

Fact Sheet 37 Epilepsy and men

Population studies have revealed that slightly more men than women have epilepsy. This may be because of a higher rate of cerebrovascular disease (such as strokes), head trauma incidents, or alcohol and drug related issues, for example. Men with epilepsy also have a higher rate of anxiety and depression than men who do not have the condition. However, there is hope in men finding the right level of support within their communities. It involves asking for help, understanding what epilepsy is, and how medications work. It is important to appreciate that epilepsy is a medical condition that for many people can largely be controlled.

Those with epilepsy experience it in different ways. For men living with epilepsy, there are certain common experiences and concerns that become apparent. Having honest conversations with others can help to change the perspective of what it is like living with epilepsy and help to provide solutions for what may appear to be an insoluble, and sometimes, an embarrassing problem. It is time to open up!

Let's talk frankly.

1. What is epilepsy? Why do I have it?

Epilepsy is a common neurological condition that affects at least 1% of the population. It can be developed at any age regardless of who you are. Many times we understand the reason why a person develops epilepsy such as having had a stroke, brain injury, bleeding in the brain, substance abuse etc but many times we do not know why it happens.

To have epilepsy, a person must experience seizures that happen suddenly and without warning at any time and with no known reason.

Some seizures are called focal and affect part of the brain. You can either be aware of them happening such as with deja vue, or you can experience something like a smell or taste change for example. Sometimes your awareness can become impaired. At other times seizures affect the whole brain and are called generalised seizures. The most common seizure that most people recognise as being epilepsy is the tonic clonic seizure.

For more information on epilepsy types see: https://ewct.org.nz/epilepsy-types/

2. Talk to me about medications. Why should I take them?

Most people respond well to anti-seizure medications and that is always going to be the first

treatment option given to a person diagnosed with epilepsy. Medications are prescribed by a neurologist once there is an epilepsy diagnosis, and there will be a discussion around how to take them safely and effectively. A pharmacist can then discuss medications further, especially if you have concerns around being able to drink alcohol or take recreational drugs.

It is strongly recommended that you take your medications routinely to avoid having prolonged seizures or being seriously harmed. The consequence of being non-compliant and having seizure difficulties usually involves emergency hospital treatment.

For more information on epilepsy medication please see our fact sheet: https://ewct.org.nz/epilepsy-medication/

3. Can I drink alcohol?

You need to have that discussion with your neurologist and/or pharmacist as they understand the anti-seizure medications that you have been prescribed and they will make recommendations for you. But, generally speaking, alcohol can make epilepsy medication less effective or make the side effects of the medications worse. Excessive binge drinking is likely to increase the risks of seizures and lead to other health problems.

What about taking recreational drugs?

The effects of <u>recreational drugs may directly affect the brain or seizures themselves</u>, or they may interact with anti-seizure medications. The effects will vary for different drugs and from one person to the next. If drug taking is combined with alcohol use, it greatly increases the chances of seizures happening.

Drinking and taking drugs is a lifestyle choice. If you need support about this issue then do have a chat with your GP or counsellor.

4. Will epilepsy affect my sex life?

Not necessarily. Many men with epilepsy have normal sex lives but there can be problems which are worth discussing.

Men with epilepsy can experience a lower sex drive (libido), decreased sexual function, and higher rates of erectile failure compared to men without epilepsy. These differences may be because of testosterone levels being below the normal control range. Testosterone is a male hormone.

Libido can also be affected if there is general anxiety or depression present. The way you see yourself, especially if you have a low self-esteem or low confidence, may also impact on your sex drive.

Some men's sex drive may be affected by the fear of having a seizure during sex, or knowing that a seizure is triggered by hyperventilation or physical exertion. Having sex is unlikely to trigger seizures and most men with epilepsy do not have seizures during sex. However, the physical and emotional impact of seizures may affect interest in engaging in it.

Some areas of the brain such as the temporal lobes may also interrupt sexual function. A man may find it difficult to get and keep an erection.

Apart from having a conversation with a neurologist or GP to discuss sexual concerns, it is also important to have that conversation with your partner. Men are often a bit reluctant to discuss sexual matters but, if you are in a sexual relationship, your partner may be frustrated by your lack of interest. It really is best to be honest and open here about how you are feeling.

5. Will anti-seizure medications affect my sex life?

Many men's sex lives are not affected by taking their medications but, if you feel that yours is, then it is time for a chat with your neurologist or GP. Simply switching medications may improve your sex life. In some cases, you may wish to seek the specialised help from an endocrinologist whose job it is to sort out the complex interactions between hormones, seizures and anti-seizure medications.

Some medications list sexual problems as a possible side effect whilst other medications list a reduction in testosterone.

6. Will epilepsy affect my fertility?

Having epilepsy may not make you as fertile as men who live without the condition The sperm produced often has abnormalities in structure and function, thereby making it more difficult to father a child.

Some medications can reduce the amount of sperm produced or affect the quality of it. In some cases, medications may have lowered testosterone levels (noted above in (4)), which makes you less fertile.

If you believe that you have fertility issues, please talk to your neurologist or GP.

7. Will my children develop epilepsy?

There is a slightly higher risk of your children developing epilepsy than the general population. If both you and your partner have epilepsy then that risk increases more.

8. Epilepsy is affecting my mental health. Why?

There are a number of reasons why your mood may be affected.

a) There is a <u>relationship between epilepsy and mood disorders</u> and it is not uncommon for person to have both. In fact, the likelihood of having a mood disorder is between around 25 and 50% higher than that of the general population when you have epilepsy.

With regard to having anxiety, there is a bidirectional relationship between anxiety and epilepsy. People with anxiety are at a greater risk of developing epilepsy and people with epilepsy are more likely to develop anxiety. It is really important, therefore, that you discuss your anxiety and/or depression with your GP or neurologist so that a treatment option can be discussed. Your treatment options may include medications and/or psychotherapy and relaxation therapies. If you continue to struggle without professional support then your mental health will impact on your seizures; they may increase despite you taking anti-seizure medications especially if you are newly diagnosed with epilepsy.

Keep talking to your GP or neurologist about how you are feeling, particularly if you are having thoughts about suicide or about death generally.

Keep a simple seizure diary to keep track of your seizures and mood.

b) Your anti-seizure medications could be affecting your mood. Most people are able to

9. I have really low self-esteem

Having epilepsy should not affect the way you see yourself since the condition does not define you as a person. Your character does that. Seeking support from a social group where you can meet others to discuss issues can be helpful. Through friendly chats you will discover the many common themes that affect men living with epilepsy. Such engagement may offer possible solutions to your problem. You can then work on the things that can be changed in life and accept those that can't.

How you feel about yourself could potentially damage family and friend relationships, cause you to become socially isolated, and contribute to problems with your general wellbeing and overall quality of life. There is help at hand, however. Seek support if there are issues around your medical condition. Improvements can usually be made around seizure control, medications, and issues associated with having epilepsy. A clinical psychologist or a counsellor, who use cognitive behavioural therapy (CBT), will challenge the way you see yourself and provide you with life skills.

Your EWCT epilepsy advisor is connected to your community and will help with other aspects of your life such as with transport and employment.

10. Having epilepsy is causing me stress

Living with a condition that is episodic can be unsettling and some people find this stressful.

The fear of living in 'amber alert' waiting on edge for a seizure to happen only increases the chances of seizures happening. Stress is a well-known seizure trigger.

We all have ways for managing stress. Please see the "Wellness" Fact Sheet on our website.

11. I don't sleep well

Having good, regular sleep is helpful for your general wellbeing. It helps your body to heal itself, for the brain to forge new connections, and sleep helps with memory retention. Poor sleep, on the other hand, can affect your overall health and make you prone to medical conditions such as obesity, heart problems, heart disease, high blood pressure and diabetes

People living with epilepsy can experience poor sleep. This poor sleep can make seizures more likely to happen during the day. For others, they may experience sleep seizures which are linked to the different stages of sleep. Keep a sleep-seizure diary to record what is happening in your life and discuss any concerns that you have with your GP, or neurologist. Be aware that sleep may be affected by the anti-seizure medications that you are taking and this is also worth mentioning. Please see the "Wellness" Fact Sheet on EWCT's website.

12. I have lost my driver's licence

Anyone having had a seizure regardless of the cause will lose their driver's licence for a period of time. This is an NZTA ruling.

Driving requires a complex array of neurological functions and skills that involve vision, thinking, attention and judgement, co-ordination, reaction time, and motor control. Any of these can be impaired by epilepsy and seizures. People who drive vehicles may present safety concerns for themselves, their passengers and the public.

For more information see our fact sheet: https://ewct.org.nz/driving-and-epilepsy/

13. My job is at risk

Having epilepsy can be seen as a barrier to employment. However, <u>many people living with the condition can participate in a variety of jobs</u> because their epilepsy does not affect their ability to work. A person with epilepsy has rights and obligations as set out under the Employment Relations Act 2000 and the Health and Safety Act 2015. Employers also have an obligation to accommodate the needs of disabled employees and provide a safe environment in the workplace under the Commonwealth Disability Discrimination Act 1995 (Disability Act).

Seek the support of your EWCT epilepsy advisor who will advocate on your behalf.

Further information

Further information about epilepsy and its management is summarised in EWCT's book entitled "<u>Understanding and managing epilepsy: an introductory guide</u>". It is available from your EWCT epilepsy advisor or it can be purchased via the EWCT website.

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.