Venous thromboembolic diseases

Information for the public
Published: 25 June 2012
nice.org.uk

About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about venous thromboembolic diseases that is set out in NICE guideline CG144.

This is an update of advice on venous thromboembolic diseases that NICE produced in 2012. There is new advice on medicines and compression stockings for people with deep vein thrombosis and pulmonary embolism.

Does this information apply to me?

Yes, if you:

- are an adult (aged 18 and over) who has or who might have deep vein thrombosis or a pulmonary embolism
- are a parent, sibling or child of someone who has an inherited venous thromboembolic disease.

No, if you are pregnant.

NICE has produced separate advice on reducing the risk of venous thromboembolism in patients admitted to hospital.

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Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include doctors, specialist nurses, anticoagulation specialists (healthcare professionals who specialise in blood clotting) and occupational therapists (professionals who teach you how to carry out everyday tasks that are difficult because of your condition).

Working with you

Your care team should talk with you about venous thromboembolic diseases. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family or carer can be involved in helping to make decisions, but only if you agree. There are questions throughout this information that you can use to help you talk with your care team.

You may also like to read NICE's information for the public on patient experience in adult NHS services.

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Venous thromboembolic diseases

Venous thromboembolic diseases is a term used to describe a group of disorders that involve blood clotting. Normally, a clot forms to stop the bleeding when a person is injured, for example by a cut to the skin. However, this can go wrong and a blood clot can form when there has been no injury. If the blood clot is deep inside a vein (most commonly in the leg), it is called deep vein thrombosis (DVT).

If the blood clot breaks away it can travel through the bloodstream to the lungs. This is called pulmonary embolism (PE) and it can be fatal.

People who have had DVT can sometimes get a condition known as post-thrombotic syndrome afterwards. Post-thrombotic syndrome causes long-term aching, swelling and skin problems (such as ulcers) in the leg.

A few people have conditions that make their blood more likely to form clots, such as thrombophilia (which can be inherited) or antiphospholipid syndrome (also called Hughes syndrome).
What causes deep vein thrombosis and pulmonary embolism?

DVT and PE can be unprovoked or provoked. Unprovoked DVT or PE has no obvious cause. However, there are conditions that can increase a person’s risk of DVT or PE, such as cancer, thrombophilia or having a close relative who has had DVT or PE.

Provoked DVT or PE can be triggered by something that happened recently, such as:

- recent surgery
- a recent serious injury (for example, a broken leg)
- temporarily reduced mobility (when a person is less active or moves around less than usual for them)
- pregnancy (you can also get DVT or PE during pregnancy)
- taking oestrogen-containing contraceptive pills ('combined' pills)
- taking hormone replacement therapy ('HRT').

Symptoms of deep vein thrombosis and pulmonary embolism

Sometimes DVT or PE has no symptoms, or the symptoms are not very noticeable. Some examples of possible symptoms are:

- pain, swelling, or hot or discoloured skin on the leg (usually the calf)
- veins in the leg that appear larger than normal or are more noticeable
- shortness of breath
- pain in the chest or upper back
- coughing up blood.
Questions you might like to ask your healthcare professional about deep vein thrombosis and pulmonary embolism

- Can you tell me more about deep vein thrombosis and pulmonary embolism?
- Is there anything I can do to reduce my risk of getting deep vein thrombosis or pulmonary embolism?
- Where can I find more information about venous thromboembolic diseases?
- Can you provide any information for my family/carers?

Diagnosing deep vein thrombosis and pulmonary embolism

If you have symptoms of DVT or PE your healthcare professional should look at your medical history and give you a physical examination. They should check whether your symptoms might be caused by a DVT or PE, or by something else. If your healthcare professional thinks you may have PE they should also offer you a chest X-ray.

Your healthcare professional should use a score called the Wells score to estimate how likely it is that you have DVT or PE. Your Wells score is calculated from a series of questions about your symptoms and medical history. Your healthcare professional should use your Wells score to decide which tests to offer you.

Tests to diagnose deep vein thrombosis and pulmonary embolism

You may be offered one or more of the following tests, depending on your symptoms, your medical history, your physical examination and your Wells score. Sometimes the results of these tests are uncertain, so you may need to have them done more than once.

- A D-dimer test is a blood test that measures how much of a protein called D-dimer is in your blood. If you have a normal level of D-dimer it is unlikely you have DVT or PE.
- An ultrasound scan can identify DVT using ultrasound waves to get an image of the veins in your leg.
A test called a CTPA uses X-rays to see if there is a blood clot in your lungs (pulmonary embolism). CTPA is short for computed tomography pulmonary angiogram.

A scan called a V/Q SPECT or V/Q planar scan measures the flow of air and blood in your lungs. V/Q SPECT is short for ventilation/perfusion single photon emission computed tomography.

Questions you might like to ask your healthcare professional about tests for deep vein thrombosis and pulmonary embolism

- Can you give me more details about the tests I should have?
- Do these tests have any side effects?
- Why have you decided to offer me these tests?
- What do these tests involve?
- Where will the tests be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have the tests?
- How long will it take to get the results of the tests?
- Will I have any treatment while I wait for the test results?
- Can you tell me what the results mean?

Treating deep vein thrombosis and pulmonary embolism

Medicines

This section explains the advice on medicines to treat DVT and PE that is set out in NICE guideline CG144. NICE has also produced information about other medicines you may be offered to help with DVT and PE. See other NICE guidance for details.

DVT and PE should be treated with either heparin or fondaparinux, which are given as injections and start working straight away. Heparin and fondaparinux are anticoagulants (medicines that help
to stop blood clots forming or growing bigger, and make it less likely that a blood clot will come loose and travel to the lungs, causing PE). There are 2 types of heparin, called low molecular weight heparin and unfractionated heparin.

You should be offered either low molecular weight heparin, unfractionated heparin or fondaparinux (see the supporting information for people starting to take an anticoagulant) as soon as possible and keep taking it for at least 5 days.

Heparin or fondaparinux are often given together with another type of anticoagulant called a vitamin K antagonist (for example, warfarin), which comes in tablet form and takes longer to start working. You should be offered a vitamin K antagonist no later than 24 hours after your DVT or PE has been diagnosed, and keep taking it for 3 months to reduce your chance of getting DVT or PE again.

If your DVT or PE was unprovoked, your healthcare professional may offer you a vitamin K antagonist for longer than 3 months. They should discuss with you the benefits and risks of continuing the vitamin K antagonist after the first 3 months.

If you have cancer you should usually be offered only low molecular weight heparin, without a vitamin K antagonist. You should take the low molecular weight heparin for 6 months. Your healthcare professional should assess the risks and benefits of continuing your medicines after 6 months.

You shouldn't normally be offered medicines called thrombolytic medicines (medicines that help to dissolve a blood clot, sometimes known as 'clot-busting' medicines) if you have DVT or PE. This is because they can increase your risk of bleeding and for most people it isn't clear that they help more than just taking anticoagulants on their own. You may be offered these medicines in some rare circumstances, for example if:

- you have PE and your blood pressure is changing rapidly (this is called haemodynamic instability)
- you have DVT, are not too unwell, and are not at high risk of bleeding.

Off-label medicines

At the time of publication some types of heparin and other anticoagulants are recommended for 'off-label' use in this guideline. Your doctor should tell you this and explain what it means for you.
In the UK, medicines are licensed to show that they work well enough and are safe enough to be used for specific conditions and groups of people. Some medicines can also be helpful for conditions or people they are not specifically for. This is called 'off-label' use. Off-label use might also mean the medicine is taken at a different dose or in a different way to the licence, such as using a cream or taking a tablet. There is more information about licensing medicines on NHS Choices.

Support and information for people starting treatment with an anticoagulant

When you start taking an anticoagulant such as heparin, fondaparinux or a vitamin K antagonist, you should be given an anticoagulation information booklet and an anticoagulant alert card and advised to carry the card with you at all times.

You should also be given information about:

- how to use anticoagulants
- how long to take anticoagulants for
- possible side effects of anticoagulants and what to do if you get these
- how taking other medications, foods and alcohol with oral anticoagulants will affect you
- monitoring your anticoagulant treatment
- how anticoagulants may affect your dental treatment
- taking anticoagulants if you are planning to or become pregnant
- how anticoagulants may affect activities such as sports, exercise and travel
- when and how to seek medical help.

Heparin is made from animal products. Synthetic alternatives may be available if you are concerned about this, and your healthcare professional should discuss the suitability, advantages and disadvantages of the available treatment options with you.

Other treatments

If you cannot take anticoagulants for your DVT or PE you may be offered a temporary inferior vena caval filter. This is a device that is inserted into a large vein to trap any blood clots and stop them
travelling to your lungs. Your healthcare professional should make sure the filter is removed when you no longer need it.

If you have had DVT you should not be offered special stockings (called ‘compression stockings’) to stop you getting it again, or to stop you from getting post-thrombotic syndrome. This is a change from the advice NICE produced in 2012, which said that people should be offered compression stockings to stop them getting DVT again. The advice has changed because new evidence has been published, showing that it isn’t clear if stockings help stop these conditions.

NICE hasn’t produced any advice on using compression stockings to help with any symptoms of DVT or post-thrombotic syndrome you have. Your healthcare professional may still offer you stockings to treat your DVT or post-thrombotic syndrome symptoms, if they think it will help.

Questions you might like to ask your healthcare professional about treatments for deep vein thrombosis and pulmonary embolism

- How long will I have to have the treatment for?
- Are there any serious side effects associated with the treatment?
- What should I do if I get any side effects? (For example, should I call my GP, or go to the emergency department at a hospital?)

Tests for people who have had deep vein thrombosis or pulmonary embolism

Tests for cancer

Cancer can increase a person’s risk of DVT or PE. If you have not been diagnosed with cancer and you have an unprovoked DVT or PE, you should be offered the following tests to check for signs of cancer:

- a physical examination
- a chest X-ray
• tests of your blood and urine.

If you are aged over 40 and this was your first unprovoked DVT or PE, you may also be offered further tests to check for signs of cancer, including:

• a computed tomography scan (known as a CT scan) of the abdomen and pelvis
• an X-ray of the breasts (mammogram) for women.

Tests for clotting disorders

If you have had unprovoked DVT or PE you may be offered a test for antiphospholipid syndrome. If you have had unprovoked DVT or PE and have a close relative who has had DVT or PE, you may also be offered a test for inherited thrombophilia.

Questions you might like to ask your healthcare professional about tests for cancer and tests for clotting disorders

• Why have you decided to offer me this test?
• What does the test involve?
• Where will the test be carried out? Will I need to have the test in hospital?
• How long will I have to wait until I have the test?
• How long will it take to get the results of the test?

Sources of advice and support

The organisations below can provide more information and support for people with venous thromboembolic diseases. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.
Other NICE guidance

- Reducing the risk of deep vein thrombosis (DVT) for patients in hospital (2015) NICE guideline CG92
- Edoxaban for preventing stroke and systemic embolism in people with non-valvular atrial fibrillation (2015) NICE technology appraisal guidance 355
- Edoxaban for treating and for preventing deep vein thrombosis and pulmonary embolism (2015) NICE technology appraisal guidance 354
- Apixaban for the treatment and secondary prevention of deep vein thrombosis and/or pulmonary embolism (2015) NICE technology appraisal guidance 341
- Dabigatran etexilate for the treatment and secondary prevention of deep vein thrombosis and/or pulmonary embolism (2014) NICE technology appraisal guidance 327
- Rivaroxaban for treating pulmonary embolism and preventing recurrent venous thromboembolism (2013) NICE technology appraisal guidance 287
- Apixaban for preventing stroke and embolism in people with atrial fibrillation (2013) NICE technology appraisal guidance 275
- Rivaroxaban for the treatment of deep vein thrombosis and prevention of recurring deep vein thrombosis and pulmonary embolism (2012) technology appraisal guidance 261
- Apixaban to reduce the risk of venous thromboembolism after hip or knee replacement surgery (2012) NICE technology appraisal guidance 245
• **Rivaroxaban for the prevention of venous thromboembolism after total hip or total knee replacement in adults** (2009) NICE technology appraisal guidance 170

• **Dabigatran etexilate for the prevention of venous thromboembolism after hip or knee replacement surgery in adults** (2008) NICE technology appraisal guidance 157

ISBN: 978-1-4731-1536-1

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