

Epilepsy information for men

Introduction

This factsheet covers specific issues which may be relevant to some men and people who have epilepsy. If you are looking for general information on epilepsy, please check out our website at www.epilepsyscotland.org.uk, particularly our Epilepsy explained guide.

Relationships and intimacy

When do you tell a prospective partner about your epilepsy? There is no right or wrong time for this. Being open might take away some of the anxiety of having a seizure in front of a partner or during sex. In the longer term, hiding your epilepsy might affect your confidence and self-esteem impacting negatively on your relationship.

Can sex bring on a seizure? Reassuringly, this is no more likely to happen during sex than at any other time.

Be mindful of stress though. It can be a common seizure trigger for many people. If this is one of your triggers, and you are anxious about seizures during sex, then your anxiety could trigger just that.

Sex drive

Some anti-seizure medications can occasionally affect a person's sex drive and/or lead to erectile dysfunction. If you are affected by this, speak to your epilepsy specialist nurse or neurologist who can help.

Never stop taking your medication unless your specialist or epilepsy specialist nurse have advised you to do so. Suddenly stopping your antiseizure medication can trigger a serious seizure.

Most people usually tolerate their medication well, and any initial side effects fade over time as your body gets used to the daily medication. If you are affected by ongoing side effects, speak to your epilepsy specialist nurse or neurologist.

Fertility

Some anti-seizure medications can lead to slightly reduced fertility in men. This is rare and most men and people will have no difficulty becoming a parent. If you want to start a family, seek advice from your specialist or epilepsy specialist nurse.

Sodium valproate

The MHRA (Medicines and Healthcare products Regulatory Authority) has issued new guidelines around the prescribing of sodium valproate. There are already strict guidelines for prescribing sodium valproate (Epilim) to women of child-bearing age because this drug may cause developmental and physical difficulties for babies when taken during pregnancy.

Recent studies have shown that men taking sodium valproate may lead to reduced fertility. There may also be a small risk of neurodevelopmental issues for the child if sodium valproate was taken before conception.

The new guidelines now also include boys/men under 55, who can only be prescribed sodium valproate if two specialists independently agree this medication is the most effective treatment, and the benefits outweigh any risks.

Your specialist will be able to give you more information if you are at all concerned. If you currently take sodium valproate, do not suddenly stop taking your medication unless this is supervised and advised by your neurologist. This could put you at risk of a serious seizure.

Will my child develop epilepsy?

Depending on what caused your epilepsy, a child of yours may have a slightly increased chance of developing epilepsy. The chances, however, remain very low. For example, if your epilepsy was caused by a head trauma, this will of course not increase the risk of epilepsy because this cannot be passed on to your child.

You can ask for genetic counselling before starting a family to help you and your partner understand any risks. The risk of epilepsy is slightly higher if the mother or both parents have epilepsy. As mentioned above, this will depend on the cause of the parent(s)' epilepsy though.

Family life

How do you cope with having a seizure in front of your partner or child/children? The truth is, everyone in your family will process this in a different way and may need some time to get used to your epilepsy. Our helpline 0808 800 2200 supports partners as well as those affected by epilepsy.

Your partner is welcome to contact us for a chat, a listening ear, or to answer some questions. We can help them understand your epilepsy and make them more confident supporting you.

We also have information for teenagers and young children. Children are usually very resilient, provided they feel included and understand what is going on. Encourage them to ask questions. Most children will be keen to support you, and if you feel it is appropriate, teach your child how to call for help.

It goes without saying that having epilepsy will not stop you from being a good and loving parent. And it does not stop you from spending quality time with your family.

Our '<u>Staying safe with epilepsy</u>' guide has a section dedicated to being a parent with epilepsy, with plenty of information on keeping yourself and any children you look after as safe as possible.

Work

Will epilepsy affect my job? This depends on the person's epilepsy, the type of seizures they have, how often these seizures happen, and what type of work they do. If you are currently employed, your employer should do a risk assessment to identify any areas of your job which require further support. You also have a right under the Equality Act to ask for reasonable adjustments.

The Equality Act also protects you against unlawful dismissal because of your epilepsy. For more information on your rights at work, have a look at our Epilepsy and Occupational Health guide and our factsheet on the Equality Act.

Entitlement to benefits

You may be able to claim disability benefits, which are not means tested. This means that even if you continue to work, you may be entitled to claim them. You may also be able to claim means tested support such as Universal Credit if you are on a low income or your income has reduced.

Always seek advice from a professional welfare rights body, such as your local Citizens Advice Bureau for a general benefits check and help with your benefits application.

You can also contact our own Welfare Rights Team at Epilepsy Scotland by phoning 0141 427 4911.

Driving

Driving can often be part of a job, or you may need a car getting to and from work. Unfortunately, as soon as you have had one seizure, you need to give up your driving licence for the time being, often for a minimum of a year.

You can apply for a <u>free bus pass</u> while you are unable to drive. For more information on driving regulations, check out our <u>Driving factsheet</u>.

And finally, talk to someone!

Facing some restrictions and unexpected changes in your life is not easy for anyone. The key is not to bottle it up. Give yourself time to process what epilepsy may mean for you, and for your treatment to work. Achieving good seizure control will minimise the impact epilepsy may have on your life.

If you are struggling to come to terms with your epilepsy, please ask for help. It can be hard if you are not used to opening up to others.

Traditionally, men may still feel some pressure to act strong and not showing their emotions. If you are a parent or carer, you may also be too focussed on looking after everyone else's wellbeing, neglecting your own. It is important to take time for yourself and find the help that works for you.

Luckily, we are talking more openly about mental health issues encouraging men to speak up and seek help.

If you do not know where to start, contact our friendly helpline officers on 0808 800 2200. Calls to our helpline are confidential and anonymous. There is always someone who can listen and guide you towards your next steps.

Our resources are always free. If you would like to support our work, please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.



Freephone helpline: 0808 800 2200

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