

Post thrombotic syndrome (PTS)

Post thrombotic syndrome, sometimes also known as post phlebotic syndrome, is a common and underappreciated complication of deep vein thrombosis. It is a chronic and potentially disabling condition, caused by damage to the veins, resulting in increased pressure on the vein walls that damage the valves which normally work to keep blood flowing up the leg. A reduction in the amount of blood being carried away from the foot and lower leg can lead to pain, swelling and, in the most severe cases, leg ulcers which are often slow to heal. Up to 30% of people who have had thrombosis in the leg will develop some post thrombotic symptoms within five years. Most episodes of post thrombotic syndrome will develop within six months to two years of the initial thrombosis. Some people will go on to develop severe problems, including venous ulcers and severe pain.

People who have had more than one episode of deep vein thrombosis in the same leg are at higher risk of developing post thrombotic syndrome. People with DVT in the upper body may also develop post thrombotic syndrome in the upper body, but this is much less common than PTS in the lower body. There are no established treatments or prevention methods for PTS in the upper body, but patients may find that wearing a compression sleeve helps reduce pain and swelling.

Post thrombotic syndrome is a persistent and debilitating long-term condition which can have a significant effect on a patient's quality of life. It can produce both physical and psychological symptoms which can limit a person's day-to-day activities, sometimes quite markedly. Some patients may need to stop taking part in certain sporting and other leisure activities, and many people find that their PTS also reduces their self-esteem and affects their family and personal relationships. At work it can cause loss of productivity, lead to adaptations needing to be made to work environments or practices, or may even mean the patient can no longer work at all.

Physical signs and symptoms of PTS may include:

- aching or cramping;
- a feeling of heaviness in the limb;
- itching, tingling or pins and needles;
- swelling;
- discoloration of the skin;
- hardening of the skin;
- varicose veins; and
- venous ulcers.

The symptoms can be mild, moderate or severe and can differ hugely between patients. PTS symptoms are typically worse after walking or standing for long periods, although we have found many people also report problems after sitting for long periods, and these symptoms often improve after resting or sitting with the limb raised.

Psychological symptoms of PTS may include:

- depression;
- anxiety; and
- loss of confidence.

The most effective way to avoid post thrombotic syndrome is to prevent deep vein thrombosis from happening in the first place. Know what your risks are and reduce them if you can. Risk factors for developing deep vein thrombosis include the following.

- A recent stay in hospital due to any illness or for surgery, especially on the hips or knees
- Increasing age (but it can and does affect younger people)
- Immobility
- Previous deep vein thrombosis
- Previous deep vein thrombosis in the family
- Cancer and its treatment
- Pregnancy
- The use of the combined oral contraceptive pill and hormone replacement therapy (HRT)
- Known thrombophilia (sticky blood)
- Long-distance travel

If you are an inpatient in hospital you will have an assessment to see whether you are at risk of developing blood clots as a result of being in hospital. If the assessment shows you are at risk, you will be given small doses of blood thinners. You can also reduce your risk by limiting the amount of time you spend either lying in bed or sitting in a chair during the day, so get up and move about regularly if possible.

Treatments for post thrombotic syndrome

Physical treatment options may include sitting with the leg raised, wearing grade-2 compression stockings, taking regular exercise, losing weight, taking painkillers and caring for the wound if you have venous ulcers. In more extreme cases, intermittent pneumatic compression, which involves using a pump to apply external pressure to the leg by inflating and deflating plastic 'boots' can be used. Painkillers are often recommended to help reduce the soreness of the calves associated with post thrombotic syndrome.

Although the treatment of post thrombotic syndrome with drugs has been studied, drugs are not widely used because none have been shown to be of major benefit. If standard treatment is not working for you, and particularly if you develop leg ulcers due to poor blood flow, your doctor may consider referring you to a vascular surgery to see if there is a surgical procedure that might help, although this is not a suitable for most patients.

An often overlooked but very common problem for many patients who have had a deep vein thrombosis, and especially those who have had a pulmonary embolism, is the overwhelming anxiety they experience in the weeks, months, and even years after their initial condition. They are often afraid that the condition will come back and they liken the condition to a near-death experience which, in some cases, it was. Psychological treatment can include counselling, group therapy and cognitive behavioural therapy (a talking therapy that can help you manage your problems by changing the way you think and behave, also known as CBT) or, in more extreme cases, antidepressants and other psychotropic drugs (drugs that affect a person's mental state).

However, we have found that in many areas of the UK it can be difficult for people to get support for the psychological side of post thrombotic syndrome, and we would like to hear from you if you have difficulties. There are still many unanswered questions about post thrombotic syndrome and much more research is needed to understand what causes PTS, how to prevent it and how to treat it, and to understand why some people seem to be more prone to it than others.

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