

# We Are HDSA!



Huntington's Disease  
Society of America

Support Group Newsletter • [www.hdsa.org](http://www.hdsa.org) • (800) 345-HDSA • Issue 9, August 2011

## 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](http://www.hdsa.org) or contact Seth J. Meyer at [smeyer@hdsa.org](mailto: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](http://www.hdsa.org) or contact Seth J. Meyer at the HDSA national office at **800-345-HDSA (4372)** or [smeyer@hdsa.org](mailto:smeyer@hdsa.org). Another website available to check on the performance of nursing homes is [www.medicare.gov/nhcompare/](http://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.