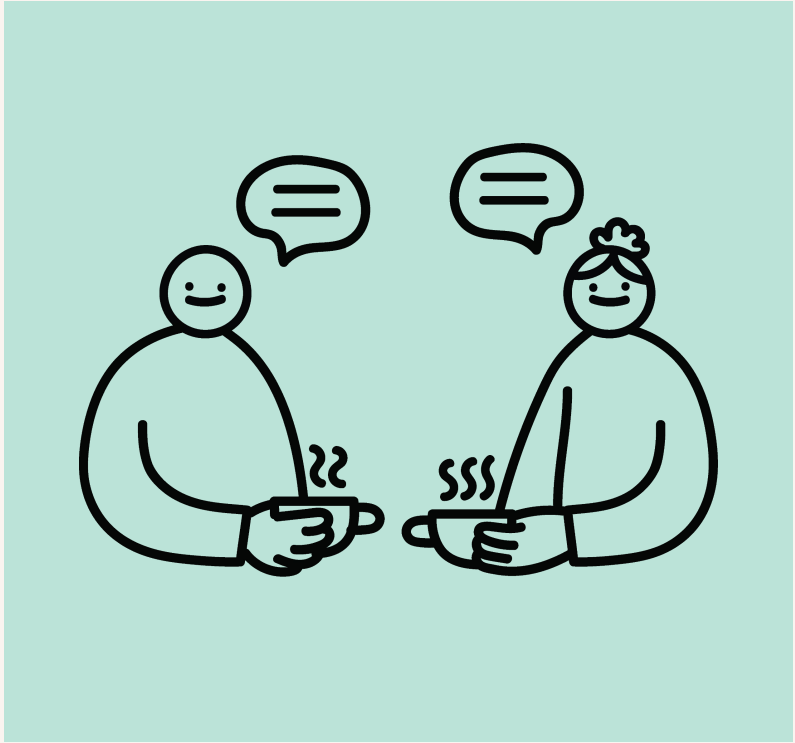
Having Conversations About Your Epilepsy:

A Supportive Guide



QUARRIERS

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About this guide

This guidance has been developed by the William Quarriers Epilepsy Centre in response to the needs of people with epilepsy, adapted from content by the Thistle Foundation and NHS Ayrshire and Arran Neuropsychology.

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General tips for all conversations

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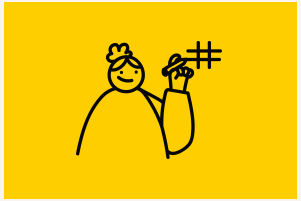
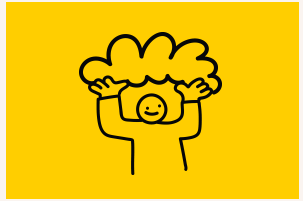


Choose the right time and place

Pick a quiet, private setting when you both have time to talk without rushing

Start with basics

Not everyone understands epilepsy - consider how you can explain your specific situation



Be honest about your needs

Clear communication about what help you might need can be very helpful to others

Have resources ready

Consider having some epilepsy information materials or website links to share

Remember

You do not owe anyone an explanation
You control how much you want to share, with who and when

Things to remind yourself

- You're not obligated to tell everyone
- You can share as much or as little as you're comfortable with
- It's okay to set boundaries
- You can ask for help when you need it
- Your epilepsy is just one part of who you are

- Remember that every conversation will be different, and that's okay. While it's not your job to educate everyone, you can choose to view these moments as opportunities to increase understanding when you feel able to do so.
- Trust your instincts about when and how much to share.
- Your comfort and safety comes first.

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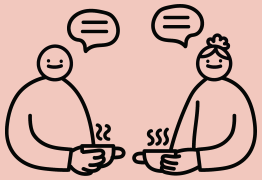

Guides for specific situations

Specific situations

Different people in your life will ask different questions. You may have to explain your situation and needs differently to each of them.

The following slides offer a starting point guide for each of these different conversations.

Friends and family

Your employer

Teachers

Someone you're dating

Roommates

Telling friends and family

When to tell them:

- When you're going through diagnosis
- When you feel comfortable sharing
- If you're planning activities where it might be relevant
- If something in your life is changing
- When you want their support

What to say:

Where to start...

"Hey, I wanted to let you know something about my health that's important to me.

I have epilepsy.

I wanted you to know in case I ever need your help."

Key points to cover:

- Any triggers and warning signs that you might have
- Basic seizure first aid
- Any activities that you might need to avoid
- How they can support you
- That you're still the same person they know and love
- That sharing this brings you closer together

Telling your employer

When to tell them:

- When you're going through diagnosis or just after
- If it's a new job, then during the hiring process or soon after accepting the role
- Before any safety-critical tasks become part of your role
- If your epilepsy might affect your work performance or attendance

What to say:

Where to start...

"I'd like to talk to you about a medical condition I have that might occasionally affect my work.

I have epilepsy.

I wanted to discuss any accommodations I might need and answer any questions you have."

Key points to cover:

- Any triggers and warning signs that you might have
- Any workplace adjustments that you might need
- Emergency and first aid practices that staff should be aware of
- Your rights under disability legislation
- How your skills and abilities make you great at your job

Telling your teachers

When to tell them:

- When you're going through diagnosis or just after
- At the start of a new term, course or project
- Before any trips or group activities
- If you need academic support or accommodations
- If you feel like you need support

Schools, colleges and universities often offer counselling services. It's always worth asking if you need emotional support.

What to say:

Where to start...

"I'd like to talk to you about a medical condition I have that might occasionally affect me in school/college/university.

I have epilepsy.

I'd like to discuss any accommodations that I might need and ensure you know what to do if I have a seizure during class."

Key points to cover:

- Any triggers and warning signs that you might have
- Any academic accommodations that you might need
- Emergency and first aid practices that staff should be aware of
- How it might affect your attendance
- Your commitment to your studies

Telling someone you are dating

When to tell them:

- When you're going through diagnosis or just after
- After a few dates, when you feel comfortable
- Before the relationship becomes serious
- Before you introduce them to your family
- If you feel it might affect planned activities

What to say:

Where to start...

"I want to share something important about my health with you.

I have epilepsy, which means I sometimes have seizures.

I'm telling you because I care about you and want you to understand this part of my life."

Key points to cover:

- How your epilepsy affects your daily life
- What a seizure might look like
- How they can help if you have a seizure
- That epilepsy doesn't define you
- That sharing this brings you closer together
- Answer their questions openly

Telling roommates

When to tell them:

- When you're going through diagnosis or just after
- If they're a new roommate then perhaps before moving in together
- During the first house meeting
- When establishing house rhythms and rules

What to say:

Where to start...

"Before we start living together, I want you to know that I have epilepsy.

I'd like to explain what that means and what to do if I have a seizure at home."

Key points to cover:

- Any triggers and warning signs that you might have
- What a seizure might look like
- First aid practice and how they can help if you have a seizure
- Your emergency contacts
- Any help that you might need

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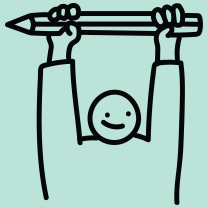

Tips for handling different responses

Tips for handling different responses

If someone seems worried

- Acknowledge their concern
- Share facts about how you already manage your epilepsy
- Give them time to process
- Offer resources for them to learn more
- Remind them that lots of people have epilepsy and everyone experiences this differently

If someone has misconceptions

- Gently correct myths with facts
- Share reliable information sources
- Be patient - many people don't understand epilepsy
- Use examples from your own experience
- Offer to answer their questions

If someone Is supportive

- Thank them for their understanding
- Be clear about how they can help
- Keep the channels of communication open
- Let them know you're happy to answer questions
- Share updates about your epilepsy management when it feels appropriate

Handling unwanted responses

Sometimes people might respond with an unwanted reaction or comment.

Try not to worry and remember that they may be processing very new information that they don't yet understand.

The following slides offer some advice for how to handle unwanted responses.

1. If someone becomes **overprotective**
2. If someone becomes **too worried**
3. If someone **treats you differently**
4. If someone **shares unhelpful advice**

1

If someone **becomes overprotective**

- ↳ Thank them for their concern while setting clear boundaries
- ↳ Where to start: *"I appreciate that you care about my safety, but I know my limits and can make my own decisions."*
- ↳ Share examples of how you already take care of yourself
- ↳ Explain that maintaining independence is important for your wellbeing
- ↳ Suggest specific ways they can support you without being overprotective

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If someone **becomes too worried**

- ↳ Remember: Their reaction often comes from lack of knowledge, not judgment
- ↳ Offer to explain more about seizure first aid to help them feel more confident
- ↳ Share statistics about how common epilepsy is
- ↳ Give them time to process the information
- ↳ Where to start: *"I understand this might seem scary. Would it help if I explained more about how I manage my epilepsy?"*

3

If someone **treats you differently**

- ↳ Stay calm and professional, especially in workplace situations
- ↳ Document any concerning interactions
- ↳ Where to start: *"I understand you have concerns, but I'm capable of [activity/job] and have successfully managed this for [time period]"*
- ↳ Consider reaching out to epilepsy advocacy organisations for support
- ↳ Remember: Their response reflects on them, not you

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If someone **shares unhelpful advice**

- ↳ Thank them for trying to help
- ↳ Explain that you work with healthcare professionals to manage your epilepsy
- ↳ Where to start: "I appreciate your suggestion, but I have a treatment plan that works well for me"
- ↳ Redirect the conversation to how they can support you in practical ways
- ↳ Share reliable information about epilepsy when you can

Things to remind yourself

Stay calm and confident

Other people’s reactions say more about them than about you

Take deep breaths if you feel upset

You don't owe anyone a detailed explanation

Prepare your responses

Prepare simple, clear responses to common reactions

Practice these responses with the people you trust

Keep your responses brief and professional

Know when to step back

It's okay to end conversations if you feel uncomfortable

You can say "Let's discuss this another time" if needed

Build support when you can

Connect with others who have epilepsy

Join epilepsy support groups

Check in with someone you trust when you can

Practice self care

If you have a difficult conversation, do something nice for yourself afterwards

Engage in activities that help you feel confident

Remind yourself of your strengths