA Center of Excellence at Johns Hopkins University

Talking to adult children (for the purposes of this article, adult children will be defined as people over the age of 21) about your or your partner's Huntington's disease (HD) is difficult, especially when the discovery of the at-risk status or diagnosis is new to the family. Regardless of the reason, once you know you are at-risk for or have HD, talking to your children is an important part of helping them make their own arrangement for their health and future.

Your adult children's reaction may be surprising. News of being at-risk for Huntington's disease can be unexpected and unsettling information. Give your children the information slowly and in a straight-forward manner and allow your adult children a chance to let this information sink in. This may include requiring you or another member of your family to answer the same questions two or three times or speaking slower than usual. Even the smartest of people may have an emotional response that could make it difficult to take in all the information at hand. It may be helpful to write down a list of points you would like to cover beforehand, such as:

- What is Huntington's disease, including the triad of symptoms (motor, cognitive, and behavioral).
- What symptoms, if any, you are exhibiting.
- What support services are available in your area, including HDSA support groups and HDSA social workers.
- Each child has a 50% chance of inheriting the gene that causes Huntington's disease.
- Options for genetic testing and the genetic testing process.

This conversation may not happen all at once, but instead take place over a few weeks. By doing this, you are allowing your children time to digest the information given.

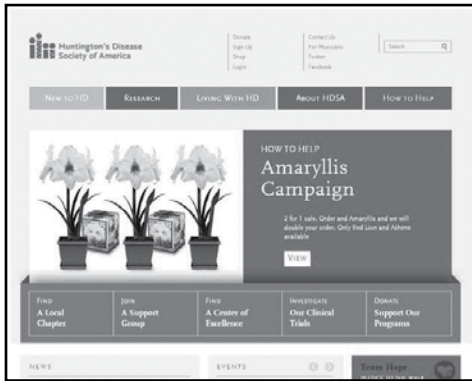
HDSA has many informative publications on Huntington's disease. For this conversation, the free publications that may be useful to provide to your children are:

- Fast Facts about Huntington's Disease
- HD Education Packet
- Clinical Trials Brochure
- Past issues of *We Are HDSA!* or *The Marker*

Providing these publications allows your children to learn more about Huntington's disease at their own pace. Giving your children information about the Huntington's Disease Society of America and our website, www.hdsa.org, allows them to do the research on their own as well as the opportunity to talk with HD knowledgeable professionals. Local HDSA social workers, found at www.hdsa.org/sw, are also available to talk about HD and local resources available.

Talking to your children about Huntington's disease can be one of the most complicated conversations you may have, as well as one of the most important. It can lead to many difficult questions, but also help bring a family closer together. For more information on Huntington's disease or materials for you and your family, please visit the HDSA publications list or call the HDSA National Helpline at **(888) HDSA-506**.

HDSA's **New Website**

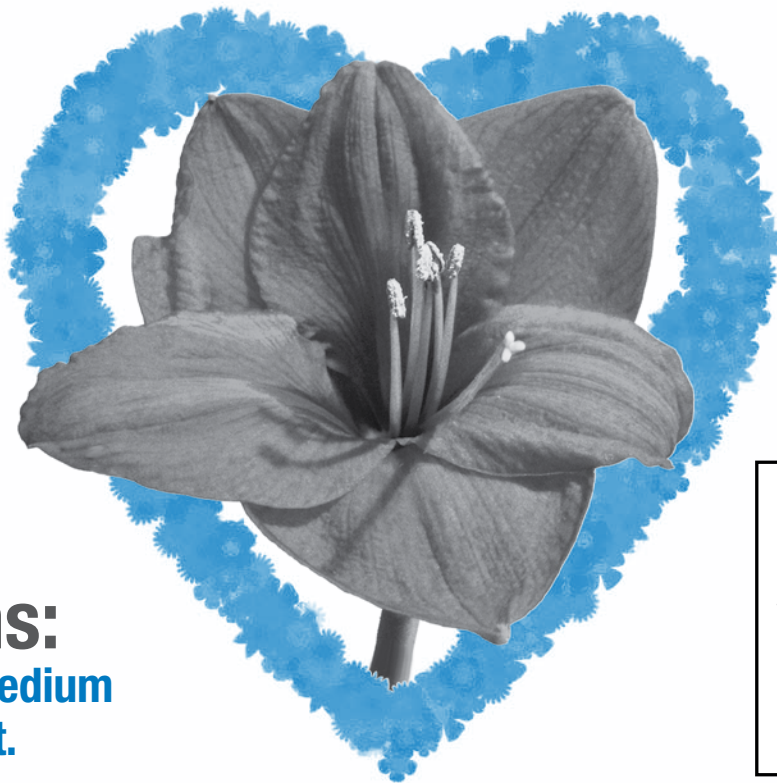


Visit us at www.hdsa.org and see the first phase of the newly launched national website. We'll be rolling out the rest of the new site throughout the year. In addition to the new look, we have simplified the navigation, made it easier to find the most-visited and requested pages, and added a section for those "new to HD."

Thanks to everyone who contributed their thoughts and suggestions and those who offered feedback during the development process. Please continue to let us know what you think and how we can improve the site. New ideas are always welcome.

Most importantly, the new site will help us provide *Help for Today, Hope for Tomorrow* to everyone affected by Huntington's disease.

Hope for Valentine's Day Give the Gift that keeps on giving...



\$5 each Kit
(Plus Shipping)

Kit contains:

**1 Bulb, planting medium
and decorative pot.**



www.hdsa.org/amaryllis

Moving Together



Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

