

Are you taking medicines for epilepsy, mood or pain?

Information for females,
their family and whānau





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If you are taking medicines for epilepsy, pain, or mood regulation, this information is important to you.

The purpose of this booklet is to help females and their family and whānau understand the benefits and risks of taking antiepileptic medicines if they are thinking of getting pregnant or are pregnant. It is important for all females who are near childbearing age and sexually active.

If you are not sure if you are taking antiepileptic medicines (used for epilepsy, pain and mood regulation), look at the list at the end of this booklet. If your medicine is not on that list, ask your healthcare professional.

Are you sexually active?

If you are having sex you need to use two effective forms of contraception (such as the Depo Provera Injection or IUD eg. Mirena/coil and condoms) so you don't get pregnant. Two forms are important as no contraceptive is 100% effective and some are affected by medicine, talk to your health provider to discuss what is best for you. Some of the problems that can happen to babies exposed to antiepileptic medicines happen in the very early weeks of pregnancy.

If you are on antiepileptic medicine see your doctor every year to check if the medicine is still right for you. Do not stop taking your medicine without speaking to your doctor as there is serious risk of harm if you do.

If you are not sure, talk to your healthcare professional, and take this booklet with you.

Thinking of getting pregnant?

- You need to plan your pregnancy 6-12 months before you start trying to get pregnant.
- Talk to your doctor as the first part of your plan.
- Keep using two forms of contraception while you are planning your pregnancy.
- **Keep taking your antiepileptic medicine until you have spoken to your doctor and have a plan.**
- You and your doctor will agree on a plan about how to manage your antiepileptic medicines and your dose (the amount of medicine you are taking).

If you think you are pregnant

- Talk to your doctor immediately. There are risks to your unborn baby.
- **Keep on taking your antiepileptic medicine until you speak to your doctor.** There is serious risk of harm to you and your unborn baby if you stop taking your medicine. If you:
 - have epilepsy and stop taking your medicine or change the dose you could have very bad seizures which could cause a miscarriage and put your own life at risk.
 - are taking medicine for mood regulation and stop taking your medicine or change the dose you could have severe mood changes that could put you at risk.
 - are taking medicine for pain and stop taking your medicine, your pain could return.

What are the risks to my unborn baby if I need to take antiepileptic medicines when I am pregnant?

Your baby can be harmed if you take antiepileptic medicines. The main risks to your unborn baby include malformations (your baby not being formed properly, and having abnormalities like spina bifida, cleft palate, or heart defects), learning problems and Autism.

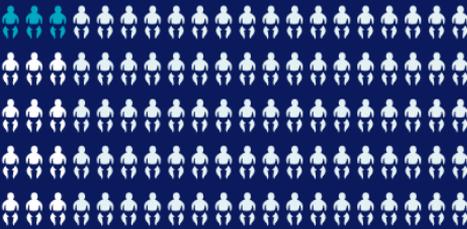
The risk to your baby depends on:

- what medicine you take –sodium valproate (Epilim®) is most likely to harm your unborn baby.
- your dose (how much you take).
- if you are taking more than one antiepileptic medicine.

Risks to my unborn baby

Malformations

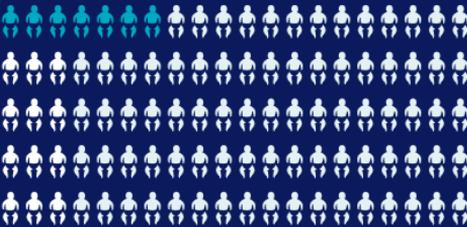
Such as spina bifida, cleft palate and heart defects



2 to 3 out of **100** babies

not exposed to antiepileptic medicines will have these problems.

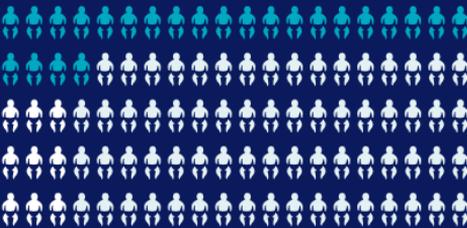
This is a low risk.



4 to 7 out of **100** babies

exposed to antiepileptic medicines of any dose will have these problems.

This is a high risk.

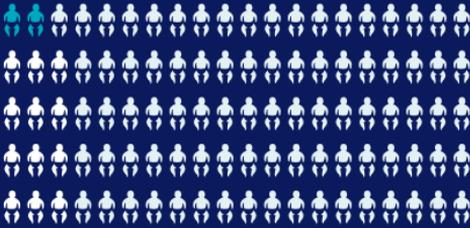


24 out of **100** babies

exposed to more than 1500mg of sodium valproate (Epilim®) will have these problems.

This is a very high risk.

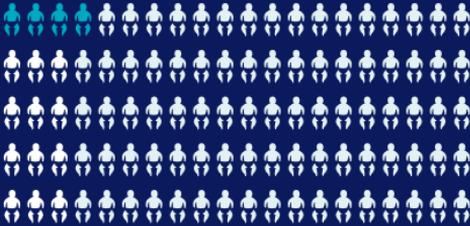
Learning and behavioural problems



2 out of
100 babies

not exposed to sodium valproate (Epilim®) will have Autism.

This is a low risk.



4 out of
100 babies

exposed to more than 800mg of sodium valproate (Epilim®) will have Autism.

This is a medium risk.

Babies exposed to sodium valproate (Epilim®) may have learning problems and a decreased IQ.



8X

more likely to need extra help at school than other children.

What can I do to reduce the risk of harm to my baby?

Talk to your doctor as soon as you start thinking you want to get pregnant.

Your doctor will talk to you about the reasons you are taking antiepileptic medicines e.g. for epilepsy or other health conditions such as headache, pain or to keep your moods regulated.

It is important you keep taking your antiepileptic medicine until you have talked to your doctor and you have a plan.

There are serious risks of harm to you and your unborn baby if you stop taking your antiepileptic medicine.

It may be possible:

- to reduce the dose of your antiepileptic medicine.
- if you are taking antiepileptic medicine because you have epilepsy, to change to a different antiepileptic medicine so there is less risk of harm to your baby.
- if you are taking medicine for headache, pain or to keep your moods regulated, to stop or change your medicine so there is less risk of harm to your baby.



It is important you keep taking your antiepileptic medicine until you have talked to your doctor and you have a plan.



You might want to take your partner or another support person with you to your appointment.

Your partner or support person can help by taking notes of the plan you and your doctor agree on.

I want to get pregnant

1. Keep taking your antiepileptic medicines and using two forms of contraception (such as the Depo Provera Injection, IUD eg. Mirena/coil and condoms). You have a serious health condition and you need to keep taking your medicine or you could put your life at risk.
2. Talk to your doctor as soon as possible and at least 6-12 months before you want to start trying to get pregnant. This is because:
 - it takes time to safely change your medicines.
 - some of the problems that can happen to your baby happen in the very early weeks of your pregnancy.
 - **you should never change or stop your medicine without talking to your doctor.**

Your planning appointment with your doctor

This appointment may take longer than your usual appointments. You and your doctor need to make a plan to reduce the risk of harm to your baby and keep you as healthy as possible while you are pregnant.

You are making very important decisions at this meeting. Take your time and make sure you have all the information you need to make decisions to keep your baby and you as safe as possible.

Your doctor will also talk to you about taking 5 milligrams of folic acid every day. This will help reduce the risk of your baby having neural tube defects such as spina bifida.

If you have epilepsy any changes to your medicine will include a neurologist (a doctor who is specially trained in treating problems that affect the brain, spinal cord and nerves) or paediatrician (a doctor who is specially trained in childhood illnesses).

All the doctors looking after you will be working to:

- make sure you do not take any more medicines than you have to, reducing the risks of harm to your baby and you.
- control your seizures as well as possible.

If you do not have epilepsy and are taking antiepileptic medicines for other health conditions your doctor will be able to tell you if it is safe for you to stop taking your medicine or to take another medicine so there is less risk of harm for your baby and you.

You might want to take your partner or another support person with you to your appointment. Your partner or support person can help by taking notes of the plan you and your doctor agree on.

Here are some questions you should ask your doctor at this appointment:

1. What else can I do, including taking other medicines, to reduce the risk of harm to my baby and me?
2. How often will I need to have check-ups while I am pregnant because I am taking antiepileptic medicines? Who will do these check-ups?

Make a list of all the other questions you want to ask your doctor. The Let's PLAN web pages have information to help you prepare for your appointment.



If you think of other questions or you are not sure about something after your appointment contact your doctor again. You might need to have a number of appointments. It is okay to want to discuss things again as you are making very important decisions for your baby and you.

I am pregnant or think I am pregnant

- **Keep taking your medicine at the right dose.**
 - If you have epilepsy and stop taking your medicine or change the dose you could have very bad seizures. These seizures could cause a miscarriage and put your own life at risk.
 - If you are taking medicine for mood regulation and stop taking your medicine or change the dose you could have severe mood changes that could put you at risk.
 - If you are taking medicine for pain and stop taking your medicine, your pain could return.
- Contact your doctor, tell them you think you are pregnant and get an urgent appointment to see them.



Contact your doctor, tell them you think you are pregnant and get an urgent appointment to see them.

If you are less than 12 weeks pregnant your doctor will recommend that you take 5 milligrams of folic acid every day. This will reduce the risk of your baby having neural tube defects such as spina bifida.

There will be a lot of healthcare professionals looking after your baby and you. Make sure you give all the healthcare professionals the same information. You might want to write information down in a notebook so you have notes to refer to rather than try and remember everything.

If you have epilepsy, changes to your medicine will include:

- a neurologist (a doctor who is specially trained in treating problems that affect the brain, spinal cord and nerves) or,
- a paediatrician (a doctor who is specially trained in childhood illnesses).
- an obstetrician (a doctor who is specially trained in pregnancy, childbirth and just after childbirth).

All the healthcare professionals looking after you will be working to:

- make sure you do not take any more medicines than you have to, reducing the risks to your baby and you.
- control your seizures as well as possible.

Your doctor or midwife will make an appointment for you to see an obstetrician as soon as possible. The obstetrician and midwife will regularly check your baby and you during your pregnancy.

If you do not have epilepsy and are taking antiepileptic medicines for other health conditions, your doctor will be able to tell you if it is safe for you to change or stop your medicine.



There will be a lot of healthcare professionals looking after your baby and you. Make sure you give all the healthcare professionals the same information.

You might want to write information down in a notebook so you have notes to refer to rather than try and remember everything.

I am not planning on getting pregnant

- Keep taking your medicines.
- If you are having sex keep using two effective forms of contraception (such as the Depo-Provera Injection or IUD eg. Mirena/coil and condoms).
- If you decide that you want to get pregnant, contact your doctor at least 6-12 months before you start trying to get pregnant.
- Some of the problems that can happen to babies exposed to antiepileptic medicines happen in the very early weeks of pregnancy.

I think my child has been affected by the antiepileptic medicines I took when I was pregnant

If your child is already seeing a paediatrician talk to the paediatrician about your concerns.

Talk to your doctor who will refer you to a specialist. This specialist will ask you a lot of questions about your child and your concerns. Make sure you tell them what antiepileptic medicines you were taking. The specialist may refer your child for other tests.

You might want to take your partner or a support person to this appointment to take notes of all the things that you and the specialist talk about.

Write down the questions you want to ask before your appointment. The Let's PLAN web pages have information to help you prepare for your appointment.



More information

Health Navigator

www.healthnavigator.org.nz

National support services in New Zealand

You can get support from these organisations.

Epilepsy Association of New Zealand

www.epilepsy.org.nz

0800 374 537

national@epilepsy.org.nz

Mental Health Foundation

www.mentalhealth.org.nz

(09) 623 4810

info@mentalhealth.org.nz

Foetal Anticonvulsant Syndrome NZ (FACS NZ)

www.facsnz.com

021 189 4483

denise@facsnz.com

Order this booklet

To order printed copies of this booklet please email treatmentinjury@acc.co.nz

List of antiepileptic medicines

Here is a list of some of the antiepileptic medicines and their brand names which are available in New Zealand.

This is not a full list of all the medicines that are available. New medicines are added from time to time and brand names can change. If your medicine is not on this list, talk to your pharmacist, doctor or nurse.

Scientific name	Brand name
Carbamazepine	Tegretol [®]
Clobazam	Frisium [®]
Clonazepam	Paxam [®] , Rivotril [®]
Diazepam	Arrow-Diazepam [®]
Ethosuximide	Zarontin [®]
Gabapentin	Neurontin [®] , Nupentin [®] , Arrow-Gabapentin [®] , Ranbaxy-Gabapentin [®]
Lacosamide	Vimpat [®]
Lamotrigine	Logem [®] , Mogine [®] , Lamictal [®] , Arrow-Lamotrigine [®] , Motrig [®]
Levetiracetam	Keppra [®] , Everet [®] , Levetiracetam Pharmacare [®] , Levetiracetam AFT [®]
Lorazepam	Ativan [®]
Oxcarbazepine	Trileptal [®]
Phenobarbital	Phenobarbitone PSM [®]
Phenytoin	Dilantin Infatabs [®]

Pregabalin	Lyrica [®]
Primidone	Apo-Primidone [®]
Sodium valproate	Epilim [®]
Topiramate	Topamax [®] , Arrow-Topiramate [®] , Topiramate Actavis [®]
Vigabatrin	Sabril [®]

I think I have had side effects from my antiepileptic medicines

If you think you have had side effects from your antiepileptic medicines or any other medicine you take you can tell your doctors, pharmacist, nurse or midwife.

Phone: 03 479 7247

Email: carmnz@otago.ac.nz

Fax: 03 479 7150

You can also report the side effects yourself to the Centre for Adverse Reactions Monitoring (CARM).

Website: <https://nzphvc.otago.ac.nz/report/>



Helping females and their families
understand the risks and benefits of taking
antiepileptic medicines.

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This information is intended to provide guidelines and general advice to health care professionals, but should not be used as a substitute for assessment with the circumstances that are relevant to the individual patient.

