

## Men and epilepsy

Epilepsy affects men and women comparatively equally. However, there is a wide range of information available for women with epilepsy, but little has been covered for men.

Epilepsy can affect one's life in many ways and some people with epilepsy experience other physical, emotional, employment and social health problems due to their condition. Here we discuss issues specific to men living with epilepsy.



## Men and Health

Traditionally in our culture, men are encouraged to be tough and independent and less likely to take an active role in maintaining their health. They are also less likely to seek professional help for problems, particularly of an emotional nature. It is well known that men visit the doctor less frequently, have shorter visits and usually only visit when their disease is in a more dire or serious state<sup>1</sup>. Therefore, many men with epilepsy fall into the same trap and only visit the doctor when they absolutely have to. Meaning seizures may not be as well controlled as they could be, or they suffer significant medication side-effects without complaint, or other health problems secondary to their epilepsy.

## Medications

### Starting medications

Sometimes finding the right treatment for epilepsy can take time. It may take several months before the best drug and dosage are determined for you. During this period, it is worth keeping a diary of your seizures, symptoms and any medication side-effects you experience.

### Medication side-effects

When starting an antiepileptic medication, any side-effects you may experience usually lessen over the first few weeks of treatment. Serious side-effects are uncommon. If you experience any side effects that you cannot live with or feel are unacceptable, contact your doctor before the next appointment. It is also important to keep all follow-up appointments with the doctor to help maximise your seizure management and minimise your risk for serious medication side effects and prevent complications.

Antiepileptic medication can cause significant reductions in bone density in adult men (and women) with epilepsy in the longer term. This increases your risk of injuries such as fractures, sometimes 2-3 times that of people without epilepsy<sup>2</sup>. Lifestyle factors such as diet and exercise can also impact bone density, so speak to your doctor about ways to help improve and maintain good bone density, and if or when a bone density test needs to be done.

### Continuing medication

We all miss our medications sometimes however it is important to try to take medication at the same time each day as most medications for epilepsy have a therapeutic blood level, so skipping doses, stopping or taking extra medication can change those blood levels leading to breakthrough seizures or increased side-effects. Check with your doctor what you should do if you did miss a scheduled dose of medication.

If you feel your medication is not working for you, you have to take it too often, or that you are taking a lot of medication, do not hesitate to raise your concerns with your doctor so you can work together to find the best treatment that works for you.

<sup>1</sup> [http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Men%27s\\_health?open](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Men%27s_health?open)

<sup>2</sup> Raj D. Sheth, Neil Binkley, Bruce P. Hermann. Gender differences in bone mineral density in epilepsy. *Epilepsia*, 49(1):125-131, 2008.

# Fact Sheet: Men and epilepsy

There are many medications used for epilepsy. For more information see **EAA medication factsheets – Guide to Medications and Medication Management.**

## Moods

Life with epilepsy can be difficult at times. Sometimes you may feel irritable, moody, tired, anxious, angry, even depressed. It may not always be due to epilepsy, seizures or the medication, however don't ignore these feelings. If things are getting tough for you seek help before it gets any worse.

## Epilepsy and low self-esteem

Self-esteem is basically the way we think about ourselves, whether it's high, low or somewhere in between, it can have substantial effect on our lives. Low self-esteem can have a major impact on mental health and wellbeing.



There are many things that can have an impact on mental health and self esteem, however the main issues affecting people with epilepsy include lack of knowledge and understanding about epilepsy in the community, lack of social support, difficulty forming relationships, family overprotection, employment and lifestyle restrictions, and seizures.<sup>3</sup>

Low self-esteem in males with epilepsy is particularly common in youth, a period of heightened self-consciousness that may be exacerbated by having epilepsy.

It's only natural to feel down sometimes, but when these feelings persist. You may experience:

- Negative feelings - you might you feel sad, ashamed, anxious, depressed or angry
- Low motivation
- Difficulty in relationships
- Lack of interest to take on new challenges
- Low resilience - it can be harder to deal with tough times because you might think that things aren't going to get any better
- Self neglect - it can be easy to neglect your sleep, food and body when you have low self-esteem
- Feelings of desperation and thoughts of wanting to harm yourself

If you've been struggling, have a go at putting some of the following tips into action to stop things from getting worse.

## Ways to help

1. Improve seizure control if you can by getting a review with your doctor, taking medication as prescribed and managing your lifestyle to reduce the risk of seizures.
2. Be honest with the doctor in regards to your seizures, and anything else, to ensure you and your doctor are making the best possible treatment choices for you.
3. Stress management has been linked to improvements in self esteem and seizure control. If you feel you are under a lot of stress, get some advice on how to best manage it.
4. Find an interest or hobby that you enjoy and perhaps join a group to meet like-minded people. There are a lot of extracurricular activities that you can engage in to find peer support. If you are in an isolated region, then there are also many online groups as well.
5. Don't be so hard on yourself and pat yourself on the back once in a while
6. Focus on the things you can change
7. Go out and get some exercise, walk, run, shoot some hoops or kick a ball around

3 <http://www.sciencedirect.com/science/article/pii/S0896697405801227>

8. Lend someone a hand, helping out can give us a boost while benefiting others
9. Surround yourself with supportive people and take a break from any negative people in your life
10. Seek professional help if your moods and self esteem are persistently low for some time.
11. Join an online epilepsy support group
12. Take back control of your life, learn as much as you can about your seizure type, how it may affect you, and any limitations you may have. Knowledge gives you more power to help manage your condition and your life.

**Its OK not to be OK**

### Lifestyle

There are many aspects of our lifestyle that can impact on seizures or can be impacted by seizures. Some of these include: sports, socialising, alcohol, driving, employment, relationships and disclosure. Many of these topics are covered in other EAA factsheets.

### Employment<sup>4</sup>

People underestimate the importance of employment, especially to men. Many studies have shown there is a direct link between employment status and men's health. Issues include:

- A man's self-esteem is closely linked to his role as breadwinner. Often men aren't as strongly encouraged to find self-worth in a primary role of homemaker or parent.
- Unemployment contributes to existing financial and emotional strains on families. There may be associated feelings of anxiety, stress, guilt or sometimes shame.
- Men without trades who go from one unskilled job to another are more likely to feel devastated by periods of unemployment.
- Men who feel in control of their lives are more likely to look after their health. Men who are unemployed often feel helpless.<sup>5</sup>

### Things you can do:

- Speak with your employer about your seizures, most employers are keen to help
- Educate your employer or offer information. Offer them options. Remember your employer has a duty of care to keep you and other employees safe
- Know your rights, especially regarding discrimination. Your employer is obliged to make reasonable adjustments for you in the workplace
- You may need to be prepared to change your role for a time - for example if you are a heavy equipment driver there are legal timeframes about when you can recommence driving
- Consider if its a time to retrain - this will depend on seizure control and your current role
- Seek advice from a specialist employment service [EAA can help with this]

Some studies indicate that there is a risk of unemployment or underemployment for people with epilepsy relative to the level of their skills and qualifications. Read our **Seizure Smart - Employment Factsheet** for more information on where to get help.

<sup>4</sup> [www.epilepsy.com](http://www.epilepsy.com)

<sup>5</sup> [http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Men%27s\\_health?open](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Men%27s_health?open)

## Sports

Epilepsy should not keep you from playing sport. An active lifestyle has positive benefits for everyone. Regular exercise has been shown to improve sleep and reduce stress, both which can help improve seizure control. Sport is also good for social, physical and mental health. Don't deprive yourself for fear of having a seizure, a few common sense precautions is all it takes.

- Tell those who matter, such as the coach, so they know what to do if a seizure happens.
- Take into account what may trigger your seizures and the impact or risk of you having a seizure during a game, or participating in your activity of choice.



Activities such as scuba and sky diving, surfing, mountain climbing, bungee jumping, car racing, hang gliding, and other sports are risky for anybody, especially if you have seizures. In the early days its all about risk management - think - what will happen if I have a seizure while doing this! If you want to get involved in these sports, be cautious and make sure you discuss your epilepsy with those around you. Once your seizures are controlled you can again do most sports (there are a some exceptions). Ask your doctor when you can again take up those more risky activities. The rule is if loss of consciousness or a seizure could endanger or threaten your life as you participate, it's wiser to avoid it.

It is OK to participate in some contact sports and wearing head protection is advised. Boxing may not be the best choice of sport though as it has a greater risk of head injuries.

## Relationships

It is common for people with chronic health conditions, like epilepsy, to experience some challenges and fears with relationships, especially when beginning new relationships. This is particularly true if there have been negative experiences in the past. Some common fears and difficulties people with epilepsy may have, include:

- Uncertainty and fear about how family and friends will respond to their diagnosis
- Worries about being a burden or not being able to look after their family
- Concerns that potential partners will not want a relationship with someone with epilepsy
- Fears that others will judge you negatively if they see a seizure
- Cultural beliefs

These fears can be stronger for someone if:

- Parents, family or friends have been overprotective
- Social life and opportunities have been restricted relating to missed schooling, inability to drive, or being unable to party as hard as peers
- Social opportunities and relationships have been avoided because of anxiety about having seizures in public, fear of rejection or depression
- There is a poor understanding of epilepsy
- There is uncertainty and fears about how, when and who to tell about their epilepsy

Some things that may help:

- Learn more about epilepsy and educate people around you about epilepsy and what to do
- Keep a diary of your seizures and any other factors related to your epilepsy. This can help identify seizure triggers and patterns
- Be open about your epilepsy
- Feeling comfortable and being prepared to talk about your epilepsy
- Ask others for help when you need it

## Seizures and Hormones<sup>6</sup>

### Epilepsy and testosterone (the male sex hormone)

Testosterone is the most important male sex hormone in men needed for normal reproductive and sexual function. It is important for the physical changes that happen during male puberty, such as development of the penis and testes, production of sperm and for typical adult male features such as facial and body hair and lowering of the voice. It is also important for overall good health and helps the growth of bones and muscles, affects mood, libido (sex drive) and certain aspects of mental ability.

### Testosterone deficiency

When the body is not able to make enough testosterone it is called androgen deficiency. It affects about one in 200 men under 60 years of age and about one in 10 older men however exact numbers are not known. Men with epilepsy are more at risk for low testosterone levels, particularly focal (temporal lobe) epilepsy. It is not life threatening, and a very treatable condition.

Some antiepileptic medications can lower the amount of testosterone in the body.<sup>7</sup>

Symptoms of testosterone deficiency include: low energy levels, mood swings, irritability, poor concentration, reduced muscle strength and low sex drive. These are also side effects of some epilepsy medications. If these symptoms occur shortly after starting your medication it is most likely the medication not a low testosterone level. Symptoms often overlap with those of other illnesses and are different depending on the age when testosterone levels are below the normal range.

**If you have any of the above symptoms, there can be a number of causes so speak to your GP as this can be easily checked. It is not always testosterone deficiency.**

## Puberty

Puberty is when the body changes from a boy to a man. The body begins to produce more sex hormones causing changes. It is a time of many physical, hormonal and emotional changes and it is a time where changes in seizures also can occur.

### Can puberty cause epilepsy?

Puberty itself doesn't cause epilepsy. However, some teenagers start having seizures during this time, and some seizure syndromes are also outgrown at this time. This could be due to the changing hormones. Epilepsy syndromes that may begin during teenage years include Juvenile Myoclonic Epilepsy and Juvenile Absence Epilepsy.

## Sex

### Does epilepsy affect sexual function?

Physical and medical conditions, such as epilepsy, can contribute to sexual dysfunction which can be a complex disorder with medical, psychological, and life circumstances all playing a part.

### What causes sexual difficulties in men?

Sexual problems most often mentioned by people with epilepsy include wanting sex less often, not becoming as excited as usual and difficulty getting or maintaining an erection (impotence). For most men the cause can be both physical and psychological. Sometimes seizures or medications can make you feel tired, fatigued, lack of energy which can contribute to a loss of interest in sexual activity.

<sup>6</sup> [www.andrologyaustralia.com.au](http://www.andrologyaustralia.com.au)  
<sup>7</sup> <http://www.cnsspectrums.com/asp/articleDetail.aspx?articleid=574>

There are many diseases and health conditions that can contribute to sexual difficulties. Alcohol or other drug use, including some prescribed drugs can affect sexual function. Rarely, some antiepileptic medications cause impotence but they are not usually the sole cause.

Psychological causes of sexual difficulties are varied and can include:

- Anxiety or stress in general
- Anxiety about sexual performance or sexual identity
- Fear of sexual contact (from issues such as pregnancy or HIV/sexually transmitted infections)
- Psychological trauma or abuse
- Sexual problems with a partner
- Depression
- Lack of communication in the relationship or other relationship issues
- Grief, the effects of illness, or having a sick family member

Sexual difficulties are more common than most people think, but because they are difficult to discuss, men often let them go on for too long and begin feeling inadequate and depressed.

**By talking to your doctor and your partner, you are taking the first step towards making your sex life better**

Effective treatments for sexual difficulties are available that will allow most men to experience a fulfilling sex life. Many sexual problems can be corrected by treating the underlying physical, medical or psychological causes.

### Is there any cure?

The success of treatment for sexual and reproductive problems depends on the main cause or causes of the problem, and, there can be many causes. Once these have been found, then a proper treatment plan can begin.



For someone with epilepsy it may look like this:

- First, focus on improved seizure control, which improves sexual functioning
- Change antiepileptic medication if necessary and possible
- Have therapy for any psychological factors such as anxiety and depression
- Have sex therapy and/or relationship counselling if necessary
- Make lifestyle changes

The prognosis is good for problems relating to a treatable or reversible physical condition. Mild difficulties related to stress, fear, or anxiety can often also be successfully treated, usually with counselling, education and better communication between partners. A wealth of information is available about this.

### Epilepsy and inheritance<sup>8</sup>

As a man with epilepsy, your children are at a slightly higher risk than the general population for developing epilepsy.

8 <http://www.epilepsy.com/learn/gender-issues/men-and-epilepsy>

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- Studies show that children of men with epilepsy have a slightly higher risk of developing epilepsy which is approximately a 2.4 percent risk compared to ~1 percent risk in the general population. That's a 97.6% chance that your baby will not inherit epilepsy.
- If both parents have epilepsy, the risk that their children will develop epilepsy increases, although estimates vary widely. Some statistics say the risk is about 5 percent, while others put it closer to 15 or 20 percent. This may depend on the type of epilepsy.

Most men with epilepsy do well despite hurdles that may arise. The key is often how well seizures are managed, both medically, socially and psychologically. It is important to take control of your health and the best start is through self education.

It is true for some people there will be a great deal of change and adjustment but for 3 out of 4 people, seizure control is possible. Deal with any issues that may arise early so they don't become seemingly insurmountable. Keep in regular contact with your specialist, especially in the early stages of treatment, keep a seizure diary and if possible surround yourself with people you can trust and offer support.

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This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.

