

epilepsy
society

just diagnosed



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This symbol means further information is available.

Call us for a large print version

helpline

01494 601 400

Monday and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm. National call rate.

just diagnosed

If you have just been diagnosed with epilepsy, this booklet is for you. It is also for you if you have had epilepsy for a while.

This booklet aims to help you learn more about epilepsy, to understand how your epilepsy might affect you, and answer some questions you might have about living with epilepsy.

There can be a lot of misunderstanding about epilepsy and **seizures** (sometimes known as 'fits' or 'attacks'). But it is a common condition. About one in a hundred people has epilepsy, so you may already know people with the condition.

People respond to a diagnosis of epilepsy in different ways, and it can take time to get used to. For some people it's a relief, especially if they have been waiting for a diagnosis for a long time. For others, it may be a shock. It can be a difficult time, with many challenges. You might experience lots of different, and changing, emotions.

Giving yourself time to work out how your epilepsy affects you, how you feel about it, and what choices to make, can be helpful. There might be people close to you who you turn to for support, and they might like to see this booklet too.

This booklet was created with the help of people with epilepsy, and includes their views and experiences, and their quotes at the bottom of some of the pages. It also includes information on topics people told us they would have found helpful when *they* were diagnosed with epilepsy.

People with epilepsy have told us that support and good information can really help when newly diagnosed. Although some people want information and support straight away, others want to wait for a while until they feel ready to start finding out more. This booklet contains information that you can dip into when you are ready, and read at your own pace.

If you are looking for more information, emotional support or time to talk, Epilepsy Society has a confidential helpline you can call. You can also make contact with us and other people affected by epilepsy via Twitter, Instagram and Facebook. Our website has lots of information and videos, and we have printed leaflets, factsheets and booklets for people with epilepsy and those close to them. You can find more details at the end of this booklet (see page 23).

Epilepsy Society offers information and support, whether you have just had a diagnosis, or epilepsy has been part of your life for a while. We believe in a full life for *everyone* affected by epilepsy.

Epilepsy Society would like to thank all the people affected by epilepsy who shared their experiences and helped develop this pack.

about epilepsy

Anyone can develop epilepsy, at any time of life. It happens in people of all ages and from all backgrounds.

Epilepsy is not just one condition, but a group of many different 'epilepsies' with one thing in common: a tendency to have seizures which start in the brain. However, in this booklet, we use the term 'epilepsy', as it is a familiar term for many people. Epilepsy is neurological, which means it affects the brain and the nervous system.

Epileptic seizures are usually sudden, last a short time, and stop by themselves. They can start when you are awake or asleep and can cause a change in awareness of where you are, what you are doing, your behaviour, or your feelings.

There are many different types of seizure and the type of seizure you have depends on which part of your brain is affected and what that part of your brain controls. Some people have seizures where they lose consciousness, and may fall down and shake. Other people might go 'blank' and stare for a few seconds, or become confused, wander around, or behave in an unusual way. Some people have seizures that other people don't notice, but which affect their senses or how they feel.

Some people have more than one type of seizure. The type of seizure and how long they last for is usually fairly constant for each person, although this can change over time.

Learning what type of seizures (and ideally, what type of epilepsy) you have can help you and your doctors to decide what treatment is likely to suit you best.



See our leaflet *seizures*.

Who will I see about my epilepsy?

You may see different people to help you manage your epilepsy. This might include the following people.

- During your diagnosis you will probably have seen a **neurologist***. Some neurologists specialise in epilepsy. It is the neurologist who will generally diagnose epilepsy and prescribe and start any treatment, such as medication. You might continue to see a neurologist while trying to get your seizures controlled, and you could also have ongoing regular reviews of your epilepsy with a neurologist.

NICE (the National Institute for Health and Care Excellence) produces clinical guidelines and sets standards for healthcare. NICE recommends that anyone who has a seizure is seen urgently (within two weeks) by a specialist (with training and expertise in epilepsy, such as a neurologist) to make a diagnosis and discuss appropriate treatment.

- Alongside the neurologist, you might see an **epilepsy specialist nurse**. The specialist nurse is often a good link between you, the neurologist, and your GP. Specialist nurses might be involved in your treatment, and they may support you in other ways, such as talking to you about your epilepsy and how you are getting on.
- Your GP might also be involved in your epilepsy management. They are usually responsible for prescribing any ongoing treatment, and they are generally the first person you go to if you have any questions or concerns. Some GPs have a specialist interest in epilepsy.
- You might also see other people about your epilepsy, depending on how things are for you. This could include an occupational therapist, community nurse or social worker.

***In this booklet, when we refer to a neurologist, this might be a paediatrician if it is a child who has epilepsy.**

My healthcare professionals

You can use the space below to write in the names and contact details of the people involved in your care.

Neurologist _____

Hospital _____

Tel _____

Epilepsy specialist nurse _____

Tel _____

GP _____

Surgery _____

Tel _____

Why am I having seizures?

Your brain controls the way you function. Inside your brain millions of nerve cells pass messages via electrical signals to each other. During a seizure these electrical signals are disrupted, and this affects how you feel or what you do while the seizure is happening.

Sometimes there is a clear cause for seizures, for example, if someone has damage to their brain from a difficult birth, an infection such as meningitis, a stroke, or a head injury.

The likelihood of someone having seizures can also be partly **genetic**. This is sometimes inherited from one or both parents, but in some cases it may be from a change that

happens only in the person's own genes. So even if someone has a genetic tendency to have seizures, in many cases epilepsy is not inherited.

Your doctor or neurologist may be able to tell you what has caused your epilepsy, but this is not always possible. Research continues into understanding more about why seizures happen in some people and not in others.



See our leaflet *what is epilepsy?*

What triggers seizures?

For some people certain situations can 'trigger' a seizure (make a seizure more likely to happen). Triggers are not the same as underlying causes. Triggers vary but can include lack of sleep, stress, excitement, alcohol, and not taking your medication as prescribed.

Flashing or flickering lights or certain visual patterns can be a trigger for some people. This is called photosensitive epilepsy and it affects around 3% of people with epilepsy. You may have had a test for photosensitive epilepsy if you had an **EEG** (electroencephalogram) during your diagnosis.



See our factsheets *sleep and photosensitive epilepsy.*

What treatment options are there?

Epilepsy is sometimes referred to as a long-term condition, as people often live with it for many years or for life. Although generally epilepsy cannot be 'cured', for most people, seizures can be 'controlled' (stopped), so that epilepsy has little or no impact on their lives. So treatment is often about managing seizures in the long-term.

Most people with epilepsy take anti-epileptic drugs (**AEDs**) to stop their seizures from happening. However, there are other treatment options for people whose seizures are not controlled by AEDs.

Medication

AEDs work by controlling the electrical activity in the brain that causes seizures. They do not cure epilepsy and are not used to stop seizures while they are happening. AEDs work best if they are taken regularly, around the same time each day. Up to 70% of people (7 in 10) could have their seizures fully controlled (stop having seizures) with the right AEDs.

The aim of treatment is to stop all of your seizures with the lowest dose of the fewest AEDs (called Optimal therapy), and with the least side effects. Usually treatment starts using a single AED at a low dose, which is increased slowly (called **titration**), until your seizures are controlled. If your seizures are not controlled with this drug, a different AED is usually tried (by adding in the new drug and then slowly withdrawing the first one). If your seizures are not controlled with a single drug, another drug might be added, so that you take two different AEDs each day.

There are lots of different AEDs, and your neurologist will usually choose the AED that is most suitable for the type of seizure you have and your particular situation. Finding the right drug at the right dose can sometimes take time.



See our booklet and chart *medication for epilepsy*.



Most AEDs have two names, a **generic** name and a **brand** name given by the manufacturer (for example, Nurofen is a brand name of the generic painkiller ibuprofen). Some AEDs have more than one generic version, and each version can be given its own name.

For some AEDs, different versions of the drug can vary slightly, and this could affect seizure control. Once you and your doctors have found an AED which helps to control your seizures, and which suits you, it is recommended that you take the *same version* of your AED consistently with every prescription, whether it is a generic or brand version. This is called ‘consistency of supply’.

If a prescription only has the generic name of a drug, the pharmacist can give any version of the drug with that name. However, if a prescription has the brand name of the drug, the pharmacist has to give that brand. It can be helpful to get your prescription from the same pharmacist each time, as some pharmacists keep records of the medication they dispense and can help with questions about prescriptions.



See our factsheet *generic and branded AEDs*.

Free prescriptions

People with epilepsy are entitled to free prescriptions for their AEDs and any other prescribed medication. This is called medical exemption. To apply for free prescriptions in England, you can fill in form FP92A available from your doctor’s surgery. It is important to carry your medical exemption card with you for when you collect your prescription. In Scotland, Wales, and Northern Ireland all prescriptions are currently free.

Treatment plans

Some people have a **treatment plan** – a written plan of the number and type of AEDs to take, when to take them, and what to do if the AEDs don't work or need to be adjusted. Treatment plans are agreed between you and your doctors, and so they may be able to help write one with you.

Medication side effects

Like all medicines, AEDs can cause side effects in some people. Not everyone will have side effects, and whether you have them or not will depend on how your body reacts to the medication. Side effects are listed in the **patient information leaflet** that comes with your medication.

Side effects are listed as 'common', 'rare' and so on. These terms reflect how many people have these side effects. For example, side effects listed as 'common' affect between 1 in 10 and 1 in 100 people. Side effects that are 'rare' happen in less than 1 in 1,000 people.

Some side effects may happen when you first start taking medication, and then wear off as your body gets used to it (so they only last a short time). However, if you have side effects that continue or that are difficult to cope with, you might find it useful to talk to your doctor about whether your medication could be changed or the dose altered.

Some other medications can affect how well AEDs work, and some AEDs can affect how other medications work. For this reason, it is essential to talk to your doctor or pharmacist before taking other medications, including 'over the counter' or complementary therapies, alongside your AEDs.



See our factsheet *making the most of your pharmacist*.

What if medication doesn't work for me?

Managing medication can often be a balance between preventing seizures and keeping side effects to a minimum. For most people, AEDs help to control their seizures, but for others, despite trying different types, the AEDs do not stop their seizures completely. In some cases, looking at other treatment options may be helpful.

For example, someone may be considered for **epilepsy surgery**, VNS (vagus nerve stimulation) therapy or a specialist medical dietary treatment, alongside their AEDs. For most people, these are considered only after several medications have not worked. However, for others, these options might be considered sooner.



See our factsheets *epilepsy surgery*, *ketogenic diet* and *VNS therapy*.

How can I manage my epilepsy?

Taking an active role in managing your epilepsy (sometimes called 'self-management') can be an important part of helping to reduce your seizures and to feel more in control. Learning about how your epilepsy affects you, and being involved and able to make informed choices about managing your treatment, is all part of this. Having a good relationship with your healthcare professionals can also help, including your GP, neurologist, epilepsy nurse if you have one, and pharmacist. They may be able to tell you about any local services and support available to you.

Some people have triggers for their seizures (see page 8) such as stress or lack of sleep. Triggers can vary from one person to another, and not everyone will have triggers.

If you can identify any triggers, you might be able to reduce the number of seizures you have by avoiding these triggers.

Some people choose to keep a diary of when their seizures happen, any triggers, any side effects, and how they feel. Diaries may also have space for details of medication, your healthcare team's details, and future appointments.



We have included a free *seizure diary* in this pack.

If you have a smartphone or tablet, our free app includes a seizure diary, and information on epilepsy and first aid.



Log on to your app store and search 'epilepsy' or visit epilepsysociety.org.uk/free-epilepsy-smartphone-app

Improving your overall wellbeing may also help to reduce the number of seizures you have. This could include having a balanced diet, keeping physically active, sleeping well, and finding ways to relax and manage any stress. Some people find complementary therapies or psychological therapies help with their overall wellbeing. For some, just talking to someone who understands can help too.



See back page for details of our helpline.

Will my epilepsy go away?

Many people need to take AEDs, or other treatment, for the long-term to keep their seizures under control. However, for some people, epilepsy goes into **spontaneous remission** and seizures stop happening. This can depend on the underlying cause of seizures. If this happens for you, you and your specialist may decide together to gradually stop your treatment, and they can help you do this safely.

day to day

Can I drive if I have epilepsy?

If you have a driving licence and you have a seizure, the **DVLA** regulations say that you must stop driving. For many people this can have a big impact on their life and be very difficult or upsetting.

If you have a driving licence, by law you are responsible for telling the DVLA about your epilepsy and returning your licence to them. This is the case whatever type of seizure you have had, whether you lost consciousness or not, and whether you are taking anti-epileptic drugs (AEDs) or not.

You can apply for a new Group 1 licence (cars, motorbikes and mopeds) after a year of having no seizures, whether you are taking AEDs or not. If your seizures only happen in your sleep, or they do not affect your consciousness nor cause any functional impairment, the regulations are different (see our leaflet 'driving and travel').

To get a new Group 2 licence (buses and lorries) you need to have had no seizures for 10 years and not be taking AEDs.

Suddenly losing your licence, even temporarily, may have a big impact on you both practically and emotionally.

If you can't drive due to your epilepsy, you can get free or discounted travel on buses, trains, tube, and other transport.

If you can't get to work using public transport, you may be able to get help towards the cost of travel to work through the Access to Work Scheme. Contact your local Jobcentre Plus office for more information.



For driving regulations for all seizure types see our leaflet *driving and travel*.

Can epilepsy affect my work?

Whether epilepsy will affect your work depends on how *your* epilepsy affects *you* and what your job involves. For example, jobs which involve driving, or working with machinery, near open water or at heights, could be affected.

Although you do not legally have to tell an employer about your epilepsy, it may be important for them to know so that they can keep you safe at work and treat you fairly.

To keep you and other employees safe at work, your employer may need to do a risk assessment of your work environment and the tasks involved in your job. They may also need to know how you would like to be supported if you have a seizure at work.

To treat you fairly alongside other employees, your employer needs to know how your epilepsy affects you so that they can consider any 'reasonable adjustments' you may need to help you do your job. For example, your employer might consider adjusting your hours if you have seizures at night that leave you very tired in the morning, or giving you time off for medical appointments that is separate from sick leave. If they know about your epilepsy, your employer needs to consider making any adjustments for you, because epilepsy is covered as a disability under the Equality Act 2010, even if you do not consider your epilepsy to be a disability.

If you feel that you might be discriminated against in employment because of your epilepsy, there is support and more information available about the Equality Act. This may help you to address any such issues at work.



See our leaflet *employment*.

Whether or not you work, you may be entitled to claim benefits or other financial help depending on how your epilepsy affects you. Your local benefits agency or Jobcentre Plus can look at your individual situation to see what you may be entitled to. You can also talk to a disability benefits helpline or your local Citizens Advice Bureau for guidance.



See our factsheet *what help is available?*

Epilepsy and safety

Keeping safe while having a full and active life, can be about balancing what is most important to you with what will keep you safe. If your seizures become controlled, your epilepsy may have very little effect on what you do.

Some activities, including some sport and leisure activities, carry more risk of accidents or injury if you have seizures. But they may be made safer with simple measures and by thinking about how your seizures affect you. If during your seizures you become confused or do things that you don't remember, you may want to think about what would help to keep you safe. Some people get a warning (when they know a seizure is going to happen) which may give them enough time to get to a safe place before a seizure happens.

Some safety issues are important to consider early on in your diagnosis. An example is your safety when bathing. Having a shower can be safer than having a bath because the water drains away and there is less chance of you slipping under the water during a seizure.



Using an 'engaged' sign on the door, instead of locking it, means that someone can help you if you need it.

There may be ways to adapt the way you cook or do jobs around the house, or to adapt your daily and leisure activities, to help keep you safe during a seizure.

Having someone with you, who knows what to do if you have a seizure, may help to keep you safe and can give peace of mind during some activities. If you live alone, there are ways to get help or contact someone if you need them, through alarm systems or mobile phones. Medical ID cards or jewellery can let other people know how to help if you have a seizure when out and about.



See our leaflet *safety* and the 'I have epilepsy' card in this pack. Visit livingmadeeasy.org.uk for information on personal alarm system suppliers.

Alcohol and drugs

Whether to drink alcohol or take recreational drugs is a personal choice, but it is worth knowing the possible effects they could have on your epilepsy. Alcohol or recreational drugs can cause epilepsy in some people.

Alcohol is a common trigger for seizures, especially in the hangover period when your brain is dehydrated. It also disrupts sleep patterns which can be a trigger for seizures. Alcohol can make epilepsy medication less effective or make the side effects of medication worse. The patient information leaflet that comes with your AEDs may say whether you can drink alcohol with that AED. However, the effect alcohol has on your seizures is individual.

Recreational drugs can trigger seizures or increase the frequency of seizures for some people and can also interact with medication. Taking recreational drugs increases the risk of seizures and of mental and physical health problems, which in turn make seizures more likely. Learning more about your own epilepsy and treatment means you can make informed choices about your lifestyle.



See our leaflet *leisure*.

What are the risks around epilepsy?

Risks of injury or harm are not always easy to avoid, and can be worrying to think about. But being aware of risks, and how you might be able to reduce them, might help you feel more in control of your epilepsy.

For some people, seizures may carry risks of injury. Although seizures are usually short (a few seconds or minutes) and stop on their own, for some people their seizures are longer and they might need emergency medical help to stop them, to keep oxygen getting to the brain. For a small number of people, there is a risk of dying due to seizures or after a seizure if the person has not recovered properly (sometimes called SUDEP or sudden unexpected death in epilepsy).

These serious risks can be very frightening to read about but they are rare. A key way to reduce risks is to prevent seizures from happening, usually through taking your AEDs as prescribed, having regular reviews with your doctors, staying healthy, and avoiding, where possible, anything that you know triggers your seizures.



See our leaflet *risk*.

Specific issues for women and girls

For some women and girls with epilepsy, hormone level changes affect when epilepsy starts, how often seizures happen, and whether epilepsy goes away. Hormone levels change during puberty, through the menstrual cycle, during pregnancy, and during the menopause.

Some types of contraception can be affected by AEDs, making them less effective in preventing pregnancy. Some types of contraceptive can affect the way AEDs work. Talking this through with your doctor is important to help you decide on the right contraception for you.

If you are thinking of starting a family, it is essential to talk to your neurologist about your epilepsy treatment for your pregnancy and for when your baby arrives. Getting specialist advice ('preconception counselling') before you become pregnant can help to keep you and your baby safe, and you can talk through any concerns.

Although the vast majority of women with epilepsy will have a healthy pregnancy and baby, some AEDs can affect the development of an unborn baby. Risks depend on the dose and each individual situation, and they need to be balanced with seizure control. Research has shown that sodium valproate (brands include Convulex, Epilim, Episenta, Epival) can cause problems in a developing baby.

These issues will be considered when deciding whether to start treatment, and what treatment would be suitable. If you start taking AEDs, your neurologist should plan for the possibility of you taking AEDs long-term, even if you are not thinking about becoming pregnant at the moment.



See our leaflets *women and pregnancy and parenting and medication for epilepsy.*

what next?

A diagnosis of epilepsy affects people differently. It can be overwhelming and challenging at first, or something that you come to terms with and adapt to quickly.

This booklet might help you to understand more about your epilepsy. But you may still have unanswered questions, both now and in the future. With epilepsy there can be many uncertainties – what will happen with your epilepsy, how it may change over time, and how you feel about it. There is no right or wrong way to deal with having epilepsy or how to feel about it. You may find that learning more, or talking to someone can help you to work out how you feel and what is most important to you.



See back page for contact details of our confidential helpline or visit our website at epilepsysociety.org.uk

When epilepsy is a long-term condition

Epilepsy is very individual: some people will have seizures all their life, but for others they might have epilepsy just for a period of their life, and their epilepsy may go away (called ‘**spontaneous remission**’). So for some, epilepsy is a long-term condition, which they live with for many years.

For most people, seizures become well controlled (they still have epilepsy but the medication is stopping the seizures) and so it has little impact on them.

For others, seizures may take longer to be controlled or may not respond to treatment. Epilepsy might have a greater impact on them, and they may need support and help with work, education, or daily life.

“Assume you can do anything until there is a good safety reason for accepting that you can’t. Then go and do something else instead.”

Epilepsy is sometimes classed as a disability. While some people find the term ‘disability’ negative or a ‘label’ that doesn’t feel right, it can be useful to know what this term means and how it might help you to find help and support.

The Equality Act 2010 is a law that aims to ensure that people are treated fairly and are not discriminated against. This applies to employment, school and learning, and accessing services (such as using shops, health services or leisure facilities). Groups specifically covered by the act include people with disabilities.

Epilepsy is considered a disability when it greatly affects someone’s ability to do everyday activities (such as concentrating or remembering things), over a long period of time. Epilepsy is sometimes described as a *hidden* disability because it is not usually obvious that someone has epilepsy unless they have a seizure.

Whether you feel that you have a disability or not, you are protected by the Equality Act if your epilepsy affects you in this way. Depending on your situation, there may be help available, such as benefits or support at home.



See our factsheet *what help is available?*

People with epilepsy may be entitled to certain financial support, for example free prescriptions and discounted travel (see pages 10 and 14).

“You are not an epileptic: you are a human being.”

Relationships and sex

Some people are concerned about relationships and sex when they are diagnosed with epilepsy. Some worry that their relationships will change, or about how people will react to their diagnosis. Some may worry that they might have a seizure during sex or feel that having epilepsy might affect their sex drive (their interest in sex).

Generally, seizures are no more likely to happen during sex than at any other time. And although some people do notice a lower sex drive, which could be for a number of reasons related to their epilepsy, having epilepsy will not necessarily affect your interest in sex. If you are concerned that your epilepsy is affecting you in this way, talking about this with your doctor might be helpful.

Those close to someone diagnosed with epilepsy often feel concerned for them, but can also be going through different emotions themselves, such as guilt, uncertainty, fear or relief. Being able to talk openly about any needs, worries or concerns may help some people to find ways of helping, supporting, and understanding each other.

Sometimes epilepsy does change a relationship. Some people might need to rely more on those around them, both practically and emotionally. Relationships can change, as epilepsy can impact on the individual and those close to them. These changes can be positive – many people with epilepsy find that their relationships with partners, family, and friends can grow, be stronger, and become more supportive and encouraging.



See our factsheet *relationships and sex*.

“You’re normal! Wanting it to go away is a ‘normal’ and a ‘sane’ reaction. However you are feeling or behaving is ‘normal’ and ‘sane’.”

Connecting with other people

Many people who contact us say that having someone to talk to, who has epilepsy or knows about epilepsy, can be really helpful and reassuring. It can be an important part of coming to terms with a diagnosis of epilepsy.

You might already have people around you who can help and support you. Your healthcare professionals might also have told you about sources of help and support. If you would like to, there are various ways in which you can make contact with other people.

Social media

You can get in contact with us, and some of our supporters, through social media such as Facebook, Instagram and Twitter.



**Find us on Facebook: facebook.com/epilepsysociety
Instagram: instagram.com/epilepsysociety and
on Twitter: [@epilepsysociety](https://twitter.com/epilepsysociety)**

Videos

Our website contains lots of free videos, including 'All about epilepsy' which is an introduction to epilepsy and the experiences of people living with epilepsy.



Visit epilepsysociety.org.uk/epilepsytv

"It gets easier as you get used to it and find out more about it – so many other people are going through what you are going through."

Websites and forums

If you have web access, there are epilepsy forums where you can contact other people online. Many people appreciate finding a supportive online community, to share experiences and ask questions. Depending on how a forum is set up, you may be able to look at what other people are saying before joining. You can register to post messages on a forum without giving your real name.

Some websites and forums are set up by people with particular experiences, some of which may seem quite frightening or negative, so it can be helpful to use forums on websites that you trust. For example, you might like to check that a forum is moderated (looked after) by some of the regular forum users or staff.

Support groups

Some people find face-to-face support through meeting other people with epilepsy helpful. You could ask your GP or hospital if they know of any local support groups, or call our helpline and ask if there are groups in your area.

Epilepsy Society's helpline

Our confidential helpline team can talk to you about what is happening and how you are feeling. We won't tell you what to do. You can talk things through and think about what you want to do. You don't have to give your personal details, and we won't pass on what you have said to anyone else.



See back page for details of our helpline.



I don't know how I should be feeling

You might be feeling lots of different emotions right now. People can react differently to a diagnosis. It may not be possible to think and feel positively. Or you may feel fine one minute, and upset or angry the next. It may be helpful to know that this is a common way to feel.

Some people find it difficult to come to terms with their epilepsy, or feel worried, down, or anxious. We have more information about how you might be feeling.



See our booklet *The Bigger Picture – epilepsy and mood*.

Some people find that self-management courses are really helpful. Self management UK offers free courses for people with long-term conditions. The courses focus on learning techniques to help individuals take control, and to develop confidence and skills to manage their condition.



To find out more, and see whether there are courses in your area, visit selfmanagementuk.org

You may feel that coming to terms with your diagnosis is difficult right now. Or you might have your own ideas about what might help you feel better. Again, there is no right or wrong answer. What do you think would make you feel better? Is there anything you can think of that you would like to do right now? Who could you talk to? What feels achievable?

If it is difficult to focus on these questions or to find answers, you can always talk this through with our helpline. They can give you the time and space to work out what feels right for you at the moment.

***“I thought he was a rubbish doctor... asking me ‘how are you?’
Then I realised he was empowering me.”***

Coming to terms with epilepsy

People can feel differently about their diagnosis: some people come to terms with it quickly, some take longer, and some feel that epilepsy will always be an ongoing issue for them. Here are some quotes from other people about what they have found helpful when coming to terms with their epilepsy.

“It was a relief to know what was wrong, so it sunk in quite easy really.”

“Having an opportunity to talk to someone and not have to wait until the next appointment.”

“Assurance that I am not the only one and talking to others with the same problems and life experiences.”

“Information. Being sent home with a diagnosis and no information made us feel extremely isolated, vulnerable, and unsure.”

“Help and support of friends and family.”

“The Epilepsy Society helpline – very supportive people who were willing to listen to me when I was upset.”

Do I need to tell other people?

Whether to tell other people about your epilepsy, who to tell, and when, is a personal choice. There might be some people around you who it may be useful to tell. It might depend on how you are feeling about your diagnosis, and whether you are ready to talk to other people about it.

Making decisions about who to tell at your own pace, may help you to feel more in control of what is happening.

***“Always ask questions, even if you think it might sound silly.
Make sure you have all the answers you want.”***

You may want to tell people about how they can help and support you, such as people you spend a lot of time with.

Some people don't know much about epilepsy, and they may expect you to explain it to them. It might be helpful to have some information that you could give to them to help them understand. You could give them a first aid card or show them this booklet.



Use the *first aid* card in this pack or contact us for more.

Some people you talk to may already have their own ideas about epilepsy. They might not understand that there are different types of seizures. They might not know what to say, or they might say something that you feel is unkind or thoughtless. Sometimes it can help to think about what you would have thought about epilepsy before you were diagnosed.

Thinking about what you want people to know about your epilepsy might help you to feel prepared if they ask you questions. Giving them something practical to do might help them to feel that they are helping you.

Perhaps saying something like "I have epilepsy and it would really help me if you could..." might help them to respond to you in a way that you would find helpful.

If other people help or support you, they may like to read this booklet.

You might also like to look at the postcard in this pack which has some thoughts and feelings that other people with epilepsy have shared with us.

Here are some things you may like to think about.

what you could say or talk about

- How to help you during a seizure.
- What support you need.
- What your epilepsy is like.
- How you feel right now.
- What is useful to you.

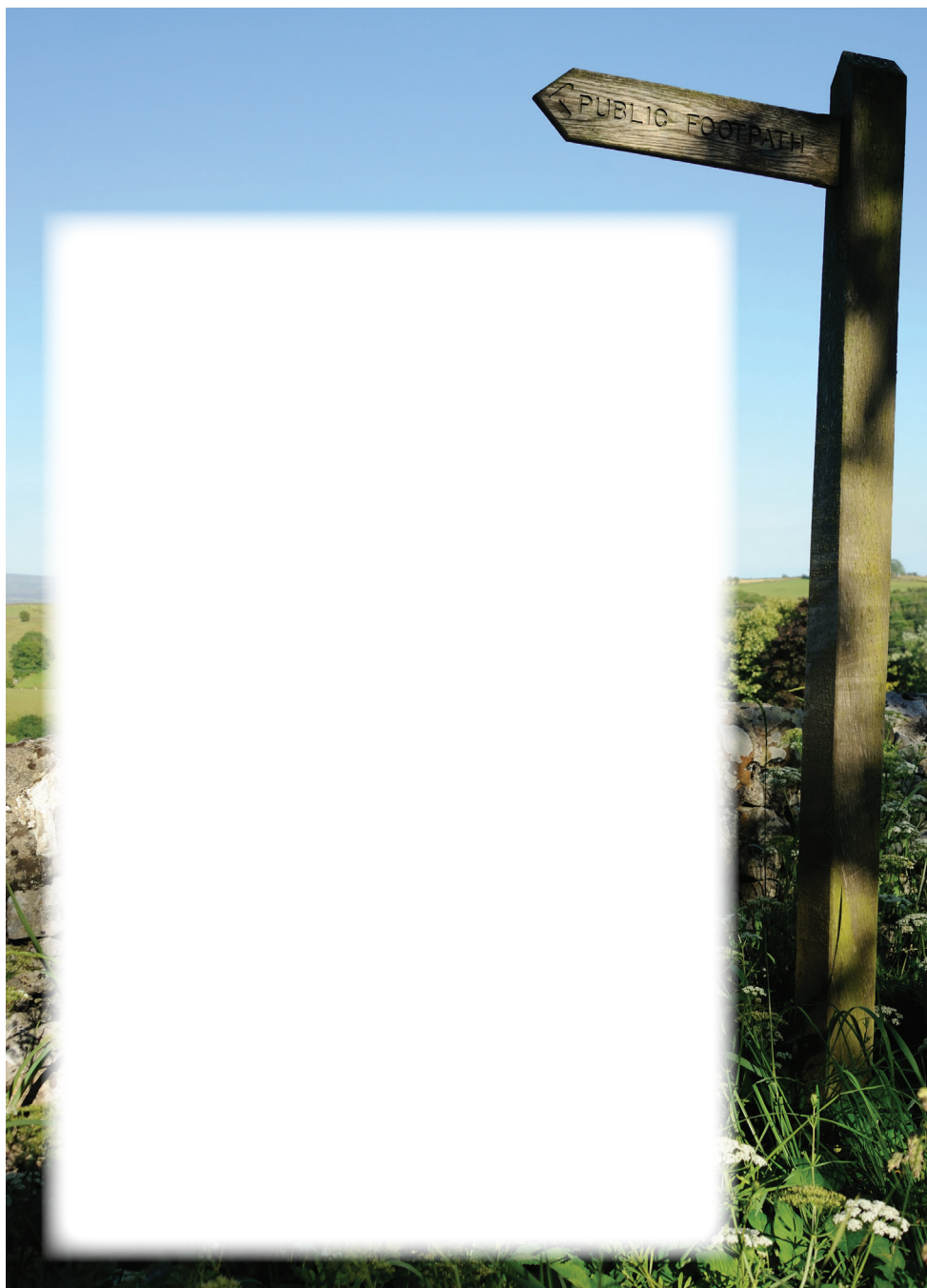
who you could tell

- People who can support you.
- People you spend time with.
- People you trust.

reasons to tell other people

- You feel that you need to talk.
- You feel that others need information.
- You feel comfortable with someone.
- You think the time is right.

You could use the space below to write in your own thoughts about your diagnosis and how you feel.



summary of terms

Here is an explanation of some of the terms included in this booklet, along with some other useful terms.

AEDs (anti-epileptic drugs) – medication taken to control epilepsy and stop seizures.

Brand name – a drug's name given by its manufacturer.

DVLA – the Driver and Vehicle Licensing Agency in Great Britain.

EEG – an electroencephalogram is a test used to record the electrical activity of the brain.

Epilepsy specialist nurse (ESN) – a nurse with specialist knowledge of epilepsy. They are often based in hospitals, although some might work alongside GP surgeries.

Epilepsy surgery – surgery on the brain to try to stop seizures from happening. Also called 'neurosurgery'.

Generic name – the name of a drug's 'active ingredient' (part of a drug that works to control or treat a condition). All drugs with the same generic name contain the same active ingredient.

Genetic – information in our DNA that decides some of our characteristics, for example hair colour, sex and height.

Neurologist – a doctor who specialises in conditions that affect the brain and nervous system.

NICE – the National Institute for Health and Care Excellence, provides guidance and advice to improve health and social care.

Patient information leaflet (PIL) – the leaflet that comes with medication that says what it is for and how to take it.

Primary care – health services such as the GP or pharmacy. This is ‘primary care’ because it is usually the first place you will go to for help with anything medical.

Secondary care – health services such as local hospitals and clinics, where you would see someone more specialised than the GP or pharmacist, such as a neurologist. This is ‘secondary care’ because you usually have to be referred by your GP. It also includes A&E departments.

Seizures – brief events where someone has unusual sensations or loses consciousness or awareness for a short time. Other names used include ‘fits’ or ‘attacks’.

Spontaneous remission – when seizures stop or go away on their own.

Tertiary care – specialist hospital or unit, that focuses on specific care for different conditions. For example, if someone is being considered for epilepsy surgery, they might be seen in tertiary care. You have to be referred to tertiary care from either primary or secondary care.

Titration – this is when drugs are started at a low dose, and the dose is gradually increased until the drug starts to work. This process is usually done very slowly to reduce the chance of side effects and to try to find the lowest dose of the drug that works for an individual.

Treatment (or drug) plan – a record of your AED doses, when to take them and what to do if they don’t work.

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

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Chesham Lane, Chalfont St Peter, Bucks SL9 0RJ

01494 601 300

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