HDSA Family Guide to Long Term Care

Huntington's Disease

Family Guide Series

Huntington's Disease Society of America

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HDSA thanks

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Disclaimer

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Introduction to Long-Term Care

Long-term care (LTC) is a term to describe medical and non-medical care that is provided over an extended period of time to people who have a chronic illness or disability. Individuals with Huntington's disease often need LTC as the disease progresses. This guide is designed to help families facing the challenge of HD learn more about LTC and to understand what may be involved in arranging this care for a loved one.

Why And When LTC May Be Needed

Huntington's disease (HD) is a hereditary brain disorder which leads to a wide range of physical and mental impairments that increase over time. In the early stages of the disease, living independently with assistance from family and friends may be sufficient to meet the needs of the individual. In-home care, provided by private home healthcare agencies, can extend the time your loved one may remain at home. Services vary by insurance provider and state so it is best to inquire directly as to what your insurance will and will not pay for while your loved one is at home.

However, as the disease progresses and symptoms increase, a person with Huntington's disease will need more and more assistance with the activities of daily living. This is when long-term care services may be indicated. The goal of long-term care services is to help maximize functioning and quality of life when the affected individual is no longer able to live independently.

There is no way to predict exactly when long-term care services will be needed. Over time, symptoms typically include declines in physical functions such as eating, swallowing and walking, reduced cognition that affects the ability to learn and reason, and emotional instability or difficulty controlling behavior. Each family dealing with HD will have a different decision as to when out-of-home placement is needed. For example, the physical demands of caregiving, in particular managing falls, or coping with urinary incontinence, can trigger the need for placement. For other families, behavioral and cognitive changes, in particular related to irritability, impulsivity or safety, can become too difficult to manage in the home environment (non compliance).

Since your loved one may require long-term care before the average age of most LTC residents, it is important to ensure that the facility you select for your loved one has the appropriate psychosocial, as well as medical services, required for a "younger" resident.

Long-term care for young adults (under the age of 20) and children affected by juvenile HD is very difficult to find. Most long-term care facilities will not accept anyone under age 18. If your child is affected by JHD, you should work with your pediatric neurologist, local children's hospital or HDSA social worker to identify potential placement and in-home care options.

Starting the Process

Finding a long-term care facility for your loved one can be a difficult process. Therefore, it is wise to consider the options for long-term care well before placement is needed or a crisis develops. Your local HDSA Center of Excellence or HDSA chapter or affiliate social worker can help you with your search. You can find these resources by visiting www.hdsa.org and clicking on "About HDSA" or Living with HD" or by calling the National Office at 1-800-345-4372. Drawing on the experiences of other HD families, through HDSA chapters or support groups, can also be very helpful in making this difficult decision. Other sources of information about long-term care facilities include hospital discharge planners, elder service organizations, advocacy agencies, the internet and family or friends who have placed a loved one in a facility.

Meeting the Long-Term Care Needs of Your Loved One with Huntington's Disease

Your loved one may require a very wide range of support services to address their complex multiple symptoms. They may need help eating, drinking, communicating, getting around and toileting. They may need behavioral health services as well as physical, occupational and speech therapy.

Taken as a whole, the symptoms and progression of HD present a challenging profile for many long-term care facilities. The number of facilities that can manage this progressive multi-faceted disease may be limited and unfortunately may not be located close by.

The Skilled Nursing Facility

Skilled nursing facilities, often called nursing homes, are by far the most common providers of long-term care. Skilled nursing facilities offer 24-hour nursing care, rehabilitation services such as physical, occupational and speech therapy, as well as assistance with Activities of Daily Living (ADL), which include dressing, bathing, eating and toileting. Many skilled nursing facilities also provide psychological care, social interaction and numerous other services. At their best, skilled nursing facilities provide care that meets the medical, psychological, social and spiritual needs of their residents, while promoting the highest level of functioning possible for each resident. Some facilities also offer short-term respite care when family members are temporarily unable to provide care (such as caregiver burnout, family emergency, or other).

Federal, State and Voluntary Evaluation and Accreditation

To ensure quality of service, care provided within facilities is evaluated in a number of ways. For instance, to participate in Medicare and Medicaid programs, facilities must comply with both federal and state regulations and are surveyed annually. In addition, many facilities also voluntarily pursue and receive accreditation from national professional organizations such as the Joint Commission or the Commission on Accreditation of Rehabilitation Facilities (CARF). Results of these surveys can be obtained online at your state's Department of Health website, from Medicare at **www.medicare.gov/nursinghomecompare/search.html** or the Centers of Medicare and Medicaid Services at **www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/NHs.html.**

Evaluating Administration and Operation

Asking the following questions may help you in evaluating a facility's administration and operations:

- Is the facility and its administrator licensed?
- Does the facility provide orientation for all new employees?
- Are employees trained regarding abuse, neglect and mistreatment of residents?
- Does the facility check the backgrounds of employees to ensure there is no history of abuse?

- Do employees receive specialized training on how to manage aggressive, combative, verbally abusive, disruptive and/or resistant residents?
- Is the facility accredited by The Joint Commission or the Commission on Accreditation of Rehabilitation Facilities (CARF)? Are the survey results available for inspection? If any deficiencies are noted, have they been corrected?
- Is the facility environment cheerful, clean and pleasant?
- Is the facility building and grounds maintained and in good condition?

The Skilled Nursing Team

In a skilled nursing facility, services are typically provided by a group of professionals and para-professionals with a wide range of expertise who may be full-time staff or as-needed consultants. You, your loved one and your family will also be members of the team. The team will develop and implement a comprehensive care plan that meets the specific needs of your loved one.

Your loved one may be younger than the other nursing home residents and may have a challenging profile of cognitive, emotional and behavioral issues in addition to their motor, speech and swallowing problems. To ensure positive outcomes, the treatment team must help your loved one maintain quality of life by identifying his/her remaining strengths while encouraging involvement of your loved one in decisions and daily routines.

Evaluating the Nursing Staff

Asking the following questions may help you in evaluating a facility's nursing staff:

- Does the nursing staff have experience working with non-elderly residents? Can they adapt to age-specific needs?
- Is the nursing staff permitted to adapt daily routines to meet individual preferences such as later bedtimes, additional snacks, social contacts and leisure interests?
- How does the nursing staff manage a resident who may be intermittently disruptive, aggressive, impulsive or demanding?
- Does the staff demonstrate respect for a resident in tone of voice; content of conversation; timely response to requests; accommodation to needs; meeting any special cultural, religious and language needs?
- How many staff will attend to your loved one? Consistency is key for a person with HD so the less change in routine and personnel the better the outcome.

Social Services

In a skilled nursing facility, social workers are responsible for assuring that the psycho-social needs of the resident are met and that each resident achieves their highest practical level of functioning. Social workers act as advocates to resolve problems and ensure that the residents' rights are observed. They also often serve as a liaison between the family, the interdisciplinary treatment team, funding sources and others. Social workers may also provide individual or group mental health counseling, or ensure that mental health and/or psychiatric services are available.

When you place your loved one in a facility, the social worker will help him/her as well as you and your family to adjust to a new living situation and cope with the changes that will occur as the disease progresses. The emotional, educational and advocacy support provided by social workers is critical given the complexities of HD and the inexperience that many long-term care facility staff may have regarding the disease.

Evaluating Social Services

When evaluating a facility, you may want answers to the following questions:

- Do they have enough social workers to meet the needs of all the residents?
- Are there family and residents' councils and are they active?
- Will care plan meetings include your loved one and the family?
- Are the rights of the residents posted in the facility?
- What are the policies around room/roommate changes?
- Are behavioral health services available?
- Will you and your loved one be allowed (and encouraged) to make choices regarding their care and daily routines?

Visit the facility you are considering on a weekend to observe any differences in how the unit and facility function. Look at staffing, activities being offered, housekeeping, etc.

Rehabilitation Services and Therapy

Many long-term care facilities provide rehabilitation therapy. Individuals with middle to late stage HD can benefit from physical therapy, occupational therapy and speech-language therapy. If possible, choose a long-term care facility where the physical, occupational and speech-language therapists have some experience or training in providing services to persons with HD.

In the Jimmo v. Sebelius Settlement, CMS confirmed that services by a physical therapist, occupational therapist, and speech-language pathologist are covered by Medicare, Parts A and B, and by Medicare Advantage Plans in skilled nursing facilities, as well as home health, and outpatient therapy, when the services are necessary to maintain a patient's current condition or to prevent or slow a patient's further decline or deterioration. The Settlement is not limited to any particular condition or disease or to people with chronic conditions. The fundamental issue for coverage under the standard clarified by Jimmo is whether the patient needs professional services to maintain function or to prevent or slow decline or deterioration.

Ask the social worker or Director of Rehabilitation Services if you believe your loved one would benefit from additional rehab services.

- Physical Therapy

HD affects motor skills and balance. Physical therapy can provide strength and conditioning exercises, compensatory training, and assessment for seating, balance and mobility.

- Occupational Therapy

HD creates difficulty in performing the activities of daily living (ADLs) – grooming, hygiene, and eating. An occupational therapist can assess skills and develop compensatory strategies, assess and train for adaptive equipment, provide an environmental safety assessment, and help manage the muscle rigidity and contractures that HD may cause.

- Speech-Language Therapy

A speech-language pathologist can intervene with communication assessment and training, cognitive retraining, dysphagia (choking) assessment and development of compensatory strategies.

- Recreation Therapy

Recreational therapy includes, but is not limited to, providing treatment services and recreation activities using a variety of techniques including arts and crafts, animals, sports, games, dance and movement, drama, music, and community outings. Recreational therapists treat and help maintain the physical, mental, and emotional well-being of residents.

Evaluating Rehabilitation Services and Therapy

When you visit a facility, you may want answers to the following questions:

- Does the facility provide restorative nursing or functional maintenance programs?
- Does the facility have therapy professionals on staff or do they use consulting professionals?
- Is adaptive equipment readily available and will it meet the needs of your loved one? Does it look well maintained?
- Is there a program in place if your loved one has eating disabilities? Does it involve both speech and occupational therapy professionals? Do these professionals have experience in HD or other neurological disorders?
- Are there professional activities/recreation staff? What activities are offered? Are they appropriate for your loved one?
- How many programs are offered during the week and how many on weekends? Note the calendar and observe whether posted activities are in progress when you visit.

Some Special Issues with Huntington's Disease

Huntington's disease presents unique challenges to the staff of a skilled nursing facility. Your loved one may need specialized programs and equipment different than those used by the other residents. They may also have special dietary needs. Some issues that need to be discussed before placement in the facility may include:

Dietary Services

A person with HD can have unique dietary requirements. It is not unusual for a person in middle to late stage HD to require extra caloric intake compared to other residents. Your loved one may benefit from receiving supplemental calories, through high protein and caloric dense drinks. As the demands of just trying to eat become more exhausting, it becomes more imperative to make eating as easy and as enjoyable as possible. Remember that hunger (and boredom) often can cause those with HD to struggle.

Below are some questions to start a discussion about nutrition.

- Will the facility provide small nutritious meals or snacks throughout the day, if medically necessary?
- Is a varied texture diet available?
- Is there an appealing pureed diet?
- Do they have support staff available to prepare and feed your loved one several small meals each day?
- Are meals served on time?
- Will your loved one be able to eat at their preferred times?
- Will your loved one be allowed to take as much time as they need to finish a meal?
- Are staff allowed to feed for as long as it takes to finish?
- How does the facility maintain food temperature and safety during prolonged feedings?

- Will your loved one be able to eat in a quiet area free from distractions?
- Will your loved one be weighed weekly?
- Are there attendants available to monitor your loved one while eating to prevent choking episodes? What are the choking protocols? Is suction equipment available in dining areas?

Environmental Concerns

Given the significant ambulation and movement issues of persons with HD, it is critical that the environment suits the needs of your loved one.

When you tour a facility, keep the following questions in mind and visualize your loved one trying to navigate the rooms, halls, dining areas and other areas.

- Is it relatively quiet in the building?
- How does it feel when you first enter the facility? Does it seem welcoming, pleasant and an inviting place to be living?
- Do you see handrails, grab bars and clearly marked exits?
- Are hallways free of clutter?
- Are rooms clean and well lit?
- Are safety bars in place in bathrooms and showers?
- Do you detect any strong odors?
- Do rooms allow space for personal belongings?

- How does the facility select roommates? Is it based on availability or compatibility?
- Is the temperature comfortable? Can heating and cooling be adjusted in the resident's bedroom?
- Can furniture be removed from rooms to eliminate sharp corners?
- Does the bed move when a resident sits down on it? Do the beds lock?
- Are kitchen and bath areas clean?
- Does the dining room have enough space to allow a person with a movement disorder to walk through without bumping into others?
- Will your loved one have access to an outdoor area?
- Does the outdoor area have landscaping or physical barriers to prevent your loved one from wandering from the facility?

Restraint Use

In long-term care facilities, it may become necessary, from time to time, to use soft restraints in wheelchairs and dining chairs on residents who are at risk for falls or accidents, or whose judgment is impaired. During your tour of a facility, observe how many residents are in chairs with restraints. This may indicate how the facility views restraints and how they might deal with an individual with HD.

There is a difference between restraints and positioning devices. Restraints prevent independent movement while positioning devices such as a lap belt or strap prevent a person with chorea from sliding or self ejecting from a chair or seat. Ask the facility about their restraint policy and their use of positioning devices.

Special Programs and Assistive Equipment

Special programs and equipment can keep your loved one safe while maintaining as much independence as possible. For instance:

- Is the facility set up to assist your loved one if they cannot walk by themselves?
- Does the facility have specialized equipment if your loved one has eating difficulties, such as lip plates, weighted utensils and cups with lids?
- Does the facility have alternative beds? Can “low beds” or other adapted sleeping arrangements be used? Does the facility have access to Broda® chairs?
- Who makes adaptations to equipment if your loved one has involuntary movements that may require extra padding in certain areas?
- Are adaptive call lights available, such as a pressure bulb, which doesn’t require much hand dexterity?
- What is the facility practice when your loved one can no longer use a call bell? Do they conduct standard checks and how frequently are the checks during the day and at night? How does the facility monitor this?

Paying for Care

Several funding sources are available for long-term care. The choice depends on a number of factors, including the level of care required, whether or not your loved one had a recent stay in an acute care hospital and the family's financial situation. Below is a description of various funding sources and the eligibility requirements for each.

Medicaid

Administered by individual states, Medicaid is a medical assistance program that pays for long-term care in a nursing facility. Medicaid for long-term care is available to those who are disabled as defined by the U.S. Social Security Administration Standards of Disability and have limited assets and income. Eligibility is based on the level of care required, the degree of functional impairment of the person and financial need. Medicaid recipients seeking placement in a nursing facility must be screened for medical eligibility. Contact your state Medicaid office to locate the agencies that perform these medical assessments.

Medicaid programs require recipients to have limited income and financial resources. The availability of funds that have been set aside for things like children's education or a spouse's retirement may affect the patient's financial eligibility. Therefore, long before your loved one applies for Medicaid, it is wise to consult with an elder law, Medicaid or estate/asset protection attorney to determine which assets can be retained and how to do so legally. Medicaid administrators can audit financial activity that occurred up to five years prior to the time that your loved one applies for assistance.

Medicare

The Centers for Medicare and Medicaid Services (CMS) administers Medicare, a federal health insurance program. The program is intended for disabled persons who have been declared disabled for two years and for individuals over age 65. Medicare provides partial payment for up to 100 days annually for skilled nursing care in a Medicare-certified unit of a Medicare-certified facility.

Medicare pays for care only when your loved one is admitted to a skilled nursing facility within 30 days of discharge from a hospital stay of at least three days. Your loved one must also require skilled nursing care or rehabilitation therapy for the same condition for which he/she was treated in the hospital.

Medicare Part A covers 100 percent of the fees for room and board for the first 20 days of a nursing home stay. For days 21 through 100, patients pay a specified amount daily, with

Medicare paying the balance. The amount changes annually. For current coverage information, check with your local Medicare office or visit the Medicare web site at **www.medicare.gov.**

Since Medicare pays for only a small portion of nursing home care, your loved one should have other funds available to pay for care after benefits have been exhausted. Medicaid and "Medigap" policies are available or there are private insurance providers.

"Medigap" Insurance

Because Medicare offers limited benefits and covers only a portion of the cost of nursing home care, most Medicare beneficiaries obtain supplemental health insurance coverage. Often called "Medigap" insurance, it is available from employers, through Medicaid or from private insurance providers. Costs and options vary; some plans like Medicare Advantage can include skilled nursing care. Medicare Advantage plans may be available in your state. Contact your state's social services agency for specific information about the plans available to you.

Private Insurance

Some health maintenance organizations (HMOs) and private insurance companies offer policies that cover a portion of nursing home care. Many HMOs will pay for care only in facilities with which they have contracts. It is a good idea to ask the facility which insurance plans they accept. Will you need to change insurance providers? Better to know well before you make your decision.

Long-Term Care Insurance

Long-term care insurance is designed to pay the cost of nursing home care as well as home healthcare. Policies vary in cost and coverage details. Many policies may have limited coverage and require that the beneficiary meet specific medical criteria. Be certain that you understand what the policy covers before buying any insurance.

With most long-term care insurance policies, you pay the cost monthly and are then reimbursed by the LTC insurance company for your loved one. Repayment time varies so ask about reimbursement before purchasing a policy.

While long-term care insurance can be a good financial decision, premiums are often quite expensive and long-term care insurance providers may exclude individuals who have tested positive for HD or have other neurologic diseases or genetic disorders in their family. Unfortunately, the Genetic Information Non-Discrimination Act of 2008 does not cover life insurance, disability insurance or long-term care insurance. Therefore, obtaining a long-term care policy must be done before undergoing genetic testing for HD.

Saving and Investing

It can be difficult to successfully navigate the various insurance programs that may provide for long-term care. An alternative is to pay for the skilled nursing facility directly. HD is a disease that develops over years, even decades, and it may be possible for some families to save and invest for the future long-term care of the loved one with HD. Some families have used a Financial Planning professional to discuss other saving options, such as investments, to help them save for future long-term care needs.

Long-term care facilities often set aside a certain number of beds for individuals on Medicaid and a certain number for those who will pay by other means. Many families have found that when it is time for placement, they can place their loved one in the facility of choice if they have adequate resources to pay the facility for a period of up to six months after which they can apply for Medicaid. A Financial Planning professional can assist families in determining how best to set aside resources to “spend down” during this time and how to apply for Medicaid when appropriate.

The Family Member as Advocate

After your loved one has been placed in a long-term care facility, family members will find that their primary role has shifted from caregiver to advocate. While social workers at the facility will be advocating for the residents under their care, there will be times when your input will be necessary to help your loved one to adjust to the nursing home environment and feel secure in his/her new home. Changes in routine are difficult for most people, but they can be especially disruptive to a person with HD.

Opportunities to Advocate

The more information the staff has about your loved one, the better the individualized care plan will be. Opportunities to advocate include:

- The day of admission

On admission day, you will meet with the facility's social worker and charge nurse. This is an opportunity to provide information about your loved one's social and education background, hobbies and preferences.

- The initial care plan meeting

Shortly after admission, you and your loved one will be able to attend a meeting with the facility's interdisciplinary team and set goals to help your loved one remain as independent and comfortable as possible.

- Quarterly care plan meetings

Every 90 days or less, the interdisciplinary team will meet to review and update your loved one's plan of care. You may attend these meetings and express any questions or concerns you may have.

- Family councils

Many facilities have family councils so family members can discuss concerns or make recommendations regarding the care of their loved one.

- Informal discussions with facility staff

You should feel free to speak to any staff member about your loved one's care but many family members take their concerns to the charge nurse on the unit. If you are not satisfied with the response, ask to speak to a nursing supervisor, your loved one's social worker, the Director of Nursing or the Administrator.

Education

Remember that Huntington's disease is rare and most nursing home personnel have had little or no experience caring for someone with HD. You will likely need to educate them about the illness by providing online websites and other educational resources whether in a book or pamphlet format. Remember that due to the high turnover of staff within long-term care, this type of education will need to be an ongoing process. Many HDSA chapter and Center of Excellence social workers provide in-person educational trainings to facilities with HD residents. These trainings can provide care staff with an ongoing knowledgeable resource for consultations as the disease progresses. Contact **HDSA (800-345-4372)** to ask if an HDSA social worker can visit the facility at which your loved one resides.

After Admission to a Facility

Counseling and support groups

When your loved one is admitted to a skilled nursing facility, family members and friends may find themselves feeling a variety of emotions. Often it is a powerful combination of both relief that the loved one is receiving professional care and supervision, and regret or guilt that it was not possible to care for the loved one at home, as well as grief or anger over the progression of the disease. It is important for family and friends to take advantage of any support groups or counseling that is available.

There are HD support groups in most states. Your local HDSA chapter or the HDSA National Office can help you locate a support group in your area. In addition, the HDSA Center of Excellence program serves as the cornerstone of HDSA's commitment to care, with over 45 facilities nationwide that provide a vast array of medical and social services to HD families. HDSA Centers of Excellence work in collaboration with HDSA chapters, affiliates, regions and support groups to form a seamless national network of resources and referrals for those affected by HD and their families.

To find local HDSA resources, call **800-345-HDSA** or visit www.hdsa.org and click on “About HD” to locate your closest HDSA Center of Excellence, chapter or affiliate.

Evaluating care

As a concerned family member, you will want to monitor the ongoing care of your loved one. It is perfectly acceptable to ask questions of the staff and administration and to investigate until you are satisfied. You may want to visit the long-term care facility at varying times of the day or week to accurately assess the care your family member is receiving. You are the HD expert for your loved one and will always be their best advocate.

Some ongoing care issues to consider include:

- Is your loved one’s care plan tailored to their specific needs/interests?
- Is your loved one bathed on a regular basis? Is he/she well-groomed and dressed appropriately?
- How long does it take for staff to answer call lights?
- Does your loved one complain about care every time you visit?
- Has your loved one lost weight since admission?
- Does your loved one seem to be always in his/her room or are they involved in activities?

Resolving Problems

Establishing good communications with the people who are caring for your loved one will make it easier to ensure the kind of care he or she receives. Here are some general tips to being an effective advocate and an integral member of your loved one's treatment team:

- Introduce yourself to the staff.

Get to know the people who are taking care of your loved one, especially the nursing assistants and aides who actually have the most contact with your loved one. Remember to acknowledge staff members and thank them when they have done a good job. They will be more receptive to your suggestions when they know you appreciate what they do.

- Express concerns calmly.

When you need to bring concerns to the staff, a firm and calm approach is more likely to get you the information you need to determine the cause of the problem and to find a solution. By not getting angry, you are also helping your loved one to stay calm.

- Know who to talk to.

Read the copy of the Residents' Rights and Responsibilities that you received when your loved one was admitted to the facility. Learn about the facility's organizational structure so you understand the internal reporting procedures for complaints and grievances. Ask questions if there is anything you do not understand. You may need to be persistent to ensure concerns are being addressed to your satisfaction.

External Resources.

If you cannot resolve a problem with the medical or administrative staff, you may need to take your concern outside the facility. The Department of Public Health, the state Attorney General's office and the facility's Ombudsman are available to mediate complaints; their phone numbers should be posted in a highly visible place in the facility, typically close to the front door. Nursing home ombudsmen are volunteer advocates who help nursing home residents resolve complaints about their care, rights, or issues affecting the quality of life in a long-term care facility.

Visiting

Visiting your loved one in a skilled nursing facility can both be rewarding and difficult. By visiting frequently, you can monitor the care your loved one is receiving and provide reassurance that he/she is still part of the family. Visiting can be difficult, however, as one clinical symptom of HD is the inability of the individual to perceive the severity of their symptoms. Your loved one may resent the loss of freedom and not understand why they can't go home.

- Remind yourself that both you and your loved one need time to adapt to the changed situation. Most people eventually adjust to their new home, but the time it takes will vary – perhaps up to three months or more.
- Remember even though you are no longer providing daily care, your stress may still be high as you adjust to "turning over care" and manage the demands of being an advocate for your loved one.
- Try to make visits fun, and a chance to do things whether

going outside of the facility, reviewing family/friend photos, or giving a hand or foot massage. Try to be creative!

- Think about bringing a family pet, favorite food treat or something that your loved one might miss from home.
- Attend one of the facility's group activities along with your loved one.
- Set limits. You do not have to stay if a loved one is verbally abusive during a visit. Tell them that you love them and that you will return another day when they are calmer.
- Visit only as often as your schedule allows. Everyone has commitments and responsibilities. It is the quality of the visit that is important, not the quantity. In addition, your loved one may be less likely to join in the facility's social groups and activities if he/she is expecting daily visits.

In some cases, your loved one will go through a period of time when he or she truly cannot tolerate the visits of family members. While this rejection is an effect of the disease, it can be hurtful to family members and cause strong feelings of guilt. Counseling or support groups can help family members through this difficult period.

Conclusion and more resources

HD is a disease that affects both the entire family and person, physically, cognitively and emotionally. This combination of disabilities can make it very difficult to care for the loved one at home as the disease progresses. As a primary caregiver it can be helpful to "draw your own line in the sand" for when the demands at home become unsustainable both for your loved one as well as yourself. This line will be different for all families and there is no right or wrong, good or bad time. There is only the time that works for your family and for your situation. It is critical to not feel or be alone in the process. Keep reaching out for the help you need. The decision to place a loved one in a long-term care facility can be a wise and kind decision for both the person with the disease and the rest of the family.

That said, placement in a long-term care facility is not a simple decision or an easy process. Your local HDSA chapter or the HDSA National Office can help you with information, resources and support. To find your local HDSA chapter, call the HDSA National Office at **800-345-HDSA** or visit **www.hdsa.org**, click on "About HDSA."

Some long-term care facilities have specialized wings for person with HD or other neurological disorders. While not every state will have such a facility, below is a list of current ones:

California – San Diego County
- Edgemore Skilled Nursing Facility (Santee, CA)

Indiana
- Byron Health Center (Ft. Wayne, IN)
- Corydon Nursing and Rehabilitation (Corydon, IN)

Minnesota
- Good Samaritan Specialty Care (Robbinsdale, MN)

New Jersey
- Leisure Chateau Care and Rehabilitation Center (Lakewood, NJ)
- JFK/Hartwyck Nursing and Rehabilitation Center (Edison, NJ)

New York State
- Archcare at Terence Cardinal Cooke (NYC)
- Archcare at Ferncliff Nursing Home and Rehabilitation Center (Rhinebeck)
- Victoria Home (Ossining NY)
- Sitrin Health Care Center (New Hartford, NY)

Vermont
- Crescent Manor (Bennington, VT)

For updated information, contact your HDSA social worker (**https://hdsa.org/about-hdsa/social-workers/**) or the HDSA website (**www.hdsa.org**).

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HELP FOR TODAY.
HOPE FOR TOMORROW

The Society is a national, voluntary health organization dedicated to improving the lives of people with Huntington's Disease and their families.

To promote and support research and medical efforts to eradicate Huntington's Disease.

To assist people and families affected by Huntington's Disease to cope with the problems presented by the disease.

To educate the public and health professionals about Huntington's Disease.

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