

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.