

Talking About Epilepsy
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1. Explaining epilepsy to a child

It is recommended that adults talk to children about epilepsy, whether the epilepsy is the child's or the adult's. This is best done in a calm, relaxed manner, as the child shouldn't feel that the parent is upset, anxious or angry - with the epilepsy or with the child. This will set the 'tone' for the child that it's okay to have epilepsy and it's okay to talk about it.

Talking to children about epilepsy helps them to be involved and can make things easier. Talking to an older child about triggers and lifestyle issues can educate the child and prepare them for managing their own epilepsy at a future stage.

Using the right words when explaining epilepsy to a child can be very important as it is a complicated area and words like 'epilepsy' and 'seizure' are difficult for young children to pronounce and understand. The following are guidelines that you can use when explaining to a child about epilepsy.

Q. What is epilepsy?

A. *Epilepsy means that someone can have a seizure.*

Q. What is a seizure?

A. *A seizure is short. It happens in a person's brain. In a seizure the person feels no pain. A seizure happens when your brain takes a little break.*

Q. Are all seizures the same?

A. *No. There are lots of types of seizures, but the one you need to know about is called ...*

*Tonic clonic/complex partial/absence/simple partial/myoclonic
(Choose from these main types, and/or add in another type if necessary.)*

Q. What does a tonic clonic seizure look like?

A. In a tonic clonic seizure a person can cry out, go stiff, fall down, shake their arms and legs and be unconscious. Being unconscious looks like a very deep sleep. They may be very tired after and need to sleep. They should feel better afterwards.

Q. What does a complex partial seizure look like?

A. In a complex partial seizure a person might wander around 'on automatic' but not know what's happening. They may pull at their clothes or they may be confused and not be able to speak properly. (Add in other signs that might be seen.)

Q. What does an absence seizure look like?

A. In an absence seizure a person seems to go blank or stare ahead unaware for a few seconds only. They do not know that this is happening, and so won't remember it afterwards.

Q. What does a simple partial seizure look like?

A. In a simple partial seizure a person may know what's happening but not be able to control it. Signs could be twitching of the face, arm or leg or shaking of part of the body. Sometimes only the person themselves knows the seizure is happening like when they get a funny taste or smell or a tingling feeling.

Q. What does a myoclonic seizure look like?

A. In a myoclonic seizure the person may make sudden jerking movements of their arms and body. These can be very short seizures and the person may be aware during them.

Q. What does a seizure look like? (Simpler explanation for a very young child.)

A. The person may stare, seem confused, or fall. The person may be sleepy but should feel better soon.

Q. What happens in the brain during a seizure?

A. It's like the screen goes blank and then turns back on again.

Or

A brain is like a computer. Sometimes it can shut down for a few seconds and then start up again, just like a computer does.

Q. Who has epilepsy?

A. Seizures can happen to anybody. Lots of people can have seizures: mums, dads, grandparents, brothers and sisters.

Q. Can I catch epilepsy?

A. No, you cannot catch epilepsy from anyone.

Q. Can it be cured?

A. The doctor can give a medicine to try to stop seizures.

2. Talking to children about their own epilepsy

Introduction

Why tell your child about their epilepsy?

Any young child can be anxious about something they don't understand. They may have fears, they may try to fill the gaps themselves, and what they believe may be distressing for them. A child with epilepsy can misunderstand their condition, for example feeling that they are in some way responsible for their seizures. It is very important to give a child a simple, friendly explanation about epilepsy and seizures, as it will help their fears disappear. The child will have a better understanding of their epilepsy and treatment.

When is the best time to tell your child?

At the time of a diagnosis of epilepsy your child may need reassurance. Firstly, they have had a seizure but may not know that has happened. They went to see a doctor, and they had to take tests in a hospital which can be worrying for them. In addition, they may have to take medicine every day. Even a very young child might wonder if something is wrong. If parents seem anxious the child may feel that it is serious. Answering any questions your child may have in simple terms it is important for lowering their fears. It is advised to tell the child as early as possible so that it is not a shock to them later.

How should you tell your child?

How you tell will depend on the age of your child and their level of understanding. Younger children need very simple explanations as too much detail can confuse them. Using puppets or toys helps support

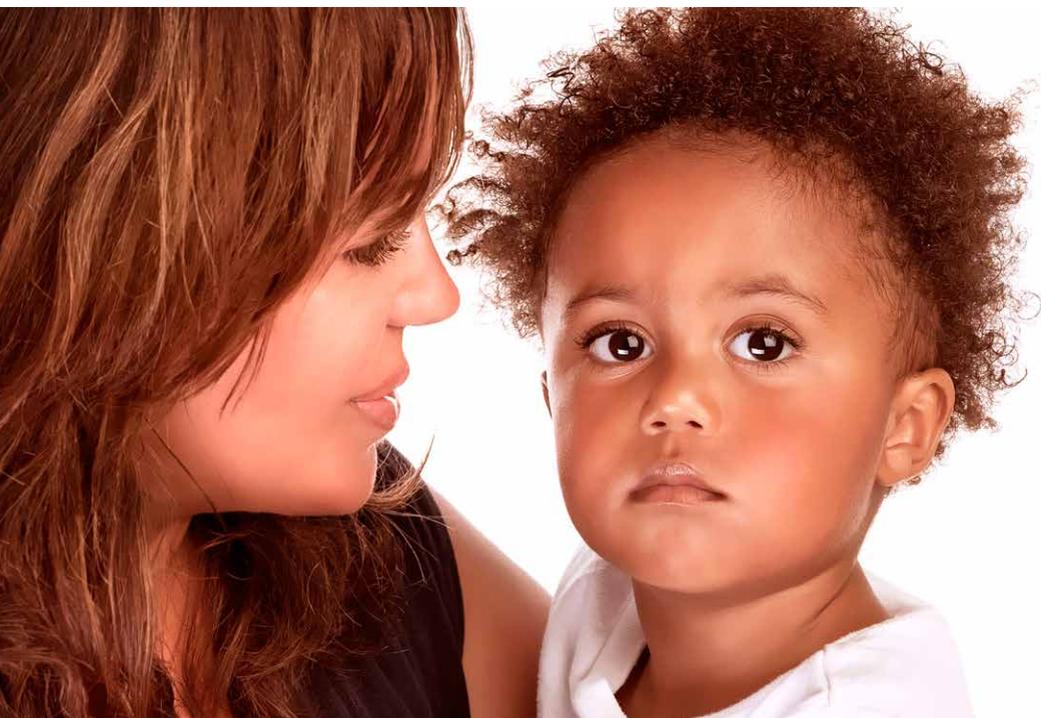
the explanation in a fun way. Often the child may ask questions about hospitals or medication. Playing games involving caring for a teddy or doll will help. A child who needs more detail may ask more questions later on. Find a quiet time to read a children's book about epilepsy which has pictures and explanations your child can understand. Books give you useful words and images to use when talking about epilepsy.

Talking to younger children, aged 3-7

Talking about seizures

Keep the explanation short at first to cover three main points

1. Seizures are short.
2. You may be tired and need to sleep just after the seizure.
3. You should feel better afterwards.



Too much detail might confuse your child at first. Be aware that they may come back to you with questions later on and that can be another good time to have a chat about their epilepsy. Simple descriptions are best, as suggested previously in this booklet.

Talking about tests

Early on, when your child is going for tests, a simple explanation can reassure them. **If they are going for an MRI you can tell them:**

“The doctor is going to take a picture of your brain and you might get some medicine to help you stay very still or even sleep. It won’t hurt, you won’t feel a thing.”

If they are going for an EEG you can say:

“The nurse will put some gooey gel in your hair and put little discs on your head. The gel is to keep the discs in place. The discs can measure electricity in your brain, imagine that!”

If it’s a sleep-deprived test you can try and make it sound like fun:

“For one special night only, you get to stay up!”

Talking about medication

Sometimes children believe that taking extra medication will make their seizures go away. They may even think that taking more frequent doses of medicine will work better. This can be dangerous. They need to know that they can only take the same small amounts of medicine at certain times.

Q. *Why do I take medication in the morning and in the evening?*

A. *Epilepsy medicine works best when you take a little bit at a time.*

Q. *If I take more medicine will it work better?*

A. *Taking lots of medicine at once wouldn't make you better; it would probably make you sick.*

Q. *Will the medicine make the seizures stop right away?*

A. *Often it does, but medicines can take time to work, so you may still have some seizures before the medicine stops them.*

Q. *What if I don't want to take the medicine?*

A. *Your medicine is important, and we take it the way the doctor has explained to us because it can help your seizures stop.*

Talking to older children, aged 8-12

Children vary in what information they can take on board and how emotionally mature they are. Some children need only basic information and others will want more detail. You are the best judge of how much detail your child needs. Here is an explanation suitable for an older child, aged 8 years upwards.

“Our brain, which is inside our head, controls everything we do: walking, talking, seeing, hearing, and even sleeping. Everyone has a little bit of electricity their brain, and this electricity helps the brain send messages to our body to tell it what to do.”

“Sometimes people make too much electricity in their brain and the messages get all mixed up. That’s what is happening when you have a seizure. It’s a bit like when a computer screen freezes for a short time before restarting.”

“The tablets you take help to stop the electricity increasing so that you won’t have a seizure as often. Lots of people, both children and adults, have this problem with too much electricity, and they all take tablets to keep it in order.”

Key Points : talking to your child about their epilepsy

- Choose a moment when you can give your child the time they need.
- Try to be relaxed, calm and open with your child.
- If necessary, reassure them it is not their fault they have epilepsy.
- Encourage them to ask any questions they might have.
- If your child has questions you can’t answer, it’s fine to say something like: “I’m not sure but we can ask the doctor or nurse.”
- Use suitable books or the Action Zone Game to help explain.
- Use star charts to help encourage them to take their medication daily.
- Use simple language that they can understand.

3. Talking to a teenager about their epilepsy

Teenagers can be encouraged to gradually take an active role in managing their epilepsy. Begin by encouraging your teen to fill in their seizure diary and write down any questions they may want to ask their medical team. Encourage them to take increasing responsibility for their medication and lifestyle. This will help them cope later on. Many teens have mobile phones and might like to keep medication reminders, seizure charts and epilepsy-related apps on these. At this stage the role of lifestyle in epilepsy management becomes more important and it can be helpful to discuss seizure triggers and ways of reducing seizures such as regulating sleep and meals, and managing stress. Your teen can benefit from learning how they can help themselves reduce their seizure risk.

As a parent you need to be aware of any potential implications for your teen's lifestyle, education and career choices. Openness is key with your teenager, as they need to have accurate information and support to make better choices for daily life. The teenage years are times when the young person is striving for increased independence. As a parent you might be concerned about whether or not your teenager will make the best choices for their own health and well-being, but it is important to balance this concern with firstly: a growing ability to educate them in their epilepsy management, and secondly: trusting them to build up their own skills in this regard.

Teens have a need to belong to a peer group and not to feel different. Someone who has epilepsy may feel different because of what they believe they can or can't do. Some of the restrictions that epilepsy brings – having to plan activities with safety in mind, rather than fun – can be frustrating. Getting the safety balance right shouldn't mean they can't have fun too. However, it may seem to a teenager with epilepsy that they

have to fight to avoid what they see as overprotection by their parents. They may resent having seizures or having to take medication. Seizures and the side effects of medication can leave them low on energy and affect concentration levels too. Teens may have worries about school, exams, future careers, driving and relationships. Peer pressure can be hard to resist and if it involves late nights and using alcohol or drugs it can cause problems for a young person with epilepsy. They may have concerns about telling others and how others react.

It is advisable to ask your teenager if they would like to see a recording of their seizures, if one is available. Some teenagers have told us that they would like to see their own seizures as such a viewing demystifies their epilepsy and allows them to regain some knowledge and control in their lives. Other teenagers don't want to. Another approach to educating a teenager is to select appropriate YouTube clips of seizures with them so that they have a familiarity with what happens during their seizure. This has been beneficial for some families.

Key points: talking to your teen about their epilepsy

- Encourage your teen to take an active role in their epilepsy care.
- Suggest they use a diary or app to log seizures, triggers and side effects.
- Encourage them to ask any questions they have at appointments.
- Discuss lifestyle issues that could affect them now or later on.
- Support them when they are finding out how to be more seizure safe.
- Discuss life choices like careers and college.
- Support them when they are making decisions about leisure activities.

- Discuss epilepsy in terms of relationships, dating and disclosure.
- Discuss any concerns they have about epilepsy, sex and sexuality.
- Be open to discussing any worries they have or changes in mood.
- Acknowledge it if they find restrictions or limitations frustrating.
- Support them if they feel they are missing out in some way.
- Reassure them that epilepsy is part of their life and doesn't define them.
- Support them when they are finding out information that is relevant to them.
- Encourage them to seek support for themselves.



4. Explaining a parent's or sibling's epilepsy to children

Introduction

Explaining a parent's or sibling's epilepsy to a young child can be difficult at first. It's important to use language at a level the child can understand. The description needs to be clear but not frightening. Every child is different and you are the best judge of what type of information your child needs.

Explaining your own or a sibling's epilepsy to a child is generally no different to explaining to a child about their own epilepsy. The explanations provided in the first section of this booklet should be used. The key points are that the seizures are short, that the person feels better afterwards, and that the person may get sleepy. In addition to this, you have to tell the child whether or not they will need to do something when the seizure happens. Explaining to the child exactly what they will see if they watch the person have a seizure can reduce the impact the event has on the child.

Young children

The child needs to know what to do if their parent or sibling has a seizure. For young children this means telling an adult who can help. It helps to prepare them by saying something like *"If Daddy has a seizure, tell Mummy"*, or *"If Mummy has a seizure, press 1 for Granny"*, or *"If your brother/sister has a seizure, tell an adult"*. Even young children have been able to raise the alarm by pressing a preset number on a phone. It helps if the person with epilepsy wears ID which includes their details.

Your child may be worried about their safety if their mum or dad has a seizure while they are together. You can explain who they can contact, if they can use a phone, or who to give a card with **'My parent has epilepsy'** on it to, to ask for help. If they are with their parent in a public place they can give this card to someone who can help keep them safe like a Garda, security guard or a person working in a shop. Epilepsy Ireland supplies these cards. Similarly, they can carry a card for a sibling.

Older children

Older children and teens need to hear the same messages to reassure them about seizures. They need to hear that seizures are usually short, that the person should recover soon and that they need to tell an adult. They may also be able to give practical help – like the correct first aid – themselves.

How can an older child or teen help?

This will depend on their level of maturity. You know best what your child or teen is able to handle. Many cope well when their parent or sibling has a seizure and can manage the situation alone. Others might be upset or need support themselves. Your older child may manage a seizure well but they should still be told to call an adult for support to deal with it. This will ensure that they are not being held responsible for the decisions made, and will not have to handle their fear or anxiety alone.

Key points : talking about a parent's or sibling's epilepsy

- Find out what your child believes epilepsy is and gently correct any misleading information.
- Keep explanations brief, giving the main points but not too much detail.
- Acknowledge their fears or anxieties about the seizures.
- Use information suitable for their age and level of understanding.
- Use the terms 'epilepsy' and 'seizure' so they are familiar .
- Tell them it's not their fault that their parent or sibling has epilepsy.
- Only give them them the level of responsibility that they can handle.
- Give them clear instructions on what to do and who to contact.
- Try not to allow epilepsy become the main focus of family life.



5. Explaining to others about epilepsy

It is important to consider who else needs to know about your child's or your own epilepsy. People often do not understand epilepsy, will not know how it affects you or your child in particular, and may wish to help but not know what to do. It is really useful for these people if you can provide them with the information that they need and discuss it with them. The main reasons that others should be told include:

- To give you or your child practical and emotional support.
- Because they have a responsibility for your child.
- To be able to provide a service for you or your child.
- To keep you or your child safe.
- To understand you or your child's seizure type(s) and therefore provide first aid.
- To understand other areas relating to the epilepsy, for example concentration or memory issues in a school environment.

Deciding who to tell:

If you are unsure who should know about your own or your child's epilepsy, it may be useful to talk it over with an Epilepsy Ireland Community Resource Officer, or an Epilepsy Nurse Specialist in adult or children's services. Epilepsy Ireland can support you with delivering talks in schools and healthcare environments if required.

When choosing who you should tell, the following questions should be considered:

- Who is around you/your child with epilepsy the most?
- Who is your child with when they are away from you?

- Who would be able to support you/them and want the best for you/them?
- Who would quickly notice any signs or symptoms of seizures?
- Who can give practical help?
- Who can be trusted to make the best decisions?
- Who can be relied on in an emergency?

Whoever you tell will need information about your child's seizure type and the correct first aid. Some people such as teachers will need further information on the effects epilepsy and medication can have on your child's behaviour and concentration. If teens are taking up work experience or part-time jobs, their employer may need to know. Consider what the following people may need to know and what information to give them:

Who may need to know?

- Family, partners and close friends need to know what to do to support you/your child.
- Health professionals like dentists, doctors and pharmacists. should know so that they can make sure any treatment is safe to use.
- Teachers need to know how to deal with seizures in class and how best to support a student with epilepsy.
- Anyone who has responsibility for a child with epilepsy needs to know, if they are supervising your child – this category includes child minders, coaches, summer camp staff and others.
- Work experience/Practical Lab in school/part-time employers may need to know.
- Employers may need to know, depending on the type of job.

- The State Examinations Commission need to know if a student needs Reasonable Accommodations in Junior or Leaving Cert. exams.
- Sports coaches, lifeguards and gym instructors need to know about first aid and safety.
- Insurers will request information about health for most personal policies/travel insurance.
- Medical assessors for disability payments will ask detailed health questions.
- The HSE Long Term Illness Scheme will need to know about your own or your child's diagnosis in order to give medication free.
- The CAO (Central Applications Office) will need to know when a student wishes to apply for the DARE (disability access route) programme for third level.
- Disability officers in colleges may need to know if the student requires extra supports. You should also let them know if the student has recently been, or is likely to be, in hospital for an extended period.
- National Driver Licence Service or Road Safety Authority will need to know for driver licensing purposes.

Special considerations when talking to other people about your teenager's epilepsy

- Keep an open dialogue with your teenager, discussing with them who they would like to tell, and why.
- As a parent, it is good to recognise how difficult it can be for teenagers with epilepsy to tell others and to support them with this and discuss it openly with them.
- Sometimes weighing up the 'pros' and 'cons' of disclosure can help when considering a particular circumstance.

- When safety is at stake epilepsy should be disclosed, as not doing so may increase risks.
- The decision regarding who to disclose to should be made as a shared decision between teenager and parent.
- Select people to tell who are close to the teenager and willing to help, and discuss with them how to manage a seizure if it happens.



6. Epilepsy Ireland resources

Younger children (aged 3 to 7)

- **My Lights Go Out:** a story book for young children with epilepsy or for young children whose siblings have epilepsy.
- **When Mummy Gets Dizzy** and **When Daddy Falls Down:** poems describing tonic clonic and partial seizures.
- **Action Zone Game:** a family board game to learn about epilepsy
- Downloadable stories for children on www.epilepsy.ie

Older children (aged 8 to 12)

- **Action Zone Game:** a family board game to learn about epilepsy
- **The Interactive Illustrated Junior Encyclopedia of Epilepsy:** Windows version CD-ROM, edited by Dr Richard Appleton
- **Everything a Child Needs to Know About Epilepsy:** a book by Dr Yemula and Dr Besag
- Downloadable resources from www.epilepsy.ie
- **Ali-A Saves the Day:** a video on the Ali-A YouTube Channel
<http://www.youtube.com/watch?v=tml-Bk7Xmnl>

Teens and young adults

- **Epilepsy and the young adult, a guide to living with epilepsy** (booklet)



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