

Huntington disease (HD) is a complex neurodegenerative disease, affecting virtually everything about a person – including control of movements, regulation of emotions, judgment, impulse control and self-awareness. As the disease progresses, people living with HD may not fully understand the consequences of their actions and can unintentionally put themselves in risky situations.

A Note for Persons with HD

As HD progresses, the ability to do the things you once did may change. By building the care team early, you will have people you trust to support you as you adapt to the progression of the disease. In planning for your future care and sharing your desires and preferences, you will ensure that your wishes are clear. See the HSC *Future Planning* factsheet for more information.

A Note for Carers

Caring and supporting a person with HD can be a challenge for family carers and professionals alike. You need to take care of yourself for you, and for the person you are caring for. Please refer to factsheet: *Caring for Carers and Families with HD*.

Safety Considerations

- The goal of care for someone with HD is to promote quality of life, including keeping independence and freedom of choice as long as possible, in a way that is safe for the person, the family, and the care team.
- Optimal care requires a team including the Huntington Society of Canada (HSC) Family Services team members, HD or Movement Disorders clinic team, health professionals, aides, daily caregivers, family, and/or friends.
- Consulting with the neurologist and/or psychiatrist regularly is important. They can review disease progression, medications and treatment options to help manage specific HD related symptoms.
- There are devices, aids and equipment that can help a person maintain their independence and dignity while coping with this disease. Consult an occupational therapist (OT), physical therapist (PT) or speech and language pathologist (SLP) for help in determining what will work best for the situation. As this is national document, HSC recognizes there may be provincial differences in the duties outlined for the various professions. Please consult your Family Services team member for up to date regional services available.
- HD progresses in stages, slowly advancing for many years. The care needs for the person living with HD will change and evolve, making it important to review the care plan regularly.
- It is helpful to anticipate changes in overall function that may trigger concerns. The aim is to prepare, be proactive and to try to avoid the need for crisis management.
- HD reduces a person's ability to cope with change. It is important to prioritize which supports should be implemented first so there aren't too many changes at once.
- Family and friends are a good source of knowledge about the person's preferences and how to meet their needs.
- As long as a choice or behaviour does not pose a serious risk to the person with HD or anyone else, you may need to consider allowing the person to continue and not engage in a power struggle. It can be helpful to discuss these situations with your FST member.

Potential Risks in HD

There are many strategies in the HSC factsheet collection, booklets and publications as indicated below.

Type of Risk	Professionals Who Can Help Assess the Risk	Resources to Help Minimize Risk
Choking, swallowing and aspiration	Speech and Language Pathologist (SLP)	<ul style="list-style-type: none"> Factsheet: <i>Eating and Swallowing with HD</i> (HSC) SLP can assess for positioning and liquid texture
Changes in driving	Physician; Neurologist; Psychiatrist; Provincial Transportation Department; Occupational Therapist (OT)	<ul style="list-style-type: none"> Factsheet: <i>Driving and HD</i> (HSC)
Dental care	Dentist	<ul style="list-style-type: none"> Factsheet: <i>Dental Care</i> (HSC)
Falls	Occupational Therapist (OT); Physiotherapist (PT); Neurologist	<ul style="list-style-type: none"> OT to determine appropriate equipment Home Care can do a fall assessment Personal alarms to call for help PT Clinical Guidelines, European HD Network (HSC website) Factsheet: <i>Home Safety</i> (HSC)
Fires (smoking, cooking, etc.)	Fire department; Occupational Therapist (OT); Family Doctor	<ul style="list-style-type: none"> Fireproof aprons, fire alarms, heat or smoke detectors, smoking aids that hold cigarettes and prevent dropped ashes, cookie sheets to place under ashtrays A nicotine inhaler/other replacements Where and when appropriate, access food preparation and delivery services (i.e. Meals on Wheels), disable stove/oven
Home safety	Social Worker; Home Care; Occupational Therapist (OT)	<ul style="list-style-type: none"> Factsheet: <i>Home Safety</i> (HSC) As care needs increase and application to long-term care is made, see HSC factsheet <i>Transitioning to Long-Term Care</i>
Involuntary movements	Neurologist; Occupational Therapist (OT); Physiotherapist (PT)	<ul style="list-style-type: none"> Adaptive beds, walkers and wheelchairs to accommodate chorea, impaired balance and changes to posture Medication <i>Occupational Therapy for People with HD Best Practices Guidelines</i> (HSC website)
Personal care (pressure sores, bathing, toileting, dressing, etc.)	Nurse; Home Care; Social Worker	<ul style="list-style-type: none"> Establish a self-care routine early Explore in-home care as appropriate As needs increase, see <i>A Carer's Guide for HD</i> (HSC website)
Psychiatric/behavioural concerns, including anger, impulsivity, boundaries, etc.	Psychiatrist; Complex Care Support Team (where available); Social Worker; Crisis Team	<ul style="list-style-type: none"> Factsheets, including: <i>Responsive Behaviour, Cognitive Changes, Improving Communication in HD, Tips When Working with Individuals with HD</i> (HSC) <i>Understanding Behaviour in HD: A Guide for Professionals</i> (HSC)
Sexual interest and function changes	Neurologist; Psychiatrist	<ul style="list-style-type: none"> Open communication and counselling Factsheet: <i>Sexuality and HD</i> (HSC) <i>Understanding Behaviour: A Guide for Professionals</i> (HSC) <i>Physician's Guide to Management of HD</i> (HSC)

Type of Risk	Professionals Who Can Help Assess the Risk	Resources to Help Minimize Risk
Sleep disturbances	Neurologist; Psychiatrist; Family Doctor	<ul style="list-style-type: none"> • <i>Understanding Behaviour in HD: A Guide for Professionals</i> (HSC) • <i>Physicians Guide to Management of HD</i> (HSC)
Suicide	Psychiatrist; Crisis Team	<ul style="list-style-type: none"> • Local crisis services, 911 • <i>A Physician's Guide to Management of HD</i> (HSC) • <i>Understanding Behaviour in HD: A Guide for Professionals</i> (HSC)
Weight loss	Dietician; Neurologist; Speech and Language Pathologist (SLP); Occupational Therapist	<ul style="list-style-type: none"> • Factsheet: <i>Eating and Swallowing with HD</i> (HSC) • Dietitian can assess need for increased calories and/or supplements • OT can assess need for assistive devices while eating and drinking • Consult with SLP for consistency of food and drinks and safe swallowing strategies

Resources

- Ongoing support, groups, education and information is available from HSC
- A listing of our Family Services team members can be found at <https://www.huntingtonsociety.ca/family-services-team-list/>
- Factsheets, booklets and publications can be found at <https://www.huntingtonsociety.ca/learn-about-hd/>
- The Huntington's Disease Association <https://www.hda.org.uk/professionals/resources-for-professionals/best-practice-in-huntington-s-disease>
- European HD Network <http://www.ehdn.org/clinical-guidelines/>
- Huntington Disease Society of America <https://hdsa.org/>
- Huntington Society of Quebec (HSQ) <http://www.huntingtonqc.org/>