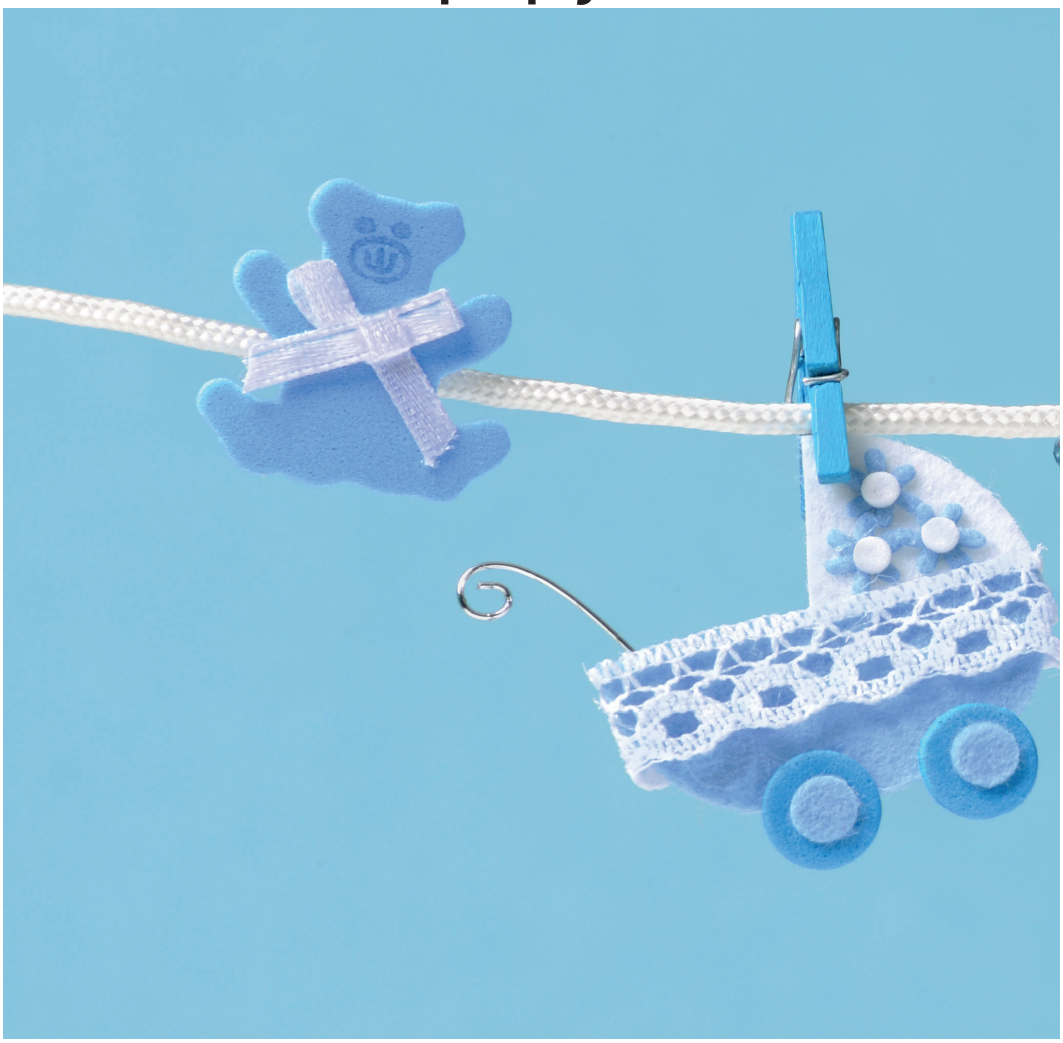
Schweizerische Epilepsie-Liga
Ligue Suisse contre l'Epilepsie
Lega Svizzera contro l'Epilessia
Swiss League Against Epilepsy

Info Epilepsy



Epilepsy and pregnancy

EPILEPSY AND PREGNANCY

People's worries about epilepsy and pregnancy generally outweigh the risks, because nowadays having epilepsy is rarely a reason not to have children of your own. It is, however, important to discuss having a baby with your neurologist and midwife well in advance – if possible two years before a planned pregnancy.

Before you conceive

Epilepsy is rarely inherited: over 95% of children whose parents have epilepsy do not have epilepsy themselves. Thus the risk is only very slightly increased – primarily because it is not the disorder itself that is inherited, but the propensity to develop seizures in certain situations. It is also highly likely that if the child does develop epilepsy, it will be a form that is relatively easy to treat. If several of your family members have epilepsy or you suspect you may have an inherited form of epilepsy then it might be worth undergoing genetic testing.

The best indicator that your pregnancy and birth will be seizure-free is if you have remained seizure-free for a year prior to conception.

Anti-epileptic drugs (AEDs)

Once you decide to try for a baby, your neurologist should optimize your medication as soon as possible. Ideally you would be prescribed a single drug (monotherapy) at the lowest possible dosage. It is extremely important for your neurologist to find out what drug concentration you need to remain free of side effects and, above all, seizure-free.

As a patient, you can help reduce the amount of medication you need by ensuring that you take it regularly and get enough sleep. Sometimes it can be beneficial to switch to a different drug – but bear in mind that there will be an adjustment period of several months. During this time you should use a reliable method of contraception.

It appears to be better for the unborn baby if the drug concentration in the mother's blood remains as constant as possible. This can be achieved if AEDs are given in slow-release form or divided into 3 or 4 doses daily.

Folic acid deficiency, which can be caused by AEDs, increases the risk of abnormalities in the unborn child. It is therefore recommended that if you are planning to become pregnant you should take a high dose (4-5 mg daily) of folic acid before conception and during the first trimester. Up to 50% of all pregnancies are unplanned, and the crucial phase during which the baby's nerve system develops is days 21 and 26 of the pregnancy, i.e. often before the expectant mother even knows that she is pregnant. So it is recommended that **all** women of child-bearing age begin taking folic acid supplements **as soon as** they are diagnosed with epilepsy. The drug product information that comes with folic acid sometimes warns that it could provoke a seizure, however this side effect is extremely rare and only occurs in conjunction with absence epilepsies, if at all.

Valproate

If taken by the mother during pregnancy and depending considerably on the dosage, medications containing the active ingredient valproate or valproic acid (trade names include Depakine®, Orfiril® and Convulex®) cause birth defects in around 4 - 30% of children. In around 30 - 40% of children whose mothers take valproate during pregnancy it can also cause developmental problems (e.g. low intellectual abilities and autism).

If you are already taking valproate and want to become pregnant or are pregnant already, you must not under any circumstances stop taking your medication without medical advice – a fall during a seizure could be more dangerous for you and your unborn child than the side effects of the drug. If you fall into either of the above categories, you should urgently consult your neurologist.

We recommend that girls and women of child-bearing age do not start or continue treatment with valproate. Only if no other alternative is effective can there be a case for taking valproate, and where possible contraception should be used. If a patient taking valproate wishes to have a child, then she should always be prescribed the lowest possible dose and take folic acid at the same time. The probability of the child developing a birth defect if the mother takes less than 700 mg per day is lower than 5%.

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During pregnancy

No significant changes should be made to AEDs during pregnancy. Specifically, you should only switch to a different medication in exceptional cases, and under no circumstances should you stop taking a drug suddenly or without consulting your neurologist. Once you have conceived you should see your neurologist as soon as possible for a medication check.

With some AEDs – primarily lamotrigine, but to some extent also levetiracetam – the drug concentration needs to be monitored from early pregnancy onwards (from the second month at the latest and monthly thereafter) as the significant hormonal changes the body undergoes can cause the concentration to fall. If this is the case, your neurologist must increase the dose so that your pre-pregnancy drug concentration can be maintained. These higher doses **will not endanger** your unborn child but are necessary to keep the level of AEDs in your body high enough to prevent seizures. Higher doses are needed because during pregnancy the liver and kidneys work much harder and process drugs much more quickly.

Comprehensive obstetric care throughout the pregnancy is of great importance, including ultrasound scans. The risk of abnormalities in children whose mothers have epilepsy that is being managed with drugs can be higher than usual, depending on the drug. The risk of abnormalities in normal pregnancies (that is in children whose mothers have no illnesses and are not taking any medication) is 2-3%.

Before you undergo any testing, you should think about what you would want to do if you found out that your unborn child had an abnormality. Even if termination is not an option for you, the tests can be helpful in ensuring that your child receives the right treatment later on.

The risk of complications in pregnancy is no greater than it is for women who do not have epilepsy.

Risk of seizure during pregnancy

The frequency of seizures does not usually change during pregnancy as long as your drug concentration remains constant – in fact 5-10% of women have fewer seizures than before. Series of seizures, tonic-clonic seizures and falls as a result of seizures can pose a significant risk to the unborn child and as such should be avoided as far as possible. You should talk to your doctor about what type of seizure would necessitate an obstetric checkup.

Birth

It is usually possible to give birth naturally. As with all other pregnancies, the only indications for a caesarean section would be if it were necessary due to the way the baby was lying or at the specific request of the mother. In rare cases it might also be a consideration if the mother were having frequent seizures, if repeated major seizures occurred during labour or if she were no longer able to labour effectively due to her seizures.

All expectant mothers should continue to take their AEDs during labour, and expectant fathers should help ensure this happens.

Vitamin K helps the blood to clot, and newborn babies are given vitamin K drops immediately after birth to protect them from the potential risk of bleeding. This is particularly important for babies born to mothers who take enzyme-inducing AEDs, as these can cause an additional lack of vitamin K.

Breastfeeding

As a general rule, breastfeeding is recommended. AEDs can be transferred to breast milk, however, so you should consult your neurologist and your child's paediatrician, especially if you are taking phenobarbital, primidone or new drugs about which only limited feedback is available. Although a significant amount of the AEDs most frequently prescribed for pregnant mothers, namely levetiracetam and lamotrigine, is transferred to breast milk, studies have shown that the levels of these in the newborn baby's blood are **minuscule** and do not cause harm.

However, if the baby is excessively tired, not suckling well or seems otherwise out of sorts, breastfeeding should be reduced, and if there is no improvement stopped completely, albeit gradually so the baby does not experience withdrawal symptoms. The recommended period for breastfeeding is three months.

The postpartum period

In the first four weeks after the birth your AED serum level can rise – if your medication was increased during pregnancy then it needs to be

reduced again in consultation with your doctor. It is recommended, however, that for the first year after you have given birth your drug concentration is a little higher (25%-50%) than it was before your pregnancy, as sleep deprivation, anxiety and stress can lead to more frequent seizures during this period. It is therefore important to get extra support at this stage – for example the baby's father could do the night-time feeds using expressed milk.

If they are alone with their baby, mothers who are not seizure-free must change nappies on the floor and breastfeed in an armchair or in bed. They must not bath their baby alone nor use a baby bath seat alone. If it is not possible for a second person to be present, they should shower their baby while seated on the floor of the shower cubicle with the water on very gently.

The EURAP pregnancy register

The international pregnancy register has been created to establish which AEDs can cause birth defects or developmental problems. It now holds information on more than 25,000 women worldwide. If you join the register, your data will be collected anonymously and your treatment will not be affected. The more women who take part, the faster it is possible to make more beneficial discoveries.

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.

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More flyers in English:

www.epi.ch/en

Further information

In German, French, English and some in Italian:

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