What are social relationships?

Social relationships are the connections we have with other people: friends, family, and loved ones. Relationships build our communities of support.



Why are social relationships important for people with epilepsy, their families, and their caregivers?



We all know epilepsy is more than seizures, and it takes a toll on quality of life. A number of factors can affect your quality of life, and sorting through these can be overwhelming. However, one factor has been consistently identified as the single best predictor of happiness and well-being—the quality of our social connections and interpersonal relationships.

Friends and family provide you with a support network—people who can help you physically and boost you emotionally. Studies have also shown that having friends can lead to better health outcomes and help you live longer.

How can epilepsy affect a person's social relationships?

- Seizures can be socially isolating.
- Fear of having a seizure in public is a common worry.
- ▶ Dealing with daily challenges of epilepsy can be exhausting and leave you with little time and energy for family and friends.
- Transportation is challenging. If you can't drive, it limits your ability to go out and socialize.
- Fear of injury may make you reluctant to take part in some social activities.
- Stigma can present a barrier—you may worry what others think of you and how you may be accepted.
- ▶Other disabilities can present challenges too, such as difficulty thinking, remembering, or even moving around.
- Chronic stress and worry affect how we relate to others. They can also lead to depression and anxiety.

What can I do to improve my social relationships?

Understand your family relationships

Epilepsy can put a strain on families in many ways. Everyone is in it together, but they experience it differently. A family member may feel helpless or angry because they can't make the seizures stop and they feel as though their lives have changed. They may be scared and try to protect their family member who has seizures. But the person with seizures may feel overprotected and want more space and independence. They may be afraid that they are a burden to their family and pull away.

- ▶ Talk about how each family member feels. When reactions aren't addressed or talked about, relationships between family members can get strained.
- Families can be a great source of support for someone with epilepsy, but it might take some work. Encourage all members of your family to learn as much as they can about epilepsy.

Find a support network

Having epilepsy can be upsetting and make you feel isolated and alone. If you have epilepsy or are a family member or friend, the good news is that you're not alone. Chances are there is a community of people in your area going through the same challenges that you are.

- ▶ Look for a support group from your local Epilepsy Foundation (epilepsy.com/local).
- Ask your doctor or other health care professionals for help.
- Check with the nearest epilepsy center to see if they have a support group or can connect you with other families.
- Connect with others on our online community at epilepsy.com/connect.

Reach out to friends

It's okay to feel nervous about telling other people about your epilepsy. You might be worried that they'll start treating you differently or that they won't handle it well. But chances are, they will surprise you. And you never know, you might discover that they have epilepsy too or that they have a relative or friend who does.

- You don't have to tell everyone as soon as you're diagnosed. Tell those closest to you as soon as you can. You don't have to tell all the details either. Decide what you are comfortable with and why they might need to know.
- Try not to hide your epilepsy—that can be dangerous. If you have a seizure, you want to make sure others are prepared and will know what to do. If you need to ask for rides or need assistance, you might find it's easier to ask for help when people know the reason.



How do I start talking about epilepsy with my friends?

Where you talk about epilepsy and how you bring it up may affect how others respond to you. It's best to pick a time and place when you're comfortable and where you won't be interrupted.

Try to stay matter-of-fact and positive. Epilepsy is only part of who you are and isn't anything to be ashamed of. If you act like your epilepsy isn't a big deal, your friends will just take it in stride.

Here are some opening lines that may help:

- ▶ "You know how I'm always wearing this necklace? It's a medical alert necklace because I have epilepsy."
- "Remember that movie we watched in health? I have seizures too, but mine are a little different"
- ▶ "Did I ever tell you why I take medicine every day? I have epilepsy, and I take medicine so I don't have seizures."
- ▶ "Remember yesterday, when I was acting strange? That was actually a seizure."

What do I say?

When you tell people you have epilepsy, talk about the type of seizures you have and what they should do if you should have a seizure. People may want to know if your seizures hurt, what they feel like, or if there's anything they can do to stop your seizures. They may also worry that epilepsy is contagious or that they might be doing something to cause your seizures.

- Try to reassure people that the seizures aren't contagious or caused by anyone.
- If you have photosensitive epilepsy, you might want to mention flashing lights can be a seizure trigger for you.
- Print some information from our website (epilepsy.com) or have some Epilepsy Foundation brochures or handouts to give the person.



When you tell people you have epilepsy, you may face a lot of questions. Depending on their culture and age, some people may have very different perceptions about epilepsy. In other instances, you might learn the person already knows about epilepsy. It could take a few days for the person to process what you've told them and to begin asking questions. Try to be patient—you've had longer than they have had to learn about epilepsy.

It's important to remember that you deserve to be treated well and that you will find friends who appreciate you for who you are—epilepsy and all.

FOR MORE INFORMATION:

- ▶ Epilepsy and social concerns: epilepsy.com/challenges-social
- ▶ Seizure first aid and safety: epilepsy.com/firstaid