

Men and epilepsy

Introduction

We have written this factsheet specifically for men with epilepsy covering those issues that are relevant and important to men. We regularly hear from men from all over Scotland how being diagnosed and living with epilepsy can raise a number of concerns. Topics which are mentioned regularly include the effect epilepsy can have on confidence, mood, general mental health and wellbeing. The issues highlighted in this factsheet can, of course, also affect women, but men often deal with these matters in a different way.

We hope this factsheet will give you some answers and allow you to seek further help and support. If you do not know where to start, phone our helpline 0808 800 2200, which is a confidential and free service.

We have a wide range of information leaflets on epilepsy, such as seizures explained, first aid, staying safe with epilepsy, alcohol, memory and much more. If you want more detailed information on any aspect of living with epilepsy, contact us or visit our website www.epilepsyscotland.org.uk.

Coming to terms with epilepsy

Being diagnosed with a long-term condition like epilepsy can be a stressful experience. It can cause a mixture of emotions such as feeling sad, isolated or angry, which some men can find difficult to discuss. Anger is a common emotion leading to feeling frustrated and resentful. After a diagnosis of epilepsy men can often develop a sense of grief as uncontrolled seizures can affect some aspects of their life such as family life, social life, sex life, work and driving. This can leave men with a sense of loss of control and unfairness.

It can take time to get your head round being diagnosed with epilepsy. Some men may see having seizures as a sign of weakness. It is, however, important to remember that epilepsy is a physical condition. Epilepsy is caused by a temporary disruption to the electrical activity in the brain.

Find out as much as you can about epilepsy from your healthcare team, and how it may affect you. Take time to digest the information, ask questions, and only when you are ready, talk to your friends and family. How much you tell them is up to you. You can also contact us on our helpline 0808 8002200 for more information about epilepsy, and someone to talk to. Having a better understanding of the condition, can often help regain a sense of control over your life. If you have any questions, contact us. We are here for you.

Sex life

The combination of having seizures and taking some anti-epileptic drugs can sometimes affect a man's sex drive and ability to have an erection. If you are affected by this, speak to your epilepsy specialist nurse or specialist who may be able to change your medication or adjust the dosage.

Please do not suffer in silence, as there is usually something that can be done to help you. If you experience any problems, as a first step, contact your GP, epilepsy specialist nurse or specialist, who may review your medication and discuss options with you.

Any change in life can be difficult to get used to. Affecting such a personal and intimate part of your life can lead to feelings of low self-esteem, loss of confidence and even depression, which can sometimes impact on relationships. Talk to someone, such as your GP, about how you feel, and discuss the possibility of counselling.

At the start of a relationship, you may be wondering at what point to mention your epilepsy. There is no right or wrong time for this. Go with your gut instinct.

Some men worry that having sex can bring on a seizure. This is no more likely to happen during sex than at any other time.

Please remember, not all men with epilepsy and on epilepsy medication will be affected by this. Medication is usually tolerated well, with minimal side effects. Many side effects will fade over time as your body gets used to the daily medication.

Even if you do not normally feel comfortable talking about your feelings, it can help to find someone you trust and open up about the fears and anxieties you have around your epilepsy. Talking about it up can help you find acceptance and move forward with your life.

Fertility

Some studies suggest that epilepsy medication can lead to slightly reduced fertility in men. If this concerns you, please speak to your specialist. Most men with epilepsy will have no difficulty fathering children.

Will my child develop epilepsy?

A man with epilepsy has a slightly increased chance of their child also having epilepsy. This does, however, depend on what caused the epilepsy. For example, if you developed epilepsy as a result of a head injury, your child will not inherit epilepsy from you.

This risk of epilepsy is slightly higher if the mother has epilepsy, and even higher if both parents have epilepsy. Overall, the chances of a child fathered by yourself developing epilepsy is still very low. You can ask for genetic counselling to find out more information about your own situation.

Family life

You may wonder how epilepsy could affect your family and / or partner. It is normal to worry about having a seizure in front of your child or partner. Your partner will

also need time to adjust and is bound to have many questions. We can help with this, so please ask them to contact us on our helpline 0808 800 2200.

Children are usually very resilient. Take time to explain what is happening to you and how they can help, such as dialling 999 or calling a family member or neighbour should you have a seizure. Our storybooks for young children help explain epilepsy in an age appropriate way and can be a starting point to talk about epilepsy with your child. Contact us for free copies.

Having epilepsy should not stop you from being a good and loving dad or spending quality time with your family. Depending on the frequency and type of seizures you have, simple safety precautions can help keep you and your child safe. We have a guide on 'Staying safe with epilepsy', which also has a section about being a parent with epilepsy.

Social life

Men can find it difficult after a diagnosis of epilepsy to cope with some of the social pressures they feel. Social pressures can, of course, affect women too, but it can often have more of an impact on men. There often is a strong desire to be 'one of the boys'. You might not feel like going out as much, at least in the beginning until your seizures are better controlled, and this can sometimes lead to a sense of isolation or even loneliness.

Epilepsy does not mean the end of going out with friends and having a social life. Alcohol is usually ok in moderation but follow your specialist's instructions. Try and limit the amount you drink to 1-2 units in a day as too much alcohol can affect how well your body absorbs epilepsy medication. Sometimes people can forget to take their medication when they have been drinking, which could trigger a seizure.

Binge drinking at the weekend is never a good idea as it can put you at risk of having a serious seizure.

If you do not feel like going out, speak to a close friend and explain how you feel about having a seizure in front of others. We often assume we know how friends and family will react, but they can surprise us. Make sure your friends know what to do in case you have a seizure, so you know you are in safe company on a night out.

Sports and leisure

After your diagnosis, you may wonder whether it is still safe for you to pursue sports and other activities.

Depending on how well your seizures are controlled, you may need to think about taking some precautions, such as taking someone with you when, for example, you are out running. If you have, good seizure control, generally there is no reason why you cannot continue doing the activities you enjoy.

Getting the balance right is important. Think about how not being able to take part in your favourite activity might impact on your mental and physical health. In fact, there is some evidence that suggests that staying active can sometimes improve your seizure control. It is all about assessing risks and taking some sensible measures to keep yourself as safe as possible. If you have any concerns, talk to your epilepsy specialist nurse.

Driving

Lots of men take pride in their car as it can provide a feeling of independence and sense of identity. If driving a car is your only means of transport losing your licence after your first seizure can have an impact on your emotional wellbeing and sense of self.

It is important to remember the driving regulations are there for your own safety and the safety of other road users. With the right medication between 50 and 60% of people with epilepsy can have their seizures completely controlled. You need to be seizure free for one full year before you can reapply for your ordinary driving licence. Stricter rules apply for passenger carrying and heavy goods licences.

While you are without your driving licence you can apply for a Scotland wide bus pass. You can also buy a Disabled Person's Railcard which gives you one third off rail fares throughout the UK. There is more in our 'Driving and epilepsy' factsheet. Contact us for your copy.

Work and career

Once you have been diagnosed with epilepsy, you have the protection of the Equality Act. This means that an employer needs to look into making reasonable adjustments to allow you to continue doing your job safely, even if your seizures are not yet controlled. Your employer can also find you a safer position, if this is possible, in your place of work. You cannot be dismissed from your work, unless your seizures remain uncontrolled and it is not possible to keep you safe.

Work is important and necessary for most of us. Often men are still seen as the main breadwinner, particularly in certain cultures, and losing your job or suffering financial losses can have a big impact on a man's self-esteem.

The first thing to do is phone our helpline on 0808 800 2200 for an initial chat. We can signpost you to another agency who can give you employment specific advice. It is important to find out about your rights and what steps to take to protect your job and income. This can also give you back a sense of control.

You may also want to get advice from a professional welfare rights service, such as your local Citizens Advice Bureau, to find out about any benefits you are entitled to claim.

Contact us

If you have any further questions, or want more information about epilepsy, contact us. Our free and confidential helpline 0808 800 2200 is here to help.