

Certified Nursing Assistants

FIRST SHIFT

with a person who has

Huntington's Disease

A brief first look at some principals of care for nursing home residents with Huntington's Disease.

In nursing homes in the United States, Certified Nursing Assistants (CNA's) work under the license and direction and supervision of a registered or licensed practical nurse. CNA's provide nearly all of the direct care of a resident.

By Jim Pollard

Edited by Carol Moskowitz

26 July 2001 & 25 Aug. 2001

Website: www.CureHD.com

Your First Shift

Huntington's (HD) is a relatively rare disease. About one person in 10,000 has HD. Many CAN's never care for one person with HD. This brochure covers care for people who have had HD for more than 5-7 years.

The last years are called the advanced stages of HD. This brochure may be helpful to you on your first shift caring for a resident with HD.

This brochure does *not* replace the care planning process in your facility or the instructions from your supervisor and other professionals on the residents clinical team. Telling you about these unique features of HD is the first step in creating a partnership in caring for this resident. The partnership includes you, the other staff, the family and the resident. No one can do this care alone.

What Is Huntington's Disease?

Huntington's Disease:

- Causes the cells in a small area of the brain to die or function inefficiently.
- Disables more and more for about a 25 year period.
- Impairs thinking, speaking, swallowing and controlling how they feel and how they move.
- Often makes people look bored, disinterested or angry, when they're not.
- Starts when most people have begun a career, started a family and have been doing well in life
- Is a genetic disease, which the person inherited from one parent. Most likely this resident has watched a parent suffer and is worried that each child has a 50:50 chance to develop it.
- Has no cure.

There is treatment for control of mood and movement.

Beware of The Risk of Choking

As Huntington's Disease worsens, residents develop a swallowing disorder.

You may not be able to see that the resident is having difficulty swallowing, so you need to closely watch them while eating to prevent choking. Some folks with HD eat too fast, forget to chew and overstuff their mouths with food. This increases the risk of choking.

Follow the choking precautions of your facility. Help them eat in a quiet area.

Help Increase Calories

Weight loss is an ongoing challenge to people with HD in nursing homes. New residents often have weight loss. They are adjusting to a new life, new food, new table mates and new people helping. If people are under-weight, it may be helpful to serve them 5 times a day and to try to double portions as soon as possible.

Think of the resident as always being very hungry. Weighing the resident weekly for the first few months will help you maintain their weight.

Prevent Falls

By the time the resident needs nursing home care it is most likely that balance is impaired. Pay close attention to walking and transfers to prevent falls.

New staff, new residents and a new setting can distract anyone from paying close attention to falls.

If the resident has bedrails, double-check their safety. Remember: if balance is impaired, more falls are likely to occur while transferring into, onto and out of bed, chairs and toilet.

Difficulty Waiting

Difficulty controlling impulses is caused by changes in the brain and not by the person being selfish or impatient. People with HD cannot wait. When they want something, they want it now.

Respond immediately. Do not make them wait. If you can possibly help, do it as soon as possible. If you promise to help them in a minute, make sure you really can do it in a minute. Only make promises you can keep. If you really mean five minutes, say that: and be there in five minutes.

All other things being equal, if two call lights are lit, respond first to the person with HD and impaired impulse control!

Expect Repetitive Insistence

The person with HD may ask you the same question over and over. Even though you take the time to answer the questions a few times, you may be asked again.

The resident understands what you're saying, but has difficulty remembering, difficulty with anxiety or cannot change the topic he's focused on.

Please be patient. HD causes this behavior. Try to gently change the topic.

See Through "The Disguise"

Weakness and changes in the tone of the facial muscles often contribute to an appearance of boredom.

Difficulties maintaining a smile while listening or speaking may make a person with HD look unhappy, bored or uninterested.

Weakness and changes in posture (such as leaning to one side) may look like attitude. Maybe you will think the person just doesn't like you.

Don't let this "*Huntington's Disguise*" fool you! This person may be smiling on the inside, very interested in what you're saying to him, and does like you. *Don't give up!*

"Big Burst of Movement"

People in the more advanced stages of HD often have difficulty controlling voice and their movements. For example, when getting up from a chair the muscles in their legs may use more force than needed to lift them off the seat, giving the misimpression that they are leaping out of the chair.

As you help bathe, the person with HD may try to gently lift their arm to help you lather them up. Instead, they have a "big burst" of arm movement. It may appear that you were hit and not helped!

"Big Burst of Movement" *Continued*

These uncontrolled "bursts of movements" may lead a new staff member to think that the resident is kicking, hitting or throwing a plate from the table, resisting care or shouting.

Always be aware of these "big bursts". Position both the resident and yourself so that your safety will not be compromised. Over time, you'll learn more precisely how to anticipate these big bursts.

Importance of Routine

People with HD have problems starting, continuing, finishing, planning and anticipating what is happening. So, these changes in thinking and processing information work best when they have a daily routine.

Nursing homes have a very orderly routine. Meals and medication passes at the same time every day are examples.

Try to work out a routine of care for activities of daily living with the whole team so that most care occurs at the *same time* every day. Set a schedule as soon as possible for bathing, dressing and eating.

The same *familiar* caregivers for this resident will help them fall into the daily routine. If doctor visits or other activities are not routine occurrences, tell the person with HD what will soon happen in order to avoid surprises.

About Smoking

If your person with HD still smokes cigarettes, you can assume that smoking is very important.

This person has suffered loss after loss; his job, his driving a car, his friends, his place in the family and his ability to live in his own home. Smoking often takes on a symbolic importance as "*the only thing I've got left*". On admission, review the facility's smoking policy and discuss the policy with the resident. Show them where they can smoke.

If people require assistance and supervision while smoking, set a daily routine schedule immediately and discuss the routine with other staff.

Remember, impulse control problems mean the person with HD cannot wait..especially for a cigarette. Supervise them closely for safety: consider using a smoking vest.

Importance of Dental Care

HD's movements make it difficult for the resident to brush his teeth effectively. It also makes it difficult for you to help them. It makes it harder for dentists to treat them.

Prevention is especially important. To increase calories many eat high-sugar diets that contribute to tooth decay. Please make the extra effort necessary to brush their teeth effectively.

Thank you for caring!

~~~~~

The above is also available in a handout brochure. Please contact Jim Pollard.