

Women and Epilepsy - Psychosocial Issues

What do you mean by "psychosocial"? Do people with epilepsy have psychological problems?

The term "psychosocial" includes how you feel about yourself, how you deal with the chronic disorder of epilepsy, and issues involving your relationships with other people, such as family, friends, or co-workers. It does not automatically mean problems although anyone can have emotional difficulties with self-esteem or relationships. People with epilepsy may be embarrassed or fearful about their seizures and they may have to contend with the ignorance and fear of other people. Some people work through these issues on their own, and others may need some help from a physician, a nurse, or a professional counselor to deal with them effectively.

When should I tell people about my seizures?

It's your decision when, or if, you tell people about your epilepsy. It is probably difficult to keep this a secret from close friends or people you spend a lot of time with. People can be frightened of situations they don't understand or anticipate. Most good friends will be supportive and understanding about your seizures and they may be interested in learning more about epilepsy. However, you may choose not to confide in casual acquaintances, just as you would not share other personal information with them.

How do I tell other people about my epilepsy?

Have a positive attitude about yourself -- epilepsy is only a part of who you are, and nothing to be ashamed of. Whenever possible, choose a comfortable place and enough time to keep you from feeling anxious or rushed when you talk about your seizures. It may help to have written material available about epilepsy to share.

I'm really nervous about telling my boyfriend about my seizures. I am afraid he will be scared off.

It may be especially important to tell your boyfriend about your seizure disorder so there won't be any unexpected surprises. Keep a positive attitude about yourself and epilepsy, and he probably will, too. If you need moral support, ask a family member or friend who knows about your seizures, or your physician, to help explain the facts to your boyfriend. Remember that intimate relationships are complicated and may have problems for many reasons. Women without epilepsy struggle with these issues, too.

People say I have mood swings. Can my personality be affected by epilepsy or my medications?

That is a complex question. Mood and personality are affected by many factors. Certain kinds of seizure disorders (those that originate in the temporal lobe of the brain, for instance) appear to affect mood and behavior during an actual seizure episode, and even an aura may change your behavior patterns. But seizures (and auras) are intermittent events and it is not clear how epilepsy affects general personality traits. Some physicians used to refer to the "epileptic personality," implying that all people with seizures shared certain

Women and Epilepsy - Psychosocial Issues

behavioral characteristics. We now recognize that people with epilepsy have a variety of personality traits, positive and negative, just as people without epilepsy do.

The intermittent and often unpredictable occurrence of seizures can make you feel anxious or embarrassed, and cause some people with epilepsy to be reluctant to socialize normally. They may withdraw and feel angry or depressed. You may have extra stresses connected with work, and financial hardships secondary to career choices or the costs associated with your seizure disorder. Any of these factors can make people seem moody. Some of these feelings may be a normal reaction to the initial diagnosis of epilepsy or to the everyday events in your life. If they persist and significantly interfere with your life, talk with your physician or nurse. They may refer you to a professional counselor (social worker, psychologist or psychiatrist) to help you address these issues.

Some women with epilepsy experience changes in their seizure patterns at times of hormonal fluctuations, especially as it relates to their menstrual cycle. Many women also notice mood swings at specific times in their menstrual cycle. It may be helpful to keep a calendar of your menstrual cycle and any mood changes along with your seizure record to share with your doctor or nurse.

In addition, seizure medications may have side effects that result in mood changes. This seems more frequent with phenobarbital (Luminal) or primidone (Mysoline), but any seizure medication can make some people feel depressed or irritable. If the dose of medication is not well tolerated, resulting in overmedication, a person's ability to think clearly may be affected. If you think your medication is having unpleasant side effects, it is important to share this information with your nurse or doctor.

I feel like epilepsy keeps me from leading a normal life.

It's understandable that you feel that way. Epilepsy does interfere with certain aspects of life for most people who have seizures. Taking medication daily, having regular blood tests, or keeping seizure records is time consuming and a frequent reminder of a chronic disorder. For some people, there are more difficult restrictions, such as inability to drive or make certain career choices.

Seizures are unpredictable and may limit some of your independent activities. Other family members and friends may be concerned and overprotective and, as a result, you may feel dependent. Realistically, some people with epilepsy may have to depend on others to help with certain tasks of daily living.

Although common sense precautions may be necessary, it helps to focus on your abilities, rather than defining yourself by your restrictions. Think of creative ways to solve the problems in your life, such as sharing rides with friends, or learning about public transportation options if you can't drive. Shopping by phone or with a computer may increase your options for independence and control.

Talk with your family and friends about these issues and your feelings. Insist that you need to be involved in the plans and decisions that affect your life. And don't hesitate to ask for help if you need it, including professional counseling.

Women and Epilepsy - Psychosocial Issues

Can I have a normal sexual relationship even though I have seizures? Can I get married and have children?

Yes, you can. Sexual relationships are a normal part of healthy living, and people with seizures fall in love and marry just like anyone else. Women with epilepsy get pregnant and most of them have normal, healthy babies. You may experience some specific problems associated with seizure disorders that can interfere with sexual expression and there are some concerns related to seizure control, certain medications and other significant issues that are important to discuss with your doctor before you become pregnant.

My doctor thinks I am overly concerned about my seizures. I just get the brush-off.

It is normal to be concerned about having epilepsy. Prepare carefully for your doctor appointments and be clear about what issues you would like to discuss. Keep written records of your seizures, response to medication, concerns about side effects, and any other questions you have. Take this information with you to appointments to share with your doctor or nurse. It may help to ask for a separate time just to discuss these issues if your physician seems rushed at a regular appointment. Take a friend or family member with you if they can help you share information about your seizures that might help the doctor understand your concerns more fully. You can contact the Foundation for information sheets on a variety of subjects written for health care providers.

You and your doctor are partners in your care. Your physician has the medical knowledge, but you are the expert on yourself. If you are not satisfied with your doctor's response to your concerns, discuss this with your doctor, and if the relationship does not change, consider choosing another physician.

My doctor told me that because I need to take antiepileptic medication, I should never get pregnant. Now that I am pregnant he recommends an abortion, but I want my baby. Am I wrong to think that my baby will be okay?

For women who have epilepsy, the risk of having a baby with a birth defect is double the risk for women in the general population. Any woman, whether she has epilepsy or not has a two to three percent chance of having a baby with a birth defect. For women with epilepsy, the risk is four to eight percent. Even so, mothers with seizures have a better than 90 percent chance of having a normal, healthy baby.

The actual cause of the increased risk of malformations has not been determined, but there are three strong possibilities:

- The birth defects are genetically related to whatever causes the epilepsy.
- The birth defects are related to antiepileptic medications needed to control seizures.
- The birth defects occur because the baby may have a genetic susceptibility to possible harmful effects of medications.

Women and Epilepsy - Psychosocial Issues

Whatever the cause of the malformations, they do not occur often enough to support avoiding or terminating a pregnancy. However, if an eight percent risk of having a child with a malformation is unacceptable to you, it is important that you make the decision that's best for you.

Stillbirths or miscarriages are also more common for women who have epilepsy, occurring in 1.7 percent of pregnancies, which is about three times the amount in the general population.

There is also a small increase in mortality rates during the first year of life for children of mothers with epilepsy. That risk is only about 0.6 percent, but is higher if the mother's seizures are not well controlled.