

Haematology Department

Information for patients following an episode of venous thrombosis (DVT or PE)

What are deep vein thrombosis and pulmonary embolus?

- It is essential that blood remains fluid within the circulation but clots at the site of an injury. Blood should not clot within a blood vessel. Thrombosis is the name given to a blood clot within a blood vessel.
- Deep vein thrombosis (DVT) is the name given to blood clots forming within the deep veins. The most common site for a DVT is the deep veins in the legs.
- A clot below the level of the knee is called a **calf-vein DVT**. A clot behind the knee or above the knee is called a **proximal DVT**.
- A DVT can occasionally affect other veins in the body.
- When a DVT forms, pieces of the clot can break away and pass through the circulation and lodge in the blood vessels in the lungs. These vessels are known as pulmonary arteries. This type of clot is termed a **pulmonary embolus (PE)**.
- When a pulmonary embolus occurs, the piece of clot that has broken away from the DVT often breaks into small pieces when it enters the pulmonary arteries and this causes multiple defects on the lung scan. Therefore, it is usual for the diagnostic scan to show 'multiple PEs'. The number of PEs on the scan at diagnosis does not usually affect treatment or outcome (see below).
- Deep vein thrombosis (DVT) and pulmonary embolus (PE) are collectively known as venous thrombosis (VT) or venous thromboembolism (VTE).

Why do DVT and PE occur, and what is the difference between a provoked and an unprovoked clot?

- The blood clotting process is in a delicate balance so that blood remains fluid within the circulation but clots at the site of an injured blood vessel. The balance can be shifted toward clotting so that clotting actually occurs in the circulation within a blood vessel, this is thrombosis.
- In about half of the patients who develop a DVT or a PE the clotting balance has been shifted by something which we call a provoking factor. When a provoking factor is identified we call this a provoked DVT.
- Recognised provoking factors include:
 - Hospitalisation in the previous three months, including operations.
 - Major trauma including major fractures.

- Pregnancy.
- Oral contraceptive use and hormone replacement therapy.
- Very occasionally, immobilisation for at least several days.
- Patients who suffer a **calf-vein DVT** are at low risk of a clot occurring spontaneously in the future, regardless of whether it was provoked or unprovoked and so they are treated with anticoagulant therapy for only three months.
- Patients who suffer a **provoked proximal DVT or a PE** are at low risk of a clot occurring spontaneously in the future and so they are treated with anticoagulant therapy for at least three months.
- Patients who suffer an **unprovoked proximal DVT or a PE** are at risk of a clot occurring spontaneously in the future. These patients are seen in the Thrombophilia clinic after stopping anticoagulant treatment. The purpose of this clinic appointment is to begin to investigate their risk of further clots and produce a personalised care plan.

How is my DVT or PE treated?

- Once a diagnosis of DVT or PE is made, anticoagulant therapy should be started. It is necessary to give a drug that acts immediately, such as heparin by injection. An oral drug such as warfarin is often started at the same time but it takes a few days (often about five days) for it to produce an anticoagulant effect, hence the need for heparin in the first few days. When the warfarin is working the heparin is stopped.
- Patients on warfarin need to have a regular blood test known as an International Normalised Ratio (INR) test.
- The INR measures the anticoagulant effect of the blood and allows the dose of warfarin to be adjusted to maintain a satisfactory level. This aspect of treatment is supervised by your anticoagulant team.
- The average daily dose of warfarin required to achieve an INR of 2.5 is between 3 and 5mg. Occasionally some patients require as little as 1mg, and some as much as 25mg.
- The INR varies continuously whilst you are on warfarin - this is expected. The aim is to keep the INR as close to target as is required (the target INR is 2.5 in most patients). We expect at least 50% of INRs to be between 2.0 and 3.0 and about 75% to be between 1.5 and 3.5. Any INR above 5.0 is undesirable.
- If you have had either a **calf-vein thrombosis** or a **provoked proximal DVT or a PE** you should stop taking warfarin on the date instructed by your anticoagulant team. You do not need to reduce the dose gradually, you just stop it. When you have stopped warfarin you do not need any more INR tests and you do not need to be seen in the Thrombophilia clinic and an appointment will **not** be made.
- If you have had an **unprovoked proximal DVT or a PE** you should be seen in the Thrombophilia clinic at the end of your initial treatment on warfarin therapy. Blood tests to determine risk of future blood clots cannot be performed in the first three months of anticoagulant treatment.

How will I know if I have another DVT or PE?

- The majority of patients who suffer a DVT or PE never have a further DVT or PE.
- Some patients who suffer an **unprovoked proximal DVT or a PE** are at higher risk of recurrence and these patients are reviewed in the Thrombophilia clinic and given a personalised care plan.
- After a DVT 50% of patients suffer recurrent pain and swelling in the affected leg. This is due to damage to the vein and is called the **post-thrombotic syndrome (PTS)**. The symptoms of PTS are very similar to DVT and so patients wonder how they will know if they are having a new DVT. Our best advice is:
 - 1) To recommend that you wear a well fitted below knee compression stocking for at least six months and in some cases up to two years as this will minimise PTS and reduce the risk of further DVT.
 - 2) If your usual symptoms tend to get worse during the day and are easier after elevating the leg or after a nights sleep then this is most likely PTS and not a new DVT.
 - 3) If you develop new symptoms, or your usual symptoms suddenly become worse and do not get better after a nights sleep, you may be developing a new DVT and you should contact your General Practitioner who can arrange for you to have an ultrasound examination at your local hospital.
- After a PE many patients suffer occasional sharp chest pain lasting no more than a few minutes. If you develop new persistent chest pain or start to have breathing difficulty or cough up blood then you may be developing a new PE. You should contact your doctor who can arrange for you to have investigations at your local hospital.

What is the major problem with warfarin?

- The major problem with warfarin treatment is bleeding. This is most likely to occur when the INR result is above 5.0. The usual cause of an INR greater than 5.0 is an intercurrent illness or prescription of a new drug, particularly an antibiotic. Therefore, we recommend that if you start a new drug that you will be taking for more than five days then you have your INR checked after five days. If your INR is rising rapidly then the dose of warfarin can be reduced.

Should I take any special precautions in the future?

After a DVT or a PE you can reduce any risk of a further clot by:

- Improving your general level of fitness and mobility.
- Reducing your weight if your BMI is above 30kg/m².
- Stopping smoking if you are a smoker.
- Avoiding use of oestrogen-containing hormones including combined oral contraceptive pills (COCs) and hormone replacement therapy (HRT).

- Women who become pregnant should contact the haematology department so a clinic appointment can be arranged and a care plan agreed.
- If you are hospitalised you must inform the doctors and nurses that you have previously had a DVT or a PE. They can arrange simple treatment to reduce your risk of a further clot if they consider you to be at risk of DVT or PE whilst you are in hospital.



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

patient.information@addenbrookes.nhs.uk



Document history

Authors	Nurse Consultant
Department	Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk
Contact number	01223 217128
Publish/Review date	March 2012/March 2015
File name	Patient_VTE_information
Version number/Ref	3/PIN2531