



Epilepsy: contraception, conception and pregnancy counselling

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Introduction

Most women taking anti-epileptic drugs (AEDs) have epilepsy, although sometimes these drugs are used for other conditions. If you don't have epilepsy, but take AEDs, some of this information may not be relevant to you. Your doctor should be able to help you further.

This fact sheet looks at how women with epilepsy can make sure they are getting the most effective contraception. It also gives information about how they can make their pregnancies as healthy as possible for themselves and their babies.

Contraception

If you have epilepsy or take AEDs, you need to get good advice about your contraception in order to avoid an unplanned pregnancy. For example, natural birth control, such as the rhythm method, is not recommended for women with epilepsy. And AEDs can make some types of contraception not work as well as they should.

For up-to-date information on epilepsy, AEDs and contraception, contact Epilepsy Action, or visit www.epilepsy.org.uk/contraception. The Family Planning Association may also be able to help you. (Family Planning Association: www.fpa.org.uk; tel. 0845 122 8690.)

Pre-conception counselling

If you have epilepsy, pre-conception counselling involves attending an epilepsy or obstetric (relating to childbirth) clinic, where you will have the opportunity to plan properly any future pregnancies. During pre-conception counselling, you will be asked about your epilepsy and your AEDs. They will then discuss with you any changes needed to your AEDs. This is to give you and your baby the best chance of a healthy pregnancy. The clinic will work with you to make any changes before you become pregnant.

Pregnancy

Most women with epilepsy can become pregnant and have healthy pregnancies. However, some women taking AEDs have a slightly higher risk of having a baby with a birth malformation than women who don't take AEDs.

During pregnancy your AEDs need to be closely monitored by your epilepsy specialist. Make a note of any changes to your seizure pattern. If it changes at any time, ask your GP to refer you to your epilepsy specialist for a review of your AEDs.

Folic acid

During pre-conception counselling, you might be advised to take five milligrams of folic acid all the time, just in case you get pregnant. This is to help reduce the risk of your baby having a malformation such as spina bifida. As it is a much higher dose than for women not taking AEDs, you will need to get a prescription for this dosage from your GP.

Folic acid can affect how well the AEDs phenytoin, phenobarbital or primidone work. Your doctor will be able to advise you about this.

UK Epilepsy and Pregnancy Register

The UK Epilepsy and Pregnancy Register was set up to find out more about having epilepsy and taking AEDs during pregnancy. Some women on the register were taking AEDs, and some were not. The information that follows is taken from the register's 2011 findings.

(The UK Epilepsy and Pregnancy Register: www.epilepsyandpregnancy.co.uk; tel. 0800 389 1248.)

Major congenital malformations

Some of the problems that may affect babies born to mothers with epilepsy are classed as major congenital malformations. Major congenital malformations are birth defects that need medical treatment. Major congenital malformations range from a damaged spine or a hole in the heart to a cleft palate (where the roof of the mouth is not correctly joined).

The risks of having a baby with a major congenital malformation may be related to epilepsy itself as well as to any AEDs taken during pregnancy.

The risk of AEDs causing your unborn baby to have a major congenital malformation seems to be greatest during the first three months of pregnancy.

Risks of having a baby with a major congenital malformation related to epilepsy

If you have epilepsy and don't take AEDs the risk is around two in a hundred. One or two babies in every hundred born to women without epilepsy who don't take AEDs have a major congenital malformation.

Risks of having a baby with a major congenital malformation related to anti-epileptic drugs

If you take just one AED			
AED taken	Daily dosage	Approximate risk	% risk
carbamazepine	any	two in a hundred	2.4
lamotrigine	below 400 mg	two in a hundred	2.4
lamotrigine	above 400 mg	six in a hundred	5.9
sodium valproate	below 1000 mg	five in a hundred	5
sodium valproate	above 1000 mg	nine in a hundred	9.1

If you take more than one AED		
AED combination	Approximate risk	% risk
sodium valproate with any other	nine in a hundred	8.9
any combination without sodium valproate	four in a hundred	4.2

Neurodevelopment problems

Some women who have taken the AED sodium valproate have had babies who went on to have neurodevelopment problems. Neurodevelopment is a term used to describe the development of a range of skills. Examples include language and communication skills and behaviour.

Recent information suggests that there is a higher risk of your baby having a neurodevelopment problem if you take sodium valproate at any time in pregnancy.

Minor congenital abnormalities

Babies born to women with epilepsy have a slightly higher risk of having a minor congenital abnormality than women who don't have epilepsy. A minor congenital abnormality is a birth defect that doesn't necessarily need treatment and might not be permanent. Examples of minor congenital malformations include small fingers, small toenails, and facial abnormalities such as wide spread eyes. Minor congenital abnormalities are not linked to any particular AED.

The risk of AEDs causing your unborn baby to have a minor congenital malformation seems to be greatest during the first three months of pregnancy.

Why it's important to take your anti-epileptic drugs as prescribed

If you suddenly reduce or stop taking your AEDs, without medical advice, you could have seizures. This could put your health and the health of your baby at risk. It could also put you at higher risk of sudden unexpected death in epilepsy.

For up-to-date information on epilepsy and having a baby, contact Epilepsy Action, or visit www.epilepsy.org.uk/info/women/having-baby.

About this publication

This fact sheet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the fact sheet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

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Epilepsy Helpline

Freephone 0808 800 5050 text 07797 805 390
helpline@epilepsy.org.uk www.epilepsy.org.uk

Epilepsy Action, New Anstey House,
Gate Way Drive, Yeadon, Leeds LS19 7XY
tel. 0113 210 8800 fax 0113 391 0300

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