

Managing the side effects of anti-epileptic drug

Many people believe that when speaking with patient's, epilepsy medication should be referred to as 'anti-seizure medicines' rather than 'anti-epilepsy medicines'. This is because they don't really treat the underlying epilepsy. Epilepsy medicines all have a different history – some were designed specifically for their job, some were lucky accidents. It can therefore be tricky to talk about all of them together as a 'class'.

Generally, AEDs are safe, and most people don't experience most side-effects. The side-effects are more noticeable when people are taking larger doses or multiple medicines at once. Sometimes the side-effects can feel worse when taken alongside other, non-epilepsy medicines, such as ones to help mental health for example.

It is also worth bearing in mind, though, that what is a negative side-effect for someone may be a benefit for another! For example, the medicine topiramate may have to be stopped because of weight loss in one person – but deliberately chosen for this effect in someone else. As another example, some people really benefit from the sedating effect of some drugs before bed-time to help them sleep.

Some of the more common side-effects from epilepsy medicines.

Epilepsy medicines generally slow the brain down a little and so people may experience drowsiness, dizziness and wobbliness. The majority also slow the metabolism, so weight gain can be an issue.

Where can I find out about the side-effects of my particular medicine?

Each box of medicine includes the information leaflet, which lists the possible side-effects. Unfortunately, this can sometimes be unhelpful as it does not give a context to the side-effects. The symptoms listed are those that were mentioned by people in clinical trials. But, really, they need to be compared to those people in the trials who took the dummy pills without the beneficial effect (known as placebo). Therefore, many of the symptoms listed are just those that people with epilepsy will report day-to-day, such as coughs, colds, tiredness and aches and pains.

Your doctor or specialist nurse should be able to tell you whether they think you are at particular risk of specific side-effects, particularly those that might worry you. Epilepsy Action has some general information on side-effects.

Is it normal to get side-effects?

Yes! Particularly when starting a new medicine or increasing a dose. Many side-effects will get better over a few weeks (such as tiredness). You will be warned by your doctor about those that need immediate help, such as the nasty pink itchy rash associated with some medicines. I also warn people about symptoms where it's not always obvious that they are a

side-effect of the medicine. These are things such as irritability and snappiness with some medicines.

Will there definitely be side-effects to my medicines?

No! I am amazed at the range of side-effects experienced by people. Some of my patients might be on multiple medicines all at once and having no side-effects whatsoever. Others can feel drunk and dizzy on tiny doses of the more 'gentle' – so-called – medicines. I imagine that over time we may be able to better predict these differences with what people call 'personalised medicine'. This is a move towards tailoring the management of a condition to each person's individual situation.

Does anything make side-effects more likely or worse?

It's very important to take medicines as they are prescribed by your doctor. Not taking them at the right time or changing things yourself can make side-effects worse (as well as possibly worsening seizures). Accidentally missing or doubling doses can make the amount of the medicine in your blood (and brain!) vary a great deal. Similarly, mixing the stronger medicines with lots of alcohol or street drugs can make people feel pretty poorly.

We tend to 'start low and go slow' when starting and increasing the medicines. This is in part to help the body adjust to the new medicines and help avoid side-effects as much as possible.

What should I do if I get side-effects from my medicines? Do I just have to live with them?

Not always. There is often a choice for most people of another alternative medicine. Some side-effects you just can't live with – such as the rash mentioned above. Some you can find ways to work around such as weight gain.

Don't feel bad about mentioning your side-effects to your doctor. If you don't, they may presume that you are right as rain. Whatever the side-effect may be – from hair loss, to sexual problems, to tremors – they will have heard it before. These are significant things that can impact your quality of life, so don't be afraid to tell your doctor.

What can my doctor do if my medicine is controlling my seizures but I'm getting bad side-effects?

Sometimes it can be possible to take the edge off the side-effects by going for a smaller dose and hoping this is equally good at controlling the seizures. It can be possible to find different forms of the medicine – such as slow release capsules. These can help keep the level of the medicine in the blood steady rather than peaking just after the medicine is taken. On occasion, we can find a way of lumping or splitting the doses or changing the time of day when they are taken. Finally, some medicines are in rough 'families' and it may be possible to

swap to another medicine in the same family and hope that the side-effects are less with the new one.

Will my medicines affect my birth control?

This is an important question and one that we sadly forget to talk about sometimes. Often, this is because birth control is not considered by the patient to be a 'medicine' and so it does not get mentioned. Or it could be because birth control is started or changed long after the epilepsy medicines start. Specialised advice is needed from your GP or epilepsy team about how these medicines may interact. However, barrier methods of birth control, such as condoms, diaphragms or the coil, are not affected.

Will my medicines affect my baby if I get pregnant? What should I do if I'm worried about this?

This is a very important question. To be frank and fair, we know most about the older medicines. This is because we have had many reports of what happens to the women and their children in these pregnancies. Sodium valproate (Epilim) is not appropriate for most women because of the increased risks of birth defects to babies exposed to it in the womb. New advice means every woman and girl who may become pregnant must discuss their valproate prescription every year with their doctor. The Medicines and Healthcare products Regulatory Agency (MHRA) has now changed its guidance on sodium valproate. It says that sodium valproate should not be prescribed to women or girls of childbearing age unless there is a pregnancy prevention programme in place.

Women are advised to take 5mg of folic acid if pregnancy is planned or likely and let their doctor know if they become pregnant. But they are advised not to take themselves off their medicines. This is because women who have convulsive seizures in pregnancy may be putting their life and the life of their unborn child at risk.

Some drugs are safer than others in pregnancy. Generally, the smallest dose of a single drug is safer than larger doses of multiple drugs. Your doctor will be able to advise you on your particular situation. It's a great idea for women who become pregnant to sign up to the UK Epilepsy and Pregnancy register. Joining the register aims to collect data on pregnancy outcomes in women on different epilepsy drugs. This information can help doctors become more aware of the safety of different epilepsy medicines during pregnancy. Your information is will be treated in the strictest confidence and registering will not require any extra visits to your GP or midwife. You can also withdraw at any time without having to give a reason. There is more information on sodium valproate, having a baby and puberty on the Epilepsy Action website.

Will my medicines affect my memory?

Memory is a tricky issue. Uncontrolled seizures make memory worse – as does anxiety and poor sleep. Some people have a poor memory because their seizures are centred around a memory area in their brain (their hippocampus). Undoubtedly, some people have sedation

and memory issues from their medicines. Sometimes this is predictable (certain medicines, large doses), and sometimes less so. If it is having a big effect on your daily functioning, let your doctor know and consider a change.

Will my medicines affect any other medicines I take for other conditions? What should I do about this?

Yes, many medicines have what we call interactions. It might be that the epilepsy medicine may make the amount of the other medicine go up and down in the blood. Or the other medicine may do the same to the epilepsy medicine. Or often, the interaction affects both medicines. This is more typical of older epilepsy medicines but is a feature of many new ones too. It is very complicated, and most doctors have to look it up in their BNF book or App! The important thing is that you inform your doctors of all the other medicines you are taking so they can try to manage any potential interaction.

If I've been taking older epilepsy medicines for many years and am living with the side-effects, is there something I can do now?

You can always consider a medicine change. One of the benefits of getting older is that often it may take smaller doses of the epilepsy medicine to control the seizures. On the flip-side, age does not come alone, and many older people have epilepsy alongside other health issues. This means that medicine interactions (described above) can be more likely. Some older people have remained on pretty old-fashioned medicines for quite some time. In these cases, they may really feel the benefit of a change to a less sedating modern medicine.

What is the Yellow Card Scheme and why is it important?

The Yellow Card scheme run by the MHRA is a way that we can continue to let people know about important but more rare medicine side-effects. It can also help identify side-effects that only occur months or years after the treatment. It is an important form of monitoring that allows us to collect negative experiences and find out about side-effects that were not apparent from clinical trials. You can report medicine side-effects through the Yellow Card scheme.

The information sheet has been produced from the article that was first published in 2018 in 'Epilepsy Today' by Dr Rhys Thomas, consultant neurologist at the Royal Victoria Infirmary in Newcastle. The article can be found at www.epilepsy.org.uk.