



What you need to know about PTS and DVT

You have been told you have a blood clot in your leg called a DVT (deep vein thrombosis). This brochure explains a common long-term side effect of DVT called Post-Thrombotic Syndrome, or PTS. If you have any questions or concerns after reading this brochure, be sure to write them down and share them with your health care provider.

What is Post-Thrombotic Syndrome (PTS)?

Post-Thrombotic Syndrome is when you have the ongoing symptoms of a blood clot, or deep vein thrombosis (DVT), in the leg. Some people who have had DVT or blood clots in the leg recover completely, but others still experience symptoms, and these symptoms are called PTS.

Why is PTS a problem?

PTS can cause leg pain and discomfort, as well as leg ulcers. These symptoms may last for many years, or for the rest of your life. PTS can interfere with some of your regular activities, such as walking or standing, and it can make your life less enjoyable. Treatment for PTS and PTS ulcers can be expensive and time-consuming.

What causes PTS?

The veins deep within the legs have tiny valves that control the direction of blood flow. A blood clot in a leg vein can cause inflammation and block blood flow, which damages the valves. When the valves are damaged, they can leak or cause blood to flow the wrong way, which creates pressure and fluid retention that people with PTS most often notice as swollen ankles or feet. The pressure makes the leg painful, swollen, and sometimes red in color. As PTS gets worse, poor blood flow through the leg can cause leg ulcers, which can be painful and difficult to treat. Ulcers occur in 5-10 percent of patients who have had a DVT.



What is the chance I will get PTS?

PTS occurs in 20-40 percent of patients after an episode of lower extremity DVT, so it is a common complication. One out of 10 patients may develop severe PTS with leg ulcers.

Over 20% of people who have had a DVT develop PTS. Will you?

You are more likely to get PTS if you:

- are over age 65 years
- have a blood clot in the deep veins above the knee (a condition called proximal DVT)
- have more than one blood clot in the same leg at least twice
- have blood clot symptoms one month after being diagnosed with the blood clot
- are very overweight
- have trouble keeping your blood thinner levels stable during your first three months of treatment

How soon after my blood clot can I get PTS?

It is difficult to predict who may or may not get PTS, but it may be any time in the first six months to two years after the blood clot develops in the leg.

How do I know if I have PTS?

These are the most common signs and symptoms of PTS that occur in the leg with the blood clot:

- Pain
- Swelling that gets worse after walking or standing for a long time, but feels better after resting or raising the leg
- Aching or heaviness in your leg or foot
- Cramping
- Itching
- Tingling
- Bluish or brownish pigmentation in the leg or foot
- An ulcer (sore) on the leg
- New varicose veins
- Skin that is flaky, dry, or red

These problems are different for every patient – you may have all of these problems or only a few. You may notice these problems all the time or the feelings may come and go.

What should I do if I think I have PTS?

Many of the signs of PTS are the same as those for new blood clots in the leg, so it is very important for you to ask your health care provider to look at your leg. Only a health care provider can tell you if your problems are from a new blood clot or from PTS.



How is PTS diagnosed?

Your health care provider will look at your leg and ask you some questions about how your leg feels. Then he or she will tell you if you have PTS. You do not need any special scans or blood tests to find out if you have PTS.

How can I prevent PTS?

Since PTS can be such a long-term problem, prevention is very important. Here are some things you can do to prevent PTS:

• Prevent blood clots. Blood clots cause the damage to the leg veins that causes PTS. If you prevent blood clots, you will prevent PTS.

• Some people are at higher risk of getting blood clots, especially patients in the hospital who have had recent surgery or are confined to bed. Patients are often given compression boots, compression stockings, or medicine to prevent blood clots while in the hospital and when they go home. If you are in the hospital and you are not given any of these things, ask your health care provider if you need blood clot prevention.

• If you have already had a blood clot in the leg, you are at increased risk of getting a second blood clot. The best way to prevent a second blood clot is to take your blood thinner medication correctly and follow your health care provider's instructions for having blood tests.

• Do not stop taking your blood thinner medication until your health care provider tells you to stop.

Lose weight if you are overweight.

Increased weight puts more strain on the leg veins.

Wear graduated (elastic) compression stockings.

Wearing a special elastic stocking on the leg with the blood clot may help prevent PTS. See the booklet called "Focus on Elastic Compression Stockings" for information on how to get stockings and how to wear them correctly. See your health care provider regularly. Your health care provider can examine your leg at every appointment to look for signs of PTS. He or she can also advise you about wearing elastic compression stockings and about taking your blood thinner medication correctly.

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What is the treatment for PTS?

PTS can be a difficult health condition to treat, so your health care provider may tell you to use one or all of these possible treatments:

Leg elevation. Often elevating your leg correctly can help with the pain and swelling from PTS.

Compression. Your health care provider may prescribe either graduated compression stockings or a device worn on the leg (or both) to improve blood flow and control pain and swelling.

Medications. Some studies have shown that herbal supplements such as aescin (horse chestnut extract) and rutosides can be helpful in relieving leg pain and swelling caused by PTS, but this preparation has not been approved by the FDA. Your health care provider may recommend these supplements if compression stockings are not enough to help your leg pain and swelling.

Special care for ulcers. If you get a leg ulcer because of PTS, you should see a special health care provider who has extra training in helping ulcers to heal. That health care provider may give you special medications or bandages for the ulcer.

How can I tell the difference between PTS and a new blood clot?

It can often be difficult to tell whether your leg problems are caused by PTS or a new blood clot. Sometimes it takes 3 to 6 months for your blood clot symptoms to get better. Anytime you have new problems with your leg, you should see your health care provider. In most cases of PTS, leg pain and swelling will get better when you

rest or elevate your leg. By contrast, if you have a blood clot, the pain and swelling will not get better with elevation and rest.

Why is PTS a problem?

PTS is a frequent side effect of DVT. Symptoms can come and go over time, but PTS is a chronic, lifelong condition. PTS leads to suffering and disability and is costly to society. Severe PTS can cause painful venous ulcers or sores on the arms or legs that are difficult to treat and tend to recur. Ulcers occur in 5-10 percent of patients who have PTS.

Why does PTS occur?

When a clot forms in a vein, the valves inside the vein can be damaged by the clot or by the surrounding inflammation. The damaged valves (as well as residual clot) block blood returning from the leg veins back to the heart, which results in increased venous pressure in the leg.

What is the difference between postthrombotic syndrome (PTS) and post-phlebitic syndrome?

Nothing – these are two names for the same condition. Another term sometimes used is “venous stress disorder.”

DVT can occur in up to one million people each year. PTS occurs in 20-40% of patients after an episode of lower extremity DVT.



Does having varicose veins make me more likely to get PTS?

Varicose veins occur in the small, superficial veins just under the skin. These veins can appear for many different reasons. People may get varicose veins even if they have never had a blood clot. On the other hand, PTS is caused by blood clot damage in the valves in the deep veins. If you have had a blood clot in your leg, you might develop varicose veins. Your health care provider will look for varicose veins to help determine whether you have PTS.

Are there medications or surgery to remove the blood clot in my leg so that my veins are not damaged?

Yes. This procedure is either called a thrombectomy, which is a surgery to remove the blood clot, or a thrombolysis, which is a surgery to dissolve the clot. These are risky procedures, and they are usually reserved for the most severe clots that may stop blood flow to the leg. It is not known whether these procedures would help prevent PTS.

If I already have PTS, can I have surgery to fix my veins?

There is no evidence that surgery to fix the veins in the leg or arm can prevent PTS. However, surgery to fix the veins in the leg or arm can improve the appearance of the veins and may help prevent further damage to the veins.

Can I do special exercises to treat PTS?

Yes. Certain types of exercise that keep your leg stronger and more flexible will improve your overall physical fitness and might help treat PTS.

If I have a blood clot in my arm, can I get PTS?

Yes. This type of PTS is called upper-extremity PTS. It is less common than PTS of the leg, but the symptoms and treatments are similar. Patients with upper-extremity PTS have pain and swelling in the arm. The treatment is to wear a special compression sleeve on the arm, similar to compression stockings for the legs.

If my blood clot was only in my lungs, can I get PTS?

Based on what doctors know now, PTS only affects patients who have had a blood clot in the leg or arm. Sometimes the blood clot starts in the leg and then breaks off and moves to the lungs. If a blood clot was found in your leg as well as your lungs, you may still be at risk for getting PTS. If you have never had any blood clot symptoms in your leg, and a blood clot was not found in your leg, it is unlikely you will get PTS.

Resources:

For more educational information on PTS, a DVT risk assessment quiz, an online support group and more: visit the Vascular Disease Foundation website www.vascular-disease.org

THE VASCULAR DISEASE FOUNDATION

Established in 1998, the Vascular Disease Foundation (VDF) develops educational information and initiatives for patients, their families and friends, and health care providers regarding often ignored, but serious vascular diseases. In fact, VDF is the only multidisciplinary national public 501(c)(3) non-profit organization focused on providing public education and improving awareness about vascular diseases. For more information, visit vascular-disease.org.

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