

Blood Clots: The First Six Months

A Look at Life with Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)

If you've recently experienced a PE or DVT, you know that it can be an unnerving experience. It can leave you feeling vulnerable and afraid that you might have another episode.

It's normal to have many questions about what you should expect after a DVT or PE. Here is a closer look at what the six months after a blood clot can hold:



THE BODY'S RESPONSE

Your body is an amazing machine and it will deal with your blood clot in its own way.

Once a blood clot has occurred, the body can handle it in different ways. Sometimes, the body can absorb the blood clot. The timeline for a clot to be absorbed varies depending on your body's ability to break down the clot, the size of the clot, and location of the clot. It's important to note that blood thinners, like warfarin, are meant to stop clots from getting larger, not necessarily to dissolve them.

In other cases, blood clots aren't absorbed, but the body continues to function around them without impairment.

If you're interested in learning more about how your body is dealing with your blood clot, ask your doctor. They can provide more personalized information.

MEDICATIONS

After being discharged from the hospital, you may be put on an anticoagulant medication for six months or more.

Many patients are initially told that they will be on anticoagulation medicine (also known as "blood thinners") for the first six months after their blood clot. However, research is showing that blood clots, also known as thrombosis, may be a chronic disease. According to Dr. Samuel Goldhaber, the director of Brigham and Women's Hospital's Thrombosis Research Group and president of the North American Thrombosis Forum, people who have had a DVT or PE have a higher risk of developing another blood clot. Because of this, patients may require more than six months of anticoagulation therapy. Ask your doctor how long you will need to take a blood thinner and if you will require extended therapy.



If you're put on warfarin, you'll need to make several lifestyle adjustments.

After an initial diagnosis, many patients are put on warfarin. This is a traditional treatment that has been used for several decades. While warfarin is very helpful, it has some challenges.

Patients on warfarin need to visit a clinic regularly to have their INR levels tested. An INR level measures how much time it takes for a patient's blood to clot. Most patients need to maintain an INR level between 2.0 – 3.0 to be considered in 'therapeutic range.'

Warfarin works differently for each person and INR levels can change from day to day. There are many patients who struggle to maintain a consistent INR level, despite their best efforts. In fact, several studies show that only about 60 percent of patients at a clinic have INR levels in the therapeutic range at a time. Anticoagulation management clinics help patients keep their INR levels in the target range. Ask your doctor if they refer patients to an anticoagulation management service.

INR levels can be affected by any type of lifestyle change, including how much vitamin K a patient is eating. Warfarin works by blocking vitamin K-dependent clotting factors in the blood, so increasing vitamin K levels in the body can make warfarin less effective. Foods with high levels of vitamin K include kale, spinach, broccoli, green tea, and Brussels sprouts. Patients can still eat these foods, but they need to be consistent in how much they eat each day.

Patients should also be aware of how much alcohol they are drinking while on warfarin. While it is recommended that patients avoid it all together, they should not drink more than one to two drinks per day. Alcohol becomes a problem when it changes how the body metabolizes warfarin.

For some, the need to visit a clinic for INR testing on a regular basis can be inconvenient. Depending on a patient's insurance coverage, home-testing can be a better option. This involves buying an in-home testing kit, which includes an INR monitor and testing strips similar to those used in clinics. Patients are trained by a medical professional to test themselves and then self-report their INR levels to their clinic.

After experiencing a blood clot, patients should follow up by scheduling an appointment with their primary care physician and establishing a network of care.

You may be prescribed a DOAC over warfarin.

Many patients are prescribed direct oral anticoagulants (DOACs) instead of warfarin after having a blood clot. While warfarin has dominated the market for the past 50 years, DOACs are now the recommended guideline-approved treatment for thrombosis. These drugs include rivaroxaban, dabigatran, apixaban, and edoxaban. Unlike warfarin, these drugs don't require regular blood draws, have minimal drug and food interactions, and they have a lower risk of bleeding than warfarin.

"We now have four approved alternatives to warfarin called DOACs," explained Dr. Christian Ruff, who works in the cardiovascular division of Brigham and Women's Hospital. "In general, the DOACs are more effective than warfarin and safer, particularly with respect to serious bleeding. DOACs cause half as much fatal and life-threatening bleeding than warfarin. Also they are more convenient than warfarin in that they do not require frequent blood monitoring and can be given safely in fixed doses."

While there are many benefits to DOACs, some doctors and patients have shied away from using them because many of them don't have a reversal agent.

"Although warfarin causes much more serious bleeding than DOACs, physicians and patients are comforted by the notion that they can reverse warfarin with vitamin K and administration of clotting factors," said Dr. Ruff. "Although the 'reversal' of warfarin is a bit of myth, the lack of an ability to reverse the DOACs is a perceived limitation of these agents."

Dabigatran is one DOAC that does have a reversal agent, idarucizumab. Given as a one-dose-only medication, it reverses dabigatran. It is often used if a patient is experiencing a life-threatening bleed or needs emergency surgery. The other DOACs have shorter half-lives than warfarin, which means they disappear from the body faster than warfarin. So, while they don't have reversal agents, their effects can be stopped more quickly.

In addition to these shorter half-lives, there may be a reversal agent on the horizon for apixaban, edoxaban, and rivaroxaban.

"For the factor Xa inhibitors (apixaban, edoxaban, rivaroxaban) there is a reversal agent in late stage clinical development called andexanent alfa that appears to work really well and is safe," explained

Dr. Ruff. “It acts as a decoy, binding to the factor Xa inhibitors and preventing them from exerting their anticoagulant effects. Andexanent alfa is not approved yet so if serious bleeding occurs while taking a factor Xa inhibitor administration of clotting factors [PCC: prothrombin complex concentrates], as we do in warfarin bleeds, is advised.”

To learn more about the specifics of these medications, please see NATF’s Anticoagulant Comparison Chart.

When it comes to medication, every patient has a different experience based on their past medical history, their diagnosis, their lifestyle factors, and more. It’s important to ask your doctor any questions you have about your personal medication. Pharmacists can also be a valuable resource for questions about different medications and their interactions.

FOLLOW-UP CARE

It’s important to schedule follow-up care after your blood clot.

After experiencing a blood clot, patients should follow up by scheduling an appointment with their primary care physician and establishing a network of care. From there, patients may be referred to specialists, such as a cardiologist, hematologist, pulmonologist, or vascular medicine specialist. These specialists can help steer patients towards the best treatment for their individual needs.

It is especially important for patients to follow up with a doctor if they’ve had an inferior vena cava (IVC) filter put in their body to stop any clots from traveling to the lungs. Some of these filters are only temporary and a doctor must decide when it’s best for it to be removed. They are often removed after a patient’s risk for PE or DVT has gone down and the benefits no longer outweigh the risks.

After a clot, patients often believe that a new ultrasound should be part of their follow-up care. They want to see if their DVT has gone away. However, this is not necessary. As mentioned above, the body often absorbs a blood clot or creates a way to work around it. An ultrasound is only necessary if a patient is experiencing new or worsening symptoms, or if a patient is changing medications. Also, many patients retain some residual clot, like a scar, that is absorbed into the wall of the vein but can be seen on ultrasound. This is not necessarily associated with a poor prognosis.

There are genetic tests that can tell you if your family is prone to blood clots.

Patients with DVT or PE may want to get genetic testing done. Genetics can make some patients and their families more likely to get blood clots. This often happens because of a mutation that occurs and is passed through a family line. Two mutations that can cause patients to be more prone to blood clots are Factor V Leiden and prothrombin gene mutation.

The decision to undergo genetic testing is a personal one that can affect families. If you would like to learn more about this option, please see the National Human Genome Research Institute and talk to your doctor about what resources are available to you.

COMPLICATIONS AFTER A BLOOD CLOT

It’s important to pay attention to what your body is telling you.

While many people do not experience another blood clot after they’ve had their first, patients with a history of blood clots are still at a greater risk than the general public. Patients who have experienced a blood clot already are roughly 25 percent more likely to experience a second episode. The risk goes down over time and varies between patients with provoked and unprovoked blood clots. It’s important to watch for the warning signs of a new blood clot.

For a DVT, symptoms include swelling and pain in the legs, especially behind the knee. This pain often feels like a long-lasting cramp. Symptoms for PE are centered in the chest or in the back. They include pain, shortness of breath, fatigue, or coughing up blood.

After a DVT or PE, it’s normal for you to experience some discomfort as you recover.

Patients with a DVT often still have swelling and soreness in their legs. They may also experience post-thrombotic syndrome.

Likewise, patients with PE may still experience mild chest pain, back pain, or shortness of breath. The level and length of this discomfort varies greatly between patients. Patients with PE are also at risk for developing chronic thromboembolic pulmonary hypertension (CTEPH). This occurs when a blood clot in the lungs causes high blood pressure.

It can often be difficult to distinguish between the symptoms of a new blood clot and the residual pain from a previous one. Always contact your doctor if you have concerns about new or ongoing symptoms.

COMPRESSION STOCKINGS

Compression stockings can help you deal with uncomfortable swelling after a DVT and can prevent additional problems.

It's normal for patients with DVT to experience swelling in their legs after a blood clot. In order to treat that, many doctors prescribe compression stockings for their patients. These stockings are personalized to each patient's condition, with different patients requiring different types of stockings. Some stockings apply the same amount of pressure to the whole area they cover, while others apply different amounts of pressure to different parts of the leg. There are also different lengths of stockings (knee high or thigh high) and different strengths of stockings (how much pressure the stockings put on your legs).

These stockings help prevent swelling, along with pain. They can also help with post-thrombotic syndrome. Dr. Goldhaber recommends that patients wear them for two years after their blood clot. It is important to replace compression stockings every 3 months, as the compression does break-down over time.

If your doctor prescribes compression stockings for you, it is important to fill that prescription and not purchase "over the counter" compression stockings, which might be less effective.

ACTIVITIES

You'll get back to doing your favorite things again.

After a DVT/PE, patients want to resume their lives. This can be more difficult for people who enjoy certain physically challenging activities.

One of the most common life-style questions that Dr. Goldhaber gets from his patients in the winter is, "When can I go skiing again?"

Dr. Goldhaber advised that patients on anticoagulants avoid vigorous activities because they have a higher risk of causing bleeding. This can include skiing, boxing, playing football, horseback riding, and a variety of other activities.

However, hope isn't lost. After a six-month period, it may be safe for patients to return to these activities with the approval and guidance of their doctor.

You need to stay active.

While patients may need to wait to resume vigorous activities, it's still important that they stay active and exercise. It improves cardiovascular health and helps prevent a recurrent PE or DVT.

"If you've recently been diagnosed with a PE, you may feel short of breath, have chest pain, and/or become easily fatigued when you start exercising. Following a DVT, your leg may be swollen, tender, red, or hot to the touch," explained Dr. Stephanie Lew in A Heart Healthy Tip: How to Safely Start an Exercise Routine After A DVT or PE. "These symptoms should improve over time, and exercise often helps. Walking and exercise are safe to do, but be sure to listen to your body to avoid overexertion."

If you have an activity that you'd like to get back to or if you'd like to start exercising, always consult your doctor before making any changes to your lifestyle or medication.

REFERENCES

For more information on any of the following, please visit NATFonline.org:

- Post-thrombotic syndrome
- NATF's Anticoagulant Comparison Chart
- Chronic thromboembolic pulmonary hypertension (CTEPH)
- Compression stockings
- NATF's in-person and online support groups

YOU ARE NOT ALONE

Thrombosis can bring a lot of uncertainty into your life, especially during the first six months after your diagnosis. NATF is here for you. We strive to be a resource that you can rely on throughout your journey. Join us for one of our in-person or online support groups to learn about how other people have handled their experience with thrombosis, or consider attending one of our educational events to keep on top of the latest research.

Looking for something else?

We are just a phone call or email away.

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