



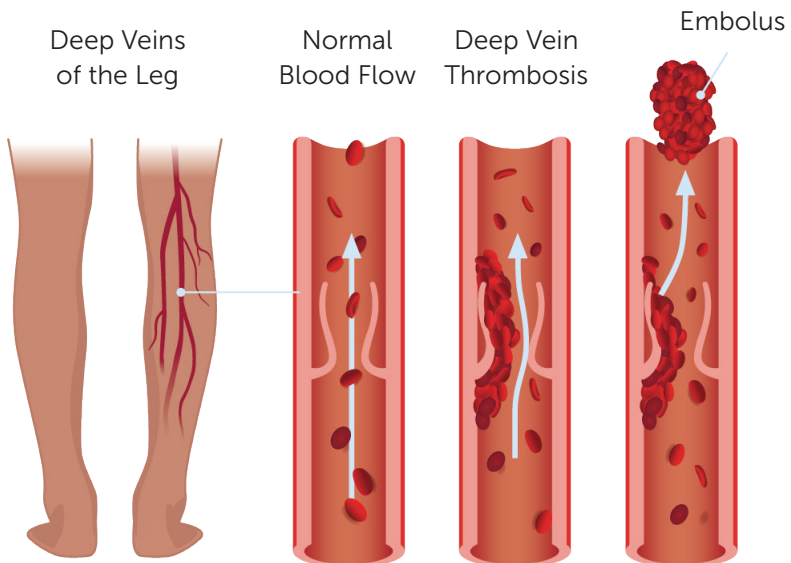
What You Need to Know After a Pulmonary Embolism

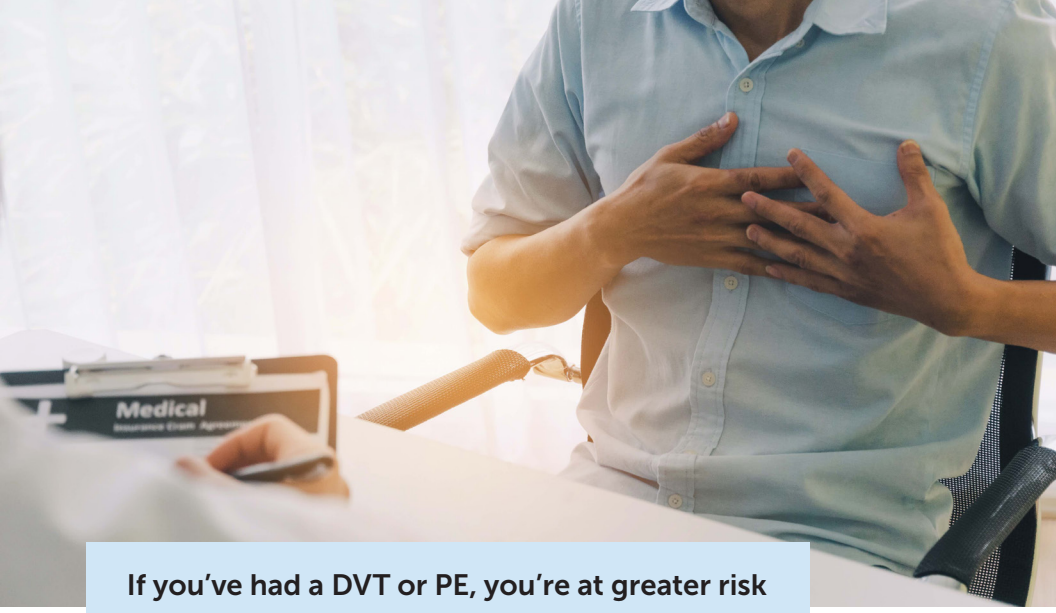
Pulmonary Embolism and Pulmonary Hypertension

Pulmonary hypertension (PH) is a rare disease characterized by high blood pressure in the lungs. One form of the disease, known as chronic thromboembolic pulmonary hypertension (CTEPH), occurs in some patients after a pulmonary embolism (PE). A PE is a blood clot in the lungs that blocks the flow of blood from the heart to the lungs.

Most people who have had a PE or deep vein thrombosis (DVT), a blood clot that forms in one of the large veins deep in the body, usually in the legs, don't have additional blood clots. When a blood clot in a vein breaks off, travels through the bloodstream and gets lodged in the arteries of the lung, it impedes blood flow between the heart and lung. The clot is called a PE. After you have a PE, your doctor will likely prescribe anticoagulants, or blood thinners, to prevent new blood clots from forming and old clots from growing larger.

Deep Vein Thrombosis





If you've had a DVT or PE, you're at greater risk than the general population for having more clots in the future.

If you've had a DVT or PE, you're at greater risk than the general population for having more clots in the future. You will need close follow-up by your doctor every few months for at least a year after your DVT or PE to ensure a smooth recovery. If your shortness of breath isn't significantly better and your activity level isn't back to your previous level within a few months, please consult your doctor. If you have had a PE, you might have developed more clots. Or the clots never went away, which can lead to high blood pressure in the lungs, or CTEPH. You, your family and your physician should be aware of CTEPH and know its symptoms and treatments.

What is CTEPH?

There are five types (groups) of PH based on different causes. Group 4 PH, or CTEPH, is among these five types of pulmonary hypertension, a complex and often misunderstood disease. In regular hypertension – known as high blood pressure or systemic hypertension – the pressure in the arteries throughout the body is higher than it should be. You can easily check this with a blood pressure cuff. But PH affects only the blood vessels in the lungs. The blood vessels in the lungs can become stiff and narrow, causing the right side of the heart to work harder to pump blood through these vessels.

Between **0.5% and 5%** of people who experience a PE can develop CTEPH.



Between 0.5% and 5% of people who experience a PE can develop CTEPH. CTEPH is caused by old blood clots in the lungs that continue to block the pulmonary arteries. The blockages make it harder for blood to flow through the blood vessels of the lungs, putting increased pressure on the right side of the heart as it pumps blood through the lungs. The heart must work harder, which can cause the right side to enlarge, weaken and eventually even fail.

CTEPH can be difficult to diagnose, especially in the early stages, because its symptoms resemble those of other diseases. In fact, the symptoms of CTEPH often are like those you experienced with your PE.

After your DVT or PE, you might have to wear compression stockings to help blood flow and reduce swelling in your legs and ankles. You might have continued shortness of breath or pain and pressure in the chest that sometimes get worse with physical activity. You might experience temporary feelings of anxiety or depression. This is common. Doctors and scientists are learning more about “Post-PE Syndrome” and how to follow and care for patients after a PE.

Common CTEPH symptoms



Shortness of
breath



Fatigue



Dizziness



Chest pain



Swelling in the ankles,
stomach or arms

WHAT DOES CTEPH MEAN?

- **CHRONIC** = old
- **THROMBOEMBOLIC** = blood clot formed in a blood vessel (thrombus) that travels in the blood stream to block another blood vessel
- **PULMONARY** = lung
- **HYPERTENSION** = high (blood) pressure



Ventilation/
perfusion
("V/Q") scan

Diagnosing CTEPH

Your doctor might perform the following tests to rule out other conditions and detect problems with the heart and lungs:

Ventilation/ perfusion ("V/Q") scan

looks for areas of the lungs that might be blocked from blood flow.

Echocardiogram ("echo")

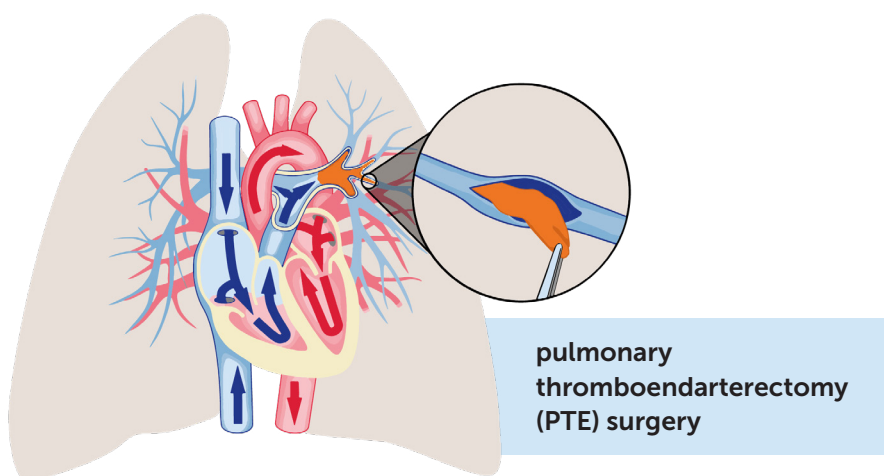
assesses if the right side of the heart is larger or pumping differently than expected.

Right heart catheterization

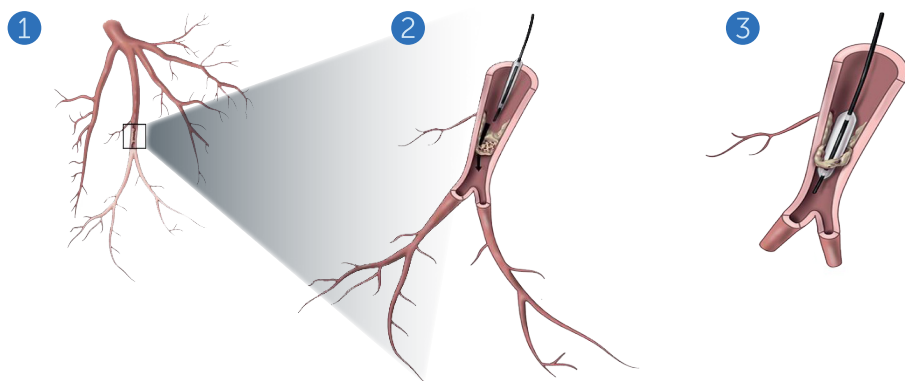
measures the blood pressure and flow in the lungs and can obtain pictures to look for clots in the lung arteries.

Treating CTEPH

If your doctor diagnoses CTEPH, he or she might recommend a pulmonary thromboendarterectomy (PTE), or surgery to remove clots. Or he or she might recommend medication to alleviate pressure and slow the course of the disease. One example is the PH-specific drug riociguat (Adempas®), which was developed for CTEPH patients who don't qualify for PTE surgery or whose PH continues after surgery. Another option for those patients is a relatively new procedure called balloon pulmonary angioplasty (BPA).



balloon pulmonary angioplasty (BPA)



What Can You Do About CTEPH?

- Know that you may be at risk.
- Monitor yourself for symptoms.
- Check with your doctor regularly at the intervals he or she recommends.
- Make an appointment to see your doctor if you begin to experience new or persistent symptoms after your PE.
- If diagnosed with CTEPH, seek specialized care at a PH Care Center.
- Connect with other at-risk people and those living with CTEPH through the Pulmonary Hypertension Association (PHA).



For more information about CTEPH, find a specialist or connect with other at-risk and experienced patients, go to PHAssociation.org/cteph or email CTEPH@PHAssociation.org.

Questions To Consider

Or Ask Your Doctor After a PE



What type of medicine will I need to take for my DVT/PE?

Oral anticoagulants are frequently used to treat DVT/PE. They include warfarin (Coumadin® and Jantoven®), or a group of medications called direct oral anticoagulants (DOACs). DOACs include apixaban (Eliquis®), dabigatran (Pradaxa®), edoxaban (Savaysa®), and rivaroxaban (Xarelto®).

Your doctor will consider medication-monitoring requirements, food/drug interactions, proximity to an expert center, cost, and safety when determining which medication to prescribe.



How long will I need to take this medication?

How long you need to take the medication depends on several factors:

- The location of the clot.
- Potential reasons you had the clot (for example, it occurred after a planned surgery).
- Risk for developing a future clot.
- Ability to tolerate blood thinners.



What type of doctor should I see after my PE?

Not everybody needs the same type of doctor after a DVT/PE. Your doctor might be a:

- Healthcare professional in an anticoagulation clinic.
- Hematologist.
- Cardiologist.
- Pulmonologist.
- Vascular surgeon.
- Internal medicine physician.
- Interventional Radiologist.



How often should I expect to see this doctor?

Your doctor will determine how frequently you should make follow-up visits, based on your medical history and risk for CTEPH.



Acknowledgements

This resource was created by the Pulmonary Hypertension Association (PHA) with the help of the CTEPH Community Programs Advisory Task Force, a partnership that advises PHA on its plans for developing resources, services and outreach initiatives for patients at increased risk for or diagnosed with CTEPH.

PHA thanks:

- Kathy Anderson, patient
- Nancy Bair, APRN, CNS-BC
- Sarah Brackett, patient
- Peter Hountras, M.D.
- Pam Kehoe, patient
- Vicky Peterson, caregiver
- Akhilesh Sista, M.D.

Phone: 301-565-3004
Support Line: 800-748-7274
PHA@PHAssociation.org
PHAssociation.org • PHAssociation.org/cteph

Copyright © 2020 Pulmonary Hypertension Association

