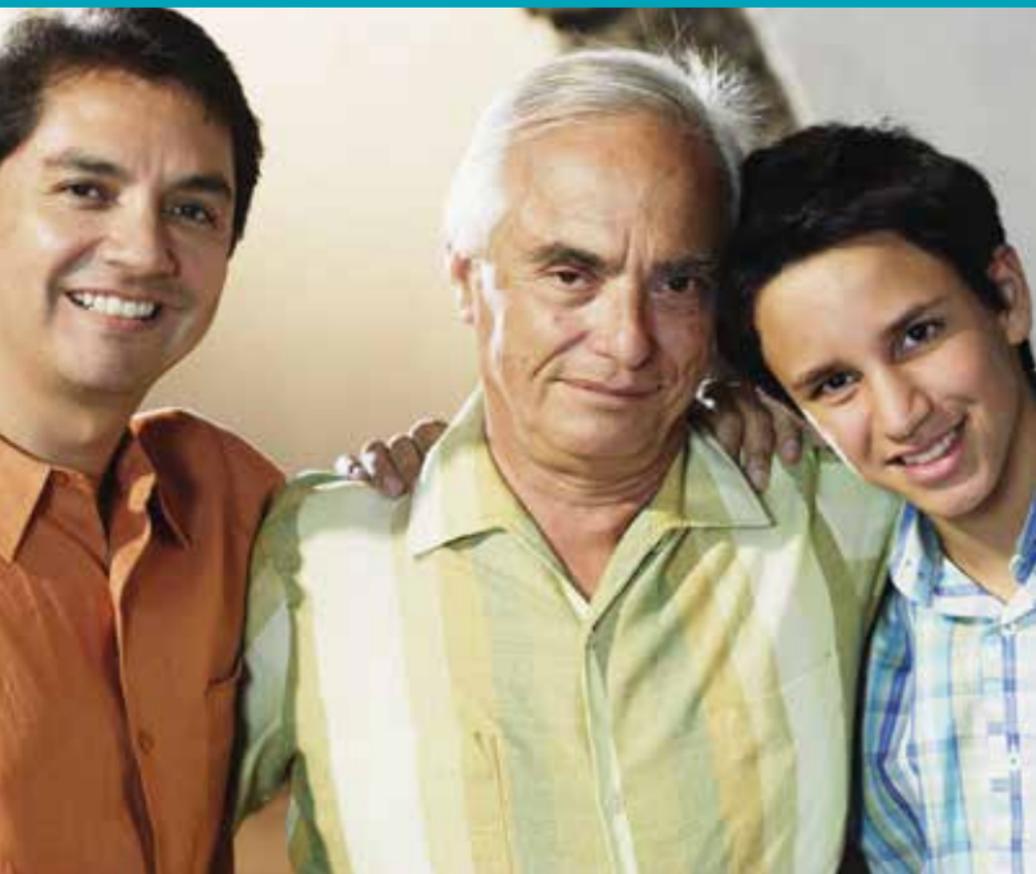


Epilepsy & Men's Health:
Information for Men Living with Epilepsy

Men and Epilepsy



**EPILEPSY
FOUNDATION**

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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.

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HORMONAL EFFECTS in Men with Epilepsy

Does epilepsy affect hormones?

Yes, epilepsy is associated with hormonal changes. For instance, experts estimate that approximately 40 percent of men with epilepsy (MWE) have low levels of testosterone, the hormone that stimulates the development of male sex organs, sexual traits, and sperm. Both epilepsy itself and the antiepileptic drugs (AEDs) used to control seizures may be responsible for these hormonal changes.

How epilepsy induces hormonal changes:

- Persistent seizures in adults may be associated with hormonal and neurological changes that contribute to sexual dysfunction.
- Seizures can alter the release of hypothalamic and pituitary hormones.
- Temporal lobe epilepsy, in particular, is known to have adverse effects on testicular endocrine function.

How AEDs cause hormonal changes:

- Studies show that AEDs directly affect brain regions that mediate sexuality.
- AEDs may cause sexual dysfunction by inducing secondary effects on reproductive hormones.
- Some AEDs change the concentrations of sex steroid hormones.

Do all AEDs have the same effect on hormones?

No. Some, but not all, AEDs have been linked to adverse hormonal effects.

- Research suggests that the AEDs phenytoin, carbamazepine, and phenobarbital adversely affect hormone levels by reducing the level of free testosterone which, in turn, reduces sexual desire.
- Some good news regarding AEDs and hormonal effects does exist. Studies show that the AED lamotrigine may not have a negative impact on sexual function. In fact, in one study, lamotrigine was shown to have a favorable effect on sexual disorders in MWE who had partial seizures and were taking other AEDs.

What is the impact of hormonal changes?

Reduced testosterone, one hormonal effect frequently seen in MWE, can adversely affect one or more of the following: energy, mood, drive, sexual function, bone density, and seizure control. A large percentage of MWE have been found to have low levels of bioavailable testosterone (BAT), the portion of total testosterone available for use. Abnormally low BAT levels have been tied to sexual dysfunction.

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Getting help

Endocrine specialists can help patients sort out the complex interactions between hormones, seizures, and AEDs.

Sometimes identifying hormonal influences on seizure patterns may lead to a better understanding of treatment options for seizure control.

Although it is still considered experimental and must be monitored very closely, treatment with testosterone supplements have been shown to improve low testosterone levels in MWE.

ANTIEPILEPTIC DRUGS (AEDs) and Men's Sexuality

What effect do AEDs have on sexuality?

The use of AEDs may result in one or more of the following adverse impacts on sexuality:

- **Decreased libido:** Some AEDs cause elevations in hormones that suppress sexual arousal and behavior.
- **Sperm abnormalities:** Some AEDs are associated with sperm abnormalities, including low semen volume, low sperm count, and abnormal sperm motility.

The following AEDs have been linked to sperm abnormalities: carbamazepine, oxcarbazepine, and valproate.

- Reduced testicular volume: Some AEDs have been linked to reduced testicular volume.
- Reproductive dysfunction: AEDs may cause alterations to androgens (substances that produce male characteristics and stimulate activity of male sex organs), thereby contributing to reproductive dysfunction.

Impact on sexuality varies among AEDs

When it comes to sexual function and reproductive hormone levels, not all AEDs have the same effect.

For instance, researchers have found that diminished libido and arousal are most pronounced in patients using sedating AEDs, such as barbiturates, although adverse effects on sexuality may also occur with any AED.

The AED lamotrigine appears to have a more favorable profile on sexual function and reproduction than several other AEDs. For instance, men taking enzyme-inducing AEDs have been shown to reach lower testosterone levels at an earlier age than men taking lamotrigine. Plus, a recent study found that, in men experiencing sexual

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disorders and taking prescribed AEDs for partial seizures, adding lamotrigine had a favorable effect on impotence.

The AED carbamazepine has been linked to significantly reduced levels of testosterone, when compared to the AED valproate. In recent studies, valproate treatment appeared to have no effect on sperm cell function in men with temporal lobe epilepsy.



Seeking help

If you are experiencing problems with sexual function, it is important to discuss them with your doctor. Your doctor may be able to prescribe alternative AEDs; many patients who experience sexual deficits with one medication will have normal sexual function with another. Plus, if you suffer from impotence, your doctor may prescribe medication to help you overcome it.

EPILEPSY AND LIBIDO in Men

Does epilepsy affect libido?

Yes. Several recent studies document that men with epilepsy (MWE) experience lowered libido. The following scientific data support this statement.

- One study found that between 50 percent and 70 percent of all MWE report decreased sexual function and/or libido.
- One survey showed that 57 percent of MWE recently experienced erectile failure, compared to 18 percent of men without epilepsy.
- A recent study demonstrated that approximately 40 percent of MWE possess bioavailable testosterone levels below the normal control range. This is a significant finding because researchers now know that bioavailable testosterone levels, rather than total testosterone levels, affect libido.

How does epilepsy affect libido?

The following factors can affect libido in people with epilepsy:

Exposure to antiepileptic drugs (AEDs)

AEDs produce direct effects on the brain regions mediating sexuality and may also cause sexual dysfunction by secondary effects on reproductive hormones. Some

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AEDs have a greater impact on libido than others. Recent data show that, among men with localization-related epilepsy, those taking enzyme-inducing AEDs had less gonadal efficiency than those taking lamotrigine. Men taking enzyme-inducing AEDs also reached abnormally low testosterone levels at an earlier age.

Diminished libido and arousal tend to be most pronounced in MWE taking sedating AEDs such as barbiturates.

In studies comparing the adverse effects of various AEDs on sexuality, researchers found the AEDs carbamazepine and phenytoin to have a much more negative effect on libido than lamotrigine.

Changes in the brain due to seizures

Sexual desire requires appropriate function of specific regions of the cerebral cortex, especially frontal and temporal lobes.

People with complex partial seizures

seem more prone to problems with sexual desire, particularly when seizures originate in the temporal lobe. Moreover, research suggests that damage to the temporal lobe, common in people with partial epilepsy, affects the ability to recognize subtle cues that are integral to establishing intimacy.

Negative emotions

Sexual desire can be disturbed by psychological factors such as depression and anxiety. Although limited data exists on depression among people with epilepsy, statistics reveal that the suicide rate for people with epilepsy is 5 times greater than that of the general population, which strongly suggests that the rate of depression is also higher.

Fear that sexual activity will induce a seizure, particularly for those whose seizures are triggered by hyperventilation or physical exertion, may also have a negative impact on libido.

Are there ways to improve libido?

Researchers are experimenting with the use of testosterone in MWE to improve libido. Preliminary results are encouraging. Researchers note improved energy and sexual drive with the administration of testosterone and decreasing frequency of seizures. Therefore, experts suggest that

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MWE experiencing decreased libido ask their doctor to order a test that will determine their level of bioavailable testosterone.

While the research on testosterone offers promise to MWE suffering from low libido, scientists caution that health care providers using testosterone to treat reduced libido in MWE should regularly monitor the following: behavioral changes (due to the possibility of developing anger or paranoia); blood count; liver function; lipid profile; and prostate-specific antigen (PSA) count, which is used to detect the presence of prostate cancer.



Preliminary results are encouraging. Researchers note improved energy and sexual drive with the administration of testosterone and decreasing frequency of seizures.

A recent survey indicates that very few MWE discuss sex with their physician despite the prevalence of sexual problems among this population. By bringing these problems to the attention of a doctor, it's possible that actions can be taken to combat them. For instance, a change in the type of AED may improve libido; so might the administration of testosterone.

REPRODUCTION AND FERTILITY in Men with Epilepsy

Does epilepsy have an adverse effect on a man's reproductive function and fertility?

Yes, epilepsy does have an impact on reproductive function and fertility. Statistically, men with epilepsy (MWE) have a disproportionately high risk of reproductive dysfunction, which manifests as diminished potency and abnormal sperm characteristics and can decrease fertility. Specific findings regarding reproduction and fertility among MWE include the following:

- One study found that MWE were only 36 percent as likely as their male siblings without epilepsy to father a pregnancy.

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- In a study comparing sperm in healthy males to sperm in MWE, researchers found that all MWE—regardless of whether they were taking antiepileptic medications (AEDs)—exhibit abnormalities in the structure and function of their sperm far more frequently than do healthy males.

How does epilepsy impact male reproductive function and fertility?

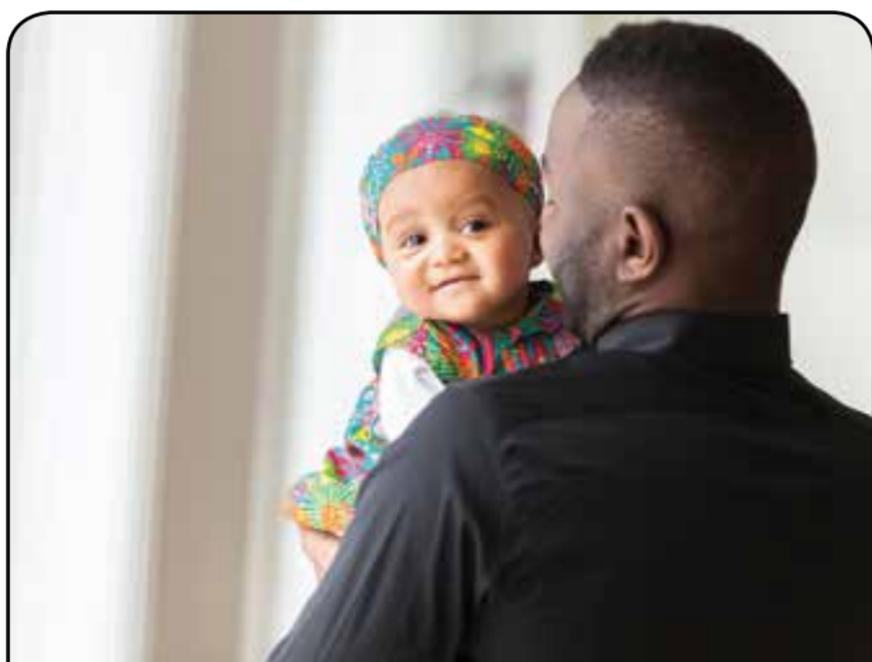
Research has found that, in many instances, epilepsy itself has an adverse effect on reproductive function and fertility. The type of epilepsy, age of onset, and family history appear to have the biggest impact on reproductive dysfunction and infertility. Specifically, studies find that:

- Men with early age onset of epilepsy (less than 10 years of age) are more reproductively disadvantaged than men who develop epilepsy at a later age.
- Men with partial onset epilepsy are more reproductively disadvantaged than those with generalized onset epilepsy.
- Temporal lobe epilepsy is linked to testicular endocrine dysfunction.
- MWE who don't have a family history of epilepsy are at a greater risk for reproductive dysfunction than MWE who do have a family history of epilepsy.

Do antiepileptic drugs (AEDs) have a negative impact on reproductive function and fertility?

Researchers have found that some AEDs are associated with reproductive dysfunction, which adversely affects fertility.

- Valproate is linked to sperm tail abnormalities and reduced testicular volume.
- Carbamazepine and oxcarbazepine may cause sperm abnormalities.



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

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Seeking help for reproductive and fertility problems

It's important to seek professional help if you are concerned about the effects of epilepsy and/or AEDs on your reproductive function and fertility. If you are unsure where to turn, ask your primary care provider to refer you to an appropriate medical professional.

Although epilepsy and many of the drugs used to control it can have adverse effects on reproductive function, thereby reducing fertility, refinements in diagnosing reproductive dysfunction and novel ways to treat it show promise. For instance, innovative means of obtaining a male hormone profile through noninvasive methods make it possible to determine each patient's precise baseline hormone activity. With this information, clinicians can introduce individually appropriate hormonal (testosterone) therapies for patients, which have been found to improve fertility in MWE.

PARENTING ISSUES for Men with Epilepsy

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 this disorder.

- Recent studies show that offspring of men with epilepsy (MWE) have a 2.4 percent risk of developing it, as opposed to the general population, whose risk is estimated at 1 percent.
- If both parents have epilepsy, the risk that their offspring will develop epilepsy increases, although estimates vary widely. Some statistics say the risk of developing epilepsy when both parents have it is about 5 percent, while others place it closer to 15 or 20 percent.

Will my children be at increased risk for other health problems because I have epilepsy?

Some research suggests that offspring of MWE may be at higher-than-normal risk for the following medical problems: neurofibromatosis, tuberous sclerosis, and genetically determined epilepsies such as juvenile myoclonic epilepsy.

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What special considerations do I need to keep in mind as a parent?

If your epilepsy is well-controlled, you face very few restrictions on caring for a child with epilepsy. However, if your epilepsy causes episodes of impaired consciousness and limited control of movement, you need to take special precautions when caring for a baby or a young child.

Keeping infants safe

Sleep deprivation and new parenthood often go hand-in-hand. Stress that is induced by sleep deprivation can aggravate seizures; sleep deprivation may also lead to missed medications. Be aware of these potential problems and develop a plan to reduce their impact.

Tips to use when caring for an infant:

- Sit on the floor while feeding a baby. If you tend to fall on the same side during a seizure, position yourself to prevent yourself from falling on the baby.
- Dress, change and play with the baby on the floor.
- Avoid bathing a baby in a tub while you are alone.
- Avoid carrying your baby around the house, especially up and down stairs.
- Avoid hot drinks around your baby.



When your children are older

Your seizures will not go unnoticed by your children as they get older, so it's important that you openly discuss your epilepsy with them. They will be comforted by knowing that you are not harmed by seizures; in fact, they may feel empowered if you can teach them how to get help if you remain unconscious after a seizure.

When discussing your epilepsy with your children:

- Keep it simple. Use words that your children 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 how to react during a seizure. Show them how to call 911 – in case you're unconscious after a seizure.
- At your discretion, add details about your condition when children are older.

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SELF-ESTEEM in Men with Epilepsy

The connection between epilepsy and low self-esteem

There is no evidence that epilepsy per se causes low self-esteem. However, recent research suggests that people with epilepsy sometimes have difficulty forming relationships with others, possibly due to neurological damage to the temporal lobe. One study of patients with poorly controlled epilepsy found that 68 percent of subjects had no personal friends. People who lack the social support that friendships offer are likely to feel isolated; subsequently, these feelings of isolation may have a negative impact on self-esteem.

Experts also cite other possible reasons why people with epilepsy are prone to low self-esteem: family over-protection, which prevents individuals from developing independence and self-esteem; the perceived stigma that accompanies epilepsy and resultant negative self-image; and general personal dissatisfaction.

Low self-esteem in males with epilepsy (MWE) is particularly common during adolescence, a period of heightened self-consciousness that may be exacerbated by having epilepsy. Surveys indicate that adolescents whose epilepsy is well-

controlled are less likely to suffer from low self-esteem than those who have frequent seizures.

Effects of low self-esteem

Low self-esteem can result in general dissatisfaction. It can also adversely affect specific aspects of life. For instance, low self-esteem may contribute to sexual problems, such as decreased libido. Low self-esteem may also be partially responsible for under-employment among MWE. A recent report by the Epilepsy Foundation documented that people with epilepsy have an unemployment rate of 25 percent. Among people whose seizures are poorly controlled, that rate approaches 50 percent.

Ways to improve self-esteem

Controlling epilepsy

Controlling epilepsy may help improve self-esteem. One study found that in children with epilepsy who successfully underwent surgery, it not only alleviated seizures at a younger age, but also improved the psychosocial status of these individuals later in life.

“ Post-intervention outcome measurements indicated an overall positive trend for quality of life improvement, suggesting that support groups would benefit MWE suffering from low self-esteem. ”



Support groups

Group interventions have proved beneficial as self-esteem boosters. For instance, a recent study demonstrated how adolescents with epilepsy benefited from a 6-week, structured psycho-educational group intervention. The intervention involved cognitive-behavioral strategies in which participants were encouraged to share their own experiences. Results showed that the intervention helped participants better understand their disease and engage in peer support. Post-intervention outcome measurements indicated an overall positive trend for quality of life improvement, suggesting that support groups would benefit MWE suffering from low self-esteem.

Stress management

Stress management has been linked to improvements in self-esteem and seizure control. Recent research indicates that, by increasing self-esteem, MWE may be able to manage stressful situations more effectively. Moreover, studies indicate that stress management may lead to improved seizure control in some MWE. Therefore, MWE who suffer from low self-esteem and anxiety may benefit by learning and practicing relaxation techniques. Examples of these techniques include aromatherapy, tai chi, reflexology, and meditation.

Seeking professional help

If feelings of low self-esteem persist for a prolonged period of time or interfere with daily living, it is advisable to seek help from a trained professional, such as a clinical psychologist or a qualified counselor. A referral can be obtained through a primary care provider.

How can I find out more?

You can contact the Epilepsy Foundation. Call 1-800-332-1000 or visit epilepsy.com. Through the website or the toll-free number, you can also find the local Epilepsy Foundation nearest you.

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About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with nearly 50 local organizations throughout the United States, has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is to stop seizures and sudden unexpected death in epilepsy (SUDEP), find a cure, and overcome the challenges created by epilepsy through efforts including education, advocacy, and research to accelerate ideas into therapies. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. For additional information, please visit www.epilepsy.com.

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