

# Moving Forward



**A Guide For Young People  
With Epilepsy**



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



Epilepsy Ireland  
249 Crumlin Road, Dublin 12

Tel.: (01) 455 7500  
Email: [info@epilepsy.ie](mailto:info@epilepsy.ie)  
Web: [www.epilepsy.ie](http://www.epilepsy.ie)

Facebook: [www.facebook.com/epilepsy.ie](http://www.facebook.com/epilepsy.ie)  
Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)

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## Foreword

In the development of this book we have met with many young people with epilepsy and their parents who have taught us a lot about what it's like to live with epilepsy and the challenges they have to face.

They have helped us to identify what young people want to know about at this stage of their lives and with their help we have developed this booklet. It has information about transition and moving to adult services. There is also a section on top tips for living with epilepsy and a small section for parents too. There are lots of links to resources at the back so you can find out more information if you want.

We hope you find it useful and interesting and that you feel more informed and empowered to face the challenges that may lie ahead on your journey towards adulthood.

*Epilepsy Ireland Team*

# Introduction

**This booklet is for young people with epilepsy and their parents. It provides information about common issues for young people with epilepsy and introduces the concept of moving to adult health services or transition as it is called. For the purposes of this booklet the follow terms are used:**

**Young person, teenager or adolescent refers to anyone aged 12 upwards who will be moving from child-based to adult healthcare.**

**Parent(s) refers to whoever the young person would identify as their main carer(s).**

**Healthcare professional refers to anyone involved in your health such as doctor, GP, nurse specialist, psychologist, or social worker.**

The content of this booklet has been developed by Yvonne Owen, Epilepsy Transition Coordinator for the National Children's Hospital Group and Epilepsy Ireland, with contributions from young people with epilepsy, parents and the paediatric epilepsy teams at:

**Temple Street University Children's Hospital**

**Our Lady's Children's Hospital Crumlin**

**National Children's Hospital Tallaght**

We would like to acknowledge all our contributors and to thank all the staff from the neurology teams at the paediatric and adult sites who have supported the transition services to date.

**Disclaimer:** This booklet provides general information about epilepsy and transition and it is important to remember that services may vary between hospitals. If you have any questions about transition or your epilepsy, please talk to your healthcare professional.

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# Section 1

## Transition

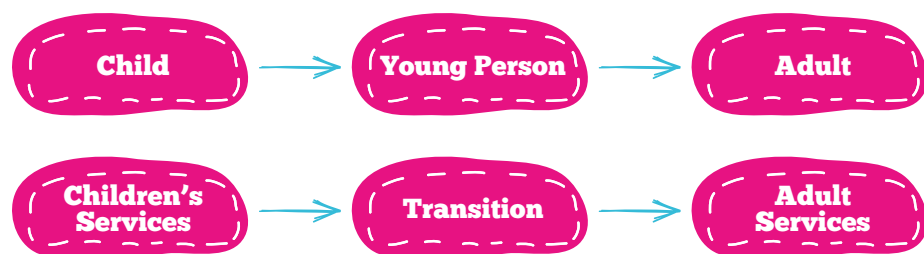




## What is transition?

Transition is all about growing up and moving on. Many teenagers/young people with a chronic condition like epilepsy may need to stay on medication and continue to attend hospitals for appointments throughout their life.

In healthcare we use the word **'transition'** to describe the process of planning, preparing and moving from a children's healthcare service to an adult's healthcare service.

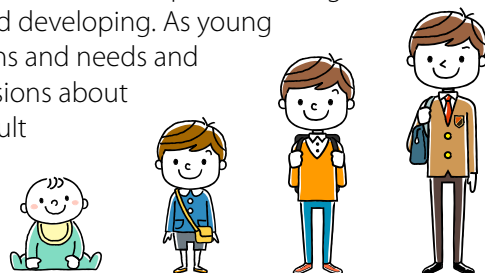


Transition should happen gradually, and starting early will give you, your parents and your healthcare team the time to talk about what healthcare you will need as an adult. You will also discuss which adult services will best suit your needs and when is the right time for you to make the move.

Not everyone's transition experience will be the same. Some young people with epilepsy may also have more complex health or learning needs. This may affect how independent they can be.

## Why do I need to move on to adult services?

Healthcare professionals in children's services are expert in looking after children as they are growing and developing. As young adults you will have different concerns and needs and you will start to make your own decisions about your lifestyle and your health. The adult services are the most appropriate place for you to get the information and support you need to make these decisions.



Sometimes young people and their parent(s) are nervous and worried about leaving the children's service and the staff that have been caring for them. This can be difficult but it is good to think of this change as a positive sign that you are growing up and becoming more independent.

By the time you are at the end of the transition process, you may feel that you have grown out of children's services and are ready to move to an adult hospital. Once you get used to the adult hospital you should settle into your new routine and get to know your new epilepsy team.

## What do I need to think about?

As you transition there are many things to consider:



These are all topics that will be discussed at different stages over the course of your transition journey. In Section 2 – Top Tips for Living with Epilepsy, you will get lots of useful information about each of these topics.

## When should I start thinking about transition?

Transition happens gradually, through stages. The sooner everyone starts talking about and planning transition, the more successful it will be.



**Start talking about transition with your doctor or nurse.**

**Get more involved in your clinic visit.**

**Practice asking and answering questions.**

**Find out about your epilepsy.**



**Practice being more independent and take on responsibility for things such as organising your own medication.**

**Learn more about your epilepsy and your medications and how they can impact on your life.**

**Spend time alone at the clinic even if only for a few minutes. It is a good chance to practice speaking up for yourself.**



**Transfer to adult services is arranged.**

**Continue to learn about epilepsy and treatment and lifestyle.**

**Try to organise your own appointments and prescriptions.**

**Spend more time alone at the clinic.**

## When will I transfer to adult services?

The best time to move will be different for each person. It usually happens after you turn 16 years old. The final decision on when you move should be made together by you, your parent(s) and the epilepsy team.

The length of time it will take for your transfer may vary depending on which adult services you will be going to. Your paediatric team will continue to care for you until your care is taken over by the adult hospital.

## Where will I transfer to?

Your doctor will help you with choosing an adult neurologist to take over your care. They will recommend what adult epilepsy service is best for you based on where you live, the type of epilepsy you have, and what services you will need.

With your permission, your medical information including letters, test results and reports will be sent to your new doctor. Your family doctor (GP) will be told which adult services you are going to. Some adult hospitals may have a specific transition clinic in place which is just for young people like you moving over from paediatric to adult care.

## What is different about the adult services?

**Healthcare professionals may speak directly to you, not your parents.**

**You may see different doctors/nurses at each appointment.**

**If you are admitted to an adult hospital, your parents may not be able to stay overnight with you.**

**Adult clinic appointments may be less frequent and waiting time may be longer.**

**Healthcare professionals may use more medical terms than you were used to in child services; don't be afraid to ask them to explain these to you if you don't understand.**

Although you may feel that the new hospital looks different and there are lots of new faces, there may be lots of things about the adult service that are similar to the children's service. Remember both children's and adult health services are there to care for you and your health.

## Privacy and confidentiality

You have a choice to be seen on your own in the clinic, without your parent/carer if you wish. Sometimes it helps to have someone there to support you and other times you might like to talk to your team on your own about things that are private and confidential.



Once you turn 16 years old, you have a legal right to go to an appointment on your own and for conversations with professionals like your doctor, nurse, psychologist or counsellor to be kept confidential. They will not discuss anything with your carer/parent without your permission.

In most cases your epilepsy team will be able to keep your consultation confidential. However they can't always promise this. If you are under 18 years old, and you tell a health care professional something about you or another child (someone under 18) being harmed or at risk of being harmed they would have to talk to your parent/guardian or a relevant authority such as Tusla (The Child and Family Agency). If the health care professional feels it is something that your family should hear about they will discuss this with you and try to help you talk to your family/carer about your concerns or worries.

## How can I prepare for transition?

Transition planning gives you the chance to start taking on some responsibility for looking after your own healthcare. Lots of practice will help you to gain the confidence and skills required to become more independent in managing your condition. This won't happen after just one clinic appointment. It will take time and may take a number of clinic appointments. If there is anything you don't understand or are unsure of, ask your doctor/nurses and parent(s). They will often have the information you are looking for.



Your parent(s) will have plenty of experience of going to the hospital, making appointments, and asking questions, and will know all about your medicines or treatments. Talk to them about how you feel about moving to adult services. Practice getting involved in looking after your health and taking more responsibility.

While you are getting ready to move on, your parent(s) will still be involved in your healthcare and still have an important role to play.



# REMEMBER



## There are no silly questions.

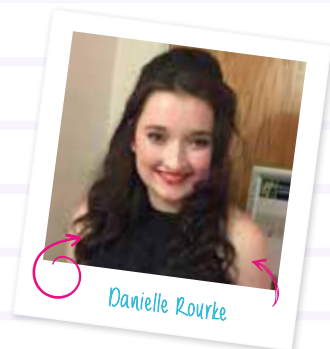
### Top 10 transition tips for teens

1. **Learn about your epilepsy and how it can impact on your lifestyle.**
2. **Spend some time in clinic on your own.**
3. **Practice asking and answering questions at clinic.**
4. **Write questions down beforehand so you don't forget them.**
5. **Find out what keeps you healthy, for example your treatment, diet and lifestyle.**
6. **Try to take some responsibility for remembering what your medicines are called, what they are for, how much to take and when to take them.**
7. **Learn how to get more supplies of your medicines.**
8. **Keep important phone numbers and appointment dates in your mobile phone, calendar or diary.**
9. **Know who your doctor, neurologist, epilepsy nurse, GP and pharmacist are.**
10. **Practice arranging appointments with your neurologist, epilepsy nurse and GP.**

## My Transition Journey

By Danielle Rourke

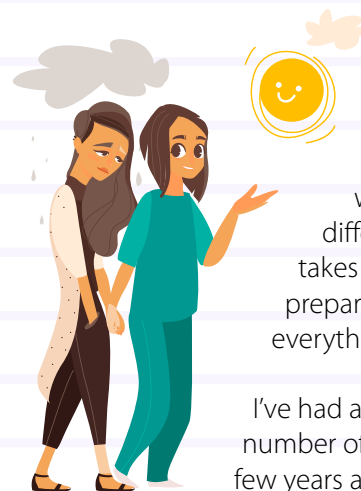
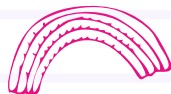
My name is Danielle and I am 20 years old. My epilepsy journey started on the first day of secondary school by getting taken off in an ambulance to the children's hospital after my first seizure in Spanish class. After a few days of doctors' examinations, MRIs and EEGs, I was diagnosed with tonic clonic epilepsy. I was in and out of hospital all the time at the beginning but I didn't mind because I was lucky that I had the perfect doctor. He kept me informed of what was happening with my illness as it got better and worse. I was very lucky and after mutual, superb decisions, I can say that I am five years seizure free and having the best year of my life doing an Erasmus in Austria.



I will admit that at the age of 15 I felt like I didn't fit in in the children's hospital with screaming kids in the waiting room. But I was lucky that in my eyes, I was treated as an adult once I set foot in the doctor's room. I have to admit I was very panicked and had a lot of anxiety about going into the adult hospital as I felt like I wasn't ready. No one had told me about my doctors. No one had shown me where the hospital was or what it looked like on the inside. I had no idea how different the system was in comparison to my previous hospital.

**I was in and out of hospital all the time at the beginning but I didn't mind because I was lucky that I had the perfect doctor. He kept me informed of what was happening with my illness as it got better and worse.**

My first impression of the adult hospital was that it was very fast paced, like a race with little time for the relaxed chat which I was used to. They ask you a lot of questions which I think people should be prepared for. I wasn't ready for the information overload they would give and at 17 I did not know I would be expected to know everything.

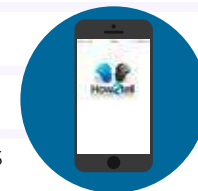


I am on Epilim Chrono which can have side effects for women and babies in pregnancy and I felt overwhelmed by the information they were giving me. I also had lots of questions I wanted to ask about travelling which I feel I didn't get time to ask. The pace and difference in approach in adult hospitals definitely takes times to get used to but once a person is prepared and knows what they are walking into, everything will be fine.

I've had a chance to review this booklet and there are a number of things I really like and wish I had access to a few years ago when I was a teenager.

I think that it is a great idea having an introduction to an explanation of the concepts of epilepsy as many people either don't know or don't remember everything. I also think the tips for medication are a great idea and I wish I had known them when I was younger as they would have really helped me. I also think that the links to websites and booklets is great as there are a lot of times that I have read something but had no source to find more information about these areas which are so interesting.

The section "Just for Girls" is brilliant as this area is often ignored and was definitely spoken to me a lot more vaguely than other topics. I know many people who rarely talked about it with their doctor. The How2tell app sounds like a great app that people will be interested to learn about as this is another thing I wish had been around when I was younger.



The link to the STEPS programme is done very well, specifically if parents are worried about their children. The activity sheets will really get young people engaged in the topic as they feel like they have a part to play and is a great way to get them to research their own illness. I would have loved to have done it when I was younger. All the important bits are included in the checklist too!







# Section 2

## Top Teen Tips for Living with Epilepsy



## My epilepsy knowledge

It is important that you know and understand what type of epilepsy you have and how it might affect you. If you don't know about your epilepsy, ask your doctor or nurse specialist to explain it to you.

### DO I KNOW and UNDERSTAND

**My diagnosis.**  
**My seizure types.**  
**My seizure triggers.**  
**My medications.**  
**My lifestyle.**  
**What to do in an emergency.**  
**Where to get help.**



## What is epilepsy?

Epilepsy is a tendency to have multiple seizures. You usually have to have two or more seizures to be diagnosed with epilepsy. Here are some epilepsy facts:

**Epilepsy affects nearly 40,000 people in Ireland.**  
**That's 1 in every 115 people.**

**Epilepsy is not a disease.**

**It is not contagious.**

**It is not a psychological disorder. See the section below on NEAD for more information.**

## What is a seizure?

A seizure happens when ordinary brain activity is suddenly interrupted by abnormal, excessive discharges of the nerve cells. It is sometimes described as an electrical storm in the brain.



There are many different types of seizures depending on where the abnormal activity is taking place in the brain.

## Seizure types

Some people can have more than one type of seizure. These are some of the most common types of seizure:

**Focal/partial seizures** – these seizures often start with abnormal activity in one part of the brain, commonly the temporal lobe. They may start with an odd feeling in your tummy or chest, strange smells, strange noises or an unpleasant feeling that is difficult to describe. Some people stay aware during this and others start to lose awareness and behave strangely. Some people carry out purposeless actions or fiddle with their clothing. The seizures can then stop or sometimes they develop into tonic clonic seizures.

**Tonic clonic seizures** – these seizures start when the whole body goes stiff and you lose consciousness. Some people get a brief warning that the seizure is about to start; others don't and it happens suddenly.

- **The tonic phase** – this is when all the muscles in your body stiffen. If you're standing up you will fall to the ground. Sometimes people make a loud noise which is air being forced out of lungs. You may bite your tongue as the jaw muscles are clenched. Your lung muscles can be affected making it difficult to breathe properly and you may go a blue-ish colour. This can look scary to others. This phase can last for up to one minute.
- **The clonic phase** – the brain does not let you stay stiff and in response it makes the muscles relax which causes them to move irregularly. These are known as clonic movements and they can be big jerks or small trembling movements. During this phase you may injure or bruise yourself. Sometimes you may wet yourself as the bladder muscles relax.

**Myoclonic jerks** are sudden, jerky movements which can affect the whole body or certain parts of it, most commonly your arms. They usually happen in the morning and last a few seconds.

**Absence seizures** are where you lose awareness, stop what you are doing and stare blankly. They are usually short, lasting less than 10 seconds, but can happen a few times a day.

### What happens after a seizure?

Usually tonic clonic seizures last under five minutes. As the jerking stops the brain activity settles down and the seizure ends. You will have no memory of what happened and you will feel very tired, confused, and sore. Some people feel like getting sick or have a bad headache. You may need to sleep for a few hours afterwards to allow the brain to recover. For information on first aid for seizures see the Resources section.

### What causes epilepsy?

There is no one reason why people have epilepsy. These are some of the common causes:

**A trauma to the brain - such as a bang to the head, a birth trauma, a brain haemorrhage (bleed), a stroke, a brain tumour or a brain infection.**

**A type of epilepsy that runs in families.**

**Some damage or slight abnormality to your brain which has always been there and which is causing you to have seizures.**

For most people we do not know the cause and there is no explanation as to why they have epilepsy.

### How is epilepsy diagnosed?

**The history or description of the seizure(s).**

**Eye witness accounts or videos of the event can be useful.**

**An EEG (electroencephalogram) test that shows the brainwaves or electrical activity in the brain.**

**An MRI scan (magnetic resonance imaging) - some people will have this detailed x-ray of the brain to see if there are any physical changes causing the seizures.**

### How is epilepsy treated?

There is no cure for epilepsy and it is mainly treated by anti-epileptic drugs (AEDs). They don't cure epilepsy but they help keep seizures under control by altering the activity of neurons in the brain.

AEDs are effective in treating about 70% of people with epilepsy. Sometimes more than one type of AED is needed. For others, treatment options such as epilepsy surgery or dietary treatments might be considered. You can talk to your doctor or nurse about what your options are.

### NEAD - Non-Epilepsy Attack Disorder

Some people have events that look and feel like seizures but are not caused by epilepsy. These events are called non-epileptic events (NEE). These are not caused by abnormal electrical brain activity but by subconscious thoughts, emotions or stress. NEAD is common in adolescents and young adults. NEEs can be treated and are generally associated with a positive outcome. Treatment usually involves psychological assessment and interventions such as cognitive behavioural therapy or guided relaxation therapy. In some cases some people can be diagnosed with both epilepsy and NEAD.

**Want to know more?** For more detailed information on epilepsy and treatments you can check out our website **[www.epilepsy.ie](http://www.epilepsy.ie)** or contact your local Epilepsy Ireland office for more information, booklets and supports for you.

## Seizure triggers

There are certain aspects of lifestyle that can bring on seizures. These are commonly called seizure triggers. Some people don't have any specific triggers, while others can clearly identify what sets their seizures off.

Recognising what your seizure triggers are can help reduce and avoid seizures occurring. It is good to keep a note of anything you think might upset your seizure control.

Here is a list of the most common triggers:

### Know your seizure triggers

**Forgetting to take prescribed seizure medication.**

**Lack of sleep.**

**Missing meals.**

**Stress, excitement, emotional upset.**

**Menstruation/hormonal changes.**

**Illness or fever.**

**Low seizure medication levels.**

**Medications other than prescribed seizure medications.**

**Flickering lights of computers, television, videos, etc.**

**Excessive alcohol or drug use and subsequent withdrawal.**

## Medications

Taking medication is a big part of living with epilepsy and managing your own medications is a way of being more involved and in charge of your health. Anti-epileptic drugs (AEDs) are the main treatment for epilepsy. AEDs will only work if you take them regularly.



AEDs can have many side effects such as drowsiness, headache, dizziness, poor memory and weight changes to name a few. Long-term use of some AEDs can also affect your bone health. If you are having side effects from your AEDs talk to your doctor or nurse about it. They may be able to change your medicine to something else that suits you better.

### Top tips for taking your medication

**Take your AEDs every day, it's really important.**

**Get a pill box/organiser from your pharmacy or online.**

**Set a reminder or alarm on your phone or watch.**

**Make it part of your daily routine so it's just like brushing your teeth!**

**If you forget your AEDs, take them as soon as you remember. If you're late by over six hours just take your evening tablet earlier than usual. Don't take morning and evening tablets together.**

**Take your AEDs even if you are feeling ill or are fasting for a test.**

**Never suddenly stop taking your tablets - this can often just make your seizures worse.**

**Carry a spare dose of AEDs with you in case you change plans.**

**Avoid running out of tablets.**

**In Ireland you can get your AEDs for free through either a medical card or the Long-Term Illness (LTI) Scheme.**

For more information check out our website [www.epilepsy.ie](http://www.epilepsy.ie).



## Alcohol and drugs

If you choose to drink it is important that you know how it can affect you and your seizures and how you can take necessary steps to drink safely and responsibly.



The legal age to drink alcohol is 18 years old. Alcohol is a drug and it can interact with your medications. It may affect how well your medications work, and the medications may increase the effect the alcohol has on you. Being under the influence of alcohol can influence your judgement and you may not recognise a seizure warning or you may forget your tablets.

If you choose not to drink it can be hard not to feel under pressure. Talking to someone other than your friends can help. If you decide to drink, it is advised that you should:

**Drink in moderation - no more than two units of alcohol per day.**

**Know your limits. Avoid binge drinking. Binge drinking can seriously increase your risk of seizures.**

**Never skip your medication before or after a night out. You will be more likely to have a seizure.**

**Stay with people you trust and make sure someone knows what to do if you have a seizure.**

Drugs, such as those you encounter at social events, can seriously mess up your brain. Like alcohol they can impair your decisions and judgement and interact with your AEDs. Once you start experimenting with drugs it can lead to serious health problems and addiction. The best advice is to **just say NO!**

For more information and advice check out our website [www.epilepsy.ie](http://www.epilepsy.ie) or [www.spunout.ie](http://www.spunout.ie).

## Photosensitivity

Only about 3-5% of people with epilepsy will be affected by lights flickering at a certain speed and brightness (e.g. from televisions, computer screens, strobe lights, video games, movies) which can trigger a seizure. This is called photosensitive epilepsy. Your doctor will be able to confirm if this is the type of epilepsy you have or not by doing an EEG (electroencephalogram) test.

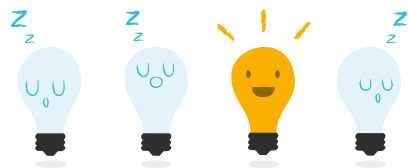
If you do have photosensitive epilepsy you need to avoid these triggers. If you start to feel funny from the lights look downwards, cover one eye, tell a friend and leave the area.

If you are not photosensitive there are no problems with going to discos, concerts or clubs with strobe lights or with using computers or consoles. You should avoid using them for too long and take breaks as it may make you tired.



## Sleep

Sleep is really important and a lack of sleep can be a trigger for seizures. With a busy life that includes school, study, sports, friends and family it can be difficult to squeeze it all in and there isn't time to get enough sleep. Also getting off to sleep can be difficult for teens due to changes in your body clock. Some AEDs can cause tiredness and you may feel more tired than your friends.



### Top tips for sleep

1. **Try sticking to a schedule of going to bed and waking at the same time every day. Eight hours a day are recommended.**
2. **Avoid stimulants like caffeine, nicotine, alcohol, and chocolate for at least six hours before bed. They can make you restless.**
3. **Close down your computer, tablet or phone at least an hour before bed.**
4. **Do something relaxing before bed like reading or listening to music.**
5. **Regular exercise will help improve your sleep. Avoid exercising late at night; try doing it earlier in the day.**
6. **Make your bedroom a calm place where you can chill out and relax.**
7. **If you are planning a late night make sure you get enough sleep the next day.**
8. **Keep naps less than an hour long.**
9. **Avoid lie-ins or sleeping for more than two hours after your usual wake up time. It can mess up your body clock.**
10. **Talk to your doctor/nurse if you feel your AEDs are making you tired.**

## Stress

Stress is an expected and unavoidable part of everyday life. It is our body's reaction to physical and emotional demands. Too much stress is not good for us and it is also one of the most common triggers for seizures. It can impact on your sleep and trigger seizures that way too. Being a teenager is a stressful time and worrying about having seizures can sometimes make you more stressed. Stress can affect people in different ways and if not managed it can lead to anxiety and/or depression.

See the section on dealing with emotions for more advice.

### Top tips on how to manage stress

**Avoid stressful situations where possible.**

**Try to relax when you can.**

**Eat well and sleep well.**

**Try relaxation methods like deep breathing, mindfulness or yoga.**

**Regular exercise can help reduce stress.**

**Do things you enjoy and have some 'me' time**

**Look for help - talk to your doctor/nurse or to Epilepsy Ireland services.**

**Your local hospital or community groups may have stress management classes or resources you can avail of.**

**Beaumont Hospital has a website [www.beaumont.ie/marc](http://www.beaumont.ie/marc) with many mindfulness and relaxation techniques.**

**Talk to your epilepsy team - they may refer you to a psychologist to talk about stress and coping with epilepsy.**

Teen Stress 101  
 parents relationships school  
 over-scheduling keeping up  
 fitting in college expectations



## Diet and nutrition

A healthy diet is important for everyone. Skipping meals can sometimes be a trigger for seizures. It is best to keep to a routine of regular meals and a balanced diet. Try to avoid energy drinks which contain large amounts of caffeine and have been linked to provoking some seizures.

Some AEDs can affect the levels of vitamins and minerals in your body. Your doctor/nurse may prescribe you supplementary vitamins and minerals to combat the effect of some AEDs, for example calcium and Vitamin D are often prescribed for bone health. If you are taking other supplements check the label or talk to your pharmacist to see if they interact with your AEDs.

Some specific diets such as the ketogenic diet or modified Atkins diet have been used as treatment for epilepsy for people with difficult to control epilepsy. Your doctor/nurse would be able to advise you if these were a suitable treatment for you.



## Sport and exercise

Being active is really important to your overall health and wellbeing and can often help you better manage your epilepsy. The majority of sports and activities are safe for people with epilepsy.

If you have regular or unpredictable seizures you may need to take extra care. Your doctor or epilepsy specialist nurse can advise you what activities are safe for you.

### Tops tips for exercising

**Consider the risks - think about what might happen if you had a seizure during that activity.**

**You should never swim or do water sports alone. Let the lifeguard know you have epilepsy.**

**No matter what you do have a buddy - someone who can help out if you run into difficulty.**

**Remember to always wear the proper safety gear such as helmets, lifejackets, padded gear etc.**

**Avoid extreme sports such as bungee jumping, hang-gliding and skydiving.**

**Contact sports: people with epilepsy have no greater chance for injury during these sports than people without epilepsy. The chances of serious injury are small compared with the positive effects of team participation.**



## Driving

For many young people driving is a real sign of independence and becoming an adult. Driving is often a big incentive for young people with epilepsy to take their medication and avoid seizure triggers.

Firstly you must be 17 to apply for a provisional licence in Ireland. When applying for a licence you must declare if you have epilepsy and your doctor has to sign a licence application form.

**For most cases a person with epilepsy can drive provided they have been seizure free for one year and are certified fit to drive by a doctor.**

There are different rules depending on your types of seizures. You need to talk to your neurologist about whether or not you are eligible to drive.

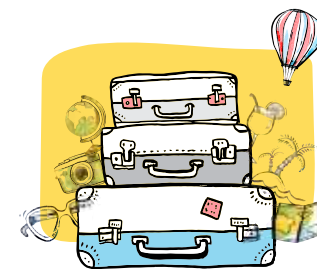
For more information see [www.epilepsy.ie](http://www.epilepsy.ie) or download the Epilepsy, Seizures and Driving Leaflet available either on the Road Safety Authority (RSA) website [www.rsa.ie](http://www.rsa.ie) or the National Driver Licence Service (NDLS) website [www.ndls.ie](http://www.ndls.ie).



## Travel

Having epilepsy should not restrict you from travelling to get out there and see the world. However, whether you are travelling at home or abroad there are some precautions you need to consider.

Ask your doctor or nurse if you have any concerns.



### Top tips for travel

**Loads of common seizure triggers can happen on holiday: hot weather, jetlag, alcohol, dehydration, skipping meals and upset stomachs.**

**Eat regular meals and drink plenty of water to avoid dehydration.**

**Ask your epilepsy team for a summary letter about your epilepsy, your medications and emergency instructions.**

**Take your medication with you in your hand luggage in case your bags get lost or delayed.**

**Keep AEDs in their original packaging.**

**Bring an extra supply of AEDs and a prescription with you in case you lose some or get delayed on your return.**

**Make sure your travel companion knows about your epilepsy and what to do in an emergency.**

**Get proper travel insurance including emergency medical treatment - shop around for the best deal. The European Health Insurance Card (EHIC) gives you cover in EU member states.**

**Plan ahead if you are travelling between time zones. Talk to your doctor, nurse or pharmacist to get advice about what time to take your AEDs.**



The International Bureau for Epilepsy has produced a travel handbook for people with epilepsy. You can get a copy from your local Epilepsy Ireland office or download it directly from **[www.ibe-travelhandbook.org](http://www.ibe-travelhandbook.org)**.

## **Keeping safe**

Having epilepsy can sometimes mean there are more dangers or risks out there to worry about. There are some easy things you can do that can make life safer for you and stop your parents from worrying so much.

### **SUDEP**

Most people with epilepsy live long lives. However they do face a risk of SUDEP which stands for 'sudden unexpected death in epilepsy'. This is when a person with epilepsy dies without warning and no cause is found. This might sound really scary but it is important to know about it and how you can reduce the risks.

Thankfully the risk of SUDEP is very small, affecting 1/1,000 adults with epilepsy and 1/4,500 children with epilepsy. There is no one cause of SUDEP but it is thought that a number of risk factors might be involved. The major risk factor for SUDEP is having tonic clonic seizures and the risk increases as the number of seizures increases.

### **Reducing the risk of SUDEP**

**Take your medication regularly.**

**Identify and avoid triggers for seizures.**

**Keep regular appointments with your doctor.**

**Never stop taking your AEDs without talking to your doctor or nurse.**

**Discuss other epilepsy treatments with your doctor or nurse.**

## **Keeping safe when at home**

**Don't lock the bathroom or bedroom doors - instead use signs to protect your privacy.**

**Take showers instead of baths to reduce the risk of drowning.**

**If you do have a bath have it when someone else is around so they can check on you.**

**Prevent burns by using a microwave rather than a stove.**

**Serve hot liquids or food onto plates at the stove rather than carrying them to the table.**



**Be careful of sharp edges of furniture. Especially around your bedside locker if you tend to have night-time seizures.**

**If you have seizures in your sleep you may consider a bed alarm. You can switch this on when you're ready to settle down for the night. This may help you parents sleep more and worry less.**

More information about safety and alarms is available on our website **[www.epilepsy.ie](http://www.epilepsy.ie)**.

## Keeping safe when going out

**Get some bling! Wear an ID bracelet or pendent, or keep an ID card (available from Epilepsy Ireland) in your wallet. There are lots of different brands and styles to choose from and they don't all look obvious.**

**Tell your friends you have epilepsy and tell them what to do and who to contact if you have a seizure.**

**Text your family to let them know you are all right. They will be more relaxed when you are out.**

## Avoid travelling alone.

**Stand back from roadways and edges of platforms while travelling by bus/train/tram.**

**Never leave your drink unattended as it may get spiked.**

**Never leave a party/club/bar with someone you don't know.**

**Add an ICE (in case of emergency) number to your phone.**



## Keeping safe online

The internet is a big part of a young person's everyday life. There are lots of blogs and websites out there where you can share information about yourself. It is a great way to learn about lots of things including epilepsy, and it is an excellent way to meet other people with epilepsy and talk about your experiences. However there are certain things you need to be careful about:



**Make sure whatever website or group you join is regulated and comes from a reputable source. See our list of recommended sites in the Resources section.**

**Protect your identity. Don't give your username or password or your bank details to anyone. Avoid giving specific details like where you live or your school.**

**Be careful what you say about others online. Be nice to people and they will be nice to you.**

**Watch what you post about yourself or others or allow others to post about you - information and photos can be copied and remain online for a long time even if you think they have been deleted.**

**Never meet up alone with someone you have befriended online. Always meet up in a group, in a public place.**

**Let someone know if something happens online that you are not comfortable with.**

For more information about online safety and cyber bullying check out **[www.reachout.com](http://www.reachout.com)**, **[www.nsteens.org](http://www.nsteens.org)**, **[www.cybersafeireland.org](http://www.cybersafeireland.org)** and **[www.internetmatters.org](http://www.internetmatters.org)**.



## Studying, exams and college

Having a diagnosis of epilepsy should not be a barrier to getting an education or going to college. However some people with epilepsy can experience difficulties with learning due to problems with memory, speed of processing information, and concentration. If you are having frequent seizures it can affect your memory. Also some AEDs can affect memory and cause tiredness which can alter your ability to learn.

### Tips for studying, exams and going to college

**Exams can be stressful and can increase the risk of seizures for some people. If you know that stress triggers your seizures, learn how you can reduce it (see the section on stress).**

**Use relaxation techniques to help with stress.**

**Get organised - use a diary/calendar to keep on track.**

**Stay ahead; avoid late night cramming sessions.**

**Get enough sleep.**

**Get support for learning and exams if needed, such as extra time allowance or a separate exam room. See the State Examinations Commission website ([www.examinations.ie](http://www.examinations.ie)) for more details.**

**Talk to your doctor or nurse. They may refer you to see a psychologist or neuropsychologist to see what your strengths and difficulties are and where you may need some help. They will also give you some more advice and support.**

**Choose a course that is right for you. Talk with your school career guidance counsellor.**

**You may be eligible to apply for the Disability Access Route to Education (DARE) programme as part of your CAO application.**

**Speak to your teachers /lecturers and let them know about your epilepsy. Meet with the disability officer to see what support is there.**



For more information see [www.epilepsy.ie](http://www.epilepsy.ie), [www.accesscollege.ie](http://www.accesscollege.ie), or the Association for Higher Education Access and Disability (AHEAD) website [www.ahead.ie](http://www.ahead.ie). See the resource section for information on Epilepsy Ireland's "Training for Success" programme.

## Career and jobs

Most people with epilepsy are able to work at whatever they choose to do and epilepsy should not get in the way. If your epilepsy is poorly controlled it may limit you from doing certain jobs.

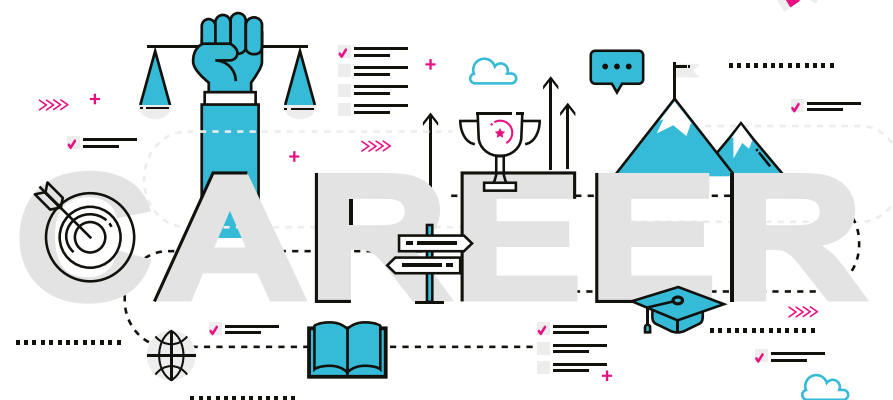
For safety reasons there are certain job restrictions for people with epilepsy:

**Driving a bus or truck - must be 10 years seizure free and off medication.**

**Pilot - restricted.**

**Enlisting for the Army or Naval Service, Garda Síochána or prison service - restricted.**

**Working with unguarded machinery or at heights may be restricted if you are having frequent seizures.**



When you are considering your career choices, think about:

## What are the risks in the job for you or anyone you work with if you have a seizure?

## Will you be working alone?

## Can you predict your seizures or do you get a warning?

### How often do you have seizures?

### Do they happen at a certain time of the day?

**Could you work nights? Nightshifts can disrupt sleep patterns. Lack of sleep can cause seizures for some people.**

For more information check out our **Career & Jobs** factsheet or the **Epilepsy and the Workplace (Advice for the Employer)** booklet, both available from Epilepsy Ireland.

## My sexual health

During puberty your body produces sex hormones that result in changes such as growing taller, altered body shape, more body hair, development of breasts and having periods. You might also feel more emotional and have mood swings.

**Puberty doesn't cause epilepsy but some teenagers, particularly girls, feel that the changes in their hormones can trigger seizures.**

**Certain types of epilepsy syndromes tend to start in teenage years such as juvenile myoclonic epilepsy (JME).**



As you become older you become more aware of your sexuality and your sexual identity. You may have some questions that you find difficult to talk about. Remember you can ask your doctor or nurse in confidence.

Whether or not you have epilepsy it is important to know that if and when you want to have sex, this should be completely your choice. It is not something you should do because you feel under pressure or someone else thinks it's a good idea.

**You are no more likely to have a seizure during sex than at any other time.**

**Some people worry that if they have a baby in the future it will have epilepsy. There is only a slightly higher risk of a child developing epilepsy if a parent has epilepsy.**





## Just for girls

Talking about pregnancy and having babies may not seem that relevant to you now in your teenage years, but your doctor and nurse specialist will need to discuss it with you and consider these issues, especially if you are likely to be taking AEDs for some time.



### Periods

For some girls their seizures get worse a few days before or during their period, or mid cycle. The hormones changing at the time of your period can sometimes affect your seizures. This is also known as catamenial epilepsy. If you think this happens to you, try to keep a seizure diary to see if there is any link between your seizures and your menstrual cycle.

### Contraception

If you are sexually active you need to think about contraception. Some AEDs can interfere with the contraceptive pill and the morning after pill and affect how it works. This may mean that you are not completely protected from pregnancy as you may think you are. Other methods of contraception can also be affected by AEDs. Talk to your doctor or nurse about your options and what suits your needs best.

### Folic acid

Some AEDs can reduce the amount of folic acid in the body. Once you begin having periods you should start taking folic acid. Folic acid is a vitamin that belongs to the vitamin B group. Your doctor/nurse will prescribe this for you (a 5mg daily dose). Folic acid helps to protect the foetus from birth defects, especially spinal cord defects. As most teenage pregnancies are unplanned it is vital you take folic acid all the time.

## Pregnancy

Most babies born to women with epilepsy are healthy, but good pregnancy care is important. Some of the AEDs can increase the risk of birth defects during pregnancy. If you have epilepsy it is really important that, if possible, pregnancies are planned. Planning to have a baby should happen at least a year in advance as this gives time to talk to your doctor or nurse about the risks and they can make changes to your medication before you get pregnant.

### Sodium Valproate/Epilim

Sodium valproate is a highly effective AED and is also known as valproic acid or Epilim. It is vital that you do not become pregnant while taking sodium valproate because it can harm the unborn baby. It may cause physical harm to a developing baby and the baby may also have developmental problems after birth such as learning or behaviour difficulties.

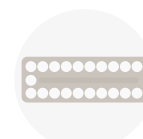
Talk to your GP, epilepsy team, or family planning services about contraception options and make sure they know that you are taking sodium valproate. If there is any chance you might be pregnant, contact your doctor or nurse as soon as possible. Do not stop taking sodium valproate, as you may have more seizures. A sodium valproate patient information booklet is available to download from our website or at: [www.hse.ie/eng/services/publications/Clinical-Strategy-and-Programmes/Valproate-Patient-Information-Booklet.pdf](http://www.hse.ie/eng/services/publications/Clinical-Strategy-and-Programmes/Valproate-Patient-Information-Booklet.pdf)

For more information about girls with epilepsy go to our website **www.epilepsy.ie** or get the **Information on Women** booklet from your local Epilepsy Ireland office.

### Types of contraception



Intrauterine devices



Oral contraceptives



Contraceptive patch



Female condom



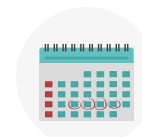
Diaphragm



Male condom



Injectables



Natural family planning



Vaginal ring

## Dealing with emotions

The teenage years can be a difficult time and you can feel like you're on an emotional rollercoaster. As well as just being a teenager you have to cope with living with epilepsy which can be hard sometimes. You may feel like epilepsy is ruling your life and no one else understands what you are going through. It can make some people feel sad, angry and frustrated, especially if it interferes with how you live your life.

Some people can feel very down and anxious for many reasons. Maybe it's because of your epilepsy, or a side effect of AEDs, or because of what someone said. This can stop you from sleeping or eating properly, affect your relationships with friends/family, or impact on your school or work life.

**Get help** – if you are feeling like this, it's important you find someone to talk to about it. No one can help if you keep all your feelings inside.

By talking to someone about your epilepsy or how you are feeling you can start to help yourself. Talk to your family, doctor or nurse. They may be able to find you the help you need.



**Get empowered** – knowing the facts about epilepsy and how it affects you can help you to understand it and help to reduce some of the stress and anxiety you may be feeling.

Understanding your epilepsy can help to improve your confidence and self-esteem and empower you to deal with whatever life or epilepsy brings.

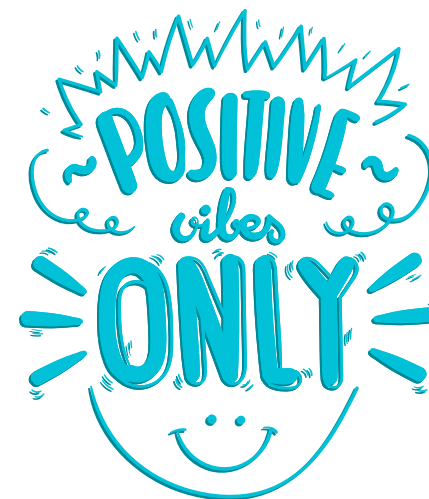


**Get involved** – talking to others who are going through the same things can also help. Joining a support group or self-management programme such as the **STEPS programme with Epilepsy Ireland (if you are 17 years or above)** can provide you with the skills to help you manage your general wellbeing as well as your epilepsy. Epilepsy Ireland also offers one-to-one support via your local EI office where you can talk to one of the community resource officers. In the Resources section there are lots of useful websites where you can find out more about epilepsy and where to get help.

## Others' attitudes

As a teenager it is hard to feel different and you may be more sensitive to what others think or say about you. Some people may react in a negative way about epilepsy. This is often because they don't know the facts. Even though it's been around for ages, epilepsy is still misunderstood. People are often frightened of seizures because they don't know what's happening or what they need to do.

Teaching people about epilepsy is a powerful way to stop negative attitudes or reactions and to eliminate fears and myths about it. If someone continues to be negative don't let this get to you. That is their problem not yours. Try to focus on the positive things in your life instead.



## Dealing with your parents

Transition and adolescence is all about you growing up and becoming more independent as you move into adulthood. Sometimes it might feel like your parents are being overprotective and nagging you.

It is important to realise that your parents may be finding it difficult to let go and are worried about your safety and health. This can be hard for many parents and they may have worries of their own.

**Try talking to them about your feelings, and give them a chance to tell you how they feel. The more you talk with your parents, the more they will know, understand, and trust you.**

**Listen to their reasons for being worried and try to come to a compromise, for example: carry some epilepsy ID, or call them when you get to a place (see the section on keeping safe).**

**Prove to them that you can take care of yourself – start taking more control of your health and managing your epilepsy.**

Your parent(s) have been really important in looking after you and your health and will be able to give you lots of help and advice. You will continue to need their support as an adult.



## Talking about epilepsy

Some people are comfortable with telling others about their epilepsy and explaining what needs to be done. This is not the case for everyone. Sometimes people worry about telling others they have epilepsy because they are afraid how the others might react. They don't want to feel different or stand out. Don't let your epilepsy define who you are – it is just one thing that is different about you.



**Who** – who you tell can depend on how close you are to that person.

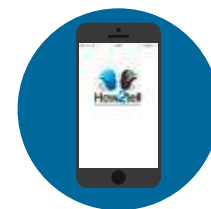
**Who cares for me and who do I trust?**

**Who do I spend most time with?**

**Who is most likely to be around if I have a seizure?**

**This means telling people like your teacher, employer, boyfriend/girlfriend and friends.**

**How** – be open and honest. Having a positive attitude about your epilepsy can help others react positively too. Our **How2tell app** will help you quickly develop your own way of telling, that you can use and adapt to your situation. You can access the **How2tell website** via the How2tell link the **www.epilepsy.ie** homepage. You can download the **How2tell booklet** there or access the link to download the apps. Alternatively you can download the app directly for the Apple App store or Google Play Store. See also 'Talking About Epilepsy' booklet from Epilepsy Ireland.



**When** – you need to weigh up when is the right time. People like teachers should know from the start. If you are in a relationship you should tell them when you feel comfortable.

**What** – no need for your full life story; just tell them what they need to know.

**That you have epilepsy and you might have seizures.**

**What your usual seizure(s) look like.**

**Tell them what to do in case you have a seizure (see the First Aid for Seizures sheet) and who they need to contact and when to get help.**



# Section 3

## Parents





## Advice for parents

The teenage years can be difficult for everyone. It's a time of great change, new challenges and some dangerous temptations.

When you have epilepsy, the risks and insecurities that go along with being a teenager are increased.

As a parent you still have a big role as your son/daughter moves to adult healthcare. But depending on your child's needs, your role might change from being their primary carer to a more supportive figure. Some parents find this change hard. They can feel 'left out' as healthcare professionals focus more on the teenager and ask for their opinions. Often parents are more anxious than their teen about the growing up and moving on. Talking to the doctor/nurse about the adult service and what to expect can help.

It is important to look after yourself during this time. It can help to be part of a support group, talk with family and friends. If you need help with the process you can ask to talk to the social worker or psychologist on the epilepsy team. Epilepsy Ireland has local community resource officers (CROs) and parent support groups in regions across the country that you may find helpful.

If you have other children, they might need extra support at this time too. Although it might be a challenging time for you and your family, it's also a time when you can all celebrate your child growing more confident and independent.

Check out our **Epilepsy and School** booklet and our **Talking about Epilepsy** booklet for further useful tips on how to talk to your teenager about epilepsy.



### Top 10 transition tips for parents

1. **Talk as openly as possible with your teenager about epilepsy and other concerns.**
2. **Help your teen find others to talk to through your local hospital service, Epilepsy Ireland's services, the adolescent advice line and other resources.**
3. **Encourage them to attend their appointments to meet the adult team who will be responsible for their care.**
4. **Teach them how to interact with medical staff.**
5. **Encourage them to speak up for themselves and help them to be involved in decision making.**
6. **Help them in understanding the adult healthcare system.**
7. **Encourage them to think of and ask their own questions. It may be useful to sit down a day or so before the clinic appointment to help them plan this.**
8. **As they get older encourage them to go to part of the clinic alone and explain that you can join them at the end to talk about any concerns.**
9. **Be there for them - with your continued support, your adolescent can learn to manage it himself.**
10. **Remember to look after yourself.**



## My story - a parent's perspective on epilepsy, the teenage years and moving to adult services.

By Caroline Murphy



My son Seán developed encephalitis when he was six years old. This was the start of a long journey for us. From our first meeting with the paediatric neurologist we knew he was in good hands. Seán's epilepsy was bad and intractable. One drug after another was tried but each was ineffective. Many panicked phone calls were made to the nurses in the neurology service and they were always returned. We never doubted that when we rang we would get a reassuring, calming call back with a new plan for treatment or just advice. These calls were our lifeline.

Over the years the number of people we came in contact with increased. Seán was put on the ketogenic diet, he had a VNS inserted. He met with and got incredible help from the neuropsychology team. Seán never once complained about having to go for an appointment.

When Seán was 13 years old I remember panicking and asking his consultant what would happen when he was 16 and had to move to adult services. How would we cope? Seán would be thrown into an overworked, under-resourced system; he would become just a number. This was not what we were used to. Our doctor tried to reassure me that he would be fine and that the neurologists all worked very closely in both paediatric and adult services, but still my worries continued.

But suddenly Seán was 16, and the day we would have to leave this wonderful supportive network was closer. About this time the nurse specialist introduced us to the idea of transition. We got the chance to meet with other parents and got to discuss our worries. Leaving the familiar family friendly care of the paediatric service was one thing but apprehensions about how our adolescent was going to make the transition into adulthood with a long-term illness was an even bigger worry. Just because they were now considered an adult by the health professionals didn't mean they were mature enough to take control of their lives.

**When Seán was 13 years old I remember panicking and asking his consultant what would happen when he was 16 and had to move to adult services. How would we cope?**

As parents we worried that suddenly we would be excluded from doctors' appointments, expected to leave all medical matters to them.

Seán got the chance to meet other young people with epilepsy which proved to be very beneficial, especially for Seán. The group of teenagers, all with epilepsy, got to chat and discuss their concerns. They discussed what it was like to grow up with epilepsy. How they felt different and found it difficult to tell their friends about their illness because they did not want to be treated differently. This was the first time most of them had met someone with epilepsy. All agreed that this was something that they would have liked to have happened earlier.

**The hospital seemed much bigger and more hectic than the paediatric hospital, but the staff were just as friendly and helpful.**

Moving on began to seem a little less scary; they were no longer kids and yes it would be possible, with help from parents, to take more control of their illness, to be more responsible for tablet taking and to prepare for consultations. Seán really enjoyed meeting other young people with similar issues to him and he definitely gained more confidence with regard to his illness as a result.

Part of the process of moving to adult services meant that we got to visit the adult hospital and meet with the new team. This was very reassuring. The hospital seemed much bigger and more hectic than the paediatric hospital, but the staff were just as friendly and helpful. Maybe moving on would not be as frightening as we thought. Maybe Seán would be fine and would get all the help he needed to take control of his illness and learn to manage it. It was not going to happen overnight, but with the support of this new team his transition would work out.



## Young people with complex needs

If your son/daughter has additional complex needs or learning difficulties, you may feel that some of the content of this booklet is not applicable to your teen's situation.

Even though they may not achieve the same level of independence as their peers they will still benefit from going through the process of transition. There are many additional issues to consider such as:

**Adult community services.**

**Funding concerns.**

**Advocacy and guardianship.**

**Supported education.**

**Supported employment.**

**Day/residential facilities.**

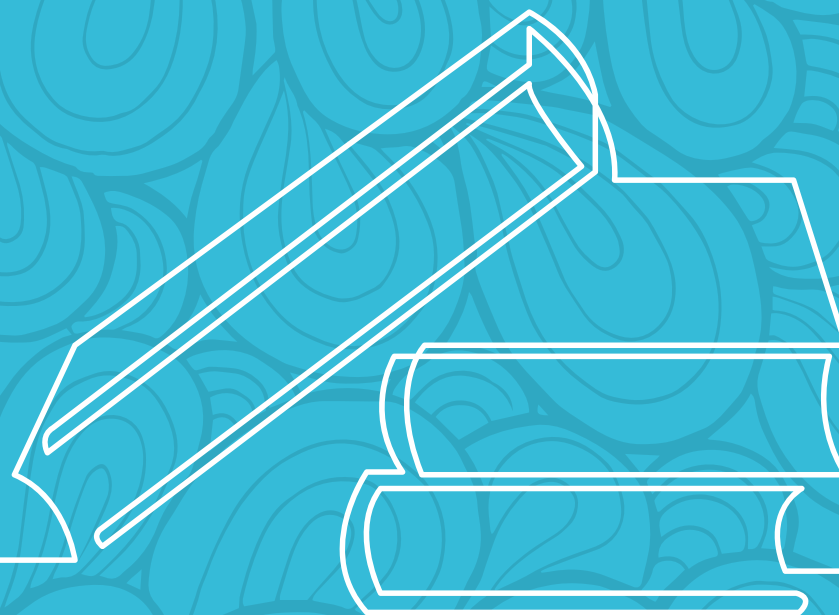
**Respite services.**

The transition process will still apply to those teens with more complex needs; however as their parents you may continue to be actively involved in their epilepsy management and in making healthcare decisions with them or for them depending on their capacity to make these choices. Start planning early. Talk to the doctor, nurse school and GP about what services you will need before your teen moves to adult services.

Transition plans and goals will take into account each young person's individual ability. Encouraging a person to participate to the best of their ability, no matter what that is, is a key factor in the transition process.

# Section 4

## Resources



## Epilepsy Ireland's services

**Epilepsy Ireland** has lots of information that can help you learn more about epilepsy as well as provide support for you and your family.

Epilepsy Ireland provides a range of services from headquarters in Dublin and from regional offices in Cork, Dundalk, Galway, Kerry, Kilkenny, Letterkenny, Limerick, Sligo and Tullamore. Contact details are available on the back of the booklet.

### Training for Success

If you can't decide what you want to do or are finding it difficult to progress into third level education you may want to consider Training for Success (TFS). TFS is a one-year course for people with epilepsy which is run in The Institute of Technology, Sligo in partnership with Epilepsy Ireland.

Epilepsy Ireland provides a **Living Well with Epilepsy** toolkit and support and training session which brings all your information and support needs together in one place.

### Becoming a member

You can become a member of Epilepsy Ireland for a small annual fee. As a member you will receive:

**Four newsletters per year with all the latest information, events and activities relating to epilepsy.**

**A free epi-alert bracelet or epilepsy anti-smother pillow with the first two-year membership.**

**A say in how Epilepsy Ireland runs and operates.**

**Subsidised rates for your national conference; free attendance or special rates at local events.**

**Belonging to our community of people with epilepsy and their families.**

Find out more at [www.epilepsy.ie](http://www.epilepsy.ie).

### Online support group



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



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



[@epilepsyireland](https://twitter.com/epilepsyireland)



[youtube.com/Brainwave/Epilepsy](https://youtube.com/Brainwave/Epilepsy)

## Seizure diary

It's a good idea to keep a seizure diary so you can keep track of when you've had a seizure, any changes to your AEDs, any side effects of your AEDs and anything else you think might be important.

You can get an actual diary to write in or download an app on your phone, whatever you prefer. Bring your diary with you to your appointments so your doctor or nurse specialist can see how things are going for you.

The **Epilepsy Ireland App** has lots of useful features:

**Personalise a seizure diary.**

**Record possible seizure triggers.**

**Record features of seizures - (what happens before, during and after).**

**Quick access to phone camera to record seizure.**

**Plan epilepsy appointments.**

**Emergency contact details.**

**Send emergency SMS with one touch.**

**Reminder system for medications and prescription renewals.**

**Email reports of seizures or missed medication events.**

You can download the app for free from iTunes or Google Play Store links:

[itunes.apple.com/us/app/epilepsy-ireland-diary-app/id1074819139?mt=8](https://itunes.apple.com/us/app/epilepsy-ireland-diary-app/id1074819139?mt=8)

[play.google.com/store/apps/details?id=com.hp.epilepsy](https://play.google.com/store/apps/details?id=com.hp.epilepsy)

## First Aid For Tonic Clonic Seizures

Convulsive seizures where the body stiffens (tonic phase) followed by general muscle jerking (clonic phase)



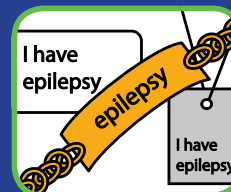
1. DO time the seizure



2. DO remove any harmful objects



3. DO cushion the head



4. DO look for Epilepsy I.D.



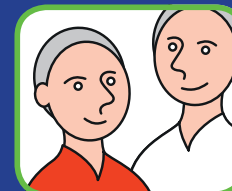
5. DON'T put anything in the person's mouth



6. DON'T restrain the person or move unless in danger



7. DO turn the person on side (into recovery position) when seizure stops



8. DO stay with the person until the seizure ends and offer assistance



**When to call an ambulance**

- If the seizure is longer than 5 minutes
- If one seizure follows another without stopping
- If you know it is the person's first seizure
- If the person is injured
- If you are in any doubt

### Complex Partial Seizures

(Non-convulsive seizures with confusion, wandering, unusual behaviours)

- Stay with the person
- Time the seizure
- Guide away from any danger
- Speak gently and calmly to reassure the person
- DON'T restrain the person unless in danger



249 Crumlin Road, Dublin 12. Tel: 01 4557500. Fax: 01 4557013 info@epilepsy.ie  
www.epilepsy.ie facebook.com/epilepsy.ie @epilepsyireland



## First Aid for Complex Partial (focal) seizures

including temporal lobe seizures

Non-convulsive seizures in which awareness is affected but consciousness is not lost

### KNOW THE SIGNS



Wandering aimlessly



Fidgeting with clothing



Agitated behaviour



Chewing & smacking of lips



Confused or slurred speech



Staring trance-like

### KNOW WHAT TO DO



DO time the seizure



DON'T restrain or grab



DO guide gently from danger



DO calmly reassure



DO stay until seizure ends



DO explain what happened



#### When to call an ambulance

- If the seizure is longer than 5 minutes
- If the person has more than one seizure
- If you know it is the person's first seizure
- If the person is injured
- If you are in any doubt



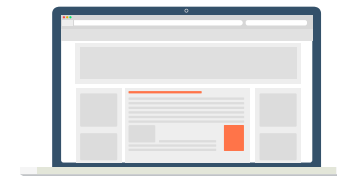
249 Crumlin Road, Dublin 12.  
T: 01 4557500. info@epilepsy.ie  
www.epilepsy.ie  
facebook.com/epilepsy.ie  
@epilepsyireland

## Useful websites

### Stepping Up

Stepping Up is an Irish website dedicated to supporting transition. It has lots of useful information and videos about transition and details of some of the adult epilepsy clinics in Ireland.

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



### Young Epilepsy

Young Epilepsy is a UK-based charity that supports children and young people under 25 with epilepsy in the UK. They provide information and support for young people with epilepsy, parents and professionals. Some of this information may be useful but note it is for UK services.

[www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)

### The TEA Room

The TEA Room is an online, worldwide forum available to young people with epilepsy between the ages 13 and 19. TEA stands for 'Teenage Epilepsy Agenda'. Young Irish people are welcome to join in the conversation with a worldwide community about the challenges that young people with epilepsy face. The website is managed by the Scottish Epilepsy Initiative, a registered charity based in Scotland. For more information log onto [www.thetea-room.com](http://www.thetea-room.com) or like their Facebook page [www.facebook.com/thetea-roomchat](https://www.facebook.com/thetea-roomchat).

### Girls with Nerve

Girls with Nerve is a US website where teens with epilepsy can find information about sexual health, stories from other teens with epilepsy, suggestions for talking with doctors about the tough stuff, and more.

[www.girlswithnerve.com](http://www.girlswithnerve.com)

### Talk About It

Talk About It is a US website where TV and movie stars share information about epilepsy and encourage kids to talk about living with epilepsy.

[www.talkaboutit.org](http://www.talkaboutit.org)

### Youth Health Talk

Youth Health Talk provides real, reliable health information by young people sharing their experiences in a specific section for people with epilepsy.

**[www.youthhealthtalk.org](http://www.youthhealthtalk.org)**

### Reach Out

Reach Out provides information on stress, anxiety, bullying, suicide, depression, bipolar disorder and other issues that can affect your mental health and well-being.

**[www.reachout.com](http://www.reachout.com)**

### Aware

Aware provide information education and support to people affected by stress, depression, mood and bipolar disorders.

**[www.aware.ie](http://www.aware.ie)**

### Spunout

Spunout is a youth information website created by young people, for young people. Their aim is to educate and inform young people about the importance of holistic wellbeing and how good health can be maintained, both physically and mentally.

**[www.spunout.ie](http://www.spunout.ie)**

### Jigsaw

Jigsaw is the National Centre for Youth Mental Health. They provide vital supports for young people's mental health by working closely with communities across Ireland.

**[www.jigsaw.ie](http://www.jigsaw.ie)**

### Bodywhys

Bodywhys is the Eating Disorders Association of Ireland, the national, voluntary organisation supporting people affected by eating disorders.

**[www.bodywhys.ie](http://www.bodywhys.ie)**

### Drugs And Alcohol Issues

Drug and alcohol information and support for teenagers, parents and carers. Includes free, confidential live chat.

**[www.drugs.ie](http://www.drugs.ie)**

### Barnardos

Barnardos is an independent children's charity working in Ireland. They work with vulnerable children and their families.

**[www.barnardos.ie](http://www.barnardos.ie)**

### Irish Society for the Prevention of Cruelty to Children

The Irish Society for the Prevention of Cruelty to Children is an Irish charity that advocates for children's rights and provides services for children in need.

**[www.ispcc.ie](http://www.ispcc.ie)**

## Books

### Navigating Life with Epilepsy

Navigating Life with Epilepsy (2016) by David C. Spencer provides accessible, comprehensive, and up-to-date information about epilepsy sharing the experience of an epileptologist.  
(ISBN-13: 978-0199358953 ISBN-10: 0199358958).

### Easy for You to Say: Q&As for Teens Living with Chronic Illness or Disability

Easy for You to Say: Q&As for Teens Living with Chronic Illness or Disability (2012) by Miriam Kaufman, Firefly Books. (ISBN-10: 1554070783; ISBN-13: 978-1554070787).

### Epilepsy: The Ultimate Teen Guide

Epilepsy: The Ultimate Teen Guide (2007) by Kathlyn Gay and Sean McGarrah. (ISBN-10: 0810858355 ISBN-13: 978-0810858350).

All books are available on **[www.amazon.com](http://www.amazon.com)**.





### My epilepsy profile

Ask your doctor or nurse specialist to help you fill this out and to explain anything you don't understand.

My Epilepsy Profile	
My Epilepsy Diagnosis	
My Seizure Types	
My Seizure Triggers	
My Current Medication	
My Past Medication	
My Allergies	
Other	

### My epilepsy team

Title	Name	Contact Details
Paediatric Consultant		
Paediatric Epilepsy Nurse		
Adult Consultant		
Adult Epilepsy Nurse		
GP		
Epilepsy Ireland Resource Officer		
Emergency Contact		
Others		

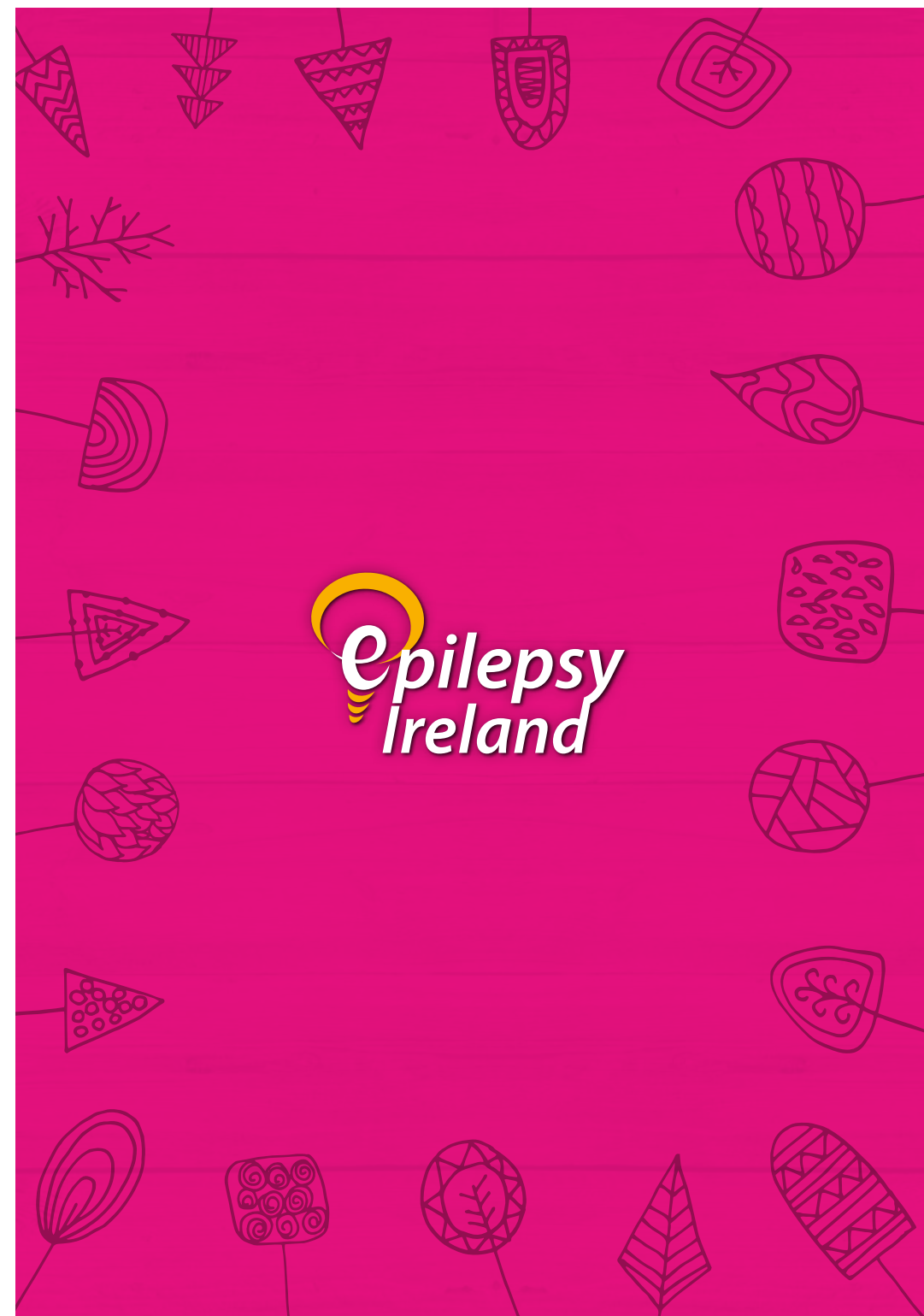


## My Epilepsy Transition Checklist

My Epilepsy Knowledge	Yes I've Got It	No I Need Help
I understand my epilepsy.		
I keep a seizure diary.		
I can describe my seizures to others.		
I can explain to others what they can do to help if I have a seizure.		
I know about the tests that I need to have.		
I know the names of my AED medications and what they do.		
I know when and how to take my AED medications.		
I know never to suddenly stop taking my medications.		
I am aware of my medical history (e.g. hospital visits, procedures).		
I am happy to talk to the chemist about my medication/treatment.		
I know who my epilepsy team are.		
I know who to call in an emergency.		
<b>Just for Girls</b>	<b>Yes I've Got It</b>	<b>No I Need Help</b>
I know about the importance of taking folic acid.		
I know some AEDs can interact with contraception and can affect a baby's development in pregnancy.		
<b>My Health and Lifestyle</b>	<b>Yes I've Got It</b>	<b>No I Need Help</b>
I know about seizure triggers and how to avoid them.		
I wear or carry an ID card/ bracelet.		
I know the importance of a healthy lifestyle - exercise, eating healthily and managing stress.		
I understand the risks of taking alcohol and drugs.		
I know where to get information about epilepsy and where to get help.		

Speaking Up for Myself	Yes I've Got It	No I Need Help
I feel ready to prepare to be seen alone in the teenage/adult clinic.		
I feel confident to ask my own questions in the clinic.		
I know that I have to take more responsibility for my healthcare as I get older.		
I keep a record of my clinic/hospital appointments.		
<b>Moving to Adult Services</b>	<b>Yes I've Got It</b>	<b>No I Need Help</b>
I understand what transition means and why I am moving to adult services.		
I understand about the transfer of my medical information to the adult health services.		
I know the differences between child and adult health services.		
I know what challenges to expect during transition and feel ready to deal with them.		



This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.





**Web:** [www.epilepsy.ie](http://www.epilepsy.ie)  
**Facebook:** [facebook.com/epilepsy.ie](https://facebook.com/epilepsy.ie)  
**Twitter:** [@epilepsyireland](https://twitter.com/epilepsyireland)  
**YouTube:** [youtube.com/BrainwaveEpilepsy](https://youtube.com/BrainwaveEpilepsy)

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### Head Office

249 Crumlin Road, Dublin 12  
**Tel:** 01 455 7500  
**Email:** [info@epilepsy.ie](mailto:info@epilepsy.ie)  
**Specialist Nurse Helpline Tel:** 01 455 4133  
Monday 9.30am – 1pm  
**Transitional Care Advice Line Tel:** 01 455 4133  
Monday 2pm – 5pm

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### North West

**Covering:** Donegal, Leitrim & Sligo  
**Community Resource Officer:** Agnes Mooney  
Letterkenny Office, Grand Central Complex, Floor 2B,  
Canal Road, Letterkenny, Co. Donegal  
**Tel:** 074 9168725  
**Email:** [amoonney@epilepsy.ie](mailto:amoonney@epilepsy.ie)  
**Tel:** 071 9141858

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### West

**Covering:** Galway, Roscommon & Mayo  
**Community Resource Officer:** Edel Killarney  
Westside Resource Centre, Seamus Quirke Road,  
Westside, Galway  
**Tel:** 091 587640  
**Email:** [ekillarney@epilepsy.ie](mailto:ekillarney@epilepsy.ie)

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### Mid-West

**Covering:** Limerick, Clare & Tipperary North  
**Community Resource Officer:** Veronica Bon  
Social Service Centre, Henry St. Limerick  
**Tel:** 061 313773  
**Email:** [vbbon@epilepsy.ie](mailto:vbbon@epilepsy.ie)

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### Kerry

**Covering:** Kerry  
**Community Resource Officer:** Kathryn Foley  
9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry  
**Tel:** 064 6630301  
**Email:** [kfoley@epilepsy.ie](mailto:kfoley@epilepsy.ie)

### Cork

#### Community Resource Officers:

South Lee & West Cork: Niamh Jones  
North Lee & North Cork: Loretta Kennedy  
Unit 1, 83 Beech Road, Muskerry Estate, Ballincollig,  
Co. Cork  
**Tel:** 021 4274774  
**Email:** [Niamh.njones@epilepsy.ie](mailto:Niamh.njones@epilepsy.ie) /  
[Loretta.lkennedy@epilepsy.ie](mailto:Loretta.lkennedy@epilepsy.ie)

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### South East

**Covering:** Kilkenny, Wexford, Carlow, Waterford &  
Tipperary South  
**Community Resource Officer:** Miriam Gray  
C/o HSE, St. Joseph's, Waterford Rd, Kilkenny  
**Tel:** 056 7789904  
**Email:** [mgray@epilepsy.ie](mailto:mgray@epilepsy.ie)

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### Midlands

**Covering:** Offaly, Longford, Laois & Westmeath  
**Community Resource Officer:** Cliona Molloy  
The Charleville Centre, Church Avenue, Co. Offaly  
**Tel:** 057 9346790  
**Email:** [cmolloy@epilepsy.ie](mailto:cmolloy@epilepsy.ie)

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### East

**Covering:** Dublin, Kildare & Wicklow  
**Community Resource Officer:**  
Dublin North, West & Kildare: Edel Curran  
Dublin South & Wicklow: Carina Fitzgerald  
National Information Officer: Geraldine Dunne, 249  
Crumlin Road, Dublin 12  
**Tel:** 01 4557500  
**Email:** [Geraldine.gdunne@epilepsy.ie](mailto:Geraldine.gdunne@epilepsy.ie) /  
[Edel.ecurran@epilepsy.ie](mailto:Edel.ecurran@epilepsy.ie)  
[Carina.cftzgerald@epilepsy.ie](mailto:Carina.cftzgerald@epilepsy.ie)

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### North East

**Covering:** Louth, Meath, Monaghan & Cavan  
**Community Resource Officer:** Mary Baker  
Unit 1a, Partnership Court, Park St. Dundalk, Co.  
Louth  
**Tel:** 042 9337585  
**Email:** [mbaker@epilepsy.ie](mailto:mbaker@epilepsy.ie)

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### Training for Success

**Managers:** Honor Broderick  
Institute of Technology Sligo, Ballinode, Sligo  
**Tel:** 071 915 5303  
**Email:** [Broderick.honor@itsligo.ie](mailto:Broderick.honor@itsligo.ie)

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### Epilepsy Specialist Nurse HELPLINE

Monday 9.30am – 1.00pm  
**Tel:** (01) 4554133

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### Transitional Care Information Advice Line

Monday 2pm - 5pm  
**Tel:** (01) 4554133