FACTSHEETS FOR HEALTHCARE PROFESSIONALS:
End-of-Life Issues in Huntington Disease

There are many ways that healthcare professionals can improve quality of life in the late stages of Huntington disease (HD), a progressive neurodegenerative disease.

Care options
A person in the end stage of HD will need 24/7 nursing care. This could be provided in a long-term care home, in a hospice or hospital, or at home.

In an ideal end-of-life care scenario:
• The person feels at home and is surrounded by personal belongings
• Caregivers recognize and respect the person’s individual preferences
• Personalized arrangements have been made for sleeping, seating, hygiene, feeding and day activities
• Needs are reassessed on an ongoing basis
• A regular routine creates a sense of safety
• A stable set of health professionals works with the person
• Staff receives ongoing education and supervision
• Family members feel understood and supported
• Palliative care physicians and nurses help to manage symptoms holistically

Identifying the wishes of the person with HD and those of the family
Ideally, issues related to end-of-life care should be discussed with the person with HD and the family while the person is still capable of making informed decisions and has the ability to communicate.

Advanced directives and power of attorney
Preferences about end-of life care should be fully documented in an advanced directive. The Values History Form (http://hsc.unm.edu/ethics/advdir/vhform_eng.shtml) can help to further clarify individual wishes and can be attached to the directive. Enduring power of attorney for both personal care and financial issues should also be in place. For further information and resources on end-of-life care and decision making, check with your local Huntington Society of Canada Resource Centre or Individual and Family Support Worker.

These documents should specify in writing which medical treatments and interventions the person would want to undergo and which would he/she prefer to have withheld, including:
• Resuscitation and ventilation
• Antibiotics
• Artificial feeding/feeding tube
• Organ/tissue donation

Personal preferences
Gradually accumulate and record information about the person’s interests, preferences and background to improve end-of-life care when they can no longer communicate. Use observations, questionnaires, conversations and reports from others. A memory book or life book can be produced with support of staff, visitors or volunteers.
Talking about end-of-life issues requires a lot of sensitivity. Keep in mind that individuals and families affected by HD experience repeated losses. Several individuals and several generations may be affected at the same time. Caregiver responsibilities can last more than a decade and may overlap as new family members become ill. Caregivers may also be at risk of developing the illness themselves. This can greatly influence decisions and grief responses.

Remember as well that preferences and attitudes can change while the patient and the family adapt to increasing disability, so they should be reviewed periodically. Make sure records are available to everyone involved in providing care.

Assessing needs
Assessing needs may be difficult if the individual’s cognition and/or communication skills are affected. It may be helpful to use simple communication systems such as having the person touch your hand to indicate yes/no. To assess for pain, consider using the Abbey Pain Scale (see “For more information” below), a checklist of non-verbal pain indicators.

Most importantly, you need to know the person you care for. A sudden change in the quality of movement, mood and thinking is not typical of HD progression. Instead, they usually result from a concrete cause, such as pain or discomfort.

Supporting the family
Family members need support from diagnosis through death and beyond. Keep in mind that the hereditary nature of HD means that the caregiver and/or other family members may be at risk of developing the disease themselves. Families with Huntington’s also undergo repeated loss, so grief work can be particularly important. For help, connect families with agencies that offer counselling and grief and bereavement support, as well as the Huntington Society of Canada.

For more information
- Abbey Pain Scale (http://prc.coh.org/PainNOA/Abbey_Tool.pdf)
- A Caregiver’s Guide for Advanced-Stage Huntington Disease, Jim Pollard, Huntington Society of Canada
- Feeding Tubes (a Huntington Society of Canada factsheet for families)
- Future Planning (a Huntington Society of Canada factsheet for families)

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