Strength & Knowledge

March 14, 2014
Volume 7, Issue 2

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. 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 or 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).

EMOTION

Psychiatric Disorders Induced through the physical changes in the brain

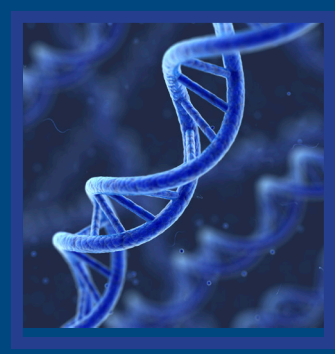
- Depression
- Anxiety
- Suicidal Ideation
- Psychosis
- Bi-Polar Disorder
- Obsessive Compulsive Disorder
- Sexual Disorders

For one out of three persons with HD, psychiatric symptoms is 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



THINKING

Cognitive Disorder and Impairment

- Difficulty with short-term memory and retrieval; long term memory stays intact
- Difficulty with 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 limitations and symptoms

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HSC 2014 National Conference

Date: October 24 & 25 2014
Holiday Inn Airport West
2520 Portage Avenue
Winnipeg, MB R3J 3T6

For more information or to Register visit:
www.huntingtonsociety.ca

Physician's Guide

HSC has published the 3rd edition of A Physician's Guide to the Management of Huntington Disease, with the assistance of HDSA.
For a copy please contact us at info@huntingtonsociety.ca or 1-800-998-7398.

Enroll!
Updates from the Enroll-HD global community

WATCH OUT FOR OUR SPRING CHALLENGE!

Youth Mentorship Program

This program is designed to support young people across Canada who face the everyday challenges of growing up in a family affected by HD.
To become a mentee or learn more about this program visit:

http://huntingtonsociety.ca / youth-mentorship-program/

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

MOVEMENT
Continued

Speech Impairment:
For most people affected by HD it will become increasingly difficult to produce clear speech. Involve speech language specialist in the care for the patient early on.

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

Swallowing Difficulties and Risk of Choking and Aspiration Pneumonia
Seek swallowing assessment and ongoing consultation from speech language therapist.

Disturbed Sensation
Pain Tolerance is often abnormally high (E.g. dental abscess or 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 volutary movements and 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
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

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 is laying 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

THINKING
Continued

Communication Difficulties

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

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.

YPAHD Young people affected by Huntington Disease
www.ypahd.ca

HDYO HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Follow us on Facebook and Twitter for daily updates!

Huntington Society of Canada · 151 Frederick St., Suite 400 · Kitchener ON, N2H 2M2
800-998-7398 · www.huntingtonsociety.ca