

We Are HDSA!



Huntington's Disease
Society of America

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Palliative CARE

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What is Palliative Care?

The National Hospice and Palliative Care Organization (www.nhpco.org) offers the following definition: "Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice."

Why is Palliative care important for families with HD?

Traditional medical perspectives focus on treating and curing illness. As of this publication, HD is a chronic, terminal illness without a cure where a person can live with symptoms for many years. Palliative care can offer a different perspective from traditional medical perspectives by focusing on alleviating suffering of individuals and families. Palliative care offers a program where conscious decisions made about care include a thorough assessment of a person and his or her family's quality of life as the disease progresses.

For example, does the person with HD want a feeding tube when he or she can no longer eat solid food? Perhaps he or she would like to recover lost weight in mid-stage of HD with a feeding tube, but not want a feeding tube to prolong life near the end of life. Perhaps the person living with HD would like to continue to walk even though the nursing home would prefer that he or she sit in a wheelchair to minimize falls. The Palliative care team can help a patient and his or her family advocate for and follow-through with these kinds of decisions.

Who is on the Palliative care team?

The Palliative care team includes the patient and his or her family, the Palliative team and other healthcare providers. The team is interdisciplinary and can include doctors, nurses, physical therapists, social workers, chaplains, and pharmacists. Often, alternative therapies such as acupuncture, massage, and meditation are offered. Palliative care is now a medical subspecialty so the team has received extra training.

It is critical that the different specialties communicate with each other to provide the best service to the patient and his or her family. In sum, Palliative care is independent of any curative or life prolonging therapies, but helps patients and families to live the best life they can with chronic illness.

Where can I find a Palliative care team?

Palliative care teams can be found in hospitals, nursing homes, home health agencies, hospice agencies, cancer clinics and some outpatient clinics.

Statistically, 63% of hospitals that have 50 or more beds offer a Palliative care program. (Life Quality Institute: Advancing Palliative Care Through Education, www.lifequalityinstitute.org)

Who pays for Palliative care services?

The Life Quality Institute educates us on its website that it "depends on the setting in which Palliative care is provided." Per the Life Quality Institute, Palliative care services delivered by hospital teams may be paid for by insurance that covers medical and nursing services. Additionally, Medicare will currently cover one Palliative care consult with a hospice physician. The Veteran's Administration will cover Palliative care within the VA system. Also, some Children's Hospitals cover Palliative care. Health insurances often do pay for Palliative care services, but it is important to find out through your provider.

How is Palliative different from hospice care?

According to the Life Quality Institute, many people – even medical professionals – believe Palliative care and Hospice care are one and the same. They are not. Hospice care involves end-of-life care for individuals thought to be in the last six months of life.

Palliative care is appropriate at any age and at any stage of a serious illness, and it can be provided together with curative treatments.

(Continued on Page 2)

Team Hope Walks

2014 has been an amazing year for Team Hope thanks to the tireless efforts and dedication of our HDSA community! Thank you to all of you, our dedicated participants, teams, volunteers and sponsors for making 2014 another successful year for HDSA's Team Hope Walk program!

With your support we are increasing awareness to local communities and across the nation about Huntington's disease and supporting the HDSA mission: to improve the lives of everyone with HD and their loved ones. Thanks to you, we have accomplished such great feats in 2014, including:

- Nearly \$2 million dollars raised for the mission and programs of HDSA!
- Over 16,000 participants walked with us across the country this year in 44 states.
- 98 Team Hope Walks took place in 2014, of which 15 were new Team Hope Walks!

Understanding Behavior

Understanding Behavior (Second Edition) by Jane Paulsen, PhD and Arik Johnson, PsyD.

This second edition contains strategies that can be shared with caregivers as well as case studies that illustrate many of the most challenging behaviors associated with HD

To obtain a copy of *Understanding Behavior* please see our website or contact Anita at amarkpaul@hdsa.org

View online: hdsa.org/living-with-huntingtons/publications/understandingbehavior

How is Palliative care tied in with Advance Directives? When should this conversation begin?

If a Palliative care benefit is available to you, it is more likely that the person living with HD and his or her family will do better in living and coping with the disease and experience less suffering at the end of life. The sooner you can get to know your Palliative care team the better.

Additionally, please consider learning about a program called The Conversation Project (www.theconversationproject.org). The Conversation Project can help you learn how to speak with loved ones about end of life decision-making. It is very important to make your wishes known early when you first learn about your HD diagnosis. In fact, it is very important for every person, living with HD or not, to let end-of-life wishes be known.

Completing advance directives documentation is imperative in order to have your wishes followed if you are not able to make decisions at the time. (Please see the HDSA Family Guide Series entitled *Advance Directives for Huntington's Disease* to assist your discussion as well.) www.hdsa.org/living-with-huntingtons/publications

What if my care providers don't ask me about Advance Directives or Palliative care options?

Ask. Bring it up. Start the conversation.

The topic of living and dying with dignity is in the news frequently these days. It is important to let those who care for you, whether they be family or professionals, know what is important to you as you live with this chronic disease. Caregivers can also get support by bringing up the need for Palliative care and a discussion about end of life decision-making.

In his newly released book, *Being Mortal: Medicine and What Matters In the End* (2014), Dr. Atul Gawande writes, "In a landmark 2010 study from the Massachusetts General Hospital...researchers found that those patients with stage IV lung cancer who received Palliative care were far more likely to choose to stop chemotherapy sooner, entered hospice earlier, experienced less suffering at the end of their lives, and they lived 25 percent longer." Although we do not yet have a complete HD-specific study regarding the successes of Palliative care intervention, other studies can be instructive for the HD community.

Where can I learn more about Palliative care services?

HDSA or non-HDSA social workers across the country.

www.hdsa.org/living-with-huntingtons/community-services/social-workers/

National Hospice and Palliative Care Organization

www.nhpco.org/

Life Quality Institute

www.lifequalityinstitute.org

HDSA Now Accepting Applications for the 2015 Donald A. King Summer Research Fellowship

The Huntington's Disease Society of America (HDSA) is now accepting applications for the 2015 Donald A. King Summer Research Fellowship. The program is named in honor of Donald King who passed away in 2004. Don was a tireless and passionate advocate for HD families and served as HDSA's Chairman of the Board from 1999 to 2003. The goal of the program is to introduce and attract the brightest young scientists into the field of Huntington's disease (HD) research, while also helping to facilitate important research that may help us better understand HD.

The 10 week summer program is open to matriculated undergraduate life science students, pre-medical students and first year medical students who are currently attending accredited institutions in the United States. Students awarded these fellowships must work under the direction of an established HD researcher/faculty member. The deadline for applications is Friday, March 6th, 2015 at 5pm EST. More details and application materials for the Fellowship program can be found at www.hdsa.org/research/grant-applications.html.

If you have additional questions, they can be directed to George Yohrling, PhD, HDSA Director of Medical and Scientific Affairs at gyohrling@hdsa.org.

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Living with the daily challenges of HD can make it difficult to plan for the future. Here are some tips which may help you now and make future events easier to manage.

Financial and Insurance Benefits:

- 1. State Health Insurance** (called Medicaid in many states) may be available to disabled individuals who meet certain income and resource restrictions. Contact your local Health and Human Services agency to identify benefits and eligibility in your area.
- 2. Disability Insurance:** State Disability and Social Security Disability Insurance (SSDI) may offer persons with disabilities financial assistance when they are no longer able to work due to their medical condition. Before applying, work with your health care team to gather medical documentation about how HD has affected the ability to work and to perform independent self-care.
- 3. Long-Term Care (LTC) Insurance.** LTC policies can help cover future caregiving needs, such as: in home care, assisted living placement, nursing home care, adult day health care and respite care. With the exception of some State Medicaid Insurance Programs, LTC needs are not covered by ordinary medical insurance policies. LTC Insurance is often offered by employers and sometimes can cover parents. Coverage for persons diagnosed with HD is not guaranteed under law.

Community Resources and Assistance:

- 4. Respite and Assistance with Care:** Over time, caregivers need help to prevent stress and burnout. Your local health department or social services office may know of community and respite resources, such as: Adult Day Health Care Programs, In-Home Assistance, and Community/Senior Centers. There may also be friends and family who can be organized to assist with caregiving and household responsibilities.
- 5. Long Term Placement:** There may come a time when it is no longer possible to provide optimal care for the person with HD at home. Consider looking into local long term care options, such as nursing homes, before placement is needed. Visiting the facility now will help you make an informed decision when the need for long term care arises.

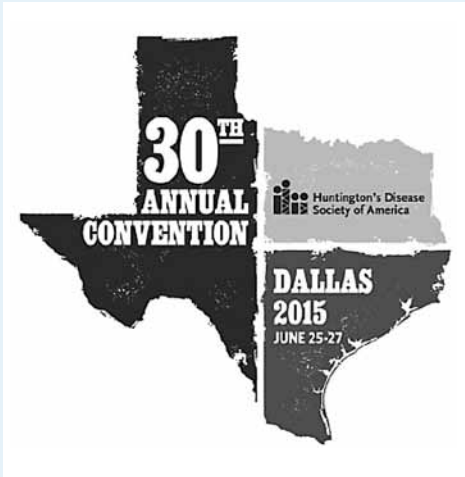
Advance Care Planning:

Talking about Quality of Life and End of Life issues can be difficult, but knowing what a loved one wants is the best way of honoring deeply held wishes and beliefs.

- 6. Quality of Life discussions may include:** what in life is important to you, how you want to live your life, your spiritual/religious preferences, and how you want to be cared for.
- 7. Medical and/or End of Life Wishes** should include preferences about: pain management; artificial nutrition and hydration; intubation, resuscitation, antibiotics, dialysis, medication, surgery, and which treatments are NOT wanted.
- 8. Durable Power of Attorney/Health Care Agent/Health Care Proxy.** It is important for the person with HD to legally designate someone trustworthy to make critical medical decisions if he or she is unable to do so.

(Continued on Page 4)

HDSA CONVENTION



The 30th Annual HDSA Convention will be held on **June 25-27, 2015**

Hyatt Regency At Reunion in Dallas, TX.

Stay tuned for more convention news

9. Brain, Body or Organ Donation. If there is an interest in donation, options should be researched and pre-registration completed in advance. Donation wishes are challenging to organize after death.

10. Documentation of Your Wishes. This is probably the single most important tip of all. There are legal documents that will ensure that medical, financial and end of life preferences are followed: Living Wills; Advance Health Care Directives, 5 Wishes, Physicians Order for Life Sustaining Treatment (POLST), and Do Not Resuscitate (DNR)/Do Not Intubate (DNI) forms. For the specific documentation available in your state please contact your local HDSA Social Worker.

BONUS TIP: Get Involved/Take Action! Participation in HD specific events/activities (HD support groups, fundraising events, research opportunities, etc.) can assist with coping and establishing a bond with a community of people that understand what you are feeling and the challenges you are experiencing.

For more information about HD and community resources available in your area please visit www.hdsa.org or contact your local HDSA Center of Excellence or HDSA Chapter Social Worker.

First published We are HDSA 2011

HDSA supports **ENROLL HD**

Enroll-HD is an international observational trial that will accelerate the development of therapies for HD by:

- Compiling uniform clinical data and biological samples critical to better understanding the natural history of HD,
- Building an even more comprehensive database of HD information – including biologic samples – that will be available for use by any HD investigator worldwide,
- Making available larger datasets from a greater number of research participants, thereby enhancing the power of data-mining and computational biology projects,
- Serving as a platform to facilitate clinical sub-studies and the development and validation of novel assessment tools for HD, and
- Expediting recruitment into global clinical trials of candidate therapeutics in the coming years.

It builds upon the COHORT (US/Canada) and REGISTRY (Europe) studies, and includes parts of South America, Asia, Australia and other areas in the future.

Eligibility: Everyone in the HD Community

Mid November enrollment = 3871 at over 95 sites around the world

Active Enroll-HD Sites

For more details please visit: www.enroll-hd.org/html/sites

Thank you Auspex



QR Code

Please scan here to visit the HDSA website

