

# Long-Term Care



## Huntington's Disease

Family Guide Series

# Long-Term Care for HD

## Family Guide Series

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## I. Introduction to Long-Term Care

Long-term care (LTC) is a term used 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 & When Long-Term Care May Be Needed

Huntington's Disease (HD) is a hereditary brain disorder which leads to a wide range of physical and mental disabilities 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.

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. Initial symptoms usually appear between the ages of 30 and 50, but the disease may strike those as young as two or as old as 80, and the progression of symptoms is different for each individual with HD. 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. It is important to remember that the affected individual may need long-term care at any age.

## Starting the Process

Finding a long-term care facility for an individual with advanced HD is not a quick or easy process. Therefore, it is wise to consider the options for long-term care well before placement is needed or a crisis develops. Your HDSA Center of Excellence or HDSA chapter or affiliate social worker can help you with your search. You can find your local chapter/affiliate or Center of Excellence by going to [www.hdsa.org](http://www.hdsa.org) and clicking on "About HDSA" or "Living with HD" or by calling the national office at 800-345-4372. Drawing on the experiences of other HD families by contacting 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 other directories.

## Meeting the Long-Term Care Needs of People with Huntington's Disease

Individuals with advanced HD require a very wide range of support services. They may need help eating, drinking, getting around and communicating. The individual may need psychological support, as well as physical, occupational and speech therapy.

Taken as a whole, the symptoms of HD present a challenging profile for the long-term care facility. The number of facilities that will accept this challenge may be limited and may not be located near to the family home.

## II. 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 - and 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, and promotes 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.

## 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 on Accreditation of Healthcare Organizations (JCAHO) or the Commission on Accreditation of Rehabilitation Facilities (CARF). Results of these and other surveys can be obtained from the facility administration.

### *Evaluating Administration and Operations*

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 on Accreditation of Healthcare Organizations (JCAHO) 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?
- Are the facility buildings and grounds maintained in good condition?

## The Skilled Nursing Team

In a skilled nursing facility, services are typically provided by a group of professionals and paraprofessionals with a wide range of expertise who may be staff or as-needed consultants. The patient and family are also members of the team. The team develops and implements a comprehensive care plan that meets the needs of the patient.

HD residents are usually younger than the traditional nursing home resident and often have a challenging profile of cognitive, emotional and behavioral issues, in addition to their motor, speech and swallowing problems.

To have positive outcomes, the treatment team must help the person with HD maintain quality of life by identifying the person's remaining strengths and encouraging involvement 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 bedtime, additional snacks, social contacts and leisure interests?
- Is the nursing staff equipped to work with residents who may be intermittently disruptive, aggressive, impulsive or demanding?
- Do the residents and staff have access to psychiatric/mental health consultation services?
- Does the staff demonstrate respect for residents in tone of voice; content of conversation; timely response to requests; accommodation to needs; meeting any special cultural, religious and language needs?

## Social Services

In a skilled nursing facility, social workers are responsible for assuring that the residents' psycho-social needs are met and that residents achieve their highest practical level of functioning. Social workers act as resident advocates to resolve problems and ensure that the residents' rights are observed. They also often serve as a liaison between the family, interdisciplinary treatment team, funding source 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 a person with HD is placed in a facility, the social worker will help the resident and family 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 of many long-term care facility staff 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 resident's needs?
- Are there family and residents' councils and are they active?
- Can care plan meetings include the resident and family?
- Are the rights of the residents posted in the facility?
- What are the policies around room/roommate changes?
- Are mental health services available?
- Are residents allowed (and encouraged) to make choices regarding their care and daily routines?
- Are there professional activities/recreation staff? What activities are offered? Are they appropriate for the individual with HD? Note the calendar and observe whether posted activities are in progress when you visit.

## **Rehabilitation Services and Therapy**

Many long-term care facilities provide rehabilitation therapy. Individuals with middle to late stage HD will benefit from rehabilitation therapy such as 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 with HD. Sadly, insurance (including Medicare) will not cover ongoing rehabilitation services for HD, so creativity on the part of the facility is necessary.

### Physical Therapy

HD affects motor skills and balance. Physical therapy can provide strength and conditioning exercise, 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.

### Evaluating Rehabilitation Services and Therapy

When you visit a facility, the following questions should be answered:

- Does the facility provide restorative nursing or functional maintenance programs?
- Does the facility have therapy professionals onstaff or do they use consulting professionals?
- Is adaptive equipment readily available?
- Is there a program in place for people who have eating disabilities? Does it involve both speech and occupational therapy professionals?

## **Some Special Issues with Huntington's Disease**

Huntington's Disease presents unique challenges to the staff of a skilled nursing facility. A resident in the advanced stages of the disease may need specialized programs and equipment different than those used by the other residents. They may also have special dietary needs. Below are some of the issues that need to be discussed before placement in the facility.

### Dietary Services

A person with HD has extensive dietary requirements. It is not unusual for a person in middle to late stage HD to require several thousand calories daily. This may require many small meals throughout the day.

Below are some questions to start a discussion about nutrition.

- Will the facility provide small meals throughout the day, if medically necessary?
- Is a varied texture diet available?
- Is there an appealing pureed diet?
- Are nutritious snacks readily available?
- Are meals served on time?
- Can residents eat at preferred times?
- Are residents allowed to take as much time as they need to finish a meal?
- Can residents eat in a quiet area free from distractions?
- Are residents weighed weekly?

### **Environmental Concerns**

Given the significant ambulation and movement issues of people with HD, it is critical that the environment suits the needs of the resident.

When you tour a facility, keep the following questions in mind and visualize the person with HD trying to navigate the rooms, halls, dining areas and other areas.

- Is it relatively quiet in the building?
- 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?
- 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 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?
- Do residents have access to an outdoor area?
- Does the outdoor area have landscaping or physical barriers to prevent residents from wandering from the facility?

### **Restraint Use**

In many long-term care facilities, it is common to use soft restraints in wheelchairs and dining chairs on residents who are at risk for falls or accidents, or whose judgment is impaired. In individuals with HD, restraint use may be frustrating and lead to increased behavioral problems. 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.

### **Special Programs and Assistive Equipment**

Special programs and equipment can protect the safety of a person with HD while maintaining as much independence as possible. For instance:

- Is the facility set up to assist people who cannot walk by themselves?
- Does the facility have specialized equipment for people with 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?
- Are adaptive call lights available, such as a pressure bulb, which doesn't require much hand dexterity?

### III. 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 the person with HD has 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 is available only to people aged 65 and over; the disabled as defined by the U.S. Social Security Administration Standards of Disability; or those under the age of 18. 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.

In addition, 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 the family member applies for Medicaid, it is wise to consult an attorney to determine which assets can be retained and how to do so legally. Medicaid administrators can audit financial activity that occurred prior to the time that the family member applies for assistance.

#### Medicare

The U.S. Health Care Financing Administration (HCFA) administers Medicare, a federal health insurance program. The program is intended for disabled persons who have been declared disabled for two years and for those 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 a patient is admitted to a skilled nursing facility within 30 days of discharge from a hospital stay of at least three days. The recipient 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 patients must pay changes annually; in 2009, patients pay \$133.50 daily after day 20. For current coverage information, check with your local Medicare office or visit the Medicare web site at [www.medicare.gov](http://www.medicare.gov).

Since Medicare pays for only a small portion of nursing home care, beneficiaries who need long-term care (more than 100 days) should have other funds available to pay for care after benefits have been exhausted. These patients can apply for Medicaid or purchase "Medigap" or private insurance.

#### "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 include skilled nursing care. 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.

### 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. Most policies have very limited coverage and require that the beneficiary meet specific medical criteria. Be certain that you understand what the policy covers before buying any insurance.

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 other genetic disorders. Unfortunately, the Genetic Information Nondiscrimination 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 to save and invest for the future long-term care of the loved one with HD.

## IV. The Family Member as Advocate

After a loved one has been placed in a long-term care facility, family members will find that their primary role has changed 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 the resident 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 people with HD.

### Opportunities to Advocate

The more information the staff has about a resident, the better the individualized care plan will be.

Opportunities to advocate include:

#### *The day of admission*

On the day of admission 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 educational background, hobbies and preferences.

#### *The initial care plan meeting*

Within two weeks of admission, you and the new resident will be able to attend a meeting with the facility's interdisciplinary team and set goals to help the resident 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 the resident'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 that family members can raise specific issues about 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, the resident's social worker, the Director of Nurses 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 may have to educate them about the illness by bringing books and pamphlets for the staff. Your local HDSA chapter or the HDSA national office can be of assistance.

## V. After Admission to a Facility

### Counseling and Support Groups

When a person with HD is admitted to a skilled nursing facility, family members and friends may find themselves feeling a variety of emotions. Often it is a potent combination of relief that the individual is receiving professional, round the clock care, regret or guilt that it was not possible to care for the individual at home, as well as grief or anger over the progression of the disease. It is important for the family and friends of an individual with HD to take advantage of any support groups or counseling that is available.

There are HD support groups in virtually every state. Your local HDSA chapter or the HDSA national office can help you locate a support group in your area. In addition, there is the HDSA Center of Excellence program which serves as the cornerstone of HDSA's commitment to care, with 21 facilities that provide a vast array of medical and social services to HD families. The Centers 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 a local HDSA chapter or a Center of Excellence in your area, call 800-345-HDSA or visit [www.hdsa.org](http://www.hdsa.org), click on "Living With Huntington's Disease", then click on "Family Care".

### 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 nursing home at varying times of the day to accurately assess the care your family member is receiving.

Some ongoing care issues to consider include:

- Is the resident bathed daily? Is he/she well groomed and dressed appropriately?
- How long does it take for staff to answer call lights?
- Does the resident complain about care every time you visit?
- Has the resident lost weight since admission?
- Does the resident 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 influence 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 residents. Having friends on the staff can be very helpful for you and 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 the person with HD to stay calm.

### **Know who to talk to.**

Read the copy of the Residents' Rights and Responsibilities that you received when your family

member 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.

### **External Resources.**

If you cannot resolve a problem with the facility staff, you can 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 conspicuous place in the facility. 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.

## VI. 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 family member is receiving and provide reassurance that he or she is still part of the family. Visiting may be difficult as one clinical symptom of HD is the inability of the individual to perceive the severity of their symptoms. The person with HD may resent the loss of freedom and not understand why they can't go home.

- Remind yourself that both you and the individual need time to adapt to the changed situation. Most people eventually adjust to their new home, but the time it takes will vary.
- 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 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, the resident may be less likely to join facility social groups and activities if he or she is expecting daily visits.

In some cases, the HD resident 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.

## VII. Conclusion and More Resources

HD is a disease that affects the entire person, physically, cognitively and emotionally. This combination of disabilities makes it very difficult to care for the individual at home as the disease progresses. 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](http://www.hdsa.org), click on "Living With Huntington's Disease", then click on "Family Care".

The Huntington's Disease Society of America (HDSA) is dedicated to:

- promoting and supporting research to find a cure for HD
- helping people and families affected by the disease, and
- educating the public and healthcare professionals about HD

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