

## 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](http://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](mailto: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.*

