SEXUALITY AND HD

As part of the human experience, sexuality plays a meaningful role in a person's life. However, illness can bring about a considerable change in one's sexuality.

Sexuality refers to more than just sexual intercourse. It reflects the need to care, be cared for, touched and caressed. It is a subject many people find difficult to discuss with their families and friends, and embarrassing to mention to their doctors or other professionals. Intimate relationships require a high level of communication, and this is even more important as changes occur in a partner with Huntington disease (HD).

Many couples affected by HD continue to have a mutually satisfying relationship for a long time and adapt to circumstances in a way to suit both partners. However, it is also common for people to experience difficulties in sexual relationships. The most common sexual problem is a loss of interest in sexual activity. This may occur fairly early in the course of the disease, when the individual is still functional in most other ways and can be very frustrating for the spouse or partner.

Each person will experience changes differently. The following is a short description of some common problems:

Physical Problems

- Difficulty in obtaining and maintaining an erection may be caused by an underlying medical problem or medications and can be examined by a doctor.
- Some couples have problems engaging in intercourse because of involuntary movements. It may be helpful to use a different position so that the affected partner is stable and well supported. Couples could experiment with different positions to find something that is pleasurable for them.

Psychological and Emotional Problems

- HD can lessen normal inhibition. This can affect sexual behaviour, and some people with HD become sexually over-active and may make inappropriate demands of a sexual partner. The person with HD may also feel depressed, frightened, isolated, and unloved. One of the ways he or she can try to be reassured is through physical closeness, which can mean sex. This overpowering need may cause excessive demands that the partner simply cannot meet. Refusal may be seen as rejection.
- With progression of the disease, the needs of the individual with HD increase and changes to personality become more prevalent. His/her partner may become less interested in sex or feel less attracted to the person affected by HD. Many partners then struggle with feelings of guilt about these understandable reactions.
- The spouse may be distressed and apprehensive that the loved one will become aggressive if sexual demands are not met. Spouses may be afraid to talk about the problem unless interviewed alone.

Other Issues

- Occasionally, in relation to personality changes and loss of inhibitions, a person with HD may desire and pursue excessive sexual activity or engage in new or inappropriate sexual behaviours, such as public masturbation or voyeurism. A person may leave the monogamous relationship and seek multiple partners.
- Open communication between a health care professional involved in the care of the person with HD and the family can help to de-stigmatize this sensitive topic, and distressing sexual behaviours can sometimes be adapted and compromises can be found.
- Interventions can be difficult in circumstances where impaired judgment is an issue. Anti-androgenic therapy (i.e. drugs to lower the libido or sexual urges) has been found to be helpful in a few of these cases.

Huntington Society of Canada • 151 Frederick St. Suite 400, Kitchener ON N2H 2M2
1-800-998-7398 • info@huntingtonsociety.ca • www.huntingtonsociety.ca

Suggestions for Couples

1. Develop a routine that includes time to "be together" with minimal tasks or distractions.
2. Expect changes in who initiates intimacy. Clear communication and consistency will be needed regarding expectations and limits for intimacy, including time and place.
3. Both partners may experience ambivalent feelings and confusing thoughts. As the affected person's sense of "timing" and ability to "attend to the subtleties of the relationship" change, expect emotional changes in both partners.
4. Think creatively about your shared experiences and the value of touching.
5. Whenever possible, try to remember to see the humour in a situation.
6. Adequate rest is extremely important for both partners. Change in sleeping arrangements may be needed to obtain sufficient rest.
7. If it is possible, the couple can try to discuss their problems between themselves, so they can understand each other's feelings. If needed, reach out for help from appropriate professionals such as a family doctor or counsellor.

Sexual Expression in Long-Term Care (LTC)

A small number of people with HD may exhibit problematic sexual behaviour when they are in long-term care. They may, for example, talk in inappropriate ways or expose themselves. Such behaviour can cause tension and anger among staff and other residents, and is often perceived as a reason for embarrassment for families. It is important that staff be educated with regard to how symptoms of HD (e.g. disinhibition, poor judgment, impulsivity, changes in hormone levels), can contribute to problematic sexual behaviour.

It is also important to understand the intent of the person's behaviour. Some behaviour, such as disrobing (removing one's clothing) may be seen by others as sexual in nature. However, this act may actually be the person's attempt to self-regulate his/her body temperature. A lack of ability to regulate one's body temperature is a common issue for people who have HD. If staff in LTC understand this, they may be able to help with solutions to this problem.

Medications used to treat the symptoms of HD can have sexual side effects. In-services and consultations from HSC Family Services staff can be very helpful in providing necessary education and developing strategies to deal with challenging situations. Long-term care facilities need to consider and balance a person's happiness, including their right to engage in sexual activity, with risk of harm and duty to protect all of the residents in their care. Staff may need to set clear parameters of physical contact with the person with HD as well as with the other residents. LTC facilities may also choose to engage behaviour teams or specialists to assist with addressing these situations.

It is also important for all involved to keep in mind that sexual drive and urges are present in all human beings, whether ill or not. They can be very strong, and a lack of opportunity to express normal sexuality can result in sexual behaviour that may seem inappropriate. Part of the strategy and planning used to deal with problems that may arise should take this into account, as well as consider the person with HD's values, beliefs and history before they experienced cognitive decline. Staff can consult with family and people involved in their care to help them understand this piece and the person's prior wishes.

Huntington Society of Canada • 151 Frederick St. Suite 400, Kitchener ON N2H 2M2
1-800-998-7398 • info@huntingtonsociety.ca • www.huntingtonsociety.ca

Sexuality in Adolescents with Juvenile HD

Adolescence is a difficult time even for youth who do not have HD. Managing a changing physical appearance, new and unfamiliar sexual urges, learning how to interact with peers who are undergoing similar changes, and moving away from relationships with parents into strong relationships with other adolescents and adults are "tall tasks" for any teenager. Facing these challenges with a disease that diminishes the ability to communicate and to understand new information, and reduces the ability to suppress impulsive or disruptive behavior, is far more difficult.

Adolescents will benefit from discussions of the following:

- Consent
- Puberty and sexuality
- Sexual activity (both appropriate and inappropriate)
- Prevention of pregnancy
- Managing sexual urges and impulsive behaviours
- How to obtain help when needed (Kids Help Phone 1-800-668-6868)

Early attention to these issues is important, as adolescents with HD may become sexually active without a real understanding of the potential consequences of their sexual activity. Individual discussion will likely be necessary to supplement any education provided in school health classes.

RESOURCES

This fact sheet was adapted from:

- Australian Huntington Disease Association "Sexuality Issues for people with Huntington Disease"
- Huntington Disease Association (UK) "Sexuality"
- Additional information from HSC resources noted below.

For further detail on the topic of sexuality and HD, find the following booklets and publications at www.huntingtonsociety.ca/hd-booklets-and-publications:

- "Understanding Behaviour in Huntington Disease", pages 49-51
- "A Physician's Guide to the Management of Huntington Disease", pages 72, 84 and 85
- "The Juvenile HD Handbook, pages 20-21

For assistance:

Kids Help Phone (1-800-668-6868) is a toll-free, bilingual telephone counselling service for children and youth. There is also a live chat (www.kidshelpphone.ca/live-chat) and a text option (text "CONNECT" to 686868).
Kids Help Phone provides emotional support, counselling, information and referrals. Local communities also have crisis support lines.

Ongoing support, education and information is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.

Huntington Society of Canada • 151 Frederick St. Suite 400, Kitchener ON N2H 2M2
1-800-998-7398 • info@huntingtonsociety.ca • www.huntingtonsociety.ca