

**Epilepsy medication** 

# **Epilepsy League**Research — Help — Information

#### **EPILEPSY MEDICATION**

Most epilepsies are managed with medication – which is often taken for many years. The term **«anti-epileptic drugs»** isn't really correct: drugs can't cure epilepsy. For this reason, the term now widely used is **«anti-seizure medication»**.

The drugs all work in different ways, but what they all have in common is that they suppress over-active nerve cells by stabilizing cell membranes. This either completely prevents seizures or makes them less likely.

Around two-thirds of people with epilepsy live seizure-free lives thanks to medication. In around 50% of cases, the first suitable drug prescribed is effective – although this varies significantly depending on the type of epilepsy. The more different medications a person needs to try, the less likely it becomes that they will achieve seizure freedom. However, even after multiple unsuccessful attempts there is still a chance of becoming seizure free, especially when new drugs are approved for use.

### Is drug treatment necessary?

After a new diagnosis of epilepsy, many people are understandably hesitant about taking medication for a long period of time. The decision on whether or not to take medication for epilepsy should be made jointly by the patient, their family and their neurologist or neuropaediatrician, because the medication only works if it is taken regularly. This means the person taking it needs to be convinced that it is necessary. Things to take into account are their personal environment, their work life, and their hobbies.

Key decision factors from a medical point of view are the number and severity of known seizures thus far and the results of an EEG (electroencephalogram measuring brain activity). It should be noted, however, that if a person has an EEG with no epilepsy-typical activity, this does not necessarily mean that without treatment they will not have any further seizures. If the cause of a first seizure is known and is temporary, then no medication is required in the long term. The same applies to seizures that take place in the first week after a person has had a stroke. Short-term preventive treatment is advisable only in the acute phase following traumatic brain injury caused by an accident.

# Advantages of drug treatment

- · Hope of becoming seizure-free
- Prospect of being allowed to drive again, swim and pursue various other hobbies
- Improved protection against falls or accidents this is particularly important for older people
- Lower risk of serious types of seizure: dangerous status epilepticus and SUDEP (Sudden Unexpected Death in Epilepsy)

- · Greater peace of mind for relatives
- Positive side effects with certain medications (see «Side effects»)

#### **Disadvantages:**

- · Medication can have undesirable side effects
- It can be a daily reminder of the illness, and doses can be forgotten
- Time and planning are required (prescriptions, pharmacy visits, supplies for trips, etc.)
- · There is a cost factor

#### Which medication?

Once the neurologist/neuropaediatrician and the patient/their family have made the initial decision to start drug treatment, the next step is to find the right medication. This is essentially a decision for the specialist treating them and is based primarily on the form of epilepsy, gender and age, other illnesses and the side-effects as well as interactions of the medication. In terms of effectiveness there are significant differences in only a small number of cases. No high-quality studies have yet fully resolved the conundrum of which drug is right for a specific individual, which is why the specialist will also draw upon their medical experience.

In some cases, prolonged-release drugs (retard tablets) can be helpful in keeping a constant level of medication and reducing the number of tablets the person needs to take each day.

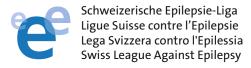
Once someone has become seizure-free on a specific medication, they should avoid changing wherever possible, following the motto «never change a winning team». This applies even to those considering changing the version of the medication they take, e.g. switching to a generic. At the start of treatment generics are not a problem, but once someone has got used to taking a specific version of a drug their prescription should be marked «No substitutions». In such cases the Swiss healthcare insurer is not permitted to levy a higher coinsurance charge for the original drug.

# **Side effects**

Generally speaking most of the commonly prescribed medications nowadays are well tolerated, and serious side effects are unusual. Some drugs even have positive additional benefits, such as mood stabilization, neuralgic pain relief or migraine prevention. It is worth noting here that natural remedies such as cannabidiol can also have undesired and serious side effects.

Apart from a few exceptions, the target dose should be increased gradually («start low, go slow»). The dose required can vary from person to person, as can tolerability of the drug. Some psychological side effects may be more noticeable to family members than to the person taking the medication.

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As a general rule, side effects should not just be accepted, they should be reported to the specialist to discuss potential adjustments or alternatives. It should be noted that not all anomalies are necessarily caused by the medication being taken. If there is any allergic reaction, especially skin redness, a doctor should be informed immediately.

In terms of side effects, medications containing the active ingredient valproate (e.g. Depakine®, Orfiril® and Convulex®) fall into a special category of their own. Although valproate is significantly more effective for primary generalized seizures, it should only in exceptional cases be prescribed for women and female adolescents of child-bearing age. If other medications are ineffective, valproate should be prescribed at as low a dose as possible; in Switzerland, the girl or woman taking the drug must sign an annual statement confirming she understands its risks.

If someone taking valproate becomes pregnant, the risk of abnormalities and of later developmental problems in the child is high. More information on this can be found in our flyer «Epilepsy and pregnancy».

Nowadays, long-term side effects occur almost only when someone has been taking an older type of medication for many years. Of particular note is the risk of osteoporosis: anyone who has been taking carbamazepine, oxcarbazepine, valproate, phenobarbital, phenytoin or primidone for over 10 years should have their bone density checked every 2-5 years from the age of 50. In some cases a change of medication may be required.

#### Tips for avoiding side effects

- For side effects in the morning: talk to the doctor about decreasing the morning dose or splitting it and taking it at two different times
- Don't take medication on an empty stomach
- For side effects in the evening: either split the dose or take it just before bedtime
- If stomach-ache is a problem: take medication with food

### If a drug isn't successful

If seizure freedom is not achieved with the first medication tried, the dose should be increased to the maximum so as to reach an effective dose. Only if the medication either has unwanted side effects or the frequency and severity of the seizures remains unchanged at the highest reasonable and tolerable dose is it clear that the active ingredient is truly of no help at all.

If seizures continue despite treatment, there are two possible strategies: test other drugs individually, or combine several (polytherapy). Taking several medications at the same time increases the risk of interactions and side effects, which are then harder to attribute to a specific

drug. On the other hand, some newer medications are only approved as additional therapy, or a medication might work but only be tolerable at a low dose. In most cases one or two medications should be sufficient. If seizure freedom is not achievable, the focus should be on tolerability and quality of life.

Only very rarely is it permissible to suddenly stop taking a drug. After consultation with the doctor, the dose should be reduced slowly (tapering).

After two years or after two medications have been tested without success it is usually recommended that the possibility of other treatment methods is explored. Specialist centres can give information on whether or not an operation would be suitable – the only way to cure epilepsy at that point.

#### **Interactions**

An advantage of most anti-seizure drugs commonly used today is that they have fewer interactions with other drugs. However, problems can still sometimes arise. As a rule those taking medication for epilepsy should consult their neurologist/neuropaediatrician whenever they wish to take a new drug, even non-prescription drugs, so that they can check for any potential interactions. Sometimes a blood level check may be required.

Birth control medication is often problematic in terms of interaction. It can reduce the blood level of anti-seizure drugs and thus reduce their effectiveness, particularly the frequently encountered combination of a birth control pill containing oestrogen with lamotrigine. By contrast, other anti-seizure drugs can substantially reduce the effectiveness of «the pill». In such cases the preferred method of birth control is a coil.

The patient information leaflets for a whole variety of different drugs carry warnings not to take them if you have epilepsy, or statements that they may cause epileptic seizures. Such statements do not mean that this medication must definitely be avoided. Instead, the prescribing doctor should seek the support of the neurologist/neuropaediatrician to weigh up the risks and benefits.

#### **Practical tips**

A dosette box can help people keep track of the medicines they need to take. It can also help identify that someone has forgotten to take their medicine, so that action can be taken if necessary. We recommend always carrying one dose of medication, in case of delay or unexpected plan changes.

Pharmacies can dispense medication in blister packs: the individual tablets are packed into individual "blisters" according to the time of day they need to be taken. Health insurance companies will cover the cost of this service if more than three medicines are taken daily.

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A phone alarm can then be used as a reminder to take the medication. Taking medication regularly is important — it's the only way of avoiding new seizures once seizure-free. Even if a person does have seizures despite the medication, they should still take it regularly, because any irregularity increases the risk of sudden unexpected death in epilepsy (SUDEP) — which is otherwise low.

Keeping a seizure diary can help identify the cause of seizures and adjust when medication is taken (e.g. the time of day). The medication, dose and time of dose should be recorded ideally also on a mobile phone.

There are apps designed specifically to remind people to take their medication, which can also be used as a seizure diary.

As there are sometimes supply problems with anti-seizure drugs, we recommend keeping a small additional supply of medication, to last at least a month. The oldest packs should always be used first.

# When can treatment be stopped?

If things go well, younger people with epilepsy can often stop taking medication after a few years – gradually of course (tapering), and in consultation with their specialist.

Doing so always comes with the risk of a new seizure and driving licences must be surrendered for at least 3 months. It is important to take into account what the person's life looks like at the time, for example if they drive a car or live alone. Another factor to consider is the fact that sometimes after such an attempt, restarting the same medication doesn't result in seizure freedom.

In many cases it is advisable for people taking medication to continue taking it throughout their lives – this applies to older people in particular.

# Epilepsy can affect us all

Five to ten percent of people will have an epileptic seizure at some point in their lives. Almost one percent of the world's population will develop epilepsy. In Switzerland, approximately 70,000 to 80,000 people live with epilepsy, of whom some 15,000 to 20,000 are children.

# **Epilepsy League – Diverse activities**

The Epilepsy League has been researching epilepsy and helping and informing people since 1931. Its goal is to sustainably improve the daily lives and standing in society of those affected by epilepsy.

# Research

It promotes knowledge gathering in all areas of epilepsy.

#### Help

Information and advice in German, English and French:

- For people with epilepsy and their relatives
- For professionals from a multitude of different areas

#### **Information**

The Epilepsy League provides information to the public, raising awareness and thus aiding the social integration of people affected by epilepsy.

#### **Medical advisors:**

PD Dr. med. Jan Novy, Lausanne; Prof. Dr. med. Stephan Rüegg, Basel; PD Dr. Lukas Imbach, Zurich

Editor: Julia Franke

#### **Swiss League Against Epilepsy**

Seefeldstrasse 84 8008 Zürich Tel. +41 43 488 67 77 Fax +41 43 488 67 78 info@epi.ch www.epi.ch

IBAN CH35 0900 0000 8000 5415 8

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Information up to date as of: January 2023

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