We Are HDSA!

Huntington's Disease
Society of America
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Honoring our losses: MANAGING GRIEF

By Karen Tarapata

It is true. Over time, HD changes everything. Living with HD – whether as the person with the disease, a family member, caregiver or friend – causes the gradual transformation of many things the average person can take for granted – health, independence, family stability and companionship. These changes are profound and they can trigger intense emotions, including grief.

There is a phrase called "disenfranchised grief," which is bereavement that is not acknowledged by society. Many of the gradual losses that occur in HD fall in this category, including:

- The inability to talk freely about your fears for the future. You may worry that others think you are predicting trouble that may never come or that sharing will result in discrimination.
- The loss of healthy relationships with our families, friends, and even casual acquaintances and coworkers as HD lessens an individual's emotional and social abilities, or the stresses of caregiving reduce time and patience with others.
- Social awkwardness when others don't know how to respond to HD or when they avoid the topic altogether.
- Sadness at seeing a spouse, partner, parent, or friend change as a result of the disease. The individual is alive but the relationship is very different.
- The loss of hopes and dreams such as growing old together, playing with grandchildren, traveling, etc.

Modern society has no patience or time for grief. There are no sympathy cards for the loss of health, independence or companionship. The world's focus seems always to be on "staying upbeat" and "moving on." How unrealistic. Grief is a natural human reaction to loss, and even the most positive person will experience moments of grief, especially when faced with the alterations to life caused by HD.

Always putting a brave face on things can feed a tendency to bury feelings of grief, as if that is the best thing to do; as if you don't deserve to mourn for what has been lost. Your former life, hopes, plans and dreams had value and you have a right to grieve for your losses. Feeling sadness and anger of grief is not the same as giving in or giving up. Grief acknowledges and honors what has changed. Hope provides the path forward.

Our HD community can provide you with support and guidance on ways to manage your feelings of grief. There are forums and chat rooms on the internet where you can talk with others living with Huntington's disease. You may want to participate in an HD Support Group. It may be helpful to talk with a counselor, a pastor, or an HD social worker. If you don't know of someone to talk to, ask your doctor or social worker for suggestions. The important thing is to know that you are not alone in your feelings.

If you are not ready to talk about your feelings, that is perfectly alright. Writing can be a private way to explore your feelings. You could write a letter to yourself about the losses you have experienced and how they make you feel. You could create a collage of what you thought your life would be and then bury it. You could write the angriest letter to God and then burn it. It's up to you. No other person can tell you how to grieve.

Acknowledging that you feel grief and that it is worthy of time and space may help prevent these feelings from becoming overwhelming. If your grief feels out of control, talk to your doctor right away. There may be treatments that can help.

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When and How to **Talk About Driving**

By Claudia Testa, MD, Ph.D.,Director
Huntington Disease Program, Virginia Commonwealth University

Driving can be an emotionally charged subject for both the family and the person with HD. Families may delay having a conversation about driving to avoid conflict. Below are some suggestions on how to have a productive discussion about driving.

Who starts the talk?

The conversation can be initiated by the family and friends or the doctor of the person with HD. While a doctor is a neutral authority and therefore can be more helpful to emphasize how the family avoid conflict, family and friends have a better feel of the person's driving ability. Many people are aware of changes in their driving ability and may understand when someone brings up the subject. If family and friends are hesitant to get into the car with the person with HD, it is time to talk about driving.

What to ask?

It is best to focus on specific questions, such as: Have there been any changes in your driving? Have you had any small fender benders recently? Avoiding certain driving tasks like highways or left turns? Have other people expressed concerns about your driving? Asking about the person's needs is helpful. This includes practical points like where do they regularly drive – lunch, church, work – and emotional needs like feeling in charge. Acknowledging that reducing driving feels unfair and is difficult can help avoid feelings of being punished, isolated, and frustrated.

Many people are happy to hear others are concerned about them but are still very willing to put themselves in danger. It may be more helpful to emphasize how continued driving puts other people at risk. For example, "it's just me in the car" doesn't acknowledge small children in the neighborhood or the family in the other car.

When there is uncertainty about driving skills, a rehabilitation driving assessment can be very helpful. A specialist, usually an occupational therapist, conducts a detailed assessment geared towards identifying what the person can and cannot do in regular driving situations and whether the car or the person's behavior can be modified to allow some driving. Your doctor and medical social worker can help set this up.

How will my loved one get around?

Many areas do not have adequate public transportation. Families may not be able to afford an alternative driver. However, there are solutions. Working with your medical social worker can help identify resources in your area. Human resource departments at work can provide carpool information. Talking to other HD families may uncover suggestions from their experience. Simply asking friends to pitch in gives people a chance to step up and maybe surprise you with willing support. Seeing how others want to help can diffuse the sense of loss around reducing driving.

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HDSA's 30th Annual Convention

Dallas, TX - June 25-27, 2015

Please visit **hdsa.org/convention** to learn more, to register online or download registration forms to attend this year's event.

HDSA is pleased to announce it is now accepting applications for scholarships to attend the **30th Annual HDSA Convention**.

To learn more about these scholarship opportunities please visit **hdsa.org/scholarship**.

Hyatt Regency Dallas
300 Reunion Boulevard
Dallas, TX 75207

If you have any questions please contact **Robert Coffey** at **rcoffey@hdsa.org**.

HDSA Information

Advocacy Update

We have had a monumental month for Advocacy at HDSA! On February 10, Representative Adam Kinzinger (R-IL) introduced the Huntington's Disease Parity Act of 2015 in the House of Representatives (H.R. 842). The bill was introduced with an astounding 103 bi-partisan original co-sponsors, representing 33 states as well as the District of Columbia. Over half of those original co-sponsors signed on to the bill after hearing from our HD Advocates tell their stories. During the last Congress, it took almost two years to get as many sponsors as the H.R. 842 has gained in just one month.

The introduction of the Parity Act has created an enormous amount of momentum, and our next obstacle to tackle is the Senate. In order to really send the message to Congress that this is a common-sense bill for all Americans, we are looking for a Republican Senator to stand alongside our long-time champion Senator Gillibrand (D-NY) and introduce the Parity Act in the Senate. We have been meeting with Senators Cassidy (R-LA) and Boozman (R-AR), but they need to hear from their constituents why they need to be the one to take action and stand up for HD families in the Senate. If you are living or working in Arkansas or Louisiana, take a minute and go to www.hdsa.org/takeaction to send a letter to your Senator today!

If you are interested in getting involved in Advocacy, whether it's talking to a Senator or Representative, starting a local grassroots campaign, or even just writing a letter, call or email me at **(212) 242-1968 x226** or **jsimpson@hdsa.org** to find out how you can get involved!

Jennifer Simpson, LMSW – Manager of Advocacy and Education

Talk About Driving

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The scary part: What if this talk doesn't go well after all?

In the end, some people simply do not recognize that their driving is dangerously impaired. This is the most stressful situation for all involved. That person's safety and public safety become serious issues. Removing access to a working car may be necessary.

Doctors can report a person to their state's Department of Motor Vehicles, which will lead the DMV to determine the ability to the driver. Making peace with this conflict can be hard for families. Reaching out for support from the community and HDSA Social Workers may ease family burden in these cases.

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Staying healthy can also help you manage your feelings. Movement and exercise are natural anti-depressants. You will be better able to handle hard times and emotions if you take care of yourself. Make sure you eat well. Schedule those necessary medical appointments and keep them. Find ways to stay physically active, with an exercise class, a walk or by working in your garden. Getting out and moving around will relieve stress and actually make you less tired. As anyone who deals with HD knows, stress and fatigue can make strong emotions even more intense. This is as true for the caregiver as it is for a person with the disease.

The HD community knows a lot about both grief and hope. Your local HDSA chapter or Center of Excellence can help you find understanding and support within our community, whether in person or online. The support groups they sponsor can be a place for you to freely share your feelings with people who genuinely understand where you are coming from. Visit the HDSA national website at ww.hdsa.org to find out more about local supports available to you.

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HDSA Information

SUPPORT GROUP SURVEY

We are committed to our support group program and need your assistance to better understand your group experience. Thank you for your help in responding to this survey.

www.surveymonkey.com/r/T3GFTFY

Stay tuned

HDSA will be launching a national newsletter soon. This will be the last edition of *We are HDSA*. Thank you for your topic suggestions over the years. You will find all the past editions of *We are HDSA* on our website at **hdsa.org/living-with-huntingtons/publications/wearehd/index.html**

You can sign up for the national newsletter at **hdsa.org/newsignup**

Thank you!

Thank you Auspex

AUSPEX
PHARMACEUTICALS

QR Code
Please scan here to visit the HDSA website

TEAM HOPE Walks - April May.

HDSA and Team Hope are excited to announce Team Hope Walks coming up all across the country this Spring. Please check out the new Team Hope website and fundraising pages, and register for one of the upcoming Team Hope Walks below!

Walk City & State	Walk Date	Walk Website
Boone, NC	4/11/2015	**www.hdsa.donordrive.com/event/thwboone**
San Diego, CA	4/25/2015	**www.hdsa.donordrive.com/event/thwsd**
St. Louis, MO	4/25/2015	**www.hdsa.donordrive.com/event/thwstlouis**
Columbia, MO	5/2/2015	**www.hdsa.donordrive.com/event/columbiamo**
Jacksonville, FL	5/2/2015	**www.hdsa.donordrive.com/event/thwjacksonville**
Sulphur, LA	5/2/2015	**www.hdsa.donordrive.com/event/thwsulphur**
Sioux Valley, SD	5/2/2015	**www.hdsa.donordrive.com/event/thwsiouxvalley**
Nashville, TN	5/9/2015	**www.hdsa.donordrive.com/event/thwnashville**
Austin, TX	5/9/2015	**www.hdsa.donordrive.com/event/thwaustin**
Winston-Salem, NC	5/9/2015	**www.hdsa.donordrive.com/event/thwwinstonsalem**
Windsor, NY	5/16/2015	**www.hdsa.donordrive.com/event/thwwindsor**
Clear Lake, TX	5/16/2015	**www.hdsa.donordrive.com/event/thwclearlake**
Laurel, DE	5/16/2015	**www.hdsa.donordrive.com/event/laurel**
Philadelphia, PA	5/16/2015	**www.hdsa.donordrive.com/event/thwphilly**
Hershey, PA	5/17/2015	**www.hdsa.donordrive.com/event/thwhershey**
Naperville, IL	5/17/2015	**www.hdsa.donordrive.com/event/thwnaperville**
Niles, MI	5/23/2015	**www.hdsa.donordrive.com/event/thwniles**
Zanesville, OH	5/23/2015	**www.hdsa.donordrive.com/event/thwzanesville**
Holland, MI	5/30/2015	**www.hdsa.donordrive.com/event/thwgrandrapids**
Visalia, CA	5/30/2015	**www.hdsa.donordrive.com/event/thwvisalia**
Morgantown, WV	5/31/2015	**www.hdsa.donordrive.com/event/thwmorgantown**
Cleveland, OH	5/31/2015	**www.hdsa.donordrive.com/event/thwcleveland**