

Epilepsy & Men's Health:  
Information for Men Living with Epilepsy

# Men and Epilepsy



**EPILEPSY**<sup>®</sup>  
**FOUNDATION**



#### **The Disclaimer:**

This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to treatment or activities based on this information without first consulting their health care provider.



[www.epilepsy.com](http://www.epilepsy.com) • 800.332.1000

## **HORMONAL EFFECTS in Men with Epilepsy**

### **Does epilepsy affect hormones?**

Yes, epilepsy can be associated with hormonal changes. About 4 out of 10 men with epilepsy have low levels of testosterone. This hormone is important for physical development in males. It affects how sex organs develop and sexual function. It's also important for bone and muscle strength, body fat, and red blood cells. Both epilepsy and seizure medicines may affect some of these hormone changes.

#### **How epilepsy induces hormonal changes:**

- Uncontrolled seizures may affect hormones and brain function.
- Seizures can change how hormones from the hypothalamus and pituitary gland are released. For example, temporal lobe epilepsy is known to effect hormone function in men.

#### **How seizure medicines cause hormonal changes:**

- Some seizure medicines directly affect brain areas involved with sexuality.
- Some of these medicines can also affect reproductive hormones and change the amount of them in the body.

## Do all seizure medicines have the same effect on hormones?

No. Some, but not all, seizure medicines have been linked to hormonal changes.

- Research suggests that phenytoin, carbamazepine, and phenobarbital can lower the level of free testosterone and reduce sexual desire.
- There is also some good news. Studies show that lamotrigine does not affect sexual function. In fact, one study showed that lamotrigine had a favorable effect on sexual problems in men with focal seizures who were also taking other seizure medicines.

## What is the impact of hormonal changes?

Low testosterone levels in men with epilepsy can affect energy, mood, sex drive, sexual function, bone density, and seizure control.

Many men with epilepsy have been found to have low levels of bioavailable testosterone (BAT). BAT is the amount of total testosterone that is available for use in the body. Very low BAT levels have been linked to sexual problems.

## Getting help

Endocrine specialists can help men sort out the complex interactions between hormones, seizures, and seizure medicines.

Sometimes, understanding how hormones affect seizure patterns can lead to other ways to improve seizure control.

Although considered experimental, testosterone supplements have been shown to improve low testosterone levels in men with epilepsy. Since this hormone can affect seizures and seizure medicines, you should be monitored by your health care team.



# EPILEPSY AND SEXUAL DESIRE

## Does epilepsy affect sex drive?

Yes. Men with epilepsy may have a lower sex drive. Studies have shown that:

- Between 50% to 70% of all men with epilepsy report decreased sex drive.
- A survey showed that 57% of men with epilepsy recently had problems with erections, compared to 18% of men without epilepsy.
- About 40% of men with epilepsy have BAT levels below normal. This is an important finding, because BAT levels (and not total testosterone levels) affect sexual desire.

## How does epilepsy affect sex drive?

The following factors can affect sex drive in people with epilepsy:

### Seizure medicines

Some seizure medicines can affect brain areas and hormones involved with sexuality. Some may have a greater impact on sexual desire than others.

- Men with focal seizures who take enzyme-inducing seizure medicines may have more problems than men taking lamotrigine.
- Men taking enzyme-inducing seizure

medicines also may have very low testosterone levels at an earlier age.

- Decreased sexual desire and arousal are more common in men with epilepsy taking sedating medicines such as phenobarbital, primidone or clonazepam.
- Carbamazepine and phenytoin have more negative effects on sex drive than lamotrigine.



### Changes in the brain due to seizures

Sexual desire requires normal function of certain brain areas, especially frontal and temporal lobes.

- People with focal (or complex partial seizures) seem more likely to have problems with sexual desire, especially when seizures start in the temporal lobe.
- Damage to the temporal lobe, common in people with focal epilepsy, affects the ability to recognize subtle cues and become intimate.

## Negative emotions

Problems with sexual desire can be due to mood changes such as depression and anxiety.

Fear that sexual activity will induce a seizure (particularly for those whose seizures are triggered by hyperventilating or physical exertion) may also have a negative impact on sex drive.

## Are there ways to improve sex drive?

Researchers are trying testosterone in men with epilepsy to improve their sex drive. Early results are encouraging. Researchers have noted improved energy and sex drive as well as better seizure control.

- Men with epilepsy who have low sex drive should ask their health care provider to evaluate their hormone levels, especially free testosterone levels.
- Health care providers and men taking testosterone should watch for changes in behavior (anger or paranoia), blood counts, liver function, lipid profile, and PSA (prostate-specific antigen) count.

## Seeking help

Many men with epilepsy don't talk about sex with their doctor or nurse, despite the sexual problems found in people with epilepsy.

Talking to your health care team about these problems can help.

- A change in seizure medicines may be recommended to improve sex drive.
- Testosterone may be recommended if levels are low.



**Early results are encouraging. Researchers note improved energy and sexual drive when testosterone is used in men with epilepsy. Improved seizure control has also been seen.**

## REPRODUCTION AND FERTILITY

### Does epilepsy affect reproductive function and fertility?

Yes, epilepsy may have an impact on reproductive function and fertility.

Statistically, men with epilepsy have a high risk of reproductive problems. For example, changes in sperm count or abnormal sperm can decrease fertility.

Some findings from studies about reproduction and fertility include:

- Men with epilepsy were only 36% as likely as their male siblings without epilepsy to father a child.
- Men with epilepsy—regardless of whether they were taking seizure medicines—had problems in the structure and function of their sperm more often than healthy men without epilepsy.

### Do different kinds of epilepsy affect reproductive function in different ways?

The type of epilepsy, age of onset, and family history appear to have the biggest impact on reproductive dysfunction and infertility.

Studies find that:

- Men who developed epilepsy at an early age (younger than 10 years) had more reproductive problems than men who developed epilepsy at a later age.
- Men with focal epilepsy have more problems than men with generalized onset epilepsy
- Temporal lobe epilepsy is linked to hormonal problems affecting fertility.
- Men with epilepsy who don't have a family history of epilepsy are at a greater risk for reproductive problems than men who do have a family history of epilepsy.



## Do seizure medicines affect reproductive function and fertility?

Some seizure medicines are associated with reproductive problems that affect fertility or the ability to have a child. For example, valproate, carbamazepine, and oxcarbazepine are linked to changes in sperm.

### Seeking help

Talk to your health care team if you are concerned about the effects of epilepsy or seizure medicines on your reproductive function and fertility.

- Start with your primary care provider to look at all issues that may affect fertility.
- Your provider may refer you to an endocrine or fertility specialist.
- Also talk to an epilepsy specialist to see if your type of epilepsy and seizure medicine may be connected.
- If fertility problems are suspected, blood tests to check hormone levels are done first.

Ways to treat reproductive problems and fertility will depend on the cause. For example, testosterone or other hormone treatments may help infertility.

Your epilepsy team may suggest changes in seizure medicine if it may be affecting fertility or other hormonal problems.

## PARENTING ISSUES

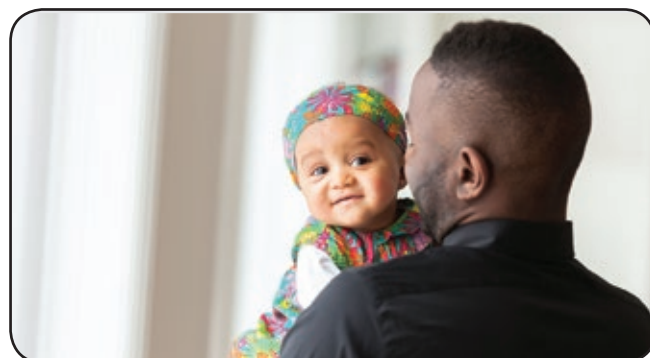
### What are the chances that my children will have epilepsy?

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

- Studies show that children of men with epilepsy have a 2.4% risk of developing it. The risk of developing epilepsy in the general population is only 1%.
- If both parents have epilepsy, the risk that their children will develop epilepsy is higher. Estimates vary widely from 5% to 15% or 20%.

### What do I need to keep in mind as a parent with epilepsy?

If your epilepsy is well-controlled, you face very few restrictions caring for a child. However, if your seizures are not controlled, you need to take safety precautions to keep you and your child safe.



This is especially important for people who fall, lose consciousness, or are confused during or after a seizure.

### **Keeping infants safe**

Being sleep deprived and new parenthood often go hand-in-hand. Stress that is induced by sleep deprivation and parenting can aggravate seizures. Both stress and sleep problems may lead to missed medicines too. Be aware of these potential problems and develop a plan to address them.

#### **Tips to use when caring for an infant:**

- Sit down when holding and feeding a baby. If you tend to fall, sit on the floor or a couch. If you tend to fall on the same side during a seizure, position yourself to prevent falling on the baby.
- With older babies and young children, secure them in a child seat when helping them eat.
- Dress, change, and play with the baby on the floor.
- Avoid bathing a baby when you are alone.
- Avoid carrying your baby around the house, especially up and down stairs.
- Use a playpen or enclosed play yard for your child to keep them in a safe place.
- Don't carry hot drinks and food around your baby.



### **When your children are older**

Your children will notice seizures as they get older. They may be scared or worry if they don't know what is going on.

It's important to tell children what seizures are and what happens when you have one—using words and books that are age-appropriate. Also let them know what they can do and what not to do if you have a seizure.

Most children are comforted by knowing that you will be okay. Many often feel better if they can help you during or after a seizure.

#### **When talking with your children about epilepsy:**

- Keep it simple. Use words that your child can understand.
- Be calm and positive.
- Explain that you won't be hurt but may need some help during a seizure.



- When your children are old enough, teach them what to do during a seizure. For example, you may want them to call an adult, hold your hand, or just stay with you, depending on the type of seizure.
- Show them how to call 911—in case you are unconsciousness after a seizure or the seizure lasts too long.
- As your child grows older, they will want to know more.
- Talk to your epilepsy team about how to talk about epilepsy with your family. Ask if you can bring your child to an appointment to learn what to do.
- Call your local Epilepsy Foundation office for information and help for children.

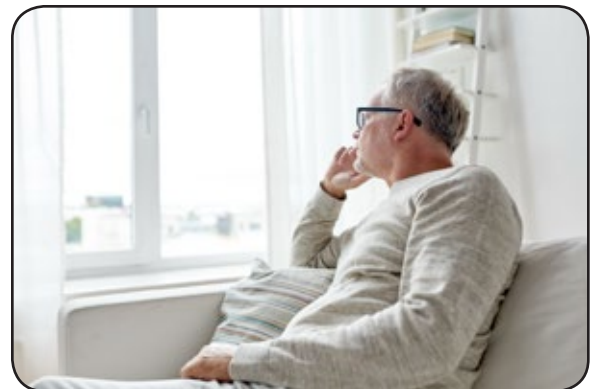


## SELF-ESTEEM

### How are epilepsy and low self-esteem connected?

There is no evidence that epilepsy causes low self-esteem. However, people with epilepsy sometimes have difficulty with social relationships or mood.

- Some people have trouble forming relationships with others. This could be due to problems in the temporal lobe.
- Not being able to drive and depending on other people for rides can affect your social life. People may feel more isolated and not want to ask others for rides. Or they may not have other ways to get around and meet people socially.
- People who lack the social support that friendships offer are likely to feel more isolated. These feelings of isolation may have a negative impact on self-esteem.



- Coping with epilepsy is also hard. People may feel worried or scared. Sometimes these feelings prevent people from going out with friends.
- Mood changes and anxiety are seen more often in some people with epilepsy. A low self-esteem may be a symptom of these mood changes.

How families react may also affect social relationships. Family members may be concerned about injury and be over-protective of the person with epilepsy.

Some people also just don't understand epilepsy and may be afraid to date a boy or man with epilepsy. These attitudes, or stigma, can affect how a person sees himself.

Low self-esteem in males with epilepsy is particularly common during the teenage years. This is a time that boys are finding themselves, becoming more independent, and may begin dating.

Problems with self-esteem and independence may affect any boy or man with epilepsy. They tend to happen more often when seizures are not controlled.

## Effects of low self-esteem

Low self-esteem can lead to someone being unhappy with their life in general or affect specific parts of their life.

For instance, low self-esteem may contribute to sexual problems, such as decreased sex drive.

## Ways to improve self-esteem

### Controlling epilepsy

Controlling seizures may help improve a boy or man's self-esteem. Studies show that children who underwent epilepsy surgery and had good seizure control afterward had less emotional and social problems later on.

### Support groups

Group interventions can help boost self-esteem and help people cope with epilepsy in many ways. Groups may offer different things.

- **Psychoeducational groups:** These groups offer emotional support, sharing experiences with others, and education about epilepsy.

“ Studies of support groups show an overall positive trend for better quality of life in people who participated. ”



- **CBT or cognitive-behavioral strategies:** These teach people practical ways to deal with problems. CBT helps change how a person thinks or acts about a problem and learn more effective ways of coping.
- **Peer support or mentoring:** Learning from peers or other people who are living with epilepsy can be very helpful. This type of peer support or mentoring may be one-on-one or in a group setting.

### Stress management

Managing stress can improve both self-esteem and seizure control. Studies suggest that by increasing self-esteem, men with epilepsy may manage stressful situations better.



Stress is a common seizure trigger for many men and women. Studies of different stress management approaches have shown improved seizure control. Examples of stress management approaches include:

- Muscle relaxation
- Deep breathing
- Meditation
- Tai chi, yoga
- Aromatherapy

### Seeking professional help

If feelings of low self-esteem last for a long time or interfere with daily living, get help from a trained professional, such as a clinical psychologist or a qualified counselor. Talk to your primary care provider and epilepsy team.

### Learn more, connect, and get involved

Visit [www.epilepsy.com](http://www.epilepsy.com) or call 1-800-332-1000 to:

- Find a local Epilepsy Foundation near you.
- Find information on different types of seizures.
- Find the latest information on treatments and services.
- Get safety tips for home, work, and school.



## **About the Epilepsy Foundation**

The Epilepsy Foundation, and its network of 50 organizations throughout the United States, leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. As an unwavering ally for individuals and families affected by epilepsy and seizures, the Epilepsy Foundation connects people to treatment, support and resources; leads advocacy and awareness efforts; funds innovative research and the training of specialists; and educates the public about epilepsy, Sudden Unexpected Death in Epilepsy, and Seizure First Aid. To learn more, please visit [epilepsy.com](http://epilepsy.com).

“Like” the Epilepsy Foundation on Facebook at [www.facebook.com/epilepsyfoundationofamerica](https://www.facebook.com/epilepsyfoundationofamerica) and follow us on Twitter at [www.twitter.com/epilepsyfdn](https://www.twitter.com/epilepsyfdn).



**[www.epilepsy.com](http://www.epilepsy.com) • 800.332.1000**

© 2019 Epilepsy Foundation of America, Inc.