

## POPULATION SPECIFIC FACT SHEET

What to Know When Assisting a Consumer Who Has Experienced,  
or is at Risk for, Blood Clots

*This fact sheet is intended to help Navigators identify what issues are unique to consumers who have experienced blood clots (also known as deep vein thrombosis and pulmonary embolism) so that they can assist them as they make decisions related to their healthcare coverage.*

### **Q1. What do I need to know about blood clots (Deep Vein Thrombosis and Pulmonary Embolism or DVT/PE; sometimes collectively called Venous Thromboembolism or VTE)?**

A. DVT and PE are often underdiagnosed and can be serious medical conditions. DVT occurs in as many as 900,000 people annually. PE affects an estimated 300,000 people each year. More than 100,000 people die from blood clots each year. DVT occurs when a blood clot forms in a deep vein in the lower leg, thigh, or pelvis, but they can also occur in the arm. It is important to know about DVT because it can happen to anybody and may cause serious illness, disability, and in some cases, death. DVT is preventable and treatable if discovered early.

The most serious complication of DVT happens when a part of the clot breaks off and travels through the bloodstream to the lungs, causing a blockage called pulmonary embolism (PE). If the clot is small, and with appropriate treatment, people can recover from PE. However, there could be some damage to the lungs. If the clot is large, it can stop blood from reaching the lungs and is fatal.

In addition, nearly one-third of people who have a DVT will have long-term complications caused by the damage the clot does to the valves in the vein called post-thrombotic syndrome (PTS). People with PTS have symptoms such as swelling, pain, discoloration, and in severe cases, scaling or ulcers in the affected part of the body. In some cases, the symptoms can be so severe that a person becomes disabled. For some people, DVT and PE can become a chronic illness.

Almost anyone can have a DVT. However, certain factors can increase the chance of having this condition. The chance increases even more for someone who has more than one of these factors at the same time.

Factors that increase the risk of developing DVT include injury to a vein, often caused by fractures; severe muscle injury, or major surgery (particularly involving the abdomen, pelvis, hip, or legs). Slow blood flow is another risk factor and is often caused by confinement to bed (e.g., due to a medical condition or after surgery); limited movement (e.g., a cast on a leg to help heal an injured bone); sitting for a long time, especially with crossed legs; paralysis; or other disabilities that limit a person's mobility. Women can face higher risk due to increased estrogen often caused by certain birth control pills; hormone therapy used after menopause; or pregnancy, for up to 6 weeks after giving

birth. People with certain chronic medical illnesses, such as heart disease; lung disease; cancer and its treatment; and inflammatory bowel disease, can face increased risks for blood clots.

Spinal cord injuries can cause a variety of changes in circulation and people with spinal cord injuries are at triple the usual risk for blood clots due to stagnation of blood flow in the large veins in the legs. Treatment includes anticoagulant drugs and compression stockings to increase blood flow in the lower legs and feet.<sup>1</sup>

Other factors that increase the risk of DVT include previous DVT or PE; family history of DVT or PE; age (risk increases as age increases); obesity; a catheter located in a central vein; and inherited clotting disorders (thrombophilias).

Everybody should know the signs and symptoms of DVT/PE and their risk for DVT/PE. They should be encouraged to talk to their health care provider about their risk, and seek care immediately if they have any sign or symptom of DVT/PE.

About half of people with DVT have no symptoms at all. The following are the most common symptoms of DVT that occur in the affected part of the body: swelling, pain, tenderness, and redness of the skin.

PE is much more serious, but a person can have a PE without any symptoms of a DVT. Signs and symptoms of PE can include: difficulty breathing; faster than normal or irregular heart beat; chest pain or discomfort, which usually worsens with a deep breath or coughing; anxiety; coughing up blood; and very low blood pressure, lightheadedness, or fainting. Anyone with these symptoms needs to seek medical help immediately.

The diagnosis of DVT or PE requires special tests that can only be performed by a doctor. These include an ultrasound scans of the legs or arms; a D-dimer test that is a blood test that shows if unusual clotting is occurring; and a CT scan to identify a PE.

Anticoagulant medication (often called blood thinners) is used to prevent and treat DVT. This can be delivered orally or by an injection. These medications increase the time it takes for blood to clot. They prevent new clots from forming and existing clots from growing larger. Anticoagulants do not dissolve a clot. The body naturally dissolves a clot over time, sometimes completely, sometimes only partially.

Compression stockings (also called graduated compression stockings) are sometimes recommended to prevent DVT and relieve pain and swelling. These might need to be worn for two years or more after having DVT. In severe cases, the clot might need to be removed surgically.

Immediate medical attention is necessary to treat PE. In cases of severe, life-threatening PE, there are medicines called thrombolytics that can dissolve the

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<sup>1</sup>[http://www.ninds.nih.gov/disorders/sci/detail\\_sci.htm](http://www.ninds.nih.gov/disorders/sci/detail_sci.htm)

clot. Anticoagulants may be prescribed to prevent more clots from forming. Some people may need to be on medication long-term to prevent future blood clots.

VTE does not cause heart attack or stroke, but PE in the lungs can be fatal. However, a clot in an artery, usually in the heart or brain, called arterial thrombosis can cause heart attack or stroke. Atrial fibrillation (Afib) is a cardiovascular condition that increases the risk of stroke because it encourages blood clots to form in the heart. These clots can then travel to the brain. People with Afib often take anticoagulation medication to reduce their risk of clots.

The duration of time a person will need to take an anticoagulant depends on a number of factors such as the location of the clot (whether the clot was in the calf only or further up in the leg in the thigh or pelvis); why the clot formed (what risk factors contributed to the clot); an assessment of the risk for developing future clots if the anticoagulant is stopped, based on what risk factors may cause another clot to develop; how well the person tolerated the anticoagulant and what the risk for bleeding is if the patient stays on an anticoagulant; and, personal preference and how anticoagulant treatment has impacted the person's lifestyle.

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 >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, life-long.

As the body naturally absorbs a clot over the course of several weeks to months, the symptoms which accompanied the blood clot gradually improve and often eventually disappear. Symptoms typically improve within a few days of starting the anticoagulant. Most patients with DVT or PE recover completely within several weeks to months without significant complications or long-term adverse effects.

However, long-term problems can occur, with symptoms ranging from very mild to more severe. Around half of patients with DVT will have some degree of chronic discomfort, and ≈15% will experience moderate to severe chronic swelling and pain known as post-thrombotic syndrome. Post-thrombotic syndrome is partly attributable to damage done when the clot formed and partly to the chronic obstruction from left-over clot (scar tissue). Graduated compression stockings may make the leg feel better.

Around 2% to 4% of patients with PE will have chronic damage to the lungs known as pulmonary hypertension (chronic thromboembolic pulmonary hypertension), which is characterized by shortness of breath and decreased exercise ability. Pulmonary hypertension can lead to heart failure if untreated.

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

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

Temporary feelings of anxiety or depressed mood can occur in the first few weeks, but the fear of a future clot recurrence can produce ongoing anxiety. The physician may recommend a support group. If these feelings do not improve or are accompanied by a withdrawal from activities or increased negative thoughts and tearfulness, they may indicate a more severe depression requiring treatment.

**Q2. What type of health care providers does someone who has experienced blood clots need to have access to?**

A. Not everybody with DVT or PE needs the same type of doctor. If you take warfarin, the ideal combination may be to have (1) a health care professional (most likely a pharmacist or a nurse) in a formal anticoagulation clinic (to manage your blood thinning medication) and (2) a physician with special expertise in blood clots (thrombosis). If you take 1 of the newer oral anticoagulants, you may not need to be followed in an anticoagulation clinic. Discuss with your doctor where you should be referred for anticoagulation management.

Multiple types of physicians may have a special expertise and interest in DVT, PE, anticoagulation, and clotting disorders, including hematologists, cardiologists, pulmonologists, vascular surgeons, vascular medicine specialists, and general internists. Many primary care physicians also follow patients with DVT or PE. Specialized Thrombosis Clinics may also go by the name of Heart and Vascular Clinic or something similar. Patients and their primary care physicians should decide together what specialty care is needed.

For health insurance purposes, it is important that the network included the type of specialists, i.e. hematologists, who provide most of the specialized care for people who have experienced blood clots.

**Q3. What are some of the prescription needs that someone with blood clots may have?**

A. Treatment of blood clots can be done using anticoagulant medications, compression devices or compression stockings, or a combination of therapies depending on the specific patient's needs. These treatments all require a physician prescription and are distributed either through a pharmacy, a durable medical equipment supplier or both. For existing patients, access to these products and suppliers is important. Since the occurrence of a blood clot is hard to predict, health plans that provide access to the multiple therapies and the suppliers of the therapies should be included in any health plan.

Since depression or anxiety may follow a blood clot experience, some individuals may also be treated with medication for these conditions.

**Q4. What type of therapies and/or devices would someone who has had blood clots potentially require?**

A. Many patients require active management through coagulation clinics, which are often part of larger medical centers. Nurses and pharmacists usually work in these clinics and coordinate patient care with primary care physicians and/or specialists in anticoagulation medicine. Physical and occupational therapy is required for people who have suffered significant disability from either a DVT or a PE. Many people who experience blood clots use compression stockings (prescription grade) or other types of compression devices (also prescription grade) to avoid complications that can be caused by DVTs.

Patients with complicated clotting problems will require regular specialty medical care and therapies, possibly for the remainder of their life.

**Q5. What other services and supports, which are not generally medically arranged therapies and devices, are typically required by persons who have had blood clots? Are these arranged and financed in some private health insurance plans or in some Medicaid programs?**

A. Individuals who have a clot induced stroke or suffer significant disability from clots may require extensive rehabilitation services, skilled nursing care or even long term custodial care. This care may be provided in the patient's home, an intermediate care facility, a nursing home or a rehabilitation facility. Insurance coverage for these services varies greatly. Medicaid is often the insurance of last resort for people who suffer these severe complications and exhaust their other resources.

**Q6. Are there any other unique medical needs that someone who has had blood clots should consider when evaluating a health plan?**

A. Depression and anxiety can affect individuals who have blood clots. Access to appropriate therapists would be important under those circumstances.

**Q7. Are there any type of accommodations I should consider when I'm planning to meet with someone who has had blood clots?**

A. Some people who have experienced severe clotting disorders or strokes may need to use a cane or wheelchair. The availability of reserved parking for people with physical challenges and the use of ADA compliant facilities will be important to such individuals. People who are experiencing depression and/or anxiety may experience cognitive issues affecting comprehension and short term memory. It is best to provide materials for individuals and families to take home, and to encourage note taking.

**Q8. Are there any resources you would recommend to obtain additional information about blood clots?**

A. The National Blood Clot Alliance offers information and education resources at no cost to anyone seeking information about blood clots. [www.stopthecлот.org](http://www.stopthecлот.org); [info@stopthecлот.org](mailto:info@stopthecлот.org); 877- 4NO CLOT.

The Centers for Disease Control and Prevention ([www.cdc.gov](http://www.cdc.gov)) and the National Heart, Blood and Lung Institute ([www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)) also provide reliable information for the general public, patients and caregivers.

American Association on Health and Disability (AAHD)  
National Disability Navigator Resource Collaborative (NDNRC)  
110 N. Washington Street, Suite 328J  
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[www.nationaldisabilitynavigator.org](http://www.nationaldisabilitynavigator.org)

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