



Pro Football Hall of Famer Harry Carson teams up with NBCA to raise awareness

See his story on page 4

### **WELCOME**

Welcome to the inaugural issue of *Personal Perspectives: My Blood Clot, My Life*, the first of what we hope will be an annual effort by the National Blood Clot Alliance (NBCA) to share this e-magazine, focused on issues important to the clotting and clotting disorders community, during Blood Clot Awareness Month. On behalf of NBCA's Board of Directors, as well as our Medical & Scientific Advisory Board, we thank you for your support of our organization's mission. We also extend our appreciation to the generous corporate sponsors whose support, in part, made the production of this new resource possible in its inaugural year.

The National Blood Clot Alliance is a 501(c)(3), non-profit, voluntary health organization dedicated to advancing the prevention, early diagnosis and successful treatment of life-threatening blood clots, such as deep vein thrombosis, pulmonary embolism, and clot-provoked stroke. NBCA works on behalf of people who may be susceptible to blood clots, including, but not limited to, people with clotting disorders, atrial fibrillation, cancer, traumatic injury, and risks related to surgery, lengthy immobility, child birth and hormonal birth control. NBCA accomplishes its mission through programs that build public awareness, educate patients and healthcare professionals, and promote supportive public and private sector policy.

Every day, two overarching imperatives guide our work: The memory of those we have lost to blood clots and a tireless commitment to alleviate further pain and suffering due to blood clots. With this new annual e-magazine, we seek to honor the legacy of those who have lost their lives to blood clots, and to give voice to the many challenges that go hand-in-hand with recovery among survivors of blood clots and their families or caregivers.

Those of us who have experienced a blood clot know that we each walk our own path. But, as a community, we share an experience that allows us to understand each other, support each other, and lift each other up. As we work together to regain strength, health, and the confidence to move forward in our lives, we also can help others learn from our experience as we work to push back on the impact of this far-reaching public health challenge. NBCA walks with you on this path, and you inspire us to keep moving forward. We hope you benefit from the work of our organization and our deeply held commitment to you.

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## Ready, Set, Go

### Live Your Best Life After Blood Clots

While recovery from blood clots can be largely inconsequential for some people, for others it can be a continuous struggle, and it can take a long time. Some people recover quickly, with little to no complications or long-term concerns, while other people face difficulty in many aspects of their lives, including physical, social, psychological, and even employment.

Recovery from blood clots can be daunting, but there are many things you can do to ensure you are recovering to the best of your ability, with as much information as possible. Although it may take some time and patience, recovery from blood clots is possible, and for most individuals who are affected by blood clots, there is hope for returning to your normal life.

#### Talk to Family and Friends About **Your Experience**

Blood clots do not discriminate. They can affect anyone. But, often times, the people closest to you may not understand what you are going through after you have experienced a blood clot or been diagnosed with a clotting disorder, because you may appear to look fine, or because you may have appeared healthy or active at the time of your blood clot. It can be difficult to share your experiences when it seems like no one understands.

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## **Pro Football** Hall of Famer **Harry Carson Teams Up with NBCA** to Raise **Awareness**

Harry Carson, a two-time National Football League (NFL) Linebacker of the Year, is no stranger to pain. He spent 13 seasons playing in the National Football League, was selected by his NFL peers nine times to play in the Pro Bowl, and is a Pro Football Hall of Famer. He's big. He's strong. He's physically fit. Carson, however, is not immune to the same health issue that strikes nearly one million people in the United States each year: Potentially life-threatening blood clots.

Today, Carson, who received his Bachelor of Science Degree in Education before kicking off his professional football career in the NFL, is retired from professional sports, but remains active with numerous business and sports broadcasting initiatives, and also dedicates his time and talent to a number of charitable activities, including important health awareness programs that allow him to exercise his skills as an educator and health advocate.

For Blood Clot Awareness Month 2019, Carson is teaming up with the National Blood Clot Alliance to help raise awareness about blood clots by sharing his personal story with others and demonstrating that dangerous blood clots can happen to anyone.



**Road Risk** 

Carson, whose illustrious football career culminated in a Super Bowl XXI Championship in 1986, describes himself as a man who is used to being in control—just getting up and going whenever he's ready to get up and go. So, it was routine for him to hit the road when he travelled with the same level of record-setting determination that marked his impressive football career.

"I was heading south a few years ago on business, and just like I had done many, many times before, I followed my routine and took only limited breaks as I flew to North Carolina, and then drove countless miles from North Carolina to Georgia, then Mobile, Alabama. I took part in an hour-long meeting and then proceeded to drive all the way back up to North Carolina again to board my return flight to New Jersey where I live."

For Carson, who grew up in South Carolina, and who makes frequent trips like this to connect with family, friends, and business associates throughout the country, this type of itinerary was not unusual: Hour upon hour of traveling hundreds and hundreds of miles all while confined with limited mobility in a car or an airplane.

"I never connected the travel I was doing with any pain or potential harm," Carson says. "I didn't realize the importance of stopping more frequently and getting out of the car, or standing up in an airplane, to walk around and stretch my legs."

That all changed the day after Carson returned from this recent road trip and when he felt a sharp pain in his calf.

"I was at home and getting ready to go to the gym that morning, and I felt a tightness in my calf, similar to a muscle cramp, and I didn't think much of it," Carson explains. "Then, suddenly, it felt like something had exploded in my calf, and so I decided to skip the gym and just rest for a few hours.

"Having been a professional athlete, I'm used to enduring pain and just brushing stuff like that off," says Carson, who has suffered two bouts with blood clots, including a pulmonary embolism, in recent years. "At the same time, as an athlete I also know to listen to my body, and my body was telling me something was definitely wrong."

Later that afternoon, I started to think that whatever this was, it could be serious, and it might be a good idea to get it checked out. I went to the hospital and the doctors there did some testing. As they talked to me about the results, it was pretty easy to accept the theory that the travel had resulted in a clot in my leg, but when the doctors told me I also had a clot in my lung, that was really scary and a much bigger deal for me," Carson stresses.

Following his diagnosis in the ER that day, Carson received an injectable anticoagulation therapy or blood thinner, and spent one night in the hospital. The next day, he was discharged, and prescribed a blood thinning pill that he was to take for the next several months.



"It's a good thing that I took myself to the hospital and didn't just brush this off," Carson says. "That's what a lot of people might do, particularly men or people who are very fit or athletic. Instead, I listened to my body, got the medical attention I needed, and avoided a real crisis or something really much more awful."

After this experience, Carson, whose doctors told him he has no genetic clotting disorders or significant risk factors other than the extended periods of immobility associated with his rigorous travel schedule, made a point of being extra careful on long road trips. He made sure to stop more frequently to stretch his legs when travelling by car, and, when travelling by air, wearing compression hose and also getting up to walk around a lot during his flight.

#### Recurrence

Despite his best efforts, a few years later in 2017, when driving back from a trip to South Carolina, Carson was trying to beat the clock and get home at a certain time to ensure that his wife Maribel, who was travelling with him, would be able to keep an important scheduled commitment. With heavy traffic working against them, Carson took fewer stops to stretch his legs and walk around. Shortly after arriving home, he felt the familiar pain in his calf again. This time, he knew exactly what it could mean, and he quickly headed to the hospital, where he learned he had a recurrent clot in the same leg. Fortunately, this time he did not experience a blood clot in his lung.

After experiencing two blood clots, Carson has worked closely with his physician to make sure that he is taking steps to prevent another blood clot now and into the future. About one-third of people who experience a blood clot in their limb or lung will have a recurrence within 10 years. Like many people who experience a recurrent clot, Carson's physician says that it's advisable for him to be on a blood thinner medication indefinitely, or for the rest of his life.

"My wife was with me when the doctor said he wanted me to stay on my blood thinner medication for an extended period of time and maybe even for life," Carson explains. "As far as we were concerned, there was really no question. You do what you have to do to protect yourself from blood clots and stay well." happens to them," Carson says. "Too often, men want to be tough and brush things off. I get that and all men can be like that, but when it comes to your health, you really need to step up and take care of yourself. if you won't do it for yourself, do it for your family."

#### **Signs and Symptoms**

In recognition of Blood Clot Awareness Month, and through his collaboration with NBCA, Carson is hoping to help educate people about the signs and symptoms of blood clots. Despite the dramatic impact of this pressing public health concern—on average, one person dies every six minutes due to a blood clot—research shows that fewer than one in four people have any recognition of blood clots or their signs and symptoms.

The signs or symptoms of a blood clot in the leg or an arm may include: Swelling, pain or tenderness not caused by injury, skin that is warm to the touch, red, or discolored. The signs or symptoms of a blood clot in the lung may include: Difficulty breathing, chest pain that worsens with a deep breath, coughing or coughing up blood, a faster than normal or irregular heartbeat. As Carson did, people who experience any of these symptoms should contact their physician or seek immediate medical help. A blood clot in a person's leg can grow or break off and travel to their lung, which can be life-threatening.

"I can play an important role as a former professional athlete to help people understand that this can happen to anyone, and I also can help get the attention of men who might hear about my experience, relate to me as a regular guy, and learn something about what to do if it On average, one person dies every six minutes due to a blood clot research shows that fewer than one in four people have any recognition of blood clots or their signs and symptoms.

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#### Blood Clot Recovery: A New Normal

When asked how blood clots have affected his life. Carson refers to his "new normal."

"Every day before my blood clots, I was used to doing whatever I wanted to do. Now, I get up knowing that there's medication that I need to take every day," he says. "I know that I have to be the Chief Executive Officer of me. I have to be responsible for myself and my health. I have to take my medication daily, eat healthy, remain fit, and stay hydrated, for example."

Blood clots do not discriminate. They can happen to anyone regardless of age, race, gender, or fitness level. Each year in this country, about one million people are affected by blood clots, and about 100,000 of these people will lose their lives, which is greater than the number of deaths due to AIDS, breast cancer, and motor vehicle crashes combined.

"I consider myself lucky, because I listened to my body and I survived," Carson adds. "There are others, including some of my contemporaries in the professional sports world, who have not been so lucky. I want everyone to understand these important health issues and the risks that exist."

#### **Know Your Risk**

Being immobile for an extended period of time can be a specific risk factor for people, like professional athletes, who are required to travel frequently. Other major risk factors for blood clots include: Surgery, physical trauma or injury, hospitalization, cancer, being overweight, being age 55 or older. If you're a woman, additional risk factors include pregnancy, childbirth, and the use of estrogen, including hormonal birth control.

#### **Road to Recovery: Keep Moving, Stay Positive**

For anyone recovering from a blood clot and facing any type of struggle, whether it's physical or emotional, Carson stresses the importance of staying fit and maintaining a positive attitude.

"It's important to keep moving and stay positive, no matter what shape you're in or what your abilities might be," he says. "Maybe all you can do is take a short walk, or a few spins on a stationary bike, but if you are able to commit to working on your fitness you will get stronger and your mental strength will improve too. It's very important to stay healthy, maintain good nutrition, and always listen to your body.



Most of all, no matter whether your recovery seems easy or difficult to manage, always live life as well as you can. Always live your best life," he stresses.

Visit NBCA's website at www.stoptheclot.org for more information about blood clots. Contact info@stoptheclot.org with questions or comments.



After a blood clot, starting or returning to a fitness routine can seem overwhelming and maybe even impossible. It is important to focus on your healing, especially in the beginning, and give your body ample time to rest and recover. People who experience a blood clot emerge from their experiences with different levels of physical ability: Some return quickly to normal mobility and exercise routines, while others may struggle to regain their strength and their previous routines. Fortunately, most people do return to the activities they enjoy, but it can sometimes take a significant amount of time to get there.

Experts suggest that after suffering a blood clot, people should resume routine activities slowly, or at a pace that they are comfortable with. There is no one right way to proceed, but experts agree that physical activity is safe after you experience a blood clot in the leg or lung. However, if you experience a lot of pain or shortness of breath, take it easy and pace yourself accordingly. Always talk to your doctor about the right level of exercise for you.

"My blood clots occurred after I underwent surgery, which is a major risk for dangerous clots," explains Eric O'Connor, an ultra-marathon runner and NBCA's Board President. "Right after my pulmonary embolism, I could barely walk across the room without becoming short of breath. But, I worked to rebuild my strength and just one year later I was running again and today I'm more fit than I've ever been before."

For most healthy adults, the U.S. Department of Health and Human Services recommends these guidelines: Get at least 150 minutes of moderate aerobic activity or 75 minutes of vigorous aerobic activity each week, or a combination of moderate and vigorous activity. For someone recovering from blood clots, simply getting in any amount of physical activity can be beneficial to overall health and wellness. Over time, as you regain your strength and mobility, you can benefit from physical activity or exercise that will help you maintain a healthy weight and offset symptoms associated with post-thrombotic syndrome. Often, the best way to start an exercise routine is by committing to do something physical each day, either by simply taking a walk or participating in some other physical activity—like dancing or light yoga-that you might enjoy.

A sedentary lifestyle and obesity are known risk factors for blood clots. Fortunately, there are ways to reduce your risk of having a serious blood clot, or to prevent blood clots. A commitment to get up and get moving can help you reduce your risk for blood clots, and increase your overall health and wellbeing. Small steps lead to healthy habits that eventually become lifestyle changes. If you don't know where to start with an exercise or fitness routine, or if you are concerned about your ability to participate in physical activities, speak with your physician about what your best fitness choices might be.

## Conquering Mountains and Clots

## Wes' Story

In February 2017, a friend of mine challenged me to climb Mount St. Helens in August. At the time, I figured this was an easily attainable goal and we signed up.

April came and I noticed some soreness in my right calf. During my lunch breaks I would climb the stairwell at work-16 floors-and my calf seemed to hurt more when I was climbing. I instantly wrote it off as muscle pain, and didn't see it as something to be concerned about. After a few days, the pain persisted and I began to take notice. A week later, I noticed an area on my calf turning red and there was some swelling. My calf and ankles would swell up a little from time to time in that leg, as I had ACL surgery in 2009, but I wrote it off as a minor irritation. Nothing really was alarming to me until the pain began to interfere with my daily life. I have a desk job and wear compression socks every day, but my calf would not stop throbbing when I stayed seated or even when I went to bed. Easter weekend came and, with some urging from my wife, I decided to go to Urgent Care. The doctor on duty took a look at my calf and told me to head straight to the ER. Ultrasounds were done on my right leg and I was informed that I had a few small blood clots causing the irritation and swelling. They put me on one of the new oral anticoagulant therapies, and advised me to follow up with my primary care physician.

My primary care doctor referred me to a hematologist for blood tests, as this was an

unprovoked blood clot. My tests came back positive for factor V Leiden with two gene mutations identified (homozygote). I was told that I would be on blood thinners for life and the hematologist strongly encouraged me to have my parents and my sister tested. My family had tests done and it turns out each one of us has factor V Leiden. We relied heavily on NBCA's



resources to educate us about how this is passed genetically and shared our results with our extended family.

I am often asked, "How has your blood clotting experience changed your lifestyle?" When this happened I was only a few months away from my planned climb to the top of Mount St. Helens and I felt discouraged and defeated. I've always been one to set a goal and do everything I can to accomplish it. August 11, 2017, I was able to make it to the top of Mount St. Helens and it felt so good. It wasn't the tallest mountain in the world, but it turned into a bigger feeling of accomplishment than I ever expected. I hope my story can inspire others to overcome their clotting experience. Don't give up!



Cancer and some cancer treatments are risk factors for developing life-threatening blood clots. In fact, about 20 percent of all blood clots occur in people with cancer. The clinical risk factors for dangerous blood clots among people diagnosed with cancer include the tumor site or type of cancer, the stage of the cancer—with the initial time after diagnosis posing the greatest risk—and the specific treatment used, including chemotherapy, hormone treatment, hospitalization, surgery.

Cancers connected with the highest risk for blood clots include pancreatic cancer, stomach cancer, brain cancer, ovarian cancer, and blood cancers such as lymphoma and myeloma.

There are medications that can be used to help prevent and/or treat venous thromboembolism (VTE) or blood clots in people with cancer, and the National Comprehensive Cancer Network® (NCCN®) recently updated its guidelines related to VTE and cancer. To learn more about these NCCN® recommendations, including the use of direct oral anticoagulants in people with VTE and cancer, visit <a href="https://www.nccn.org">www.nccn.org</a> and click

on NCCN® Guidelines > NCCN® Guidelines for Supportive Care > Cancer Associated Venous Thromboembolic Disease and then register.

If you have been diagnosed with cancer, it's important to understand your risk, and also crucial to be acutely aware of blood clot symptoms. Speak with your cancer doctor about how to reduce your risk for blood clots, and make sure to notify them if you experience any blood clot symptoms.

Lastly, while people with cancer are more at risk for developing clots, thrombosis can be a first sign of cancer, and experts estimate that about 10 to 15 percent of people diagnosed with unprovoked deep vein thrombosis—or who experience a blood clot with no known risk factors—will be diagnosed with cancer over the next two years. With this information in mind, if you are diagnosed with a blood clot, make sure you get all of your age-appropriate cancer screenings, including colonoscopies, mammograms, and Pap smears to carefully monitor your cancer risk.

## You've Experienced a Blood Clot... Now What?

#### **Blood Clot Recovery Clinical Considerations:** It's Not "One Size Fits All"

Each year in the United States, up to 900,000 people will be affected by blood clots in their legs or arms (deep vein thrombosis or DVT) and blood clots in their lungs (pulmonary embolism or PE). For some people, recovery from this experience is swift and largely uneventful, but for many others, it can take weeks, months, or possibly even years to feel well again. Some people struggle with longterm, or lifelong, complications from blood clots. The spectrum of potential recovery times, like the diversity of blood clot experiences themselves, varies widely, and it often seems that no two situations are exactly alike.

However, one thing is certain: Recovery from blood clots can be difficult and overwhelming. It can also be life-changing, and have serious physical, psychological, social and even financial implications for the people who are affected. Frequently, people wonder or ask, "I've been diagnosed with a blood clot, what happens next?" While these challenges can be devastating and perhaps even seem impossible to overcome, the good news

is, most people do recover completely from blood clots and go on to resume their normal lives and activities. While it can take time to heal, recovery from blood clots is possible, and most people will not go on to experience another blood clot.

#### **Hospital or Home: Initial Care and Treatment**

While blood clots can occur anywhere in the body, they commonly occur in the legs or arms. Blood clots that occur in the leg or arm are called deep vein thrombosis, or DVT.



Signs and symptoms of DVT may include: Swelling, pain or tenderness not caused by an injury, skin that is warm to the touch, and redness or discoloration of the skin. If you are concerned that you have a DVT, call or see your doctor right way. Doctors may use a variety of diagnostic tools to look for a DVT, including a Duplex ultrasound or a D-Dimer blood test, which may indicate the presence of a blood clot.

When a blood clot that forms in the leg or arm breaks apart and travels through the blood stream, it can create a lifethreatening situation, such as a blood clot in the lung, also known as a pulmonary embolism or PE. Signs and symptoms of a PE may include: Difficulty breathing, chest pain that worsens with a deep breath, coughing or coughing up blood, and a faster than normal or irregular heartbeat. If you experience any signs or symptoms of PE, call 9-1-1, or go to the nearest emergency room, where doctors can look for a PE using several diagnostic tests, such as a CT scan of the chest.



Blood thinners may be administered in the hospital, particularly during the first 5 to 10 days following diagnosis, considered the most serious or acute phase of the condition. However, blood thinners may be prescribed initially for home use in individuals with suitable risk profiles. Often times, if or how long someone is admitted to the hospital depends on the severity of the clotting situation, or what other damage has been done

in the body, such as damage to the heart or lungs.

Emerging studies show that in many cases, blood clots can also be treated at home, although initial care should be sought from a doctor or hospital if you are experiencing symptoms. Blood clots cannot be treated at home without a physician's prescribed plan of care and involvement. Extended time in the hospital is a known risk factor for blood clots, so if a person can begin treatment in the emergency room, for example, and then be sent home, that is often the case. The introduction of new oral anticoagulants, which are not dependent on frequent blood monitoring to ensure effectiveness, have helped to make at-home care like this a more viable treatment option.

#### Finding a Doctor Who is a Partner in Your Care

Sometimes, it may feel like healthcare professionals don't understand, or fully appreciate, the implications of a blood clot diagnosis and subsequent recovery. This may be due, in part, to how varied recovery times and experiences can be. It is often difficult to adequately explain recovery to a person when situations vary so widely, and just like searching for any type of service, it can sometimes take a couple of tries before you find a doctor, or specialist,



who you trust and consider a partner in your care.

A primary care physician or general practitioner will be responsible for your initial care and treatment, but often times it is also important to see a specialist, with specialized knowledge, to discuss your treatment plan. Many people start by seeing a hematologist to discuss the cause of their blood clots, or blood clot risks, and length of treatment. If you need help finding a hematologist, you can explore the tools and resources on NBCA's website that can help you do so, or ask your primary care physician to provide you with a referral to a specialist. Some people may also benefit from seeing a vascular surgeon, pulmonary specialist, cardiologist, interventional radiologist, or pain management specialist, depending on their specific treatment needs. A psychologist or counselor, as well as an obstetrician or gynecologist, may also be a part of your healthcare team.

It's a good idea to meet with your primary care physician as soon as possible after your diagnosis to discuss your needs and ask any questions about treatment and recovery that you may have. From there, work with your doctor to build a specialized care team that can fully investigate your situation and provide you



with the most comprehensive care possible.

"I survived a pulmonary embolism in my late 20s, and quickly came to appreciate the incredible physician who saved my life, and then the amazing team of doctors who made it possible for me to bring three of the sweetest little boys into our family with no clots and no complications."

- Amy K., NBCA Board Member

#### **Medication Management: Life with Blood Thinners**

Anticoagulants, or blood thinners, are the most commonly prescribed treatments for blood clots. While medications like these do not actually thin the blood, they do prevent new clots from forming, or existing clots from growing larger or breaking apart and causing further damage or complications.



For many people, treatment with blood thinners may continue for weeks, months, or years following diagnosis. The most commonly prescribed blood thinners are unfractionated heparin, low molecular weight heparin, warfarin, and direct oral anticoagulants.

#### **Warfarin: Managing Your INR**

Warfarin is an anticoagulant that may be taken for a period ranging from a few weeks to lifelong, depending on the individual's diagnosis and future clot risks. It works by inhibiting the liver's ability to make coagulation proteins that require vitamin K for their synthesis. Warfarin dosing is highly individualized and not based on a patient's weight. It requires regular monitoring to ensure that blood clotting time—or prothrombin time is within the correct range. The prothrombin time (PT) is generally reported as the International Normalized Ratio (INR) which standardizes the PT test results so that they are comparable from lab to lab. The

PT/INR is conducted using a sample drawn from an arm

vein or finger prick. It is initially performed several times weekly at the beginning of warfarin treatment and then gradually testing becomes less frequently as the correct dose for an individual patient is determined, eventually decreasing to about once per month.

Most patients on warfarin do well with an INR between 2.0 and 3.0. However, a higher or lower INR may be appropriate for certain patients. If the INR falls below the therapeutic

### **At-Home INR Testing**

Some patients can monitor their INR at home with a finger-stick machine and test strip. The same instruments used to collect a finger sample from a patient in an office or clinic setting also can be used by patients at home or while traveling to check INR levels.

While it may be more expensive than labbased tests, at-home testing is covered by many insurance plans, including Medicare and Medicaid, and can offer significant advantages for patients with limited mobility and other obstacles to regular laboratory monitoring. Also, research shows that, compared to standard INR monitoring, patients who self-monitor their warfarin therapy have better therapeutic experiences without an increase in side effects or harmful outcomes.

After testing their INR at home, a person simply reports the results to their physician, who can then monitor and, if needed, adjust their warfarin dose. INR home testing requires



that patients meet certain criteria, and that a physician recommends or prescribes athome testing. But, it is not ideal for every individual. For example, people affected by antiphospholipid syndrome are not good candidates for at-home testing.

If you are on warfarin and interested in checking your INR at home, discuss your options with your physician. They will need to write a prescription for the device, be available to instruct you in dosage adjustments, and remain medically responsible for your anticoagulation management.

The National Blood Clot Alliance offers a comprehensive guide about INR self-testing, which you can read <u>here</u>.

range, the risk of clotting is greater and if the INR rises above the therapeutic range, the risk of bleeding complications is higher.

Warfarin therapy can present several lifestyle challenges, most notably careful effort to reduce food interactions involving vitamin K specifically. Many common dietary staples, such as green leafy vegetables, are high in vitamin K. Altering the amount of vitamin-K rich foods you consume can affect your INR and require warfarin dose adjustments to keep clotting and bleeding risks in check. If you are taking warfarin, try to be consistent in your eating habits and be sure to discuss any major dietary changes with your doctor.

Similarly, supplements, prescription and over-thecounter medications, and alcohol can all affect your INR, so be sure to talk to your healthcare team if you are making any changes to your regular routine.



Your doctor may require more frequent INR monitoring, or medication dosage adjustments, to keep your INR in a therapeutic range.

#### **Take Note: Keeping Track of Your Recovery**

It is important to track or make note of what you experience during your recovery from blood clots. You might want to use a notebook, or a simple electronic list of questions that you have for your doctor. It also helps to note things like: Any unusual symptoms or experiences you notice, pain, INR, food and exercise, etc.

When attending follow-up appointments, take a trusted friend or family member with you initially to ensure you hear and understand important information and to ask any important questions that may arise.

- 1. What are my risk factors for blood clots, or are there any? Do I need any further tests?
- 2. What will my treatment plan consist of?
- 3. What do I need to know about my anticoagulant? Are there instructions for taking it?
- 4. Will I need to make follow up appointments to monitor my treatment or to get other prescriptions?
- 5. Do I need to meet with specialists like a hematologist, cardiologist, pulmonologist, etc.?

- 6. What can I expect my recovery to be like? How do I know if I need to call the doctor or go to the hospital?
- 7. What is an approximate timeline for me to return to work, or do I need to take time off?
- 8. When can I resume activities I enjoy, such as travel and exercise again?

#### **Consequences of Clotting:** What to Do When You're Not **Feeling Better**

While most people recover fully from blood clots, some people will struggle with longterm, or lifelong, complications with their legs, arms, or lungs.

One of the potential complications of DVT is postthrombotic syndrome, or PTS, which is characterized by ongoing leg or arm swelling, pain, aching, heaviness, and cramping. Approximately 60 percent of people who experience a blood clot will recover from a leg DVT without any residual symptoms, 40 percent will have some degree of postthrombotic syndrome, and 4 percent will have severe symptoms. The symptoms of post-thrombotic syndrome usually occur within the first six months, but can occur up two years after the clot.

Prevention is the key issue when addressing PTS. If you have leg swelling after a DVT,

# Interventional Therapies for DVT

Some patients who have massive blood clots, or disease that progresses despite anticoagulant treatment, may require clot-dissolving drugs or surgeries to remove blockage. These are aggressive options, but can help to save the lives, limbs, and organs of individuals with extensive and/or complicated clots.

Likewise, they can be valuable approaches for relieving debilitating symptoms that persist after blood thinner use and may prevent post-thrombotic syndrome (PTS), a condition in which limb pain, swelling and other symptoms become chronic and long-term problems after a person experiences a deep vein thrombosis (DVT) or a blood clot in their leg.

Interventional treatments for DVT—which are performed in a hospital setting by vascular surgeons and interventional radiologists—are not without risk. They should be considered on a case-by-case basis as a means to reduce early DVT symptoms or reduce the potential severity of PTS. You can read more about interventional treatment of DVT on NBCA's website here.

Thrombolytic drug therapy involves the use of fibrinolytic agents that break up fibrin, a core component of clots. These medications are normally infused into the clot through intravenous catheters. Bleeding risks are a serious concern with these agents, so patients must be thoroughly evaluated for bleeding potential before undergoing this course of treatment.

In some instances, surgery is warranted to physically remove the clot from the affected vein. Surgeries are most common with pulmonary embolism (PE or blood clots in the lungs) and a procedure known as pulmonary thromboembolectomy. Again, patients need to be carefully screened to minimize bleeding risk and ensure that surgical benefits outweigh the risk of complications.

you should discuss wearing compression stockings to decrease the swelling with your healthcare provider. If it is determined that compression stockings are necessary, you should be professionally measured and fitted by a medical supply company, or your pharmacist.



Some people may also suffer from long-term reduced lung function after PE. Always talk to your doctor if you experience shortness of breath, difficulty breathing, or chest pain after your blood clot. While these symptoms may be experienced during recovery from a blood clot in your lung, if symptoms like these persist or worsen, your physician will need to carefully monitor you for more serious lung problems.

## Blood Clot Recurrence: How Likely Is It & How to Manage Your Fears

Although most people do not experience a recurrent blood clot, one-third (about 33 percent) of people with DVT/PE will have a recurrence within 10 years. Chief among the concerns raised by people who have experienced blood clots is the worry, or fear, of a blood clot recurrence. The worry about recurrence, or repeat blood clots, can be an obstacle that is difficult to manage and overcome, but there are three important steps that can take to help address your fear.

## 1. Know Your Risk for Blood Clots:

One of the most important things you can do to protect yourself from blood clots is to know and understand your risk. Blood clot risk factors include:

- A personal or family history of blood clots
- Spending time in the hospital or surgery
- Pregnancy and childbirth
- Hormonal birth control
- Estrogen for the treatment of menopause symptoms
- Thrombophilia
- Smoking
- Overweight or obesity
- Other prolonged immobility, such as travel for more than four hours, and long-term diseases, such as heart and lung conditions

Talk to your doctor about your risk factors, and if you need ongoing to treatment to reduce your risk.

## 2. Know the Signs and Symptoms of Blood Clots:

If you experience any of the signs or symptoms of blood clots, talk to your doctor or seek help immediately.

Symptoms of a blood clot in the arm or leg may include:

- Swelling
- Pain or tenderness not caused by an injury
- Skin that is warm to the touch
- Redness or discoloration of the skin

If you have these signs and symptoms, call your doctor as soon as possible.

Symptoms of a blood clot in the lung may include:

- Difficulty breathing
- Chest pain that worsens with a deep breath
- Coughing, or coughing up blood
- Faster than normal or irregular heartbeat

Seek immediate medical attention if you have any of these signs or symptoms.

## 3. Take Measures to Prevent Blood Clots:

About 30 percent of people do not know why they had a blood clot—they had no known risk factors—but there are still precautions everyone can take to help prevent blood clots, which may include:

- Talk to your doctor and other family members if you learn that there is a history of blood clots among your relatives
- Ask your doctor about options to prevent blood clots
- Move around if you have been sitting for a long time or traveling for a long time by plane, train, or car
- Maintain a healthy weight, and not smoking or taking steps to quit smoking

In addition to these steps, talk to your doctor, or a mental health professional, if you feel that your anxiety is interfering with your daily life. Blood clots are dangerous, but they are also treatable, and often preventable. Work with your healthcare team to identify your individual blood clot risks, and develop a plan to reduce your risk in the future.

It can be a difficult path, and for some a long path, but you will likely find that physical recovery improves with time, and, if not right now, soon you may be living your "after clot life" in a more comfortable and happy space that more closely resembles your "before clot life." Stay strong, together we will all get there.

## Being Your Own Advocate Can Save Your Life: **Tiffany's Story**



For my college graduation trip a few years ago, I went to Hawaii with my family. After our red eye flight back to LAX, I got up and out of my seat and suddenly experienced severe calf pain in my left leg. I attributed it to running and didn't think much of it. The next day, it was still bothering me, so I went to the urgent care and the doctors there believed it was probably a blood clot. They ran an ultrasound which came out negative, and then told me to go home, use crutches, and rest. Nearly two days later, my leg was still throbbing, and the pain reliever I was prescribed was not helping.

When it got to the point where I could not walk from my bedroom to the bathroom, I went to the ER, where they performed another ultrasound, which also came back negative. I was still in a lot of pain, so my mom pressed for more tests. The doctors wound up doing an MRI, which showed one blood clot, but since it was below the knee, they did not want to put me on blood thinners. The next day, I followed up with a vein specialist who took a third ultrasound and found a second blood clot. He started me on low molecular weight heparin injections right away.

I was supposed to continue the injections on my own for one week. Unfortunately, the following morning—which was five days after I had returned home from Hawaii—I had severe chest pain. It felt like an elephant was stomping on my chest. I went to see my doctor, who then rushed me to the hospital, where it was determined that one of the blood clots had moved to my lung.

### "Within 12 hours, the blood clot had moved from my calf to my lung."

I was hospitalized for one week. After being discharged from the hospital, the doctors determined that my blood clots were the result of several risk factors: I have two genetic blood disorders that I was unaware of, I had recently taken a long airplane ride, and I was on hormonal birth control.

This minor setback slowed down my running career, but it has not stopped me. After using the walker, oxygen tank, and crutches to recover, I started slowly running again. I started running to my vein, lung, and blood doctors' appointments, and I just ran my 43rd half marathon in December 2018 in 1:39:47, which is 7:38 pace per mile. Originally, after my DVT and PE, the doctors said I may not be able to run again, but I proved them wrong.

My best advice to others going through something similar is to be persistent and be your own advocate because it could save your life.

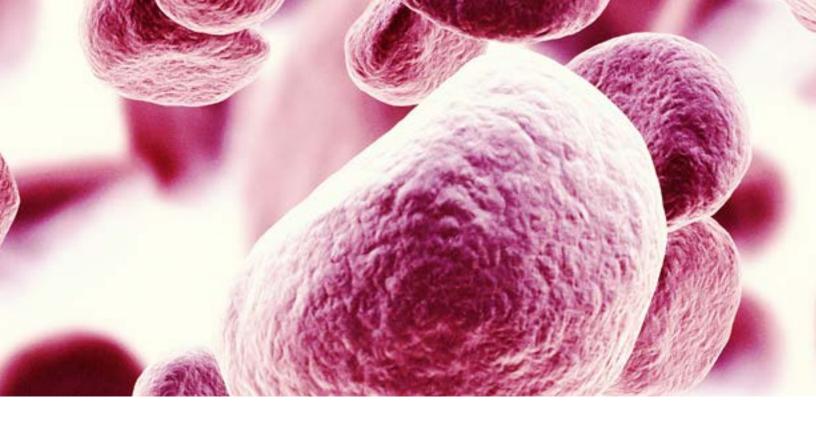
## Bleeding When It's a **Nuisance** and When It's Serious

Each year, millions of people in the United States will need to take an anticoagulant or blood thinner medication. Blood thinners save lives, because they can treat or prevent dangerous blood clots. However, these medications also pose a potentially serious side effect: Bleeding.

Clotting is a normal process that your body needs when healing after a cut or scrape. Since blood thinners slow the clotting of blood, unwanted and sometimes dangerous bleeding can occur with the use of these medications. If you use blood thinning medication, you should tell your doctor about any bleeding or unusual bruising you might experience, as well as any serious falls or hard bumps to the head you might suffer. While it is infrequent, bleeding caused by blood thinners can be very serious or life-threatening, like bleeding into the brain or stomach. Serious or lifethreatening bleeding requires immediate medical attention.

Most of the time, however, bleeding caused by blood thinners is not serious or life-threatening. For example, bleeding after a skin tear from yard work. Bleeding like this is less serious, but can still be troublesome and inconvenient, and it can seriously impact the quality of a person's day-today life. In fact, more than half of emergency room visits by people who take blood thinners are for nosebleeds and other types of nuisance bleeding caused by superficial wounds to the skin.

More than half of emergency room visits by people who take blood thinners are for nosebleeds and other types of nuisance bleeding caused by superficial wounds to the skin.



With a few added precautions, people who take blood thinners can still engage in most of the activities they enjoy:

- Be cautious about activities, such as high-risk sports, that may result in injury, and always wear proper safety gear, for example, a bike helmet when cycling
- Wear protective gloves when working with tools, such as gardening shears or other sharp instruments, and wear shoes to protect your feet
- Be careful when shaving, or trimming hair and nails
- Use a soft toothbrush and care when brushing your teeth
- Talk to your doctor, or seek emergency medical attention, if you have bleeding that does not stop in a reasonable amount of time, if you suffer a serious injury, or if you hit your head
- Consider purchasing a medical ID with your contact information, or an emergency contact's information, and the name of your blood thinner on it. Wearing a medical ID can help first responders identify you and your treatment needs in the event of an emergency.

Regardless of how cautious you might be, accidents can still happen, and nuisance bleeding may still occur. When it does, experts recommend that you apply pressure with a clean bandage or cloth to stop the bleeding. If nuisance bleeding continues, there are several products, including special bandages, wound dressing, gels and powders that can help stop nuisance bleeding more quickly. These products are available at most local pharmacies, outdoor recreation stores, and online. They may be used safely while taking blood thinners, and they don't require a prescription. Talk to your doctor about options for managing nuisance bleeding if it's something that's causing you concern.

## **Diagnosis Anxiety**

Prominent among the many lifestyle issues people in the clotting community voice concerns about are the feelings of anxiety and depression they often confront after experiencing a blood clot.

For some people, it may be the nagging and, at times, even debilitating anxiety and fear that they will be struck by another blood clot, or the concerns they may have after being prescribed an anticoagulant or blood thinner medication. For others, it may be depression that goes hand-in-hand with the dramatic changes to their lifestyle, including potential leg pain or reduced lung function, for example. In either case, the feelings are real, and research has shown that, anxiety and depression pose tremendously difficult obstacles to overcome.

"There was a lot of anxiety to contend with after my pulmonary embolism. It was scary and overwhelming, and sometimes, wondering about 'what's next' kept me up in the middle of the night."

#### -Brenda C.

Research has shown that high levels of anxiety and depression are common among people who experience a pulmonary embolism, or a blood clot in the lung, and more recently a study out of Denmark showed that one in five young DVT/PE patients will require psychotropic drugs, such as anti-depressant or anti-anxiety medications, within five years of their diagnosis. Not surprisingly, when NBCA shared this new information on its Facebook page, we heard from numerous people who said that these feelings are not age-dependent,

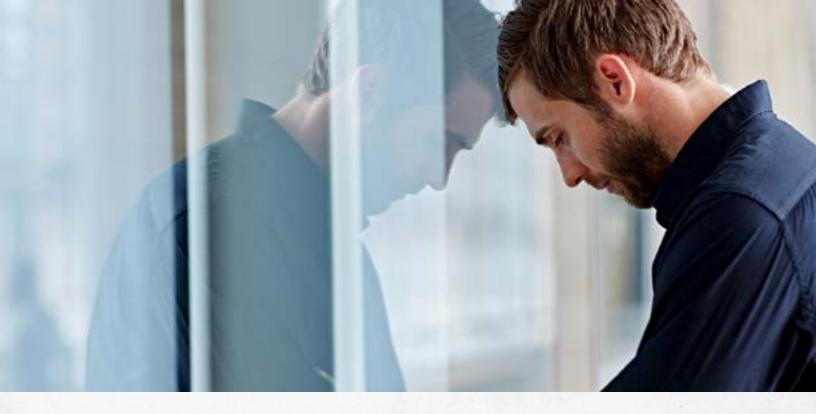
as these fears and anxieties can and do affect DVT/PE survivors of all ages, and can last beyond five years. Some people deal with anxiety and depression very long term. Also, since this study focused only on those individuals prescribed drug therapy, it does not account for the individuals who were either too young, or perhaps not clinically diagnosed or prescribed medication. Without question, anxiety and depression affect many people in our community.

Good nutrition and an appropriate exercise regimen can contribute to a person's mental health, but, for many individuals, these issues will be among the greatest challenges they face after experiencing a blood clot.

You should never suffer in silence or feel like you are alone. You are not alone. There are many others who share these same feelings. Always reach out and get the help you need. Speak to your healthcare provider if you are struggling with anxiety, depression, or any other troubling emotions in the aftermath of your blood clot experience. There are different ways these issues can be successfully managed and your doctor should be able to recommend strategies or resources that can help you.

"Working with my doctor to understand my situation helped me with those 3:00 a.m. moments when I was too scared to sleep. My doctor served as a good barometer to address my questions, and it helped me to know what to expect during my recovery from blood clots."

- Chris R.



It's also important to keep in mind how much you have learned from your experience andto recognize that you are in greater control of your health if you now know you are at risk, or since you are now well aware of your risk for blood clots, as well as the signs and symptoms of blood clots. As the old saying goes, "information is power," and your new-found information can become a more positive aspect of your experience from which you can derive strength.

The Anxiety and Depression Association of American recommends several steps to help manage and anxiety and stress, including:

#### MIND

- Accept that you cannot control everything
- Maintain a positive attitude
- Do your best instead of aiming for perfection
- Learn what triggers your anxiety and tackle those triggers

#### **BODY**

- Limit caffeine and alcohol
- Eat well-balanced meals
- Get enough sleep
- Exercise daily, even if it means just a short walk or light stretching

#### **ACTIONS**

- Take deep breaths
- Give back to your community, which can create a support community and give you a break from daily stress
- Take time to listen to music, meditate, or practice other relaxation techniques
- Talk to someone about how you're feeling and let them know how they can help you

For a patient's perspective regarding depression, you can read this moving and informative blog post on *Blood Clot Recovery Network:* Dealing With Depression. You also can join the Stop the Clot® Online Peer-to-Peer Support Group and Discussion Community, powered by Inspire and moderated by the National Blood Alliance, to meet up with and get support from people who share your same experience.

If you are struggling or feeling overwhelmed, always speak to your healthcare provider or a therapist who can help you take steps to manage your anxiety or depression. The National Blood Clot Alliance has resources on its website to help you find a spectrum of healthcare professionals in your local community: Find a Doctor.

### Ready, Set, Go

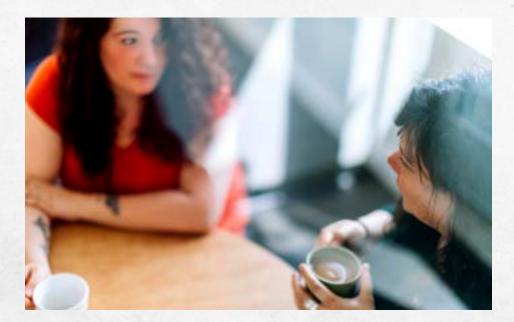
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Sharing information about blood clots is one of the best ways to educate people, and to help shed some light on what you may be going through. You can share information about blood clot risks, signs and symptoms, and also ways to prevent blood clots with your friends and family members. NBCA has a spectrum of resources on its websitewww.stoptheclot.org-to help you help others understand all of these things. Sharing resources like these may also help provide people who are unfamiliar with blood clots some insight into what it can be like to recover from one.

experiences, or in the multitude of questions you might have. Connecting with peers who understand your situation, and your journey back to health, is very important, and can truly make a difference, especially if your recovery has been difficult.

"My friends and family didn't always understand what I was going through during my blood clot recovery. It helped me to connect with people who shared my experiences, the people who truly get it."

- Adam W.



#### **Connect with People Who** Understand

If you have experienced a blood clot or been diagnosed with a clotting disorder, you do not have to recover alone. Most likely, you are not alone in your

It is often a crucial part of a person's successful recovery from blood clots, and research suggests that sharing our stories benefits both patients and caregivers, by helping patients better

understand their needs and priorities, and also by enabling healthcare providers to have a more meaningful relationship with "the person behind the patient." (The New York Times, Letting Patients Tell Their *Stories*, April 11, 2016) Ask your doctor or hospital if they have any resources to help you connect with other patients in your community. You also can join NBCA's online Stop the Clot® Peer-to-Peer Support Group and Discussion Community, powered by Inspired, where you can chat with people who share your same experience.

#### **Health History Matters**

If you or a family member has experienced a dangerous blood clot, you may have an underlying condition known as thrombophilia. Thrombophilia increases the risk for dangerous clots in your arms, legs and lungs. Some people are born with thrombophilia (inherited thrombophilia), while other people develop thrombophilia later in life (acquired thrombophilia). In either case, the condition has many forms and may affect people in different ways, and sharing information with your family members is a good way to address any clotting concerns that may arise in your family.

Talk to your family members about your history of blood clots and thrombophilia, if you have been diagnosed with one. You can also direct them

to numerous thrombophilia tools and resources, including information about different types of thrombophilia, treatment options, and genetic testing available on NBCA's website. Your family members should also make an appointment with their healthcare provider to discuss their personal risk factors for blood clots, as well as any blood clot prevention that may be necessary.

#### Back to Work: Am I Ready or Not?

One of the unexpected challenges of blood clots may be returning to work. Some people return to work in a few days or weeks, while other people may be forced to take extended time off from their job, or stop working altogether.

"After my blood clots, it was a challenge for me to go back to work. I had to take it slow, and give my body time to heal, before I was able to go back to work fulltime."

#### - Jennifer M.

There is no right or wrong time to return to work after a blood clot. You should discuss your recovery, and your limitations, if there are any, with your healthcare team. Ask them to help you decide when it may be okay to return to your job. If appropriate, talk to your employer about any accommodations you



Thrombophilia is a medical term used to describe the condition where the blood has an increased tendency to clot, and there are many reasons why the blood can have this increased tendency.

Thrombophilia is usually categorized into two types: Acquired and inherited. In acquired thrombophilia, the abnormal clotting is usually related to a specific cause, such as prolonged periods of bed rest after surgery, physical trauma, or having cancer. People with inherited thrombophilia tend to form clots due to a genetic predisposition inherited from their parents, and may have a family history of relatives with abnormal or excessive blood clotting. While there are a number of genetic mutations that can cause inherited thrombophilia, the most common DNA mutations are named factor V Leiden and prothrombin G20210A.

Many people diagnosed with thrombophilia may never experience a blood clot, while others may experience a lifethreatening clot or even a series of them. About 90 percent of all people with thrombophilia never develop a blood clot and may go their entire life not even aware they are at risk for blood clots. Unfortunately, however, there are some less common types of thrombophilia, such as hereditary antithrombin deficiency, that do carry a much higher risk.

You should talk to your physician about any questions you might have about thrombophilia or your potential risk for blood clots.

You can learn more about thrombophilia and its many forms, including risks and potential complications, current perspectives about testing and diagnosis, and an overview of potential treatment options that you and your physician may want to consider on NBCA's website at <u>Understanding Thrombophilia</u>.

may need at your job, such as reduced or flexible hours, or accommodations to sit, stand, or walk around as needed. If you cannot return to work, you may talk to your employer about what benefits may exist, such as paid or unpaid time off, short-term disability, or medical leave. You may also discuss longer-term solutions, such as a change in career, or even disability, with your doctor.

Ultimately, it is up to you to decide what you share with your employer and colleagues, and sharing is not always comfortable or even advisable for everyone. The Patient

Advocate Foundation may be able to help you determine if you have any questions about your insurance, or if you are under- or uninsured. Take your time when returning to work, or when searching for work, and make decisions that ultimately benefit you and your health.

## Get Out and Enjoy Your Life: Travel After Blood Clots

Experts agree that extended immobility due to travel may increase your risk for a blood clot, but that doesn't mean that you can't enjoy travel or exploring new places. Typically, flights, car, train, or bus journeys that are longer than four hours pose the highest risk.

If you have been recently diagnosed with a blood clot, consult with your physician to determine when they



recommend you can resume air travel.

When you're cleared for take-off, particularly if you're traveling long distances, make sure you take precautions to help reduce your risk for a blood clot. If possible, take breaks on your journey to stand up and move your arms and legs every one to two hours on a long trip. Also, wear lose and comfortable clothing, avoid crossing your legs, and hydrate with water (avoid caffeine and alcohol). If you are in a situation where you cannot get up on a plane or stop the vehicle, you can do arm and leg stretches and movements from your seat, such as writing the alphabet with your feet or pumping your legs from time to time. With air travel, securing a bulkhead seat or an emergency exit row may also provide for extra leg room.

Talk to your doctor about if and when it is safe for you to travel

"In many ways, it was truly awful, but ultimately it gave me greater appreciation for life. Don't wait for tomorrow to be happy."

Amaris W.

NBCA Board member who, after surviving a life-threatening pulmonary embolism, has since backpacked around the world.

again after blood, and ask about the best ways for you to prevent blood clots.

Even after a blood clot, you can still enjoy new and exciting adventures. It can be overwhelming to think about traveling or other activities after a blood clot, but the more you get out and do the things you love, the more confidence you will gain and the stronger you will get—physically and emotionally. Like any other journey in life, small steps can lead to great rewards. The joy of experiencing new sights and new places can be very empowering. Whether you are journeying abroad, exploring portions of the country you've never visited before, or simply stopping in at local tourist attraction you previously shunned, get out there and get your travel on...reward yourself by living your best life.

## Every Day, Life is a Gift: Kimberly's Story

My pulmonary embolism story began when I had surgery in May of 2018. I went in for a laparoscopic hysterectomy and I was released from the hospital that same day. I didn't realize that I was at risk for a blood clot due to the type of surgery I was having, as well as being age 49 and I was a smoker.

I was up and moving around the day after the procedure. A few days later, I noticed that I didn't have an appetite, and this continued along with an overall feeling of not being well. I had to force make myself to eat and this was not like me.

Nine days after surgery I experienced an incredible pain in the bottom of my lung that radiated all the way around to my back. I was having trouble getting air into my right lung and was trying to cough with little success. Trying to take deep breaths only made the pain worse.

After calling the after-surgery emergency number, I was told to sit up and apply heat and the pain did slowly get better over time, but I was still unable to take a deep breath. The intense pain was part of my lung dying due to lack of oxygen. I am lucky I didn't die that night. The next morning, I called my doctor's office and spoke directly to him and was told I needed to consider going to the ER and have a CT scan to rule out a blood clot. He told me that if it was a blood clot it could be fatal.

That is all I needed to hear. I have four kids who I love very much and I was not ready to leave them.



I went to the ER and was admitted to the hospital for a pulmonary embolism. I wondered if I was dying and I really didn't understand what this meant for me.

I started searching on NBCA's website for information and support. I found it helpful to read the stories of other people who had blood clots and survived. Nine months later, I have a new outlook on life. My kids and family, my friends, and all of those cool life moments are the most important things to me. I don't sweat the small stuff. I have learned that I am stronger than I thought I was, and that you should never give up no matter how bad things might seem. I just needed time to recover and you have to give yourself that time.

Walking helped me to recover. The more I walk the better my lung gets. The elevated breathing got better, and the shortness of breath improved too. I don't think that I will ever be the same as I was before my pulmonary embolism, but I am returning to work and feel like I can accomplish anything after what I have been through. Every day, life is a gift and I celebrate being here.

# Women's Health:

# A Continuum of Concern and Care

Women face a continuum of blood clot risks throughout their lives. These risks are connected to family planning and birth control, pregnancy and childbirth, and the use of hormone therapies to treat menopause symptoms later in life.

Women should be aware of all of their blood clot risks, and remain vigilant about milestones in their life that may signal a heightened risk for clotting. And, if they are taking blood thinning medication or anticoagulants, they should also should be prepared to manage heavy menstrual bleeding.

#### Pregnancy and Childbirth: Have a Plan to Prevent Blood Clots

Pregnancy is a major risk factor for the development of dangerous blood clots. Women who are pregnant or who have just given birth are at increased risk for blood clots. Pregnancy does not directly cause blood clots, but, in comparison to women who are not pregnant, it does pose a four-fold increased



risk for the development of a blood clot. That risk actually increases to about 20-fold in the weeks immediately following childbirth, and is at its highest—a risk of 100-fold—in the first week after the baby is born. This tendency for a woman's body to form clots during pregnancy is the result of a natural biological response intended to protect women against the potentially major bleeding challenges of miscarriage and childbirth.

A blood clot in the lung is one of the leading causes of pregnancy-related death in the United States. Pregnancy, childbirth, and the three-month period after delivery are times when there are major risks for the development of dangerous blood clots. With the right information and a prevention plan, however, blood clots during pregnancy and childbirth can be prevented. If you're planning a pregnancy or expecting a baby, talk with your physician about your risks and the steps you can take to prevent dangerous blood clots.

#### **Birth Control and Blood Clots: Making Informed** Choices

There are more than 60 million women of child-bearing age in the United States, and the majority of them report using some form of birth control. In fact, the birth control pill is their number one choice. Birth control methods that contain estrogen—including the pill, patch and ring—can increase a woman's risk for blood clots. While estrogen does not directly cause blood clots, it does cause the body to think it is pregnant, which in turn increases a woman's natural clotting mechanisms in preparation for childbirth. Women who are planning to take or who take hormonal birth control should be aware of their increased risk for dangerous blood clots, as well their options to reduce that risk.

Women who take birth control with estrogen are at increased risk for a blood clot. This risk is further increased in women who have previously suffered a blot clot, have a family history of clotting, or have a clotting disorder. If you are a woman who is considering taking hormonal birth control, you should speak with a trusted healthcare provider about your options. You can also complete NBCA's onepage Risk Assessment and discuss your results with your doctor if you are considering hormonal contraception.

There are safe alternatives if you want to avoid the increased risk of blood clots associated with birth control methods that contain estrogen. Several of these options include: barrier methods, spermicides -progestin implant, copper IUD, progestin IUD, progestinonly pills, tubal ligation or vasectomy for your partner.

Birth control methods that contain estrogen—including the pill, patch and ring—can increase a woman's risk for blood clots.

#### **Treating the Symptoms** of Menopause: Reduce Your Blood Clot Risk

Just like with birth control methods that contain the hormone estrogen, estrogen for the treatment of menopause symptoms can increase your risk for blood clots. For women looking to avoid the risk of blood clots connected to hormone therapy, the troublesome physical effects of menopause, such as mood changes, hot flashes, sleeplessness and vaginal dryness, can be managed without estrogen for symptomatic relief. It is also important to keep in mind that most women, but not all women, will experience the severity of menopause symptoms for about six

months before they begin to subside. Talk to your doctor about symptom relief without the use of estrogen.

#### **Anticoagulation and** Menstruation

Lastly, if you have previously experienced a clot or are at risk for a clot and, therefore, taking an anticoagulant therapy, you may struggle with heavy menstrual bleeding. Talk to your healthcare provider if your menstrual cycle is abnormal for you, or if you experience dangerous menstrual bleeding. Experts define dangerous menstrual bleeding as any bleeding that lasts more than 7 days, bleeding that is very heavy, or if you need to change your tampon or pad after less than 2 hours or you pass clots the size of a quarter or larger. If you experience this type of bleeding, you should see a doctor.

Heavy menstrual bleeding can not only impact your quality of life, but it can lead to serious complications, like anemia. Talk to your doctor about ways to manage your bleeding, which may include: Use of non-estrogen birth control, a procedure called uterine ablation to remove the uterine lining, or management with pads, tampons, or menstrual cups.



Nutrition plays a crucial role in achieving optimal health. Obesity is widely recognized as a risk factor for blood clots, and it is important for people with a history of blood clots or a clotting disorder to maintain a healthy lifestyle. However, eating well after a blood clot can also seem unachievable at times, and it can be difficult to make changes that last while you're also facing the challenge of recovering from a potentially life-changing diagnosis. If you struggle with making healthy eating choices after your blood clot, you are not alone.

It is important to maintain a healthy and balanced diet-rich in fruits, vegetables, lean proteins and whole grains—as a means of nurturing the body during the healing process. Interestingly enough, blood clots are not commonly seen in societies where diets are primarily based on unrefined plant foods, or when the intake of animal products and highly refined foods is low. The reasons for this are not exactly known, but experts agree that low-fat, high fiber diets, when combined with regular exercise, can help improve the normal biological process, called fibrinolysis, that prevents naturally occurring blood clots from growing and causing problems, and thereby help to reduce blood clot risk.

Experts stress that good nutrition also requires consistent nutrition if you have been prescribed the anticoagulant warfarin. If you are taking warfarin, the thought of achieving or maintaining a healthy diet can be overwhelming, especially when you stop to consider that healthy fruits and vegetables could interfere with your medication. Some of the healthiest foods we eat-green, leafy foods like spinach and broccoli, for example—contain high levels of vitamin K. Vitamin K can interfere with the way warfarin works, and can even lessen its effectiveness.

There are no known dietary interactions with the newer oral anticoagulants, which make them an appealing option for some people who must take anticoagulants for an extended period of time.

#### **Making Healthy Choices with Warfarin**

It's always very important to understand how different things, like food, might affect how your medication works. Foods that are high in vitamin K can reduce the effectiveness of warfarin, or lower your INR, depending on how much or how sporadically you consume these foods. However, if you eat foods that are rich in vitamin K consistently—in the same amounts over time with no sudden changes—you can enjoy the wonderful nutritional benefits they provide as part of a healthy diet. Speak with your healthcare provider before making any changes in what you eat, including the addition of vitamin K-rich foods. You can also talk to a registered nutritionist to help make sure that your food intake is healthy and consistent. Your doctor may be able to make a referral to a nutritionist



on your behalf. The United States Department of Agriculture has a nutrient database that provides information about vitamin K levels in many of the foods you might choose.

#### Alcohol

Alcoholic beverages, including hard liquor, beer or wine, also can affect how anticoagulants work, increasing your risk for unwanted, or even dangerous, bleeding. Experts advise that, as with food, consistency is key here as well. You should avoid drinking too much at any one time and always avoid binge drinking.

#### Herbs, Supplements, and Medications

Herbs and dietary supplements, including vitamin and mineral supplements in both pill and liquid form, may also interfere with your anticoagulants, particularly warfarin. The amount of vitamin K content in herbs and dietary supplements can vary a lot and be unknown.

For this reason, experts recommend that you avoid taking over-the-counter herbs and supplements if you are taking warfarin, unless directed to by your doctor.



Similarly, certain medications, such as antibiotics, can interfere with blood thinners. If you are instructed to take a medication to address another issue or condition, make sure your prescribing doctor and pharmacist know you are on anticoagulants. If you are taking warfarin, your doctor may require more frequent INR checks to ensure you are receiving the correct dosage during your treatment with other medications.

#### **Seeking Cumulative Care**

Talk to your healthcare provider about what you are eating, and also about any herbs or dietary supplements you are taking. Your doctor is the best resource to help you determine if your blood thinner and your diet are working together in the best way possible for you to obtain and maintain a healthy lifestyle.

### **NBCA RESOURCES**

#### Life-Saving Resources You Can Share

Below is a list of resources you can use to learn more about blood clots, share life-saving information with the people that you know, and connect with the National Blood Clot Alliance (NBCA).

#### **NBCA Website Resources**

Visit NBCA's website for more information about blood clots, blood clot treatment, help finding a doctor, and personal stories. Also, visit our website for the latest news and information about blood clots, plus learn more about how to get involved, including joining our Share to Stop the Clot® social media sharing initiative, and our signature public awareness programs.

- stoptheclot.org
- Share to Stop the Clot®
- Stop the Clot, Spread the Word™
- Women & Blood Clots

#### **Online Peer Support**

Join NBCA's online Stop the Clot® Peer-to-Peer Support Group and Discussion Community, powered by Inspire and moderated by NBCA. With more than 3,500 members, there's always someone available here who understands what you're going through.

Peer Support

#### Connect with NBCA on Social Media

Make a connection with us on social media and get daily updates, information, and news important to our community.

- Facebook
- Twitter
- Women & Blood Clots on Twitter
- Instagram
- Women & Blood Clots on Instagram
- Pinterest

#### Sign up for our Monthly e-Newsletter

Each month, NBCA distributes its e-Newsletter to thousands of people in the clotting community. Sign up here: NBCA e-Newsletter Sign Up

#### **NBCA Programs & Services**

To get more information about NBCA's learning resources, contact our Communications & Health Marketing Department, or read about our programs and services here: Programs & Services

#### Get Involved with NBCA

There are numerous ways you can get involved with NBCA at the grassroots level. If you would like to help support NBCA's mission, read more

here: Get Involved

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#### **National Blood Clot Alliance**

8321 Old Courthouse Road Suite 255 Vienna, VA 22182

www.stoptheclot.org

Email: info@stoptheclot.org