

How and when to stop anti-epilepsy drugs

Introduction

Epilepsy starting in childhood is not necessarily life long. Some children grow out of their epilepsy as they get older. If you are taking an anti epilepsy medication and have not had a seizure for two years we should decide if you still need the medication.

If I stop medication will my seizures come back?

After 2 years of being seizure free, 7 out of 10 children can stop their medication and still not get seizures. 3 out of 10 will get seizures again.

How can I tell which group I am in?

You cannot tell. The only way is to stop the medication and see if the seizures start up again. We will help you plan a safe and sensible way to stop your medication.

What about another EEG test to see if my epilepsy has gone?

This is not usually helpful. Some people still have abnormal brainwaves even after their seizures have stopped. Hence, The British Paediatric Neurology Association (BPNA) and the Eastern Paediatric Epilepsy Network (EPEN) do not advocate doing another EEG before stopping treatment.

Why can't I just stay on my medication?

Modern anti epilepsy drugs are probably not harmful even if taken for many years. Even so there are lots of reasons for stopping them if possible.

- It is better to stop medication when you are young. As an adult with a job and a driving licence stopping medication can be very difficult.
- For girls it is good to stop medication. Contraception and pregnancy can be more difficult for those on medication.
- You don't really want to take a medication for years if it's not necessary.
- As long as you are on medication you carry a diagnosis of epilepsy.

So how do I stop my medication?

We will agree a good time for this. We usually try to avoid exam time, holidays and other big events in your life. You should reduce your medication slowly, using a plan that we will give you. This usually takes two or three months. You will also need to think about first aid and safety. There is a risk of your seizures coming back so you need to be careful. Think about safety in the bathroom, while swimming, cycling and on heights. Talk to us about

any special advice you might need. Also inform nursery/school about weaning medication so that staff can monitor your child more closely during this time.

What do I do if the seizures start again?

- If you are sure you have had a seizure while reducing your medication please contact your Children's Epilepsy Team
- If you have a seizure after stopping medication you should restart the medication more slowly. Ring the Children's Epilepsy Team for specific advice
- If you are not sure if your seizures have come back contact the Children's Epilepsy Team for advice.

How long before I am sure the epilepsy has gone?

- The research evidence derived from the Taskforce at the International League Against Epilepsy (ILAE) states that 'Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.'
- Once a person has epilepsy, they will always remain at higher risk of having seizures than the general population. However, the longer you remain seizure free, the less likely it is to come back. This is called remission.
- One should be aware and be prepared for a possibility of seizure to re-occur while weaning or after stopping medications. Hence, it is important to follow the safety advice for seizures given by your epilepsy team, while weaning or after stopping medications. Three- quarters of seizure relapses occur within the 1 year of stopping medications, but, given that a quarter of seizure recurrence could be outside this time frame, safety precautions should continue to be followed long term

Do I need to come back to clinic?

No. The Children's Epilepsy Team will get in touch by phone to make sure all is well after 3 months of stopping medication.

If my seizures stay away can I forget about epilepsy?

Not quite. Some jobs are not open to those who had seizures as children. These include the armed forces and jobs involving flying. You cannot drive a lorry, a bus or a train for 10 years after your last seizure. Before you set your heart on a career check whether it is open to you, conversely, if you feel a career is not open for you, check this on the Epilepsy Action website.

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Dec 2009

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