Information for families

Great Ormond Street Hospital for Children NHS Foundation Trust
This leaflet from Great Ormond Street Hospital (GOSH) explains about the anticoagulant (blood thinner) medication warfarin, how it should be taken and how it will be monitored.

**Contents:**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is warfarin?</td>
<td>3</td>
</tr>
<tr>
<td>Why is warfarin used?</td>
<td>3</td>
</tr>
<tr>
<td>How blood clots</td>
<td>3</td>
</tr>
<tr>
<td>How warfarin works</td>
<td>4</td>
</tr>
<tr>
<td>Warfarin and target INR</td>
<td>4</td>
</tr>
<tr>
<td>Frequency of blood tests</td>
<td>4</td>
</tr>
<tr>
<td>How will my child's INR be tested?</td>
<td>5</td>
</tr>
<tr>
<td>Anticoagulation record book</td>
<td>5</td>
</tr>
<tr>
<td>Before starting warfarin</td>
<td>5</td>
</tr>
<tr>
<td>How warfarin should be taken</td>
<td>6</td>
</tr>
<tr>
<td>Safe storage of warfarin</td>
<td>6</td>
</tr>
<tr>
<td>Obtaining further supplies</td>
<td>6</td>
</tr>
<tr>
<td>Complications of warfarin</td>
<td>7</td>
</tr>
<tr>
<td>Side effects of warfarin</td>
<td>8</td>
</tr>
<tr>
<td>Effects of other drugs on warfarin</td>
<td>8</td>
</tr>
<tr>
<td>Some common drugs that will affect the INR</td>
<td>9</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>9</td>
</tr>
<tr>
<td>Diet</td>
<td>9</td>
</tr>
<tr>
<td>Sports</td>
<td>10</td>
</tr>
<tr>
<td>School and college</td>
<td>10</td>
</tr>
<tr>
<td>Injury advice</td>
<td>11</td>
</tr>
<tr>
<td>Everyday life</td>
<td>12</td>
</tr>
<tr>
<td>General childhood illness/ill health</td>
<td>14</td>
</tr>
<tr>
<td>What to do if...</td>
<td>14</td>
</tr>
<tr>
<td>Who to contact</td>
<td>16</td>
</tr>
<tr>
<td>Further information</td>
<td>16</td>
</tr>
</tbody>
</table>
What is warfarin?
Warfarin is an anticoagulant medication (known as a ‘blood thinner’) that will slow down blood clotting to prevent abnormal blood clots from developing or worsening. Warfarin is an anticoagulant tablet or liquid suspension taken by mouth.

Why is warfarin used?
Some medical conditions cause blood clots to be produced more easily than normal. These conditions include:
- Cardiomyopathy (heart muscle problem)
- Patients with artificial heart valves
- Individual clinical condition after some heart operations
- Previous clots or embolisms
- Some specific medical conditions at a greater risk of clotting – such as Kawasaki Disease

How blood clots
The human body depends on the blood circulating all the time to provide its organs such as the heart, brain, and skin with oxygen and nourishment. To keep the blood flowing well, it needs to be of a certain consistency (not too runny and not too thick) and it needs to be able to ‘plug’ any leaks that may occur, like when you cut your finger. The wall of the damaged blood vessel is sealed off by a tiny blood clot. This clot is formed as a result of proteins that circulate in the blood in a dissolved form. This is a natural process and necessary to stay healthy. Blood clots can form if there is ‘foreign’ material in the body or if the blood flow is slow, clots could then be carried to other areas of the body and cause damage. This is called an embolism and this can then lead to serious problems, such as a stroke or a blood clot in the lung. This is the reason for the blood thinning treatment.
How warfarin works

Warfarin works by slowing down the blood clotting process. It is a ‘Vitamin K antagonist’, which means it prevents a group of clotting proteins (which need Vitamin K to make them active) from doing their job fully. Vitamin K is naturally present in food and milk (see section on diet).

Everybody reacts differently to warfarin so the dose must be worked out each time for every patient. The effects of warfarin can last quite a long time in the body but it takes about two to four days to see these effects. This means that a change in dose will not be reflected in the blood test until this time. All this needs to be taken into account when deciding on the dose of warfarin. The only way to test how the treatment is working is by taking a blood sample and seeing how long it takes the blood to clot.

The blood sample used to measure the effect of warfarin is called the INR (International Normalised Ratio). This is a simple numerical scale. A normal INR (without warfarin) is reflected as 1. The higher the number, the longer it takes the blood to clot.

Warfarin and target INR

Different medical conditions will require a different level of anticoagulation and this level (number above 1) will be decided by the nature of the condition and the doctor managing your child’s care. Many things can affect how warfarin works in the body, such as other medications, diet and ill health and can result in an increase or decrease in their INR level. Many children and young people will not be in their range all of the time.

Your child’s target INR is [ ] to [ ]

Frequency of blood tests

A blood test is required regularly to check that your child’s INR level is within the target range. If the INR is not in range then their warfarin dose may need to be changed. A repeat test will be required in the days following this to ensure there has been a correct response to the change in warfarin. Please do not adjust your child’s warfarin dose without the advice of the Anticoagulation Team managing your treatment.
How will your child’s INR be tested?

There are a few options that can be considered for testing your child’s INR:

- **Home monitoring** – using a monitor at home to take the blood sample from a finger prick test – similar to a diabetic blood test

- **Community Nursing Team** – visiting your child at home and undertaking the test either by taking blood from a vein or finger prick testing

- **GP or local hospital service** – There are excellent services run in local areas which provide INR testing (vein or finger prick sampling) and warfarin management.

The most appropriate service for you and your family will be discussed and a joint decision made.

Anticoagulation record book

Your Anticoagulation Team will give you a book to record your child’s INR, warfarin dose and all their treatment details. Always bring this to every medical appointment and when requesting repeat prescriptions of medications. New books can be requested from your GP, Pharmacy or Anticoagulation Team.

Before starting warfarin

Warfarin is a complex drug which can be affected by the many different factors in the body, including liver and kidney function, what medications your child is on, and any changes in their general health. Therefore, before starting the medication your child will need to:

- Receive an initial in depth warfarin information session
- Have a plan made for testing INR levels
- Have specific blood tests – decided by condition, cardiologist and Anticoagulation Team
- Have a plan for who will be responsible for dosing the warfarin
How warfarin should be taken

Warfarin should be taken at the same time every day, ideally in the evening. It can be taken with or without food, and can be taken at the same time as any other regular medications. Warfarin is available as a liquid or tablets:

- **Liquid**
  - This is 1mg in 1ml – so if you need to give a 3mg dose, you would give 3mls, for instance.
  - You **MUST SHAKE** the bottle before every dose as the contents can settle and cause the doses from the end of the bottle to be stronger causing an increase in INR.

- **Tablets**
  - 0.5mg white
  - 1mg brown
  - 3mg blue
  - 5mg pink

Tablets are scored and can be halved with a tablet cutter for half or quarter doses. If tablets are cut then one half should be taken on one day, and the other half the following day to ensure dosing accuracy.

Safe storage of Warfarin

Warfarin is hazardous medication if taken by someone who does not require it.

- Keep medicines in a safe place where children cannot reach them.
- Keep medicines in a cool, dry place out of direct sunlight and away from heat.
- If your doctor decides to stop treatment with warfarin, return any unused medicine to your local pharmacist. Do not flush down the toilet or throw it away.

Obtaining further supplies

The GP will need to give you a repeat prescription for warfarin. A prescription can take 48 hours to obtain at some GP Practices, and then the local pharmacy may need to order in the medication. Please ensure all medication is ordered in good time. All medication has an expiry date; you should ensure you are aware of the date, so replacements can be ordered in good time.
Complications of Warfarin

If your child’s INR is above the target range they are at an increased risk of bleeding. Warfarin does not make your child bleed, but makes a source of bleeding bleed more.

Major Bleeding – If any of these occur seek urgent medical attention with 999 or going to Emergency Department.
- Haemorrhage (severe bleeding) – Seek urgent medical attention (999).
- A cut that does not stop bleeding after 5 to 10 mins of pressure
- Blood in the urine
- ‘Coffee ground’ or bright red vomit
- Red or black bowel movement
- Coughing bright red blood
- A serious fall or hit to the head (see section on head injury advice)

Minor Bleeding – do not stop giving warfarin, but contact your Anticoagulation Team to discuss.
- Nosebleeds that last longer than 5 to 10 minutes or frequent nose bleeds (see section on management)
- Bleeding gums (consider using a softer toothbrush)
- Bruising easily
- Bleeding after a cut that can take a little longer to stop
- Heavy periods

If you see any of these signs or other unexpected or unexplained signs, you should do an INR check and ask your healthcare provider/ Anticoagulation Team for advice.

If your child’s INR is below your target range they are at an increased risk of developing a clot. This risk will relate to the reason they are on warfarin and not all the symptoms will apply to your child.

The symptoms of this include:
- Pains in the legs or chest can be a symptom of a clot
- Breathlessness
- Behavioural changes – suggestive of a stroke

In some cases, if an INR drops too low, the risk of a clot developing may be considered too great and so a second form of anticoagulation may be required. This is normally in the form of a Low Molecular Weight Heparin (dalteparin) which is administered as an injection – normally twice a day. If this is required for your child, we will discuss this with you. This can either be administered by health care professionals or you can learn to administer this yourself.
Side effects of warfarin
As with any medication these are rare and unpredictable, but may include:
- Hypersensitivity
- Rash
- Alopecia (hair loss)
- Diarrhoea
- Nausea (feeling sick)
- Vomiting (being sick)
- Changes to skin circulation which may cause a purple or black colour change to the skin
- Jaundice (yellowish tinge to skin colour)

If you see any of these signs, please inform your Anticoagulation Team as soon as possible.

Effects of other drugs on warfarin
The drugs your child takes regularly, that are prescribed will have already been taken into consideration when starting warfarin. Any new medicines may interact with warfarin and affect the INR level, such as some antibiotics or medicines you buy from the pharmacy for a cold. You must tell the chemist that your child is already taking warfarin so they are aware of what medications may interact with it. You should also check if you wish to use any herbal or homeopathic treatments as some also interact with warfarin. Some drugs stop warfarin from working as effectively, but some increase its effectiveness.
Some common drugs that will affect the INR

- Some heart drugs such as amiodarone
- Some analgesics (pain killers), such as long term use of paracetamol
- Ibuprofen
- Some antibiotics such as erythromycin and clarithromycin
- Vitamins
- Steroids
- Legal and illegal recreational drugs – These can have a serious and unpredictable effect on your child’s general health and INR and should be avoided at all costs.

This is not a complete list, so it is important to check with a pharmacist if buying ‘over the counter’ medicines or your prescriber when starting any new medicines.

Your Anticoagulation Team should be made aware of any changes to your medication, or when starting a new medication so that they can advise you when an INR check is needed.

Lifestyle

Any change in lifestyle or wellbeing may also influence the effectiveness of warfarin therapy. An example of this may be going on holiday to a place where there is a big change in climate or diet. If your child is unwell, for instance, with flu, sickness or diarrhoea, or starts any new medication you should inform your Anticoagulation Team and check their INR. They will advise you about the best time to check it and any dose adjustments if necessary. You should also try to stick to a fixed time of day for giving your child their warfarin medicine- between 6pm and 7pm is ideal.

Diet

Some foods that we eat every day contain vitamin K, which counteracts the effectiveness of warfarin. It does not really matter how much vitamin K your child eats when they start warfarin as the dose is worked out according to the normal diet. Foods rich in vitamin K include: green leafy vegetables such as cabbage, brussel sprouts, broccoli and spinach. Avocado, soya bean products and Swiss hard cheese are also rich in Vitamin K. Cranberry juice is known to have varying affects on warfarin levels so we suggest it is avoided. Your child does not need to limit their diet, however binge (short term) diets are
not recommended as major changes in diet may have an effect on warfarin levels. Your child should eat a healthy balanced diet like everyone else.

Formula milk has added vitamin K, and therefore any changes to a baby’s diet that include an increase or decrease in their formula milk intake should be planned in advance with your Anticoagulation Team.

**Sports**

Exercise is important to staying healthy, so your child can continue their regular activities, but remember that the risk of bleeding or bruising from injury is much higher once on warfarin. We would suggest that they avoid contact supports such as rugby or martial arts due to the risk of injury. Sports such as football, hockey or cricket are fine provided you remember that any contact injury sustained during play is likely to result in bruising or possibly bleeding. Wearing protective gear is essential. Children may do PE and games at school; however care should be taken with other more rough or extreme activities. Please talk with your Anticoagulation Team about any sports or activities you wish to do for further advice as necessary.

We strongly recommend wearing cycle helmets to reduce the risk of a head injury when riding a bicycle.

**School and college**

It is essential that staff, in particular sports teachers, are aware of students on warfarin therapy should an injury occur. You can give a copy of this leaflet to your school or college. Further information is also available from the contacts listed in the back of this leaflet or your Anticoagulation Team.
Injury Advice

Cuts
Press for 5 to 10 minutes with clean cloth. If bleeding does not stop, go to your nearest Accident and Emergency (A&E) Department.

Head injury
Be more vigilant, as cuts to the skin can be seen clearly however, head injuries which may cause internal bleeding are not so obvious. If you have more than a very minor bump it is advisable to have a medical assessment.

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 or convulsions

If any of these symptoms occur after a known injury you must go to your nearest Accident and Emergency (A&E) Department straight away.

Nose bleeds
If your child has a nose bleed carry out normal first aid.
- Lean their head forward
- Pinch their nose just above the nostrils for 5 to 10 minutes.

Leaning forward and breathing through their mouth will let blood drain out of their nose instead of down the back of the throat which may cause vomiting.

If the nose bleed carries on for more than 5 to 10 minutes, you should go to your local Accident and Emergency Department for treatment and their INR may need to be checked. Contact your Anticoagulation Team to inform them so that they can manage your INR levels as required.

If you go to the Emergency Department, make sure you tell the staff that your child is taking warfarin.
Everyday life

Surgical or dental procedures
If your child has any planned medical investigations, operation or dental procedures it may be necessary to change the warfarin dosing or to stop the warfarin for a few days. The doctor/surgeon will usually consult your Anticoagulation Team to arrange this.

Injections, immunisations and vaccinations
All injections and vaccinations should be given under the skin (subcutaneously). Intramuscular injections (given into the muscle) should not be given to people on warfarin therapy as this may cause bruising. Apply firm pressure to the site for 10 minutes afterwards. If your child needs an injection of any kind, then discuss this with the health care provider before the appointment. They may wish to contact your Anticoagulation Team for advice.

Holidays and travel
If your child is going on holiday let your Anticoagulation Team know in advance so INR checks can be planned before you go. Make sure you have enough warfarin tablets/suspension for the stay plus a few days’ extra and carry them in your hand luggage in case of lost suitcases. Letters to support the carrying of medications can be written by your Anticoagulation Team. Travel insurance is essential if going abroad.

Medic alert tag/jewellery
A medical identification tag bears a message that the wearer has an important medical that might require immediate attention. The intention is to alert medical personnel of the condition even if the wearer is not conscious enough, old enough, or too injured to explain. It is recommended that people taking warfarin have a medical alert tag. Various types are available online, such as www.medicalert.org.uk.
**Shaving**
We advise electrical razors rather than blades.

**Periods/pregnancy**
Periods may be heavy and last longer than normal. It is very important that all girls taking warfarin should be informed that warfarin can be harmful to an unborn baby, particularly in the first 12 weeks of pregnancy, and that pregnancy will affect their INR levels. You may find it helpful to discuss these issues with a member of the team managing your child’s warfarin therapy for further advice, and specialist advice can be organised should it be required.

**Body piercings and tattoos**
Body piercing and tattoos are not recommended due to the risk of bleeding and infection.

**Alcohol**
Alcohol can affect the INR and should be taken in moderation. Excessive alcohol should be avoided as it increases the risk of bleeding. Vomiting after drinking too much alcohol leads to dehydration which will affect the INR.
General childhood illness/ill health

This is a part of everyday life especially for young children. Fever, coughs, colds, headaches and simple childhood illnesses can affect the body’s way of processing warfarin. Fever and diarrhoea increases the metabolic rate which may result in depletion of clotting factors and therefore an increased INR. Being ill can also alter diet leading to changes in the INR. If your child is unwell, inform your Anticoagulation Team for advice. Paracetamol can be given to alleviate symptoms, but can affect INR levels. Ibuprofen is not normally permitted when taking warfarin.

Diarrhoea and Vomiting

Diarrhoea and vomiting will affect the absorption of warfarin and your child’s INR level very quickly. Ensure they drink plenty of fluids to prevent dehydration – water, very dilute squash or rehydration sachets from the pharmacy. If symptoms worsen or persist for more than 24 hours, seek medical advice from your GP or nearest Accident and Emergency Department. If you are abroad, the same advice applies about drinking plenty of fluid but it may be safer to stick to bottled water and drinks. If symptoms carry on or worsen, seek medical advice. If you are unsure how to do this, speak to your holiday representative or travel insurance provider for further information and support.

What to do if...

If your child forgets a dose –
- Give it if you remember it later the same day
- If you do not remember it until the next day, skip the forgotten dose, and give the planned dose for that day
- Contact your Anticoagulation Team if your child misses a dose of warfarin or has the dose late

If your child vomits after taking the medicine –
- Do not give a double dose
- Contact your Anticoagulation Team
Who to contact

The team managing your anticoagulation therapy

This should be written in the yellow anticoagulation record book, and include an ‘out of hours’ telephone number. The Cardiac Nurse Practitioner team at GOSH are based on Bear ward, you can call them on the ward’s direct line 020 7829 8829 or via the switchboard on 020 7405 9200 ext 5774.

Further information:

The Children’s Heart Federation

A national children’s heart charity which provides a range of information leaflets. Visit their website at www.childrens-heart-fed.org.uk or call their helpline on 0808 808 5000

British Heart Foundation

A national charity which provides a range of information leaflets and support. Visit their website at www.bhf.org.uk or call their helpline on 0300 330 3311

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