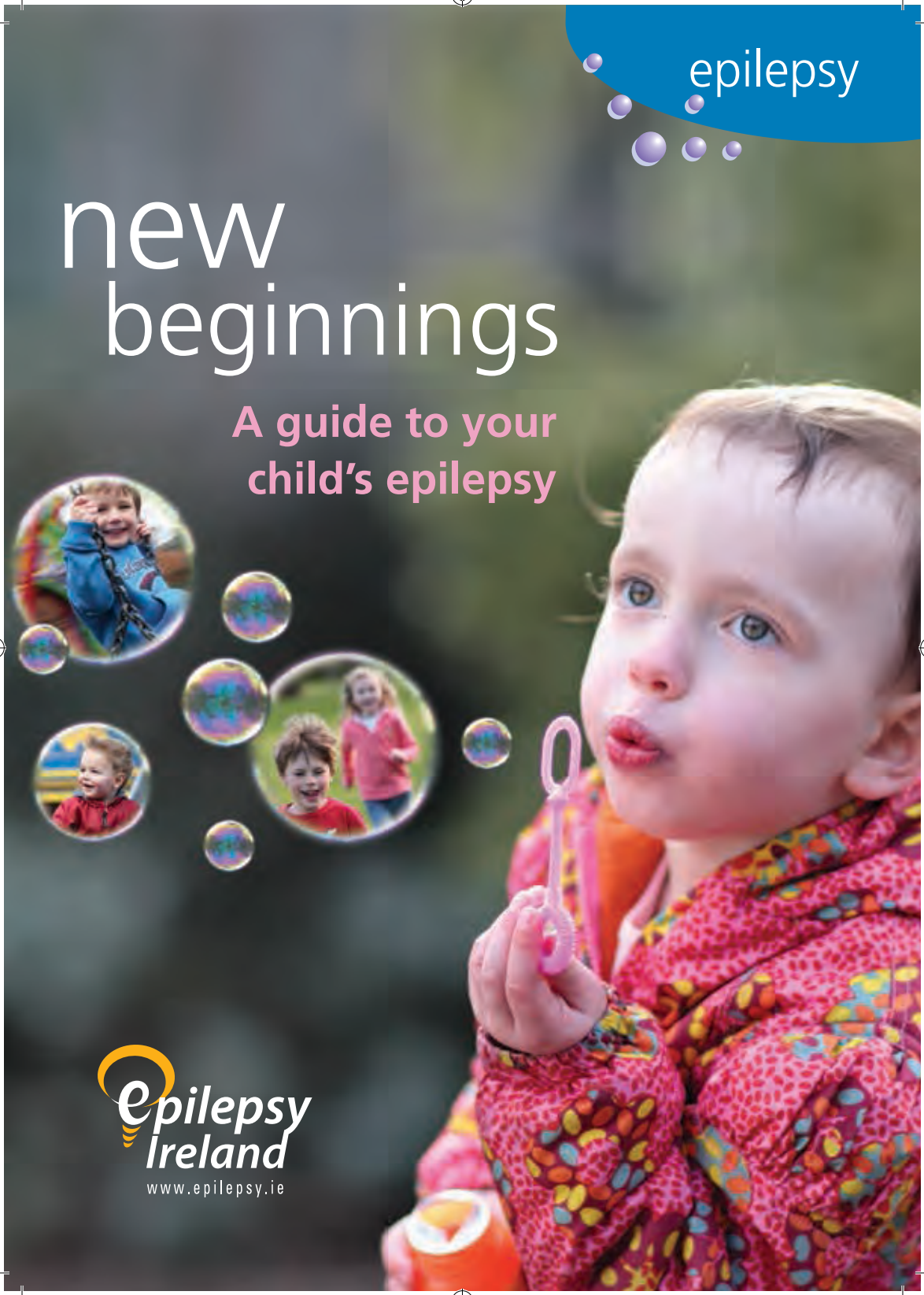
epilepsy

new beginnings

A guide to your child's epilepsy



Epilepsy Ireland

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Epilepsy Ireland was established in 1966 in order to help and support people with epilepsy, their families and friends. We also aim to improve public understanding of epilepsy and eliminate prejudice and misunderstanding about it. We work to encourage and assist research into the causes and treatment of epilepsy and to promote an awareness of the need for education and rehabilitation.

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1010622 Epilepsy Irl Brochure V3.indd 2 17/12/2013 17:03

Contents

Introduction	2
Describing Childhood Epilepsy	2
How does the brain work?	3
How is Epilepsy Diagnosed?	4
Treatment of Epilepsy in Children	6
Seizure Types	9
First Aid for Seizures	10
What to do When your Child Has a Seizure	11
What Parents Need to Know	13
Keeping a Seizure Diary	14
How to Help Your Child Live with Epilepsy	16
Epilepsy and Leisure	18
Useful contacts	20

Introduction

At least 1 in every 200 children in Ireland have epilepsy. Many people with epilepsy have their first seizure in childhood or adolescence. However, most children with epilepsy enjoy a full and active life and only some continue to have epilepsy into adulthood.

Epilepsy is a complex condition but research and knowledge of the area is growing and there are also many new treatments available.

This booklet is designed for parents but may also be useful for people who want to learn more about epilepsy in children.

The brain is like a computer for the body. It controls every single action of your body. It works 24 hours a day, seven days a week.

Describing Childhood Epilepsy

What is epilepsy?

Epilepsy is one of the most common neurological conditions. Children with epilepsy have a tendency to have recurring seizures without any obvious cause.

What is a seizure?

Just like a computer, the brain can suddenly malfunction. When it does, an epileptic seizure often results. A seizure occurs when there is a sudden burst of intense abnormal electrical activity within the brain. This causes a temporary disruption to the way the brain normally works. Symptoms experienced during a seizure depend on the part of the brain that is affected.

What causes epileptic seizures?

Epilepsy may begin at any age and for many children the cause is unknown. This can be confusing and difficult for parents to understand. When a cause is identified, it is usually one of the following: previous severe head trauma, brain injury at birth or previous infection of the brain e.g. meningitis or encephalitis. In rare cases it can be linked to problems with metabolism or genetic disorders, brain tumours, brain malformations, stroke and degenerative nervous system diseases.

1010622 Epilepsy Irl Brochure V3.indd 4 17/12/2013 17:03

How does the brain work?

1. **Occipital Lobe**
   This part of the brain processes visual information.

2. **Parietal Lobe**
   This part of the brain controls sensation such as touch and taste, judgement of texture, weight, size and shape.

3. **The Frontal Lobe**
   This part of the brain is involved in planning, organising, problem-solving, personality, behaviour and emotions. It also controls the movement of muscles.

4. **Temporal Lobe**
   This part of the brain is involved in memory and speech comprehension.

5. **Cerebellum**
   This part of the brain helps co-ordinate movement (balance and muscle co-ordination).

The size of your brain has nothing to do with how clever you are

The average brain cell can have between 1,000 and 10,000 connections with other brain cells

How is epilepsy diagnosed?

When your child has a suspected seizure, it is essential that the doctor determines that s/he is definitely having epileptic seizures. To establish this the doctor will:

- **Take a detailed medical history** This will include details relating to pregnancy, birth history, early development, general health and family medical history
- **Take a detailed history of the events experienced to date** including what happens before, during and after each event
- Perform a **medical examination**

If the doctor thinks your child may have epilepsy, further investigations may be requested. These may include:

- **EEG**
- **CT**
- **MRI**

In some children their epilepsy can 'go away' as they grow up whilst in others it continues into adult life

1010622 Epilepsy Irl Brochure V3.indd 6 17/12/2013 17:03

How is epilepsy diagnosed?

Investigations

Epilepsy is difficult to diagnose and while medical history, examinations and investigations are very important, the diagnosis can only be confirmed by a doctor who has all the information.

The EEG (Electroencephalogram)

An EEG is a test that can help diagnose epilepsy. Small discs are applied to the child's scalp. These discs are attached to small electrodes which record the electrical activity of the brain. This information transmits to a computer which produces a printed record of brain wave activity. The procedure is painless and lasts approximately one to two hours. Children can sleep during the test. Sleep makes the recording more informative. Sometimes a child has a seizure during the test which helps detect abnormal brain waves. However, the brain of people with epilepsy can show abnormal activity, even when no seizure occurs.

CT (Computerised Tomogram)

A small number of children may require either a CT or MRI scan. Both procedures identify brain abnormalities but will not tell if your child has epilepsy. A CT scan is an X-ray that provides a computer reconstruction of the brain. It gives valuable information about the structure of the brain. The scan usually takes about 40 minutes.

MRI (Magnetic Resonance Imaging)

MRI scanning does not involve X-rays. It uses the body's own magnetism to generate detailed images of the brain. Images from an MRI scan are often more detailed than those from a CT scan, but only a small percentage of children require MRI scanning. The procedure takes about one hour.

Results/Reports

All tests are studied and reports are sent to your child's doctor or discussed in the clinic.

There are still some things we do not as yet fully understand about epilepsy. Sometimes the only honest answer your doctor or nurse specialist will be able to give will be "I don't know".

1010622 Epilepsy Irl Brochure V3.indd 7 17/12/2013 17:03

Treatment of epilepsy in children

The best treatment for epilepsy begins with you and your child (if old enough) getting to know more about epilepsy. The main source of information about your child's condition is your doctor or nurse specialist so don't be afraid to ask questions.

The type of epilepsy your child has, the likely prognosis (outcome) and treatment plan should be discussed with you at clinic. It is important to realise, however, that it is often not possible to be certain about the prognosis for epilepsy and part of the coming to terms with it may be learning to live with this uncertainty. There can be a lot of information to take in at first, therefore it is worth asking what support is available so that you can access it at a later date. Epilepsy Ireland provides support for parents and carers and has a range of leaflets and information on epilepsy.

Medication

Anti-epileptic drugs (AEDs) are the most common way to treat epilepsy. These medications don't cure epilepsy but are designed to treat and stop seizures occurring.

Choosing medication

There are many AEDs to choose from. The drug which the doctor chooses will depend on the type of epilepsy that your child has. It is important to note that certain groups of drugs are more effective with particular types of epilepsy. The doctor will choose the one that's most appropriate for your child.

Once a drug is chosen it is usually started at a low dose and gradually increased over a period of weeks to months. This minimises the risk of side effects. However, some children are more sensitive to drugs than others and it may be necessary to go slower than recommended. Where possible one drug (monotherapy) will be used to treat seizures; however, when seizures prove difficult to control more than one drug (polytherapy) may be necessary.

AEDs are available in tablet, liquid or granule form. Tablets come in various dosages and some are available in slow-release form which permits a more convenient dosage regime. Granules may suit infants and young children. Granules are easily administered, they can be sprinkled on food or directly into the mouth.

Note: Once AED treatment has begun, switching between different brands or generic versions of the AED should be avoided.

1010622 Epilepsy Irl Brochure V3.indd 8 17/12/2013 17:03

Medication Side Effects

Any type of medication can have side effects. These side effects can range from mild to severe. Often side effects are short lived. Once the body adjusts to the new drug they often lessen or disappear completely.

If you are concerned about side effects you should discuss them with your child's doctor or nurse specialist. It may be possible to adjust the dosage and if this isn't an option, another drug may be used. **Never stop or change the dose of drugs yourself.**

Medication Entitlements

It is important to know that medication used to treat epilepsy is free. Parents need to apply for free medication using a long term illness form obtained from the hospital, GP or local pharmacy. Further information on your entitlements can be obtained from Epilepsy Ireland.

Getting Control

It is difficult to predict how long it will take to gain control of seizures as this differs for each child. The majority gain control of seizures fairly quickly. For others, it can take time to find the right drug and dosage. This can be frustrating for parents and children. It is important to remember that everyone is trying to achieve the same goal - *'seizure freedom with no side effects from treatment'*.

Drug Levels

At certain times, it may be necessary to monitor drug treatment. This is done by blood tests to measure medication levels in the blood. However, not all drugs can or need to be measured. It is not necessary to perform drug levels routinely. Your doctor will advise you if levels are required.

Duration of treatment

Most children with epilepsy must take anti-epileptic medication until they are at least two years seizure-free. At the end of that period, depending on the type of epilepsy, the doctor may consider reducing treatment gradually.

1010622 Epilepsy Irl Brochure V3.indd 9 17/12/2013 17:03

Missed dose of medication

Occasionally a dose of medication may be forgotten. If this happens, give your child the missed dose as soon as you remember. If it is close to the time the next dose is due just give the next dose early. **Never** give a double dose of medication. If vomiting occurs within half an hour of taking a dose, repeat the dose ONCE. If vomiting continues, consult a doctor.

Other treatment options
Surgery

Various types of surgery are available for treating certain types of childhood epilepsy. Surgery is not an option for everyone. Further information is available from Epilepsy Ireland, your doctor or nurse specialist.

Ketogenic Diet

The Ketogenic Diet is a *special diet, high in fat,* which can have an antiepileptic effect. The reason for this is not clearly understood. This diet is not suitable for every child. **Children who are on this diet must be carefully monitored by hospital doctors and a specially trained dietitian.** Parents need to be aware that it can be particularly unpleasant and difficult. There are several issues to be considered before commencing the diet to ensure safety, optimal growth and development.

1010622 Epilepsy Irl Brochure V3.indd 10 17/12/2013 17:03

Seizure Types

	PARTIAL AFFECTING A SPECIFIC PART OF THE BRAIN			GENERALISED AFFECTING THE WHOLE BRAIN				
WHERE?								
NAME?	SIMPLE	COMPLEX (e.g. TEMPORAL LOBE)	SECONDARY GENERALISED	TONIC CLONIC	TONIC	ATONIC	MYOCLONIC	ABSENCES
WHAT HAPPENS?	Seizure activity while person is alert. The seizure may consist of an 'aura' or warning. This could be a feeling of fear or an unusual taste or smell. Numbness, twitching or tingling sensation in one part of the body may occur.	May start with an 'aura' or warning. The person loses awareness, appears confused, distracted and unresponsive. The person may be still or carry out automatisms (automatic movements) despite lack of awareness.	A partial seizure which starts in one part of the brain but then becomes generalised. →	May start with a sudden cry, staring, stiffening of the body and a fall. Difficulty in breathing (blue colour) followed by convulsions. Lasts for a few minutes, then breathing and colour gradually return to normal. Confusion and sleepiness is frequent afterwards.	Body will stiffen, breathing irregular. May lead to a fall.	Brief attacks where muscles slacken. Can lead to severe falls.	Jerking movements of the body or limbs.	Person looks blank and stares. The eyelids may twitch, flutter or blink. This will only last for a few seconds.

1010622 Epilepsy Irl Brochure V3.indd 11 17/12/2013 17:03

First aid for seizures

Tonic-Clonic Seizures

DO

- Protect your child from injury (remove any harmful objects nearby)
- Cushion their head
- Gently place your child in the recovery position
- Stay with them until recovery is complete
- Calmly reassure your child

DON'T

- **Don't** restrain your child
- **DO NOT** put anything in their mouth
- **Don't** try to move them unless they are in danger
- **Don't** give your child anything to eat or drink until they are fully recovered

Seizures Involving Altered Consciousness or Behaviour

DO

- Guide your child from danger
- Stay with your child until recovery is complete
- Calmly reassure
- Explain anything that they may have missed

DON'T

- **Don't** restrain your child
- **Don't** panic
- **Don't** assume your child is aware of what is happening or what has happened
- **Don't** give your child anything to eat or drink until they are fully recovered

When to call an ambulance

- If it's your child's first seizure
- The seizure continues for more than five minutes
- One seizure follows another without your child regaining awareness between seizures
- Your child is injured during the seizure
- You believe your child needs urgent medical attention

1010622 Epilepsy Irl Brochure V3.indd 12 17/12/2013 17:03

What to do when your child has a seizure

Rescue Treatment

Often drugs, such as buccal midazolam and rectal diazepam are prescribed for the treatment of prolonged or repetitive seizures. An individual plan for the administration of rescue treatment will be drawn up for your child and explained to you. Further advice can be obtained from your doctor and nurse specialist.

Status epilepticus (SE)

SE is:

- any seizure lasting 30 minutes **or**
- several seizures following one another over a period of 30 minutes without the child recovering awareness

Can seizures cause brain damage?

Most recurring seizures do not cause brain damage. There may be rare exceptions in the case of very prolonged, severe and frequently repeated seizures but, generally speaking, the brain does not suffer any lasting ill-effects after the seizure. Prompt intervention with rescue treatment will reduce the risk.

You cannot swallow your tongue!

1010622 Epilepsy Irl Brochure V3.indd 13 17/12/2013 17:03

Encourage your child to wear an Epi-Alert bracelet which can be obtained from Epilepsy Ireland.

1010622 Epilepsy Irl Brochure V3.indd 14 17/12/2013 17:03

What Parents Need to Know

What to look for when your child has a seizure

1. What was your child doing at the time - sleeping, waking, playing etc?
2. What alerted you to the seizure - cry, fall, stare, head turn etc?
3. Did your child talk or perform actions during the seizure?
4. Which parts of the body were affected?
5. Was one side affected more than the other?
6. Did the body stiffen, jerk or twitch?
7. Were there any eye changes - moving right/left, rolling, blinking, pupils dilated etc?
8. Was your child aware during the event?
9. Did your child's skin colour change - pale, flushed, blue?
10. Did breathing change?
11. Did your child wet/soil themselves?
12. Did your child vomit?
13. Were there any injuries?
14. How did your child behave after the seizure - alert, drowsy, confused?
15. Did your child remember any 'funny feelings' before the seizure started?
16. How long did seizure activity last?
17. How long did it take your child to return to normal activity?

Triggers

It may be possible to identify things that make seizures more likely to occur. These are known as triggers. The following are some common triggers:

- Tiredness
- Lack of sleep
- Illness
- Stress/anxiety
- Constipation
- Missed doses of medication

Many parents find that by avoiding or managing triggers they can avoid seizures.

1010622 Epilepsy Irl Brochure V3.indd 15 17/12/2013 17:03

Keeping a Seizure Diary

Recording seizures is important in managing your child's epilepsy. Describe each seizure type in your own words and give each a number/letter. It is **not** necessary to describe every seizure in detail.

Keeping a diary helps to:

- remember when seizures occurred
- identify seizure types and frequency
- identify **specific triggers**
- determine effectiveness of treatment
- determine response to medication changes

Things to record

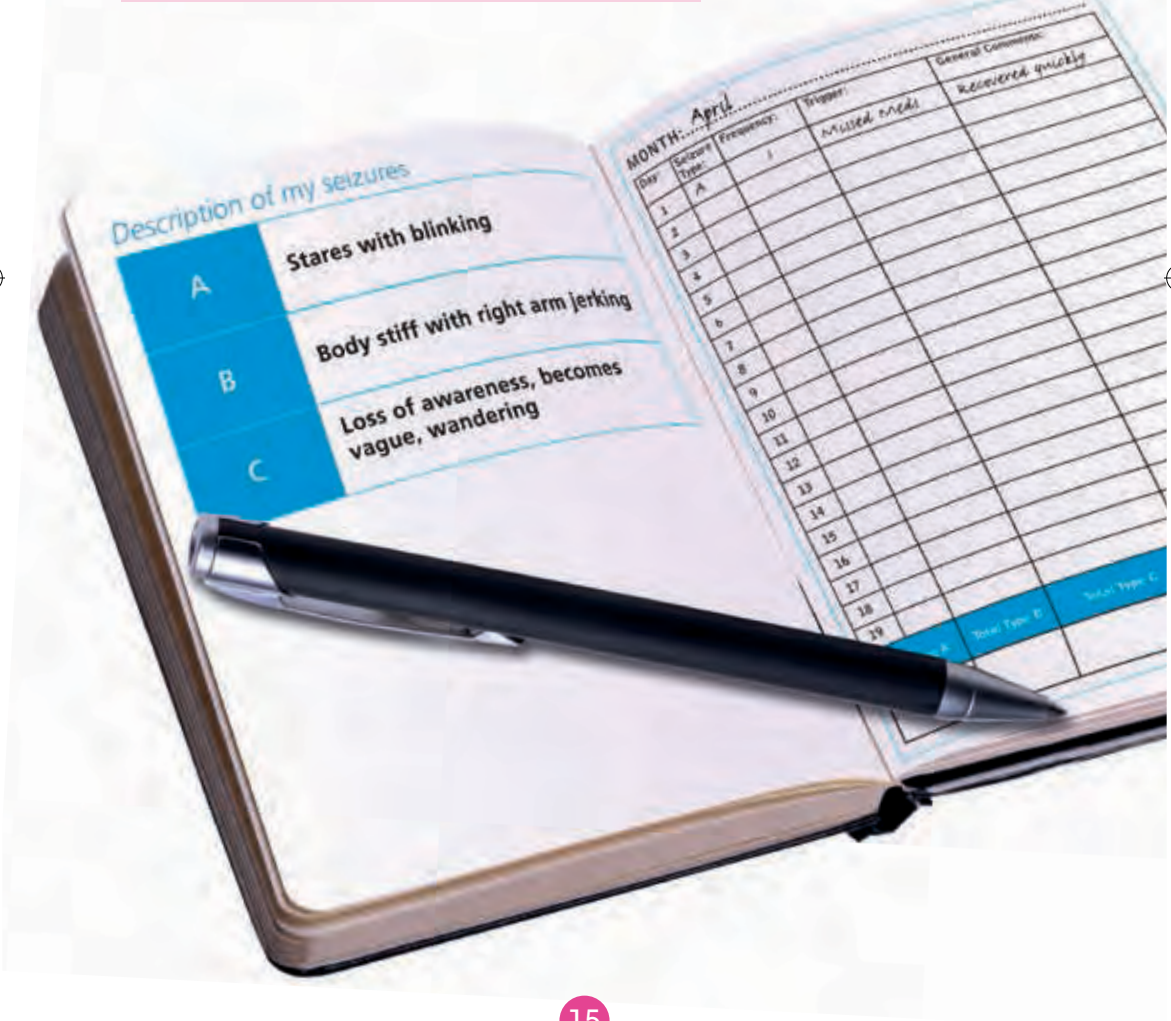
1. Date and time of the seizure
2. Type of seizure
3. Length of seizure
4. Changes in medication/treatment
5. Triggers
6. Life events e.g. first communion, fish oils started, head injury
7. Total seizures per day/week/month
8. Side effects

Recording seizures is important in managing your child's epilepsy.

1010622 Epilepsy Irl Brochure V3.indd 16 17/12/2013 17:03

Useful things to bring to clinic

- Medication
- Copy of reports e.g. psychology report
- Seizure diary
- List of questions for your child's doctor



How to help your child live with epilepsy

Studies have shown that a positive attitude to epilepsy is an important predictor of success in later life. Accurate information combined with a positive outlook will help you and your child deal with their epilepsy effectively.

The following points may be useful:

DO

- Accept your child for who they are - a unique individual who happens to have a tendency to have seizures. Encourage them to do the same
- Concentrate on what they can do rather than what they cannot do

DON'T

- **Don't** restrict your family life because of your child's epilepsy
- **Don't** allow your child to think of themselves as 'sick' or use epilepsy as an excuse

1010622 Epilepsy Irl Brochure V3.indd 18 17/12/2013 17:03

How to help your child live with epilepsy

What to tell your child

Children's questions about epilepsy need to be answered honestly. This builds confidence and helps them understand their epilepsy. Epilepsy Ireland has a range of books and information leaflets on how to explain epilepsy to a child.

Who needs to know your child has epilepsy?

You must tell people who have to take responsibility for your child. This includes teachers, childminders, close family members, sports coaches etc. It is important to provide information specific to your child's seizures. The more information provided, the better a seizure will be managed. Even if your child does not have seizures, their teacher probably should know that they are on medication.

Parent's feelings

Every parent whose child is diagnosed with epilepsy goes through an initial period of adjustment. At this stage all kinds of feelings may be felt. Sharing your feelings and talking about them is important. This is not always easy. It can help to talk to someone who is not involved emotionally in the situation, who will listen, help you express your feelings and clarify your thoughts. This may be a counsellor, nurse, doctor or Community Resource Officer (CRO) in Epilepsy Ireland.

1010622 Epilepsy Irl Brochure V3.indd 19 17/12/2013 17:03

Epilepsy and Leisure

All children with epilepsy should enjoy their leisure time. Research has shown that being active reduces the likelihood of having seizures. It is important not to impose unnecessary restrictions on your child because of their epilepsy. **However, a common sense approach to safety is encouraged. Always follow normal safety procedures.** If you have any questions ask your child's doctor or nurse specialist.

Swimming (Pool):

If your child is seizure free or seizures are well controlled there is generally very little risk as long as your child is supervised. If seizures are not well controlled it is necessary to have one to one supervision by someone who knows what to do in the event of a seizure occurring. **Always tell the lifeguard and swimming coach that your child has epilepsy.** Further advice can be obtained from Epilepsy Ireland and your child's nurse specialist.

Cycling:

Always ensure your child wears a helmet and does not cycle alone. If your child has poorly controlled seizures, avoid cycling until controlled.

Climbing:

Heights are a potential danger to anyone with epilepsy. The risk involved should be considered against the benefits from the activity. **Supervision is recommended.**

Contact sports:

Epilepsy should not stop your child from playing football, rugby, basketball, hurling, hockey, camogie etc. provided **normal safeguards (including head protection) are followed**. An exception to this is boxing due to the risk of being hit on the head. This could trigger seizures.

1010622 Epilepsy Irl Brochure V3.indd 20 17/12/2013 17:03

1010622 Epilepsy Irl Brochure V3.indd 21 17/12/2013 17:03

Useful Websites

Epilepsy Ireland	www.epilepsy.ie Facebook: facebook.com/epilepsy.ie Twitter: @epilepsyireland YouTube: youtube.com/BrainwaveEpilepsy Online Support Group: support.epilepsy.ie
Epilepsy Society (UK)	www.epilepsysociety.org.uk
Epilepsy Action (UK)	www.epilepsy.org.uk
Epilepsy Action Australia	www.epilepsy.org.au
Epilepsy Action New Zealand	www.epilepsy.org.nz
Neuroscience for Kids	http://faculty.washington.edu/chudler/neurok.html
VHI A-Z Health Information	www.vhi.ie
Beyond Epilepsy	www.livebeyondepilepsy.com
Matthew's Friends	www.matthewsfriends.org
The Charlie Foundation	www.thecharliefoundation.org/
Young Epilepsy (UK)	www.youngepilepsy.org.uk
Epilepsy Foundation (US)	www.epilepsyfoundation.org
Epilepsy Scotland	www.epilepsyscotland.org.uk
Epilepsy.com	www.epilepsy.com

1010622 Epilepsy Irl Brochure V3.indd 22 17/12/2013 17:03

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