



Oxford University Hospitals
NHS Foundation Trust

BEING ON WARFARIN

**Information for
parents and carers**



What is this booklet for?

This booklet has been given to you because your child has started to take a medicine called warfarin, which is an anticoagulant.

A doctor or nurse will talk with you (and your child, if appropriate) about this, to explain what it all means and answer any questions you might have.

What information does this booklet contain?

This booklet gives you important information about your child's treatment. It also has details of who you can talk to if you need more information or advice.

Please keep this booklet, so you can look at it when you need to.

Contents of this booklet

- Anticoagulation record book
- What is warfarin and how does it work?
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Anticoagulation record book

Your child's anticoagulation team will give you a 'yellow book' to record their INR, warfarin dose and all their treatment details.

Please make sure that you take it with you to all your child's medical appointments.

What is warfarin and how does it work?

Warfarin is an anticoagulant medicine taken by mouth. Anticoagulants make the blood take longer to clot than normal. This reduces the risk of harmful blood clots forming.

Why does my child need to take warfarin?

With some diseases, procedures or medical problems, blood clots are produced more easily than normal. These include:

- following insertion of a mechanical heart valve
- some heart operations, e.g. Fontan procedure
- cardiomyopathy (heart muscle problem)
- an abnormal heart rhythm
- when a clot has developed and treatment is needed to prevent further clots (e.g. deep vein thrombosis, pulmonary embolism, stroke)
- a blood clotting disorder.

How should my child take the warfarin?

It is very important that your child takes the warfarin exactly as directed. Do not change the prescribed dose unless the team managing your child's anticoagulation tells you to.

Your child will need to take the warfarin once a day. They should take it at the same time each day (between 6-7pm is ideal). This then becomes part of their daily routine, so you are less likely to forget to give a dose.

What should I do if I miss a dose or give the wrong dose?

If you forget to give a dose of warfarin, and it is before midnight, give it as soon as you remember.

If you miss a dose completely, do not give a double dose the following day to 'catch up'. Contact the team that manages your child's anticoagulation for advice.

If you have given the wrong dose, contact the team that manages your child's anticoagulation for advice.

What do warfarin tablets look like?

Different brands of warfarin may have different markings, but each strength will always be the same colour.

Warfarin tablets available:

0.5 mg (white)

1mg (brown)

3mg (blue)

5mg (pink)

You will be told the dose of warfarin that your child should take in milligrams (mg). You may need a mixture of different strength tablets to make up the correct dose.

Warfarin may sometimes be prescribed in liquid form. If your child has liquid warfarin (1mg in 1ml) please make sure that you shake the bottle very well before drawing up a dose, as sometimes the contents can settle to the bottom of the bottle.

Checking and monitoring your child's anticoagulation and knowing what dose to give

Everyone responds differently to warfarin and a number of things can affect this response (such as other medicines, diet and illness). This means that the dose of warfarin that your child is taking must be carefully monitored and changed if necessary.

Your child will need regular blood tests to make sure their dose is correct. This blood test is called an INR test.

What is the INR?

INR stands for 'International Normalised Ratio'. It is a measurement of how long blood takes to clot.

A normal INR (for people not taking warfarin) would be around 1.0.

The longer blood takes to clot, the higher the INR level. For example, if your child's INR is 2.0 this means their blood is taking about twice as long as normal to clot.

Warfarin and the target INR

Your child's INR will be used to decide what dose of warfarin they need to take. We will try to keep their INR at a particular level. This will depend on their medical condition and why they need to take warfarin. This is their **target INR**.

We will try to keep their INR within a safe range, known as the 'therapeutic range'.

Many things can affect how warfarin works in the body and most people will not be in their range 100% of the time, which is why regular blood tests are necessary.

If your child's INR is too low, their warfarin dose will be increased and they may be given an additional medication.

If their INR is too high, their warfarin dose will be reduced or perhaps omitted (deliberately missing a dose).

Please do not adjust your child's warfarin dose yourself, without the advice of the anticoagulation team managing your child's treatment.

How often will my child need an INR test?

Your child will need a blood test regularly, to check their INR level is within their target range.

It is very important that blood tests are done when you have been told, to reduce the possibility of your child's INR going outside their target range.

If your child is unwell or starts any new medicines you should do a blood test earlier than planned, to see if this has affected their INR level.

If their warfarin dose is adjusted, a blood test will be required soon afterwards to check the effect.

What are the side effects of warfarin?

Like all medicines, anticoagulants have side effects.

The most serious side effect of warfarin is bleeding. Keeping your child's INR in their target range reduces the risk of unexpected bleeding.

Other side effects include:

- hypersensitivity to warfarin
- rash
- alopecia (hair loss)
- diarrhoea
- nausea (feeling sick)
- vomiting (being sick)
- changes to skin circulation, resulting in purple coloured toes or skin necrosis
- jaundice (yellowish tinge to the skin).

You should contact the team managing your child's anticoagulation if they experience any persistent side effects while taking warfarin.

Overdose

The following signs can mean that your child is having too much warfarin:

- a high INR (over 5.0)
- heavily bleeding gums
- heavy periods or bleeding at other times
- bruising for no reason or severe bruising
- nosebleeds that last longer than 10 minutes or regular nosebleeds
- unusual headaches
- coughing up blood
- blood in the urine
- blood in vomit
- black or bloody stools.

If you observe any of these signs, or other unexpected or unexplained symptoms, you should do an INR check and ask the team who manage your child's anticoagulation for advice.

If heavy bleeding occurs, or bleeding that you cannot stop, you should seek urgent medical attention for your child either by calling an ambulance or going to the nearest Emergency department.

A low INR (less than 1.5) may be a sign that your child is taking too little warfarin. This may cause their INR to drop and they may develop blood clots.

More serious symptoms would be:

- pains in their legs or chest, which may be a symptom of a clot (thrombosis) or embolism
- breathlessness.

If either of these symptoms occur, you should seek urgent medical attention for your child either by calling an ambulance or going to the nearest Emergency department.

Effects of other medications on your child's INR



Many medicines can affect the way that warfarin works; either by increasing or decreasing your child's INR. The medicines your child takes regularly will have already been taken into consideration when prescribing the warfarin. Please talk to the team managing your child's anticoagulation before starting or stopping any medication, whether prescribed by a doctor, bought over the counter or any herbal or homeopathic treatments. They will let you know if your child needs an earlier blood test. You may need to check your child's INR level, to make sure that it has not changed.

You should always tell the doctor, nurse, dentist or pharmacist that your child is taking warfarin, before starting or stopping any medication (including herbal and homeopathic treatments).

Your child should not take aspirin or a medicine that is a 'non-steroidal anti-inflammatory drug' (NSAID), such as ibuprofen,

unless it has been prescribed by a doctor. These can cause increased bleeding.

They can take paracetamol, but not more than the recommended dose and not on a regular basis.

If you are unsure about whether you should give your child a particular medicine, talk to the team managing their anticoagulation.

Some common drugs that will have an effect on the INR:

- some antibiotics
- some analgesics (painkillers), including regular use of paracetamol
- aspirin
- ibuprofen (Nurofen, brufen)
- some heart medications, e.g. amiodarone
- the flu vaccine: it is best to check your child's INR level a few days afterwards, to make sure it has not been affected.
- levothyroxine
- steroids
- lactulose

Make sure the team that manages your child's anticoagulation is aware before they start or stop any medicines, so they can tell you whether they will need additional INR checks.

What other things can affect INR?

Any change in lifestyle or wellbeing may have an effect on your child's warfarin treatment.

Diet

It is important that your child eats a healthy balanced diet, but if they have major changes to their diet this may affect how their body responds to the warfarin. Binge diets are not recommended.

Some foods that your child may eat every day contain a substance called vitamin K, which is involved in the blood clotting process. Your child should try to have a consistent amount of vitamin K containing foods. If you make big changes to the amount of vitamin K containing foods that they eat, it can affect the stability of their INR.

Foods rich in vitamin K includes:

- green leafy vegetables, such as kale, cabbage, Brussels sprouts, broccoli, spinach and lettuce.
- avocado, soya bean products,
- cereals containing wheat bran and oats
- liver
- vegetable oils
- cranberry juice. Cranberry juice is thought to increase the effect of warfarin, so should be avoided.



Infant formula

Babies on formula milk may require higher doses of warfarin, as there is more vitamin K in formula than in breast milk.

Diarrhoea, vomiting, high temperatures and other illnesses

Diarrhoea and vomiting will affect the absorption of warfarin and your child's INR could change very quickly.

If your child is unwell, with a high temperature, or has diarrhoea and vomiting for more than a day, you should make sure their INR is checked, even if a test is not due. You should inform the team managing your child's anticoagulation.

Other useful information

Going to the dentist

Most dental treatment can go ahead as normal without warfarin being stopped. Make sure that the dentist is aware that your child is taking warfarin.

You should confirm with the dentist when they would like you to check your child's INR before a procedure. Their INR should be within normal range.

Having an operation

If your child is due to have any medical investigations or an operation, you should make sure that the team looking after them is aware that they are taking warfarin.

You may need to stop their warfarin for a few days before the operation. Please make sure that you discuss this with the team managing their anticoagulation.

Immunisations and vaccinations

All injections and vaccinations should ideally be given into the layer of fat underneath the skin (subcutaneously) and not into the muscle, as this should cause less bruising. Check that your child's INR is in range before the injection.

Firm pressure applied to the site of the injection for 10 minutes afterwards may help to prevent bruising.

Holidays and travel

If you are going on holiday in this country or abroad let your child's anticoagulation team know. You may need to arrange an INR check before you go.

You should carry their anticoagulation book with you. You should also take their most recent clinic letter with you, in case they need to see a doctor whilst you're away.

If your child has a CoaguChek machine, you should take it with

you. Remember, if you are flying that it should be carried in your hand luggage, as it is sensitive to low temperatures. You can ask the team managing your child's anticoagulation for a letter to take with you about this.

Make sure that you have a supply of enough warfarin and carry this in your hand luggage in case your suitcases are lost.

Travel insurance is essential if going abroad, as the cost of medical treatment in another country can be extremely expensive.

Sports

It is best for your child to avoid contact sports, such as rugby, martial arts and kick boxing, due to the risk of injury. Sports such as football, hockey or cricket should be fine if not played competitively, provided you remember that if your child is injured when playing these sports then they are more likely to have more bruising or possibly bleeding.

Wearing appropriate protective gear is essential.

Children can do PE and games at school, other than the sports mentioned above. Please make sure the sports teachers are aware that your child is on warfarin.

Talk to your child's anticoagulation team for advice if they want to do any more unusual sports or activities.

We strongly recommend that they wear a cycle helmet, to reduce the risk of head injury when riding a bicycle.

Nursery/School

It is important that staff at nursery or school know that your child is on warfarin, in case they are injured. You could give a copy of this leaflet to them.

The team managing your child's anticoagulation or the Children's Cardiac Nurse Specialists can speak to the nursery or school about the implications of being on warfarin if necessary.

What should I do if my child has an injury?

Cuts

Press firmly over the cut for 10 minutes with a clean cloth. If bleeding does not stop, after 10 minutes, go to the nearest Emergency department.

Head injuries and bumps to the head

You need to be more vigilant, as cuts to the skin can be clearly seen, however bumps to the head which may cause internal bleeding are not so immediately obvious. If your child has more than a minor bump you should call 999 or go to the nearest Emergency department.

Symptoms to look out for following a head injury include:

- drowsiness
- feeling dizzy when walking or standing up
- vomiting
- worsening headaches
- problems with vision, such as blurring
- changes in behaviour
- fits/convulsions.

If any of these symptoms happen you should call 999 or go to the nearest Emergency department.

Nosebleeds

If your child has a nosebleed carry out normal first aid: cold flannel/compress on bridge of their nose/forehead.

- Lean their head forward.
- Pinch the bridge of their nose firmly for at least 10 minutes.
- If the nosebleed continues for more than 10 minutes, take your child to the nearest Emergency department for treatment.

You should contact the team that manages your child's anticoagulation, if they have a nosebleed that lasts for longer than 10 minutes or if they are having frequent nosebleeds.

When going to an Emergency department, make sure you tell the staff your child is taking warfarin.

Growing up and getting ready for adulthood

As your child grows their needs will change. Knowing what to expect can help you prepare for these changes.

Medical alert jewellery

You might want to think about getting your child medical alert jewellery, particularly if they are going to be away from home.

These have written information on them to tell people about any medical conditions they have or medicines they are taking. There are a number of different styles of bracelets and necklaces available.

They will need to take extra care to avoid cutting or injuring themselves while taking warfarin, because of the risk of excessive bleeding.

For example they should:

- take care when shaving (use an electric razor rather than blades, as they are less likely to cut themselves)
- take care when brushing their teeth
- wear appropriate protective clothing when playing sports.

Body piercing

This is not recommended due to the risk of bleeding and infection.

Alcohol

Binge drinking or excessive alcohol intake should be avoided, as it increases the risk of bleeding.



Periods/pregnancy

Periods may be heavy and last longer than normal. If this happens you (and your daughter, if appropriate) should talk to their GP or the team managing their anticoagulation about how to manage this.

It is necessary with some heart conditions to take a particular type of contraceptive pill (progesterone only). You (and your daughter, if appropriate) should discuss this with their cardiologist, to see if this is necessary.

Warfarin can affect the development of a baby in early pregnancy. It is very important that your daughter uses a reliable form of contraception to prevent an unplanned pregnancy.

Plans for pregnancy should be discussed with the medical team looking after your daughter, as it may not be safe for them to become pregnant, depending on the condition for which they are taking warfarin.

If it is safe for your daughter to become pregnant, then plans can be made before any pregnancy to adjust the anticoagulation treatment and any other medication she may be taking.

If your daughter thinks she may be pregnant while taking warfarin, she will need to have a pregnancy test as soon as possible. If this is positive, an urgent appointment should be made to see the GP or cardiologist, so that an alternative anticoagulation can be started.

It is safe to breastfeed while taking warfarin.

You (and your daughter) may find it helpful to discuss this with a member of the team managing her anticoagulation.

Important things to remember

- If you forget to give your child a dose of warfarin at the normal time, give it to them as soon as you remember, before midnight. Do not give a double dose the following day.
- You should contact the team managing your child's anticoagulation if you miss a dose of warfarin completely or give an incorrect dose. They will give you advice about what to do next.
- If your child vomits after taking the warfarin do not give them another dose.
- If your child is unwell for more than a day, with a high temperature, diarrhoea or vomiting, you should check their INR. It can become too high or too low when ill.
- Your GP will need to give you a repeat prescription for the warfarin. Please make sure you order it in plenty of time, so that you do not run out.

Safe storage of medicines

- Keep all of your child's medicines in a safe place, out of the reach of children.
- Keep the warfarin in a cool, dry place, out of direct sunlight.
- If your doctor decides to stop the warfarin, please return any unused medicine to a pharmacist.

Who to contact

For further information, advice, or if you have any questions about your child's warfarin, contact the team managing their anticoagulation. Their contact information should be written in the yellow anticoagulation record book.

Checklist

Please make sure that you have understood the contents of this booklet and ask if you have any questions.

Check that you have:

- a yellow anticoagulation record book
- warfarin tablets or liquid, and that you understand how to order further supplies
- details of the dose of warfarin to give your child
- details of when the next INR check is due
- contacted their nursery or school, if relevant
- details of who to contact if you have concerns.

How to contact us

Children's Cardiac Nurse Specialists

Tel: **01865 234 985**

Email: **orh-tr.ccnsoxford@nhs.net**

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

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