Unprovoked Venous Thrombosis (VTE) or unexplained blood clots:

This leaflet explains more about blood clots that happen for no apparent reason

What is VTE?

A clot that occurs in the veins (tubes that carry blood towards the heart) is called venous thrombosis or VTE

This is **different** from a clot that occurs in your arteries (tubes that carry the blood away from our heart) example stroke/heart attack.

Deep vein thrombosis (DVT): This is a clot (also known as a thrombosis) that forms in a deep vein, most commonly in your leg or pelvis. Very occasionally it can happen in your arms too. It may cause no symptoms at all or cause swelling, redness and cramping pain.

Pulmonary embolism (PE): if a clot moves through your blood vessels it can become stuck in your lungs, this is called a PE. Symptoms include breathlessness, fainting, coughing up blood, and chest pain.
Quite often, a lung clot or PE can occur without any leg related symptoms suggestive of leg clot (DVT). Lung clots (PE) in some cases can be life threatening, particularly if left untreated or someone decides to stop treatment on their own.

Health professionals use the term **venous thromboembolism (VTE)**, to cover both DVT and PE.

It is rare for a DVT or PE to be life threatening if it is treated appropriately.

Why has my DVT/PE been called ‘Unprovoked’?

A DVT/PE is called **unprovoked** or idiopathic when there is **no explained reason** for it.
i.e. it has happened “out of blue”. About half of all DVT’s or PE’s (VTE) are unexplained.

If there is a reason for a clot we call it “Provoked”. Examples of this would be clots occurring following major surgery/trauma, orthopaedic procedures, OR in association with pregnancy or being on oestrogen treatment (example combined oral contraceptive pill).

If you have had any of these problems, or a family history of blood clots – particularly in a first degree relative – (your parent, sibling or child), you should let a doctor know, as it may influence your treatment plan.

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Why is it important to know if it is 'Unprovoked' or 'Provoked'?

This is important as it influences the duration of your treatment. Usually, most people with **Unprovoked DVT/PE** will need to take **long term** blood thinning medication (anticoagulant) to prevent the clot from occurring again.

With a **Provoked DVT/PE** the **treatment duration is shorter** (3 to 6 months).

How long do I need treatment for?

Unprovoked DVT/PE have a quite high risk of occurring again if you stop the anticoagulant.

Approximately 10% of people with an unprovoked DVT/PE will get another DVT/PE within a year if they stop their anticoagulant after just few months. This goes up to 16% in 2 years, 25% in 5 years and 36% in 10 years.

That means that if someone develops a blood clot with no obvious cause, and they stop their treatment after 3 or 6 months, it is very likely they will have another clot in the next 10 years. Some blood clots can be life threatening, particularly if untreated, so it is important not to stop treatment with anticoagulants too soon.

We now believe that for people with an unprovoked clot, blood thinners should be taken long-term (often lifelong), in order to try and reduce the risk of it happening again. However, we take into consideration the size of the clot and likelihood of recurrence individually and will discuss with you the options at your specialist review appointment.

Are there any risks of being on anticoagulant (blood thinner) treatment?

Yes. Unfortunately, no medication is without any risk, however, millions of people take anticoagulant treatment without a problem.

Anticoagulants increase the time to form a clot so if you hurt yourself you may bleed for slightly longer or have a bigger bruise. We do advise, therefore, against heavy contact sports which would put you at risk of a serious injury. If you were to accidently have a potentially serious injury, eg. bang your head, you should quickly tell a doctor and get checked out immediately.

The overall risk of bleeding on anticoagulation (from small bleeds to big bleeds) is still thought to be very small, around 1.2 in 100 every year. (12% risk in 10 years.).

The risk from bleeding when taking anticoagulants is a lot lower than the risk of developing a clot (36% in 10 years)

Who should I discuss ongoing treatment for a blood clot with?

If you have been diagnosed with unprovoked clot (VTE) you will get an appointment for a specialist clinic review at the hospital. Please do not stop taking the anticoagulant until you have been seen in the specialist clinic where you can discuss any questions you have about your condition or treatment.

After this appointment your GP will be responsible for your future treatment.

Will the dose of my anticoagulant ever change?

At the start of your treatment you will be asked to take a bigger dose and this will be reduced after 1 week or 3 weeks depending on the medicine you are prescribed. You will receive an information booklet and the medicine will be clearly labelled with the amount of medicine to take and when the dose will be changed. Do not run out of tablets or stop taking. If you are unsure about how to take your medicine please ask your pharmacist or nurse.

After 6 months, the dose of your medicine **may** be again reduced as the risk of developing further clots will be lower. If you have other conditions that increase the risk of clots the dose would not be reduced.

Please contact your doctor if you are not clear what dose you should be taking.

Why has someone suggested I need a CT scan of my abdomen?

Sometimes we decide to perform a CT of your abdomen and pelvis.

When there is no reason for a clot, very rarely, around 1 in 20 people, especially where the clot is big, will have an underlying cancer. Therefore we like to do certain tests afterwards to screen for this. The tests usually include a chest xray to look at the lungs, breast examination in females, certain blood tests, and a CT scan of the rest of your body (abdomen and pelvis).

Sometimes these detailed tests may show little things that we were not intentionally looking for. Doctors call these 'incidental findings'. Incidental findings can then cause extra anxiety and the need for more tests. If you would not like to have this scan for some reason, please do feel free to tell us.

Do I need any scans to show the clot has gone?

In most cases no. The anticoagulant treatment you have should mean that your symptoms improve. We would only do more tests if your symptoms were very significant or getting worse after a few weeks or months. With some bigger blood clots, improvement can take a month or two though. Quite a number of patients, following a lung clot, experience very short episodes of chest pain (few seconds to minutes) despite treatment but these are usually incidental and nothing to worry about. However, if you experience persistent pain or symptoms – please seek prompt medical help.

When can I resume normal work or activities?

There is no one answer as blood clots affect people in different ways. Some people have a blood clot with hardly any symptoms; others really find it difficult to even walk.
We would suggest you can return to work 'after an appropriate period of recovery', which is usually a few days, but in some cases can be longer. Feel free to ask your doctor for their perspective on your own personal circumstances.

Can I take part in sporting activities?

Most individuals can continue sporting activities. We do advise avoiding heavy contact sports such as rugby whilst taking anticoagulants as you are more likely to bleed with injury. Most other sporting activities should be fine.

Should I take anticoagulants if I am or become pregnant?

No. They are not licenced for pregnancy and could do harm. There are other treatments available for individuals who are pregnant. Please ask your doctor if this applies to you.

Are there any long term complications of a DVT?

One complication of DVT is called post-thrombotic syndrome or PTS. Most individuals will not develop this complication, however, people who have bigger blood clots are at higher risk. Damage caused by the original blood clot causes longer term symptoms of: aching or cramping of the leg, a feeling of heaviness, tingling or pins and needles, discoloration, hardening of the skin, or varicose veins.

If you develop these symptoms see your GP. It usually does not mean your blood clot has come back, but that the veins in your leg may have been damaged by the increase in pressure caused by the blood clot. This can happen even after the clot has dissolved. Treatments include raising your leg when you are sitting, taking regular exercise, sometimes losing weight and taking painkillers. None of these treatments are 100% effective and you may need to use a combination of them all in order to try and relieve symptoms. We do not advise wearing special compression stockings routinely at present as evidence does not support this.

Another complication of a DVT is that it can travel to the lungs and cause a pulmonary embolism (PE). This can cause chest pain that hurts when you take a breath in, and shortness of breath or sudden collapse. These symptoms usually come on suddenly. If you experience any of these symptoms seek medical advice straight away.

Note: The risk of you developing a PE is very low if you are taking your prescribed anticoagulant.

Do I need a test to check for Thrombophilia?

Thrombophilia is when your blood is abnormal in some way and means you will be at higher risk of developing blood clots. There are a few genetic tests that are done in certain circumstances, particularly when someone with a blood clot has a first degree relative who has also had an unprovoked DVT. Guidelines suggest we only refer people for genetic testing when it might influence management, for example if we were thinking about stopping treatment early for some reason. Even if someone had a thrombophilia, we would be recommending ongoing protective anticoagulation in most individuals so it is not something that influences ongoing treatment. Thrombophilia testing, therefore, is not recommended unless you or your doctor was planning to stop treatment for some reason.

Is it safe for me to travel following VTE?

Most people following an ‘unprovoked VTE’ will continue to take blood thinners (anticoagulation) long-term. This will provide protection against getting a new VTE (blood clot) and so you will be safe to travel. However, if you have stopped taking blood thinners (anticoagulation) or you are due to stop taking them and you are planning long haul journey, we advise that you **seek specialist advice before travelling.**

If you have any comments about this leaflet or the service you have received you can contact :

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If you would like this information in another format or language contact the above.

Potřebujete-li tyto informace v jiném formátu nebo jazyce, obraťte se prosím na výše uvedené oddělení

Jeżeli są Państwo zainteresowani otrzymaniem tych informacji w innym formacie lub wersji językowej, prosimy skontaktować się z nami, korzystając z www. danych kontaktowych

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Written by: R Karadi / A Hashimi (Consultant Physicians CHFT)

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