

# Treatments for Epilepsy

## Epilepsy Medication and Side-effects



Medicines that are used to treat epilepsy work by stabilising the electrical activity of the brain. You need to take medication every day to control seizures. In about 8 in 10 cases, seizures are well controlled by medication. Surgery is an option in some cases. There are different types of epilepsy.

## Epilepsy medication

Epilepsy cannot be cured with medication. However, with the right type and strength of epilepsy medication, the majority of people with epilepsy do not have seizures. The medicines work by stabilising the electrical activity of the brain. You need to take epilepsy medication every day to prevent seizures.

## Medicines used to treat epilepsy

Sodium valproate is commonly used as medication for epilepsy. In April 2018, the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK recommended that valproate must no longer be used for any women or girl who could become pregnant unless a Pregnancy Prevention Programme is in place. The Pregnancy Prevention Programme is a system of ensuring all female patients taking valproate medicines:

- Have been told and understand the risks of use in pregnancy and have signed a Risk Acknowledgement Form.
- Are on highly effective contraception if necessary.
- See their specialist at least every year.

## How effective is epilepsy medication?

The success in controlling seizures by medication varies depending on the type of epilepsy. For example, if no underlying cause can be found for your seizures (idiopathic epilepsy), you have a very good chance that medication can fully control your seizures. Seizures caused by some underlying brain problems may be more difficult to control.

The overall outlook is better than many people realise. The following figures are based on studies of people with epilepsy, which looked back over a five-year period. These figures are based on grouping together people with all types of epilepsy, which gives an overall picture:

About 5 in 10 people with epilepsy will have no seizures at all over a five-year period. Many of these people will be taking medication to control seizures. Some will have stopped treatment having had two or more years without a seizure whilst taking medication.

- About 3 in 10 people with epilepsy will have some seizures in this five-year period but far fewer than if they had not taken medication.
- So, in total, with medication about 8 in 10 people with epilepsy are well controlled with either no, or few, seizures.
- The remaining 2 in 10 people experience seizures, despite medication.

## Which is the most suitable epilepsy medication?

Deciding on which epilepsy medication to prescribe depends on such things as:

- Your type of epilepsy.
- Your age.
- Other medicines that you may take for other conditions.
- Possible side-effects.
- Whether you are pregnant or planning a pregnancy.

There are popular first-choice medicines for each type of epilepsy. However, if one medicine does not suit, another may be better.

A low dose of epilepsy medication is usually started. The aim is to control seizures at the lowest dose possible. If you have further seizures, the dose is usually increased. There is a maximum dose allowed for each medicine. In about 7 in 10

cases, one medicine can control all, or most, seizures. Medicines may come as tablets, soluble tablets, capsules or liquids to suit all ages.

## **What if seizures still occur after taking epilepsy medication?**

In about 3 in 10 cases, seizures are not controlled despite taking one medicine. This may be because the dosage or timing of the medication needs re-assessing. A common reason why seizures continue to occur is because medication is not taken correctly. If in doubt, your doctor or pharmacist can offer advice.

If you have taken a medicine correctly up to its maximum allowed dose but it has not worked well to control your seizures, you may be advised to try a different medicine. If that does not work alone, taking two medicines together may be advised. However, in about 2 in 10 cases, seizures are not well controlled even with two medicines.

## **When is epilepsy medication started?**

The decision when to start medication may be difficult. A first seizure may not mean that you have ongoing epilepsy. A second seizure may never happen, or occur years after the first. For many people, it is difficult to predict if seizures will recur.

Another factor to consider is how severe seizures are. If the first seizure was severe, you may opt to start medication immediately. In contrast, some people have seizures with relatively mild symptoms. Even if the seizures occur quite often, they might not cause much problem and some people in this situation opt not to take any medication.

The decision to start medication should be made by weighing up all the pros and cons of starting, or not starting, treatment. A popular option is to wait and see after a first seizure. If you have a second seizure within a few months, more are likely. Medication is commonly started after a second seizure that occurs within 12 months of the first. However, there are no definite rules and the decision to start medication should be made after a full discussion with your doctor.

## **What are the side-effects of epilepsy medication?**

All medicines have possible side-effects that affect some people. All known possible side-effects are listed in the leaflet which comes in the medicine packet. If you read this it may appear alarming. However, in practice, most people have few or no side-effects, or just minor ones. Many side-effects listed are rare. Each medicine has its own set of possible side-effects. Therefore, if you are troubled with a side-effect, a change of medication may resolve the problem.

When you start a medicine, ask your doctor about any problems which may arise for your particular medicine. Two groups of problems may be mentioned:

Side-effects which are relatively common but are not usually serious. For example, sleepiness is a common side-effect of some medicines. This tends to be worse when first started. This problem often eases or goes once the body gets used to the medicine. Other minor side-effects may settle down after a few weeks of treatment. If you become unsteady, it may indicate the dose is too high.

Side-effects which are serious but rare. Your doctor may advise what to look out for. For example, it is important to report any rashes or bruising whilst taking some types of medicine.

Note: you should not stop taking a medicine suddenly. If you notice a side-effect, you should ask your doctor for advice.

### **Taking your epilepsy medication correctly**

It is important to take your medicine as prescribed. Try to get into a daily routine. Forgetting an occasional dose is not a problem for some people; however, for others this would lead to breakthrough seizures. One of the reasons why seizures recur is due to medication not having been taken properly. A pharmacist can be a good source of advice if you have any queries about medication.

### **Prescription medicines are free if you have epilepsy**

You will need an exemption certificate. Ask your pharmacist for details.

## **What about other medicines that I take?**

Some medicines taken for other conditions may interfere with medication for epilepsy. If you are prescribed or buy another medicine, always remind your

doctor or pharmacist that you take medication for epilepsy. Even preparations such as indigestion medicines may interact with your epilepsy medication, increasing your chance of having a seizure.

## What about epilepsy medication and pregnancy?

For women with epilepsy, the risk of complications during pregnancy and labour is slightly higher than for women without epilepsy. The small increase is due to the small risk of harm coming to a baby if you have a serious seizure whilst pregnant. There is also a small risk of harm to an unborn baby from anti-epilepsy medicines.

Before becoming pregnant it is important to seek advice from your doctor. Any potential risks can be discussed. For example, to go over your current medication and to see if it should be changed to minimise the risk of harm to a developing baby. One important point is that you should take extra folic acid (folate) before becoming pregnant and continue it until you are 12 weeks pregnant.

The National Institute for Health and Care Excellence (NICE) recommends that your specialist should give you specific advice about the risks of using sodium valproate to your baby if you take it when you are pregnant. Higher doses of sodium valproate (more than 800 mg/day) and using multiple treatments, especially if one of them is sodium valproate, carry a greater risk. Therefore sodium valproate should be avoided if you are pregnant or if you are planning to become pregnant, unless there is no alternative.

Carbamazepine, gabapentin, lamotrigine, levetiracetam, oxcarbazepine, phenobarbital, phenytoin, pregabalin, topiramate and zonisamide should only be started by a specialist if there is any chance you could get pregnant in the future. Even then, they should only be considered if other treatments have not controlled your epilepsy or you cannot take them.

If you have an unplanned pregnancy, you should not stop epilepsy medication, which may risk a seizure occurring. Continue your medication and see a doctor as soon as possible

# How long do I need to take epilepsy medication for?

You may wish to consider stopping epilepsy medication if you have not had any seizures for two or more years. It is important to discuss this with a doctor. The chance of seizures recurring is higher for some types of epilepsy than others.

There are many different types of epilepsy, some of which are age-dependent but some that will need medication for life. Your epilepsy specialist should be able to offer you more advice about the long-term outlook for your particular type of epilepsy.

Your life circumstances may influence the decision about stopping medication. For example, if you have recently regained your driving licence, the risk of losing it again for a year if a seizure occurs may affect your decision.

However, if you are a teenager who has been free of seizures for some years, you may be happy to take the risk.

If a decision is made to stop medication, it is best done gradually, typically over at least three months. It is important to follow the advice given by your doctor.

## How to use the Yellow Card Scheme

If you think you have had a side-effect to one of your medicines you can report this on the Yellow Card Scheme. You can do this online at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard).

The Yellow Card Scheme is used to make pharmacists, doctors and nurses aware of any new side-effects that medicines or any other healthcare products may have caused. If you wish to report a side-effect, you will need to provide basic information about:

- The side-effect.
- The name of the medicine which you think caused it.
- The person who had the side-effect.
- Your contact details as the reporter of the side-effect.

It is helpful if you have your medication - and/or the leaflet that came with it - with you while you fill out the report.

## Are there any other treatments for epilepsy?

- Surgery to remove a small part of the brain, which is the underlying cause of the epilepsy. Surgery is only possible for a minority of people with epilepsy and it may be considered when medication fails to prevent seizures, especially focal seizures (used to be called partial seizures). Only a small number of people with epilepsy are suitable for surgery and, even for those that are, there are no guarantees of success. Also, there are risks from operations. However, surgical techniques continue to improve and surgery may become an option for more and more people in the future.
- Vagal nerve stimulation is a treatment for epilepsy where a small generator is implanted under the skin below the left collarbone. The vagus nerve is stimulated to reduce the frequency and intensity of seizures. This can be suitable for some people with seizures that are difficult to control with medication.
- The ketogenic diet is a diet very high in fat, low in protein and almost carbohydrate-free. This can be effective in the treatment of difficult-to-control seizures in some children.
- Complementary therapies such as aromatherapy may help with relaxation and relieve stress but have no proven effect on preventing seizures.
- Counselling. Some people with epilepsy become anxious or depressed about their condition. A doctor may be able to arrange counselling with the aim of overcoming such feelings. Genetic counselling may be appropriate if the type of epilepsy is thought to have an hereditary pattern.

## Standby medicine to stop seizures

Some people with epilepsy are prescribed a medicine that a relative or friend can administer in emergencies to stop a prolonged seizure. In most people with epilepsy, seizures do not last more than a few minutes. However, in some cases a seizure lasts longer and a medicine can be used to stop it. A doctor or nurse should give instruction on how and when to administer the medicine.

The most commonly used medicine for this is diazepam. This can be squirted from a tube into the person's anus (rectal diazepam). This is absorbed quickly into the bloodstream from the rectum and so works quickly. More recently, a medicine called midazolam has been used which is easier to administer. It is squirted into the sides of the mouth where it is absorbed directly into the bloodstream.

## What can I do to help myself?

There is often no apparent reason why a seizure occurs at one time and not another. However, some people with epilepsy find that certain triggers make a seizure more likely. These are not the cause of epilepsy but may trigger a seizure on some occasions.

- Possible triggers may include:
- Stress or anxiety.
- Heavy drinking.
- Street drugs.
- Some medicines such as antidepressants, antipsychotic medication.
- Lack of sleep, or tiredness.
- Irregular meals which cause a low blood sugar level.
- Flickering lights such as from strobe lighting.
- Periods (menstruation).
- Illnesses which cause a high temperature (fever), such as flu or other infections.

If you suspect a trigger it may be worth keeping a diary to see if there is any pattern to the seizures. Some are unavoidable but treatment may be able to be tailored to some triggers. For example:

- Keeping to regular mealtimes and bedtimes may be helpful for some people.
- Learning to relax may help. Your doctor may be able to advise about relaxation techniques.
- A small number of people with epilepsy have photosensitive seizures. This means that seizures may be triggered by flickering lights from the TV, video games, disco lights, etc. Avoiding these may be an important part of treatment for some people. (Photosensitive epilepsy can be confirmed by hospital tests. Most people with epilepsy do not have photosensitive seizures and do not have to avoid TVs, videos, discos, etc.)