

THE FAMILY GUIDE SERIES

Long Term Care

Written By:

Suzanne Imbriglio, P.T.

Director of Rehabilitation

SunBridge Care and Rehabilitation for Lowell

Virginia Goolkasian, L.S.W., M.S.

Community and Professional Liaison

SunBridge Care and Rehabilitation for Lowell

Ann Murfitt, M.S.W., L.I.C.S.W.

National Director of Behavioral and Social Services

SunBridge Care and Rehabilitation for Lowell



Huntington's Disease Society of America

158 West 29th Street, 7th Floor

New York, New York 10001-5300

212-242-1968 • 1-800-345-HDSA • www.hdsa.org



The Huntington's Disease Society of America is dedicated to eradicating Huntington's Disease by promoting and supporting HD research; to helping families cope with the problems presented by HD; and to educating the public and professionals about Huntington's Disease.

Disclaimer

Statements and opinions expressed in this publication are not necessarily those of the Huntington's Disease Society of America, nor does HDSA promote, endorse or recommend any treatment or therapy mentioned herein. The reader should consult a physician or other appropriate health care professional concerning any advice, treatment or therapy set forth in this publication.

Reproduction in whole or in part without express written permission of the Huntington's Disease Society of America is strictly forbidden.

© 2001 All rights reserved.
Printed in the United States of America.

Contents

Meeting the Special Long-Term Needs of Patients with Huntington's Disease	5
The Skilled Nursing Facility	6
Skilled Nursing Facility Services	7
Some Special Issues for Huntington's Disease Patients	12
Paying for Nursing Home Care	15
The Family Member as Advocate	18
Conclusion	23

Meeting the Special Long-Term Needs of Patients with Huntington's Disease

Huntington's Disease (HD) is a progressive neurological condition characterized by a complex set of symptoms including declines in physical function, reduced cognition, emotional instability and/or behavioral problems. In the early stages of the disease, living independently or with assistance is very appropriate. However, as the disease progresses, a person with Huntington's Disease reaches a point when it is no longer possible to perform basic activities of daily living independently. At this time, long-term care services may become necessary.

For those who require long-term care, a skilled nursing facility can provide the most appropriate services by providing 24-hour nursing care, rehabilitation services—such as physical, occupational and speech therapy—and assistance with activities of daily living, like dressing, bathing, eating and toileting. Skilled nursing facilities also provide psychological and social care and numerous other services. Essentially, skilled nursing facilities may be required to provide care that meets the medical, psychological, social and spiritual needs of their residents, and to promote the highest level of functioning possible for each resident.

For people with Huntington's Disease who require long-term residential care, the chosen facility will become home. Therefore, it is important for HD families to carefully select a nursing home that most effectively meets the prospective resident's needs. It is best to consider the options for long-term care well before placement is needed or a crisis develops. The information in this brochure can guide you to evaluate and select the right skilled nursing facility.

Information about skilled nursing facilities can be obtained from a variety of sources, including hospital discharge planners, elder service organizations, advocacy agencies, the Internet and other directories, as well as from the Huntington's Disease Society of America (HDSA) and its local chapters.

The Skilled Nursing Facility

Skilled nursing facilities provide long-term residential care for individuals of different ages, characteristics and health concerns. In addition to caring for the traditional geriatric patient, some nursing facilities also provide care for people with permanent disabilities, chronic illnesses, a variety of neurologic disorders, and other health concerns with special or unique needs. Some facilities also provide short-term care for patients who require short-term skilled nursing or rehabilitation therapy after hospitalization. Many facilities also offer short-term respite care when family members are temporarily unable to provide care.

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

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?
- Are 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 building and grounds maintained in good condition?

Accreditation of Rehabilitation Facilities (CARF). Results of these and other surveys can be obtained from the facility administration. In addition to obtaining survey information, the general questions at left, will help in evaluating the facility's administration and operation.

Skilled Nursing Facility Services

In a skilled nursing facility, services are typically provided by a group of professionals and paraprofessionals with a wide range of expertise. Some of the team members may be full-time staff, while others may be periodic or as-needed consultants. The patient and family are also members of the team. The focus of the interdisciplinary treatment team is to develop and implement a comprehensive care plan that meets the needs of the patient. The most critical of these services are described below.

Nursing Services

Nursing services touch all aspects of a resident's life while in the nursing home. This includes medical, physical, grooming, eating, bathing, toileting, communication, vision, hearing, nutrition, cognition, psychosocial, mood/behavior. 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.

Because of the multiple complex clinical issues of a resident with HD, collaboration between nursing staff and other disciplines is crucial to effective treatment. To have positive outcomes, the treatment team must help the person with HD maintain quality of life. This also includes helping him/her to maintain a sense of control and a sense of empowerment. The team can also help to identify the person's remaining strengths and encourage involvement in decisions and daily routines.



Relevant questions to ask include:

- Does the nursing staff have experience working with non-elderly residents? Can they adapt to age-specific needs?
- Is the nursing staff able to adapt daily routines to meet individual preferences, such as later bedtime, additional snacks, social contacts and leisure interests?
- Is the nursing staff able to work with residents who may be intermittently disruptive, aggressive, impulsive and demanding?
- Does the nursing staff have access to psychiatric/mental health consultation services?
- Is the facility willing to provide additional training to nursing staff regarding HD?

Social Services

In a skilled nursing facility, social workers are responsible for assuring that the residents' psychosocial needs are met and that residents achieve their highest practical level of functioning. Social workers act as resident advocates to resolve problems if they occur, ensuring that the residents' rights are continuously 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 even more critical given the complexities of HD and the inexperience of many nursing home staff regarding the disease.



To ensure that social services meet the needs of HD patients, the following questions should be addressed:

- Does the facility have adequate staff to meet resident's needs?
- Are the family and residents' councils active?
- Do care plan meetings include the resident and family?
- Are resident rights posted clearly?
- Do room/roommate changes occur in the resident's best interest and as allowed by law?
- Are mental health services available?
- Are residents encouraged and allowed to make choices regarding their care and daily routines?
- Does the facility have professional activities/recreation staff? Are activities calendars posted? Do activities meet the social, psychological and spiritual needs of residents? Note the calendar and observe whether posted activities are in progress when you visit.
- 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?

Rehabilitation Services

Although most do, not all nursing homes provide rehabilitation therapy. Those that provide rehab services may do so in a variety of ways. A facility may have staff therapists who are available daily. Some facilities may have consulting therapy personnel regularly scheduled or on call as needed. Still others may contract with an agency to provide services.

Unfortunately, many facilities do not have rehabilitation professionals experienced in providing rehabilitation services for residents with HD. In fact, once nursing home rehabilitation staff understand that HD is progressive and incurable, they may erroneously conclude that the patient will gain little from rehabilitation therapy. However, a

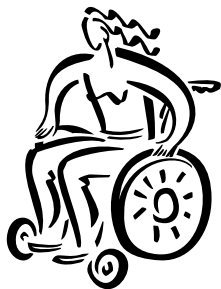
person in the middle to late stages of HD will benefit from therapeutic intervention. Therefore, it is wise to choose a nursing home with a rehabilitation department that includes physical, occupational and speech therapists with some experience or training in providing services to persons with HD. Insurance (including Medicare) will not cover ongoing rehabilitation services for HD, so creativity on the part of the facility is necessary.

Physical Therapy

As the motor skills of HD deteriorate, the individual will have increasing difficulty with balance and will experience frequent falls. Other symptoms will include decreased strength, poor physical condition and difficulty remaining upright in traditional seats. Physical therapy can provide strength and conditioning exercise, compensatory training, and assessment for seating, balance and mobility.

Occupational Therapy

The person with HD will lose cognitive skills that will eventually create difficulty in performing the activities of daily living (ADLs) — grooming, hygiene and eating. Impaired judgment will also affect safety awareness. In later stages of the disease, the muscles may become rigid, leading to contractures or permanent shortening of the muscles. Occupational therapy can assess cognitive skills and develop compensatory strategies, coach compensatory ADL activities, assess and train for adaptive equipment, provide an environmental safety assessment, and manage contractures.



Speech and Language Therapy

As cognitive and motor skills decrease, people with HD experience problems with communication, leading to increased frustration and subsequent behavior problems. In addition, dysphagia, or difficulty swallowing, is a common and severe issue. Most HD patients experience choking episodes by the middle to late stage of the disease. A speech/language pathologist can intervene with communication assessment and training, cognitive retraining, dysphagia assessment and development of compensatory strategies.

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

- Does the facility have therapy professionals available from either on-staff or consulting professionals?
- Does the facility provide restorative nursing or functional maintenance programs?
- Is the use of adaptive equipment evident throughout the facility?
- Is there an established restorative dining program involving both speech and occupational therapy professionals?

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. Discuss whether the facility is equipped to handle these needs as they arise.

Additional issues include, but not limited to:

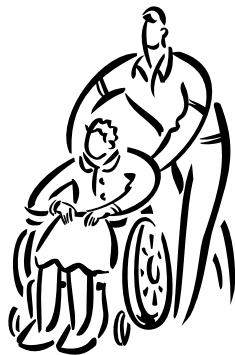
- Is a varied texture diet available?
- Is there an appealing pureed diet?
- Will the facility provide small meals throughout the day, if medically necessary?
- Are nutritious snacks readily available?
- Are residents weighed weekly?
- Does food look and smell appealing? Is it served at the proper temperature? 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?

Some Special Issues for Huntington's Disease Patients

A resident with Huntington's Disease may face some unique barriers to acceptance in a traditional nursing home setting. Some issues to consider include the facility's policy on using restraints, whether the facility offers the specialized programs and equipment needed by people with HD, whether the facility's physical environment is appropriate, and whether the facility can meet the extensive dietary requirements of HD patients.

Restraint Use

People with HD have balance deficits, poorly coordinated movements, stiffness and involuntary, or choreic, movements that put them at higher risk for falls and accidents than other nursing home residents. For traditional nursing home residents who are at risk and whose judgment is impaired, it is common practice to use soft belt restraints in wheelchairs and dining chairs. But for people with HD, restraint use can sometimes increase behavioral problems and subsequently lead to additional physical problems.



During a tour of the facility, observe how many residents are in chairs with restraints. This may indicate that the facility uses restraints more frequently than recommended. Such a facility may not be willing to incur the sometimes greater risk involved in caring for a person with HD.

Environmental Concerns

All nursing home residents must adapt to their new environments once moved into a nursing home. Floor surfaces, table heights, stairways and other environmental features can vary significantly from the patient's home, as well as between nursing facilities. Given the significant ambulation and movement issues with persons with HD, it is critical that the environment suits the needs of the patient. When you tour a facility, take special care to observe these features, visualizing the person with HD trying to navigate the rooms, halls, dining areas and other areas.

Additional questions include:

- Can furniture be removed from rooms to eliminate sharp corners?
- Are safety bars in place in bathrooms and showers?
- Do beds lock? Does the bed move when the resident sits on it?
- Does the dining room have enough space to allow a person with a movement disorder to walk through without bumping into others?
- 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?
- Do you detect any strong odors?
- Is the temperature comfortable? Can heating and cooling be adjusted in the patient's bedroom?
- Do rooms allow space for personal belongings?
- Are kitchen and bath areas clean?
- Do residents have access to an outdoor area?
- Does the outdoor area have landscaping or physical barriers to prevent patients from wandering from the facility?



Special Programs and Equipment

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

Additional questions include:

- Does the facility have a program for assisted walking for 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?

Paying for Nursing Home Care

Several funding sources are available for nursing home stays. The choice depends on a number of factors, including the level of care required, whether or not the patient has had a recent stay in an acute care hospital and the family’s financial situation. Following 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 ages 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 patient 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. Many families fear the loss of their savings when a family member applies for Medicaid. 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. You should be aware that Medicaid administrators may audit the family’s 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 2000, patients pay \$97.00 daily after day 20. 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, 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. 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. Be sure to read and understand any policy that you are considering to make sure you know what the plan will cover. Most policies have very limited coverage and require that the beneficiary meet specific medical criteria. Many HMOs will pay for care only in facilities with which they have contracts.

For individuals who are still relatively healthy, long-term care insurance can be a good financial decision. However, premiums are often quite expensive. Before making a decision, you should carefully consider your family’s financial situation and the amount of time until the person with HD will need nursing home care. Saving and investing is another method to finance long-term care.

Some questions to ask yourself are:

- Is the resident bathed daily? Is he/she well groomed and dressed appropriately?
- Has the resident lost weight since admission?
- Does the resident seem to be always in his/her room instead of in an activity?
- How long does it take for staff to answer call lights?
- Does the resident complain about care every time you visit?
- Is the staff responsive to your concerns? Refer to the section on advocating for residents, page 13. If the staff is not receptive, seek external resources to help resolve the problem.

The Family Member as Advocate

After a loved one has been placed in a long-term care facility, family members are a most important source of advocacy for the resident. This is especially true for residents with HD who are likely to have cognitive or speech impairments that make them unable to advocate for themselves.

As discussed earlier, the facility social worker's role includes acting as an advocate for the residents. However, only a family member has a detailed and comprehensive understanding of the resident and what he or she needs to ensure a better quality of life. Additionally, sometimes residents feel more comfortable voicing concerns to family members rather than directly to staff, especially when they are new in the facility. Therefore it is up to the family to communicate with staff about any questions or concerns that may arise.

The more information the staff has about a resident, the better the individualized care plan will be. Although admission and initial assessment forms collect a lot of data, facility staff depend on the family to add information that will help them meet the resident's individual needs.

It is important to remember that the person with HD is facing many changes when he or she moves to a nursing home. Staff and family need to work together 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.

As previously discussed, various nursing home staff and public agencies are charged with monitoring nursing homes to assure quality. However, as a family member you may discover issues that others may not notice, either because they lack time or because your loved one has confided a problem to you that he or she has not shared with anyone else. It is your responsibility to advocate on behalf of your family member. Trust your instincts; if you have a sense that something is wrong, investigate until you are satisfied.

How to Be a Resident Advocate

In addition to considering the issues discussed above, here are some general tips to being an effective advocate as well as an integral member of the interdisciplinary treatment team:

Educate yourself about nursing homes.

Read a copy of the Residents' Rights and Responsibilities that you received when your family member was admitted to the facility. Ask questions if there is anything you do not understand. Learn about the facility's organizational structure so you understand the internal reporting procedures for complaints and grievances.

Introduce yourself to staff.

Get to know the people who are taking care of your loved one. You will meet the interdisciplinary team members at care planning meetings. However, the certified nursing assistants (CNAs) who actually



have the most contact with residents may not attend those meetings. It is important to meet the CNAs and develop relationships with them. Having friends on the staff can be very helpful for you and your loved one.

Use the right approach.

When you need to bring concerns to the staff, using the right approach will improve communication rather than develop friction. Try to remain calm even if you are upset. Unless the resident's safety is in immediate jeopardy, take a moment to calm yourself before raising your concern. Remind yourself that there may be a reasonable explanation for the situation. If you approach in a positive way and do not put staff on the defensive, you are more likely to get the information you need to determine whether there is a problem and find a solution.

Remember to acknowledge staff and thank them when they have done a good job. Staff can be more receptive when they know you appreciate what they do.

Make regular visits.

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

Opportunities to Advocate

There are many times when your input is necessary and appropriate. Use these opportunities to provide information that will help create the best possible situation for your family member.

Day of Admission

You will meet with the facility's social worker and charge nurse on the day of admission. This is an opportunity to provide information that will help staff care for your loved one. A detailed history will help the social worker better understand the resident's social and education background, hobbies and preferences. You will also want to provide a history of the resident's illness. 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. Contact a local HD clinical program, if available, and request that an inservice be conducted.



Initial Care Plan Meeting

Within two weeks of admission, you and the resident will be able to attend a meeting with the facility's interdisciplinary team. This meeting will develop an individualized care plan that includes measurable goals for the resident. At this meeting, you will meet with key professionals who are providing care for your family member. This is also an opportunity to share information about the resident's abilities and set goals to help the resident become as independent and comfortable as possible.

Quarterly Care Plan Meetings

Every 90 days, the interdisciplinary team will meet to review and update the resident's plan of care. The meeting may be held earlier than 90 days if the resident has had a significant change of status or if he/she has been discharged to a hospital and readmitted to the nursing home. You may attend these meetings. If you cannot attend in person, some facilities will be able to let you join the discussion on a speakerphone.

Family Councils

Many facilities have family councils that meet regularly. The facility administrator, recreation director or social worker may chair the meeting. These councils are organized so family members can discuss concerns or make recommendations regarding the facility or raise specific issues about the care of their loved one.

Discussions With Facility Staff

You should feel free to speak to any staff member to voice a concern or ask a question about a resident's care. Choose the most appropriate person to respond to the nature and severity of your concern. Try to establish a good rapport with a staff member who is responsive to your needs. Often family members will speak 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.

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.

Visiting

The more frequently you visit, the better you can monitor the care that your family member is receiving. Visiting also reassures the resident that you still care about him/her and helps you remain part of the resident's life in his/her new home. Your visits also demonstrate to the staff your continued care for and involvement with the resident.

Visiting can be difficult, however. Many people with HD are in denial about their disease or do not perceive the severity of their symptoms. It can be challenging for family members to help them understand why they need long-term care. If the person with HD resents being in the nursing home, he/she is likely to focus anger on visitors. He/she may try to make family members feel guilty, request to go home with them, yell or shout, or refuse to speak to them. Such behavior can be very difficult for the family; many people cannot handle the stress and stop visiting. The following suggestions may help family members maintain contact with their loved ones through difficult times. Some things to consider when visiting include:

Remind yourself that the resident needs time to adapt. The adjustment will be most difficult in the beginning. Most residents eventually do adjust to their new homes, but the time it takes will vary.

Set limits. If the resident shouts or yells at you, express your love and affection but add that you will leave if

he/she continues to be verbally abusive. Assure the resident that you will visit another day. You may need to do this often in the beginning until the resident understands and accepts the new situation.

Get support from others who understand what you are experiencing. Joining a support group can help you stop feeling guilty about the placement. Many nursing homes facilitate support groups for family members. If the facility does not have a group, talk with the social worker or another counselor.

Do not try to visit more often than your schedule allows. How frequently you should visit depends on your other commitments and responsibilities. If you are tired and under stress and visit to avoid feeling guilty, the visit will not be pleasant for either you or your loved one. 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 if he/she is focused on your daily visits.

In some situations, the HD resident truly cannot tolerate the visits of family members. The caregiver can continue to monitor the family member's care through telephone contact with nursing and social service staff and provide personal items the resident requires. In this instance, the HD resident may become more accepting of family visits as the disease progresses and the ability to carry out a violent act or express verbally abusive statements become less possible.

Conclusion

The decision to place a loved one in a long-term care facility is never an easy one. For people with Huntington's Disease, the decision can be especially painful. For more information about nursing home care for people with Huntington's Disease, contact the Huntington's Disease Society of America at 1-800-345-HDSA or visit our web site at www.hdsa.org. We will be happy to refer you to a local HDSA chapter near you.