

# Nursing Approaches

## for Clients with Huntington's Disease

by Winkie Simpson

Clinical Nurse Manager, Runnymede Chronic Care Hospital, Toronto, Ontario  
with acknowledgment to the Runnymede Chronic Care Hospital Interdisciplinary Team,  
The Nursing Staff and Clients with Huntington's disease and their families

The following article is a summary of the presentation given by Winkie Simpson at the Huntington Society's annual conference in Vancouver, October 1994.

Fourteen years ago we admitted our first two patients with Huntington's at Runnymede: a young woman and a man in his forties who had been transferred from another hospital. We started on a journey to learn how to care for people with Huntington's. Working closely with the Huntington Society of Canada, families and patients we developed individualized care plans. I would like to share some of our experiences, and address therapeutic care and practical interventions we have developed.

All HD clients at Runnymede are in the late stages of the disease and are integrated with our other clients (114) whose ages range from mid thirties to over 100. They have a variety of progressive neurological and other disorders, including Huntington's disease.

### Quality of Living

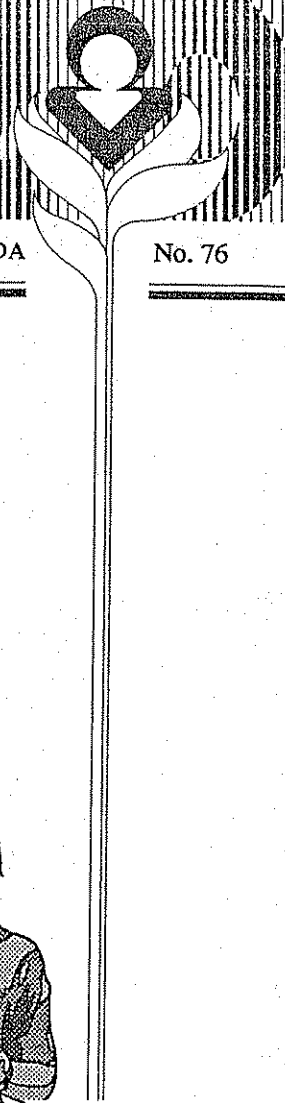
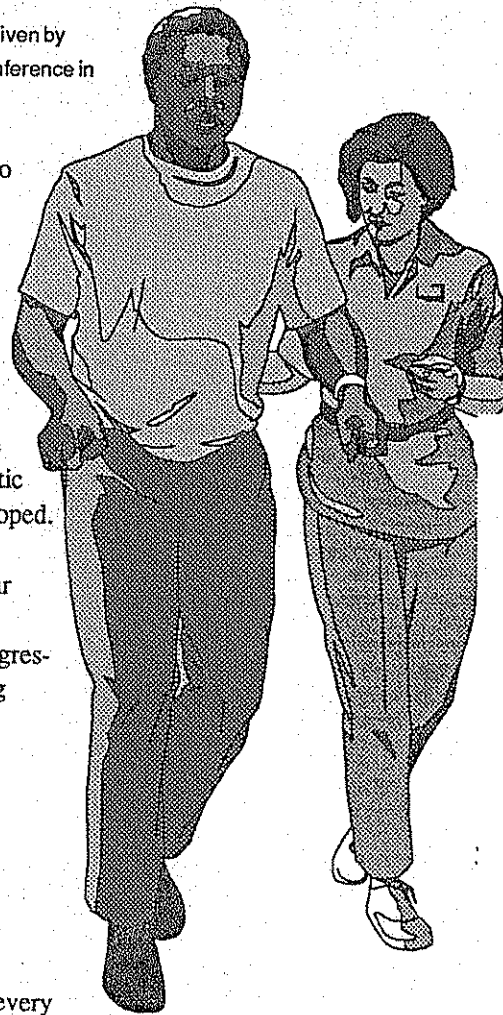
At Runnymede Chronic Care Hospital our interdisciplinary team is committed to working closely with patients and families to achieve therapeutic changes which will result in "better quality of living".

It is important to remember that HD affects every aspect of a person's life eventually, and the key to understanding "quality of life" is to acknowledge that it means different things to every person.

As caregivers, the challenge in our interventions is to identify issues that are important to our client (the issue may not be the least bit important to us but it *is* to the client).

### Power and Control

All health workers acknowledge that clients should be primary decision makers in



their care, but traditionally, the very complexity of our institutions does not allow this to happen easily. The balance of power and control between caregiver and client is often an issue. How do we help the client feel more in control and therefore, more powerful?

#### What is Power?

Knowledge and information bring power

Respect is power

Communication is power

Making choices is power

Receiving help to maintain control is power

Many of our approaches are developed with this in mind—developing individual strategies to help patients feel more in control of their care and their lifestyle.

#### Dementia

Dementia means intellectual deterioration, impaired memory and disorientation as a result of a progressive brain disease.

We were told that Huntington's patients were demented, but we saw that it was not total or complete and that they remained alert and aware of events and their surroundings, even to the very final days of their lives.

The dementia of HD is quite unique: the main defect in intellect is one of disorganization of intellectual functions,

operations that are largely taken for granted.

HD patients typically experience problems in organizing or planning. They may lose their problem-solving abilities early in the course of the illness. Retrieval of information can be aided by "cueing"; for example, developing a word or set of words that helps the person to trigger the desired response.

#### Periodic Explosive Outbursts

Behavioural outbursts in clients with HD are not readily understood nor easily managed. It is possible, however, to examine the problem and try to recognize just what we can manage. We often get caught up in the problem rather than trying interventions. We had virtually no success with behavioural modification in the classical sense, but we have had a measure of success in behaviour management. (In reality, it is the staff who do the major behaviour change.)

We recently dealt with a client who was very disruptive. He was an explosive, violent person who would chase staff and hurt them if he caught them. Needless to say, our staff were in a state of disruption and in need of help.

Staff conferences indicated that there were two overriding emotions: fear and concern for the client; so we started a journey to see if we could manage the situation more effectively.

We compiled a list of words to describe the behaviours that were disruptive (eg. very demanding, self-absorbed, disinhibited, impaired judgement, impulsive). We then developed a data collection tool using the descriptors chosen from the list of words developed. People were asked

to record observations every half hour.

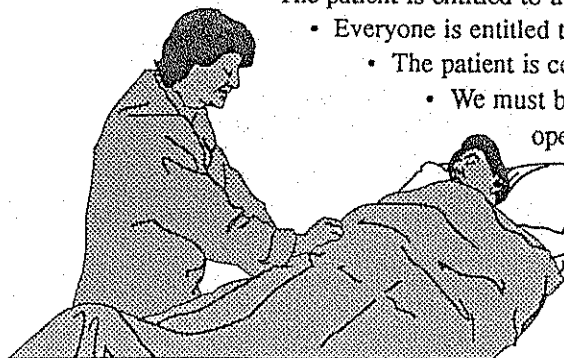
Data was collected for two weeks. It was checked and discussed with the unit manager and staff on a regular basis. There were very few incidents of disruptive behaviour in the two week period and none that could be considered violent. During this time, staff gave the client lots of attention—the half hourly observation for data collection reinforced this. The behaviour management approach is one in which a person is given lots of attention for behaviour you wish to encourage and less attention for behaviour which is disruptive.

Staff expressed fear of coming too close to the client because he was so unpredictable. This was an issue that needed some strategies. We learned to always put something solid between us. For example we would chat with him from the other side of the desk. What we needed to do was to be safe but attentive. Eventually, there was enough time between outbursts for staff to feel a measure of confidence and less need for distance. This was the beginning of a "new age" for us, and a new understanding of Mr. X. He was allowed to become a person.

One day, after we had been concentrating on this gentleman's behaviour, he became disruptive: threw himself on the floor, vocalized loudly. The staff calmly ignored him, walked around him, gave him space and time. Once he had been quiet for a while someone checked on him to help him up again. This was a major behaviour change *on our part* and it worked; 30 minutes later he was up in the hall, calm and in control. A few incidents like this eventually convinced us that

The following principles should guide any interventions we undertake:

- The patient is entitled to the best quality of care.
- Everyone is entitled to a sense of hope for a better life.
- The patient is central to our care.
- We must be flexible, innovative and keep an open mind.



- Value your own style, but also value others. Your personality is your most valuable asset—use it!

there is merit to this approach.

Behaviour management is neither a miracle nor a cure. But, it helps to have a strategy ready as it reminds us to try to seek a solution that is good for the client and good for ourselves at the same time.

A word of caution when dealing with behavioural problems in clients with HD: we have learned to suspect any sudden behavioural changes especially in the late stages of HD. The client should always have a thorough medical work-up as there is often a cause for the change, such as pain. We have had this experience with dental caries, bladder infections, and constipation to name a few. They need prompt attention and then usually the behaviour returns to "normal".

### Mobility

We spend a lot of time trying to keep clients safe and mobile. We combine this with a standard that each person will have freedom of movement and independence in the performance of daily activities, recognizing the physical limitation imposed on the individual by their HD.

One of our clients, a 32-year-old woman with HD, is unable to talk other than an occasional single word. The client had a series of incidents where she was found sitting on the floor at various times of the day and night. I had the staff indicate on a floor plan exactly where she fell. All her falls (sitting down) occurred two feet from her bed. Clearly she needed help getting out of bed. She is unable to use a call bell or any other deliberate system to ask for assistance.

Once we had this information we:

- installed wind chimes in strategic places where she would brush them as she moved toward the end of the bed. (They were also enjoyed by her room mates and visitors). They could be heard throughout the unit, especially on night shift.
- we located an electronic monitor device that alarms as she approaches the end of the bed. It acts as an early warning device and has worked effectively to date. Periodically the alarm needs adjustment as she has slipped under the beam a couple of times.

### Other important facts

It has been estimated that an HD

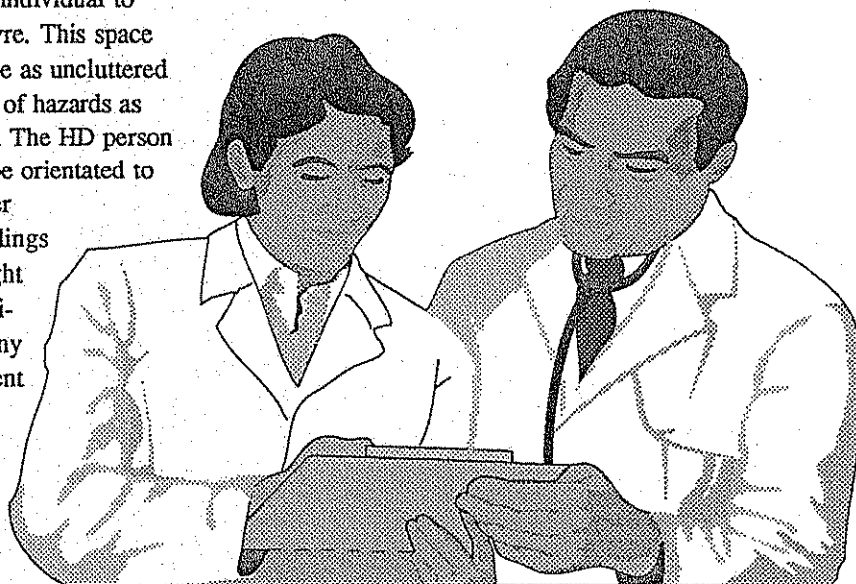
person needs twice the space of an average individual to manoeuvre. This space should be as uncluttered and free of hazards as possible. The HD person should be orientated to his or her surroundings and taught peculiarities of any equipment which may be used.

It is important to keep everything in top notch working order, such as side rails on the bed, brakes on the chairs, etc. This will prevent undue trauma.

When purchasing equipment for an HD person, keep in mind that it will probably be subjected to heavy duty wear and tear. In our experience everything should be simple, strong and have as few moving parts as possible. Personal clothing should have as few belts and buckles as possible. We have found jogging suits to be the most practical, but personal taste will dictate. It should be washable. Some other environmental concerns include furniture that is well padded, recessed drawer pulls, water temperature set at a safe level and so on.

The process of assessment is critical for the client, because there are no ready answers. Safety always needs to be balanced with freedom and risk taking, and choice is essential for the sense of worth and dignity. We are often challenged with preventing injury from severe involuntary movements, and providing a safe environment for our clients, balanced with an attitude of "let's try it". If it will make a difference for the client it's worth the effort and it will give the team an unbelievable sense of worth too. It's professional and it's therapeutic.

The Huntington Society of Canada invites approaches and tips from caregivers, family members and professionals, which can be shared with others.



The following is a sample of diagnoses which will likely be present for someone in the late stage of HD in a long term care setting.

**Alteration in regard for Safety**, especially of self, compounded by impulsiveness, unrealistic expectation and memory problems.

**Alteration in Mobility**, related to uncoordinated movements.

**Alteration in Emotional Comfort**, which may result in behavioural manifestations, eg. depression, loneliness, anger, explosive outbursts and alienation.

**Alteration in Communication**, especially speech which results in difficulty being understood which results in powerlessness, frustration and alienation.

**Alteration in Social Relationships**. This is a family disease in which there are enormous changes in "normal family life".

**Alteration in Elimination**. Incontinence is an eventuality in the late stages.

All of these diagnoses need to be defined as closely as possible in order that the approaches to care be appropriate. Safety impacts on every strategy and loneliness is present at every level as well.