BLOOD CLOTS IN CHILDREN

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WHAT ARE “DVT”, “PE”, AND “VTE”? HOW COMMON ARE THEY IN CHILDREN?

Definitions

Deep vein thrombosis or DVT: A blood clot in your deep veins.

Pulmonary embolism or PE: A blood clot in your lungs.

Venous thromboembolism or VTE: The term members of your health care team use to refer to both DVT and PE together.

Blood clot: The way most people outside the medical field describe VTE.

Pediatric hematologist: A type of doctor specially trained to treat children’s blood disorders.

Arterial Thromboembolism: Blood clots in the arteries that move oxygen-rich blood from the heart to the rest of the body.

“We:” We use the word “we” to refer to all of the members of your health care team, doctors of all kinds, nurses, and others.

DVT can happen in the veins that carry blood away from the arms or legs. DVT can also occur in other veins. These include the veins that carry blood away from the brain and neck, the liver, and kidneys.

Blood clots can happen at any age. Although blood clots happen more commonly in adults, they can also happen in children. About 1 in 10,000 children get blood clots, including as many as 1 child in 200 children in hospitals.

We present an overview of blood clots for children, their families, and their health care providers. We explain the causes, signs and symptoms, diagnosis, treatment, and long-term effects of blood clots. We explain that the best treatment for children with blood clots is a team approach.

This team should include a pediatric hematologist with experience in VTE (blood clots). Some of this information we discuss here also applies to arterial thromboembolism. However, this in this overview, we focus on blood clots in the veins.
WHAT CAUSES BLOOD CLOTS IN CHILDREN?

Definitions
Genetic Thrombophilia: Inherited clotting conditions that can increase your child’s tendency to form blood clots.

**Acute:** A sudden or short-term illness.

**Chronic:** A long-term illness.

**The following can cause blood clots in children:**

Poor blood flow in the veins can cause blood clots. This may happen when children are confined to bed in the hospital.

Damage to the inner lining of veins can cause blood clots. This damage can happen when we place a “central line” catheter, such as a “Port” or “PICC,” in a vein.

- These are long flexible tubes we may need to insert through your child’s veins.
- Damage can also happen when certain drugs or toxins circulate in the blood.

Inherited clotting conditions can increase your child’s tendency to form blood clots. We call these inherited clotting conditions “genetic thrombophilia.”

Other illnesses and certain medications can cause blood clots in children.

Birth control pills, patches, or rings that contain estrogen and other hormones increase the risk of blood clots for teenage girls.

Occasionally, unusual structure or function of the blood vessels can cause blood clots. Both of these conditions can cause blood clots:

- In May-Thurner syndrome, a vein in the left leg (iliac vein) narrows.
- In Paget-Schroetter syndrome, a vein where the arm meets the chest (subclavian vein) narrows.

In most children with blood clots, we find more than one risk factor caused their blood clot.

These risk factors often include an acute or chronic illness, such as a severe infection, cancer, an abnormal heart structure, and disorders of the immune system.

Sometimes, though not often, we don’t know what causes your child’s blood clot.

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WHAT ARE THE SIGNS AND SYMPTOMS OF BLOOD CLOTS IN CHILDREN?

DVTs or blood clots in young people can happen in different parts of the body.

Signs and symptoms depend on the area of the body affected. It also depends on how much the blood clot blocks the blood flow through the vein.

DVTs in the leg or arm usually cause painful swelling in the area.

Children can experience blood clots in the deep veins in the brain.

These veins bring blood flow back toward the heart.

Children with these brain blood clots often have severe prolonged headaches.

This headache is usually worse in the early morning and may include blurred vision.

PE or lung clot symptoms include shortness of breath and chest pain that worsens with deep breathing.

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HOW DO WE DIAGNOSE BLOOD CLOTS IN CHILDREN?

Definitions

**Scan**: A way to take pictures of something inside the body, such as a blood clot.

**Ultrasound**: A painless procedure that bounces sound waves off the veins to create an image on a computer. The picture shows the veins and the blood flow through them. To see if veins close normally, we use the ultrasound wand to gently press down on the skin and muscle on top of the vein.

**Computed tomography [CT] venogram**: A special scan of the veins done after we inject dye through an IV. This scan gives us a picture of the veins and blood flow through them.

**IV**: A small flexible tube placed in a vein, usually on the inside of the elbow.

**Magnetic resonance [MR] venogram**: A type of Magnetic Resonance Imaging (MRI) scan that allows us to see the flow of blood through the veins. This includes the blood coming from the internal organs going back to the heart.

**Catheter-based dye study (conventional venogram)**: A scan that shows pictures of the veins after we put dye in your child’s blood through a catheter or tube.

**CT pulmonary angiogram** – A special scan that uses dye injected through an IV to see the blood flow through the lungs.

**Ventilation-perfusion (“V/Q”) scan**: A special scan that measures airflow and blood flow throughout the lungs.

To diagnose blood clots in children’s veins we rely on x-rays and scans.

If we suspect a DVT or blood clot in an arm and a leg, we do an ultrasound.

If we suspect a DVT in another part of your child’s body, we may need to use other scans. These include:

**Computed tomography [CT] venogram**

We use this to check for DVT or blood clots in the belly or brain.

**Magnetic resonance [MR] venogram**

We use this to check for DVT or blood clots in the belly or brain.

**Catheter-based dye study (conventional venogram)**

This gives us more detail on a leg or arm DVT or blood clot.

We use this to follow-up on one of the other scans if we think your child may have a structural issue with a blood vessel. This can happen with May-Thurner or Paget-Schroetter.

We confirm PEs in children with one of two specialized scans.

**A CT pulmonary angiogram**

**A ventilation-perfusion (“V/Q”) scan**
Anticoagulants: The term your health care team members use to refer to medications that treat blood clots. Most people outside the medical field call them “blood thinners” or anti-clotting medication. These medications don’t really thin the blood. They just make it harder for your blood to clot.

Heparin “drip”: A type of blood thinner or anti-clotting medication we give nonstop through an IV or flexible tube directly into your child’s vein.

Low-molecular-weight heparin: A type of anti-clotting medication or blood thinner we give by a shot under the skin about every 12 hours.

Warfarin: An anti-clotting medication or blood thinner that patients take in pill form. In the United States, you may hear it called by the brand name Coumadin®.

INR test: A blood test that measures clotting levels in the blood of patients who take warfarin.

Thrombolysis: Clot-buster therapy. We give clot-buster therapy in different ways. Most clots do not require this kind of treatment. When doctors diagnose your child with blood clots for the first time, they will usually treat your child with blood thinners.

Blood thinners decrease the risk of getting more blood clots. They also help prevent life-threatening PEs or lung clots.

No one has proven that blood thinner can “get rid of” blood clots.

Doctors and scientists do not yet understand the factors that lead blood clots to resolve over time. One factor may include how well your child’s own body “breaks down” a clot.

We usually start to treat children’s blood clots with blood thinners while they are still in the hospital.

Most often, we either start children on a heparin “drip” through an IV, or with “low-molecular-weight heparin” shots. We give low-molecular-weight heparin shots under the skins about every 12 hours.

Before they go home, doctors usually switch children over to low-molecular-weight heparin shots for home use. Your child’s doctor may also switch your child to a once-a-day blood thinner pill called warfarin or Coumadin® in the U.S.
If your child can’t swallow pills, you can crush warfarin and give it to your child mixed with certain liquids. A children’s pharmacist can give you instructions.

Diet and other medicines can affect warfarin’s ability to control your blood clotting. Because of this, warfarin requires weekly to monthly blood tests to check clotting levels in your child’s blood. We call this an “INR” test.

The INR test requires a blood sample drawn from a vein, usually on the inside of the elbow.

The federal government has approved other blood thinner pills beside warfarin to treat blood clots in adults. Scientists continue to study these newer blood thinners to check their safety and effectiveness in children.

In some severe cases of blood clots, doctors may recommend clot-buster therapy - called thrombolysis. Clot busting therapy removes or breaks up your child’s blood clot soon after the doctor diagnoses it.

After children finish clot-busting treatment, they will take other more common blood thinners, like low-molecular-weight heparin or warfarin.

In addition to treatment with blood thinners, you and your doctor must address the blood clot risk factors that may have caused your child’s blood clot. This helps prevent new blood clots. For example:

Your doctor will prescribe antibiotics to treat severe bacterial infections that may have caused the blood clot;

Your doctor will stop or remove birth control pills, patches and rings that can cause blood clot.

Your doctor will also remove “central line” catheters when no longer needed.
When your child takes blood thinners, it lowers the risk of new blood clots. However, it does not lower the risk to zero. You need to look for new signs and symptoms of blood clots, or signs and symptoms that get worse.

If you see new signs and symptoms of blood clots as described above, or if the signs and symptoms get worse, it could mean your child has a new blood clot.

You need to seek prompt medical attention for new or worse symptoms of blood clots. You also need to look for signs of bleeding. When your child is on blood thinners:

- Small cuts on the skin will ooze more than usual;
- Nose-bleeds can occur more frequently or last longer;
- Bruises in areas of injury occur more easily and tend to grow larger; and
- Teenage girls and young women may have heavier periods.

If your child bleeds often, you should contact your doctor. If your child becomes pale or tired or bleeds for a long time, you must seek prompt medical care.

You and your child should talk with your hematologist about what to do when bleeding starts, and when you should seek prompt medical care.

Can children on blood thinners participate in the regular activities that children do?

You and your child should talk to your pediatric hematologist about specific activity limits.

Your child should avoid activities that are high-risk for injury - especially head injury.

In general, your child should avoid high-impact sports like American football, ice hockey, etc.

Your child should always wear seat belts in motor vehicles.

Your child should wear helmets on bikes and skateboards.

Your child’s hematologist will help decide with you whether your child needs other activity limits. You and your doctor will need to think about your child’s:

- Age, development and judgment
- Coordination and history of injuries, and
- Skill with a particular activity

Activities supervised by an adult tend to decrease the risks of injury and bleeding.

However, to reduce the risk of new blood clots, children must stay active. So, while on anti-clotting medications:

Your child can and should still participate in regular exercise.

For example, age-appropriate, supervised, low-impact/low-injury-risk sports, such as walking, swimming, and biking on a well-paved surface while wearing a helmet can help lower the risk of blood clots.
Clinical Trial: Research to test whether a drug or medical device or procedure is safe +/- effective.

Provoked blood clot or VTE: A blood clot caused by certain health conditions, procedures, or medications, such as infections, “central line” catheters, recent surgery, and birth control pills.

Unprovoked blood clot or VTE: A blood clot not caused by any known health condition, procedure, or medication.

As mentioned above, blood thinners reduce the risk of new blood clots.

The length of time your child must take blood thinners for a blood clot varies with the child’s risk of new blood clots:

Your doctor will base the length of time your child needs to take blood thinners on the time your doctor believes your child is at a higher risk for new blood clots.

This decision also involves balancing the higher blood clot risk with the risk of bleeding while your child takes blood thinners.

We know of no perfect way to measure or predict how long children face a higher risk of blood clots. It is also difficult to balance that risk with bleeding risk.

Clinical trials provide several recommendations for adults with blood clots.

Adults with a first provoked blood clot should take blood thinners for 3-6 months.

Adults with a first unprovoked blood clot generally should take blood thinner for 6-12 months.

Recommendations to treat blood clots in children exist. We follow recommendations similar to the recommendations listed above for adults. However, clinical trials are underway in children with blood clots, to find out how long to treat with blood thinners.

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Chronic venous insufficiency: A condition where veins no longer work well to bring blood back toward the heart.

Post thrombotic syndrome or PTS: When chronic venous insufficiency occurs after a DVT in the arm or leg or in the veins that return blood from the arm/leg to the heart, we call that post-thrombotic syndrome (PTS). Symptoms may include swelling of an arm or leg where a DVT has occurred, color changes, a rash, or sores on the skin, and pain or tingling.

Esophagus: The part of your digestive system that carries food and liquid from your mouth to your stomach.

Graduated compression stockings: Custom-fit stockings that can provide some relief from the symptoms of post-thrombotic syndrome or PTS.

Hepatic: Refers to the liver.

Portal vein: The main vein that brings blood from the liver to the intestine.

Hepatic and portal vein blood clots: Blood clots in veins that return blood back to the heart from the liver and digestive system.

Low blood cell counts: A decrease in white blood cells, red blood cells, and/or platelets that indicates a problem with your health.

Pulmonary artery: The large artery that brings blood from the heart to the lungs.

Pulmonary hypertension: Increased pressure in the pulmonary artery that can cause long-term breathing problems.

Renal: Refers to the kidneys.

Renal vein blood clots: Blood clots in the vein that returns blood from the kidney back toward the heart.
HOW CAN BLOOD CLOTS AFFECT YOUR CHILD IN THE FUTURE?

Potential long-term effects of blood clots depend on the parts or of the body or organs involved. For example:

- **Children with renal (kidney) vein blood clots can develop high blood pressure.**

- **Blood clots in the hepatic (liver) vein or portal vein can enlarge your child’s spleen.**

- **These blood clots also can cause bleeding problems in the stomach and esophagus from increased pressure in the veins that return blood to the heart from these areas.**

- **The enlarged spleen can cause your child to have low blood cell counts.**

- **Following a PE, children can sometimes develop long-term breathing problems from "pulmonary hypertension." This not common in children. When it happens, pressure increases in the pulmonary artery that brings blood from the heart to the lungs.**

- **After your child experiences a DVT, the vein with the DVT and veins that drain into it may no longer work as well.**

- **Your child’s veins may not bring blood back toward the heart as well as they did before the DVT.**

- **We call this condition “chronic venous insufficiency.”**

- **If your child’s had an arm or leg DVT, this can cause long-term changes in your child’s arm or leg.**

- **These changes can include swelling, color changes, a rash or sores on the skin, and pain, aching or tingling.**

- **We call this type of chronic venous insufficiency “post-thrombotic syndrome,” or “PTS.”**

- **In mild cases of PTS, the symptoms come and go. In more severe cases, symptoms do not go away.**

- **About 25% of children and adults will develop PTS after an arm or leg DVT.**

- **The risk appears much higher in children who develop a second DVT in the same leg or arm.**

- **The use of custom-fit elastic stockings called “graduated compression stockings” can provide some relief from the symptoms of PTS.**

- **Some preliminary research suggests a specific exercise regimen can improve PTS symptoms in adults who had leg DVTs.**

- **The exercise program includes calf strengthening and stretching, and regular use of a treadmill.**
Research shows blood thinners can safely prevent blood clots in many adults who need hospital care, or after recent joint replacement surgery.

We give a lower and less frequent dose of blood thinners to prevent clots in adults than we use to treat blood clots.

Research in children will help us understand safe and effective ways to prevent blood clots in children who face an increased risk of blood clots.

Pediatric hematologists, primary care doctors, nurses, and physician assistants can still offer helpful general advice about blood clot prevention in children.

All children—especially those with prior blood clots or family members who had blood clots before age 50—should take steps to prevent clots.

Your child should stay hydrated and drink plenty of fluids without caffeine in them.

Your child should avoid smoking, exercise on a regular basis and maintain a healthy weight.

Teenage girls and young women with prior blood clots, or with family members who had blood clots before age 50, should avoid estrogen-containing pills, patches, and rings.

You and your child should discuss other ways to prevent blood clots with your child’s doctor, based on your child’s own health.