National Blood Clot Alliance
Stop The Clot®

# National Blood Clot Alliance®
# **New Patient Guide**

"We know the patient because we are the patient."

stoptheclot.org

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@stoptheclot

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# Welcome to the NBCA Community

You have been diagnosed with a blood clot.* We understand this life-changing experience can be both upsetting and confusing.

You may be asking yourself: What is a blood clot? How did this happen to me? Will I be okay? Will my life ever be the same? These are important questions that deserve to be answered.

The National Blood Clot Alliance (NBCA) developed this guide for newly diagnosed patients and their caregivers to help answer common questions and provide the resources to help navigate life, post-diagnosis. Blood clots can be deadly, but you are a survivor. We are here to help you through every step of your blood clot journey.

> ***I came out of the doctor's office with my head spinning, full of anxiety, and found the National Blood Clot Alliance. I am not alone! Thank you!***
>
> — *Paul from North Carolina*

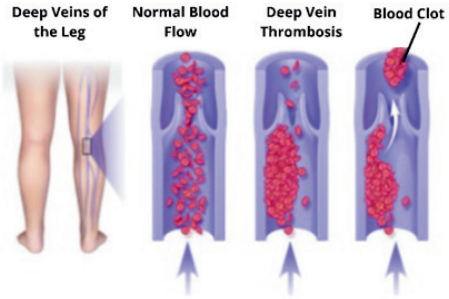
**Blood clots can occur in arteries and veins. Deep vein thrombosis (DVT) and pulmonary embolism (PE) are known as venous blood clots, as they form in the veins. We will reference DVT and PE as "blood clots" throughout this guide.*

This new patient guide does not replace medical advice. Please consult your physician for any medical questions.

## What is a Blood Clot?

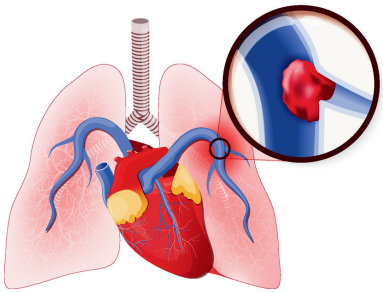
Blood clots are gel-like clumps of blood, which are beneficial when they form in response to an injury or cut. But blood clots can also form when they shouldn't and cause serious medical problems, such as deep vein thrombosis (DVT), pulmonary embolism (PE), and cerebral venous sinus thrombosis (CVST).

A DVT is typically a blood clot that forms in one or more large veins of the arms or legs (or at other sites). These blood clots can block the flow of blood and can cause swelling, pain, and red or purplish discoloration.



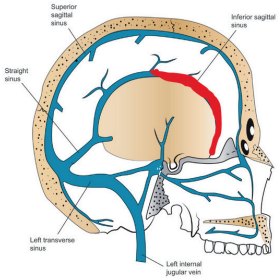

**Deep Vein Thrombosis (DVT)**

If a DVT is not treated, it can move or break off and travel to the lungs, which is called a pulmonary embolism (PE). This can be fatal and requires immediate medical attention.



**Pulmonary Embolism (PE)**

A CVST is a rare form of stroke and happens when a blood clot forms in one or more veins in or around the brain. This is a serious medical condition and requires attention right away.




**Cerebral Venous Sinus Thrombosis (CVST)**

# Common Risk Factors

Blood clots can either be “provoked” or “unprovoked.” Provoked blood clots have an identifiable trigger, such as a hospital stay. An unprovoked blood clot has no identifiable cause. It’s important to know the difference in these terms, as it can impact your treatment protocol.

Some of the most common risk factors for venous blood clots include:

- Hospitalization for illness or surgery
- Major surgery, such as a hip or knee replacement
- Severe trauma, such as a car accident
- Injury to a vein
- Cancer and cancer treatments
- Increased estrogen through birth control, pregnancy, or use of hormone replacement therapy
- Family history of blood clots
- Acute or chronic inflammatory conditions
- Being overweight
- Immobilization, such as confinement to a bed, wheelchair, or plaster cast
- Sitting too long, especially with legs crossed
- Smoking
- Being of older age
- Having long-term diseases including diabetes, heart, or lung conditions
- Dehydration
- COVID-19

Know your risk. Talk to your healthcare provider about your risk for future blood clots and use this risk assessment tool as your guide:

**General Risk Assessment Tool**

bit.ly/3PIIKQ9

Use this women's risk assessment tool when considering the use of birth control with estrogen, family planning, before/after childbirth, hormone replacement therapy, and as you age.

**Women's Risk Assessment Tool**

bit.ly/3EzGDHS

# Blood Clotting Disorders (Thrombophilia)

Thrombophilia is a predisposition to developing blood clots. You can either acquire or inherit thrombophilia during your lifetime.

Thrombophilia can be caused by abnormalities of the blood, such as too many red blood cells (polycythemia), too many platelets (thrombocytosis or thrombocythemia), the development of abnormal proteins or antibodies, diseases of the kidney or liver, COVID-19 or HIV infection.

Inherited thrombophilia can either be heterozygous (meaning you inherited one copy of the gene mutation from one parent) or homozygous (meaning you inherited two copies of the gene mutation, one from each parent).

The risk of developing a blood clot is higher for homozygous individuals versus heterozygous.

The presence of thrombophilia may be suspected when unexplained blood clotting occurs, blood clots occur in younger individuals, blood clots occur in an unusual area of the body (i.e., brain or abdomen), a family history of blood clots is present, or in women who have experienced multiple pregnancy losses.

The most common inherited thrombophilias include:

- Factor V Leiden
- Prothrombin G20210A
- Protein C Deficiency
- Protein S Deficiency
- Antithrombin Deficiency

**Learn more about thrombophilia**

bit.ly/3PwbRG7

## Genetic Testing for Thrombophilia

Genetic testing for thrombophilia is not routine in people with blood clots. Testing may be considered in some people with unprovoked blood clots but only if some aspect of their care or lifestyle will be positively impacted by knowledge of the results. Therefore, this is a complex decision with some potential benefit in some people but also with limitations and potential harms. It is important to discuss these issues with a knowledgeable healthcare provider who can make recommendations regarding thrombophilia testing for your situation, can interpret the results properly, and is able to provide appropriate counselling.

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Find a genetic counselor who has experience and expertise in helping individuals and families with these issues.

Learn about guidelines produced by the American Society of Hematology (ASH) that provides thrombophilia testing recommendations.

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## Blood Clot Recovery


Time is important in your blood clot journey. The first year can be filled with a range of emotions. It is normal to feel confused, anxious, and angry in those first few days and months post-diagnosis.

However, NBCA hopes that patients will discover a renewed sense of strength as they begin to learn more about blood clots, their risk factors, and develop strategies for a healthy recovery.

**0 - 30 Days:** The first 30 days are very important. The highest risk of recurrence for a blood clot is in the first 30 days post-diagnosis. This time will be filled with activity – learning new information, more medical appointments than usual with new providers, and taking new medications, which could result in unfamiliar side effects. Please attend all your medical appointments, take your medication as prescribed, and understand that it may take time to recover. Resuming physical activity should begin shortly after your diagnosis unless your symptoms prevent this. Note that everyone recovers at their own pace.

**1 - 3 Months:** Your medication dosage may change over time and, for some patients, anticoagulation may be discontinued after 90 days. Please follow any dosage adjustments instructed by your doctor. This can also be a time of information gathering as you learn about your medical team, blood clots, your diagnosis, and what your contributing risk factors were. This can lead to uncertainty and feelings of anxiety, which is completely normal.

**3 Months - 1 Year or Longer:** This can be a period of adjustment and figuring out your "new normal." At this stage, your medical appointments will primarily be follow-up appointments. These are still important appointments to maintain. If you were unprovoked or have a genetic clotting disorder, your timeline will likely go beyond 365 days. This will involve a discussion between you and your healthcare provider.

## Medical Team

A blood clot can affect various parts of your body, which means that you may need to meet with different medical specialists. Each provider plays an important role in your care and should work with your other providers to ensure your optimal health.

**Hematologist:** A hematologist is an internal medicine doctor who specializes in blood disorders, bone marrow, and the lymphatic system. A hematologist may be one of the first physicians that you visit post-diagnosis. These providers may prescribe anticoagulants (blood thinners) to aid your treatment as well as schedule additional imaging tests to monitor your recovery.

**Pulmonologist:** A pulmonologist is a doctor who specializes in lung conditions. If a blood clot is not treated, it can break off and travel to the lungs and cause a pulmonary embolism (PE). You may see a pulmonologist for treatment if a blood clot has affected your lungs.

**Cardiologist:** A cardiologist is a doctor with specific skills and training in finding, treating, and preventing diseases of the heart. Some people with PE may be seen by a cardiologist to assess if their heart has been affected.

**Primary Care Provider (PCP):** A primary care provider can be a doctor or a nurse practitioner who treats individuals with undiagnosed health conditions and provides continuing care for various medical conditions. PCPs also provide referrals to specialists. Your PCP may be the first to suspect a blood clot and can refer you to a specialist or to the emergency room for further imaging to determine if there is a clot. Make sure to keep your PCP informed about what is happening when you visit other providers, provide them with copies of test results, and let them know the medications that you are taking. You may already have a PCP, but if you don't, you should find a PCP who can help monitor your overall health.

**Interventional Radiologist/Vascular Surgeon:**

Interventional radiologists are doctors who may use minimally invasive procedures to treat or prevent blood clots, such as catheter-directed thrombolysis, thrombectomy, or the placement of a vena cava filter

Vascular surgeons can also perform these procedures, but are often called in when a more invasive, open surgical procedure is needed to remove a blood clot from a vein or artery.

**Pharmacist:** Pharmacists are a key part of your healthcare team and a valuable resource to patients.

In addition to dispensing your medication, pharmacists can help educate and counsel you on how to take your medications safely and appropriately. They protect patient safety by ensuring that the medications and doses are correct, and routinely check for any drug interactions.

**Mental Health Professional:** A mental health professional, including a psychologist, psychiatrist, or counselor, can help you deal with feelings of anxiety, depression, or other issues that may interfere with your daily life due to your diagnosis. A blood clot diagnosis can be scary and can come out of nowhere. Many patients speak with mental health professionals to help develop the tools to manage these emotions and a healthy mindset moving forward.

**Genetic Counselor:** If you have had multiple, or recurrent blood clots, you may choose to get tested for genetic disorders that may be contributing to your clotting. Genetic counselors can help families at risk for inherited clotting disorders, investigate the family's past medical history, interpret information about the disorder, analyze inheritance patterns, interpret risks to other family members, and review available management options.

**Caregivers:** Even though caregivers are not an "official" part of your medical team, they play a valuable role and can help you heal physically and emotionally. Caregivers provide an additional layer of support and can help advocate for your care. If possible, we recommend you bring your caregiver to all of your medical appointments. They may think of additional questions to ask your medical provider, assist with note-taking during appointments, identify potential care gaps, and help you rehabilitate.

# Blood Clot Treatment

Treatment for blood clots depends on where the blood clot occurs in the body and the severity of the clot. The primary treatments for blood clots are known as anticoagulants or "blood thinners."

Anticoagulants increase the time it takes for the blood to clot, stop new blood clots from forming, and keep existing clots from growing. Technically, anticoagulants do not actually thin the blood, despite being called a blood thinner. Anticoagulants also do not dissolve a clot – our body's own clot busting system dissolves existing clots. Anticoagulants may be taken orally, by injection, or intravenously.

Common anticoagulants include:

- Coumadin (warfarin): This medication requires regular INR testing. (See page 19)
- Lovenox (enoxaparin): This medication is typically given to pregnant women.
- Eliquis (apixaban)
- Xarelto (rivaroxaban)
- Savaysa (edoxaban)
- Pradaxa (dabigatran)

Eliquis, Xarelto, Savaysa, and Pradaxa are also known as Direct Oral Anticoagulants (DOACs).

It is important to take your medication as prescribed. Skipping doses or stopping your medication could increase your risk for a life-threatening blood clot. Taking more medication than prescribed can also be dangerous and can cause bleeding.

Some people experience side effects while taking anticoagulants, which can vary from person to person. If you have any problems with your medication, please consult your physician.

Taking an anticoagulant may pose financial challenges. Several pharmaceutical companies have financial assistance programs to help patients cover the cost of medication. (See pages 17-18)

**Xarelto:** If you are prescribed Xarelto, Janssen CarePath is a financial assistance program that aids patients in finding the resources that they need to stay on track for their treatment. This program helps patients who have commercial insurance, government coverage, and the uninsured.

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**Eliquis:** If you are prescribed Eliquis, Eliquis 360 Support is a program through Pfizer that helps patients understand their prescription coverage and learn about ways to save on out-of-pocket costs.

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**Savaysa:** Daiichi Sankyo helps eligible patients who are not enrolled in a state or federally funded prescription benefit program (such as Medicare Part D or Medicaid) pay as little as $4 a month with their savings card. Eligibility for this program varies.

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**Pradaxa:** Boehringer has a savings card for patients who are currently taking this prescription, or who have just received a prescription. This program helps patients who have commercial insurance, government coverage, and the uninsured.

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**Patient Advocate Foundation:** This organization has a patient financial resources directory that contains a list of potential organizations that provide patient assistance programs, including copayment and medication assistance to patients with a variety of medical conditions. Eligibility for these programs varies.

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In addition to anticoagulants, you may require other interventions, including surgical procedures, implantable devices, support stockings or other medications and products.

**Learn more about other treatment options**

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# INR Testing

Patients taking warfarin are required to undergo routine INR (international normalized ratio) blood tests at least once a month and sometimes as frequently as twice weekly to ensure proper dose.

The target INR range is between 2 and 3. If the INR is below the target range, there is an increased risk of developing a blood clot, and if the INR is above range, there is an increased risk of bleeding.


This is important for your doctor to monitor so that your medication dosage can be adjusted accordingly.

Some patients are eligible for INR self-testing to avoid frequent trips to the lab. If you are interested in doing INR self-testing at home, you should talk to your physician about the pros and cons, and carefully consider your individual medical history, diagnosis, current situation, treatment plan, long-term goals, and insurance coverage.

**A patient's guide to INR self-testing with warfarin**

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# How to Prevent a Recurrence

Even though you have been diagnosed and treated for a blood clot, there is still a risk of recurrence if anticoagulants are stopped. Three in 10 people who have a blood clot will have another episode within 10 years after stopping anticoagulants. However, if you are taking your medication as prescribed, the chance that you will have a recurrence is very low. Regardless, it is important to learn how to recognize the signs and symptoms of a blood clot in case of a recurrence.

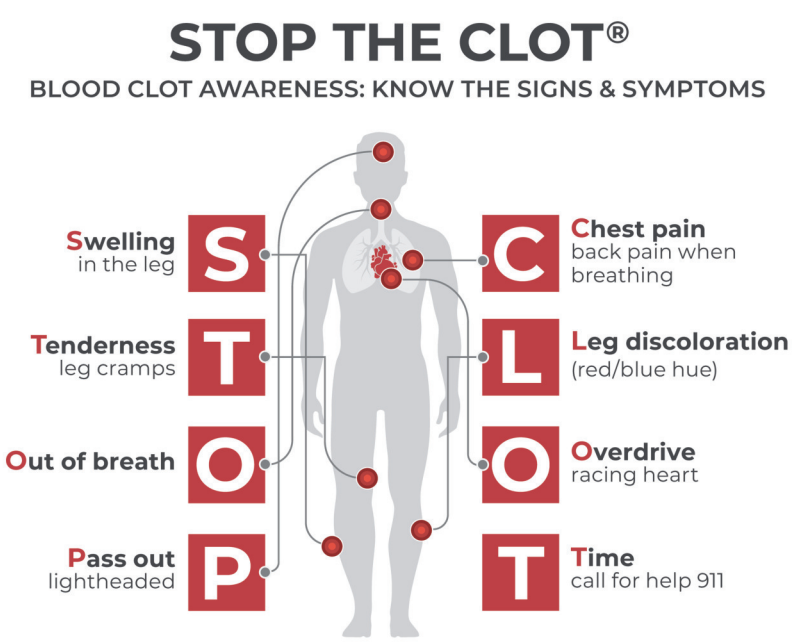
**DVT specific symptoms:**

- Swelling in the arm or leg
- Pain or tenderness not caused by an injury
- Skin that is warm to the touch
- Reddish or bluish skin discoloration,

**PE specific symptoms:**

- Difficulty breathing
- Chest pains that worsen with a deep breath
- Coughing up blood
- Faster than normal or irregular heartbeat
- Passing out

If you experience any of these symptoms, please contact your medical provider immediately. If these symptoms persist, please go to the emergency room or call 9-1-1.




# Blood Clot Complications

Most patients do not develop long-term complications and will recover completely. However, some people develop long-term complications including:

**Post-thrombotic syndrome (PTS):** Persistent swelling, pain, and skin discoloration in the affected leg or arm. Providers sometimes prescribe compression stockings that can help increase blood flow and reduce PTS symptoms.

**Chronic thromboembolic pulmonary hypertension (CTEPH):** Abnormally high pressure in the lung blood vessels after a PE. Only 2-4% of PE patients will develop this condition.

**Chronic thromboembolic disease (CTED):** Dyspnea, or shortness of breath. This can occur if a PE does not resolve after standard anticoagulation therapy.

**Anxiety and/or depression:** Nearly 75% of blood clot patients report feeling moderately anxious or depressed after a blood clot diagnosis.

**Additional clotting episodes:** People who have had blood clots are at higher risk for developing new blood clots in the future.

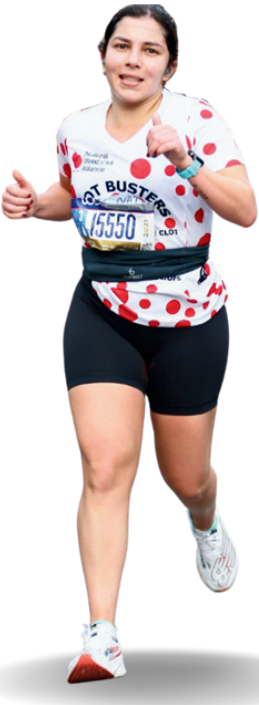
Please contact your healthcare provider if your symptoms don't improve.

## Healthy Lifestyle

Maintaining a healthy lifestyle is important. You may be wondering when you can resume physical activity. The amount and type of exercise that is safe for you is a decision that you should make with your doctor. Exercise is good for you physically and mentally.

Diet is also a key component to a successful recovery and for overall health. Try to maintain a healthy weight, as being overweight is linked to an increased risk for blood clots.

NBCA developed a Sports and Wellness Institute to help athletes of all abilities understand and manage their blood clot diagnosis, support them with the resources and tools needed to get back in the game, and regain strength and confidence as an athlete.

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Athletes may have unique blood clot risk factors and contributing factors such as

- Previous injury
- Above average height
- Immobilization
- Dehydration
- Repetitive motion

NBCA provides athletes, and anyone with an interest in sports, with resources and tools to resume their lives in a healthy way with strength and confidence, and ensures that people who regularly listen to their bodies have information about early blood clot prevention and detection.

# Questions to Ask Your Doctor

Below are some, but not all, of the important questions that you might want to ask your medical team. If your current doctor cannot answer some of the questions you ask, make sure they help you find someone who can. Remember, you are your best health advocate, and if you feel like you aren't being heard, get a second opinion and find a doctor who makes you feel comfortable.

- Why did I have a blood clot?
- What are my chances of a recurrence?
- Are there any side effects of anticoagulants?
- How long will it take for me to recover?
- Do I need to make any lifestyle changes? (smoking, diet, exercise, etc.)
- What risks are involved with pregnancy and childbirth?
- Will anticoagulants affect my periods?
- Can I drink alcohol on an anticoagulant?
- Can I get a massage, tattoo, or use a hot tub?

**Download the full list of questions to ask your doctor and patient FAQs**

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# NBCA Resources

NBCA is here for you. Please visit our website stoptheclot.org, where you can learn about the latest in blood clot resources, research, upcoming NBCA activities, and ways to get involved.

Sign up for our email list to receive relevant news and learn about upcoming webinars, events and volunteer opportunities. bit.ly/3Pfccvh

Connect with NBCA @StopTheClot on social media platforms including Facebook, Instagram, Twitter, YouTube and LinkedIn.

Join NBCA's Facebook Support Group, a safe place for blood clot survivors who are seeking support to come together as a community. bit.ly/3ZjUvQ8

Watch PEP Talks (Patients Educating Patients) to learn more about recovery, treatment, mental health, and lifestyle changes. bit.ly/3ZenbtJ

Listen to our podcast, "Taking a Breath" to hear real-life stories from blood clot survivors, and vital information for prevention and awareness. bit.ly/407Zwvm

Thank you for accessing NBCA's new patient guide. We're glad you found us as a resource and hope you find this guide, and the NBCA community, helpful in your recovery.

If you have any questions or need assistance, please feel free to reach out to us at info@stoptheclot.org.

Let's work together to improve your health and well-being.

Welcome aboard!

# Notes and Questions