Physical and Occupational Therapy

Huntington's Disease

Family Guide Series

Huntington's Disease Society of America

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Introduction

Understanding Huntington's Disease

Huntington's Disease (HD) is a hereditary neurological disorder that leads to severe physical and mental disabilities. Over time, HD causes the progressive loss of nerve cells in the brain, impacting movement, cognition, emotions and behavior.

In people with the gene that causes HD, symptoms usually begin to appear between the ages of 30 and 50, but the disease may strike those as young as two or as old as 80. Initial symptoms may include involuntary movements, alterations in voluntary movements, difficulty in concentration or changes in behavior. Although there are commonalities, the onset and progression of symptoms will vary from person to person.

Movement Disorders in HD

Changes to the brain caused by HD, impacts control of voluntary movements and can also cause involuntary movements. Surprisingly, involuntary movements may have less of

an impact on quality of life than changes to voluntary motor control.

Reduced voluntary motor control can make it difficult to do simple things like button a shirt, use a remote control, or even go to the toilet without assistance. It can also affect the ability to read, eat, speak and swallow.

Currently there are no treatments that slow or stop the progression of the disease, but physical therapy, occupational therapy and speech/language pathology have been shown to help with the movement disorders found in HD. Assistive devices and medication may also improve quality of life:

Involuntary Movement Disorders – Chorea, Akathisia, Dystonia

The most commonly recognized movement disorder in HD is chorea. *Chorea* is a term for involuntary jerking or twitching movements which may have either low or high amplitudes. Chorea may show itself in finger flicking, shoulder shrugging, facial grimacing and may also include flailing of the arms or legs. Chorea may also contribute to difficulty with speaking, chewing, swallowing and reading.

Research has shown that chorea is not the primary disabling factor in the movement disorder, and in many cases can be left alone. This is particularly important for therapists to be aware of since the first inclination is often to suppress the chorea.

There are several types of medications that can be used to control chorea. Because medications have the potential for side effects, it is important to work closely with a

physician or neurologist familiar with HD when considering medication for treatment of chorea.

Akathisia, or motor restlessness, can be an early symptom of HD, presenting as difficulty maintaining one position or a need for constant movement. People have described this feeling as one of being "supercharged" all the time. One person said it felt as if she just wanted to run for hours.

Dystonia is an abnormal, sustained posturing of a body part, typically the arms, head or trunk. It can appear as an arching of the back or twisting of the neck to one side, both of which are held in those positions for several seconds. In juvenile onset HD, dystonia can cause arms and legs to become stiff or rigid.

Voluntary Movement Disorders

Disorders of voluntary movement control found in HD include:

Akinesia, or the delayed initiation of movement, caused by changes to the functioning of the basal ganglia. This delay can last up to several seconds and may be mistaken for lack of interest or lack of attention. Delayed reaction to externally produced disturbances can be devastating to balance. For example, uneven ground or suddenly being startled can cause a fall when the ability to recover from outside stimulus is slowed.

Bradykinesia or slowed movement. Rather than being a slowness in initiation (akinesia), bradykinesia describes a slowness in the execution of movement.

Incoordination of movement or the alteration of rhythmical, repetitive movements. This

can affect walking, chewing and even breathing (dyspnoea). Persons with HD commonly walk with the feet held widely apart and may walk with an unsteady or "drunken" appearance. They may bump into furniture or doorways. They may dip at the knees or kick the legs when walking. They will have trouble recovering their balance if they trip and may have spontaneous falls.

Loss of Small Motor Control

People with HD have increasing trouble with smaller movements and hand-eye coordination. They may drop things. Over time, the ability to use tools and utensils is affected. Writing and keyboarding skills will also decline. The progressive loss of muscle control will also reduce oral motor control, causing indistinct speech, drooling, choking and difficulty eating.

Impairments in Modulation of Force Of Movement

This is frequently evident in later stages when small movements are intended but result in large bursts of movement. For example, a person wishing to rise from a sitting position may find him/herself unintentionally vaulting out of a chair or bed.

Cognitive Disorders in HD

HD causes changes in the brain that lead to the progressive loss of brain cells, affecting the ability to concentrate, remember information and multi-task.

Changes in cognition due to HD may include difficulties with:

- Multi-tasking, attention and concentration
- Short term memory/new learning
- Beginning/ending activities (initiation)
- Repeating the same thought or ideas (perseveration)
- Controlling impulses
- Irritability/outbursts

For many reasons, persons with HD may doubt the need for physical therapy or resist following the program. Explanation of the benefits of physical conditioning may be needed, as well as persuasion to follow the program. The individual may also need support in remembering to attend sessions.

Because of the changes in cognition caused by HD, there is an added need for coordination and communication with the persons who will be involved in implementing the therapy program - family, healthcare professionals, and caregivers. Instructions given to the person with HD should also be communicated to these individuals.

The Movement Disorder and Nutrition

Serious loss of weight can be a consequence of the movement disorder. The involuntary movements of chorea use a lot of energy and the person with HD will need to eat an enormous number of calories each day. This is challenging because chorea and reduced muscle control may make it difficult to take in enough calories. Therapy may be useful to improve oral motor control.

Physical Therapy in Early-Stage HD

Physical therapy has an important role to play in retaining quality of life for people with early stage HD. Physical therapy has been shown that it can improve physical conditioning, health-related quality of life, strength, balance, and gait in people with basal ganglia disorders, such as HD.

With the onset of the disease come physical changes. There may be weakness of the stabilizing musculature of the upper back and trunk, affecting posture and the ability to take deep breaths. These changes often lead to a sedentary lifestyle, which, in turn, results in an overall decline in health. Often, changes in cognition and/or emotions cause these physical changes to be overlooked. A general fitness plan at this time can be significantly helpful. This type of program could be prescribed by a physical therapist and then carried out at home or at a local health club.

Beginning a fitness program early in the disease process not only serves to maintain physical function, but also helps to reduce some of the stress associated with

catastrophic illness. A routine fitness program can also be very helpful in treating depression, which is common in HD. While a program of this type can stabilize a person's symptoms, however, it does not alter the course of the disease.

Pre-Program Evaluation

Because of the individual variations in the severity of symptoms in HD, an evaluation should be performed before beginning a PT program.

The evaluation may include:

- Patient information and demographics
- Current condition: individual concerns/ current and past therapeutic interventions/ current stage of HD and age of onset
- Past medical history: hospitalizations, pre-existing conditions, etc.
- Current medications and any noted side effects
- Social history and participation restrictions (ability to live independently)

In addition to the general background information, an evaluation of the individual's limitations on functional activities (how much help they need from caregivers) should be performed with specific skills analyzed:

Neuromuscular evaluation

- Dystonia
- Chorea
- Balance
- Vision
- Bradykinesia
- Akinesia

Musculoskeletal evaluation

- Posture
- Range of motion
- Strength
- Pain

Cardio respiratory and cardiovascular evaluation

- Dyspnoea (breathlessness)

With this information, the physical therapist can create a final report that includes:

- Summary of the individual and diagnosis
- Statement of individual's limitations and key impairments, and potential disabilities resulting from limitation
- Statement summarizing potential to benefit from physiotherapy and why it is/is not indicated

Tests and outcome measures used for other basal ganglia disorders (i.e. Parkinson's) are generally appropriate for persons with HD.

Common Motor Deficits in HD

Muscle Weakness

Common areas of weakness are:

– The extensor muscles of the neck

– The postural muscles of the trunk

– The intrinsic muscles of the hands and feet

These weaknesses may lead to a forward head, rounded shoulders, or protruding abdomen. Picking up small objects with fingertips may become difficult. Similarly, weakened foot muscles prevent the toes from grabbing the floor when balance is offset, causing loss of balance.

Other consequences include shortness of breath upon exertion or difficulty taking a breath deep enough to clear secretions.

Balance

The combination of changes in the postural musculature that support the trunk, and changes in balance, can lead to falls. Balance is further compromised as reaction time slows. An early indication of balance problems is the inability to stand on one foot.

Balance training and core stability to enhance postural control should begin in the early stages of the disease and take place in the environment where the individual's problems are more apparent.

Balance and proximal stability exercises can be incorporated into strengthening or endurance activities at a gym by using free weights or pulley machines whereby body stability is needed to achieve the exercise performance.

To avoid falls, the person with HD should be taught to deliberately prepare for impending threats to balance, or to focus on maintaining balance before a task in which equilibrium will be challenged. This strategy allows people to use frontal cortical systems to regulate stability, rather than rely on the impaired basal ganglia for a response.

In general, balance training activities should be task specific, progressing from a wide to a narrower base of support, from static to dynamic activities, from a low to high center of gravity, with increasing degrees of freedom that must be controlled.

Unawareness

Subtle changes in sensation (the ability to notice changes in the environment) and perception (the ability to interpret information from the senses) may also be occurring. This can result in falls and other injuries. A physical or occupational therapist can assess changes in these areas and make suggestions to prevent accidental injury.

Some common problems are:

- Decreased spatial awareness. For example, misjudging the distance of an object or the height of a stair or curb, leading to loss of balance
- Unawareness of fatigue. Many people with HD are unable to identify fatigue and the balance problems it can cause. They have a tendency to continue their daily routine, oblivious to changes in their gait pattern as as they tire, thus leading to falls.

General Physical Conditioning For Early Stage HD

- Strengthening exercises for muscles involved in postural control
- General strengthening exercises for major muscle groups of the body
- Advanced balance activities
- Aerobic activity to enhance cardiovascular function

Exercise bikes and swimming have been shown to safely improve cardiovascular fitness in people with HD. Because people with HD can be easily fatigued, more frequent exercise of shorter duration may be most effective. Adherence is more likely if the person with HD, and their

caregiver, are involved in the choice of exercise mode and the exercise profile that is developed.

Setting Functional Goals

Appropriate goal setting is probably the most important aspect of developing a physical therapy program for an individual with HD. Because HD is a degenerative neurological disorder, certain impairments, such as chorea, will not respond to physical therapy. Functional improvements, though, are possible and can increase safety and quality of life in the person with HD.

Components of exercise should be related to the requirements of a functional activity – if walking to the store is the goal, train for the distance required.

Examples of Functional Goals

Goal for an individual who is falling or having trouble walking:

- Will improve speed of walking
- Will walk a certain distance with appropriate assistive device
- Will not experience falls in a 2 mo. period

Goal for an individual with difficulty sitting upright for eating or watching TV:

- Sitting upright for 20 minutes with adaptive seating system

Cognitive Functioning and Physical Therapy

As motor problems progress, the cognitive disorder may interfere with learning new tasks. Therefore, it is recommended that exercises, activities, and functional enhancement strategies be taught and rehearsed in the earlier stages of HD before they are absolutely necessary. If activities are to be done at home, give the instructions to a family member/caregiver, as well as to the person with HD.

To help the person with HD to remember instructions:

- Provide a quiet environment with few distractions
- Make expectations clear and direct
- Break the activity into simple steps
- Help the person to focus on performing each task separately
- Practice through repetition
- Allow ample time to teach activities
- Underline or repeat key points in directions
- Keep directions/materials to a minimum

Physical Therapy in Mid-Stage HD

As Huntington's Disease progresses, the difficulties encountered in the earlier stages become more pronounced. Increasing safety and comfort during physical functioning will become more important.

In mid-stage HD, interventions should focus on maintaining current levels of physical functioning, including:

- Coordination skills
- Ambulation skills
- Relaxation skills
- Sensory awareness

Assessment in Mid-Stage HD

People in mid-stage HD should be reassessed periodically for changes in functional abilities that may require new strategies, or the introduction of assistive devices to reduce the risk of injury while helping the person with HD to maintain as much independence as possible.

The assessment should look at:

- Range of motion
- Muscle strength
- Leg length

- Trunk mobility
- Standing and sitting balance
- Posture
- Sensation
- Cardiopulmonary status
- Pain
- Transfers
- Gait

Chorea

Involuntary movements, most often chorea, may worsen in mid-stage HD. Medication to suppress the movements may be considered, although there is the potential for side effects. Many of the problems that chorea poses are social ones and people with HD can often manage their chorea without the use of medications.

Muscle Weakness

Changes in muscle tone and weakness of the postural muscles may make it more difficult for the individual to sit upright comfortably. Adaptive equipment and seating supports may become very helpful.

Balance Impairments

Loss of balance and falling may increase, especially when the individual:

- Turns quickly, especially when carrying a load
- Suddenly changes direction
- Tries to sit down and stand up
- Is unaware of fatigue

Functional Strategies for Balance and Seating

Touch Turn Sit

This three-part process can help the person with HD sit down without losing balance. The person approaches the chair and touches it (to stabilize him/herself), then turns and finally sits. This simple strategy solves the balance problem as well as the perceptual problem of being unable to judge distance.

Standing Safely

This strategy allows the person with HD to stand up without losing balance. To stand up safely, the person should first place his/her hands on knees, bringing the weight forward and ensuring that he/she is bending from the waist. The feet should then be placed directly under the knees. The final step is to "push up" to a standing position.

Walkers

Specialized equipment such as a walker may be helpful. A rollator walker with swivel casters is the walker of choice, as long as the person has adequate motor control in the arms. A rollator walker with adjustable hand positions is preferable for people who have less motor control and need to have their center of gravity brought forward to reduce backward falls.

Wheelchairs and Seating

Wheelchairs and adaptive seating can improve quality of life by increasing comfort, mobility and endurance.

- Many people with HD have an easier time mobilizing a wheelchair with their feet. In this case, a hemi-height or drop seat wheelchair is most appropriate so that the

person's feet are firmly planted on the floor.

- A small wedge cushion or lumbar support may be helpful in providing the proper support for extended sitting.
- Padding of the armrests may be necessary if chorea is pronounced. Commercially made armrest bolsters work well and provide lateral support.

The following suggestions, developed by Lori Quinn, EdD, PT, may be helpful in determining optimal seating for a person with HD:

- Allow enough room for the person to move around freely and without injury
- Use proper padding to cover hard surfaces and sharp edges
- Make sure there is solid, sturdy foot support
- Adjust seating to be at the right height for use at the table.
- Keep restraint use to a minimum. It is often counterproductive in HD (see the section on restraints in Later Stage HD).

Safety Equipment

Safety equipment, such as a helmet or elbow and knee protectors, can provide protection while learning new skills or trying to maintain independence. Not surprisingly, it is often difficult to convince an individual to wear a helmet or other protective gear. A soft head protector is sometimes more acceptable and can offer good protection from injury caused by falls.

Begin by having the person wear the protective gear for very short periods each day, allowing him or her to decide what time of day to wear it. This will give the individual some control

over the decision, which may help foster acceptance and encourage regular use.

Small Group or Individualized Sessions

Ideally, the structure of physiotherapy is patient dependent. For some, individualized sessions reduce distractions and stress, while other persons with HD prefer group work. Small group sessions can provide therapy, along with support and social interaction, while allowing the person with HD to be individually managed.

Physical Therapy in Later Stage HD

While some people with later stage HD are cared for at home, others will reside in nursing homes. Most nursing homes are unfamiliar with the symptoms of HD, and unprepared to successfully care for an individual with the disease because of its complex combination of physical, cognitive and behavioral symptoms. These include:

- Personality changes, mood swings and depression
- Forgetfulness and impaired judgment
- Unsteady gait and involuntary movements
- Slurred speech and difficulty in swallowing

In the advanced stages of the disease, motor control is greatly diminished. The person with HD may have difficulty modulating the force of his or her movements. Chorea and/or rigidity may also worsen. Speech will be difficult to understand and the ability to get enough nutrition may also be a challenge. Physical therapy will probably become less focused on conditioning and mobility and more directed toward safety and comfort.

Restraints and Specialized Seating

Although restraint use has been highly regulated in nursing homes since the late 1980's, its use for people with HD continues to be commonplace. Unfortunately, restraints tend to create more problems than they solve.

A common use of a restraint is a seat belt or waist restraint to prevent falling out of a chair. What may be overlooked is the reason why the person is falling out of the chair. Uncontrolled movements can often be minimized by a change in position or improved seating. For example, a chair with a high back, increased seat depth, foot support, armrests, and padding, if chorea is present, may be necessary. Chairs that have been designed with these features in mind are commercially available.

The Sleeping Environment and Bedding

Sleeping in a regular bed can be difficult for many people with HD. Decreased spatial awareness may reduce the ability to sense the edge of the bed during sleep, causing the person to fall out of bed. Inability to modulate force of movement may also cause the person to "vault" out of bed when he/she simply wanted to turn over or sit up.

In the home setting, placing a mattress on the floor and clearing the surrounding area of any furniture often is sufficient to create a safe sleeping environment. In the nursing home, however, this is not always possible. Side rails fixed to the bed are frequently tried as a solution, but more often than not they become obstacles to climb over or bang up against.

People who are still able to rise to sit and stand tend to do best with a very low bed – three to five inches off the floor. A thin, high-density mat can be placed on the floor at the side of the bed to cushion a fall should it occur. In some cases, one side rail can be used with at least two inches of foam padding to provide a sensory boundary, leaving the other side open for entering and exiting the bed.

In extreme cases of inability to modulate force of movement, a more confining arrangement is required to prevent serious injury. Unfortunately, commercially available options are few.

An alternative is a Modular Rehab Bed (Craig bed). This bed features a mattress that sits eight inches off the floor, surrounded by four-foot high foam padded walls. One side of the bed opens completely for ease of transfers and care. An additional riser can be added under the mattress. A drawback to this kind of bed is the appearance of isolation, but the opportunity of a good night's sleep, the ability to change position without the risk of falling and to sit up without crashing into a side rail, usually outweigh the drawbacks.

Accommodating the Cognitive Disorder in Later Stage HD

A person with later stage HD, who has impaired balance, impaired self-awareness, spatial perception deficits and impulsivity, creates huge challenges to the caregiver. This individual may appear never to sit still, constantly attempting to stand up and experiencing a large number of falls. They may have short term memory impairments or obsessions, asking for the same thing repeatedly and becoming agitated when their requests are ignored or denied.

The cognitive disorders associated with HD can often be managed by establishing a consistent routine that incorporates the individual's wishes and needs. By accommodating the individual with HD in small things, caregivers can improve overall care and safety.

The chosen routine for a person with HD may include:

- Several opportunities to walk with assistance throughout the day
- Frequent position changes
- Frequent meals and snacks

Occupational Therapy in Early-Stage HD

HD creates a complex combination of movement, cognitive and behavioral disabilities that will increase as the disease progresses. To be effective, programs to improve safety and mobility through occupational therapy must be presented in a manner that takes the cognitive and behavioral disabilities into consideration. By using strategies that improve communication and foster learning in persons with HD, the OT, the family or caregivers can help the person with HD maintain the highest possible quality of life.

Addressing the Cognitive Disability

As stated at the beginning of this pamphlet, HD causes changes in the brain that lead to the progressive loss of brain cells, affecting the ability to concentrate, remember information and multi-task.

Changes in cognition due to HD may include difficulties with:

- Attention and concentration
- Short term memory/new learning
- Beginning/ending activities (initiation)
- Repeating the same thought or ideas (perseveration)

- Controlling impulses
- Irritability/outbursts

The functioning of a person with early stage HD may be improved with these strategies:

- Establish a consistent daily routine.
- Avoid open-ended questions. Instead, offer a list of choices and ask questions requiring a "yes/no" answer.
- Offer hints, such as word associations, to aid in the retrieval of information.
- Label items around the house with their name and function.

Distractions often interfere with the ability of a person with HD to process or remember information. To improve communication and comprehension:

- Use short sentences when giving directions.
- Ask the person to repeat important points back to you.
- Reduce outside stimuli whenever possible.
- Underline key points in directions.

Difficultly starting, stopping and sequencing actions are also a hallmark of early stage HD. Tasks may take twice as long or never be completed at all. To help a person with HD address this disability:

- Use a list, calendars or notes to keep track of tasks that need to be completed
- Break the complex task into simple steps
- Write down all steps in a logical order
- Review the steps to ensure that they are clearly understood
- Encourage completion of each step prior to moving on to the next step in the task

Safety in the Home

The movement disorder in HD causes changes in balance, mobility and motor control. HD also causes involuntary movements (chorea). A home consultation by an occupational therapist can identify areas where safety and mobility can be improved. Analysis of meal preparation skills, personal hygiene, and other activities of daily living (ADL's) can lead to strategies which foster independence. Here are some examples:

In the Kitchen

- Use unbreakable dinnerware
- Avoid storing commonly used items in high cabinets
- Use a kitchen timer as a reminder to turn off appliances
- Lower the hot water temperature to prevent scalding
- Use covered mugs for hot liquids
- Use oven mitts rather than potholders

In the Bathroom

- Use a non-skid mat in the tub or shower
- Use 'soap on a rope'
- Use a shower bench or chair
- Use safety bars

In the Living Room and Bedroom

- Stabilize furniture so that it cannot move
- Use chairs with high backs and armrests
- Clear rooms of any unnecessary furniture
- Remove scatter rugs or thick-pile carpeting
- Keep tables and lamps away from walkways
- Pad doorways and furniture when contact is frequent

Occupational Therapy in Mid-Stage HD

In mid-stage HD, the combination of motor control problems and cognitive deficits creates a number of difficulties in activities of daily living. The individual with HD may begin to lose the ability to perform tasks they previously did without problems or may forget things they learned previously. These are symptoms of the disease. Below are some of the problems that may be encountered in mid-stage HD, with strategies and equipment options:

Lack of Initiation

The inability to start a task may necessitate a 'jump-start.'

- Suggest an activity or task and offer help. Often this will provide the necessary impetus for the person to complete the task independently

Fatigue

Fatigue often plays a role in preventing the completion of tasks

- Build rest periods into the routine

Eating

Impaired postural control creates positioning problems at the table. Slouched sitting and the inability to maintain proximal stability cause a great deal of food spillage as well as fatigue.

- Have the person sit in a sturdy chair as close to the table as possible
- He/she should wrap their legs around the chair legs to stabilize the pelvis and put the elbows ON the table to stabilize the upper trunk

Motor impersistence and muscle weakness causes difficulty holding utensils, or difficulty bringing hand to mouth.

- Use utensils with built-up handles
- Utensil should be put down after each bite to rest muscles and prevent fatigue

Incoordination of movement makes simple tasks such as cutting food seem very difficult.

- Use non-skid placemat to prevent dishes from moving
- Use covered cups or mugs (travel mugs are ideal) to prevent spills

Hygiene

Difficulty with motor control and sequencing tasks can make even the most routine activities seem insurmountable. Though some people with HD lose interest in personal hygiene as a result of depression, the inability to start, stop and sequence tasks may also be the cause.

- Write out separate lists of morning and evening hygiene tasks
- List steps for completing each task and post the list in a visible place

Maintaining balance while performing ADLs, such as shaving or brushing teeth, can become difficult and even hazardous.

- Use a shower bench or chair to prevent fatigue and assist with balance

Combining a fine motor task, such as holding the soap, with a gross motor task, such as washing the torso may present difficulties.

- Use a shower mitt (the soap can be put right inside the mitt so it won't fall out) or 'soap on a rope'
- Use an electric razor or chemical hair remover
- Build up the handle on a toothbrush or hairbrush by wrapping and taping a washcloth around it

Dressing

Decreased decision-making ability may cause people with HD to avoid changing their clothes because they have difficulty deciding what to wear.

- As with other complex tasks, reduce the routine to a list of simple steps
- Pair favorite items and label them to keep decision-making to a minimum

As the small muscles of the hands weaken, the ability to grasp objects is diminished.

- Avoid clothing with multiple fasteners
- Put a ring on zippers to aid in opening and closing
- Encourage dressing while sitting in a sturdy chair to reduce falls and fatigue

Occupational Therapy in Later Stage HD

In the later stages of the disease, preventing injury to the body becomes the utmost concern. Although some people with HD appear to be moving all the time, they are often not able to change position voluntarily, and therefore are susceptible to skin breakdown from constant shearing movement.

The occupational therapist can assist the caregiver by suggesting a routine of frequent position changes. The OT can also assist in designing a protective environment for the person with a lot of involuntary movement. Padding of hard furniture, wheelchair parts and sharp corners helps to prevent injury from falls or choreic movements. In cases of very severe chorea, it may be necessary to pad a part of the body if constant contact is being made.

Because the person with advanced HD is no longer able to control movement, certain muscle groups are no longer used. This disuse, combined with changes in muscle tone, can lead to permanent disability called contracture.

Contractures

A contracture is the permanent shortening of a muscle. Contracture management in HD can be difficult because of fluctuations in muscle tone and the presence of chorea. Frequent position changes and range of motion exercises are important weapons in the battle against contractures.

In some cases splinting can be helpful. New air-assist-type splints, which use air bladders to provide support and have enough "give" in them to avoid skin breakdown, have proven very helpful in the management of elbow and knee contractures. Foam core and hand splints have also proven useful for maintaining functional positioning of the hand. These are very lightweight and have a washable cover for easy care. Many people are able to wear splints during the night. This gives them eight to ten hours of appropriate positioning and slows down the contracture process.

Hope for the Future

Quality of care for people with HD is improving. Early intervention from health professionals such as physical and occupational therapists can introduce strategies that improve functioning, mobility and quality of life for persons with HD.

Information, such as this Guide, provides therapists and caregivers, both in the home and in long term care facilities, with tools and strategies to help maintain quality of life for individuals suffering from the disease.

HD researchers are beginning to collaborate with researchers of other brain disorders, such as Parkinson's and Alzheimer's diseases. With good reasons for optimism, we foresee the worldwide HD community of families, friends, clinicians and researchers working together to find the final pieces of the puzzle of HD, and to develop effective therapies for those facing this devastating disease.

Resources: For more information visit the HDSA website at **www.hdsa.org** or phone the HDSA National Office at **1-800-345-HDSA**. HDSA can direct you to local chapters, HDSA Centers of Excellence for Family Services, and other sources of information.

HELP FOR TODAY.
HOPE FOR TOMORROW

HDSA Mission

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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