

Pulmonary Embolism

Information for Patients

What is a Pulmonary Embolism?

A pulmonary embolism (PE) is a blood clot in one or more of the blood vessels of your lungs. Symptoms of PE include breathlessness, chest pain, coughing up blood, and dizziness. PEs can affect people in a broad range of ways; from very mild symptoms through to a life-threatening event.

PEs dissolve over weeks to months inside the blood vessel of your lungs. They do not travel elsewhere in your body.

Treatment of PE, with blood thinning medications, is highly effective. This information leaflet covers frequently asked questions but if you have any questions that are not covered here then speak to your hospital team or GP.

What causes a PE?

A PE usually comes from a blood clot which has formed in the veins in your leg (deep vein thrombosis; DVT) and travelled in the veins to your lungs. There are several factors which may increase the risk of DVT and PE. These include:

- Severe illnesses, injuries or operations requiring bed-rest or hospitalisation
- Pregnancy or some types of oral contraceptive pill and hormone replacement therapy
- Serious medical conditions such as cancer
- Long-haul travel
- If you or a close family member has had blood clots previously
- Some underlying health conditions causing “sticky blood”
- Being overweight.

In some cases, a cause for DVT or PE cannot be found.

How is a PE treated?

The treatment for a PE is to thin your blood using medications called “anticoagulants” (blood thinners). In NHS Lothian, the anticoagulants we most commonly use are:

- Apixaban (tablets)
- Warfarin (tablets)
- Dalteparin (injections).

In some circumstances other types of anticoagulant will be used; if this is the case your doctor will explain this to you.

All of these medications work by preventing the blood clot from getting bigger or new clots forming, while your body naturally breaks down the blood clot that is already there.

Before you go home from hospital a doctor, nurse or pharmacist will explain your new medication to you and give you written information to take home. They will also give you an “anticoagulation alert card”, which you should keep with you at all times while you are taking the medication.

What are the risks of anticoagulants?

The main risk is bleeding. The vast majority of bleeding complications are minor, such as bleeding for longer than normal after a minor cut e.g. shaving. Women may have heavier menstrual periods and if this is a problem they should seek advice from their GP.

While taking anticoagulants, you should always seek medical advice immediately if you have a serious injury, especially a head injury. Bleeding inside the body can also occur without injury - important symptoms of this include vomiting blood or dark, tarry stools. Again, you should seek immediate medical advice if you have these symptoms.

Heavy alcohol intake can increase the risk of bleeding if you are taking anticoagulants; it is recommended you only drink within recommended limits (14 units of alcohol per week: this is approximately 6 pints of beer or 6 small glasses of wine).

How long will I need treatment?

This depends on several factors. Usually people will stay on anticoagulants for at least 3 months after a PE. Sometimes, people will be advised to continue them for longer or even indefinitely (long-term). Your doctor will advise you on how long to continue taking anticoagulant medication and this will be reviewed when you are seen in the clinic.

It is very important that you continue taking anticoagulant medication and do not miss any doses until your doctor advises you it is safe to stop.

What should I do after I go home and what should I expect?

Each person's recovery from PE is different and depends upon your level of fitness before the PE, your age, and any other medical conditions you might have.

Symptoms

It is normal for you to continue having symptoms after you go home from hospital. Most likely you will feel breathlessness and tiredness as you start to do more for yourself again. These symptoms can last for several weeks or even months, but will gradually improve. If you have these symptoms

longer than 3 months, or if they do not improve at all during this time, you should contact your GP or hospital doctor.

Some people can experience anxiety after their PE. This is a completely natural response to the physical and psychological stress of the event. For the vast majority of people, this settles with time.

Exercise

You should not try to push yourself too much in the first few weeks after having a PE. You should gradually build up your exercise levels again once you feel able to do so.

Work

You should return to work as and when you feel able to and there is no time limit. This will be different for each individual and will depend on your symptoms and the level of activity that your job requires. This should be discussed with your employer.

Medications

Always tell your doctor or pharmacist before starting a new medication (including herbal treatments and medications bought “over the counter”) to make sure that it does not interfere with your anticoagulant tablets.

If you have pain after going home- it is safe to take paracetamol with your anticoagulant medication.

You should not take aspirin or non-steroidal anti-inflammatory drugs (NSAIDs e.g. ibuprofen) as these may interfere with your anticoagulant or increase the risk of bleeding.

Pregnancy

If you are a woman who is considering becoming pregnant, always speak to your doctor first if you are taking anticoagulants. If you become pregnant while on anticoagulants you must inform your GP and ante-natal team immediately, as your type of anticoagulant medication may need to be changed. Your medical team will closely monitor the health of you and your baby during your pregnancy.

Travel

Long distance travel, where you may be unable to move around for long periods of time, is not recommended in the first 4 weeks after being diagnosed with a PE. After this, there is no reason for you not to be able to travel, including flying. If you do take a flight, remember to move around the plane as often as you can, keep well-hydrated by drinking plenty of water, and avoid alcohol. When making travel plans, you should inform your travel insurance company that you have had a PE.

When should I seek further medical advice?

It is normal for some symptoms to take some time to get better. However, you should urgently seek medical attention if you develop any new symptoms, such as:

- New severe chest pain
- Worsening or sudden breathlessness
- Dizziness or collapsing
- Your heart beating very fast
- Coughing up or vomiting blood
- Bleeding when you go to the toilet (bladder or bowels) or if your bowel motions are black and tarry
- Any other serious bleeding, such as prolonged nosebleeds
- Serious head injury or any head injury with loss of consciousness (blackout).

What follow up will I get?

Most people will be followed up by the acute medicine or respiratory (lung) team in a hospital clinic. This is usually between 3 and 6 months after being diagnosed with a PE. At this clinic appointment, you will be able to discuss your progress and symptoms and ask any questions that you may have. The doctor or nurse will discuss with you how long treatment should continue as well as whether any other tests are needed. It is very important you attend this appointment. If you are unable to attend you should telephone the clinic in advance to rearrange it.

Routine follow up does not normally include a repeat CT scan.

Before you come to your clinic appointment, there are several things you can do to help with your recovery, improve your general health, and to help your doctor make decisions on your treatment. These include:

- Stopping smoking
- Losing weight (if you are overweight)
- Making sure you know your previous medical history and that any other medical conditions (such as diabetes, high blood pressure, etc) are well controlled
- Finding out if your immediate family members (parents, siblings, children) have had a PE or DVT before
- Bringing a list of your current medication to the clinic
- Write down any questions you have and bring them with you to the clinic.

In some cases, your hospital team may organise tests before your clinic appointment (for example: a heart ultrasound scan called an echocardiogram to estimate the pressure in your pulmonary artery). Not everyone will need this test – you can ask your hospital team if you will need this.

Remember, if you have any questions or concerns that are not covered in this leaflet then please speak to your hospital team or GP.

Useful resources:

British Lung Foundation: <https://www.blf.org.uk/support-for-you/pulmonary-embolism>

NHS: <https://www.nhs.uk/conditions/pulmonary-embolism/>