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## Is it safe to take epilepsy medication during pregnancy?

Hannah\* was first prescribed sodium valproate to control her [epilepsy](#) when she was 13 years old. "At the time, I wasn't told about any of the risks and then I fell pregnant at 16," she says. "The pregnancy miscarried at four months, due to severe abnormalities with the baby, which were caused by my medication."

More than 20 years later, UK drug regulator the [MHRA](#) last month [announced a ban](#) on prescribing sodium valproate to women and girls of childbearing age, unless they sign a form to say they understand the risks.

As well as physical abnormalities, taking [sodium valproate](#) during pregnancy also puts babies at risk of developmental disorders and learning difficulties. But, if you rely on this medication to control your potentially life-threatening [epileptic seizures](#), planning a pregnancy can be fraught with stresses and concerns about how best to manage your own health, without putting the baby's at risk.

Retired neurologist Dr Jim Morrow says the best advice is to speak to an epilepsy specialist before you get pregnant. "Get a referral to a neurologist and they will talk you through the pros, the cons, the risks and the benefits of the particular [epilepsy drug](#) you're on," he says.

"I would do that with any drug, not just valproate," Morrow adds. "Although some other epilepsy drugs seem to be safe from a congenital malformation [birth defects] point of view, [there are others that appear to carry some risks](#) - these include phenytoin, primidone, phenobarbital, carbamazepine, topiramate and possibly lamotrigine. What's more, levels of epilepsy medicines in the bloodstream can drop during pregnancy, because of metabolism changes. That means they're not as effective, so seizures can break through."

## Understanding the risks

As well as being a clinical advisor to [Epilepsy Action](#), Morrow founded the [UK Epilepsy and Pregnancy Register](#), which was responsible for bringing these risks to light when they studied the effects of a range of new and older epilepsy treatments.

"What we found was the new drugs are largely safe but sodium valproate, which has been around since the 1970s, was associated with much higher risk of major malformations and learning difficulties than any of the other drugs," he explains.

"For women taking it during pregnancy, there's an 8-10% risk of malformations - including [spina bifida](#), [cleft palate](#), and talipes ([club foot](#)) - and up to 30% of kids have some sort of learning difficulties," he adds.

"This drug has damaged more children than thalidomide, because it's probably still the second most commonly used anti-epileptic drug in the UK and worldwide."

The problem, Morrow explains, is that it's a very good anti-epileptic drug. In fact, for certain types of epilepsy - particularly [juvenile myoclonic epilepsy](#) - he says: "It really is the best drug by far, and actually probably the only drug that really works for that type of epilepsy."

It's an impossibly difficult risk to weigh up - and, even then, women like Hannah have too often in the past found themselves let down by a lack of accurate information.

## 'I did as I was told'

After the trauma of her [miscarriage](#), Hannah knew to plan ahead the second time around. "I stopped taking sodium valproate and started taking [folic acid](#) before I became pregnant with my son, when I was 23," she says. "I didn't have any seizures, so I didn't take any medication for the epilepsy, and it was a happy, healthy pregnancy. My son was absolutely fine."

By the time of her third pregnancy, however, Hannah says her epilepsy wasn't well controlled, and she was back on valproate.

"We'd given up trying by the time I fell pregnant but I was taking daily folic acid just in case," she explains. "When I did fall pregnant, the doctors took me off valproate because they were concerned about spina bifida and physical abnormalities to the baby."

Due to having regular seizures, Hannah was prescribed a different anti-epilepsy drug, but it didn't keep them under control. "Once I was into my second trimester, the doctors said I should go back on sodium valproate because the seizures could cause premature birth," she says.

"I was told the medication only affects fetuses during the first trimester, when physical abnormalities can occur. Nobody told me about any risks to the baby as far as neurological problems," she adds. "So I did as I was told, but even the sodium valproate didn't stop my seizures that time."

Hannah's daughter was born with severe learning difficulties, has been on medication since she was 10 years old, and needs one-to-one care at school.

"It's heartbreaking that her life is limited because of something I took, that I was told was helping her. I feel horrendously guilty," Hannah says. "If I'd been properly advised of the risks, I definitely would not have gone back on to sodium valproate," she adds.

## Stopping or changing medication

The crucial thing to remember is that, whether your pregnancy is planned months in advance or comes along more unexpectedly, you should never stop your medication suddenly. Any changes should always be done slowly, under medical supervision, in consultation with a neurologist who specialises in epilepsy.

"If somebody had been seizure-free for more than a year, or preferably two years, you would like to consider them coming off their drug, but you have to weigh up the risks of relapse, because that can be dangerous for both mother and baby," Morrow explains. "Another option is to try to change to a drug that's safer in pregnancy, and for most types of epilepsy there are alternatives that are equally as effective as valproate - we tend to use [lamotrigine](#) and [Lamictal®](#) (the brand name for lamotrigine)," he adds.

You should also discuss taking a folic acid supplement from the moment you stop using completely reliable contraception. All women are advised to take 400 micrograms a day of folic acid to cut the risk of spina bifida, from before they get pregnant until three months into the pregnancy. But if you're on epilepsy medication, the recommended dose is almost always 5 mg (milligrams) a day for the same period.

If valproate really is the only medication that works, Morrow says doctors would try to minimise the dose, although this can be difficult in practice.

"The other option, of course, is for the woman, if she wants, to come off it anyway, if she is willing to accept that she could have seizures," he explains. "The baby is pretty well insulated from seizures, to be honest, so it's more of a risk to the woman herself. People can die in seizures though, if they occur in the wrong place at the wrong time. And going into status epilepticus (a single seizure or cluster of seizures lasting more than half an hour) can lead to brain damage or even death."

Finally, Morrow advises, check if there's a joint neurology/obstetric clinic in your area and get yourself booked in if possible, so a neurologist can work alongside your obstetrician to monitor the situation throughout your pregnancy.

\*Names have been changed to protect identities.

*To assist with further research on epilepsy and pregnancy, you can join the [UK Epilepsy and Pregnancy Register](#).*

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