
Sexuality

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. It is a misconception that inheriting a degenerative disease will cause and end their sexual relationship.

It is by no means inevitable that individuals with Huntington disease and their partners will have any problems with sexuality. Many couples 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 not uncommon for people to experience difficulties in the area of sexual relationships.

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, friends and embarrassing to mention to their doctors or other professionals. All intimate relationships require a high level of communication, this is even more important as changes occur in the partner with Huntington disease.

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

Physical

Difficulty in obtaining and retaining an erection: This may be caused by an underlying medical problem or medications and should be checked by a doctor.

Difficulties because of chronic movement: Some couples have problems maintaining intercourse because of the involuntary movements. It may be helpful to use a different position so that the affected partner is stable and well supported. Couples will need to experiment with different positions

to find something that is successful for them.

Psychological and Emotional Problems

One of the features of HD is the lessening of normal inhibitions. This is also true of sexual behaviour and some sufferers become sexually over-active. In an acute form it may mean that this person will make inappropriate demands (i.e. time or place). The person with HD may also be feeling 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.

As the needs of the individual with HD increase, there may be decreased interest with the partner. Someone with choreic movements and behaviour problems may become unattractive in the eyes of the partner. Many partners feel very guilty about this, blaming themselves for what are natural reactions.

If it is possible the couple should try to discuss their problems between themselves, or with the help of a counsellor, so they can understand each other's feelings.

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. The care partner will need to be clear and consistent regarding expectations and limits for intimacy.
3. The care partner 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” changes, expect emotional changes in both partners.

4. Think creatively about your shared experiences and the value of touching.
5. Do not forget to see the humour in a situation.
6. Adequate rest is extremely important. Change in sleeping arrangements may be needed for adequate rest.
7. Reach out for help from appropriate people if needed such as a family doctor, counsellor, etc.

*Taken from:
Australian Huntington Disease Association
“Sexuality Issues for people with Huntington
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