



Preventing Falls

As HD progresses, the muscles that support an upright neck and trunk grow weak. As a result, people with HD tend to hold their head in a forward or hanging position and slump their shoulders. Changes in muscle tone cause some people to have asymmetrical posturing in their trunk, arms, or legs. This creates the appearance that they're leaning forward, backwards or to one side. The normal, unconscious reflexes to prevent falling become slower. It gets increasingly difficult to keep from falling or to avoid injury during a fall. Walking is more and more difficult as balance becomes progressively impaired. Although it may appear that the involuntary movements cause falls, research has shown that this may not be the case. Instead, falling is more likely to occur as people with HD develop stiffness and rigidity and as their balance deteriorates. Because most of the medication used to treat chorea can cause or worsen rigidity, many physicians prefer not to treat chorea unless it is very severe.

Consider footwear when trying to prevent falls. As strength in certain foot muscles decreases, sensory changes in the feet may also be taking place. This can lead to abnormal foot placement when walking and, consequently, tripping. Although orthotics may have been helpful earlier, high-topped sneakers with a wide heel or light-weight work boots are more likely to help in later stages. Avoid high heels, sandals and other shoes that offer little support. Check for wear regularly. Shoes in poor repair cause falls.

Three of the most common places that falls occur are in front of a chair, a toilet, or a bed. Turning to sit down requires him to place all his weight on one foot, to balance, and to pivot on it for a moment. If the ability to balance on one foot is impaired, the person may fall. Similarly, if judgement or spatial awareness is impaired, he is likely to misjudge his distance from the bed, chair or toilet. He may turn to sit and miss it completely, falling to the floor. Teaching simple strategies to compensate for these problems helps reduce falls or prevent them altogether.

One such strategy is to teach a simple procedure called "touch-turn-sit". Instruct the person to bend over slightly and actually touch the chair, toilet, or the side of the bed before turning to sit on it. Touching the chair assures him that he is close enough to sit in it. Touching also provides support for better balance. Here is an easy procedure to prevent falls. When he is getting up out of a chair, teach him to place his hands on his knees and lean forward. This, in effect, brings his trunk forward—a better position for getting up.

Caregiver Tips

Consider these environmental changes to prevent falls:

- Stabilize furniture so that it cannot move.
- Use chairs with armrests and high backs.
- Clear rooms of any unnecessary furniture.
- Remove scatter rugs and high-pile carpeting.
- Remove tables and lamps from frequently used household pathways.
- Pad furniture or doorways if they're hit often.
- Use sliding doors.
- Round off sharp corners of furniture or fixtures.

You can also reduce or prevent falls if you...

- don't call a person with HD from behind, causing him to turn quickly and lose balance.
- don't interrupt him suddenly.
- don't give a medication while he is standing.
- don't try to stop him from "bouncing off the wall." (Some individuals with dystonia walk quickly up on their toes. This gives the appearance that they are about to walk into or bounce off the wall. Rarely do they ever touch the wall. However, well-meaning people often actually cause falls in their efforts to protect them from hitting walls.)

As he struggles to maintain his independent mobility in the face of balance problems and the other complications caused by the movement disorder, he will inevitably fall. As often as falls may occur, they can never be accepted as commonplace events. Even minor falls can lead to cuts that require stitches, or cause painful bruises, broken bones, or injury to the brain. Anyone who has fallen should be examined carefully. Changes in movement, mood, thinking, or neurological function could be a warning sign of a subdural hematoma, or bruise on the brain, even if the changes develop a few days after the fall. Notify your supervisor or a physician immediately if you see these kind of changes in someone who has fallen.

ABOUT HELMETS AND OTHER PADDING

It may be difficult to convince someone to wear a hard bicycle or hockey helmet for protection from injuries to the head due to falls, especially if no one else around him is wearing one. Sometimes a soft head protector, made of leather bands with a Velcro chin strap, is more easily accepted. Although certainly not fashionable, they offer some protection from striking the head while falling. Sadly, it's often right after a fall that someone is most willing to try wearing one. Thinking about head protection before falls become severe may help to avoid serious injury. Setting up a schedule to wear one for a very short period each day is a way to introduce it. To allow the person wearing the helmet to maintain some control over his day, he can select which time to wear it.

Some people repeatedly injure their heads with falls; others seem to repeatedly injure one elbow or both knees when they fall. Wearing hockey-type protectors for the joint or joints may help to prevent traumatic joint swelling.

ABOUT WALKERS

Although for many people with moderate or severe chorea a walker is not helpful, these devices can work well for those who are able to maintain a firm grasp. With a stable base, the rollator or rolling walker has been especially helpful to many folks because it allows a physiotherapist to set its hand grips in a way that shifts the patient's centre of gravity forward. Although they are simple devices, many physical and dynamic factors need to be considered in selecting one. Consult a physiotherapist to evaluate which type of walker best matches his abilities and disabilities. Occasionally some may benefit from wrist or ankle weights to decrease chorea.

Some people with HD get around by themselves in "merrywalkers". They are best used in homes or facilities with ample space to accommodate their considerable size.

Nutshell Case Study:

Introduce Assistance Before It's Needed

When Andrea first came to her nursing home about three years ago, she had significant balance problems from her HD and had seriously injured herself falling. But she was determined to continue walking... alone! Andrea's gait and strength improved for a while but, given the severity of her problems, it was inevitable that she would soon need assistance walking.

Physiotherapists began a daily programme of teaching her how to wear a helmet and use a walker before she absolutely needed one. Andrea practiced her "workout" every day as her "coaches" would encourage her to practice her balance exercises with a helmet on. They taught her how to use a walker and practiced those skills before she needed them. One day she had a serious fall. It was suggested that she wear the helmet full-time. The idea stuck; she agreed. Three months later another fall prompted the introduction of the walker on a full-time basis. Already familiar with it, she accepted it readily. Over the next six months she had far fewer falls.

As soon as Andrea accepted the walker, her coaches started to teach her how to use a wheelchair as part of her daily workout, long before she actually needed it. She especially enjoyed doing "wheelies" when visitors were watching. Eighteen months later Andrea began to fall frequently in the evening. She agreed when it was suggested that she use the wheelchair just at supper time and in the evening. Again, she had far fewer falls.

Progressively introducing assistive devices earlier than actually needed prevents their introduction from becoming a symbol of yet another loss of function. The same principle can be used with eating assistance as well as wearing adult incontinence pads.

ABOUT FATIGUE

We know when we're tired. And the people around us know when we're tired as well. Recognizing our fatigue, we might yawn and say, "I'm exhausted. I've been on my feet all day." Or eyes may droop so that a friend says, "You look beat." We walk a bit slower and talk a bit more softly. It usually happens at the end of

Caregiver Tips

To prevent fatigue:

- Schedule and allow rest periods throughout the day.
 - Offer the use of a wheelchair at the time of day when the patient usually gets tired.
-

the day or after an extended period of work. You usually don't have to know someone well to know when they're tired.

In the more advanced stages of Huntington disease, fatigue affects people dramatically, but it is often difficult for caregivers to recognize it for several reasons. We are not accustomed to seeing someone very tired early in the day. The person with HD may not be able to communicate how he feels in words, but his behaviour or his motor function may get worse. People with HD use great effort for simple

things like walking and standing and may become fatigued early in the day. After a half-hour struggle to chew and swallow safely, trying to sit up straight, and frightened all the while of choking, breakfast can be exhausting. When a person who has problems with balance, poor posture, and severely impaired walking falls down one afternoon it comes as no surprise. It is not always obvious, however, that the primary reason for the fall was fatigue. If there is a pattern to behaviour or motor problems that a particular person shows, consider whether fatigue is playing a role. Offer a nap or rearrange the daily routine to better fit the person's needs and abilities.

ABOUT WHEELCHAIRS

The importance of choosing the right type of wheelchair cannot be overstated. Selecting an appropriate wheelchair prolongs mobility, prevents deformity, conserves energy, and allows the individual with HD to do many activities without help. A poorly selected wheelchair can discourage mobility, contribute to deformity, and jeopardize safety.

Many people with HD have an easier time propelling a wheelchair with their feet than they do with their hands. If this is the case, your physiotherapist will likely recommend a "hemi-height" or "drop seat" wheelchair so that the person can firmly plant his feet on the floor.

It may be very difficult to find an appropriate wheelchair or "seating system" for some individuals. They have involuntary movements, rigid or fluctuating muscle tone, unstable posture, and an inability to modulate the force of their movement. One option is the Broda semi-reclining chair. It has a wide base of support, can be pushed easily in any direction, has a deeply angled seat, and is padded to prevent injury. Its

frame is made of tubular steel and covered with a plastic webbing with a lot of “give.” New models allow the chair to tilt so that the user’s position can be easily changed and pressure spots relieved. Bands that lie across the thighs to prevent the user from sliding out of the chair can be attached to it. Chest pads for those needing additional trunk support are also available. This chair, as well as other adapted or specialty chairs, are widely available and often reduce the need for other restraints.

Selecting a Wheelchair

Selecting an appropriate wheelchair is a team effort involving the person using it, his caregivers, his physician and his physiotherapist. To determine the best wheelchair, physiotherapists make these considerations:

- Does the chair restrain the person as little as possible?
- Does it allow enough room to move freely and without injury?
- Are its hard surfaces and sharp edges padded?
- Does it allow the user to get into and out of it easily?
- If appropriate, does it provide independent mobility?
- Does it offer solid steady support for the feet?
- Does its height allow it to be used at a table or with a lap tray?
- Will involuntary movements cause the chair to tip over?

Adapted from Lori Quinn, Ph.D., PT

AVOIDING RESTRAINTS

The long-term care industry has made great strides in reducing the use of restraints in the last five years. However, the use of restraints is not uncommon among residents with HD in long-term care facilities, even though it may be particularly risky in this group of residents. Restraints do not prevent involuntary movements but can lead to injury of the limb, chest or abdomen, or even strangulation. Adam and Brenda serve as two examples.

Nutshell Case Study:

Alternatives to Restraints

Adam has involuntary movements and keeps sliding down and out of his wheelchair. To help him remain seated in the chair, his nursing home staff restrain him with a seat belt. A more thorough assessment of his movement disorder might suggest a high-back seat, increased seat depth, foot supports, arm rests, and padding to prevent him from sliding out of the chair without the risk of a belt restraint.

Brenda’s balance is impaired. She has a deficit in spatial awareness and impulse control disorder. She’s always hungry and never sits still. She constantly stands up from her wheelchair and quickly falls down. Brenda’s nurses and therapists initially recommended a waist restraint to keep her safe in her

chair and to prevent her from falling. On further reflection, though, they came up with alternatives to restraint. Anticipating Brenda's needs and wants, they arranged a daily routine by scheduling periods out of her chair to walk with supervision, to eat more frequent smaller meals, and to get out of her chair to relax on a couch or bed. They also use bed and chair alarms to alert them when she gets up so they can quickly respond to her.

ABOUT BEDS

Although most people with HD have no involuntary movements while sleeping, many have difficulty remaining in their beds. Deficits in spatial awareness make it difficult to sense the edge of the bed. Although bed rails provide protection for some, in other cases, they may serve as nothing more than objects to bang up against, or they may serve merely as obstacles to climb over when the patient feels an urge to go to the bathroom in the middle of the night.

For those who walk, "low beds", which are between 12–20 cm off the floor, may be safer. A thin, high-density mat can be placed on the floor next to the side used most often. In some cases one side rail may be left up and padded with several centimetres of foam, leaving the other one down for easy access.

In the presence of very severe chorea when side rails are necessary but traditional side rail pads are inadequate, an alternative method of padding may be necessary. A foam mattress overlay (Ultraform, for example) can be easily cut in half lengthwise with an electric knife. This creates two side rail pads with enough padding left over to pad the head and foot boards. The pads, covered with thin plastic and a sheet, are secured to the side rails by clip-style buckles with belts of webbing. This should protect the patient from bruising or abrasion.

A few individuals seem to "vault" out of their beds. This is caused by an inability to regulate or "modulate" the force of voluntary movement. The large muscle groups in the legs are used while turning over or adjusting the position in bed. Large poorly modulated extensions and contractions of these muscle groups can result in the individual flipping out of bed. There are no traditional beds available that allow a great deal of freedom of movement and protection from serious injury from the vaulting. One possible solution to this problem is to build a modified Craig bed. A platform the size of a standard double-bed mattress is built 20 cm off the floor with four "walls" 1.2 m high padded with foam and covered with smooth vinyl. One side of the bed opens to allow access for transfers and care.

These beds are often criticized for their odd boxy appearance and the degree to which they shelter the person from stimulation in the room around them. However, experience has shown that people with HD who use them are grateful for a good night's sleep, the chance to roll over and change position without "vaulting" out, and the opportunity to sit up without crashing into a side rail.

Other possible adaptations are simply placing mattresses on the floor; using a double or queen-size bed rather than a single or twin bed; and using chairs, lounges and beds made of moulded foam.