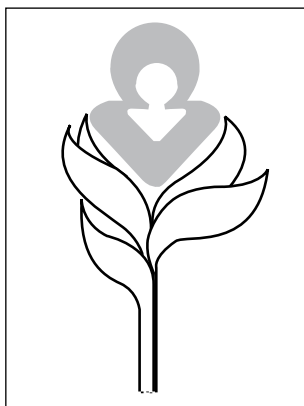


Huntington's Disease Association



Sexual Problems

Fact Sheet

11

Sexual Problems

It is by no means inevitable that Huntington's disease sufferers and their partners will have any sexual problems at all. Many couples continue to have a mutually satisfying relationship for a long time and adapt to circumstances in a way suited to both partners. However, it is not uncommon for people to experience difficulties in the area of sexual relationships.

It is a subject many people find difficult to discuss with their families or friends, and embarrassing to mention to their doctors or other professional helpers. Every individual situation is different, and we are not going to try to give easy answers but rather to explore some of the problems we know people are facing and to see what or who could help.

Physical Problems

Difficulty in obtaining or retaining an erection

There may be a medical cause for this which should be checked through with your doctor. If the problem has only occurred since drugs have been prescribed – or changed – then this could well be the cause. Again check with your doctor.

Difficulties because of choreic movements

Some people have had 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 probably need to experiment to find out what is the most successful position 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 these persons will solicit a number of other people but much more commonly they make extra demands on their partners. These demands may be quite inappropriate as to the time and place, and can be very exhausting for the partner either in meeting them or standing the consequences of refusal.

The sufferer may well be feeling quite seriously depressed, frightened, isolated and unloved. One of the ways he or she can try to fight these feelings is by gaining reassurance through physical closeness and therefore sex. The overpowering need may cause excessive demands which the partner simply cannot meet. Refusal may be seen as rejection.

As the needs of the sufferer increase, there may well be a diminished interest by the partner. Someone with choreic movements and behaviour problems may become unattractive in the eyes of the spouse and sexual contact an ordeal rather than a pleasure. Many partners feel very guilty about this, blaming themselves for what are quite natural reactions.

There are no easy answers to any of these problems. In cases of acute sexual over-activity there are drugs available. However they can have side-effects and should only be used when really necessary.

If it is at all possible the couple should try to discuss their problems between themselves, or with the help of a counsellor, so that they can understand each other's feelings. Extra attention and affection may reduce the need for actual intercourse, although some people have found that this has the opposite effect and any physical contact is misinterpreted. As said before, a person with Huntington's disease may need a great deal of reassurance and may easily feel rejected. A caring and affectionate attitude should help, together with an acknowledgement of some of the feelings the sufferer may have.

Because of the confused feelings on both sides, some partners have felt that the only way they can manage is by very clearly ending all sexual relationships. This may mean separate beds or even separate rooms and may be a distressing decision to have to take because it is indicative that the previous marital relationship has come to an end. However, we know of a number of people who have done this and remained adamant in their refusal of all sexual contact as the only way they can cope. If the physical side of the relationship is intolerable to them, then this way they can continue to give affection and practical care.

This information sheet is an initial effort to reassure people that difficulties are not uncommon but it is also aimed at gaining more information about the problems people are facing and the ways in which they have dealt with them. We would be grateful if you could help us by telling us about your experiences. This would enable us to write a far more comprehensive fact sheet and will most definitely be treated in the strictest of confidence.

Fact sheets available from the HDA:

1. All about the Huntington's Disease Association
2. General Information about Huntington's Disease
3. Predictive Testing for Huntington's Disease
4. Talking to Children about Huntington's Disease
5. Information for Teenagers
6. Eating and Swallowing Difficulties
7. Huntington's Disease and Diet
8. The Importance of Dental Care
9. Communication Skills
10. Behavioural Problems
11. Sexual Problems
12. Huntington's Disease and the Law
13. Huntington's Disease and Driving
14. Advice on Life Assurance, Pensions, Mortgages etc.
15. Seating, Equipment and Adaptations
16. Checklist for Choosing a Care Home
17. Advance Directive or "Living Will"

Booklets

Huntington's Disease in the Family (1997)

A booklet produced for young children

For a publication order form, membership form, details of our Regional Care Advisers and local Branches and Groups, please telephone or write to:

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