IMPLICATIONS OF EPILEPSY: BEYOND SEIZURES

Epilepsy, Hormones, & Reproductive Health

Seizures and the Menstrual Cycle

In some people with epilepsy, seizure frequency is connected to hormonal changes that occur throughout the menstrual cycle. This is called catamenial epilepsy. With this type of epilepsy, the majority of seizures happen more frequently at certain times of the menstrual cycle, particularly around the beginning of a person's period or around ovulation (which is calculated as fourteen days before their period starts).

For those who have anovulatory cycles (when a person menstruates but does not ovulate) this may occur during the latter half of the menstrual cycle. People who notice a connection between their menstrual cycle and seizure frequency should discuss this with their doctor, as there may be treatment options available to improve seizure control.

■ Birth Control Pills & Contraception

Some anti-seizure medications can reduce the effectiveness of birth control pills, and birth control pills can reduce the effectiveness of some anti-seizure medications. Ontario's Epilepsy Implementation Task Force recommends that physicians avoid prescribing "enzyme inducing anti-seizure medications" to people using birth control pills. These medications include Phenytoin, Phenobarbital, and Carbamazepine. Newer agents, including Oxcarbazepine, Eslicarbazepine, Perampanel and higher doses of Topiramate and Lamotrigine, can also have enzyme-inducing effects.

People who are taking enzyme-inducing anti-seizure medications will need to take a higher dosage of the morning-after pill when compared to the standard dosage.

Those who are taking anti-seizure medications and birth control pills or need/are using the morning after pill may want to talk to their doctor about their options.

The following contraception methods are not affected by anti-seizure medications: barrier methods (e.g. condoms), intrauterine devices (IUDs), intrauterine systems (IUSs), and contraceptive injections.

Fertility

Some people who are assigned female at birth (AFAB) and have epilepsy may have a slight decrease in fertility. Fortunately, this effect is often treatable with fertility drugs. Taking anti-seizure medications does not prevent people with epilepsy from receiving fertility treatment. A few people will notice a marginal increase in the number of seizures they experience while taking fertility drugs.

Pregnancy

Valproic Acid can have negative impacts on pregnancy, such as increased risk of major congenital malformations. People with epilepsy may wish to discuss the risks and benefits of this medication choice with their treating epileptologist/neurologist.

 The vast majority of people with epilepsy who get pregnant will have healthy pregnancies and healthy babies.

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- People with epilepsy whose seizures are well controlled are likely to remain seizure-free during pregnancy. The best predictor of seizure freedom during pregnancy is seizure freedom in the nine months prior to conception.
- People with catamenial epilepsy have an increased chance of seizure improvement during pregnancy.
- People with epilepsy who smoke while pregnant have increased risk of premature contraction and premature labour.
- As of 2022, the safest medications appear to be Levetiracetam and Lamotrigine according to the latest review of the North American Pregnancy Registry. However, Lamotrigine and Levetiracetam levels may fluctuate significantly during pregnancy. It is recommended that people with epilepsy speak with their doctor about monitoring drug levels and dose adjustments during pregnancy.
- Ideally, people with epilepsy should work with their health care provider before becoming pregnant to achieve the best seizure control possible with the fewest number and lowest dose of anti-seizure medication(s) possible.
- Some people may be tempted to stop taking their epilepsy medication once they find out they are pregnant. However, it is highly recommended that medication is not stopped without first consulting with a member of the healthcare team, as this could result in an increase in seizures, which could harm the parent or baby.
- Testosterone and other masculinizing hormones do not prevent a person from becoming pregnant. Testosterone treatment may negatively impact the fetus development. It is recommended that people with epilepsy speak with their endocrinologist or hormone doctor if they are taking masculinizing hormones and become pregnant or are considering pregnancy.¹

TIPS:

- Work with a healthcare provider to aim for seizure freedom before getting pregnant.
- Work with a healthcare provider to simplify medication regimens, aiming for monotherapy (managing seizures with one medication) at the lowest dose possible.
- Using folic acid (1-5 mg/day) is highly recommended, starting months before conception.
- It is recommended that anti-seizure medication levels are monitored more often during each trimester of pregnancy.
- It is recommended that there is close monitoring for complications during pregnancy.
- It is best to quit smoking if intending to become pregnant.
- For most people with epilepsy, breastfeeding is recommended and safe.

Menopause

- People with catamenial epilepsy may notice a slight worsening of their seizures during perimenopause (the time period before menopause begins).
 However, there may be an improvement of seizures after menopause.
- Some anti-seizure medications can increase the risk of bone fractures. It is recommended that people with epilepsy discuss with their doctor their anti-seizure medications and the role of a bone scan to assess for osteoporosis. Consider taking vitamin D and calcium supplements daily.



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- Estrogen levels in HRT are low enough that it usually doesn't increase seizures. However, it can sometimes happen. It is recommended that people who are taking HRT and have an increase in seizures talk to their doctor about finding a different treatment or a different combination of estrogen and progesterone.
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- Hormone therapies in gender affirming care may have interactions with anti-seizure medications. It is recommended that people with epilepsy work with their neurologist/epileptologist and endocrinologist to reduce risks.

Gender Affirming Care & Hormone Therapies

 Estrogen treatments may cause an increase in seizure activity.

- People taking enzyme-inducing anti-seizure medication and testosterone should work with their endocrinologist or hormone doctor to monitor for testosterone dosing.
- Transmen and non-binary people who previously had catamenial epilepsy may see an increase in seizure management when menstruation ceases due to hormone therapy.
- Certain herbal supplements and other treatments can make anti-seizure medications less effective, resulting in breakthrough seizures. If using substitute treatments from non-medical sources, due to lack of access or affordability of hormone therapy, consider consulting a neurologist about this to fully evaluate the risks and potential drug interactions.

Adapted from: Provincial Guidelines for the Management of Epilepsy in Adults and Children (Epilepsy Implementation Task Force); Epilepsy in Pregnancy: A Fine Balance, Dr. Esther Bui (Epilepsy Toronto); Caring for transgender patients with epilepsy, E.L. Johnson and P.W. Kaplan in Epilepsia (2017); Contraceptive Choices and Sexual Health for Transgender and Non-Binary People (The Faculty of Sexual & Reproductive Healthcare of the Royal College of Obstetricians & Gynaecologists, October 2017); Menopause and Epilepsy (Epilepsy Society). With thanks to Dr. Esther Bui (Epilepsy and Pregnancy Clinic, Toronto Western Hospital).

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