Post thrombotic syndrome (PTS) and chronic venous insufficiency

This leaflet explains the pathway followed at Guy's and St Thomas' Hospitals for patients with PTS and chronic venous insufficiency. It also gives information on what you can expect when you come to hospital. If you have any questions or concerns, please speak to the doctor or nurse looking after you.

What is PTS?
It 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 5 years. However, most symptoms will happen within 2 years. People with a history of recurrent DVT (more than one DVT), and people whose first DVT was extensive (involving the veins in the pelvis and groin) are at higher risk of PTS.

Thrombosis may be asymptomatic (show no symptoms), so PTS can appear without a previous 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. At first this is managed with anticoagulation (medication that stops the blood clotting as quickly as usual). 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 to 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 of PTS?
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 discoloration (hyperpigmentation) around the ankle
- ulceration (in severe cases).

Some of these symptoms may also occur in people who have not suffered from a DVT. These cases are called 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.

**The difference between DVT and 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. An 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 DVTs it might be due to an underlying blood clotting problem, which a haematology doctor will investigate if necessary.

**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.

**Consent – asking for your consent**

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 you can do to help yourself?**

- If you smoke, you might 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 our stop smoking service, t: 020 7188 0995, or call the NHS Smoking Helpline, t: 0300 123 1044. You can also speak to your GP.
- Exercise can improve PTS outcomes. It helps develop collateral vessels and calf muscle pump function.
- Eating a healthy, balanced diet with plenty of fresh fruit and vegetables (high in fibre) and drink plenty of water is important. This also helps with the constipation that some painkillers can cause.
- Trying to lose weight (if you are overweight) is helpful, because increased weight puts more strain on your 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. Getting advice quickly from your GP or practice nurse is recommended.
What happens after your appointment
After your appointment at the venous clinic, your case will be discussed in our venous multidisciplinary team meeting with other members of the team (haematology, interventional radiology and vascular doctors). This is so that we can make sure all aspects are covered as it is often a complex problem. Also, most patients will be referred for review by the haematology team in the thrombosis clinic. If this is the case, you will be sent an appointment through the post.

Other treatment options available
Treatment options for PTS include:

- **Conservative** (such as 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’ Hospitals or on prescription from your GP. You will need to replace them at least every 3-6 months, or if they become damaged and lose elasticity.
- **Endovascular procedure** (done in our hybrid theatre or interventional radiology department)
- **More extensive** surgical reconstruction procedure.

Sometimes it may be a combination of all the above options. It is important to understand that all treatment options (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 about treatment is made.

What happens if you 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 you 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 2 weeks and see your consultant in the outpatient clinic after about 6 weeks.

Useful sources of information
Thrombosis UK - thrombosis charity, w: www.thrombosisuk.org

Contact us
If you have any questions or concerns, please contact the vascular clinical nurse specialist for deep venous disease, t: 020 7188 7188 extension 50890.

Out of hours, you can speak to the ward sister or nurse in charge on the vascular ward, Sarah Swift Ward, t: 020 7188 8842.

For more information leaflets on conditions (such as DVT), procedures, treatments and services offered at our hospitals, visit w: www.guysandstthomas.nhs.uk/leaflets

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Our values: Put patients first | Take pride in what we do | Respect others | Strive to be the best | Act with integrity