

## Venous thrombosis in Children and Adolescents

## What is Venous Thrombosis?

Venous thrombosis is when a blood clot occurs in a vein.

## Types of Venous Thrombosis

Most commonly, thrombosis affects a deep vein in the leg or arm - this is known as 'deep vein thrombosis' (DVT). It can also break off and travel through the body and block the arteries in the lungs, known as 'pulmonary embolism' (PE) Clots in the veins of the brain, are known as 'cerebral venous sinus thrombosis' (CVST).

Less often it can affect the veins of other organs such as the kidney or liver.

#### Venous thrombosis in children and adolescents

Although venous thrombosis is far commoner in adults, it can also happen in children of all ages. In fact it has become more common in children over the last 20 years for the following reasons:

- The treatment for illnesses that cause a higher risk of thrombosis (such as congenital heart defects, cancer and prematurity) has improved and this has led to more children surviving with these conditions;
- Doctors are more aware that children can have thrombosis;
- The tests to diagnose thrombosis have improved.

The risk of thrombosis in children is very low. A blood clot affects approximately 1-5 per 100,000 children in the population each year. The risk is much higher in children who are in hospital with thrombosis occurring in as many as 1 in 200.

Those who at highest risk are babies under one year of age and adolescents.

Children can also have a blood clot in an artery but this fact sheet focuses on venous thrombosis.

## Risk factors for thrombosis in children include:

- A central venous line<sup>1</sup>
- Cancer
- A congenital abnormality of the heart
- Prematurity
- Severe trauma
- Serious infection
- Surgery

- The combined (oestrogen and progesterone) oral contraceptive pill
- A congenital venous malformation<sup>2</sup>
- A chronic health condition- e.g. nephrotic syndrome, inflammatory bowel disease, sickle cell disease or autoimmune disease

Most children who have thrombosis have more than one risk factor and many have several risk factors. Although not always, the majority of children who have thrombosis are seriously unwell in hospital when the blood clot happens.

Occasionally, some children, usually adolescents, have a thrombosis that occurs without any warning. These children are usually found to have an inherited problem with the way in which their blood clots ('thrombophilia' or sticky blood), making them more at risk of thrombosis. There may also be a history of thrombosis in other family members.











## How is thrombosis in children diagnosed?

A 'deep vein thrombosis' (DVT) can cause swelling and pain in the limb which may feel warm and tense or may often only cause pain. It is usually diagnosed using an ultrasound scan where a probe is placed over the limb to look for abnormal blood flow in the veins.

A 'pulmonary embolism' (PE) can cause any of the following: breathlessness; pains in the chest that are worse when taking a breath; coughing up blood; or sometimes collapse. It is usually diagnosed using computerised tomography after an injection of gadolinium which highlights blood flow (a CT pulmonary angiogram or CTPA) scan of the chest.

A 'cerebral venous sinus thrombosis' (CVST) can cause: headache; fits; vomiting; weakness or numbness of an arm or leg. It is usually diagnosed using a CT or MRI scan of the head.

Thrombosis in the kidney or liver may cause pain in the tummy or abnormal blood test results. It can be diagnosed using an ultrasound scan or a CT/MRI scan of the abdomen.

## How is thrombosis in children treated?

Thrombosis is treated using 'anticoagulants' which are drugs that prevent the clot from getting any bigger and also stop new blood clots from forming.

Babies and younger children are usually treated with low molecular weight heparin injections whereas older children and adolescents are more likely to be treated with warfarin.

Warfarin is more likely to be used when treatment is needed for a longer duration as it may be difficult to give daily injections for a long period of time. The new direct oral anticoagulants such as rivaroxaban, apixaban, edoxaban or dabigatran are starting to be used in children too.

### Heparin infusion

Children who are very unwell or who have a high risk of bleeding, for example because they have had recent surgery, may be started on a heparin infusion. This is a given through a very small needle or tube placed into a vein and is monitored by frequent blood tests.

#### Low molecular weight heparin injections

Low molecular weight heparins are used increasingly in children and include enoxaparin, tinzaparin and dalteparin.

- Low molecular weight heparins are given by injection just under the skin (subcutaneous injection) once or twice a day
- When a child goes home from hospital a parent may be trained to give the injections or it may be necessary for a community nurse to visit the house to give the injections
- Some centres use a small port, known as an 'Insuflon', that is inserted just under the skin and kept there for 5-7 days for the drug to be injected into. This can be better for the child than using a new needle for every
- It may be necessary to do a blood test every now and then to check that the right dose is being given. This blood test is usually taken 3-4 hours after an injection









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#### Warfarin tablets

Warfarin is an anticoagulant that is taken as a tablet.

- It is difficult to predict how much warfarin will be needed by each child because the levels are different in different individuals and affected by what is eaten and drunk. Having too much warfarin in the blood can increase the risk of bleeding, having too little warfarin can increase the risk of the clot getting bigger or another clot forming
- Warfarin treatment needs to be monitored. This is done using a test called the INR, short for International Normalised Ratio. This measures how much 'blood-thinning' effect the warfarin is having and helps to decide on what dose of warfarin should be given. Without warfarin most people have an INR value of 1, with most thrombotic problems the INR target is 2-3, occasionally 3-4. Once the INR is stabilised, the INR is usually tested every 2 -4 weeks
- The INR is tested on a finger-prick blood sample. Although this may be done in the hospital some clinics will provide a home INR testing machine (e.g. Coaguchek machine) that can be used by a parent. The parent will then call their nurse to get advice on how much warfarin to give. This can be more convenient for families as the child does not miss school/college to go to a hospital monitoring clinic and the parent does not miss work to take them there



There are a number of things that can cause the INR to be too high or too low:

Medicines - warfarin interacts with many other medicines. This includes 'over-the-counter' drugs and herbal remedies; Illness - any illness, but particularly diarrhoea and vomiting, may affect the INR;

Diet - the INR is affected by the amount of vitamin K in the diet. Vitamin K is found in green vegetables and salad; Alcohol - binge drinking of alcohol can cause a high INR and a risk of bleeding

If a female becomes pregnant while taking warfarin the drug can affect the unborn baby. It is important that the warfarin is stopped as soon as possible and an alternative is given.

Side effects of warfarin are uncommon but include hair loss and, rarely, a rash.

## Newer treatment options

There are some newer types of anticoagulant that are being used in adults. These are called the direct oral anticoagulants (DOACs). These are tablets that are different to warfarin as they do not require monitoring. These may be of benefit to children but currently not enough is known about their use in children to know for certain.

There are some clinical trials taking place in the UK to compare these anticoagulants to standard care for children with thrombosis.











# Frequently Asked Questions About Thrombosis in Children & Young People:

## How long does a child with thrombosis need an anticoagulant for?

This may vary depending on the known cause and the child's medical history.

Anticoagulants are usually continued for 3 months when the thrombosis has been 'provoked', meaning that there was a recognised reason for it happening.

Anticoagulants are likely to be continued for 6-12 months or longer when the thrombosis was 'unprovoked', meaning that there was no particular reason for it happening.

In some children, stopping the anticoagulant can be too risky as there is a high likelihood that they will have another clot. In these children it may be necessary to continue the anticoagulant long-term. The reason for this is usually that there is an abnormality (thrombophilia) making the blood more likely to clot, a congenital abnormality of the veins, or a long term disease that increases the risk of thrombosis.

## What are the side effects of anticoagulant treatment in children?

A child who is taking an anticoagulant may bruise more easily than normal and may bleed for a little bit longer from minor cuts and grazes. The major side effect of anticoagulant treatment is serious bleeding and this can include:

- Nosebleeds lasting for longer than 10 minutes
- Persistent bleeding from a cut or graze
- Heavy periods
- Blood in the urine
- Blood in the stool or dark stool
- Intracranial bleeding Bleeding in or around the brain. This can cause disability or death but is rare and would usually only occur if there was a significant head injury. Symptoms of intracranial bleeding include headache, drowsiness, change in behaviour, vomiting or fits

If any of these occur the child would need to be brought urgently to hospital for assessment.

IT IS IMPORTANT that anyone who looks after a child on anticoagulant treatment should be aware of the potential for bleeding and should know who to contact in an emergency. This includes relatives, nursery staff and their school-teacher.

Some parents arrange for their child to wear a Medicalert bracelet or necklace that provides information about their medical condition and anticoagulant treatment just in case something happens when there is no one around who knows about this.









## Can children still do physical activities or sports when they are on an anticoagulant?

It is important for children who have had a thrombosis to remain active as activity can reduce the risk of them having another blood clot. However, the risk of bleeding when a child is on anticoagulant therapy means that there are some restrictions:

- Boxing, rugby and martial arts have a high risk of head injury so should be avoided;
- A helmet should always be worn when riding a bike or a skateboard;
- There are many other sports that children like to do most of these are possible but protective equipment might need to be worn;
- It is important for the sports teacher to know about the child being on anticoagulant treatment.

## What are the consequences of having a thrombosis as a child?

Deep vein thrombosis can cause long-term problems with swelling, pain and skin changes of the affected limb. This is known a 'post-thrombotic syndrome' and it occurs in around 25% of children with DVT. It is usually mild but may mean that the child has to wear a tight stocking to help drain the blood from the limb and relieve the symptoms.

Pulmonary embolism can increase pressure in the blood vessels of the lung causing breathlessness on exertion.

Cerebral venous sinus thrombosis can cause neurological problems including fits, headaches and persisting weakness or numbness

A thrombosis in a kidney can cause high blood pressure or reduced kidney function.

A thrombosis in the liver can cause enlargement of the spleen gland. In some cases this can cause low blood counts and bleeding from vessels in the stomach and around the gullet.

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