

We Are HDSA!



Huntington's Disease
Society of America

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HDSA Information

Long Term Care Information

Want more information on long term care facilities in your area? Our HDSA social workers are an excellent resource for finding the facility that is right for you and your loved one. They are available to answer questions, explore possibilities based on you or your loved ones needs, and find a place that will provide appropriate services. HDSA social workers are also available to provide educational services and trainings to long term care facilities. To find your local social worker, visit www.hdsa.org or contact Seth J. Meyer at smeyer@hdsa.org or **800-345-HDSA (4372)**.

Also available on the HDSA website is a growing list of long term care facilities that have, in the past, accepted people with HD. Please note that information is maintained for informational purposes only. Inclusion on the HDSA website does not constitute endorsement by HDSA.

Long Term Care Placement

Gwen Johnson, RN-BC, HD Unit Nurse Manager, Good Samaritan Society Specialty Center

Huntington's disease comes with many challenges, requiring increasingly more care as the disease progresses. There may come a time that the family or caregiver is no longer able to provide the care at home even with the help of family, friends and other services.

It is never an easy discussion for any family when long term care placement may need to be considered. It brings up so many mixed emotions of guilt, grief, and loss on top of being already physically and emotionally exhausted.

So where do you begin? There are a few long term care facilities around the country that specialize in HD. As these organizations are knowledgeable and familiar with taking care of people with HD, these sites provide an excellent starting point. If there are no long term care facilities in your area that specialize in HD, start by contacting your local nursing homes, seeing if they will accept someone with HD, and requesting a tour. Warning: often when places hear the diagnosis of Huntington's disease, they say "we are not able to meet their needs." This may be true, but it is often that they have only heard of the challenging issues that are associated with HD, such as aggressive behaviors or the risk of falling. It will be up to you to educate long term care facilities about Huntington's disease and how it affects your loved one.

When talking to a nursing home you will want to be honest about the challenges of caring for your loved one but also be sure to talk about the person's routine, what they like to do and what makes them the most happy. Hopefully you will meet a professional who is interested, compassionate and will understand that although admitting a person with HD may be a challenge, it will be very rewarding to take care of this individual.

Be prepared that there are many questions that will be asked not only about your loved one but also about your loved one's financial situation. These questions can be overwhelming. Remember that you are not alone and there is help out there. Enlist your HDSA social worker, doctors, neurologists, psychiatrists, and anyone else who knows your loved one.

HDSA has social workers around the country that have a great deal of knowledge and can assist you. Support groups are another place where you can get ideas and a place where others really understand what you are going through. To find your local social worker or support group leader, please visit www.hdsa.org or contact Seth J. Meyer at the HDSA national office at **800-345-HDSA (4372)** or smeyer@hdsa.org. Another website available to check on the performance of nursing homes is www.medicare.gov/nhcompare/.

Remember to let what you see and feel help guide you as to where to place your loved one to ensure not only quality of care but quality also of life.

Family Guide Series :

Our Family Guide Series provides information about a variety of other topics. Currently available in English and Spanish are:

Huntington's Disease

Long Term Care

Genetic Testing

Nutrition and HD

Physical and Occupational Therapy

Caregivers' Guide to Communicating with Healthcare Providers

If you would like to request a free copy of any of our Family Guide publications, please contact Anita Mark-Paul at **212-242-1968 ext. 219** or amarkpaul@hdsa.org. Or you can download these and many other publications on our website at www.hdsa.org.

Physician's Guide :

Thanks to a generous educational grant from Lundbeck, HDSA is able to provide a complimentary copy of *A Physician's Guide* to every HD Family when they send or call the HDSA national office with the name, address, and phone number of both the neurologist and primary care provider seen by your loved one with HD so they can be added onto the HDSA list of online resources with the doctors approval.

Upon receipt, HDSA will send one free copy of the all new *A Physician's Guide* to you as well as a copy to your neurologist and primary care provider.

Call Anita Mark-Paul at **800-345-4372 ext. 219** or e-mail Anita at amarkpaul@hdsa.org

Please note that your correspondence with HDSA is completely private. HDSA does not share any information provided by you with anyone.

By Barb Heiman, LISW, Social Worker

HDSA Center of Excellence, Ohio State University/Central Ohio Chapter.

How do I know if my loved one is ready for placement?

Sometimes we just keep on keeping on – one more day becomes one more week and then one more month – the changes that happen around us can be so insidious that in our day to day circumstance we hardly notice that our loved one is getting more difficult to handle, physically or emotionally, or both. We are getting more exhausted and our stress level is at the max. But, we just continue to “adjust.” Eventually it takes a friend, a family member, or crisis for us to recognize the seriousness of our situation and decide to take that next step.

The real question can sometimes be “When am I ready to place my loved one in a long term care facility?” This dreaded decision is made even more difficult when a person is younger than the average facility age. The following are some considerations that might help to clarify that decision and put things in perspective.

The “Home Alone” Situation:

Is the primary caregiver (husband, wife, son, daughter) working out of the home, thus leaving the person with HD unattended for long periods of time each day? Is your loved one safe getting out of bed, using bathroom facilities, or fixing something to eat? Does he/she use the microwave and/or stove responsibly? Does the person with HD smoke? Are medications taken on time and in appropriate dosages? Will the person with HD attempt to drive a car, motor bike, or walk? If a fire started in the home could this person get out safely? Is he/she at high risk for serious falls or choking? Does your loved one have a medical alert system and know how to use it responsibly?

Children:

Because HD often begins during a person's primary working years it disrupts the family unit. Children in the home may range from pre-school to teens. If the well partner is working to support the family, are the children expected to be responsible for the needs of their adult HD parent?

Even though a teenager can “look” like an adult, he/she is still developing emotionally, cognitively, socially, and spiritually, and needs to have the necessary nurturing to develop these qualities. When life at home is confusing and chaotic, a child can build anger and resentment toward their parent and their home life, feeling robbed of their growing up years. Over the HD continuum, children not only lose the parent/child relationship with their HD parent but they can also lose a quality relationship with their well parent due to the extensive demands on that parent.

Behaviors

Caregivers try to manage these behaviors but sometimes behaviors are just “unmanageable”. Are the behaviors that your loved one is exhibiting too difficult to control?

There comes a time when one person managing the care, the children, the home, a full time work schedule, with little sleep and no relief in sight will build resentment toward their loved one. Questions that may arise can include, “Is this what I really signed up for?” and “When do I get time for myself?” These are natural human reactions in an overwhelming situation. Managing your own feelings of sadness, fear, loss, guilt and confusion can become impossible. Most families deeply regret placing their loved one in a long term care facility but they ultimately admit it was the best thing to do given the circumstances.

Ask the Social Worker

In this month's *Ask the Social Worker*, Stacey Barton, Social Worker at the HDSA Center of Excellence at Washington University, discusses Long Term Care Insurance. You can find *Ask the Social Worker* at www.hdsa.org/atsw. If you have any comments on *Ask the Social Worker* or would like to ask a question, send an e-mail to Seth J. Meyer at smeyer@hdsa.org with the subject "Ask the Social Worker." We look forward to your questions.

Going Green!

We Are HDSA! is going green! Starting in October, 2011, issues will be published in electronic form and, along with being available on our website, will be sent out via e-mail. Don't wait until we stop printing *We Are HDSA!*. Sign up for the electronic version today! Send an e-mail to Seth J. Meyer at smeyer@hdsa.org with your name, e-mail address, and city and state so you can be added onto our *We Are HDSA!* e-mail list.

By Karen Tarapata

The U.S. Department of Health and Human Services estimates that nearly 70% of all adults over 65 will need long term care during their lifetime. For people with HD, the need may arise at a younger age. The costs can be significant; contrary to what many people believe, Medicare and private health insurance programs do not pay for the majority of long-term care services.

There are ways to plan and prepare for the cost. HD is a disease that progresses over many years, even decades. People with HD and their families may be able to save, invest or buy long term care insurance to meet long term care needs.

Below are some of the options for funding long term care, along with the strengths and limitations of each.

Long Term Care Insurance

Long term care insurance is designed to pay the cost of nursing home care as well as home healthcare services. Policies vary widely in cost and coverage. Some policies offer very limited benefits. Persons who are thinking about buying long term care or disability insurance must do so before they undergo genetic testing for HD as insurers are allowed to refuse coverage to individuals who have tested positive for HD or other genetic disorders. For more information on long term care insurance, please see the August edition of *Ask the Social Worker*, found at www.hdsa.org/atsw.

Savings and Investments

Some families choose to pay a skilled nursing facility directly. With the help and a financial advisor (and enough time), it may be possible to build an investment portfolio that will pay for the future long term care of the loved one with HD.

Medicare

Medicare is a federally administered health insurance program for persons over 65 and younger persons who meet disability requirements. Medicare provides only partial payment for a stay in a Medicare-certified unit of a Medicare-certified facility and even then, for only up to 100 days annually. Medicare has other restrictions on long term care as well. The Medicare website, www.medicare.gov, has current information on benefits, requirements and restrictions.

Medicare Supplemental Insurance

Private insurance that can be bought to supplement Medicare is called "Medigap." Many Medigap plans will help pay for skilled nursing care, but only when that care is covered by Medicare. Check the website of your state's social services agency for information about the plans that are available.

Medicaid

Medicaid is a state administered program that may pay for long term care in a nursing facility. Eligibility is based on the level of care required and the degree of functional impairment, as well as on income and financial resources. Talk to an attorney or a social worker well in advance of applying for Medicaid in order to legally protect as many family assets as possible.

Private Insurance

Some managed care plans cover a portion of nursing home care in facilities with which they have contracts. Check your policy or talk to your benefits administrator.

Taking Charge

More and more, persons with HD and their families are seeking information that allows them to plan for their future, including planning for long term care. To get started, visit www.longtermcare.gov or talk to your HDSA social worker about your options.

HDSA Annual Convention:

Did you miss the HDSA Annual Convention? Was there a workshop that you were unable to attend? Select convention presentations will be made available online www.hdsa.org/convention.



Educational Events:

August 13:

Lawton, OK

September 17:

Englewood, CO
Warren, MI

September 23:

Dallas, TX

October 8:

Baton Rouge, LA

Caregiver's Corner:

August 16:

Crisis situations and
De-escalation Strategies

September:

To Be Announced

October:

Care for the Caregiver

November:

Gait and Balance

Watch your inbox for the invite to participate or contact Jane Kogan at JKogan@hdsa.org for more information.

Nursing Homes: Recommendations and Observations to Ponder

Jessica Hancock, LSW, HDSA Minnesota Chapter Social Worker

When your loved one needs 24-hour care, it can be a very difficult and emotional time for and your loved ones. It is important to find the best home and long term option, as moving a person with Huntington's disease and changing their routine can be a very difficult process.

Finding a long term care facility for your loved one may take some time, as many areas have limited willingness to work with people with Huntington's disease. Careful thought into what is best for your loved one and what will make him or her the happiest is the most important consideration when you are faced with options. Here are some things to consider when you reach this juncture:

- *Are the management and staff open to learning more about Huntington's disease? If they are not very open, chances are they may not be very understanding or willing to work with the person if behaviors or issues arise for the person with HD.*
- *Besides the physical building itself, what is the vibe the staff gives you? Are the staff smiling? Do they appear to be enjoying their work?*
- *Does the staff treat the patients with kindness and respect?*
- *What types of activities do they have that may be tailored to a person with HD, or one who may be younger than their usual population? Would they be open to adapting their activities to be HD friendly?*
- *Ask a couple of the residents what they think about living at the facility. You will probably get candid opinions and they will probably be your best advice as to what it is like to live there.*
- *Have they ever had a resident with Huntington's disease? At times a facility may have had a very limited or negative experience with one or very few HD residents, and they can be afraid of working with another HD patient. This is unfair as every person with HD experiences different symptoms, but may have been the only HD reality these facilities have encountered.*
- *What types of services come into the facility? Going out to appointments can be very nerve wracking for people with HD, so the more onsite services the better (i.e. Dental, Optometry, Podiatry, Psychology, Psychiatry, Neurology, etc ...)*
- *What types of interventions do they take when someone falls, has behavioral symptoms, or when someone is attempting to leave.*
- *Do they have music or pet therapists on staff for their residents?*

At times, the transition is more difficult for families than for the person with Huntington's disease. Long term care facilities can often provide the person with HD more socialization, friendship, structure, and routine than they had when living in the community.

Thank you

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

