



# ***Living with Epilepsy Memory and Wellbeing***



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# Introduction

This booklet explains why some people with epilepsy have memory problems. The aim is to talk you through why this might be and provide you with some ideas that may help to enhance and improve your memory. This is also a guide to help you to understand how your epilepsy may affect your emotional wellbeing. The majority of people with epilepsy have good seizure control and are able to live life to the full. However, a number of people feel their epilepsy is holding them back and they struggle to cope with it on a daily basis. We hope that reading this guide will give you some tips on how to cope better.

## What is epilepsy?

Epilepsy is one of the most common neurological conditions around the world, with approximately 40,000 people in Ireland living with the condition. People with epilepsy have repeated seizures. Up to 70% of people in Ireland will achieve control of their seizures with the right Antiepileptic Drugs (AED's). It is possible for someone to have a single seizure and not go on to be diagnosed with epilepsy. The reason this might happen could be as a result of a high temperature or a head trauma.

Seizures usually last a short time and the brain works normally between seizures. Our brain cells process billions of messages to each other and these control what we say and do. A seizure can occur if there is a disruption in the processing of these messages.

Epilepsy Ireland has a range of information on epilepsy including the different types of seizures, treatment, safety and lifestyle. You can visit our website to view further information on [www.epilepsy.ie](http://www.epilepsy.ie) or contact your regional office (details are on the back cover) for further support and guidance.

# Memory

We all experience problems with forgetting people's names and where we left our car/house keys. This can be very frustrating when it happens. Our memory holds so much information it is not surprising it can sometimes let us down. Our memory lets us recall events, people and places and all the facts we know. We use it to store and remember everything we have learned and experienced.

Our memory has two parts; our short term memory and long term memory.

## Short term memory (STM)

This part of our memory is where we remember information for a short time and it might be a few seconds or minutes. Then the information is forgotten as it is no longer needed. Often we only remember long enough in order to carry out a task, for example, buying today's groceries. How many of us have gone to the shop for bread and come home with milk and no bread?

## Long term memory (LTM)

This is the part of our memory where we store and hold details for a long time. We can usually recall these memories as we need them. For example, when we are given our bank card security number we have to learn it and use it before it stays in our long term memory for the years ahead. Each time we need to withdraw money, our memory gives us the card's number in order for us to proceed.

Information we want to store in our LTM needs to be practiced or linked to something we already know. It then passes successfully from our short term memory to our long term memory. This process of repeating information is known as encoding or learning.

When we want to remember something we find it in our short or long term memory. Information is continually passing daily between these two memory stores.

# Memory Problems

Memory problems can happen for many reasons. There are three stages to memory:

1. Learning
2. Storing
3. Recalling the memory



Mistakes can happen at any of these stages causing us to forget. We may have problems with certain types of memory, such as those listed in the grid below.

## Different ways to remember

We all use different ways to help us to remember the information we are looking to recall. We have to be able to memorise faces, facts, dates and places we have been and how to do things.

The most common types of memory we use are:

Memory	Use	Example
Short term memory	This is our working memory. It holds information for a short time.	Remembering a new person's name during the first conversation.
Long term memory	This is our memory bank	Remembering our home address.
Visual memory	This is the memory we use to recognise faces and objects.	Recognising our friends and family.
Verbal memory	This is the memory we use for spoken word.	Remembering the words of songs/ rhymes/poems.
Procedural memory	This is the memory we use to do something.	Riding a bike, washing dishes, brushing our teeth or getting dressed.
Semantic memory	This is the memory we use to remember facts.	Remembering capital cities.
Episodic memory	This is the memory we use for events in our life.	Remembering events from our childhood.

## Memory and Epilepsy

People with epilepsy often report that they have memory difficulties. There can be a number of factors that may cause this:



## **Cause of epilepsy**

Some people have a cause for their epilepsy. This might be due to damage to the brain from a head injury or infection. If part of the brain that deals with memory is damaged this could lead to some memory loss. People with temporal lobe epilepsy often have memory problems as a result. This is because the temporal lobe is where we learn new memories.

## **Seizures**

A person's memory can be affected before, during and after a seizure. Changes in the brain before the seizure can mean information is not processed well enough to pass into our long term memory. Awareness can also be affected during a seizure. This means that people have little or no recollection of what has happened. Even between seizures a person's memory may be affected. This is because the brain activity may be disrupted even though it is not enough to lead to a seizure.

## **Epilepsy medication (AEDs)**

Many people worry that the medication they take for their epilepsy causes poor memory. The side effects of some medication, for example poor concentration and drowsiness can have a knock-on impact on their ability to remember. However, your memory will be improved if your AEDs successfully stop or lower the number of seizures you have. If you feel your medication affects your memory speak to your GP, nurse or epilepsy specialist. **Do not stop your epilepsy medication without medical advice.**

## **Mood**

How we are feeling can affect our concentration and attention, which can in turn affect our memory. Research has shown that people with epilepsy are more likely to be anxious or depressed. If our brains are overloaded by these feelings we can become distracted and unable to focus on information. In turn this will affect our memory.

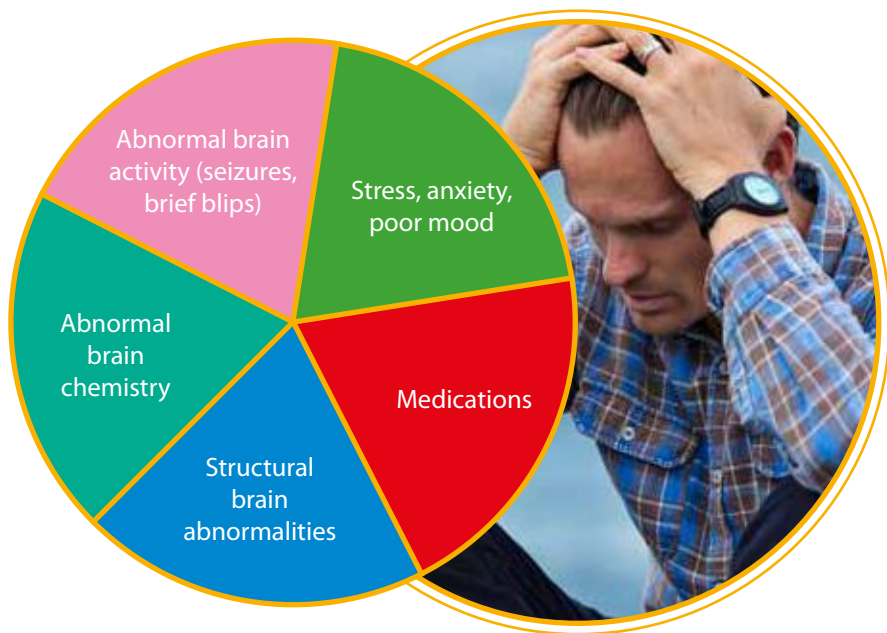
## **Lack of sleep**

People with epilepsy need to make sure that they get enough sleep because a lack of sleep is one of the leading triggers for seizure activity. When you are well-rested your memory improves. This is because tiredness makes people less able to concentrate, learn and store new information.

## **Surgery**

A number of people each year undergo surgery to try and stop their seizures. Sometimes the memory problems can be as a result of the surgery.

## Components of memory impairment in epilepsy



## Improving memory

Some people have general memory problems. Others have particular difficulties such as remembering names or how to get somewhere. People with epilepsy will have extra information to remember, like taking their AEDs, noting seizure triggers and keeping medical appointments.

If you know that you are forgetful, there are many ways and things you can do to help you remember. Your family and friends may also be able to remind you.



Try these tips to help your memory:

### **Focus on one thing at a time**

It helps to do one thing at a time. Try to focus. If you are not paying close attention to a task or to new information you may not remember it later. Develop daily routines and try to be as organised as possible. This will help you to plan the things you want to do and complete.

### **Don't overload your memory**

Mistakes are more likely to be made if your memory has to deal with many things all at once. If there is too much information, your brain may become overloaded. You can then forget things.

### **Record information**

It helps to write things down. Try to keep a diary and calendar of events. Our phones are all equipped with calendars and they are set up to send us reminders of the events that are noted. Also write out to-do lists of tasks that you need to get through. This way you will see a record of what you have also achieved.

### **Staying active**

Keep your mind active by doing things that you enjoy. This could be anything from crosswords and Sudoku to playing computer games. Physical exercise like walking can also help.

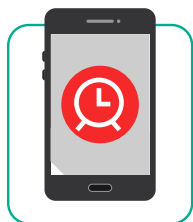
### **Looking after yourself**

Stress can affect epilepsy as well as memory. Speak to your GP or nurse about relaxation tips. There are many local mindfulness and yoga groups in all areas so do some research as to what is available to you locally. You could also contact Epilepsy Ireland to enquire about other supports that might be available to you in your area.

## Extra help

Talk to your pharmacist about the possibility of getting your medications delivered. They can also support you by blister-packing your medication into the days of the month so you have one less thing to think about. Some pharmacies may charge for blister packing.

Use the memory aids available to us such as, diaries, calendars, notepads, post-it notes, digital voice recordings, talking clocks and mobile phone alarms. The more you use them the more they become part of your routine and it reinforces the information that you are storing.



## Problem areas

Once you have figured out that you are having problems with your memory you can work on ways to improve this:

### If you often forget names:

#### Do

- ✓ Focus when you are first learning the name
- ✓ Say the name out loud in conversation
- ✓ Try to link the name to someone or something you know. This could be another person you know with the same name
- ✓ Think back to the first time that you met. What was the memory link you made?

#### Don't

- ✗ Worry or panic. You can chat to someone without saying their name
- ✗ Feel bad saying you have forgotten. Most people find it hard to remember names

## If you are forgetful:

### Do

- ✓ Use back up methods like a diary and calendar
- ✓ Check your diary and plan your day with set routines, for example, taking your tablets with breakfast
- ✓ Leave your calendar, notes and reminders in places where you will see them easily
- ✓ Ask friends and family to remind you of important dates
- ✓ Set your mobile phone, computer or smart devices to remind you of appointments. This is good if you are doing an activity different to your usual routine
- ✓ Think about using the first letter of words or words that rhyme (mnemonics) to help your memory. For example, if you need to buy bacon, apples and tomatoes you could use the word BAT as a reminder if it would help
- ✓ Plan your journey if you have difficulty finding places. Try to remember landmarks on the way there. This can be easier than memorising a map

### Don't

- ✗ Worry or panic if you forget the way. You can ask someone for directions
- ✗ Put things off. Write them down as soon as you remember

## If you often lose things:

### Do

- ✓ Make it a habit to put important objects like your keys or money in the same place each day
- ✓ Focus on the task as you put your belongings away
- ✓ Use labels on drawers and cupboards to remind you where things are kept

## Final Points

*All of us can learn new ways to improve our memory. It certainly helps if we have set routines. Think over any information you need to remember.*

*It takes time and work to form new routines and don't get frustrated with yourself if it takes you longer than you'd like. Our memory holds huge amounts of information so for this reason we should not be too hard on ourselves when we forget.*

*People with epilepsy can often worry that they will lose their memory completely and develop dementia.*

*This is rarely the case. Speak to your GP if you are worried about your memory.*

*Ask them if they could put you in touch with a memory specialist such as a neuropsychologist. You can also make contact with your regional office in Epilepsy Ireland and speak to the Community Resource Officer to discuss supports that may be suitable for you.*



# Emotional Wellbeing

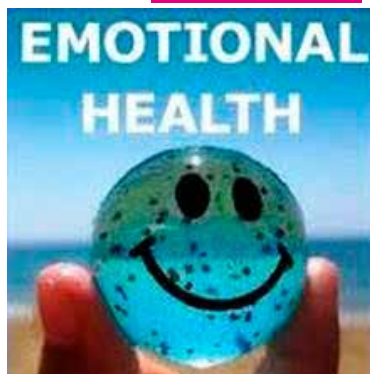
## It's normal to feel down and out of sorts

When you are told that you have epilepsy it's completely normal to feel anxious, sad or even angry. Coming to terms with a diagnosis of a long term condition is not easy. Often people struggle with this. Over time, however, many people find that it becomes easier to carry on with their lives as normally as possible. There are many things that you can do to make you feel better.

Once you have begun to feel more positive, you may find that your seizures will also reduce. The more you look after both your mind and body, the better you will cope.

It takes time and patience to accept your condition and how it may affect your life and work. Often just talking to someone about how you feel will help you move forward. It might also help to speak to someone who has been through a similar experience, but always do what you feel is right for you at any given time.

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# The link between emotional wellbeing and seizures

It's important to address how you feel. Being stressed, anxious or depressed are all negative feelings. These may prevent you from carrying on with your daily life as normal. They can also have a direct impact on your epilepsy and how well your seizures are controlled.

When you are feeling low, you may sometimes forget to take your medication. Some days you may not feel like taking your medication at all.

Sometimes, people try and cope with these feelings by drinking alcohol or taking drugs. All of this can make your seizures worse. It can also lead to you feeling more depressed.

It is well known that stress and anxiety may trigger seizures. This is another reason why you should not ignore how you are truly feeling. Changing the way you feel can make a big difference to your seizure activity.

Anxiety is a very common condition. Any one of us, irrespective of age, gender or background can be affected. It is possible to minimise the impact of anxiety by accessing information and support, and finding ways to manage the condition.

Here is a brief check-list of possible anxiety symptoms. If you feel that these are occurring frequently, please contact your GP for follow up and support.

1. Feeling restless or finding it hard to relax
2. Feeling like your thoughts are racing or that you can't stop worrying about things
3. Feeling that your heart is racing or thumping
4. Feeling scared or panicky
5. Feeling tension in your muscles



## Reasons for feeling low

If you have been feeling low for a while, the best thing to do is speak to your GP, epilepsy nurse or epilepsy specialist. They may be able to help you to understand what is making you feel this way. Then you can get the support you need.

There are many reasons why you may feel out of sorts. Here are some of the more common ones:

### **You may be upset because you feel everything has changed about you since your diagnosis.**



We have already mentioned this but it's worth stressing again that it's perfectly normal to feel upset or angry for a while. The more you know about your epilepsy the easier it can be to put things into perspective. Talk to someone you trust about how you feel or phone your local Community Resource Officer for your region (contact details are on the back cover) for further support.

### **You may be upset because your friends and family treat you differently.**

Remember, they will need some time to adjust too. You may find that they have become more overprotective of you.

This can affect the way you feel about yourself. They may be acting like this for your protection, but speak to them if it is concerning you. Once they know and learn more about epilepsy and how it affects you, they will become more relaxed about it.



### **You may struggle with how other people view you.**

Sadly, you may come across some stigma which has been historically attached to epilepsy. The good thing is that this is changing for the better in communities around the country. Accept that you cannot change what other people think and remember that you may be the first person that they have met with the epilepsy. In many cases,





people are unaware of the true impact of the condition. Inform those close to you about epilepsy and how it impacts you and what you can and cannot do. This will usually change how people will view you.

### **You may struggle to accept the way your life has changed.**



This may be the case if your seizures are not well controlled. Living with frequent and unpredictable seizures can be difficult. Having these seizures can make you feel like you have lost control of your own body. Some people start avoiding public places, such as the cinema, or won't use public transport because they are afraid of having a seizure.

If you have frequent seizures, you will have to make some changes to your life to keep you safe, but you do not have to cut yourself off from friends and family. Any loss of independence can be hard to accept. However, talking to someone can give you many ideas on how to strike a balance between keeping as safe as possible and allowing yourself to get some or all of your independence back.

### **Feeling low may be a side effect of your AEDs.**

Side effects are usually mild and once your body gets used to the medication, these tend to disappear. Common side effects are drowsiness, nausea, weight gain or loss. Mood swings and more permanent changes to your mood can be part of it. If you feel more irritable or your mood has changed in an extreme way since you've started your treatment, talk to your doctor or nurse to inform them of these changes.

Keep a diary about how you feel. You can score between 0 and 10 (0 for worst and 10 for best) on how you feel in the morning, afternoon and evening. Write down anything that's changed since starting your treatment and take this with you to your next appointment. This will help your consultant or nurse decide whether your mood swings are side effects of your medications, if this is the case, you may be given a reduced dosage or a different



type of medications. **Never reduce your dosage yourself: this could be dangerous and make your seizures worse.** Sometimes, your doctor may introduce other medication such as anti-depressants to help you cope with the way you feel as a short-term measure.

### **Your low mood could be part of your seizures.**

Many people find that they feel very strong emotions before and after a seizure. This can be anything from feeling very low to feeling excitement or even euphoria. Some of these emotions can occur up to 72 hours before a seizure and 3 days after a seizure. It is important that you discuss this with your Neurology team if you find that this is something you experience. Your doctor will want to try and reduce the number of seizures you have as much as possible. Once your seizures are better controlled, you may find that these strong emotions disappear.

### **Your low mood could be linked to the cause of your seizures.**

For a small number of people their seizures may be caused by scarring to one part of the brain. If this scarring is in an area of your brain which also deals with your emotions it can be the cause for the way you feel. One such area is the temporal lobe. Low mood, anxiety and depression are therefore more common for people with seizures occurring in this part of the brain. Your consultant will check to see if other medications may be suitable to help you.

### **There could be a link to your family history.**

Sometimes others in your family may have experienced depression. However, just because someone in your family has a history of depression, this does not mean that you will be affected. Remember that depression is a very common condition which affects more than half of all people at some point in their life. Family history is just another factor worth bearing in mind. Ensure that your medical team are aware of this so they can treat you more effectively if needed.

## When should you get help?

Everyone is different and copes differently with a diagnosis of epilepsy. They soon begin to feel better without needing support. Others, however, need help with the way they feel. They may continue to feel anxious, sad, angry or depressed. They may find that they are becoming increasingly irritable with those around them. They may also begin to experience feelings of fear or panic. Sometimes they may have physical pain that cannot be explained by another medical condition.

You may find it is beginning to have a more serious impact on your ability to work and interact with people, including your own family.

Give yourself time to adjust. If you find you cannot shake off these feelings after a few weeks, and they are stopping you from getting on with your life, get help.



**If you find some or most of the following apply to you, make an appointment to see your doctor:**

- + You feel sad most of the time
- + You begin to lose interest in the things you used to enjoy, such as a hobby, sport or leisure activity
- + You no longer want to go out with friends and mostly prefer to be left alone
- + You lose interest in your sex life
- + You feel bad or guilty for no good reason
- + Your appetite has changed. Suddenly you don't want to eat at all or you are over-eating
- + You find it difficult to get to sleep at night and wake up frequently throughout the night
- + You feel tired all of the time even though you sleep for many hours at night and during the day
- + Friends notice that you no longer pay attention to how you look



## What to do if you are suicidal

Sometimes people who struggle to come to terms with epilepsy think about suicide. They find it difficult to imagine that things will get better. If you have these feelings talk to someone you trust. This could be a member of your family or a close friend. Some people prefer to speak to their doctor or phone a helpline. You will be listened to and will not be judged. It can help to talk to someone about the reasons why you want to end your life.

**If you are feeling suicidal right now, please pick up the phone and speak to someone. It's important that you do.**

[Samaritans](#)

116 123 (free)

[Pieta House](#)

1800 247 247

[Aware](#)

1800 804 848 (10am – 10pm Mon-Sun)

[Teenline](#)

1800 833 634

*It may be difficult to imagine feeling better but speaking to someone will help.*

## Where to go if you need help

Your doctor is usually your first point of contact. If you are feeling low, they can look at your AEDs to see if mood changes are a possible side effect. Your doctor will also check whether your low mood is caused by another medication. Your Doctor will be able to advise you of the best treatment for you including counselling, psychiatry, the community mental health team or anti-depressants for further support. If your epilepsy medications need to be reviewed, your doctor will refer you back to your consultant.

You can also talk to your epilepsy nurse. You can ask for advice on medications and possible side effects, as well as how to keep as safe as possible with seizures. You can talk about anything that worries you such as the impact epilepsy may have on your relationships. The nurse will understand how epilepsy can affect your life and how it can make you feel. They may be able to suggest ways to help you accept and deal with the condition better.

Epilepsy Ireland help people to come to terms with their epilepsy. We are here to listen and give you some emotional support. We understand it's not always easy to describe how you are feeling. If you cannot find one word, use lots. What does it feel like inside your head? What does it make you feel like doing? We may be able to suggest different ways to help you to get on with your life. Our contact details for all of the regional offices can be found on the back cover.

There are also many other organisations and helplines you can contact for support. We have listed these on the previous page. If you don't know who to phone, talk to us. We can refer you to someone that can best support you.



## Changing the way you think and feel

Once you identify the things that may influence the way you feel about yourself, you can start to address these. Many of them are probably practical things. For example, if you are upset about restrictions on your life because of your seizures, talk to people who can help you put things into perspective. There may be things you can do to adjust to the changes. This might be an adjustment to your job or leisure activities. Don't give up. Don't listen to well-meaning people who tell you that you can no longer do certain things without good reason.

Remember that you are more than your epilepsy and you don't have to be defined by it. If you act confidently, people will react in a more positive way towards you.

How you think about your life and other people can affect your emotions, feelings and behaviour. Therefore, changing how you think can change the way you feel and behave. A counsellor can help you work through this in more detail.

**Try some simple steps towards changing the way you think, feel and act. Practising just some of these steps on a regular basis can make a big difference.**

- + **Stop negative thoughts** before they turn into destructive statements. Some people find that saying 'no' aloud helps to stop these thoughts. Replace them with positive thoughts. Over time this will become a habit and you will start to feel better.
- + **If you feel overwhelmed by a situation and this makes you anxious or depressed, break it down into small manageable chunks.** What was the situation that made you feel anxious? What did you think at the time? How did this make you feel? How did you react? Could you have thought differently at the time? Would this have changed the way you felt? Realising that you can choose your own thoughts can be powerful.



- + **Focus on good.** Ask a friend to help you list all that's good and bad in your life. When you are down it's easy to see only the bad things. A friend can remind you of all the positive things in your life. Once you have a list of all the good things, remind yourself of this several times a day. If you do this for a while, you will automatically focus on the positive.
- + **Imagine a friend in the same situation as you are.** Then imagine giving them advice. What would you say to them? Try to be as objective as possible. This will allow you to step back and look at your situation in a slightly different way. Then follow your own advice and be the expert on your own life.
- + **Take responsibility for your actions.** Accept that you are responsible for every decision you make, and for every action you take. Realising this can be very empowering. You don't have to be passive but can play an active role in what happens to you.
- + **Learn how to deal with criticism.** Nobody is perfect, we all make mistakes. You will miss the point of helpful criticism if you immediately take it personally. Criticism when it's justified can be an opportunity for you to learn. Be open to this kind of criticism, and react calmly.
- + **Learn how to deal with anger in a healthy way.** Being angry is a normal emotion. How you express this though can make a big difference. There are many different techniques you can learn on how to manage your anger better. Recognise when you are angry. Try to keep calm and think about the situation first. Check out the facts – are they correct? If not walk away from the situation. Uncontrolled anger can be destructive to both yourself and those around you.



## Other ways to help yourself

Hopefully by now you will recognise that the way you feel about your epilepsy is perfectly normal. There is help if you need it, but there are also many more things you can do to take control of your life again.

It's important to remember that stress or anxiety can be a common trigger for seizures in many people. So, if you learn to control this aspect of your life, you may remove a contributing factor to your seizures. You may find after a while that you have fewer seizures.



**You need to find what works best for you. Here are some tips others have found useful:**

- + **Know as much as possible about your epilepsy.** The more you know the less scary it is.
- + Be aware of how you approach your epilepsy. Stop it from being the focus of your life. **It's part of you but there is a lot more to you than epilepsy.**
- + Find out if you have any **seizure triggers**. Avoiding them may prevent some seizures.
- + **Take responsibility for your own health.** Eating a healthy balanced diet, taking regular exercise and getting plenty of sleep can have a positive impact on how you feel. It can also help to reduce seizures.
- + **Be confident.** Let others know what you want or don't want. Learn to express yourself with confidence. Learn to stand up for yourself. Being confident also means learning to feel good about yourself.





- + **Reward yourself.** Whenever you have achieved something, treat yourself to something you enjoy. This can help you focus more on the things you do well rather than those you don't.
- + **Keep a diary of your moods,** in the same way you keep a diary of your seizures. Also write down what you do to counter those moods and if it is successful. This will help you learn to recognise what works for you.
- + **Learn how to use breathing exercises** to let go of tension. When you are stressed, your breathing becomes shallow. If this goes on for a long period of time, this can affect the oxygen levels that are circulating around your body. This in turn can affect your health and energy levels. When you feel stressed, take some slow and deep breaths. Make time to do this several times a day.
- + **Take time to relax.** Many of us are constantly on the go, trying to do too many things at the same time. This can put you out of touch with how





you feel. Allocating an amount of time to relax every day is important. Simply going for a walk can change the way you feel. Some people enjoy

meditation, yoga or tai chi as a way of relaxing and winding down. Find what works best for you and take regular time out for yourself. This will make your life less stressful and will improve your health and wellbeing.

- + Explore how **complementary therapies** can help you to relax. Check with your doctor or epilepsy nurse to make sure the therapy you chose is safe for you.
- + **Do things you enjoy.** Take up a hobby or leisure activity. Try gardening, join a walking club, go dancing, play golf..... there's something for you to get involved in. If you feel isolated because of your epilepsy, choose an activity where you meet other people. Your doctor or nurse can advise you if it is safe.
- + **Help other people.** Feeling needed is important. Contact your local volunteer centre to see how you can get involved with helping others. Remember that everyone has something to contribute.

## Final Points

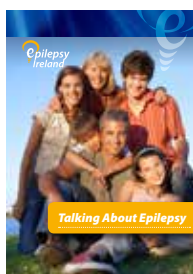
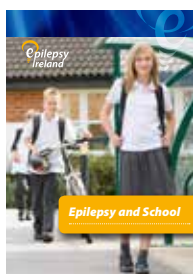
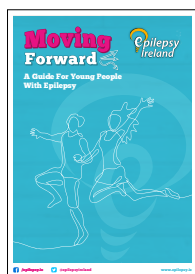
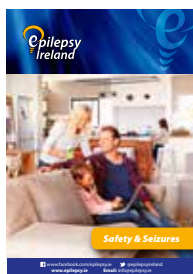
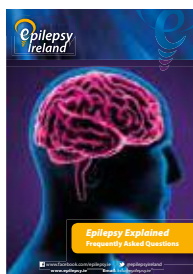
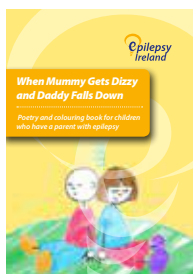
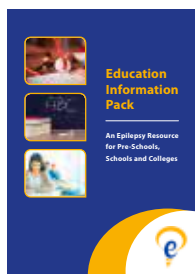
*If you experience any other feelings, emotions or sensations not mentioned in this booklet, speak to your doctor. This could be seeing things or hearing voices (hallucinations) or having unusual thoughts (delusions). All of this can be part of having seizures, but it is important to tell your doctor about this.*

*We hope this booklet has given a better understanding of the many things that can affect your emotional wellbeing. Remember, negative feelings and emotions are a normal part of life and epilepsy, but if they don't go away, talk to your doctor. **Epilepsy affects your life but doesn't have to control it.***



# Epilepsy Ireland Resources

## FREE TO DOWNLOAD from our website [www.epilepsy.ie](http://www.epilepsy.ie)



## Notes

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Epilepsy Ireland would like to thank Dr Sarah Clarke, Senior Clinical Neuropsychologist, Beaumont Hospital and Sinead Murphy, Registered Advanced Nurse Practitioner, Epilepsy Ireland and Beaumont Hospital for their invaluable input into the information contained in this booklet.



Thank you and credit to Epilepsy Scotland who has kindly shared their information on this topic with Epilepsy Ireland for use with people living with the condition.



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

**Facebook:** [facebook.com/epilepsy.ie](https://facebook.com/epilepsy.ie)

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**YouTube:** [youtube.com/BrainwaveEpilepsy](https://youtube.com/BrainwaveEpilepsy)

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