

Getting the same version of your anti-epileptic drugs every time

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Introduction

Epilepsy Action believes it is important for people with epilepsy to have exactly the same version of their anti-epileptic drug (AED) every time they pick up a prescription. This fact sheet explains why. The information is mainly for UK residents. If you live outside the UK, please contact your local epilepsy group.

Why some drugs have more than one name

Most drugs have a generic name and a brand name. The generic name is the same as the name of the main ingredient of the drug. The brand name is given by the drug company. For example, carbamazepine is the generic name and Tegretol is the main UK brand name, given by the drug company.

You may also come across drugs with other names because they have been brought in from abroad. These drugs are known as parallel imports.

More information on generics and parallel imports is given below.

Generics and generic prescribing

The drug company that first makes the drug owns the 'patent' (exclusive right) to make it. They also give the drug its main brand name. After a number of years (usually 10-12), the patent runs out. Once this happens, other companies can make their own version of the drug. These other versions are known as generics. Generics might be a different shape or colour to the main branded drug. The other drug companies may also give the generics different brand names. For example, there is a generic version of carbamazepine called Epimax.

Generic prescribing is when your doctor writes only the generic name of your anti-epileptic drugs (AEDs) on your prescription. This means the pharmacist can give you any version of your AED made by different drug companies. They may therefore choose a cheaper version, to keep costs down.

Parallel importing

Some drug companies make the same drug at factories in the UK and abroad. For example, Tegretol is made in a number of countries as well as the UK. Parallel importing is when a drug wholesaler buys from a drug company's overseas factories to supply to UK pharmacies. So, if you are prescribed Tegretol, it could have been made in a number of countries, including the UK, Netherlands and Italy.

There are a number of things that could indicate that your anti-epileptic drugs (AEDs) are parallel imports. For example, the packaging may look different or have wording in another language. The drug might also have a different name. For

example, a slow release version of the generic drug carbamazepine, called Tegretol Retard in the UK, is called Tegretol Divitabs in a number of European countries.

You might be given a parallel import if the wholesaler that supplies your pharmacy can buy a particular drug from abroad more cheaply than they can buy it in the UK.

Why getting a parallel import may matter

In theory, a drug with the same brand name, such as Tegretol, should be the same, whether it is made in the UK or another country. However, a number of people have reported problems with their epilepsy when they have been given parallel imports. This may be because there are very small differences in the overall make-up of the drugs from the ones they have been used to. Or it may be that the worry of being given a different version leads to stress and anxiety, which in turn could trigger a seizure. Quality is also a concern with parallel imports as they may not always be stored in perfect conditions during the import/export process.

Other imported drugs

Some drugs, available on prescription in the UK, have to be imported because they are not made in the UK. An example is the anti-epileptic drug (AED) topiramate (UK brand name Topamax).

Why it is important to get the same version of an anti-epileptic drug every time

A number of people, who have switched between different versions of anti-epileptic drugs (AEDs), have reported an increase in side-effects. They have also reported having more, or different, or breakthrough seizures.

In Epilepsy Action's 2009 Anti-epileptic Medication Packaging Survey, 43 per cent (almost a half) of people were given different versions of their AEDs. Of these, 25 per cent (a quarter)

said their epilepsy was worse as a result. This means that out of every 100 people, an average of 10 are likely to have problems.

Having a breakthrough seizure can have a major impact on someone's life. It can mean the loss of driving licence for a year and, for some people, it may mean loss of employment. The seizures themselves may be unpleasant or cause injury. And, rarely, seizures can be fatal.

An increase in side-effects can also bring major problems. Unwanted side-effects can affect learning, work and social life.

Not all healthcare providers believe that taking a different version of an AED can affect someone's epilepsy. However, the National Institute of Health and Clinical Excellence (NICE) supports Epilepsy Action's concerns. NICE recommends that people with epilepsy continue to get the same make of AED wherever possible. NICE is an organisation that provides guidance on treatments and care for people using the NHS in England and Wales.

How to get the same version of an anti-epileptic drug

The most reliable way to get the same version of your drug is to ask your doctor to prescribe by brand name. The current law says that if the brand is written on your prescription, the pharmacist must give you that specific brand. If you are already taking an anti-epileptic drug (AED) without a brand name, and are happy with it, you could ask your doctor to write the name of the drug company, as well as the drug name, on your prescription. Although you can ask your doctor to write 'no parallel imports' on your prescription, your pharmacist doesn't have to take any notice of this. However, many pharmacies will do their best to help their customers, so it may still be worth asking your doctor to do this.

When the same version of an anti-epileptic drug is not available

There are some circumstances where it can be difficult, or impossible, to get the same version of an anti-epileptic drug (AED). For example, your pharmacy may decide to buy in their drugs from a different wholesaler.

If you have to change to a different version of your AED, you could keep a chart or seizure diary to record any changes to your seizure control or side-effects. You may then want to show this to your doctor so they can review your treatment and advise you on the best course of action.

Reporting problems with anti-epileptic drugs

You, or your doctor, can report any problems with your anti-epileptic drugs (AEDs) to the Medicines and Healthcare Products Regulatory Agency (MHRA), using the Yellow Card Scheme. Yellow Cards are available from your GP, pharmacist, NHS Direct or the Yellow Card hotline. You can also download or complete a Yellow Card online.

Yellow Card: hotline: 0808 100 3352;
www.yellowcard.gov.uk

No changes to the law

In 2009, proposals were made by the Department of Health to allow pharmacists to change the brand of drug given to a person if a cheaper version was available.

In 2010, the Department of Health withdrew this proposal after opposition from Epilepsy Action, patients and doctors.

The law remains that if the brand is written on your prescription, the pharmacist must give you that specific brand.

Further information

If you have been affected by any of the issues in this fact sheet and would like some advice or information, please contact our helpline.

About this publication

This fact sheet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the fact sheet, please contact us.

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