

**FACTSHEETS FOR HEALTHCARE PROFESSIONALS:
 Minimizing Risk in Huntington Disease**

While risk is an inevitable part of life, we use our knowledge, understanding and judgment to make informed choices about what risks we want to take and what risks we want to minimize. However, people living with Huntington disease (HD) may not fully understand the consequences of their actions.

Because HD affects parts of the brain involved in judgment, impulse control and self-awareness, people with HD can put themselves in risky situations without recognizing that fact.

To manage that risk, it's helpful to have a multidisciplinary team involved in caring for the person with HD.

Potential risks in HD

Type of risk	Professionals who can help assess the risk
Choking and aspiration	Speech and language therapist
Malnourishment	Dietitian
Falls	Occupational therapist or physiotherapist; neurologist
Pressure sores	Nurse
Personal neglect	Social worker; nurse
Impulsive behaviour	Psychiatrist
Aggression to others	Psychiatrist
Inappropriate sexual behaviour	Psychiatrist
Dangerous driving	Family doctor; department of transportation
Fires (smoking, cooking, etc.)	Fire department; occupational therapist; family doctor
Suicide	Psychiatrist

Managing risk

As the disease progresses, the level of risk for the person living with HD will change, so it should be reviewed regularly. The aim is to avoid the need for crisis management.

Keep in mind that HD reduces a person's ability to cope with change. While many risks may be identified, it's important to prioritize which should be addressed first so there aren't too many changes at the same time.

Discuss boundaries with the person with HD. Explain what is acceptable and what

isn't and what the consequences will be if their risk levels are unacceptable.

While there are few medications to reduce specific symptoms of HD, some people may find anti-depressants and/or anti-psychotics helpful for a period of time. Medications to reduce involuntary movements can also help some people with HD at certain stages of the disease: by limiting excessive movement, these medications can help reduce the risk of falls and help people with HD maintain a healthy weight by burning fewer calories. Keep in mind that HD is a progressive disease, so the person's quality

of life and the effectiveness of any medications should be re-assessed regularly by qualified professionals.

Equipment to help minimize risk

Smoking:

- fireproof aprons
- fire alarms, heat or smoke detectors
- an “automatic smoker” or “smoker’s robot” that holds the cigarette and prevents ashes and embers from being dropped
- a nicotine inhaler

Involuntary movements:

- specialized bed sides to prevent limbs from getting trapped

Falls:

- walking aids such as rollator frames or gutter frames (note that because HD affects coordination and the

ability to multi-task, some walking aids can actually increase a person’s risk of falling)

- elbow and knee padding
- helmets
- personal alarms to call for help in the event of a fall

For more information

- *Driving* (a Huntington Society of Canada factsheet for families)
- *Swallowing* (a Huntington Society of Canada factsheet for families)
- *Living Life to the Fullest: Families Sharing Their Ideas* (a Huntington Society of Canada booklet for families)
http://www.huntingtonsociety.ca/english/uploads/Living_Life_to_the_Fullest.pdf

Adapted from: *Huntington’s Disease Association’s Standards of Care*, Huntington’s Disease Association / St. Andrew’s Healthcare

<http://www.hda.org.uk/download/fact-sheets/HD-Standards-Of-Care.pdf>