



Frequently Asked Questions and Answers

Where Can I Find Out More Information About Epilepsy?

There are many websites for epilepsy information.

- Centers for Disease Control and Prevention (<https://www.cdc.gov/epilepsy/index.html>)¹
- Epilepsy Action (<https://www.epilepsy.org.uk/>)²
- Epilepsy Foundation (<http://www.epilepsy.com/>)³
- National Association of Epilepsy Centers (<http://www.naec-epilepsy.org/>)⁴

If you go to the Epilepsy Foundation website, you can search for local support groups in your area.

Where Can I Find Support From Other People with Epilepsy?

You may be able to find a local Epilepsy Foundation support group. There are also many online support groups for people with epilepsy. Here are some trustworthy online communities:

- The Epilepsy Foundation has online community forum (<http://www.epilepsy.com/forum-topics>)⁵ and also a chat room (<http://www.epilepsy.com/connect/chat>)⁶
- Patients Like Me (Epilepsy Community) (<https://www.patientslikeme.com/conditions/3>)⁷
- WebEase (<https://www.webease.org/>)⁸
- Living Well With Epilepsy (<http://livingwellwithepilepsy.com/epilepsy-101>)⁹
- My Epilepsy Team (<https://www.myepilepsyteam.com/>)¹⁰





How Can I Talk to My Family About Epilepsy?

Epilepsy affects not only you, but also your family members as well. They need to know how to help you when you have a seizure. All members of your family should know what to do, and what not to do, when you have a seizure. You can create a seizure action plan and talk about it with your family. You can also practice what to do when a seizure happens, the way you might have a fire drill. Your family members might also be able to help you manage your epilepsy by helping you make sure you take your medicine and assisting with lifestyle management. Talk to your family about what it's like for you when you have a seizure. Ask them what questions they have.¹¹ The Epilepsy Foundation website has more information about talking to your family

(<http://www.epilepsy.com/article/2014/12/epilepsy-and-family>).¹¹



How Can I Talk to My Friends About Epilepsy?

Even though you might feel nervous talking about your epilepsy, or feel like you want to hide your epilepsy, it's important to tell your friends. If you have a seizure, your friends will need to know what to do to help you. Also, your friends will probably want to support you. Pick a time and place when you're comfortable and won't be interrupted. You might want to use a conversation starter, such as "Did I ever tell you why I take medicine every day? It's because I have epilepsy and the medicine helps prevent seizures."¹² The Epilepsy Foundation website has other conversation starters that might be helpful (<http://www.epilepsy.com/learn/age-groups/youth/talking-about-epilepsy/talking-friends-and-family>).¹²



What About Dating?

Dating is hard for anyone, and it can be doubly hard to decide when to tell someone you are in a relationship with that you have epilepsy. If your seizures are well controlled, you may want to wait until you feel comfortable with the other person before talking about your epilepsy. If your seizures are not well controlled, you might want to talk about your epilepsy sooner rather than later.¹³ Either way, if you are spending a lot of time with someone, you probably want to talk about your epilepsy so they know what is happening if you have a seizure and what they can do to help keep you safe.¹² The Epilepsy Foundation website has more information about dating (<http://www.epilepsy.com/learn/age-groups/youth/dating>).¹³ You could also talk to other people with epilepsy about how they handle dating situations. Psychologists and social workers might be able to provide tips about how to talk to people you are dating about your epilepsy.





Status Epilepticus and SUDEP

Is status epilepticus the same thing as SUDEP?

No. Status epilepticus is a prolonged, severe seizure that can cause brain injury.¹⁴ SUDEP is a sudden unexpected death related to epilepsy. SUDEP can happen with or without a seizure.¹⁵

Can status epilepticus lead to death?

It can lead to death, but it does not always lead to death.¹⁶

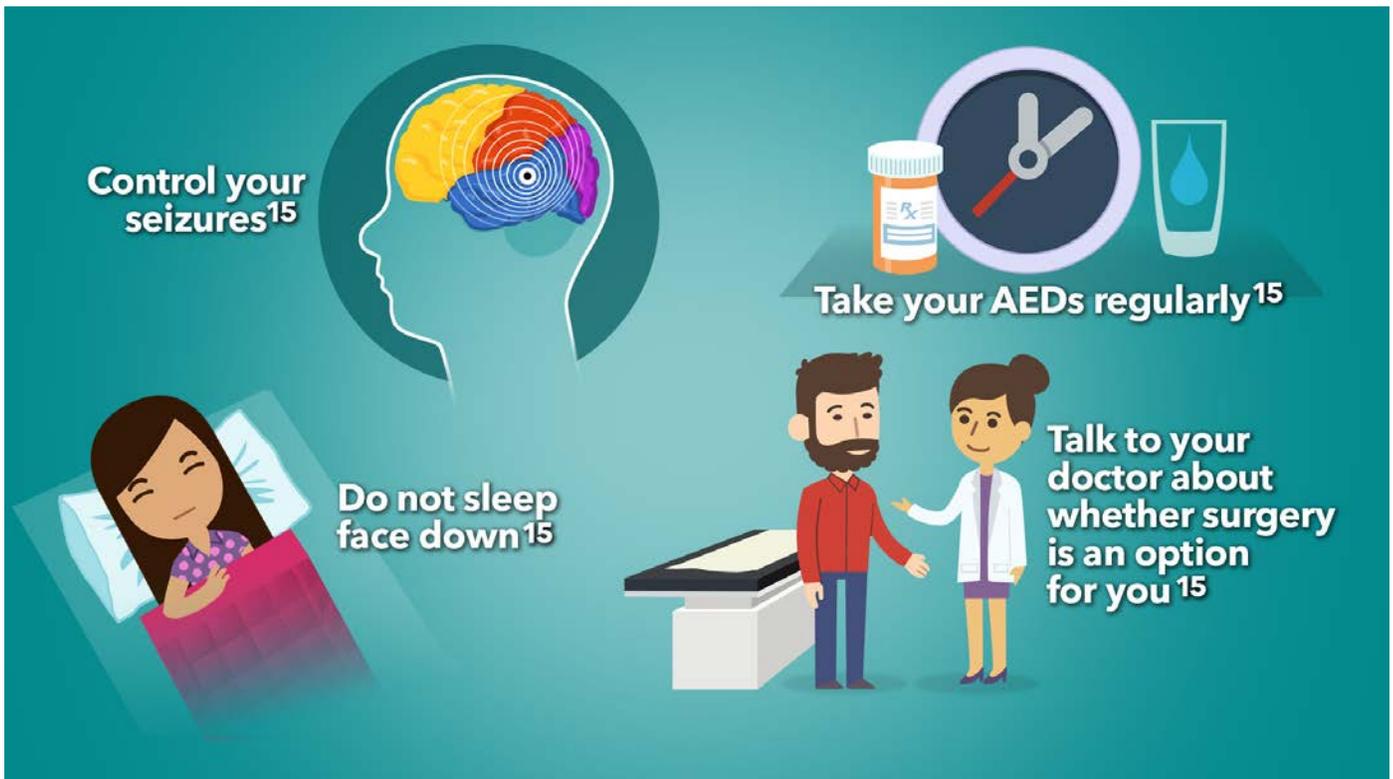
Can SUDEP affect anyone with epilepsy?

SUDEP can affect anyone with epilepsy, but people with generalized tonic-clonic seizures are at the greatest risk of SUDEP.¹⁵

How can I prevent SUDEP?

The best way to prevent SUDEP is to take your AEDs regularly to help control your seizures. Here are some other things you can do¹⁵:

- Do not sleep face down
- Talk to your doctor about whether surgery for epilepsy is an option for you





References

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