

We Are HDSA!



 Huntington's Disease Society of America

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ON THE ROAD with Huntington's Disease

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Since the fifties, driving a car has become the primary mode of transportation in the US. More so than any other type of mobility, driving a car offers the freedom and independence to travel anywhere at any time. Cessation of driving is associated with social isolation, lower quality of life, and depression. Driving is a complex activity which requires healthy vision, cognition, and physical abilities. It is a privilege that needs to be earned and maintained by showing adequate knowledge of the traffic rules and regulations, successfully completing a road test, and meeting medical, physical, and cognitive criteria for driving fitness. Each state in the US has its own fitness to drive criteria. Most states have specific visual requirements and require minimum physical and cognitive abilities for driver's license reinstatement.

Depending on their stage and severity of illness, people with Huntington's disease (HD) have progressive difficulties with movement [e.g., gait/balance impairment, stiffness, slowness], attention, and cognition,[1] reducing their ability to gauge the traffic circumstances, make appropriate decisions, and respond timely to hazards [2]. Therefore, patients with HD are at higher risk for unsafe driving, crashes, and driving cessation [1-3].

We would like to note that driving difficulties may surface early in the course of the disease [4]. It is important that the driving issue is discussed as early as possible between the patient, family, and healthcare providers. Some drivers are well aware of their driving difficulties and start to self-regulate themselves by driving less frequently, avoiding peak traffic hours, and driving only in familiar areas [1,3,4]. Other drivers have less insight to their diminished driving skills. Usually, their loved-ones will be the first to express concerns about their continuation of driving.

In addition to clinical examination by a neurologist, a group of tests to evaluate visual perception, working memory, and motor speed can predict performance on a road test [3]. If the patient is found safe for a road test by the state agency or a driving

specialist, a driving test can give further information about safety. While they may give valuable information, driving simulators are mainly used in research settings and cannot replace road testing currently.

Restriction of driving and finally driving cessation is a gradual, although difficult process, which require guidance by healthcare providers familiar with the disease and demands of driving. A team of health care professionals consisting of the neurologist, neuropsychologist, occupational and physical therapists, and social workers can evaluate various different aspects of this problem as needed and offer adequate counseling, including exploration of alternative modes of transportation, family and friend support, and the use of volunteer services. There are no established driving rehabilitation methods for HD at this time and further research needs to be done.

In summary, drivers with HD are advised to seek professional advice on continuing to drive and need be monitored periodically so that they can maintain their vehicular independence as long as possible without jeopardizing safety on the road.

References

- [1] Beglinger LJ, Prest L, Mills JA, Paulsen JS, Smith MM, Gonzalez-Alegre P, Rowe KC, Nopoulos P, Uc EY. Clinical predictors of driving status in Huntington's disease. *Mov Disord* 2012;27:1146-52.
- [2] Rebok GW, Bylsma FW, Keyl PM, Brandt J, Folstein SE. Automobile driving in Huntington's disease. *Mov Disord* 1995;10:778-87.
- [3] Devos H, Nieuwboer A, Tant M, De Weerd W, Vandenberghe W. Determinants of fitness to drive in Huntington disease. *Neurology* 2012;79:1975-82.
- [4] Williams J, Downing N, Vaccarino AL, Guttman M, Paulsen JS. Self reports of day-to-day function in a small cohort of people with prodromal and early HD. *PLoS Curr* 2011;3:RRN1254.

We Are HDSA! Goes Green!

Starting in 2014, *We Are HDSA!* will be going green! *We Are HDSA!* will be available via e-mail and on the HDSA website every other month. To receive *We Are HDSA!* via e-mail, please contact Seth J. Meyer at smeyer@hdsa.org.

Survey Opportunity

Heather Voigt is a second year genetic counseling student at the University of California, Irvine and is working on her thesis which looks at the psychological effects of presymptomatic testing for HD and the impact on familial and romantic relationships.

If you are interested in helping Heather, please complete her online survey which is open to anyone over the age of 18 who has had presymptomatic testing for HD, regardless of whether the test came back negative or positive. The survey has about 30 questions that ask about your testing process and how it may have affected your relationships. Some questions are open ended and you are asked to elaborate, if you so desire.

The survey link is:

www.surveymonkey.com/s/HDSA_Survey

This is an IRB approved study from the University of California, Irvine under application number HS# 2013-9502. If you would like more information on the study, please contact Heather so she can send you the Study Information Sheet.

Phone: 714-456-5837

Email: hvoigt@uci.edu

Thank you for your time and interest in this survey.

By Seth J. Meyer, LMSW

*Community Services and Resource Development Manager,
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While Life Insurance has usually been seen as a program to help pay for expenses following a person's death, including funeral expenses, there is another use that can help a person with HD and their family during their lifetime. Certain Life Insurance policies can be utilized to pay for Long Term Care by cashing out of the policy early. Not every Life Insurance policy will allow a person to do this.

Before taking part in any of the following programs, it is important to explore both the tax implications and how this income may affect ones benefits. While most programs are not taxed, a percentage of certain programs through certain agencies may count as taxable income. Before choosing an agency to use, it is important to confirm what percentage of the payout, if any, is taxable. Furthermore, the income may affect eligibility for certain income-dependent programs, such as food stamps or Medicaid. Talk to local reps and to make sure that this increase in income will not affect other help that you receive.

The two types of Life Insurance programs applicable to most people with HD are:

Accelerated Death Benefits

An Accelerated Death Benefit provides people with a certain percentage of their Life Insurance policy in advanced, tax free. Every policy provides a different percent and some policies may charge a higher premium to have this included. Accelerated Death Benefits are generally available in instances of:

- Terminal Illness
- Life-Threatening Diagnosis
- Long Term Care services are required for an extended period of time
- A person is incapable of handling certain Activities of Daily Living and/or is confined to a Skilled Nursing Facility

Some payouts from Accelerated Death Benefits lead to a lower overall payout of one's life insurance policy. One does not have to (and in certain states, one is unable to) get an early payout of the entire plan. Instead, one can get anywhere from 25%-96% of the plan early, still leaving money for the family after their passing.

Viatical Settlements

A Viatical Settlement allows a person to sell their life insurance policy to a third party to help pay for long term care. This process, available only to those who have terminal illnesses, provides a certain percentage of the policy before the person passes. This process is sometimes tax free. Using this means that there will not be any money from one's life insurance policy left for their beneficiary. When this is done, a buyer only receives payout once the holder has passed away. Therefore, the buyer may call occasionally to ask about the policy holders health. The agency will provide a privacy form outlining what information will be kept and who has access to this information. It is important to read and understand this form before a decision is made.

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Disability:

For more information on applying for disability, please visit the HDSA Disability section, found at www.hdsa.org/disability. There you will find helpful tips and webinars. If you have been denied disability and have questions, please contact our Manager of Education and Advocacy, Jane Kogan, at jkogan@hdsa.org.

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!

Social Worker CEU Course

HDSA is pleased to offer a free Continuing Education course on the HDSA website. Social workers can earn up to 5 FREE CEUs. To learn more, visit www.hdsa.org/ceu.

Raise your voice for HD parity

The Huntington's Disease Parity Act (S. 723/H.R. 1015) would improve access to Social Security Disability and Medicare benefits for individuals disabled by HD by updating the outdated medical criteria that SSA uses to evaluate individuals with HD, and by waiving the two year waiting period to receive Medicare once an individual is granted Disability.

Please take 1 minute to speak up for HD by sending an email to your Representative and Senators at www.hdsa.org/takeaction

29th Annual HDSA Convention

Save the date! The 29th Annual HDSA Convention will be from June 21-23, 2014 in Louisville, KY. For more information, please visit www.hdsa.org/convention.

By Eva Leonard, Editor-in-Chief, CVC Community Magazine

Caring Voice Coalition is one of the many agencies that HDSA collaborates with to provide services and help to people nationally. For a complete list of resources, please visit www.hdsa.org/resources or contact the HDSA National Helpline at (888) HDSA-506 or via e-mail at hdsainfo@hdsa.org.

Caring Voice Coalition (CVC) is a nonprofit organization working in collaboration with HDSA to provide a wide range of free services, including financial, emotional, and educational support, to thousands of people across the U.S. who are living with specific rare diseases, including Huntington's disease.

For patients with Huntington's disease, Caring Voice Coalition's free services include assistance with:

- Paying out-of-pocket costs for FDA-approved medications and health insurance premiums.
- Finding and exploring new or improved health insurance options.
- Applying for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Caring Voice Coalition's Patient Services Department

Caring Voice Coalition's Patient Services department works alongside HDSA to help patients with HD get financial assistance for medication and health insurance coverage. Individuals with chronic conditions like HD often face expensive copayments for their prescription medications. Caring Voice Coalition provides monetary grants to ease the burden of these medication costs, allowing patients to start and remain on their drug therapies.

CVC helps individuals with HD to pay premiums for health insurance coverage. We work with individual with HD to help them find health insurance, and we also provide free representation to individuals with HD to help them to apply for SSDI and SSI.

One individual with HD who had no health insurance and no income contacted CVC. We researched insurance options for him and found a plan that provided the coverage he needed. We verified that the plan covered his medication, so we were able to pay his insurance premium. We also confirmed that his doctors accepted the insurance, and that the plan's co-pays were affordable for him.

CVC helped another individual with HD get Social Security Disability, taking him step-by-step through the process, from application to approval. Another individual with HD called us because he was confused about where to order his medication. He had already been on the phone for about 45 minutes trying to figure it out before he called us. His case manager offered to conference call the specialty pharmacy with him and helped him order his medication.

We also provide guidance and emotional support to caregivers. One caregiver's husband and son both have HD. We walked her through the insurance and disability processes, and were there when she needed to talk to someone who understood what she was going through.

CVC takes a holistic approach, helping patients with a wide range of needs, from calls to their specialty pharmacies, to helping them understand their health insurance options.

Patient Privacy, Support, and Community

On our Cloud 9 online portal, individuals with HD can securely and privately apply for financial assistance, update personal information, and communicate with their care team. For more information about Caring Voice Coalition, call us at 1-888-267-1440, or visit our website, www.caringvoice.org, and our Facebook and Twitter pages.

Things to Consider:

Is the agency reputable:

- Before using any agency, make sure you search for information and reviews on the web or through friends. It is important that the company you use is a reputable agency.

What percentage of my life insurance will I receive?

- Not every policy provides a recipient with all of their life insurance through these products. Some agents may also charge fees. Talk to several companies to figure out which one is best for you.

What will my family need after I pass?

- Will your family need this money to pay for funeral or other expenses? What will your family's financial situation be once you pass?

How long will the money last?

- Based on your needs, how long do you feel this money will be able to support your needs? What happens if the money runs out?

How will this affect your income and your services?

- Sometimes, these products are taxed. How will your taxes change by getting this income? This money may also count as income for certain income dependent programs, including food stamps and Medicaid. Check with your local agencies to make sure you will still be eligible for these services.

More Information

It is best to talk with a financial planner in your state to figure out which plan(s) is right for you. You can also talk to your insurance company to figure out what services are available with your particular plan. Accelerated Death Benefits and Viatical Settlements can sometimes be added onto a plan later for no additional cost.

For more information on these and other ways to use a Life Insurance plan, please visit the Cost's and How to Pay section of www.longtermcare.gov.

Clinical and Observational Trials

Below is a list of clinical and observational trails happening around the country. For more information or to sign up for any of our monthly research webinars, please visit www.hdsa.org/research. To receive more information on clinical & observational trials, sign up at www.hdtrials.org. Please note, this is for informational purposes only. If you have a question about the study, please contact the study coordinator directly.

ENROLL-HD: A 40+ site international observational trial. To find the site closest to you, please visit www.enroll-hd.org.

FIRST-HD & ARC-HD: A Phase II trial to see if SD-809 helps reduce chorea. This trial will last about 5 months and is currently in 10 sites around the country. To find the site nearest to you, please visit www.hsglimited.org.

HDQLIFE: An observational study to look at quality of life measures. To be eligible, you must have tested positive for the HD gene and have been clinically diagnosed with HD. For more information, contact the HDQLIFE team at (734) 764-0644 or via e-mail at PMR-HDStudy@med.umich.edu.

Role of Genetic Counselors in the Lives of Those At Risk for HD: A study that looks at how children of people with HD have learned about their family history. The survey can be found at www.surveymonkey.com/s/5K8KS7B and takes about 30 minutes to complete.

*From everyone at HDSA,
may you and your family have a happy, healthy, and safe
Holiday Season.*

QR Code

Please scan here
to visit the
HDSA website

