

Are anti-epileptic drugs for life?

Some people with epilepsy will need to take anti-epileptic drugs (AEDs) throughout their lives. Others may only need to take them for a limited time. The possibility of coming off AEDs depends on a number of factors, such as:

- the type of epilepsy and seizures you have
- how old you were when you had your first seizure
- how long you have been seizure free
- whether you are taking more than one AED
- whether you continued to have seizures after starting on AED(s)

Minimum period on AED(s)

The SIGN guidelines¹ suggest that *'continued treatment or AED withdrawal should be discussed with people with epilepsy who are at least two years seizure free, so that they can make an informed choice.'*

So, if you have been seizure-free for two to three years you could talk to your specialist about the possibility of coming off your drugs. This would be done slowly and over a period of time during which you will be monitored carefully by a specialist. Generally, the longer you have been seizure free, the less likely it is that you have another seizure when coming off your AED(s).

There is always a risk that your seizures might return. Your specialist will be able to advise you further on how likely this would be given your particular clinical history and circumstances.

¹ Scottish Intercollegiate Guidelines Network 143, Diagnosis and Management of Epilepsy in Adults, May 2015

Reasons for wanting to come off AED(s)

Long term effects

Many people are concerned about long term side effects of AED(s). Generally, AED(s) are very safe when taken over many years, but some people on AED(s) may experience long term effects. These vary depending on which AED you are taking and may include a decrease in bone density putting those on AED(s) at an increased risk of fractures. Other side effects such as possible weight gain may be difficult for some people to accept.

Pregnancy

Some women who want to start a family are concerned about the impact their AED(s) may have on their baby and want to come off their drugs before becoming pregnant. It is important to seek specialist medical advice (pre conceptual counselling) when planning a pregnancy as there are some AEDs that should be avoided because they may carry a higher risk to the unborn baby when taken during the first trimester of pregnancy. On the other hand, **suddenly stopping AEDs can lead to a breakthrough seizure, which can sometimes be more harmful to an unborn baby than possible medication side effects.**

Other

Some people simply do not like the idea of taking drugs for the rest of their lives.

Whatever your reason for wanting to come off your drugs, you should, in the first instance, discuss this with your specialist or epilepsy specialist nurse.

Issues to consider before making a decision

Before you make this important decision, you need to think carefully about what impact having another seizure would have on your life.

Driving

The DVLA recommend that if you are coming off your medication you should stop driving for the duration of your drugs being withdrawn, and for a period of six months thereafter. This means that even if you do not have any breakthrough seizures, you are still likely to be without your driving licence for anything between six months and one year. You can only start driving again once your doctor says it is safe for you to do so.

If you have a breakthrough seizure, you need to stop driving immediately and notify the DVLA. Once you have reinstated your previously effective medication and you have remained seizure free for a period of six months, you can re-apply for your driving licence.

Employment

If you need your car for work, consider how you could do your job without a car. Could you get to and from work on public transport? Would having a seizure at work put you or someone else at some kind of risk? Many people who have been seizure free for a number of years do not necessarily tell their employers about their epilepsy. Would your employer/colleagues know what to do if you had a seizure, would you want to tell them? In some lines of work health and safety regulations may leave you no option but to disclose your epilepsy and your intention of coming off your AED as having a seizure could put you or someone you work with at risk.

Leisure activities and sports

Coming off your AED(s) does not necessarily mean having to give up the leisure activities you enjoy. But you may want to think about any precautions you want to put in place to make this safer for you during the transition period. For example, if you like swimming, you may want to tell the life guard about the possibility of a seizure so that they can keep an eye out for you. If you usually pursue your leisure activities on your own, it may be safer for the time being to ask a friend to come with you, someone who would know what to do if you had a seizure. Your doctor may

advise you to stop doing certain riskier leisure activities until you have been seizure free for a period of time after medication withdrawal.

Holiday and travel

If you go on holiday, you may find you have to pay higher travel insurance premiums, particularly if you have another seizure. Most insurance companies require you to notify them about a change in circumstances which may put you at an increased risk. This could result in higher premiums in general.

Family and social life

Talk to your family and friends as they often are in a good position to provide you with the emotional and practical support for making the right decision. The people in your life who may be impacted most should you have another seizure may also want to have a say and have an opportunity to air any concerns. Bear in mind that losing your driving licence may have an impact on your family life and mobility, particularly if you live in a remote/rural area with limited public transport.

Emotional impact

You may want to think about how you would cope with a possible fear of having another seizure. There are no guarantees you will remain seizure free when coming off your drugs, so it can be good to mentally prepare yourself for the possibility of having a seizure.

If you have another seizure, you may feel a range of emotions, anything from devastation, anger, guilt or sadness. It may feel to you like starting all over again and you may need to go through a similar process of adjustment as before.

Unfortunately, there is no guarantee that returning to your old drug regime will allow you to turn the clock back. However, having had seizure freedom before, you know it could be possible again. This should give you some encouragement to persevere especially if you do not respond straight away to reintroducing AED(s). You may

have to go through a period of trying a number of different drugs and/or dosages again to find the combination that gives you the best possible outcome.

Risk of Injury

Depending on the type of seizures you used to have, you will also need to consider the risk of injury should you have another seizure.

If you have decided to come off your AED(s)

It is important that you do not come off your drugs on your own. First of all, speak to your neurologist or epilepsy specialist nurse. If you are no longer under the care of a neurologist, ask your GP to refer you back to one as you will need specialist medical advice and guidance to make this process as safe as possible for you. SIGN guidelines² recommend that the *'rate of withdrawal of AEDs should be slow, usually over a few months, and longer with barbiturates and benzodiazepines. One drug should be withdrawn at a time'*. So if you are on more than one AED, the process will take longer.

Be trigger aware

Bear in mind any triggers for seizures in general, such as lack of sleep, stress, flickering lights (if you are photosensitive), alcohol, recreational drugs, hormonal changes (particularly for women), feeling unwell/running a temperature or sometimes low blood sugar from not eating regularly. Pay particular attention to these possible triggers during the transition phase and afterwards to maximise your chances of remaining seizure free.

Choosing the right time

Choosing the right time is also crucial to make this a success. If you are, for example, under a lot of stress at work, are in the process of moving house, or have

² Scottish Intercollegiate Guidelines Network, 143 Diagnosis and Management of Epilepsy in Adults, May 2015

just suffered a major bereavement, this may not be the best time for you to come off your drugs as this could increase your chances of having another seizure.