

Patient Decision Support Leaflet

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## Making a Decision About Valproate



Is Valproate the Right  
Epilepsy Treatment for Me?

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## What is this leaflet?

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This patient decision support leaflet is for women, girls, people assigned female at birth, and people who could become pregnant aged between 12-55 who are thinking about taking valproate for epilepsy. It can help you decide if valproate is the right medicine for you.

The information in this leaflet is important because you should not get pregnant if you are taking valproate. If you take valproate when you are pregnant, it can seriously harm your baby.

This leaflet provides information, not advice. It is not intended to replace your epilepsy specialist's advice about valproate or any other anti-seizure medications.

**This leaflet is designed for you to work through. There are spaces in the leaflet for you to make notes and write down any questions you may have. You can then take the leaflet with you to your next epilepsy appointment to help you talk with your epilepsy specialist or someone from your epilepsy team about how you feel about taking valproate. At your appointment, you can ask any questions you have, so that you can make a decision together that is right for you.**

The leaflet may also be helpful if you want to talk about valproate with your family, partner, or friends.

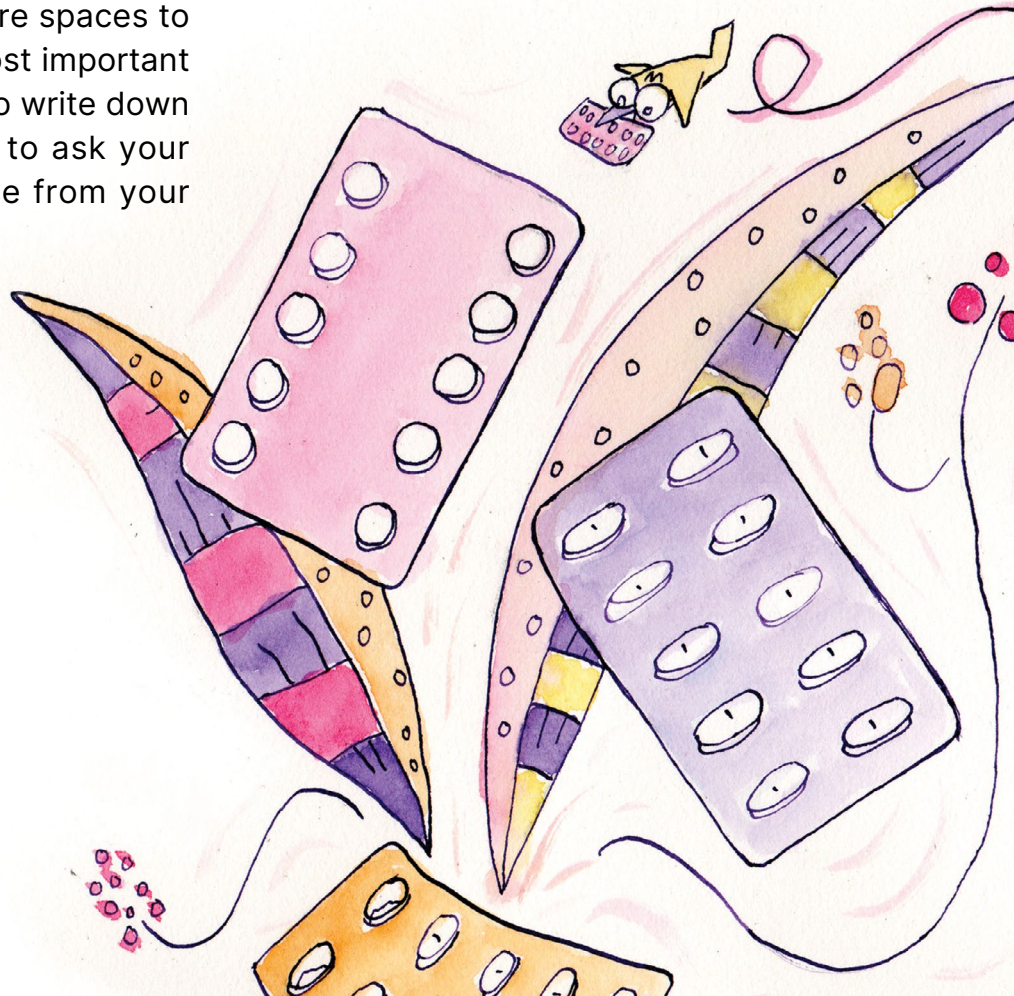
- **Pages 1 - 8:** About valproate
- **Pages 9 - 13:** More about the benefits and risks of valproate
- **Pages 14 - 21:** The Valproate Pregnancy Prevention Programme and highly effective contraception
- **Pages 22 - 24:** Planning for pregnancy (if a future reproductive health goal)
- **Pages 25 - 29:** Thinking about what is important to you
- **Page 30:** Planning for your next epilepsy appointment
- **Page 31:** Where more information can be found and contact details of patient support groups

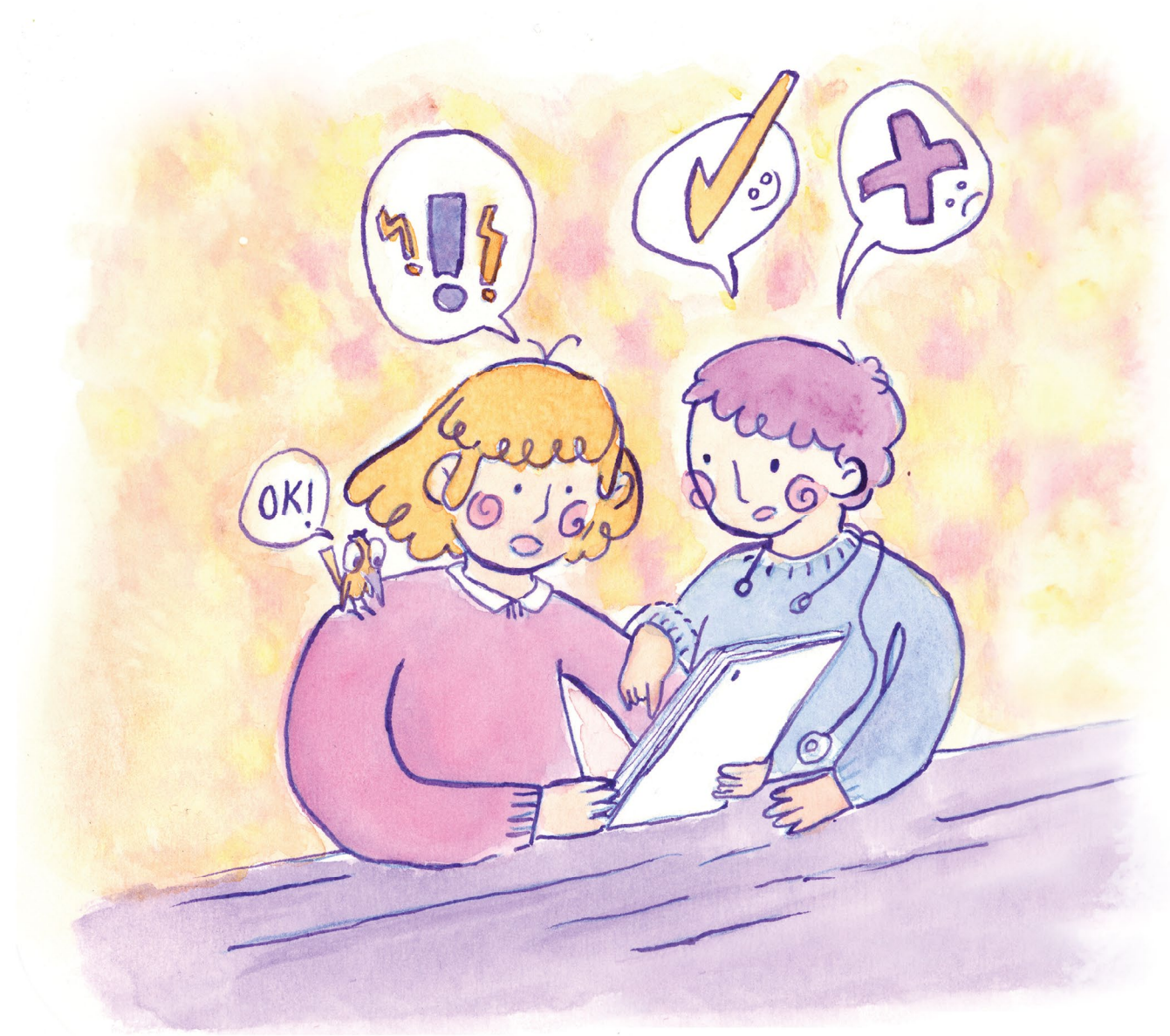
Throughout the leaflet, there are spaces to write down what you feel is most important to you. There are also spaces to write down any questions you would like to ask your epilepsy specialist or someone from your epilepsy team.

In January 2024, the Medicines and Healthcare products Regulatory Agency (MHRA) gave healthcare organisations new guidelines on the prescribing of valproate which state:

- *Valproate must not be started in new patients (male or female) younger than 55 years unless two specialists independently agree that there is no other suitable treatment,*
- *At their next annual specialist review, female patients of childbearing potential and girls of any age should be reviewed using the latest valproate Annual Risk Acknowledgement Form. This includes the need for a second specialist to agree that valproate is the most suitable treatment if the patient is to continue with valproate.*

**For many patients, other effective anti-seizure medications are available.**





## Who is this leaflet for?

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This leaflet is for you if you are a woman, girl, were assigned female at birth, or someone with pregnancy potential and are thinking about valproate as a treatment option for epilepsy.

This leaflet is not intended for people who are pregnant.

If you are taking valproate and are pregnant or think you may be pregnant, please contact your GP or epilepsy team immediately for a same-day urgent appointment.

Please don't worry. You are not alone. Your doctor will help you decide what to do next.

Tell the receptionist that you urgently need to speak to a doctor that same day because you are taking valproate and think you might be pregnant.

Do not stop taking valproate or any other anti-seizure medication unless your GP or epilepsy specialist tells you to.

Your epilepsy specialist will be able to answer any questions you have about valproate.



## Thinking about valproate, what is right for you?

Your decision whether valproate is the right treatment option for you will depend on several things. This leaflet will help explain some of the things to think about when deciding whether valproate is the right anti-seizure medication for you.

The information in this leaflet is important because you must not get pregnant when taking valproate. If you take valproate when you are pregnant, it can harm your baby in two ways:

- Major birth defects and/or
- Developmental disorders

Everybody's epilepsy is different, and everybody's reproductive healthcare goals, values and choices are different. For many people, planning for pregnancy or using contraception to avoid pregnancy is an important part of their reproductive healthcare.

This leaflet will help you to think about your reproductive healthcare goals, values and preferences, such as if you want to get pregnant in the future or how you feel about using highly effective contraception.

If you are aged between 12 and 55 years, are able to get pregnant and take valproate, you will also have to make decisions about your reproductive healthcare to prevent pregnancy for the entire duration of your valproate treatment (and until your epilepsy specialist agrees that it is safe to get pregnant if pregnancy later becomes a reproductive health goal for you).

When thinking about valproate, you may feel that some things are more important to you than others. This leaflet will help you think about how valproate could affect your epilepsy and reproductive healthcare so you can talk to your doctor about what matters to you most.

Your epilepsy specialist should only prescribe sodium valproate if no other anti-seizure medicine works and if you and your epilepsy specialist have decided together that this is the best treatment for you.

Your epilepsy anti-seizure medication needs, or reproductive healthcare goals may change over time. Please keep this leaflet where you can easily find it to review your decision should your reproductive healthcare goals change in the future.

## Is valproate the right epilepsy treatment for me?

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You may know valproate by other names including sodium valproate, valproic acid, *Epilim*, *Epilim Chrono*, *Epilim Chronosphere*, *Episenta*, *Epival*, *Convulex*, *Orlept*, *Dyzantil* or *Depakin*.

Your epilepsy specialist can help you decide if valproate is the right anti-seizure medication for you. Please work through this leaflet, then take it with you to speak to your epilepsy specialist about your options.

### Important information:

You must not get pregnant if you take valproate. Valproate can seriously harm an unborn baby.

At your next appointment, you can ask your epilepsy specialist any questions you may have about valproate and how it might affect your reproductive health.



## What questions can I ask?

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It might help you to think of these 3 questions as you work through this leaflet:

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

Never stop taking valproate or any anti-seizure medication unless agreed with your doctor. Suddenly stopping your anti-seizure medication could result in life-threatening seizures.



## What are the risks?

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**Taking valproate during pregnancy can seriously harm an unborn baby.**

Approximately 1 in 9 babies (11%) exposed to valproate during pregnancy are born with major birth defects, and up to 4 in 10 babies (40%) will have lifelong developmental problems, including learning difficulties and/or autism.

If you were assigned female at birth, are taking valproate, are aged between 12 and 55 years, and are able to become pregnant, you will need to meet the requirements of the Pregnancy Prevention Programme.

You can read more about the Valproate Pregnancy Prevention Programme at [www.medicines.org.uk/emc/rmm/1204/Document](http://www.medicines.org.uk/emc/rmm/1204/Document)

If you are taking valproate and have started having periods, you will need to use highly effective contraception. You may need to use highly effective contraception even if you are not currently sexually active.

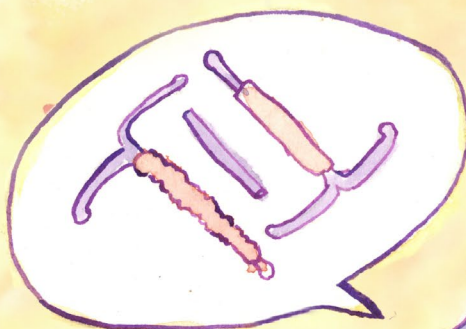
**Pages 12 - 13 have more information on the risk of major birth defects and developmental problems.**

## What is highly effective contraception?

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Methods of contraception are considered to be 'highly effective' if fewer than 1 in 100 sexually active females would get pregnant each year when using the contraception. There are different types of highly effective contraception. You can decide which option may suit you best.

**Pages 14 - 21 have more information on highly effective contraception options and the Pregnancy Prevention Programme.**





## Why is this information important to me?

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For many people, their reproductive health is an important part of their overall health. Taking contraception to avoid pregnancy or planning to have a baby is an important part of reproductive health.

This leaflet can help you think about your reproductive health and what is most important to you when thinking about valproate.

If you take valproate and you later decide that you want to get pregnant, you will need to speak to your epilepsy specialist about changing anti-seizure medication. If you choose to have a baby in the future, you will need time to plan to change your anti-seizure medication before it is safe to get pregnant.

**Pages 22 - 24** have more information on planning for pregnancy (if this is a future reproductive health goal for you).



## What are the benefits and risks of valproate?

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All medicines have potential benefits (pros) and risks (cons). There are benefits and risks to taking valproate.

The main benefit is that valproate is a highly effective anti-seizure medication. For some individuals, it is the only effective treatment for their epilepsy.

The main risk with valproate is that approximately 11% of babies born to people who use valproate during pregnancy will be born with birth defects, and/or up to 40% will have lifelong developmental problems, including learning difficulties and/or autism.

Your baby could be harmed by valproate at any time during pregnancy, even in the very early days and weeks of pregnancy, before you even know you are pregnant.



## What are the benefits of valproate to you, and how do they compare to the benefits of other anti-seizure medications to you?

| Benefits (pros) to you taking valproate  | Benefit (pros) to you taking another anti-seizure medication that is not valproate  |
|--|---|
| <ul style="list-style-type: none"> <li>• If you currently take valproate and continue to take valproate, your seizure control will likely stay the same.</li> <li>• If you currently take valproate and can drive, you should be able to continue driving.</li> <li>• If you currently take valproate, your usual lifestyle is not likely to change.</li> <li>• If you currently take another anti-seizure medication that is not controlling your seizures and you start to take valproate, your seizure control may improve.</li> <li>• Valproate may be the best anti-seizure medication to control your type of epilepsy.</li> </ul> | <ul style="list-style-type: none"> <li>• A different medication may have a lower risk of harming an unborn baby.</li> <li>• The risk of harm to an unborn baby from valproate is higher than with other anti-seizure medicines, apart from some anti-seizure medications where the risk is unknown. Please speak to your epilepsy specialist about alternative anti-seizure medications and how the risks in pregnancy compare.</li> <li>• If you have irregular periods while taking valproate, they may become more regular if you take an alternative anti-seizure medication.</li> <li>• If you have gained weight when taking valproate, you may lose weight if you change to a different anti-seizure medication.</li> <li>• If you have experienced valproate-related tremors or unusual eye movements these may resolve.</li> <li>• If you take valproate and feel sedated, you may feel less sedated on an alternative anti-seizure medication.</li> <li>• If you have experienced other side effects of valproate (which can include feeling or being sick, stomach pain, diarrhoea, sore mouth or swollen gums, memory problems, headaches, hair thinning or changes in hair colour or texture) these may improve with a different anti-seizure medication.</li> </ul> |



## What are the risks of valproate, and how do they compare with the risks of other anti-seizure medications?

| Risks (cons) to you if you take valproate   | Risks (cons) if you choose to take a different medication  |
|---|--|
| <p><b>Thinking about the main risks</b></p> <ul style="list-style-type: none"> <li>You must not become pregnant when you are taking valproate because it can seriously harm a baby before it is born.</li> <li>You must use a form of highly effective contraception, which may carry its own risks and benefits.</li> </ul> <p><b>Thinking about other risks</b></p> <ul style="list-style-type: none"> <li>You may experience weight gain when you start taking valproate.</li> <li>You may get a tremor in part of your body or unusual eye movements.</li> <li>You may experience side effects from taking valproate, including feeling or being sick, stomach pain, diarrhoea, dry or sore mouth or swollen gums, tremors (or shakes) in part of your body, or unusual eye movements, memory problems, feeling tired or sleepy, headaches, weight gain, hair thinning or changes in hair colour or texture, irregular or delayed periods.</li> <li>In rare cases, valproate may increase your risk of polycystic ovary syndrome (PCOS), which can reduce fertility.</li> </ul> | <ul style="list-style-type: none"> <li>Other anti-seizure medications may also harm an unborn baby. Please ask your epilepsy specialist for up-to-date advice and risk information on alternative anti-seizure medications.</li> <li>If you currently take valproate and change anti-seizure medication, your seizures may increase.</li> <li>If you currently take valproate and drive, you will need to stop driving if you change to a new anti-seizure medication. You will need to be seizure-free for at least 6 months on any new anti-seizure medication before you can drive again.</li> <li>If you currently take valproate and change anti-seizure medication, your work and home life could be disrupted by increased seizures.</li> <li>If you change anti-seizure medication and your seizures are not controlled while you change medications, you may be at more risk of accidents, injury or rarely death. See page 28 for information about Sudden Unexplained Death in Epilepsy (SUDEP).</li> <li>It may take several months to change anti-seizure medication and regain seizure control.</li> <li>All anti-seizure medications can cause unwanted side effects. Other anti-seizure medications may have side effects such as tiredness, mood change, headaches.</li> <li>If you stop taking valproate and then decide to use it again, it may not control your seizures as well as it did in the past.</li> </ul> |



**Risk of developmental problems  
(out of every 100 babies born)**

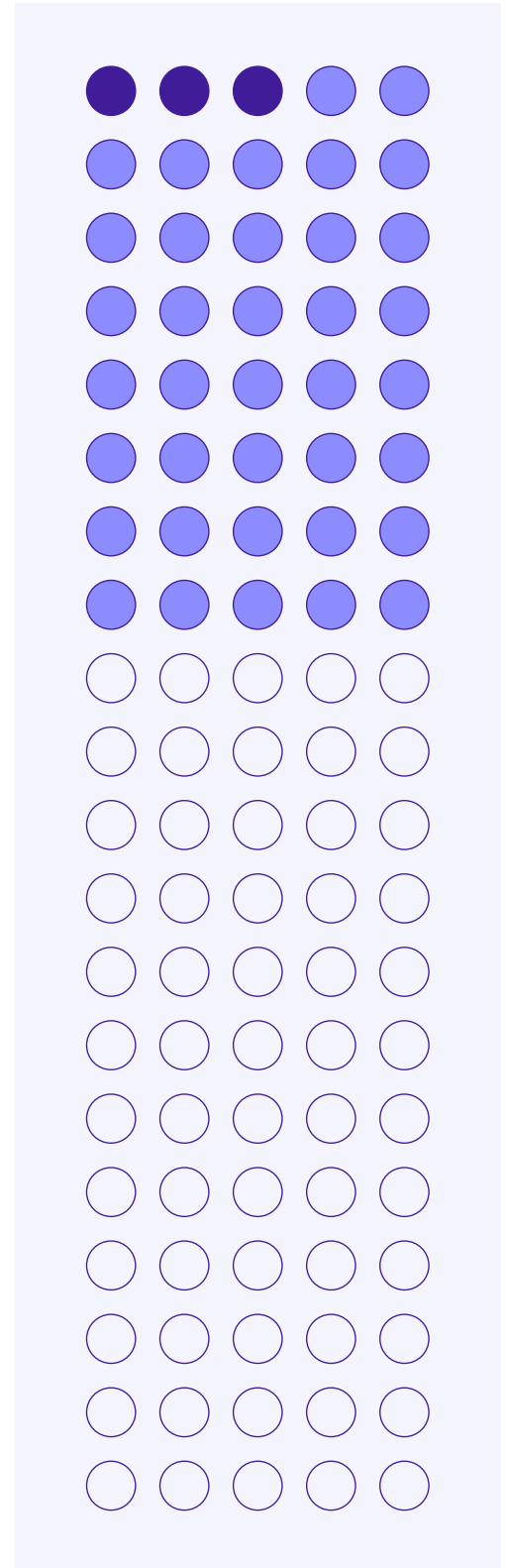
In the general population, around **3 in every 100** babies born will have developmental problems. This means that around 97 babies are not.

When valproate is used during pregnancy, up to **40 in every 100** babies born will have developmental problems. This means approximately 60 babies will not be diagnosed with a developmental problem.

An extra **37 in every 100** babies born to people who took valproate when they were pregnant will be diagnosed with developmental problems.

Developmental problems may include:

- Being late in learning to walk and talk
- Lower intelligence than other children of the same age
- Poor speech and language skills
- Memory problems
- Autism or autistic spectrum disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Attention Deficit Disorder (ADD)
- Lifelong learning problems



Babies exposed to valproate during pregnancy may be born with a complex range of both physical birth defects and developmental disorders that can lead to life-long disability.



## So, what decision do you need to make?

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**Option One:** Start taking valproate

**Option Two:** Continue to take valproate

**Option Three:** Change to a different anti-seizure medication

If you decide to take valproate, you will need to use **highly effective contraception** and be enrolled on the **Pregnancy Prevention Programme**.

## What is the Pregnancy Prevention Programme?

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If you are prescribed valproate, your epilepsy specialist will tell you about the Pregnancy Prevention Programme and the importance of using highly effective contraception.

Highly effective contraception means contraception methods that have a very low failure rate when used correctly. With correct use, fewer than 1 in 100 sexually active females will get pregnant each year when using highly effective contraception.

Some examples of highly effective contraception include:

- the implant
- the intrauterine system (IUS or hormone coil, e.g., Mirena coil)
- the intrauterine device (IUD or copper coil)

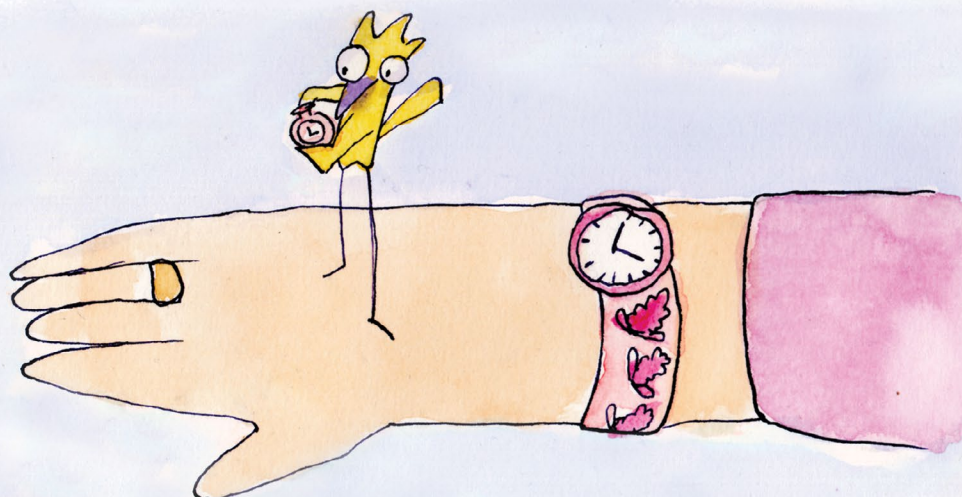
The pill or a barrier method such as condoms, diaphragms or caps alone are not as effective at preventing pregnancy as highly effective contraception. If used alone, the pill or barrier methods are not suitable forms of contraception for someone taking valproate.

Female sterilisation is a permanent form of contraception. You should not consider female sterilisation if you think you may want to get pregnant in the future.

Please talk to your epilepsy specialist or epilepsy team about valproate and your reproductive health goals and preferences. Your reproductive goals may change over time. It is important to speak to your epilepsy specialist or team to plan for pregnancy well before getting pregnant. If you take valproate and decide you want to have a baby in the future, you will need time to change anti-seizure medication before it would be safe to get pregnant.

If you decide you want to have a baby in the future, other anti-seizure medications will have a lower risk of harm for a baby.

You can read more about the Pregnancy Prevention Programme here: [www.medicines.org.uk/emc/rmm/1204/Document](http://www.medicines.org.uk/emc/rmm/1204/Document)



## How effective is your contraception?

No contraception is 100% effective. Highly effective contraception means a risk of less than 1 out of every 100 sexually active women would get pregnant in a year if using this method. Talk to your epilepsy specialist or someone from your epilepsy team about choosing a suitable highly effective contraception for you.



## What is the right highly effective contraception for me?

The most reliable reversible methods of contraception are:

- The implant
- Intrauterine system (IUS or hormonal coil, e.g., Mirena coil)
- Intrauterine device (IUD or the copper coil)

You do not have to remember to take or use these methods.

You can use the implant, IUS or IUD even if you have never been pregnant, had a baby, or are not currently sexually active.

The implant is suitable if you are taking valproate on its own. However, the contraceptive implant might not be suitable if you are taking certain other anti-seizure medications in addition to valproate.

Please talk to your epilepsy team or GP to discuss highly effective contraception.

**Important: the above contraceptive methods will not protect you against sexually transmitted infections. Condoms are the only methods of contraception that help protect you from sexually transmitted infections (STIs).**

## Are there any questions you want to ask your epilepsy team or GP about highly effective contraception?

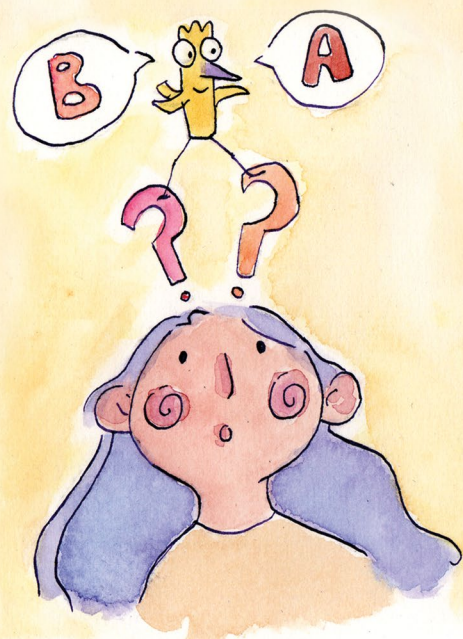
It might help you to think of these 3 questions about highly effective contraception:

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me now?

It might help to think about your reproductive health goals and what they are at this stage in your life.

Your reproductive goals may change over time. If you think you might want to have a baby in the future, talk to your epilepsy specialist or epilepsy team now. They can tell you more about epilepsy and planning for a baby in the future.

You can find out more about contraception on the NHS website at: [www.nhs.uk/conditions/contraception/](http://www.nhs.uk/conditions/contraception/)



## What is the most appropriate highly effective contraception option if I am taking valproate?

The following table can help you to think about your choices for highly effective contraception. The highly effective contraception options table lists contraception that is suitable for females when taking valproate.

It can help you compare the benefits and risks of each option. You can use the table before your appointment or with your epilepsy specialist.

| Highly Effective Contraception Options |  |  |   |  |
|--|--|--|---|--|
| Highly Effective Contraception Option  | Implant  | Intrauterine system (IUS or Hormonal Coil e.g., Mirena)  | Intrauterine Device (IUD or Copper Coil)  | Female Sterilisation   |
| Typical use effectiveness              | 99% effective  | 99% effective  | 99% effective   | 99% effective  |
| How long does it last?                 | Up to 3 years  | 5 years or 3 years, depending on the brand   | 5 to 10 years, depending on the brand   | Permanent  |
| Who can use this method?               | <p>The contraceptive implant may not be suitable for everyone. It might not be suitable for you if you have:</p> <ul style="list-style-type: none"> <li>cardiovascular disease (a condition affecting your blood vessels or heart) or have had a stroke</li> <li>liver disease</li> <li>breast cancer or have had it in the past</li> <li>unexplained vaginal bleeding between periods or after sex</li> </ul> <p>The implant can be used at any age. It is often suitable for people who can not use contraception that contains oestrogen.</p> <p>However, while the implant is safe to use with valproate, some alternative anti-seizure medications may reduce the effectiveness of the implant.</p> | <p>Most people with a womb can use an IUS. It is not affected by other medicines.</p> <p>The IUS may not be suitable if you have:</p> <ul style="list-style-type: none"> <li>breast cancer, or have had it in the past 5 years</li> <li>uterus (womb) cancer or cervical cancer</li> <li>liver disease</li> <li>unexplained vaginal bleeding between periods or after sex</li> <li>arterial disease or a history of heart disease or stroke</li> <li>an untreated sexually transmitted infection (STI) or pelvic infection</li> <li>problems with your womb or cervix</li> </ul> | <p>Most people with a womb can use an IUD. The IUD may not be suitable if you:</p> <ul style="list-style-type: none"> <li>think you might be pregnant</li> <li>have an untreated STI or a pelvic infection</li> <li>have problems with your womb or cervix</li> <li>have unexplained bleeding between periods or after sex</li> <li>People who have had an ectopic pregnancy or who have an artificial heart valve must consult their GP or clinician before having an IUD fitted.</li> </ul> | <p>Almost anyone with pregnancy potential can be sterilised, but it should only be considered by people who do not want any more children or do not want children at all.</p> <p>Once someone is sterilised, it's very difficult to reverse it, so consider all options before making your decision.</p> <p>Sterilisation reversal is not usually available on the NHS.</p> <p>Individual risks of surgery should be discussed with a healthcare practitioner.</p> |

| Highly Effective Contraception Options |   |  |  |  |
|--|---|--|--|--|
| Highly Effective Contraception Option  | Implant   | Intrauterine system (IUS or Hormonal Coil e.g., Mirena)  | Intrauterine Device (IUD or Copper Coil)   | Female Sterilisation   |
| How do you get started?                | <p>You can get a contraceptive implant fitted for free at:</p> <ul style="list-style-type: none"> <li>• Contraception clinics</li> <li>• Sexual health or genitourinary medicine (GUM) clinics</li> <li>• GP surgeries</li> </ul>   | <p>You can get an IUS fitted for free at:</p> <ul style="list-style-type: none"> <li>• Contraception clinics</li> <li>• Sexual health or genitourinary medicine (GUM) clinics</li> <li>• GP surgeries</li> </ul>   | <p>You can get an IUD fitted for free at:</p> <ul style="list-style-type: none"> <li>• Contraception clinics</li> <li>• Sexual health or genitourinary medicine (GUM) clinics</li> <li>• GP surgeries</li> </ul>   | <p>Female sterilisation involves an operation to permanently prevent pregnancy. You would need to make an appointment with your GP and ask to be referred for a consultation with a gynaecologist who would discuss the procedure with you. It is important to make sure it is the right permanent method of contraception for you.</p>  |
| What is it?                            | <p>The implant is made from soft plastic that is put under the skin of the inside upper arm. It releases the hormone progestogen.</p> <p>A local anaesthetic is used to numb the inside of the upper arm, and a specially trained doctor or nurse will insert the implant.</p> <p>It can last for 3 years but can easily be removed by a specially trained doctor or nurse at any time.</p> | <p>The IUS (or hormonal coil) is made of plastic and releases the hormone progestogen.</p> <p>It is placed in the womb by a specially trained doctor or nurse.</p> <p>It can last for 3 or 5 years, depending on the brand, but a specially trained doctor or nurse can remove it at any time.</p> | <p>The IUD (or copper coil) is made of plastic and copper. The IUD does not contain any hormones.</p> <p>It is placed into the womb by a specially trained doctor or nurse.</p> <p>It can last for 5 or 10 years, depending on the brand, but can be removed by a specially trained doctor or nurse at any time.</p> | <p>Female sterilisation is performed surgically during an operation.</p> <p>It involves either a general anaesthetic, where you would be asleep for the procedure or a local anaesthetic, where you would be awake but not feel any pain.</p> <p>The fallopian tubes are blocked, tied or cut to prevent the eggs from reaching the sperm and becoming fertilised.</p> <p>Female sterilisation is a permanent form of contraception.</p> |
| What do you need to do once fitted?    | Nothing. No action is needed for 3 years.   | Nothing. No action is needed for 3 or 5 years depending on the brand.  | Nothing. No action is needed for 5 or 10 years depending on the brand.   | Nothing. No action is needed. It is a permanent form of contraception.   |
| Possible bleeding changes              | Your periods may become lighter, heavier, longer or irregular, or your periods may stop   | Your periods may become lighter, shorter and less painful. They may stop after the first year of use.  | Your periods may become heavier, longer or more painful in the first 3 to 6 months of use. You might get spotting or bleeding between periods.   | There may be some slight vaginal bleeding after the procedure. Periods will remain the same.   |

| Highly Effective Contraception Options  |   |   |   |  |
|---|---|---|---|--|
| Highly Effective Contraception Option   | Implant   | Intrauterine system (IUS or Hormonal Coil e.g., Mirena)   | Intrauterine Device (IUD or Copper Coil)  | Female Sterilisation   |
| <p><b>Possible side effects</b></p> <p>Common side effects affect between 1-in-10 and 1-in-100 people using the contraception.</p> <p>Uncommon side effects affect between 1-in-100 and 1-in-1000 people using the contraception.</p> | <p>Common temporary side effects may include headaches, nausea, breast tenderness and mood swings. These should settle within a few months.</p> | <p>Common temporary side effects include headaches, acne and breast tenderness. Some people experience mood swings. These should settle within a few months.</p> <p>There is a small chance that an IUS will be rejected or expelled from the womb (expulsion) or that it will move from its set place in the womb (displacement).</p> <p>Expulsion is one of the more common complications and can occur in 5% of people using an IUS.</p> <p>An uncommon side effect of the IUS is that some people can develop small fluid-filled cysts on the ovaries. These usually disappear without treatment.</p> | <p>There are no hormonal side effects, such as acne, headaches or breast tenderness.</p> <p>There is a small chance that an IUD can be rejected or expelled from the womb (expulsion), or it could move from its set place in the womb (displacement).</p> <p>Expulsion is one of the more common complications and can occur in 5% of patients using an IUD.</p> | <p>After a general anaesthetic, it is normal to feel unwell or uncomfortable for a few days. Patients usually return to work 5 days after the procedure but must avoid heavy lifting for about a week. There may be some slight vaginal bleeding and some pain, like period pain. You can take painkillers for this.</p> |
| <p><b>If stopped, when can you get pregnant?</b></p>  | <p>Your fertility will return to normal as soon as the implant is removed.</p>  | <p>Your fertility will return to normal as soon as the IUS is removed.</p>  | <p>Your fertility will return to normal as soon as the IUD is removed.</p>  | <p>This is a permanent method of contraception and should not be considered if you think there is any chance you may want to get pregnant in the future.</p>   |

The pill or a barrier method such as condoms, diaphragms or caps used alone are not as effective at preventing pregnancy as highly effective contraception. If used alone, the pill or barrier methods are not suitable forms of contraception for someone taking valproate.

**Important:** the above contraceptive methods will not protect you against sexually transmitted infections (STIs). Condoms (external condoms and internal condoms) are the only methods of contraception that help protect you from STIs.

If you do not want to use a highly effective form of contraception listed above, please talk to your epilepsy team (which may include your epilepsy specialist, GP, or sexual health clinic) about your contraception options.

You can find out more about contraception on the NHS website at: [www.nhs.uk/conditions/contraception/](http://www.nhs.uk/conditions/contraception/)



## Do you think you might want to get pregnant in the future?

If you take valproate and later decide that you want to get pregnant, you will need to speak to your epilepsy specialist or someone from your epilepsy team about planning for pregnancy. You will need to plan for pregnancy well before getting pregnant. If you decide to have a baby in the future, you will need time to make changes to your anti-seizure medication before it is safe to get pregnant. You should start having this discussion as soon as possible, as it may take some time to safely change anti-seizure medications.

### How long before having a baby do you need to start thinking about planning for pregnancy?

If you take valproate and you later decide you want to get pregnant, you will need time to take the following steps:

1. You will need time to make an appointment with your epilepsy specialist to plan for pregnancy. This will include discussing your anti-seizure medication changes. Please note there may be a waiting list to see an epilepsy specialist in your area to plan for pregnancy.
2. You will need time to change anti-seizure medications to one that is safer to use during pregnancy. This may involve the gradual reduction of valproate and the gradual introduction of an alternative anti-seizure medication. This process may take several weeks or months to complete.
3. You will need to allow time for the new anti-seizure medication to work. You may need several months of good seizure control before it is safe to get pregnant.
4. You will need time to plan for a healthy pregnancy (e.g. take folic acid well before conception, stop smoking if you smoke, cut down or stop drinking if you drink, review any additional long-term health conditions you may have, stop using any illegal drugs if you take illegal drugs, lose weight if you are overweight, increase weight if you are underweight etc.).
5. Depending on the method of contraception used while taking valproate, you may need time for your fertility to return to usual.
6. You may need time to try for a baby before you conceive.



If you take valproate and you later decide you want to plan for a baby, some of these steps may happen together, but you will need plenty of time to prepare for a safe pregnancy.

Please talk to your epilepsy specialist or someone in your epilepsy team about your treatment options and treatment planning as soon as you start thinking about having a baby. They will tell you how long before pregnancy you will need to begin planning anti-seizure medication changes.

Remember, you must not get pregnant if you are taking valproate.

Never stop taking valproate or any other anti-seizure medication unless agreed with your epilepsy specialist



## Are there any questions you want to ask your epilepsy specialist or team?

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Space to think... Thinking ahead: your reproductive healthcare goals may change over time.

Questions I would like to ask my epilepsy specialist or team about valproate, especially when I am thinking about my reproductive healthcare goals:

For example:

- How long would I have to wait to speak to my local epilepsy specialist for advice about planning for pregnancy?
- How long before having a baby should I start thinking about planning for pregnancy?
- What alternative anti-seizure medications would be available for me if I decide I want to have a baby in the future?
- How long before pregnancy would I need to switch medications for it to be safe to get pregnant?

It may also help to think of the following 3 questions:

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me now?





## What is important to you?

Your feelings are important and can help you decide which anti-seizure medication is best for you. You may want to complete this section with your epilepsy specialist, someone else from your epilepsy team, your partner, a close friend or relative, or on your own.

Thinking about what's important to you, tick the option that best shows how you feel about the following:

**Having the choice to become pregnant soon (if this is a reproductive health goal for this stage of your life):**

- Very important
- Important
- Moderately Important
- Not very Important
- Not Important at all

**Avoiding unplanned pregnancy:**

- Very important
- Important
- Moderately Important
- Not very Important
- Not Important at all

**Making sure my seizures are well-controlled:**

- Very important
- Important
- Moderately Important
- Not very Important
- Not Important at all

**Being able to continue driving (if applicable):**

- Very important
- Important
- Moderately Important
- Not very Important
- Not Important at all

**Other (Please use this space to write anything that is important to you)**

## Thinking about valproate and your reproductive health, what's important to you?

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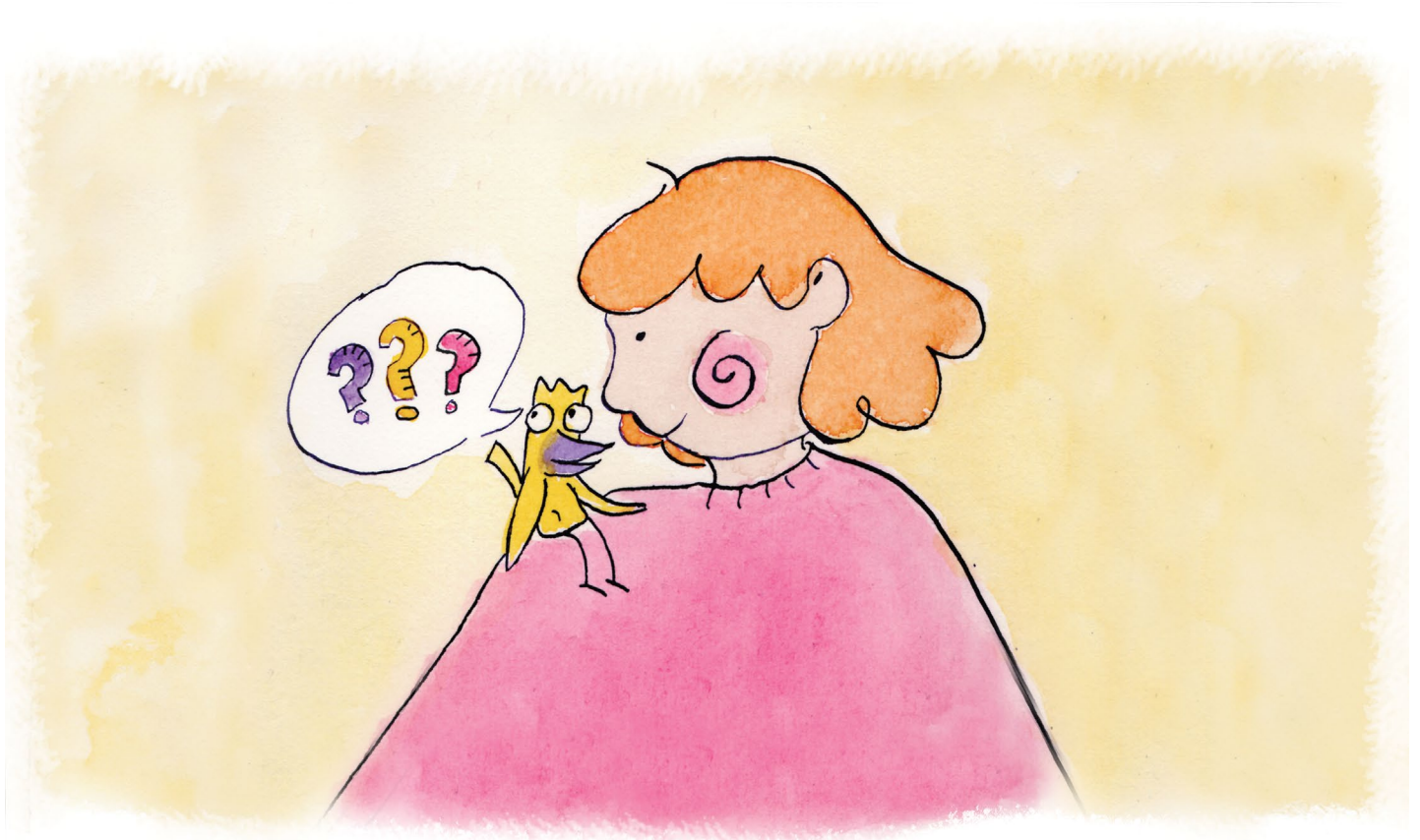
Your reproductive health goals, values and choices are important. They can help you decide if valproate is the best anti-seizure medication for you.

Do you have any questions about valproate and your reproductive health that you want to ask your epilepsy specialist?

Please write your questions here and take this leaflet to your next appointment. You can then talk to your epilepsy specialist or epilepsy team about any questions you have.



**My questions:**



## How do you feel about taking valproate as a treatment for epilepsy?

Tick the option you prefer.

- I would prefer to take valproate
- I'm still not sure
- I would rather not take valproate

### How do you feel about using highly effective contraception?

- I would not mind using highly effective contraception
- I am not sure how I feel about using highly effective contraception and need more information
- I would not want to use highly effective contraception

Please talk to your epilepsy specialist or epilepsy team about how you feel about taking valproate to treat your epilepsy and how you feel about using highly effective contraception.

You may want to ask your epilepsy team, epilepsy specialist or GP questions about:

- Your current and future reproductive healthcare goals and plans, such as preventing pregnancy or having a baby in the future.
- Your seizure control and how your anti-seizure medication options might affect your independence, work, and driving.
- Different areas of your life that might be affected if your seizures increase or decrease if you change your anti-seizure medication.

Please talk to your epilepsy team or GP about how you feel about taking valproate. Do not stop taking valproate or any other anti-seizure medication without speaking to your epilepsy specialist, epilepsy team, or GP.

## What is SUDEP?

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### SUDEP

#### (Sudden Unexpected Death in Epilepsy)

SUDEP is the sudden and unexpected death of a person with epilepsy who was otherwise healthy. While SUDEP is rare, the best way to prevent SUDEP is to control seizures and take your anti-seizure medication as prescribed.

Although the exact reasons for SUDEP are not fully understood, it is known that poor seizure control may increase the risk.

**Never stop taking valproate or any other anti-seizure medication without speaking to your doctor. Taking your anti-seizure medication to control seizures as prescribed by your doctor is the best way to lower SUDEP risk.**

Talk to your epilepsy specialist, someone in your epilepsy team, or GP about SUDEP to help you evaluate your personal risk factors.

## Is there anything you would like to talk to your epilepsy specialist or epilepsy team about to help you decide whether valproate is right for you?

For example:

- What are the benefits or risks if I take valproate?
- If I decide to take valproate, what is the best choice of highly effective contraception for me?
- Do I have to use highly effective contraception if I take valproate?
- What if I do not want to use highly effective contraception?
- Is there another anti-seizure medication that might be a better choice for me?



Is there anything you would like to ask your epilepsy specialist or epilepsy team about your reproductive health or planning for pregnancy (for example, if you are thinking about pregnancy in the future):

- How would valproate or another anti-seizure medication affect my reproductive health?
- What are the risks of my current medication during pregnancy?
- What alternative medications might be available to me if I decide I'd like to get pregnant in the future?
- How does pregnancy affect the health of someone with epilepsy?
- How likely is it that my child(ren) would have epilepsy?
- How can I plan for pregnancy (if I decide I want to get pregnant in the future)?
- How far in advance would I need to plan for pregnancy (if I want to get pregnant in the future)?

Is there anything else you would like to know to help you decide whether valproate is the right choice for you? Use the space below to note any questions you would like answered about the benefits and risks of taking valproate or changing anti-seizure medication.

If you have any questions you want to ask your epilepsy specialist, epilepsy team, or GP about valproate or alternative anti-seizure medications, please write them here:

## Preparing for your next epilepsy appointment

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Once you have read through the decision aid and filled in the parts you feel are important to you, please take this leaflet to your next appointment with your epilepsy specialist, epilepsy team or GP to talk about how you feel about taking valproate.

### Thinking about your options

Do you feel you know enough about the potential benefits and risks of each option?

- Yes
- No

Do you feel clear about which potential benefits and risks matter to you most?

- Yes
- No

Do you feel you have enough information and support to make a decision?

- Yes
- No

Do you feel sure about the best choice for you?

- Yes
- No



If you have answered 'No' to any of the questions, please talk to your epilepsy specialist about any questions or concerns you have.

Is there anything else you want to speak to your epilepsy specialist or epilepsy team about? Please write any questions you have here and take this leaflet with you to your next appointment:

Remember, everyone's epilepsy is different, and everyone's personal circumstances and reproductive healthcare goals and plans will be different. Please speak to your epilepsy specialist about what you feel is most important to you.

## Where did we get our information from?

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You can read more about valproate on the NHS website at:

[www.nhs.uk/medicines/sodium-valproate/](http://www.nhs.uk/medicines/sodium-valproate/)

The valproate patient information booklet for women and girls can be found at:

[www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/950801/107995\\_Valproate\\_Patient\\_Booklet\\_v05\\_DS\\_07-01-2021.pdf](http://www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/950801/107995_Valproate_Patient_Booklet_v05_DS_07-01-2021.pdf)

You can read the NHS Contraception Guide at:

[www.nhs.uk/conditions/contraception/](http://www.nhs.uk/conditions/contraception/)

You can read about contraception and epilepsy medications at:

[www.epilepsy.org.uk/living/sex-and-contraception/contraception-an-epilepsy](http://www.epilepsy.org.uk/living/sex-and-contraception/contraception-an-epilepsy)

You can watch a Welsh Government video about valproate and the pregnancy prevention programme here:

[www.youtube.com/watch?v=wKwesIRmMhg&ab\\_channel=JammyCustardAnimation](http://www.youtube.com/watch?v=wKwesIRmMhg&ab_channel=JammyCustardAnimation)



If you have concerns or questions about the risks associated with valproate and pregnancy, please speak to your epilepsy specialist, someone from your epilepsy team, your GP, pharmacist or other healthcare professional.

You can also contact a patient support network such as:

- [Epilepsy Action](#) - 0808 800 5050
- [Epilepsy Society](#) - 01494 601 400
- [Mind](#) - 0300 123 3393
- [SUDEP Action](#) - 01235 772850

If you or your child has been affected by valproate used during pregnancy, you can contact a support network:

- [The Organisation for Anti-Convulsant Syndrome OACS](#) - 07904 200364
- [The Independent Fetal Anti-Convulsant Trust INFACT](#) - 01253 799161

Please keep this leaflet where you can easily find it and read it again should your reproductive healthcare goals change in the future.

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**Valproate use by women and girls:**

[www.gov.uk/guidance/valproate-use-by-women-and-girls](http://www.gov.uk/guidance/valproate-use-by-women-and-girls)

**Antiepileptic drugs: review of safety of use during pregnancy:**

[www.gov.uk/government/publications/public-assessment-report-of-antiepileptic-drugs-review-of-safety-of-use-during-pregnancy/antiepileptic-drugs-review-of-safety-of-use-during-pregnancy](http://www.gov.uk/government/publications/public-assessment-report-of-antiepileptic-drugs-review-of-safety-of-use-during-pregnancy/antiepileptic-drugs-review-of-safety-of-use-during-pregnancy)

**The Pregnancy Prevention Programme:**

[www.medicines.org.uk/emc/rmm/1204/Document](http://www.medicines.org.uk/emc/rmm/1204/Document)

**NHS contraception guide:**

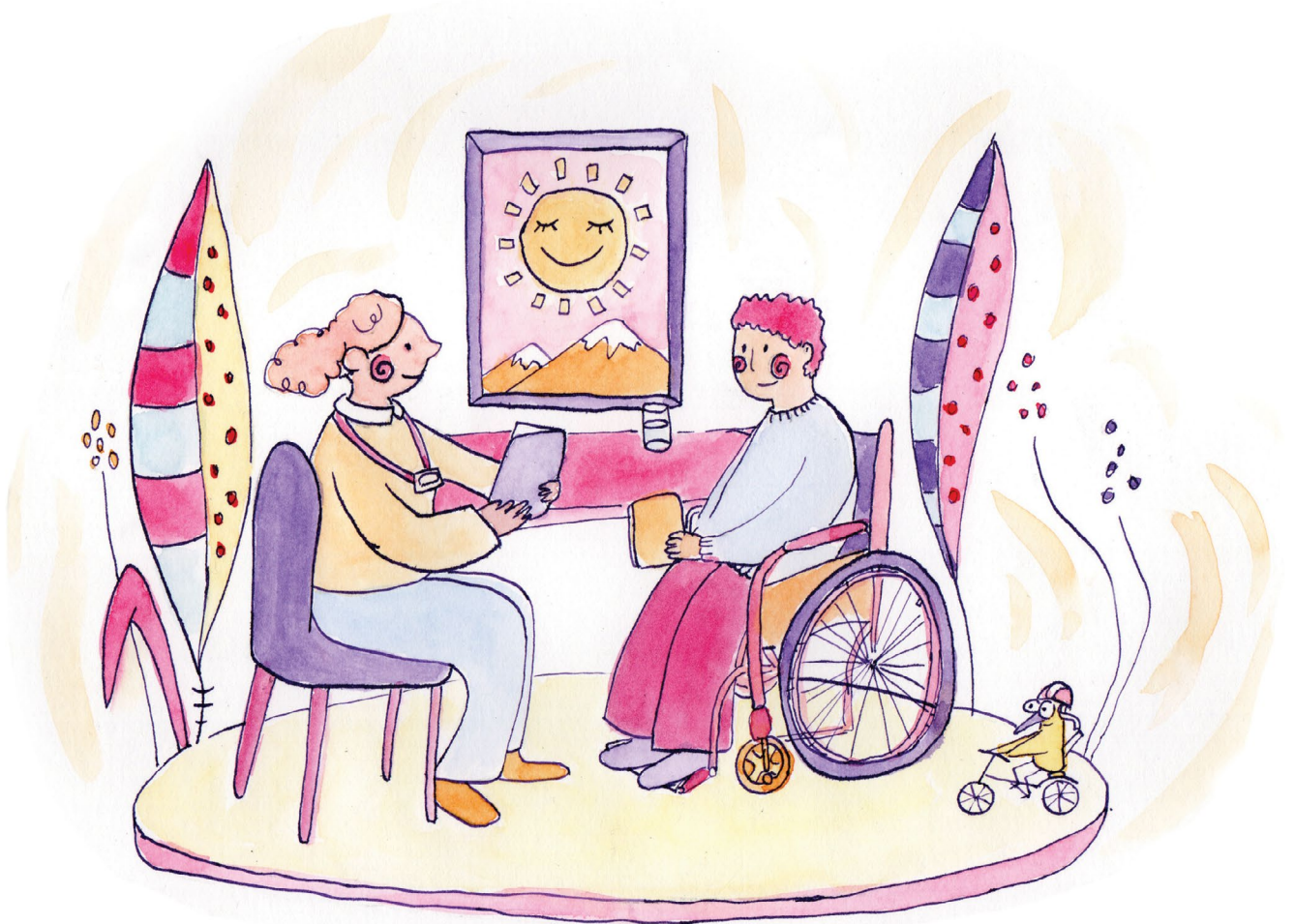
[www.nhs.uk/conditions/contraception/](http://www.nhs.uk/conditions/contraception/)

**Sudden Unexpected Death in Epilepsy:**

<https://www.nhs.uk/conditions/epilepsy/living-with/#:~:text=Sudden%20unexpected%20death%20in%20epilepsy,it%20may%20sometimes%20be%20preventable.>

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