



**For people  
with epilepsy,  
by people with  
epilepsy**

***This How2tell booklet is for  
people with epilepsy who want  
to learn HOW to tell others  
about their epilepsy.***

Using the experiences of other people (aged 18+) with a range of forms of epilepsy, How2tell gives practical information about how to:

1. become comfortable with your epilepsy,
2. understand the value in telling people,
3. decide on who you should tell about your epilepsy and when is the best time and place to bring up the subject,
4. use different opportunities to tell,
5. tell people depending on who they are,
6. make the message ordinary, and
7. deal with reactions from who you tell.

# 1

# Being comfortable with MY epilepsy

Before you tell other people about your epilepsy, it will be of great value that you have come to terms with your diagnosis and become comfortable with your epilepsy. This will influence how you tell other people.

***“I think sometimes that it comes back to the acceptance... Because this is only a blip, and that comes across that you don’t have any problem with it and therefore then other people don’t either.”***

When you are officially diagnosed by a doctor, you may experience a lot of different emotions. At the beginning you may feel relieved in knowing what is happening to you. But you may also feel anger, shock, sadness, and confusion. You may feel alone, feel you don’t fit in anymore or feel frustrated because of changes you need to make to your life.

It can take a while getting used to your epilepsy. Especially the changes you need to make to living your life. Here are some actions to help you become comfortable with your epilepsy:

- Learn more about your type of epilepsy by reading leaflets, booklets, and epilepsy websites such as Epilepsy Ireland. Talk to health professionals such as your Epilepsy Specialist Nurse, consultant, GP or psychologist.
- Join a support group such as Epilepsy Ireland or an online forum where you can pick up more

information by talking to people who also have epilepsy. By doing this you might meet other people who have your type of epilepsy and pick up tips on managing it.

- Tell someone close such as a friend or family member and share with them what is happening with your epilepsy.
- Practice how you would tell an employer or people in other formal situations. This will help you to make sure that you give them all the facts when the time comes to tell.



*“I mean there was the relief when I was told and that was the automatic instant reaction. But I had to face the fact that there was now elements of isolation in my life that weren’t there before. So there was feelings of anger, but they became feelings of depression, feelings of anxiety, feeling of isolation and feelings of insecurity. They came along in the processing of having said, ‘Oh well I’m glad I’ve got this diagnosis and I’m glad that I know what it is’. And then as my life pattern changed in the months afterwards, the other feelings did creep in.”*

Being comfortable with your epilepsy may take time. It is important to remember that epilepsy doesn’t define you; it’s only a part of you, you’re not a part of it!

# 2

## Why tell?

When you start telling other people about your epilepsy, it will be a massive weight lifted from your shoulders. It's a huge help to talk about it for a number of reasons:

### Increase your safety

If someone is aware you could potentially have a seizure and they know what to do, it will help ensure your safety.

*"It was more for my safety and the safety of the others around, in case I had a seizure and they knew what to do. So I'd show them how to administer the [rescue medication]."*

### Strengthen relationships

Telling people who are important to you in your personal life or who you spend a lot of time with is helpful. It could deepen the bonds between you. Equally, telling the appropriate people in work or school/college helps develop a relationship of trust.

*"I just told her the truth I have epilepsy, I'm normal day by day. I just felt she was just so good to me and I bonded with her from day one, when I moved into my apartment."*

*"I have certain friends who I would be more honest with. I could turn around to them and say, I'm having a really lousy day, I've had three or four seizures, not feeling the best. And then I'll be able to talk about it more openly with them."*

### Develop a personal support network

The more people you tell in various environments the bigger your personal support network. This network ensures there is at least one person in your various social and work situations who can provide the support you need. For example, someone who knows what to do in the event of you having a seizure, someone to vent your frustrations with or someone at work who can manage any work/study problems.

*"If it's a situation, like a few girls, when I had to go away with them if they didn't know I would always tell people. If I'm going away with them, if I'm spending a lot of time with them, just obviously in case something happens, but also if they find a medication or something, it's so they don't find something and feel they can't ask."*

### Reduce any alarm

If someone witnesses a seizure and is unaware of what is going on, it can alarm them. They might also panic as they don't know what to do to help. However, if you inform them of what to expect to see during your seizure and guide them on how to help, they will be much more assured.

*"I give them a little bit of what could happen, and then they maybe can adjust to it mentally before, or if it happens, rather than have them panicking and not know how to help me best if the worst came to the worst."*



# 3

## When and who to tell

Everybody doesn't need to know you have epilepsy. You need to weigh-up WHEN is a good time, where is a good place to bring up the subject, and WHO needs to know about your epilepsy.

**WHEN** is a good time and where is a good place to bring up the subject? As a guide to weighing-up WHEN is the best time and place to tell, consider:

- Am I comfortable and ready to talk about my epilepsy?
- Will telling benefit me? (does it help ensure my safety, help me manage work/college commitments and help make me feel at ease?)
- When telling informally, are we in a relaxed setting, such as watching TV, chatting in the canteen over lunch or tea breaks?
- Do I need to give an explanation, such as after a seizure or after missing work/studies?

- When telling a child, are they aware I have epilepsy and will they understand?

*“So you just choose your place and time and I think in a relaxed environment.”*

*“You must weigh up the odds before you disclose to someone. Don't be afraid to judge people in the sense of how they might react, because you might know them for a few years, but if you don't think it's going to be any benefit to them finding out, don't tell them, only if it's of benefit to you and them in some way do you disclose you have epilepsy.”*

*“I'd be showing trust if I tell. Or kind of it'd be safer 'cos like if I actually had a grand seizure, you know they'll have the safety precautions.”*

*“I think when they [children] become old enough to be aware of situations.”*

*“I actually brought it up at a party, like I had been to the doctor the day before and we were at a friend's house and they were just asking me – because they knew that there was something going on.”*

**WHO** needs to know?

As a guide to weighing-up WHO needs to know about your epilepsy, consider:

- How much time do I spend with the person?
- What is the chance of having a seizure in front of them?
- Am I close to this person and do I trust them?
- Am I in a new relationship and feel it's going somewhere?
- Do I want to strengthen my relationship with this person?
- Who do I want to tell at work/college?

*“If you meet them every day because they get to know about it eventually. Sometimes there might be people that you trust a bit more and you get a feeling they're more reliable, you might kind of mention there's something that I better tell you about.”*

*“If I'm after going on a few dates with them, kind of getting closer to somebody, I'll always say it, and I have no problem saying it.”*



# 4

# Opportunities for telling

When you feel you are ready to tell, there are various opportunities you can use to start the conversation. You can:

## Use opportunities to tell

There are certain questions that come up in conversation where you can let people know of your epilepsy, such as questions about driving or what you like to drink. If you feel it's the right moment to tell, using these opportunities will help keep it casual.

*"When I would ask them could I have a spin home, and people would say, where's your car? Then I'd say I actually have epilepsy and people would be very surprised – so that would have been the first experience of having to tell people."*

You can use opportunities such as having a medical appointment for your epilepsy or after a seizure to tell.

*"I said I was going to hospital in a couple of weeks for just an EEG, that I had epilepsy. I haven't had a seizure in 10 years and they're just checking up on it."*

In work situations where you want to explain sick-leave or what supports you need, you can use these opportunities to tell your employer or supervisor.

*"I've tried to raise awareness with epilepsy on social media. I'm sure everyone knows at this stage. People that I haven't seen in years I'm sure know I've epilepsy. Because any time there's an epilepsy event I'm promoting it. Or if it's raised in the news..."*

*"I have to explain why I'm going to be tired or I'm not going to be around for a couple of days or something. It's more likely it's after the fact if I haven't been around for a while, it's a way of explanation sometimes."*

## Create opportunities to tell

If you feel the moment is right to tell someone, you can create an opportunity to bring it into conversation. There are various props you can use, such as taking your medication in front of the other person, wearing an epilepsy badge/bracelet, and leaving epilepsy booklets around at home. If the person doesn't show interest by asking you questions, then don't force the issue at that time.

*"I had to take tablets and when he was chatting to me there, I took them. Then he asked...I didn't have to go oh I've epilepsy, like it kind of broke it in. I'd go well I'm on these because and explain that."*

You can create opportunities such as showing interest in epilepsy issues or raising awareness of epilepsy by posting articles or links using social media.

## Wait for opportunities to tell

When you are out with friends or work colleagues, opportunities for sharing personal information crop up and provide you with an opening to tell. When a relevant topic such as health or medication comes up in conversation, or is being discussed on the radio/television, you can drop it into the conversation. The right time and place will come which makes telling a natural part of the conversation.

*"He was quite straight with me – he suffered with anxiety and depression and he told me. I said well actually, I suffer with temporal lobe seizures. We were just being honest with each other and it's kind of a comfort now because we feel like we're on a par. We've both been quite straightforward with each other."*



# 5 How to tell

When you are telling, keep it simple. There are 3 parts to the message. Start by stating that you have epilepsy, follow this with some reassuring words and finish with practical information on what you want the person to do if you have a seizure.

## For example,

*“I have epilepsy, it’s not a big deal but it will be grand, just do ... if this happens.”*

The basic message can be adapted depending on the situation.

## Formal telling

You can adapt the basic message to take into account your employer/school/college needs. You should try and set up an appointment to tell the necessary people or call them aside for a private discussion. State you have epilepsy in a direct, factual way. Follow this with words of reassurance, giving information about how your epilepsy does or doesn’t effect you at work/studies. If you want, you can offer references from previous employers or your consultant/GP about your epilepsy and how it relates to your work.

*“I would just put it quite simply – I have another matter I have to mention to you, I actually have*

*“I said to her, sometimes in the morning when mam gets up and she just falls over and it seems a bit silly, well she suffers from something called epilepsy. I don’t know if you’ve heard about that before and it’s just where there’s a lot of electricity in somebody’s brain that just fires off together and they just make you just fall over. But there’s nothing wrong, I’m not even sick, but I’ll be actually fine in five minutes and I just need to sit in the corner and just put my head between my knees and maybe have a glass of water would be good.”*

*epilepsy. I may experience an occasional seizure, it’s nothing to be concerned about, it can easily be controlled in that regard, and there are things which we can follow. I can bring information to you, there’s plenty of information, there’s contacts I can give for you as well. So if you have any further questions for me.”*

## Informal telling

You can adapt the basic message when you want to tell someone casually about your epilepsy, and in a way that strengthens your relationship with the person you are telling. When opportunities arise during casual conversation, just be upfront about it and say you have epilepsy. Follow this with reassuring words giving some information about how your epilepsy affects your life. Depending on the person’s level of interest, you can provide more information. You can end with giving practical information about what they can do to help if you have a seizure.

If you think the person is uncomfortable with the information and worried about handling it, you can give them a contact number for them to call in the event of a seizure.

## Telling children

You can adapt the basic message in order to try and prevent the child feeling frightened about your seizures. Keep it simple based on the child’s level of understanding. Using reassuring words, describe what they may see before, during or after a seizure. If you compare your epilepsy to something they are more familiar with, this can also help. Use plenty of reassuring language. You can end with giving practical information about what you want the child to do if they see you having a seizure. Keep this information simple so as not to overburden them.



# 6

## How to make it ordinary

How you deliver the message that you have epilepsy can influence how people react. If you don't make a big deal, then other people will respond in the same way. Here are some things you can do:

### **Tell before they see you having a seizure**

Describe what the person will see during YOUR seizure. This allays panic reactions because then, they will know what to expect and what to do.

*"I'd tell them what happens and I said I can drift off or I can do things you mightn't realise; sometimes I could fall down. I wouldn't be going to over exaggerate it. I'd be kind of telling them straight out what can happen, so that if something does happen that they won't say, oh it's worse than she said it was going to be."*

### **Tell in a casual way**

Convey that your epilepsy is just an ordinary part of your life. Using a casual setting such as watching TV or chatting with friends helps to keep the atmosphere relaxed. It also helps to tell during conversation rather than making a big announcement.

*"It's all part of how you deliver it. You make a big deal about it, they'll say she's very sensitive*

*"So just be open to the idea of giving a little bit of information as calmly or as coolly as you can, with a bit of sense of humour if you can do it that way. It always takes the sting out of things for people and then just carry on."*

*about this, we'd better not mention it, there must be something horrific here, I'd better not and they shy away from it. Where if you just say it's okay, it's just part of life, people get the flu, people get gastroenteritis or whatever. But just it's all about how you portray it and the more you do it, the easier it becomes and the more natural. How you deliver a message, is extremely instrumental on how people pick up on the message."*

### **Tell the person not to worry**

Think about what the other person might be feeling or anxious about and use that as part of reassuring them. You can help reassure the person by using phrases such as, *"it's nothing to worry about, it's not a big deal, just relax I'll be fine and I will come out of it."*

### **Tell about YOUR epilepsy**

This may be the first time the person has met someone who has epilepsy, so it helps to give brief information about YOUR form of epilepsy. You may also come across people who

are mis-informed about epilepsy or what to do and this can be a good opportunity to correct this.

*"I would explain that I don't have a certain type of epilepsy, what my epilepsy is. Also because you do find people who don't know what epilepsy is. So then you have to make sure that they know what it is. Some people I'm sure are afraid to ask because they're like 'my goodness she might think I'm stupid' or else 'I don't want to pry' but I would always be in there filling them with knowledge."*

### **Using humour**

If you are comfortable using humour when talking about your epilepsy, it can lighten the situation.



# 7

## Dealing with reactions

When telling someone about your epilepsy, the person may react in different ways. The majority of people will be interested, understanding and concerned with your well-being. Some may not know how to handle it. On occasions you may receive a negative reaction.

*"I brought it to my work colleagues as well, and if anything it was more simple, if anything there was interest, and there was support from them. People were quite quite happy about that as I recall now, quite quite easy, and quite quite happy about that."*

*"The reaction was 'okay, that's good, thanks for letting us know' ...And there wasn't much discussion around it. "*

Here are some responses you can use:

- If the person is interested and asks questions, continue the conversation about your epilepsy.
- If the person is quiet and doesn't ask questions, leave it and wait until they are ready to talk about it.
- If the person is shocked or panics, reassure them and allow time to process the information.
- If the person is mis-informed about epilepsy, you can give them the correct information.
- If the person reacts in a negative way, don't let it distress you. This is the other person's problem, not yours and you can walk away from that person.

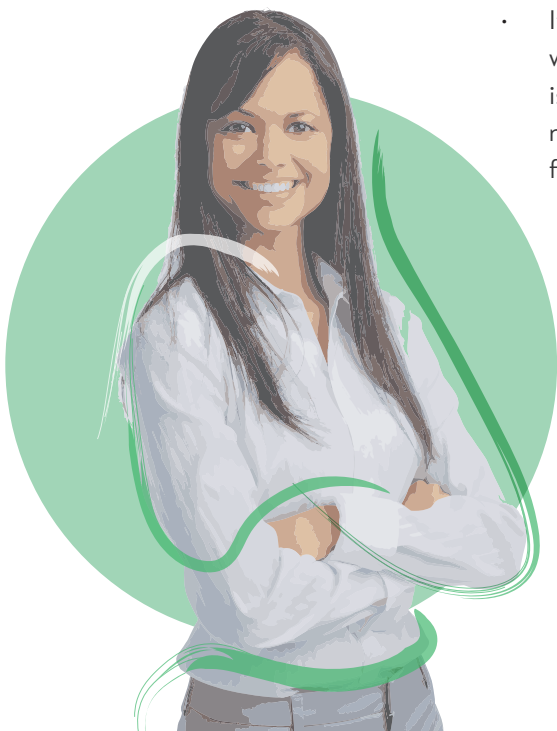
*"I just give it [I have epilepsy], then I wait for them to process it. And I'd say it can be a bit terrifying when I shove all this information on them."*

*"I just write them off, they obviously can't handle something that's just part of life...I just say right do not spend time with them. If they're going to have that issue, definitely not."*

*"One of them [supervisor at work] didn't react too well to it, so I reported it."*

As we mentioned at the start, as long as you are comfortable with your epilepsy, the vast majority of people will also become comfortable with it and give you the support to get on with living your life.

*"When I tell people, they would change but unknowingly. They might be a bit more cautious like, 'oh are you sure you can do that' and I'm like 'don't question me'. Or they might kind of distance themselves without knowing it."*





# About How2tell

The How2tell study was conducted by a research team led by Prof. Naomi Elliott from the School of Nursing & Midwifery, Trinity College Dublin, Ireland.

The research team thanks the people with epilepsy who shared their invaluable experiences and everyone who supported the study. The quotes are written as spoken by people with epilepsy.

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## Further Information

For more information about epilepsy please visit the Epilepsy Ireland website.

[www.epilepsy.ie](http://www.epilepsy.ie)

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## Disclaimer

The information contained in this booklet is for educational and informational purposes only. It aims to assist people with epilepsy who want to learn HOW to tell others about their epilepsy. While the information is based on a research study of the experiences of adults (aged 18+) with a range of forms of epilepsy, it is provided without knowledge of the reader's medical condition or specific circumstances. The application and impact of the information may vary from person to person and therefore, it is intended as a guide only. This is not a substitute for medical advice. Neither Trinity College Dublin nor Epilepsy Ireland shall bear responsibility for any direct or indirect loss or damage resulting from the use of the information.



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