Sexuality and Epilepsy

What is my “sexuality”?

Sexuality is an important part of all of our lives. We are defined as sexual beings the moment a child is born, and the parents ask, “Is it a boy, or a girl?”. Being sexual has many meanings, including the release of physical tension, an expression of emotional intimacy for a couple, and occasionally to make a baby. How each of us expresses our sexuality is unique and depends on many factors including gender, age, sexual orientation, cultural background, life experiences and medical factors.

Does having epilepsy affect sex?

Epilepsy can have effects on sex, and sex has effects on epilepsy. Many people with well controlled epilepsy have a comfortable, satisfying sex life. Having a supportive partner who provides emotional closeness, as well as sexual intimacy, is perhaps the greatest asset in helping people with epilepsy feel positive about themselves, which in turn improves seizure control. Anxiety and stress are known seizure “triggers”. Sex can release stress, and help relax people, thereby reducing seizure frequency.

People living with epilepsy frequently encounter sexual difficulties. These can be due to the epilepsy itself, the medications used to treat the illness, or due to reactions of partners and others to the diagnosis of epilepsy.

Can epilepsy lower my sexual desire?

One of the commonest sexual effects of epilepsy is the decrease or loss of desire. This is variable depending on the type of epilepsy a person is dealing with. For example, while about half of men with epilepsy note decreased desire, this is greater for men with temporal lobe epilepsy (63 per cent), as compared to tonic-clonic epilepsy (12 per cent). Erectile dysfunction is also a common problem for men with epilepsy. These is less scientific literature about the effects of epilepsy on women’s sexuality, but desire changes appear similar for women.

Sexual difficulties are found to be more significant in people whose epilepsy started before adolescence. While this might be due to more severe illness, another explanation is that these teenagers may have had a more difficult time with dating than their friends without seizures. Epilepsy can affect a person’s self-confidence, body image, and mood, both of which are important when relating with others.

What effects do anti-seizure medications have on sex?

Drugs used to treat epilepsy (such as diphenylhydantoin, phenobarbital, carbamazepine, valproic acid, and others) have common side-effects than can depress sexual responsiveness, desire, arousal (erection problems for men, and lubrication problems for women), as well as orgasmic difficulties. Often these drugs can cause fatigue which can interfere with an evening out. Some drugs like Dilantin can cause physical changes such as gum over-growth which has cosmetic effects. Finding the right balance of seizure control and side-effect reduction can be challenging. Stopping
cosmetic effects. Finding the right balance of seizure control and side-effect reduction can be challenging. Stopping drugs due to frustrating side-effects might feel like a good solution in the short term, but doesn’t help reduce seizures and can be dangerous.

Who can I talk to about sex and epilepsy?
Discussing sexual side-effects can feel embarrassing, but most doctors should be able to deal with them appropriately. As more and more drugs become available for epilepsy, as well as other diseases, quality of life issues are becoming significant factors in medication choices. Helping your physician by bringing up sexual concerns if they don’t, can focus their attention on this area as needed.

When should I tell someone new that I have epilepsy?
Potential partners are often scared of the unknown, which leads them to avoid someone with epilepsy. At times people with epilepsy will hide their illness from someone new. It is appropriate to know someone a bit before divulging such private information. At times this leads to increased anxiety. Partners have fears regarding the myths and realities of what epilepsy actually is.

Could having sex trigger a seizure?
It is rare that sex will trigger a seizure, although it does occasionally happen. An intimate partner needs to be taught how to deal with seizures in general, those that occur with lovemaking would be no different than if the seizures occurred on the tennis court!

What can I do if I’m encountering problems with sex?
To be able to communicate with others the meaning of epilepsy, and the sexual needs of both partners is perhaps the greatest challenge. Through talking with doctors - family physicians, neurologists, and others - about our sexual concerns, is helpful and it is possible that adjusting medications or other treatments would be beneficial. You can also get a referral for individual, couple, or sex counselling and psychotherapy.

Finding a way for partners to talk about sexual needs and concerns can break through the guilt surrounding the avoidance of discussing issues for fear of causing pain, anger or rejection. Being able to directly talk about sexual difficulties can lead to other solutions. For example, treatments exist for erectile dysfunction; lubricants can help for dry vaginas. Conflict over sexual problems can heighten stress and worsen seizure control, as well as causing emotional pain. Making love with a partner involves emotional intimacy which can be helped by both partners sharing their concerns, as well as their affection with each other. Love can be the best medicine for a couple living with epilepsy.

Dr. Stephen Holzapfel is Director of the Sexual Medicine Counselling Unit at Women’s College Hospital, and Assistant Professor, Department of Family and Community Medicine, University of Toronto.