

## ***OCCUPATIONAL THERAPY***

From 'The Family Guide series – Physical and Occupational Therapy for Huntington's Disease'  
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### ***Occupational Therapy in Early Stage HD***

As cognitive changes begin to occur, an occupational therapist can help the person with HD and family members develop compensatory strategies. By employing these strategies early in the disease process, the person with HD learns that he/she can have some control over the disease and is therefore less apt to feel helpless.

### ***Memory Strategies***

- Offer hints, such as word associations, to aid in the retrieval of information
- Use lists, calendars and notes
- Establish a consistent daily routine
- Label items around the house
- Avoid open-ended questions. Instead, offer a list of choices and ask questions requiring a "yes/no" answer. Difficulty in sequencing tasks is another common problem experienced in the early stages. Family members report that tasks that used to be completed in a few hours now take all day or are never completed at all. The strategies listed below can help to remedy this problem.

### ***Planning Strategies***

- Write down all tasks in a logical order
- Review the steps to ensure that they are clearly understood
- Break complex tasks down into parts
- Encourage completion of each step prior to moving on to the next step in the task

### ***Concentration Strategies***

- 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 or recipes

### ***Safety in the House***

A home consultation by an occupational therapist can identify unsafe practices and provide suggestions to improve safety. 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 storage of 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 Middle Stage HD***

The combination of motor control problems and cognitive deficits creates a number of difficulties in activities of daily living. Again strategies and equipment can be of great use in prolonging independence.

### ***Eating***

#### **Problem**

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

#### ***Strategies***

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

#### **Problem**

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

#### ***Strategies***

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

#### **Problem**

Inco-ordination of movement makes simple tasks such as cutting food seem very difficult.

#### ***Strategies***

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

## ***Hygiene***

#### **Problem**

Difficulty with motor planning 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, this apparent lack of interest is often a result of diminished planning and sequencing ability.

#### ***Strategies***

- Divide morning and evening routines into simple steps
- Write out steps for completing all hygiene tasks and post in a visible place

#### **Problem**

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

#### ***Strategy***

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

#### **Problem**

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

#### ***Strategies***

- 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 handle on toothbrush or hairbrush by wrapping and taping a washcloth around it

**Problem**

Fatigue often plays a role in preventing the completion of tasks.

**Strategy**

- Build rest periods into the routine

**Dressing****Problem**

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

**Strategies**

- As with other complex tasks, reduce the routine to simple steps
- Label and pair favourite items so that decision-making is kept to a minimum

**Problem**

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

**Strategies**

- 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

**Problem**

Lack of initiation – the inability to start a task – may necessitate a ‘jump-start.’

**Strategy**

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

**Occupational Therapy in Late-Stage HD**

In the later stages of the disease, preventing injury to the body becomes of 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 caregivers by suggesting a routine of position changes. The OT can also assist in designing a protective environment for the person with a lot of choreic movement. Padding of hard furniture, wheelchair parts and sharp corners help 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 a 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 a 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 proved 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.

**Conclusion**

Today, more than ever, there is hope for people with Huntington’s disease. Rapid progress is being made toward potential treatments for HD. Likewise, quality of care for people with HD has improved greatly in recent years. By seeking early intervention from health professionals such as physical, occupational and speech language therapists, the person with HD can have control over the disease and over his/her life. By learning strategies to help them cope with the many changes that are brought on by Huntington’s disease, people with HD can live meaningful, productive lives well into the final stages.