

Transition for Adolescents, Youth, and Young Adults with Epilepsy

Reproductive Health

What are the chances that my child will have epilepsy?

Some types of epilepsy are inherited and tend to run in families. There is a higher risk of having a child with epilepsy if:

- one or both parents has epilepsy (the risk is higher if the mother has epilepsy)
- one or both parents has generalized epilepsy
- parents' seizures started early in life

However, epilepsy can often skip a generation.

How do seizures affect my ability to have children?

For Males only:

Men should know that epilepsy is associated with hormonal changes that may affect their ability to have children. For instance, experts estimate that approximately 40% of men with epilepsy (MWE) have low levels of testosterone, the male hormone that stimulates the development of male sex organs, and sexual traits. Both epilepsy itself and the anti-seizure medications may be responsible for these hormonal changes. Medications such as phenytoin, carbamazepine, and phenobarbital reduce the level of free testosterone which, in turn, reduces sexual desire. Another anti-seizure medication Valproate is linked to sperm abnormalities and can affect the development of sex organs. Some good news regarding anti-seizure medications and hormonal effects does exist: studies show that the medication lamotrigine may not have a negative impact on sexual function.

Persistent seizures may be associated with hormonal and neurological changes that contribute to sexual dysfunction. The type of epilepsy, age of onset, and family history appear to have the biggest impact on reproductive dysfunction and infertility. Men with early age onset of epilepsy (less than 10 years of age) have more fertility and sexual difficulties than men who develop epilepsy at a later age. Men with focal epilepsy have more fertility and sexual difficulties than those with generalized epilepsy. In particular, temporal lobe epilepsy is linked to low testosterone production. Limited data show that men with epilepsy (MWE) who do not have a family history of epilepsy are at a greater risk for sexuality and fertility problems than MWE who do have a family history of epilepsy.

*To learn about safety precautions while caring for a baby go to page 5 of this handout.

For Females only:

With advances in medication and management, most women with epilepsy are able to safely have children. At one time, women with epilepsy were advised never to get pregnant. That is not the case anymore. Epilepsy should not prevent you from having children.

People with epilepsy seem to have fewer babies than people in the general population. There are probably several reasons for this:

- **Social factors:** People with epilepsy are less likely to marry and have children than people in the general population. This in turn may be partly related to problems with social development and poor self-esteem. Also, people with epilepsy may face family or social pressure not to have children.
- **Sexual and physical factors:** epilepsy and anti-seizure medications (ASM) can interfere with sex hormones and this may lead to sexual and fertility problems:
 - Polycystic Ovary Syndrome (PCOS). Women with epilepsy seem to be
 more likely to develop a condition, PCOS, which causes women to have

elevated male hormone levels (testosterone). This may cause ovarian cysts and can interfere with menstrual cycles and the ability for having children. It is especially common in women who are taking the anti-seizure medication Valproate. Many of the symptoms can be reversed when the drug is stopped. This condition is also common in women without epilepsy.

- The risk of infertility increases when more anti-seizure medications are taken.
- Women with temporal lobe epilepsy are more than 3 times as likely to have a menstrual cycle in which no egg was released from the ovaries, compared with women without epilepsy. This could obviously reduce their fertility.

Despite these problems, recent studies showed that women with epilepsy are just as likely to achieve pregnancy and have the same pregnancy outcomes as their peers without epilepsy.

How do anti-seizure medications and birth-control medications affect one another?

It is possible that your ASMs may make your hormonal birth-control medicines less reliable, resulting in an unwanted pregnancy. There are complex interactions between the hormones contained in birth-control pills (contraceptives) or devices, and the anti-seizure medications that increase the breakdown of contraceptive hormones and their levels in the body. Such medications are Carbamazepine, Oxcarbazepine, Phenytoin, Phenobarbital, Primidone, and Topiramate. If you take any of these medications, discuss with your OB/GYN specialist the need for more effective contraceptives. It is a good idea to use barrier methods (condom, diaphragm, etc.) in addition to the contraceptive. On the other hand, drugs such as Levetiracetam and Lamotrigine will not affect your oral contraceptive efficacy.

In general, hormonal birth control is not expected to change your seizure pattern although it has occurred in some rare cases.

Talk with your doctor if you take or Lamotrigine or Valproate. Hormonal birthcontrol medicines increase the breakdown of these medicines in the body and this may make them less effective and lower your seizure control.

Taking hormonal birth-control medicines may be beneficial for women who have catamenial seizures (seizures occur mostly around menstrual periods). Seek professional advice about this issue **from both** a neurologist and an OB/GYN specialist.

How do seizures and anti-seizure medications affect pregnancy?

You should know that pregnancy is relatively safe for you and your baby. Seizure frequency is unchanged in about 50% of women with epilepsy (WWE). Pre-pregnancy seizure control can predict how likely you are to have seizures during pregnancy. The better the seizure control within 9 months before conception, the higher your chances for seizure freedom throughout pregnancy.

Taking Folic Acid (a vitamin) before you become pregnant will not harm your baby and might help. There is evidence that Folic Acid (4mg/day) has a positive effect on your baby's brain development and lowers the incidence of birth defects by 70%.

Taking an anti-seizure medication (ASM) during pregnancy is not likely to lead to a difficult pregnancy. There is good evidence that taking ASM while you are pregnant will not put you at an especially high risk of pregnancy complications, miscarriage, premature labor, and delivery.

There is also good evidence that the babies of women with epilepsy are not at any higher risk of dying in the first month after birth than the babies of women without epilepsy.

Taking ASMs during pregnancy, especially valproate, has some risks. But there are many good reasons to consider staying on ASMs during pregnancy. Seizures can be dangerous to both you and your baby. So, working toward being free of seizures is important. Some ASM levels can drop during pregnancy, so be sure to work closely with your doctor to maintain the right ASM level for you. Some ASMs (e.g. Lamotrigine, Levetiracetam, Oxcarbazepine, Carbamazepine) are safer than others (e.g. Valproate, Phenobarbital, Phenytoin, Topiramate).

WWE should consider taking one ASM instead of more than one during their first trimester to lower the risk of major birth defects. Be aware that there is some evidence for avoiding Valproate in particular as part of your therapy during pregnancy because of a higher risk of birth defects and the child developing poorer thinking ability.

Stopping your anti-seizure medications, whether before or during pregnancy, might not be best for you. Also, if you are pregnant and taking an ASM, switching to another ASM now might bring on other health problems. Whatever your situation is, talk to your doctor about making the right choice for you.

Can I breastfeed my baby if I take anti-seizure medicines?

Breastfeeding for most women taking anti-seizure medicines is generally safe. ASMs are able to pass through the umbilical cord from the pregnant woman to her baby. The data are limited but show that breastfed babies of WWE do just as well as, and even better than, non-breastfed babies. Negative effects in the

breastfed child are rare and consist mainly of sedation and poor suckling. We advise close monitoring.

What safety precautions should I follow while caring for an infant?

- Sit on the floor while feeding a baby. If you tend to fall on the same side during a seizure, position yourself to prevent yourself from falling on the baby.
- Dress, change, and play with the baby on the floor.
- Avoid bathing a baby in a tub while you are alone.
- Avoid carrying your baby around the house, especially up and down stairs.
- Avoid hot drinks around your baby.

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Author: Temenuzhka Mihaylova, MD, PhD Plain Language Editor: Ruti Volk, MSI, AHIP

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