

Is valproate the right epilepsy treatment for me?

Valproate is also known as: Sodium valproate, Valproic acid, Epilim, Epilim Chrono, Epilim Chronosphere, Episenta, Epival, Convulex, Syonell, Belvo, Orlept, Depakote, Dyzantil, Depakin

This information is for women, girls and anyone who could become pregnant, aged between 12 – 55, taking valproate for epilepsy.



This document is designed to be read and then discussed with your doctor.



This information is important because you should not get pregnant if you are taking valproate.



This is because if you take valproate when you are pregnant it can harm your baby and cause learning difficulties.

Your options

Keep taking valproate

Talk to your doctor about changing your medication

because you are pregnant, might want to get pregnant or might have an unplanned pregnancy.

This document

- Will explain the risks and benefits of valproate.
- It will help you to work out what is important to you when making a decision about taking valproate or getting pregnant.
- You should work through this document and then arrange an appointment with your doctor to talk about this.

Key points

- All medications have potential harms as well as benefits.
- Valproate can help control epilepsy.
- Valproate might seriously harm unborn babies. This harm can happen at any time during pregnancy, even those first few weeks before you know you're pregnant.
- Other anti-epileptic drugs also have a risk of affecting the unborn baby, but the risk from those drugs are smaller than with valproate.
- If you are between 12 and 55 years old, medical advice is that you **should use a highly effective contraception (see page 6)** with valproate and are sexually active. Medical advice is to use contraception even if you're not having sex.

Important

Never stop taking valproate or any anti-epileptic medicine unless agreed with your doctor.

If you are taking valproate medical advice is that you should **always** use a highly effective form of contraception if you are between 12 and 55 years old.

There is more information about forms of contraception at the end of this document.

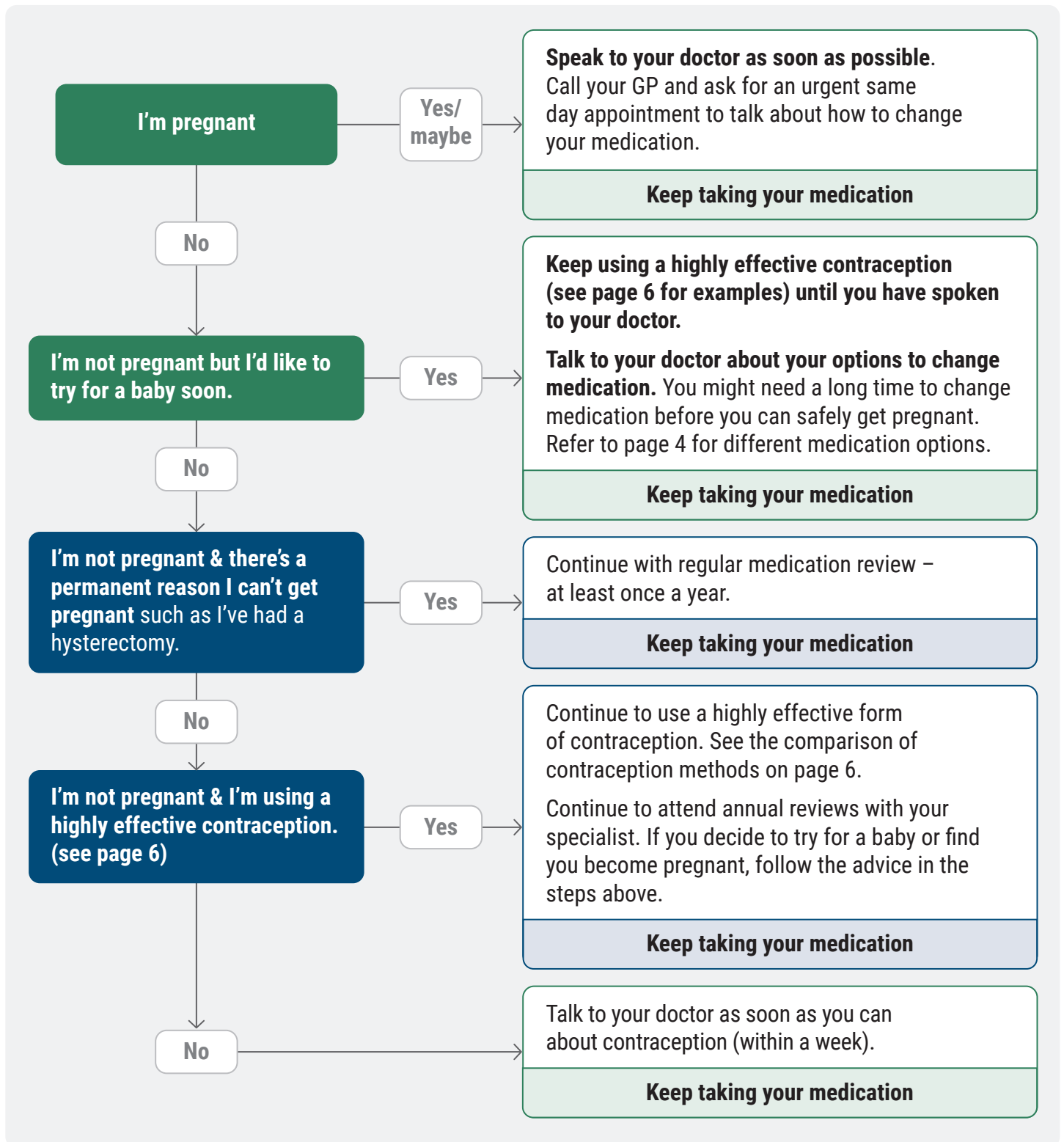
If you are currently taking valproate and are pregnant or think you might be pregnant, call your GP and ask for an emergency appointment, tell them you need to speak to a doctor that day and tell them you're taking valproate and that you might be pregnant.

Do not stop taking your medication.

Please don't worry – Your doctor can make a plan with you about what to do next.

I'm taking valproate

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Important

If you haven't had a medication review in the last 12 months

- ✓ **Book one with your doctor as soon as you can (within 4 weeks)**
- ✓ **Keep taking your medication**
- ✓ **Keep using a highly effective form of contraception**

What's important to you?

Your personal feelings are an important part of making a decision. Think about what matters most to you in this decision.

On each question, consider your answer and put an **X** where you feel your answer lies then **talk the answers through with your doctor. Not all answers carry the same weight in the decision.**

Definitely	No strong opinion	Definitely
<p>I am not worried about my seizure control changing if I change medication</p>	<p>Thinking about current seizure control</p>	<p>I am worried about my seizure control changing</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
<p>Thinking about the kind of seizures I have (your doctor can explain this to you if you don't know)</p>		
<p>Generalised epilepsy</p>		<p>Focal epilepsy</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
<p>I will not get pregnant</p>	<p>Thinking about family planning</p>	<p>I might want to get pregnant soon</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
<p>I have tried other medications</p>	<p>Thinking about your medication history</p>	<p>I haven't tried any other medications</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
<p>Visiting my specialist is difficult (distance, stressful, expensive, time off work)</p>	<p>Thinking about visiting your specialist</p>	<p>Visiting my specialist is easy</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
<p>I do not want to risk losing my licence</p>	<p>Thinking about driving a car</p>	<p>I don't drive or don't need to drive</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
<p>I am happy with my contraception</p>	<p>Thinking about contraception</p>	<p>I am struggling with contraception</p>
<div style="border: 1px solid black; width: 100%; height: 20px; background-color: #d9ead3;"></div>		
Definitely	No strong opinion	Definitely

More 'X's' this side
Leaning towards valproate

Results

More 'X's' this side
Leaning towards changing medication

Your doctor will talk to you about staying on valproate or changing medication. Switching to other medication may be better for some medical conditions such as focal epilepsy, bipolar disorder, or migraine.

You continue to take valproate

(Sodium valproate, Valproic acid, Epilim, Epilim Chrono, Epilim Chronosphere, Episenta, Epival, Convulex, Syonell, Belvo, Orlept, Depakote, Dyzantil, Depakin)

You change medication

(Carbamazepine, phenobarbital, phenytoin, lamotrigine (Lamictal), levetiracetam (Keppra) topiramate), pregabalin

Benefits to you

- Your seizure control remains the same
- If you are able to drive, this will continue
- Your normal lifestyle can continue
- Valproate may be the best drug to control your type of epilepsy

- You may lose weight
- You may be less sedated
- If you have a tremor it may resolve
- Your periods might become more regular
- If you are considering pregnancy, different medication may have lower risk to a baby. **See details below**

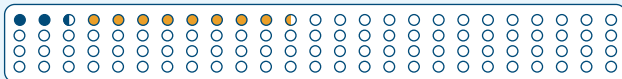
Risks to you

- Valproate may not be controlling your seizures well
- You may experience side effects of valproate: excessive weight gain, tremor, memory problems, irregular periods, infertility
- You **must** use a highly effective form of contraception and some of these carry their own risks
- Being advised not to become pregnant may be important to your sexual partners as well

- Your seizures may increase
- This could affect your work and home life
- Increased seizures could put you more at risk from accidents, drowning or SUDEP (explained below)
- You will have to stop driving during the period of medicine withdrawal, and for 6 months after the withdrawal is complete
- It may take many months to switch over
- If valproate is started again it may not work as well as it did before
- Every drug has its own side effects

Risk of multiple major birth defects

For women not on valproate, **2 – 3 in every 100** babies tend to be born with these birth defects, **97 – 98** are not. For women on valproate, an extra **8 – 9 in every 100** of their babies tend to be born with these birth defects.



Lamotrigine and levetiracetam affect around **2 in every 100** pregnancies. This is the same as for the general population of non-epileptic women who are not on medication. Carbamazepine, Phenobarbital, Phenytoin, Topiramate, Pregabalin affects an extra **1 – 4 out of every 100** pregnancies.



Risk of multiple developmental problems

For women not on valproate, **3 in 100** tend to be born with developmental problems, **97** are not. For women on valproate, at least extra **37 in 100** of their babies tend to be born with these problems.



The MHRA (medicines regulator) says with current data:
Carbamazepine, lamotrigine, levetiracetam – no increased risk of developmental problems
Phenobarbital, phenytoin, topiramate – some low quality evidence suggesting an increased risk
Gabapentin, oxcarbazepine, pregabalin, zonisamide – we do not yet have evidence about risk of developmental problems
More data could change advice on all these drugs.

SUDEP – (Sudden Unexpected Death in Epilepsy)

This is where some people with epilepsy die suddenly and prematurely of no clear cause or reason. There are around 600,000 people with epilepsy in the UK, sadly around 1000 of these die each year due to epilepsy (so around 599,000 do not die). Half of these deaths are due to SUDEP, half are due to other causes.

Whilst the causes of SUDEP are not clear, uncontrolled epilepsy or changing medication may put you more at risk. **The best way to lower risk of SUDEP is to control seizures. Talk about SUDEP to your neurologist or specialist to help you assess your risk.**

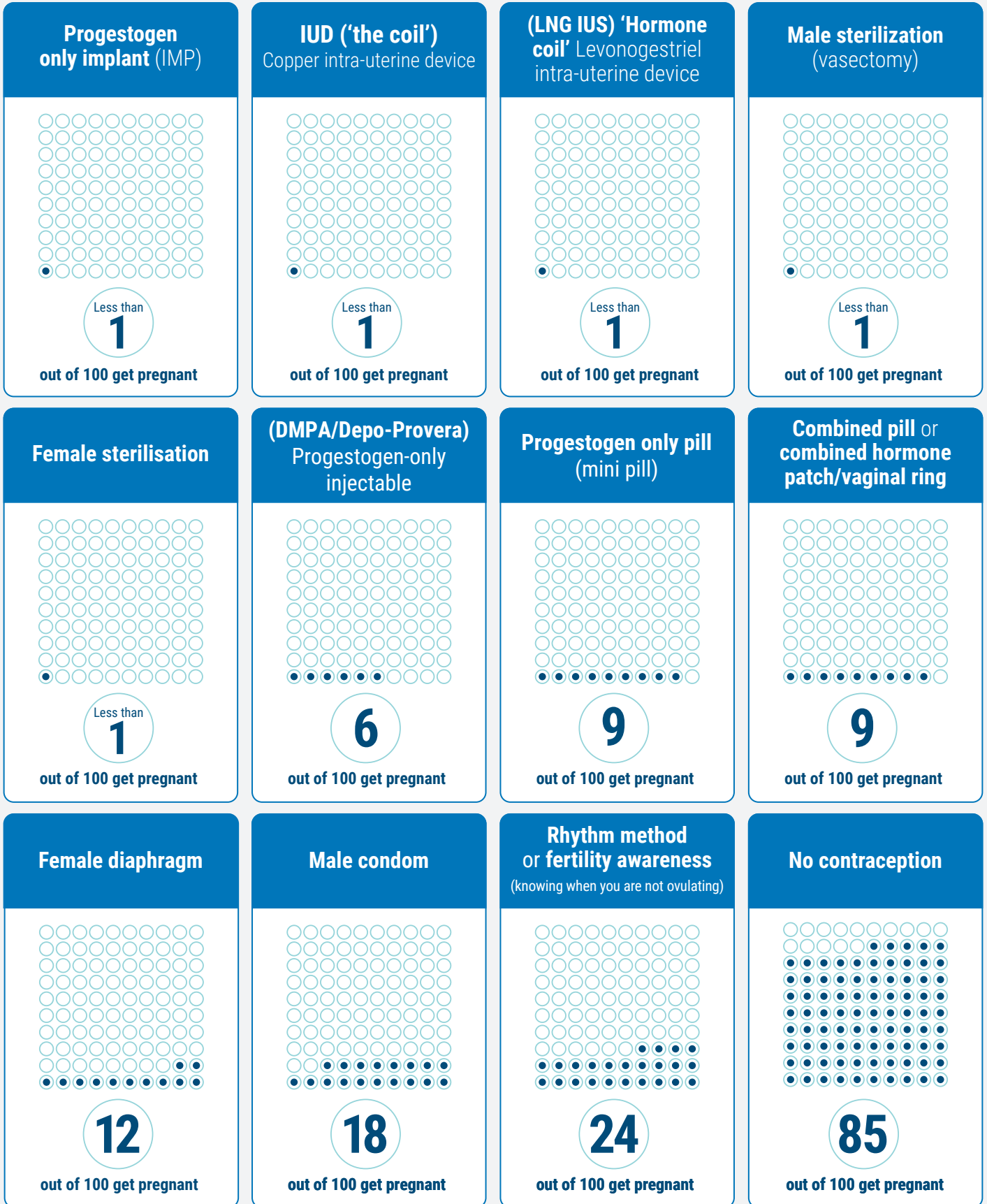
Developmental problems Includes; learning to walk & talk later than normal, lower intelligence than children of the same age, poor speech & language skills, memory problems, increased risk of autism or ADHD, behaviour problems that don't always respond to treatment.
Birth defects Includes; Spina bifida, cleft palate; malformed limbs, heart, kidney, urinary tract or sexual organs; hearing problems, deafness.

How effective is your contraception?

No contraception is 100% effective.

Highly effective means a risk of less than 1 out of every 100 women would get pregnant in a year.
Talk to your doctor or healthcare provider about choosing a suitable contraception for you.

How many women, out of every 100, would get pregnant in one year if they used in a typical way:



Making the decision

Do you feel sure about whether to stay on valproate or switch medicine? Yes No

Do you know the risks and benefits of each option? Yes No

Are you clear about which risks and benefits matter most to you? Yes No

Do you have enough support or advice to make a choice? Yes No

If you answered 'No' to any of these, talk to your healthcare team about your questions or concerns.

Questions for your specialist

Next appointment

Where/who

Telephone

Contacts

	Name	Telephone
GP		
Specialist		
Specialist Nurse		
Other		

Where did we get our numbers from?

SUDEP information:

Study looking at 255 SUDEP cases (2020): <https://doi.org/10.1212/WNL.00000000000008741>

Valproate and other drug risks: MHRA Report:

<https://bit.ly/36YIOaA>

Population cohort study from Denmark:

<https://doi.org/10.1136/bmj.o1010>

Contraception data:

<https://www.nhs.uk/conditions/contraception/how-effective-contraception/>

Risk in the general population:

Public Health England Report on how many babies are born with birth defects: <https://bit.ly/3LM3oK3>