

Deep Vein Thrombosis
and
Pulmonary Embolism



ClotConnect.org

Information for
Newly Diagnosed Patients



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Terms and abbreviations used in this document

Arteries

The blood vessels that carry blood away from the heart, to the extremities (the legs and the arms), the organs in the abdomen, and the brain.

Deep Vein Thrombosis (DVT)

When a clot forms in the deep veins of the body, it is called deep vein thrombosis, often referred to as DVT for short. DVT occurs most commonly in the leg; although it can occur anywhere in the body, such as the veins in the arm, abdomen, or around the brain.

Pulmonary Embolism (PE)

A potentially life-threatening complication of deep vein thrombosis (DVT) is pulmonary embolism, often referred to as PE. A PE occurs when a blood clot breaks off, travels through the blood stream and lodges in the lung.

Thrombosis

The medical term for a blood clot that forms within a vessel.

Thrombophilia

The medical term for a blood clotting disorder.

Veins

The blood vessels that carry blood back to the heart from the extremities (the legs and the arms), the organs in the abdomen, and the brain.

Venous Thromboembolism (VTE)

DVT + PE are collectively known as VTE



A *Blood Clot Basics*

a) What is a Blood Clot?

Blood clotting is a normal, complex process that prevents excessive bleeding when a blood vessel is injured. Sometimes, clots form abnormally within a blood vessel. Clots can occur in both arteries and veins.

Arteries are the blood vessels that carry blood away from the heart, to the extremities (the legs and the arms), the abdomen, and the brain. **Veins** are the blood vessels that carry blood back to the heart from the extremities, the abdomen, and the brain.

→ Blood clots which form in veins are different from clots which occur in arteries.

1. **Clots in Arteries:** Blood clots which form in arteries lead to stroke, transient ischemic attack (TIA or mini-stroke), heart attack, or peripheral arterial clot and gangrene.
2. **Clots in Veins:** Blood clots which form in the deep veins of the body lead to **deep vein thrombosis** (DVT) and pulmonary embolism (PE). When a clot forms in the deep veins of the body, it is called deep vein thrombosis, often referred to as **DVT** for short. DVT occurs most commonly in the leg; however, it can occur anywhere in the body, such as the veins in the arm, abdomen, pelvis, or around the brain.

A potentially life-threatening complication of deep vein thrombosis (DVT) is **pulmonary embolism**, often referred to as **PE**. A pulmonary embolism occurs when a blood clot breaks off from a DVT and travels through the blood stream and lodges in the lung. Occasionally, a PE forms in the lung itself, without there being evidence of DVT in arms, legs, pelvis or the big vein in the abdomen. DVT and PE are collectively known as VTE (venous thromboembolism). Clots that break off from a DVT and travel do not typically lead to stroke, as they get filtered out by the lung.

→ Because blood clots which form in veins and arteries are different, their risk factors, symptoms, prevention and treatment are also different. This pamphlet focuses on clots which occur in the veins. Thus, in the following text, the term “blood clot” is used as meaning DVT and/or PE.

Clots in Arteries

Stroke

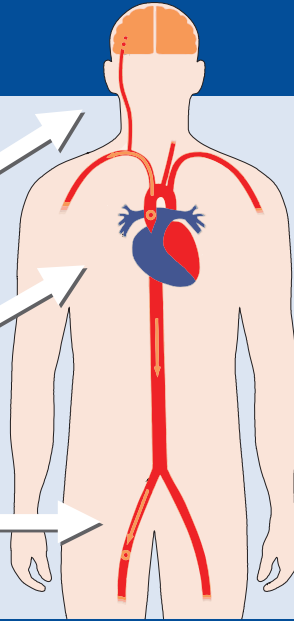
- Symptoms last less than 24 hours = TIA = ministroke
- Symptoms last more than 24 hours = stroke

Heart attack

= MI = myocardial infarction

Peripheral arterial clot

- = Gangrene. Extremity is:
- painful
 - cold
 - white/pale, later black



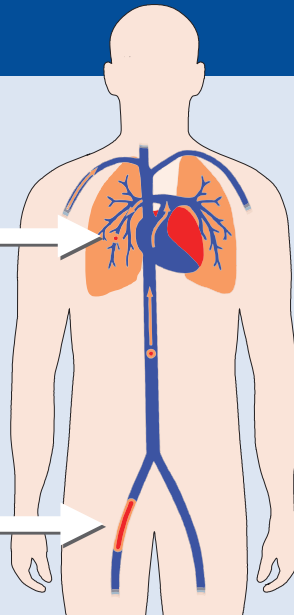
Clots in Veins

Pulmonary embolism (=PE)

- shortness of breath
- chest pain
- cough
- bloody sputum

Deep vein thrombosis (=DVT)

- swelling
- pain
- warmth
- blue-purple discoloration





b) What Causes a Blood Clot?

Blood clots may form when either the flow of blood in a vein slows, damage to a vein occurs, or the blood is more clotable. Many factors can increase a person's risk for developing a blood clot in a vein.

Common risk factors for developing a blood clot:

Immobility:

- Hospitalization
- Being paralyzed
- Prolonged sitting

Surgery and Trauma:

- Major surgery (especially of the pelvis, abdomen, hip, knee)
- Bone fracture or cast
- Catheter in a big vein (PICC line, central venous catheter, or port)

Increased estrogens:

- Birth control pills, patches, rings
- Pregnancy, including up to 6 weeks after giving birth
- Estrogen and progestin hormone therapy

Medical conditions:

- Cancer and chemotherapy
- Heart failure
- Inflammatory disorders (lupus, rheumatoid arthritis, inflammatory bowel disease)
- The kidney disorder called nephrotic syndrome

Other risk factors:

- Previous blood clot
- Family history of clots
- Clotting disorder (inherited or acquired)
- Obesity
- Older age
- Cigarette smoking
- Varicose veins

c) What are the Symptoms of a Blood Clot?

Symptoms of a blood clot can range widely from mild and barely noticeable to severe. While many patients have warning signs, some have no symptoms at all. The classic symptoms of deep vein thrombosis and pulmonary embolism are listed below.

Deep Vein Thrombosis (DVT):

A clot that most commonly occurs in one leg, but can also occur in the arm, abdomen or around the brain. Symptoms may involve the foot, ankle, calf, whole leg or arm.

- Pain
- Swelling
- Discoloration (bluish, purplish or reddish skin color)
- Warmth

Pulmonary Embolism (PE):

A blood clot in the lungs

- Shortness of breath
- Chest pain (which may be worse with deep breath)
- Unexplained cough (may cough up blood)
- Unexplained rapid heart rate

Symptoms of blood clots may also be subtle and easily confused with other medical conditions.

- Deep vein thrombosis (DVT) may be confused with sprained ankle, ‘Charley horse’, or pulled muscle.
- Pulmonary embolism (PE) may be misinterpreted as ‘a touch of pneumonia’, new onset of asthma, respiratory infection, inflammation of the joints of the breast bone or ribs.

Because symptoms of DVT and PE can mimic these conditions, a wrong or delayed diagnosis can occur in patients who eventually get diagnosed with DVT or PE.

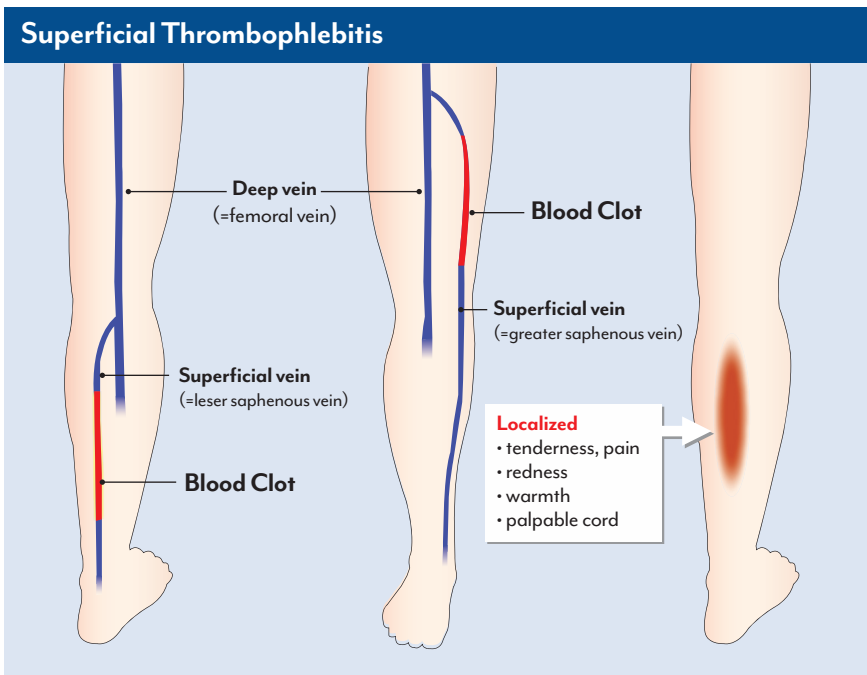


d) Superficial Blood Clots

Superficial thrombophlebitis, commonly called phlebitis for short, differs from a deep vein thrombosis (DVT). Phlebitis means ‘inflammation of a vein’.

- The veins which are affected in superficial phlebitis are near the surface of the skin. Superficial veins are smaller than deep veins and the risk for clots to break off and travel to the lung is much smaller.
- The veins which are affected in deep vein thrombosis (DVT) are much deeper inside the body and not near the skin. They are bigger than superficial veins and bigger pieces of clot are more likely to break off, travel to the lung and cause PE.

Clots associated with superficial phlebitis are usually not considered dangerous because there is a low risk of the clot breaking off, traveling through the blood stream and leading to a pulmonary embolism.



Symptoms of superficial phlebitis, which most commonly occurs in the legs or arms, are

- Tenderness or pain
- Redness
- Warmth
- A palpable cord may be felt

Treatment of superficial phlebitis includes application of heat or cold to the affected area for symptom relief, and use of NSAIDs (non-steroidal anti-inflammatory drugs) medications, such as ibuprofen, naproxen, ketoprofen, etc. Prescription ‘blood thinning’ medication is usually not needed, unless the clot is extensive or extends close to the deep veins. In that case “blood thinners” may be given for up to 6 weeks.

B *Diagnosis*

To determine whether you may have a deep vein thrombosis (DVT) or pulmonary embolism (PE), your doctor will ask you questions about your current symptoms and obtain your medical history to better assess your risk factors. A physical examination will be done to check for extremity swelling, tenderness and skin discoloration. If your symptoms, medical history and physical examination suggest that a blood clot is likely, testing will be done which may include:

Blood tests:

- **D-dimer** is a substance found in blood which is often increased in people with blood clots. A blood test can be used to rule out presence of a DVT. If the D-dimer test is negative and you are determined to have a low-risk for DVT (based upon the history and physical examination), further testing with an imaging study to rule out a blood clot may not be needed. However, if the suspicion that you have a blood clot is intermediate or high, an imaging study needs to be done.

Imaging studies which diagnose DVT:

- **Doppler ultrasound** (Duplex) is a painless and noninvasive test used to diagnose DVT. During a Doppler ultrasound, sound waves are used to



generate pictures of the blood vessels. In most cases, Doppler ultrasound is the preferred test to diagnose DVT.

- **Contrast venogram** is often reserved for situations in which a Doppler ultrasound is not feasible. During contrast venogram, a catheter is inserted into a vein and dye is injected, allowing your doctor to see the vein with an x-ray.
- **Magnetic resonance imaging (MRI)** uses a strong magnet to create an image of inside the body. MRI is reserved for situations in which a contrast venogram cannot be performed.
- **Computer tomography (CT)** venography or MRI venography are the preferred tests to look at blood clots in the pelvis or the abdomen.

Imaging studies which diagnose PE:

- **Computed tomography (CT scan)** uses a combination of x-rays taken from many different angles to produce detailed pictures of inside the body. An intravenous injection of contrast dye is given to make blood vessels more visible. A CT scan is the most common imaging study used to diagnose PE. It is also referred to as “CTA”, “spiral CT”, or “PE protocol CT”.
- **Ventilation/perfusion lung scan (V/Q scan)** is a nuclear medicine scan that uses a small amount of radioactive material to study the airflow (ventilation) and blood flow (perfusion) in the lungs.
- **Pulmonary angiography** involves insertion of a catheter into a vein—usually in the groin area. A dye is injected into the catheter and an x-ray is taken which highlights the blood vessels in the lungs. This is rarely done.

A chest x-ray cannot diagnose a pulmonary embolism.

A chest x-ray may be done to rule out conditions with symptoms which mimic pulmonary embolism. However, an X-ray typically is normal even when a pulmonary embolism is present. Thus, a normal chest X-ray does not rule out a PE - Additional imaging studies are required to diagnose pulmonary embolism.

C Treatment

The treatment of deep vein thrombosis (DVT) and pulmonary embolism (PE) are similar.

The goals of treatment are:

- To prevent an existing clot from growing in size
- To prevent the formation of new clots
- To prevent a DVT from breaking off, traveling through the blood stream and becoming a PE
- To prevent or minimize long-term complications.

a) Blood-Thinning Medications

The primary treatment for blood clots is blood-thinning medication, known as an **anticoagulant** or 'blood-thinner'.

These medications increase the time it takes for your blood to clot. They prevent new clots from forming and existing clots from growing larger. Over time, the body absorbs the clot, more or less successfully getting rid of them. Blood-thinners themselves do not dissolve the clot. They can be given as a tablet, or as an injection under the skin into the fat tissue, typically the abdomen, or into a vein.

1. Blood-thinners given into the vein or the skin

Fast-acting blood-thinners are given immediately after the diagnosis of a blood clot to prevent the clot from growing larger. So that the medication can begin to work immediately, these blood-thinners are given either intravenously (directly into a vein; i.v.) or by injections (a shot) into fatty body tissue (subcutaneously; s.c.). Several blood-thinners are available and your doctor will decide which of these medicines is best for you. They include:

- Heparin (given intravenously/directly into a vein), also called unfractionated heparin.
- Low-molecular weight heparin (abbreviated LMWH), which are medications injected into the fat tissue. (s.c., or subcutaneously). These drugs are **enoxaparin/Lovenox®**, **dalteparin/Fragmin®**, or **tinzaparin/Innohep®**.



- The injectables given into the fat tissues called **fondaparinux/Arixtra®** or **desirudin/Iprivask®**.
- LMWH, fondaparinux and desirudin are dosed based on a patient's body weight. They do NOT need to be monitored with the INR. In addition, their effect is NOT influenced by vitamin K in the diet, so there are no dietary restrictions for patients on these drugs.

2. Warfarin

While you are receiving one of the fast-acting injectable blood-thinners, you may be started on a blood-thinning pill called **warfarin**, which also goes by the brand names **Coumadin®** and **Jantoven®**.

- Blood-thinning shots and warfarin are given together at the start of treatment because it takes several days (at least 5 days) for the protective blood-thinning effect of warfarin to build up in your body.

The amount (dosage) of warfarin varies by person and is influenced by many factors (mostly metabolism, diet, and other interacting medications). Also, the same person can require different doses of warfarin at different points-in-time.

- You will need to have **frequent blood testing** to ensure you are getting the correct blood-thinning effect from warfarin, and your warfarin dose will be adjusted based on the blood test result.

This blood test is called **INR**, which stands for International Normalized Ratio. Sometimes this test might be referred to as **PT** or protime. The INR/PT test may be done as a finger stick test or by drawing blood from a vein.

INR testing measures how fast your blood clots and indicates how well your warfarin therapy is working and whether you are on the right dose. INR is expressed as a number. If the person is not on warfarin, the value is around 1.0 (typically 0.8-1.2). The goal number range of your INR, or target INR, will depend upon your medical condition and other issues. In most instances in the treatment of patients with DVT and PE the goal is 2.0-3.0. Your doctor will determine the appropriate INR range for you.

- Ask your doctor what your goal or target INR range should be.

Your health care professional will tell you how much warfarin you need and when to return for the first INR test. This is typically within 2-3 days of starting warfarin. In the first week after starting warfarin INR testing may be done 2-3 times. It is then stretched to 1-2 times per week in the following week. If the INR is in the desired range, testing is spread out. If the INR is stable, testing may only be done once per month. Your health care professional will provide you with additional information about starting warfarin. Many medications interact with warfarin. Foods which contain vitamin K also impact the blood-thinning effect of warfarin.

- Talk with your health care provider about **warfarin food and drug interactions** and be certain you understand how these affect your INR.
- Detailed information on foods rich in vitamin K can be found on www.clotconnect.org in the resource section.

3. Additional Oral Blood Thinners

Several oral medication choices are available to treat DVT and PE. Which drug to choose depends on a number of individualized factors and your doctor will decide with you which one of these medicines is best for you. As each of these drugs is different in its dosing, frequency and interactions, your doctor will give you specific instructions on how to take the drug recommended for you.

Make sure you understand how to take the medication you are prescribed. It is important to take blood thinners exactly as directed.

The oral blood thinner warfarin was the mainstay of treatment for nearly 50 years. In recent years, new oral anticoagulants have emerged which also offer effective treatment for DVT and PE. A comparison of these is in the table shown on the next page.



	Warfarin (Coumadin®, Jantoven®)	Apixaban (Eliquis®) Dabigatran (Pradaxa®) Rivaroxaban (Xarelto®) Edoxaban (Savaysa®)
Monitoring	Frequent testing (INR) required to determine blood thinning effect	No monitoring to determine blood thinning effect
Dosage	Variable dosing for each patient, with frequent dosing changes sometimes required. Dosing dependent upon coagulation test to keep blood thinning affect within desired therapeutic range	Same dose for each patient.
Food interactions	Vitamin K containing foods (such as salads and green vegetables) influence warfarin's blood thinning effect. Patients on warfarin must carefully monitor what they eat to maintain a consistent vitamin K intake.	No food interactions.
Drug interactions	Many common drugs influence the blood thinning effect of warfarin, such as antibiotics, thus requiring more frequent blood monitoring tests.	Fewer drug interactions.
Time to fully active	Warfarin takes 5 days after starting to reach its full blood thinning effect. Therefore, patients who start warfarin need to be treated with an additional blood thinner (typically injections underneath the skin) during those first 5 or more days.	Full blood thinning effect is achieved within 2-3 hours. Therefore, there is no need for the initial injections with an additional blood thinner.
Time to being out of system	After being stopped, warfarin takes 5-7 days to clear the body.	Takes 24 to 48 hours to clear after being stopped.
Reversal in cases of excessive bleeding	There are proven reversal methods in case of excessive bleeding on warfarin.	There is no antidote or reversal strategy that is guaranteed to work if major bleeding occurs.
Cost	Depends on insurance, but generally lower-cost.	Depends on insurance, but generally more expensive.
Effectiveness in preventing recurrent clots	Same	Same
Safety	Same risk of major bleeding, but higher risk of bleeds into the head	Same risk of major bleeding, but lower risk of bleeds into the head

Abbreviations: INR = International Normalized Ratio

4. The risk of bleeding with blood thinners

Every blood thinner increases the risk of bleeding. You may develop easy to recognize external bleeding (bruising, bleeding from a cut, nosebleeds, increased menstrual bleeding, etc.), or more occult internal bleeding. These are the signs and symptoms patients should look out for:

- The worst headache ever. This may indicate a bleed into the head (around or into the brain).
- Confusion, weakness, slurred speech, loss of vision, i.e. symptoms of a stroke. This may also indicate a bleed into the head/brain.
- Very heavy nosebleeds.
- Vomiting of bright red blood or something that looks like coffee grounds. This may come from a bleed in the esophagus or stomach.
- Bowel movements that contain bright red blood or look dark, black, and tarry. This may come from a bleed in the intestines.
- Blood in your urine.
- Unusually heavy, frequent or long vaginal / menstrual bleeding.
- Bleeding from your skin that does not stop after applying significant pressure or abnormal bruising that does not improve over several days or continues to worsen.
- Significant weakness, dizziness, shortness of breath, and low blood pressure. This may indicate anemia, i.e. low blood counts due to significant blood loss.
- Craving of ice or the wish to eat chalk or clay. This may reflect iron deficiency from chronic blood loss and anemia.

Medical alert jewelry

If you take a blood-thinner, you should wear a medical-alert bracelet, necklace or similar alert tag. If medical treatment is required and you are too ill to explain your condition, the tag will alert emergency personnel of your use of a blood-thinning medication and your risk for excessive bleeding.

5. How long is treatment with blood-thinning medications needed?

The length of time you will need to take blood-thinners is a **highly individualized decision** that will depend upon a number of factors your doctor will review with you, such as:

- The location of the clot
- Why the clot formed (what risk factors contributed to your clot)



- An assessment of your risk for developing future clots if your blood thinner is stopped (what risk factors you have which may cause a clot recurrence)
- How you have tolerated the blood thinner and what your risk for bleeding is if you stay on a blood thinner.

In general, if the risk of another clot is low, then short-term treatment for 3 months is often sufficient. This is long enough for the present clot to heal. However, if the risk for developing another clot is high, then treatment for more than 3 months may be appropriate. This typically means long-term (also referred to as “extended”) treatment which can last several years and, in some cases, lifelong.

- If you take blood-thinners long-term, you should have a visit approximately once per year with your doctor to discuss how well you have tolerated the medication, if the medication is still needed, and to learn of any new medications or research advances which might change how you get treated.

b) Thrombolytic therapy (‘Clot Buster’ Medication) and/or Thrombectomy

While clots often dissolve on their own, certain medications can dissolve clots quickly and are known as thrombolytics or “clot busters”. The most commonly used drug is called tPA (tissue plasminogen activator). These medications are given intravenously (directly into a vein) to break up the blood clots. Because these medications may increase the risk for serious bleeding, they are usually reserved for very extensive clots and for life-threatening situations. In DVT, sometimes “thrombectomy” is done. This is a procedure done by a vascular surgeon or radiologist, where a catheter is advanced into the clot and clot buster medication is injected into the clot to soften it up. The clot is then sucked out to open up the occluded veins. The patient is then put on blood thinners as usual. As it is not known whether this procedure is more effective than just letting blood thinner and time do their job by themselves, it is not routinely used. In the case of severe, i.e. extensive PE, clot busters may also be given. Only very rarely is major open surgery done to remove a clot from the lung or the leg.

c) IVC filters (Vein Filters) and Stents

The large vein in the abdomen that returns blood from your legs and pelvis to

your heart is called the inferior vena cava (IVC). IVC filters are umbrella shaped devices placed into this large vein in your abdomen. They are sometimes referred to as “**Greenfield filters**” because that was the name of the original filters. By now a number of filters exist with other names. Some cannot be removed after placement and stay in as permanent filters. The newer ones can be removed weeks to months after placement and are referred to as removable or transient IVC filters. Removal is most successful up to 3 months after placement, but may still be successfully removed after 6-9 months. The IVC filter traps blood clots that have broken loose from a DVT and prevents them from reaching the lungs, where they could become a pulmonary embolism. IVC filters are used in patients who have a fresh blood clot but cannot take blood-thinning medications because they are actively bleeding heavily or have a high risk of bleeding. They are also sometimes placed (a) when a patient has had a big PE and has poor lung function, (b) during catheter-thrombectomy, or (c) when somebody develops a new DVT while on blood thinners.

Stents are metal meshwork tubes that are occasionally placed into veins to keep them open. Typically, a balloon widening (angioplasty) of a narrowed vein is done first, and then a stent placed to keep the vein from collapsing. Most commonly stents are placed into a narrowed pelvic vein on the left side, called May-Thurner syndrome. However, not everybody with **May-Thurner syndrome** needs a stent.

d) Special Considerations: Cancer and Blood Clots

Patients with cancer are at increased risk for developing blood clots. There are several reasons for this: (a) Some cancers produce substances that activate the clotting system; (b) some chemotherapy drugs used to treat cancer can increase clotting risk; (c) some cancers, particularly breast cancer, is treated with hormonal therapy (Tamoxifen) that increase the risk for clots; (d) some patients have catheters in their veins (PICC, port, power-port, central venous lines) and these may narrow the blood vessel and, thus, increase the risk for clots. In addition, the usual risk factors – major surgery, hospitalization, immobility, overweight, hormones and inherited and acquired clotting disorders increase the risk further.

If you have cancer and are diagnosed with a blood clot, your initial treatment will likely be intravenous heparin or injection into the fat tissue of low molecular



weight heparin (LMWH). The names of the low-molecular weight heparins are enoxaparin/Lovenox®, dalteparin/Fragmin®, or tinzaparin/Innohep®. While some patients with cancer and DVT or PE get treated with warfarin, LMWH is typically preferred as in many patients it is more effective than warfarin. The length of blood thinners treatment is typically at least 3 months. If the cancer is still active at that time or the patient is still receiving chemotherapy or radiation therapy, the blood thinners are often continued. They are stopped once (a) the cancer is cured or in remission, and (b) the chemotherapy or radiation therapy is completed.

Cancer patients may develop low blood platelet counts due to chemotherapy. During those times patients are at increased risk for bleeding and the blood thinner maybe temporarily reduced in dose or stopped.

D *Preventing Complications*

Most patients with DVT or PE recover within several weeks to months without significant complications. However, long-term problems can occur.

a) Post-Thrombotic Syndrome (PTS)

If you have had a DVT in your leg, you are at-risk for developing chronic (long-term) pain and swelling, called post-thrombotic syndrome (PTS). PTS occurs in approximately 40% of persons with DVT and varies from person-to-person in its severity. It can be mild, not interfering with daily activities, of severe and disabling.

Symptoms of PTS include:

- Chronic swelling
- Chronic pain, pressure, heaviness, tightness or leg tiredness
- Skin hardening, dryness, or itching
- Dark pigmentation, visible spider veins
- In severe cases, ulcers (skin breakdown)

It is not clear whether your risk of developing PTS is decreased by wearing special **graduated compression stockings** which are designed to decrease extremity swelling.

However, the support they provide may make your leg feel better.

Compression stockings are made of a special elastic. They are very tight at the ankle and are less tight as the stocking moves up the leg. This graduated tightness helps the leg muscles squeeze fluid up the leg, which decreases leg swelling and pain. PTS of the arm can also occur after an arm clot, but is less common and typically less severe. Compression sleeves (also called lymphedema sleeves) may be beneficial to treat PTS of the arm.



- For maximum effectiveness, compression stockings should be started as soon as possible after being diagnosed with DVT – typically within 7 to 10 days, once the initial more pronounced swelling has decreased after the blood thinners are started.

Compression stockings come in different levels of tightness. The level of tightness is expressed in millimeters of mercury (mmHg). The most common recommended tightness to prevent and treat PTS is 30 to 40 mmHg pressure. It is also referred to as “grade 2”. A prescription is needed to get stockings with the recommended tightness to prevent and treat PTS. Many pharmacies and medical supply companies carry compression stockings.

- Compression stockings should be individually fitted.

A compression stocking should be worn during the day on the leg affected by the blood clot and taken off at night. Some stockings are below the knee while others cover the entire leg. Your doctor can discuss with you which length is best for your condition. Typically, below knee is chosen when the swelling is below the knee, and above-knee when swelling also includes the thigh.



b) Pulmonary Hypertension

Blood clots in the lung can sometimes cause left-over symptoms of shortness of breath, decreased exercise ability, or chest discomfort, but most people recover completely. However, in a few patients, clots do not completely dissolve and significant chronic damage to the lung results. If this damage is severe, then this is called pulmonary hypertension. It has also been given the name CTEPH, which stands for Chronic Thromboembolic Pulmonary Hypertension.

- Persistent or worsening shortness of breath, particularly with exercise, is the most common symptom of pulmonary hypertension.

Pulmonary hypertension can be a serious and life-threatening complication, leading to heart failure. Patients who have had a pulmonary embolism and who have persistent or recurrent symptoms should be evaluated by their doctor for signs of pulmonary hypertension, particularly if the PE was extensive.

Such an evaluation should be considered several months after the PE, if you fail to get back to your baseline of feeling well.

E *Emotional Impact of a Blood Clot*

A diagnosis of DVT or PE brings many things to cope with, both physically and mentally. Immediately after a diagnosis, you may be dealing with physical pain, trying to understand why the clot happened and adjusting to the lifestyle impact of taking a blood thinner.

- It is normal to feel shock, anxiety and fear following the diagnosis of a blood clot.

Temporary feelings of anxiety or depressed mood can occur in the first few weeks. The fear of a future clot recurrence can produce ongoing anxiety. Tell your doctor if your feelings do not improve or are accompanied by a withdrawal from activities or increased negative thoughts and tearfulness, as these may indicate a more severe depression requiring treatment.

Finding support: First, know that **you are not alone**. Blood clots are a common medical condition. It is estimated that between 300,000-600,000 people in the United States develop DVT and PE each year.

In-person support groups do exist, but unfortunately, they are uncommon. Ask your health care provider if one exists in your area.

Secondly, know that blood clots are treatable and manageable. Most patients recover without significant complications. Educate yourself about your condition. Be clear on your treatment plan. Ask your doctor any questions you might have.

F *Common Questions*

1) When will my clot and pain go away?

Blood-thinners themselves do not dissolve the clot. The body naturally absorbs a blood clot over the course of several weeks to months and the symptoms which accompanied the blood clot gradually improve and often eventually disappear disappear.

→ Most patients with DVT or PE recover within several weeks to months without significant complications or long-term effects.

In some patients, the clot never goes away completely: about half of the patients with DVT will have left-over (residual) clot if a follow-up Doppler ultrasound is done 6 months after the acute clot. This is not a clot that can break off, but rather scar tissue within the blood vessel. Because other blood vessels take over and bypass the narrowed or damaged veins, patients are often without symptoms, even if they do have left-over damage at the area where the DVT was.

The risk of clot breaking off and forming a PE is mostly present in the first few days, up to approximately 4 weeks, while the clot is still fresh and fragile and not scarred. Some people have chronic (long-term) problems after a clot due to damage done when the clot formed and partly due to the chronic obstruction from left-over clot, i.e. scar tissue.



Post-thrombotic syndrome is one complication from a blood clot in the leg which results in long-term swelling and pain. PTS occurs in approximately 40% of persons with DVT and varies from person-to-person in its severity. Post-thrombotic syndrome is discussed in detail in Section D of this guide.

Blood clots in the lung can sometimes cause left-over symptoms of shortness of breath, decreased exercise ability, or chest discomfort, but most people recover completely. However, in a few patients, clots do not completely dissolve and significant chronic damage to the lung results, called pulmonary hypertension.

Pulmonary hypertension is discussed in detail in Section D of this guide.

It is not helpful to obtain regular follow-up Doppler ultrasounds of the legs to see whether the clot is gone or still there. Finding left-over clot or scar tissue does not change management. The only time a follow-up Doppler ultrasound is really helpful is once a patient comes off blood thinners. A new ultrasound at that time provides a new baseline, so that it is easier to tell in the future, if new symptoms occur, whether a new clot is present or whether the changes seen are old. Follow-up CT scans are also typically not helpful. Because of the radiation exposure, even though relatively low, a routine CT of the chest is typically not obtained as a new baseline when a patient stops the blood thinner.

2) Do I need to alter my daily activity following DVT or PE? How soon can I exercise?

a) How quickly to expect improvement?

In general, patients often improve significantly over the first 7-10 days, once blood thinners are started. After that, there is often further, yet slower additional improvement over the next several weeks. There may even be further improvement after a few months. The best predictor as to whether a patient will improve further is probably how the person has done so far: if improvement has leveled off and there hasn't been any further improvement in several weeks, then the patient may not improve any further. However, if there has continued to be improvement, even if only at a slow rate, then the patient may expect further improvement in the coming weeks and months.

b) How active to be after a clot?

Patients with a newly diagnosed DVT or PE should use common sense and listen to their body. Physically, they should only do what they feel comfortable doing. They do not speed up recovery by pushing themselves aggressively through symptoms of pain and swelling. But they also do not make things worse by being active. Classically, it is fine for the patient to be physically active right after the diagnosis of an acute DVT or PE – walk, do light household or other work. However, if somebody has a lot of leg pain from the DVT or shortness of breath from the PE, the person should take it easy. Having a blood clot is a stress to the body and a patient / the body needs time to heal and recover. It is appropriate to take time off from work and let the body recover. However, if the DVT or PE was only small and the patient feels fine and wants to go back to work, then that is certainly fine, too.

c) Sports, Yoga

It appears that being highly active one month after a DVT is not detrimental; it may, actually be beneficial and lead to less symptoms of post-thrombotic syndrome. This can be used as an argument to encourage individuals to return to physical activity relatively soon after a DVT. No official guidelines exist as to when and how quickly an athlete might return to exercising. Each patient will need an individualized exercise plan. It seems appropriate to refrain from any athletic activities for the first 10-14 days after an acute DVT or PE until the clot is more attached to the blood vessel wall and the risk of having the clot break loose (causing a PE) has decreased. To lessen deconditioning during this period of relative inactivity, the athlete may do some strength training – arm and trunk exercises in the case of a leg DVT, leg and trunk exercises in the case of an arm DVT. The athlete may then increase activity between week 2 and 4 and return to pre-clot activity levels by week 4, if the body lets him/her. A similar approach is probably wise regarding yoga: it seems safest to take it easy and avoid yoga activities associated with more extreme body positions in the first 4 weeks after a clot.

d) Airline travel

Airline travel in the first 4 weeks after a DVT or PE is not recommended. However, scientifically it is not known whether airline travel in the first few weeks after an



acute DVT or PE is truly detrimental and should really be avoided. Thus, the recommendation to avoid flying in the first few weeks after a DVT or PE is not firm.

3) Should I be screened for cancer?

As blood clots can be associated with cancer, your doctor will (a) take a good medical history, (b) do a good physical examination, (c) order some basic blood work, and (d) make sure you are up to date with your routine cancer screening (colonoscopy, mammogram, pelvic exam with PAP-smear). More extensive search for cancer is typically not done, unless something in the history, exam or labs raise a red flag.

4) Should I or my family members be tested for genetic causes of blood clotting?

Some persons have either a genetic (inherited) or acquired predisposition to develop blood clots, known as a **thrombophilia** or clotting disorder. There are several types of thrombophilias which contribute to varying degrees of clot risk.

For most patients, knowing they have a clotting disorder does not change treatment. Because having a clotting disorder often does not impact treatment decisions, thrombophilia testing is not always done. In patients who had an unprovoked blood clot (situations when no risk factor which caused the clot can be clearly identified), thrombophilia testing may be determined helpful to guide decisions on the length of treatment with blood-thinning medication. However, no consensus exists amongst health care professionals on which patients should be tested for a clotting disorder.

Routine testing of family members of persons with a diagnosed thrombophilia is not recommended. In the case where a patient has a strong thrombophilia (a clotting disorder which carries a high-risk for developing clots), family testing may be appropriate to guide family member's medical decisions (for example, in case of surgery, birth control choices or pregnancy).

Decisions on whether testing to look for a thrombophilia is appropriate (for both the patient and family members) requires an **individualized approach** which should be discussed with your health care provider.

5) What kind of doctor do I need?

Not everybody with DVT or PE needs the same type of doctor. The best combination is probably to have (a) a health care professional in a formal Warfarin Clinic (Coumadin Clinic) if the patient is on warfarin, and (b) a physician with special expertise in blood clots (thrombosis). A patient and his/her primary care physician should decide together what specialty care is needed. The decision whether to send a patient to a formal Thrombosis Clinic has to take into consideration whether a physician, clinic, or center with special expertise in thrombosis is geographically available. A Thrombosis Clinic may also go by the name of “Heart and Vascular Clinic” or something similar.

6) Are there any clinical trials/studies that I can or should consider participating in?

While a fair amount is known about how to best diagnose and treat blood clots, there are a lot of things we do not know well about DVT and PE, such as: (a) who develops clots? (b) why do clots form in certain people? (c) why do they form at the time that they do? (d) who will have future clots once blood thinners are stopped? (e) how do you best prevent the long-term complications from clots? (f) which blood thinners are most effective and safe? (g) how is the patient on blood thinners best treated at times of surgery or when pregnant?, etc. Clinical studies on these and a number of other issues are needed to find answers. These answers will lead to continued improvements in the care that health care professionals can provide to their patients and families. Patients should consider enrollment into a clinical trial. Information on ongoing trials is available at <http://www.clotconnect.org/patients/research>.

7) For more information

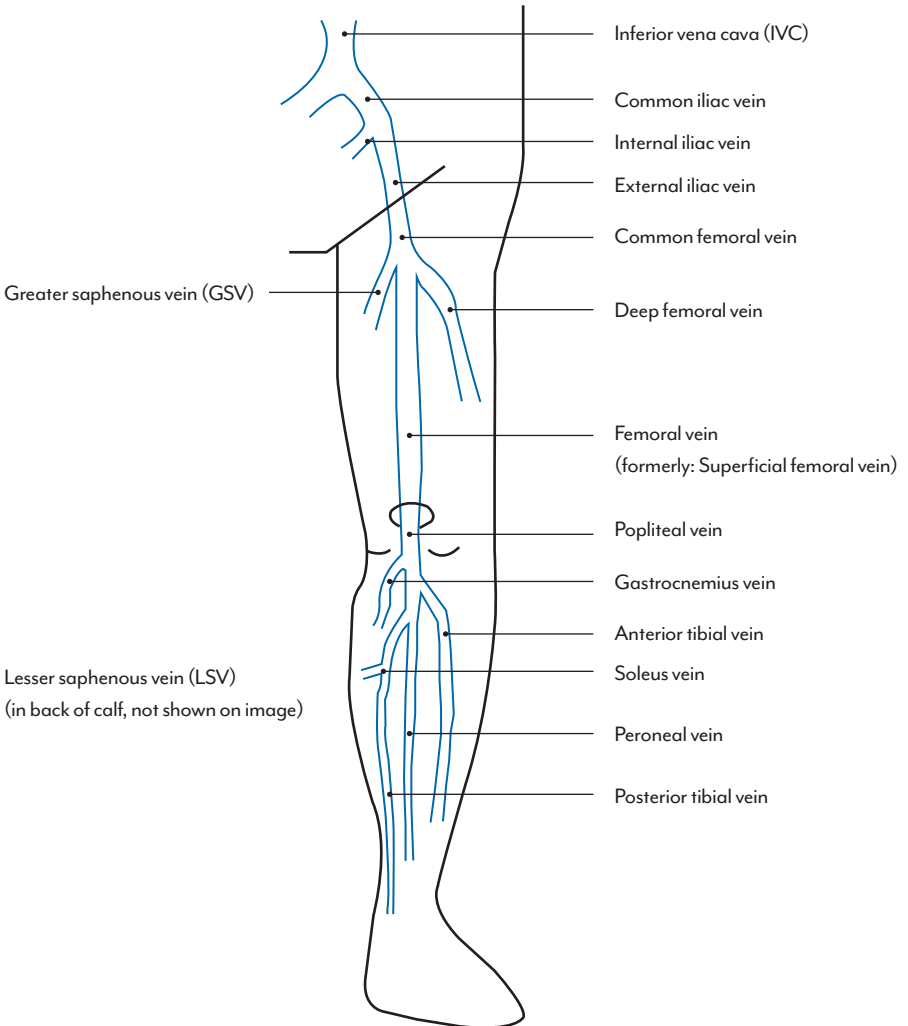
For more information about blood clots, clotting disorders and blood thinners, visit online www.ClotConnect.org.



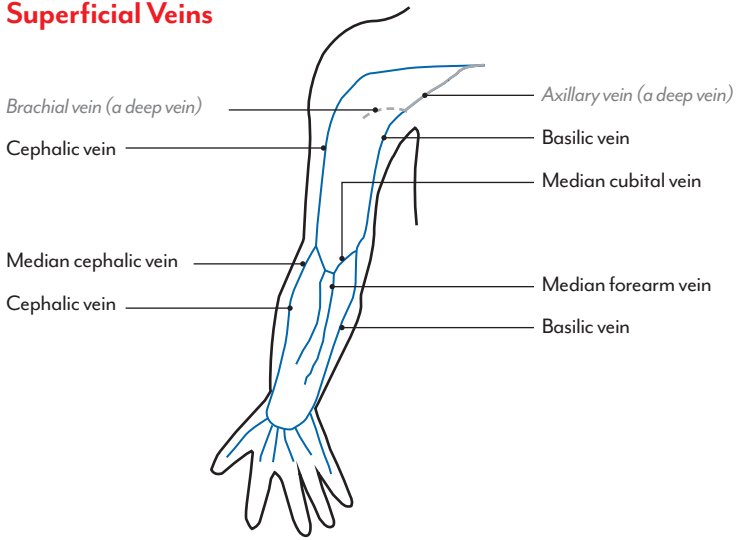
For you and your doctor: Anatomy of veins

Superficial Veins

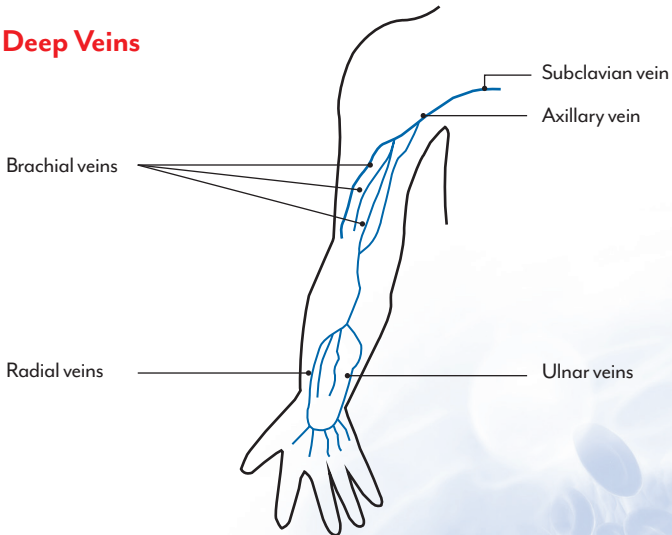
Deep Veins



Superficial Veins



Deep Veins



WHERE ELSE CAN I GO FOR MORE INFORMATION?

ON THE INTERNET:

Clot Connect (www.clotconnect.org) has information material for patients and health care professionals on blood clotting disorders, blood clots, and blood "thinners."

OUR NEWSLETTER:

Receive our monthly email newsletter with helpful articles and research news. Be notified when there are educational events. Sign up at www.clotconnect.org.



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