

Epilepsy Diary & Information Booklet



Acknowledgement

UCB wishes to thank Epilepsy Action for their help and collaboration in the development of this Epilepsy Diary and Information Booklet. We would also like to thank Epilepsy Action for enabling UCB to modify the booklet for use outside of the UK and hope that it will continue to encourage people using this diary to get the best possible treatment for their epilepsy.

Taking Control of your Epilepsy

If you have epilepsy, the information from UCB is for you. The information aims to help you, or perhaps someone who cares for you, to get the best possible treatment for your epilepsy. Better treatment could mean:

- Fewer, less severe, or even no seizures.
- Fewer, less severe side effects.

Treating epilepsy isn't easy. Quite a lot of people continue to have seizures despite trying many of the different medications and treatments currently available. However, it is possible that around seven out of 10 people with epilepsy could become seizure-free for at least one year on their first medication. Almost seven out of ten people with epilepsy can become seizure free for at least one year on their first medication.⁽¹⁾

Unfortunately, medications can cause side effects and epilepsy medications are no different. The type of side effect and their impact can vary from one person to another. It is important that you discuss how you are feeling with an epilepsy specialist. Your specialist can help determine whether you are experiencing medication side effects and how best to manage them.

(1) 70% of 423 people in the study by Kwan & Brodie 2000

What can you do?

Just making some small changes to the way you manage your epilepsy, could make a significant improvement to your day-to-day quality of life. This booklet can help you.

- It gives you an easy-to-use epilepsy diary.
- It gives you some basic information about epilepsy.

You can use this information to help your doctor make sure you are receiving the best medical treatment on offer, and with that the best possible chance of stopping your seizures. Of course your doctor can't give you any guarantees, because everyone's epilepsy is different and the way you respond will also be different to another person. Most importantly, you will have started to explore your treatment options together with your physician.

About the Diary

At the end of this booklet, you will find a diary designed to help you to record your seizures and any treatment side effects you may experience.

Filling out this diary as accurately as possible should help you, and any doctors treating your epilepsy, understand your epilepsy. This means doctors should be able to give help and advice that is really tailored to your own experience and needs. Together, you can review your treatment and make changes that could improve the management of your epilepsy.



How to use the Diary

You should fill in the diary, every day, for six weeks.

It may take you some time to get used to using the diary so you may find it helpful to fill it in at the same time every day (for example in the evening). The diary has been designed to allow you to fill in the diary in the evening in the comfort of your home.

You might want to ask someone who knows you well to help you. They could notice some things that aren't immediately obvious to you.

You should complete this diary even if you feel that your epilepsy is under control, as there may be some things that only become obvious when you make a note of them. For example, perhaps you are experiencing side effects from your anti-epileptic medication. Or you may realise that your epilepsy is affecting your daily quality of life. Gathering this kind of information will give your doctor detailed information about your epilepsy. It will help them decide if you are receiving the treatment that is right for you.

Discuss with your doctor if you notice side effects that are

- having an impact on your day to day life,
- an increase in seizures,
- new type of seizures,
- change in seizure duration.

Your doctor may decide an appointment with an epilepsy specialist is appropriate. This will be an opportunity for you to find out about any treatment options that could offer improved seizure control and fewer side effects.

Even if you and your specialist decide not to change your medication, there may be ways of reducing the side effects you are experiencing, or the control you have over your seizures. Your doctor should be able to discuss those options with you. Please note that you should not change the dose or stop your medication yourself.



Seeing your Doctor

Once you have filled out your diary and booked to see your doctor, make sure you get the most out of your appointment.

- Before you go to your appointment, mark in your diary, in some way, any areas that you particularly want to discuss with your GP.
- Take your Diary with you to discuss your seizures or how you are feeling generally. Your diary may show something about your epilepsy that you may not be aware of.
- If you don't already see an epilepsy nurse ask if there is one in your area. An epilepsy nurse would be able to spend time answering any questions you may have.
- If writing notes during your consultation with the GP would make it difficult for you to focus on the conversation, you could take someone with you to your appointment, and ask them to take notes. If the person you take is someone who has seen you having a seizure, this can also help as they will be able to describe it in detail to the doctor.
- If your time with your doctor is taken up with discussing basic medical details like seizure control and drug doses, ask for another appointment if there are other issues that you need to discuss with them.
- If when you get home you find that you are unsure of anything that was discussed, don't hesitate to telephone or ask to see your doctor to go over it again.

Seeing an epilepsy specialist



It is important that anyone with epilepsy (children and adults) have a regular review with an epilepsy specialist. A specialist could provide additional information and advice on how to manage your epilepsy.

The number of visits you have with a specialist could vary according to your particular situation, for example, if you continue to have seizures or side effects.

During times in your life you may have need for specific advice (for example if you are a woman considering starting the contraceptive pill or planning a pregnancy) you could discuss with your GP if an appointment with an epilepsy specialist is appropriate.

It may be useful to bring this epilepsy diary to your next appointment as it is a daily record of how well your seizures have been controlled and of any changes you have noticed whilst on your medication.

Information about epilepsy

What is epilepsy?

Epilepsy is currently defined as a tendency to have recurrent seizures (sometimes called fits). After migraine, epilepsy is the most common neurological condition in the world. In the UK approximately 456,000 people have epilepsy, that's one in every 131. However, in spite of the huge numbers of people who have epilepsy, many people with the condition still face prejudice from others, and barriers at work or at school. This is often through lack of knowledge about what having epilepsy really means.

What is a seizure?

A seizure is caused by a sudden burst of excessive electrical activity in the brain, causing a temporary disruption in the normal message passing between brain cells. This results in the brain's messages becoming temporarily halted or mixed up.

Our brains are responsible for most of our bodily functions, so what someone experiences during a seizure will depend on where in the brain the epileptic activity begins and how widely and rapidly it spreads. For this reason, there are many different types of seizure, and everyone will experience epilepsy in a way that is unique to them.

Seizures can happen at any time. They generally last only a matter of seconds or minutes, after which the brain cells return to normal.

There are many different types of seizures. These are classified into generalised seizures and partial seizures.

- Generalised seizures involve most, or the whole, of the brain.
- Partial seizures involve a limited part of the brain, and can be either:
 - 'simple', when consciousness is not affected; or
 - 'complex', when consciousness is affected to some degree.



Medication side effects

Any type of medication, not just anti-epileptic drugs, can have side effects. These side effects can range from mild to severe.

Examples of short-term effects

Some side effects happen at the start of taking anti-epileptic drugs, while the body is adjusting to them. Once this has happened, they may lessen or disappear completely.

- Sleepiness / fatigue
- Feeling unsteady, 'woozy' or dizzy
- Allergic reaction / skin rash

Examples of long-term effects

More troublesome side effects can happen when certain drugs are taken for a long time. They may include the following.

- Poor memory and concentration
- Irritability
- Swollen gums
- Acne
- Weight gain / loss
- Hair loss or thinning / excessive hair growth in unusual places

You should always inform your doctor if you suffer from these or any other side-effects. Never stop or change the dose of drugs yourself.

If you suffer side effects from your medication, your doctor may be able to adjust the dosage. If this isn't an option, they may be able to switch you to another drug that might suit you better.

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