

Have you M.E.T. HD?

Have You M.E.T. Huntington Disease (HD)?

Affected Brain Areas

Caudate Nucleus: responsible for the control of movement

Frontal Lobes: responsible for the evaluation of perceptions and emotions to plan and direct actions (planning, organizing, judgment, reasoning, decision making, attention, working memory)

HD has three major areas of impact:

MOVEMENT

Involuntary movements

E.g. Legs, arms, torso and face.

Diminished coordination of voluntary movements.

E.g. Unsteady gait and slurred speech can create an intoxicated appearance.

Falls are a common risk for persons with HD. Persons with HD will eventually become unable to walk.

Physiotherapy or occupational therapy assessment or treatment can extend mobility and independence and decrease the risk of falls and injuries. Consider possible side effects of medications.

Increased nutrition and hydration needs

Assure easy access to high caloric meals, drinks, supplements. Allow for sufficient time to support the person; if needed, provide several smaller meals; create a supportive environment (reduce disturbances, increase measures of comfort).

Speech impairment:

For most people affected by HD it will become increasingly difficult to produce clear speech. Involve speech language therapist (SLT) in the care for the patient early on.

EMOTION

Psychiatric disorders induced through the physical changes in the brain

- Depression
- Anxiety
- Suicidal ideation
- Psychosis
- Bipolar disorder
- Obsessive compulsive disorder
- Sexual disorders

For one out of three persons with HD, psychiatric symptoms are the initial manifestation of the illness.

Three out of four persons with HD have concomitant associated psychiatric diagnosis.

50% affective disorder or greater than 10% a psychotic disorder

- Seek psychiatric consultation
- Review medication
- Provide counselling and support

Emotional Disturbances

Common emotional reactions when diagnosed with a chronic, incurable, terminal disease are fear and grief.

- Loss of hopes and wishes for the future
- Loss of abilities and competences
- Loss of control and independence
- Possible future abandonment
- Possible pain and suffering

THINKING

Cognitive Disorder and Impairment

- Difficulty with short-term memory and retrieval; long-term memory stays intact
- Difficulty understanding complex information and sequencing
- Slow response time, short attention span
- High level of distractibility
- Difficulty learning new things (but not impossible)
- Lack of ability in problem-solving and reasoning, poor judgment skills
- Altered visual-spatial sense
- Altered sense of time
- Tendency to perseveration and repetition
- A narrow focus on what is coming next
- Lack of self-awareness
- Unawareness of limitations and symptoms

Communication Difficulties

- Word-finding difficulties
- Difficulties beginning conversations and staying on topic
- Poor listening skills and concentration
- Lack of spontaneous communication
- Impaired facial expressions
- Impaired reading and writing ability

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MOVEMENT

Continued

Speech Impairment Continued

Take time to get to know the person and learn to better understand the individual way of articulation

Swallowing Difficulties and Risk of Choking or Aspiration Pneumonia.

Seek swallowing assessment and ongoing consultation from speech language therapist.

Disturbed Sensation

Pain tolerance is often abnormally high (e.g. dental abscess/cigarette burn). Small changes in behaviour or appearance can be signs of serious illness.

Incontinence

Possible unawareness of full bladder and bowel; impaired control of voluntary movements, regular toileting routine can be helpful.

Altered perception of body temperature

Adjust room temperature and clothing to individual needs.

Excessive Perspiration

Respond to increased needs for personal care.

EMOTION

Continued

Emotional Disturbances Continued

These emotional reactions can be intensified and complicated through the genetic component of HD.

- HD affects lives over generations
- HD can overshadow childhood
- People affected by HD might have more knowledge about what lies ahead than they might wish for
- Inherent risk for children and grandchildren

Personality changes induced through the physical changes in the brain.

- Low frustration tolerance and short temper
- Impulsivity and irritability
- Perseveration
- Inflexibility and obsessive compulsive behaviour
- Apathy, loss of drive and initiative
- Decreased ability to empathize the feelings and needs of others

For more information visit:

www.huntingtonsociety.ca

THINKING

Continued

Communication Difficulties Continued

Sometimes behaviour can be the most effective method of communication for a person with HD.

Sometimes the person with HD can only communicate through behaviour.

An improvement of communication and comprehension can lead to a decrease of undesirable behaviour.

Caregivers need to take the responsibility for effective communication.

Communication will be highly impaired in the advanced stages of HD.

Be aware that the person has comprehension of his or her whereabouts and of the situation, and can hear and see you.

It is the ability to communicate that decreases, not the need.

The information in this fact sheet was originally developed as part of an educational presentation for long-term care facility staff.