

Post thrombotic syndrome and chronic venous insufficiency

This leaflet explains the pathway followed at this Trust for patients with post-thrombotic syndrome and chronic venous insufficiency. It also provides information on what you can expect when you come to hospital.

If you have any further questions or concerns, please speak to the doctor or nurse looking after you.

What is post-thrombotic syndrome (PTS)?

Post-thrombotic syndrome (PTS) is the long-term effects that can occur after a deep vein thrombosis (DVT) in the legs. Generally, one in three (33%) people who have had a DVT will develop some degree of PTS within five years. However, most symptoms will happen within two years. People with a history of recurrent DVT (more than one DVT), and people in whom the first DVT was extensive (involving the veins in the pelvis and groin) are at higher risk of PTS.

Thrombosis may be asymptomatic, so PTS can appear without a prior diagnosis of DVT.

When you have a DVT, it causes a blockage in the vein which affects the blood flow returning from the leg back to the body. This is initially managed with anticoagulation (medication which stops the blood clotting as quickly as normal). Sometimes, despite this treatment, some degree of blockage remains and can lead to symptoms of PTS.

DVT can also damage the valves in the veins which are there to help return the blood back towards the heart. Scarred veins (with old clot) and/or damaged valves can cause PTS. For more information about DVT, see our leaflet, **Deep vein thrombosis**, please ask for a copy.

What are the signs and symptoms?

The signs and symptoms of PTS are individual to each person, and may include:

- Chronic pain, aching and heaviness of the leg
- Itching
- Pins and needles
- Oedema (swelling) of the leg
- Varicose veins
- Brown discolouration (hyperpigmentation) around the ankle
- Ulceration (in severe cases).

Some of these symptoms may also occur in people who have not suffered from a DVT. In such a case this is referred to as chronic venous insufficiency (CVI).

The pain, heaviness and swelling of the leg in PTS are often worse after sitting or standing for long periods. It is usually helped by mobilising (walking).

If severe PTS remains untreated, it can lead to skin ulceration, particularly around the ankles.

We normally use a tool called the Villalta Scale to measure the severity and degree of your PTS. The clinical nurse specialist (CNS) will assess this when you come to the clinic.

What is the difference between deep vein thrombosis (DVT) and post-thrombotic syndrome (PTS)?

It is often difficult to distinguish a new DVT from PTS, but if you experience a sudden onset of increased leg swelling and/or pain, you should seek urgent medical advice. It is important to report any sudden changes in the leg affected by PTS so that a new DVT can be excluded by your doctor. Blood tests and an ultrasound scan can be done to rule out a new DVT. The ultrasound is a painless test that checks the blood flow in your leg and pelvis.

The risk of having a recurrent DVT is determined by the original cause of your DVT. If you have recurrent DVT's it may be due to an underlying blood clotting problem for which a haematology doctor will investigate if needed.

Your appointment with us

We have dedicated venous clinics where you will be seen by a member of the venous team. These clinics take place in Gassiot House at St Thomas' Hospital. In addition to your outpatient clinic we run a dedicated same day pre-assessment clinic. If you are expecting to be listed for surgery please allow enough time to attend this.

Giving my consent (permission)

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

Is there anything I can do to help myself?

- If you smoke, you may be asked to stop smoking, as this increases the risk of developing a chest infection or DVT. If you would like to give up smoking, please speak to your nurse or call the Trust stop smoking service on **020 7188 0995**, or call the NHS Smoking Helpline on **0300 123 1044**. You can also speak to your GP.
- Exercise can improve PTS outcomes. It helps in the development of collateral vessels and calf muscle pump function.
- Eat a healthy balanced diet with plenty of fresh fruit and vegetables (high in fibre) and drink plenty of water. This would also help with the constipation that some painkillers can cause.
- Try to lose weight (if you are overweight), because increased weight puts more strain on the veins.

- Avoid dry skin on your legs. Wash and moisturise your legs regularly. Dry skin is more easily damaged.
- Do not try to heal any leg wounds yourself, even though they appear to be small. Small bites or scratches can soon develop into ulcers, prompt advice from your GP or Practice Nurse is recommended.

What happens after the appointment?

After your appointment at the venous clinic, your case will be discussed in our venous multidisciplinary team meeting (MDM) with other members of the team (haematology, interventional radiology and vascular doctors). This is so that we can ensure all aspects are covered as it is often a complex problem. In addition, most patients will be referred for review by the haematology team in the thrombosis clinic. This may be decided after discussion in our venous MDM. If this is the case, you will be notified and sent an appointment through the post.

What treatments are available?

Treatment options for PTS include:

- Conservative (i.e. management with anticoagulation therapy and/ or compression stockings and exercise). Compression stockings may help manage some of the symptoms (swelling, heaviness and even pain). They help with the blood flow in your legs and the venous return. Stockings can be obtained from the patient appliances department at Guy's and St Thomas' hospital or on prescription from your GP. You will need to replace them at least every three to six months, or if they become damaged and lose elasticity.
- Endovascular procedure (performed in either our hybrid theatre or interventional radiology department)
- More extensive surgical reconstruction procedure.

On occasions it may be a combination of all the above options. It is important to understand that all treatment options (either conservative or interventional) carry risks together with the benefits they may offer. These are specific to individual patients and will be discussed with you before any decision to treat is made.

What happens if I do not receive treatment?

There is no cure for PTS, it is a chronic condition. However, the treatments offered above are to control or reduce symptoms and reduce the risk of ulceration.

Will I have a follow-up appointment?

You will be sent a follow up appointment in the post. Your follow-up appointment will usually be in the vascular outpatients department at Gassiot House, St Thomas' Hospital. This appointment will be with your vascular consultant or a member of the venous team. If you have had surgery, you will need to have scans at regular intervals to make sure that the stent remains open. You will have your first scan after two weeks and see your consultant in the outpatient clinic after around six weeks.

Useful sources of information

The vascular unit at St Thomas' hospital is one of the leading vascular units in Europe for treatment for deep veins disease and post-thrombotic syndrome. For more information, please visit our website www.guysandstthomas.nhs.uk

Help to stop smoking:

Guy's and St Thomas' stop smoking service - 020 7188 0995
NHS Smoking Helpline - 0300 123 1044

Thrombosis UK - Thrombosis Charity

www.thrombosisuk.org

Contact us

If you have any further questions or concerns, please do not hesitate to contact the vascular clinical nurse specialist for deep venous disease on **0207 188 7188 ext 50890**.

Out of hours, you can contact the vascular wards **Luke Ward on 020 7188 3566 or Sarah Swift Ward on 020 7188 8842** (24 hours) and speak to the ward sister or nurse in charge.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals (i.e. DVT information leaflet), please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Leaflet number: 4403/VER1

Date published: May 2017

Review date: May 2020

© 2017 Guy's and St Thomas' NHS Foundation Trust