

Pulmonary embolism (PE)

Information for patients

This information sheet explains pulmonary embolism (PE) and the anticoagulant medication used to treat it. If you have any questions please do not hesitate to contact a member of staff.

What is pulmonary embolism (PE)?

PE is the term used to describe a blood clot (or multiple clots) that have become lodged in the blood vessels of the lung. A PE usually starts as a clot in the deep veins of the leg (when it is called a deep vein thrombosis or DVT) and can break away and travel to the lung.

What are the signs and symptoms of PE?

PE commonly causes chest pain and shortness of breath. Other symptoms include coughing up blood, feeling dizzy or faint and sometimes collapse. PE can occasionally be life threatening. Some people do not have symptoms at all, and the PE is an unexpected finding on a scan performed for another reason.

Why did I get a PE?

It is not always possible to identify a reason but there are several things that can increase the chance of having DVT or PE. These include:

- Surgery
- A hospital stay
- A previous DVT or PE in yourself or in a first degree relative
- Reduced mobility e.g. caused by surgery, an illness or injury, or long journeys
- Active cancer/cancer treatment
- Pregnancy
- Use of hormonal contraceptives/ hormone replacement therapy
- · Blood clotting disorders such as thrombophilia
- Increasing age.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you do not have an ID band we will also ask you to confirm your address. If we do not ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

Pulmonary embolism Pulmonary arteries Pulmonary embolism Inferior vena cava Femoral vein **Embolus** Greate sapheno IS Thrombus vein Venous valve Popliteal vein

How is PE treated?

You have been prescribed an anticoagulant (often referred to as a 'blood-thinner') which can be given as a tablet or an injection depending on your individual circumstances. Anticoagulants stop the clot from getting larger, prevent the body from making more blood clots and allow your body to break down the blood clot. For life-threatening PE, a treatment to dissolve the clot (called 'thrombolysis') may be used before an anticoagulant is started.

When taking anticoagulants it is important to:

- take medication regularly at the same time each day
- keep all clinic appointments
- keep your anticoagulant alert card with you at all times
- let your doctor know if you become pregnant or are planning on becoming pregnant
- report any new bleeding symptoms (see below).

Anticoagulants can increase the risk of bleeding which may require medical review.

If you experience any of the following symptoms please seek medical attention

- unexpected or uncontrollable bleeding
- a fall or injury to your head
- blood in your urine
- coughing or vomiting blood
- severe unexplained bruising
- black stools or blood in your stools
 a severe headache that will not go away, dizziness or weakness

Frequently asked questions

How long will my symptoms last?

It is common to have chest pain, breathlessness and fatigue for weeks or even months after a PE. Recovery from PE varies, and it can take many months to return to your previous level of fitness. Sometimes symptoms do not improve over time and further tests may be needed to help work out why. A small proportion can develop a condition called pulmonary hypertension and specialist input may be needed to help manage this.

How long will I be on anticoagulants?

This will vary from person to person. Some people only need to take anticoagulants for 3 months, while others need to take them for their rest of their lives. This will depend on several factors and will be discussed with you in detail at your clinic appointment.

When should I be concerned about my symptoms?

If you develop worsening shortness of breath or chest pain, go to your nearest hospital emergency department to be assessed.

When should I return to work?

Depending on the severity of your symptoms and the nature of your work you may feel able to return to work within weeks. Your DVT nurse will be able to advise you about when it might be suitable to return to work.

Will I have another scan?

Repeat scans are not routinely performed as the results do not usually change your management. There are certain circumstances when more imaging may be required but your haematology doctor will discuss this with you in your thrombosis clinic appointment if this is recommended.

When can I travel / fly?

In general, flying (especially long-haul) is not advised in the first four weeks after a PE. Once your symptoms have settled and you are tolerating anticoagulation well, it should be fine for you to travel but you may wish to discuss this with your GP or at your anticoagulation/haematology clinic appointment.

What is the risk of having another PE?

Each individual's risk is different. You will have an appointment with a haematology doctor within 3 months of having a PE. At this appointment, your case will be reviewed in detail and your individual circumstances reviewed. The need for extra tests will be considered and further advice will be given to reduce the risk of recurrent PE.

This may include continuing anticoagulation for those at high risk of recurrence or using anticoagulants during periods of high risk and/or lifestyle changes. This will be discussed with you in detail at your appointment. A plan will be made to decide how long you will remain on an anticoagulant.

How much activity should I do?

After a PE, it is advisable to avoid strenuous exercise, but you should try and carry out your normal daily activities, including walking if you feel able. Bed rest is not usually necessary. While you are on an anticoagulant, you should also avoid activities that will increase the risk of bleeding e.g. contact sports. Be guided by your body - if normal activity makes you feel short of breath or unwell you will need to rest until you feel recovered. Once your symptoms have settled you can start slowly increasing your activity.

Follow up appointments

Date:	Time:	Location:
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King's College Hospital

DVT Clinic Monday – Friday, 9am – 5pm Tel: 07623 901 822 (the operator will ask for a call sign, answer 'DVT1')

The Princess Royal University Hospital

DVT Clinic Monday – Friday, 8.30am – 4.30pm Tel: 01689 864273

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS: Tel: 020 3299 3601 Email: kch-tr.palsdh@nhs.net

You can also contact us by using our online form at www.kch.nhs.uk/contact/pals

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Sheffield Teaching Hospitals **NHS**



NHS Foundation Trust

Pulmonary embolism

1 **Information for patients** Specialised Medicine







What is a pulmonary embolism?

A pulmonary embolism (PE) is a blood clot, or more usually a number of clots, which lodge in blood vessels in the lungs. The blood clot usually comes from a vein elsewhere in your body, most often from the veins in the leg. Blood clots in the veins of the leg are called deep vein thromboses (DVTs). PEs often cause chest pain, shortness of breath and some people feel dizzy or lightheaded. The blood clot will stay in your lungs until it dissolves. It will not travel anywhere else in your body.

After starting treatment, the pain and breathlessness often improve after a few days, and in most people these symptoms have improved by 6-8 weeks. Some people continue to have intermittent discomfort for some months after the PE.

Why did I have a pulmonary embolism?

Pulmonary embolisms can be split into two categories:

- provoked which account for 60% of cases
- non-provoked: in about 40% of cases no cause can be found

As the name suggests provoked pulmonary embolisms usually have an obvious cause or there is a contributory factor. Provoking factors for blood clots include;

- surgery or a serious limb injury
- pregnancy
- long haul flights or car journeys lasting more than 6 hours
- the combined oral contraceptive pill
- a period of inactivity such as a hospital stay

As people get older they are more likely to develop a blood clot and some people have blood conditions that increase their likelihood of developing blood clots. However, for a significant number of people it is impossible to say exactly why they have developed a clot. If you are overweight then losing weight helps to reduce your risk of further blood clots and other illnesses.

Is there a link between pulmonary embolism and cancer?

Some types of cancer or certain cancer treatments such as chemotherapy or radiotherapy, can increase the risk of developing a blood clot.

What treatment is offered for pulmonary embolism?

Medication (called anticoagulants) will stop the blood clot getting larger and prevent new blood clots from forming. Your body, on its own, will break down the blood clot that has already formed. This process usually takes between 4 and 6 weeks.

Anticoagulant treatment comes in various forms including:

- low molecular weight heparin (LMWH) injections
- direct oral anticoagulants (DOACs) such as Rivaroxaban, Apixaban, Edoxaban tablets
- warfarin tablets

Your doctor or nurse will discuss with you which type of medication may be most suitable for you.

You will be given an anticoagulation alert card for whichever treatment is used, and you should keep this with you whilst you are taking the anticoagulant medication.

Most patients are advised to take anticoagulant medication for at least 3 months after a PE, and some patients are advised to continue on treatment for longer. This will be discussed with you when you are seen for a follow up appointment (see below). It is important to continue

anticoagulant medication and not miss any doses until you are advised it is safe to stop.

Risks of anticoagulants

Anticoagulant medicines cause chemical changes in your blood to stop it clotting easily. Your body will absorb or dissolve the clot and the medication will stop it getting larger. Anticoagulants may have side effects and you may bleed more easily. Any bleeding you have may be slower to stop.

In everyday life this should not affect you and most people taking anticoagulant medications have no bleeding problems. Women can develop heavier menstrual periods when taking an anticoagulant medication. If your periods are interfering with your quality of life or causing your concern please do ask your GP or Thrombosis Nurse in the Anticoagulant clinic for advice.

If you need to start any new medication while on anticoagulants always check with you GP or pharmacist that it is safe to take with anticoagulants.

If you need a painkiller, paracetamol is safe with anticoagulants. Aspirin and non-steroidal anti-inflammatory drugs such as ibuprofen should be avoided unless advised by your doctor.

What should I expect when I go home?

It is normal to feel some breathlessness and experience occasional sharp pain in the chest or back when you breathe. Patients often feel quite tired when they return home as they start doing a bit more for themselves; this is usual and will improve with time.

Is there anything I should look out for when I go home?

You should seek medical advice immediately by urgently contacting your GP or returning to the A&E department if you develop:

- severe central chest pain or severe breathlessness
- loss of consciousness or dizziness on exertion
- an injury to the head with any loss of consciousness
- bleeding from your bowels or when you pass urine
- if your bowel motions become black and sticky as this can be a sign of bleeding from the bowel
- prolonged nosebleeds or any other bleeding of concern

Who should I contact if I have any concerns?

Your General Practitioner (GP) will be informed that you have had a PE, and the treatment you are receiving when you go home.

For questions about your treatment, during working hours, contact your GP or call the Thrombosis Nurse in the Anticoagulation Clinic at the Royal Hallamshire Hospital on **0114 271 3820**.

If you are worried about new symptoms that might be associated with the PE or you have concerns with your treatment, you should seek medical advice urgently.

In the event of serious new symptoms, call an ambulance.

When can I return to usual activities and work?

Once on anticoagulation and discharged from hospital you should try to continue with normal daily activities. You do not need to 'rest'. Be guided by symptoms such as breathlessness and stop to rest if you feel chest tightness or lightheaded. Over the next 6 weeks you should gradually be able to return to normal levels of exercise.

If your work is physically strenuous you should build up slowly to your previous activity levels. If you have any concerns or questions please discuss these with your nurse or doctor.

Is it safe to travel?

Air travel should be delayed until 4 weeks after the diagnosis of PE. Longer term, your PE is no reason why you should not be able to fly safely again. You need to inform your travel insurance company that you have had a pulmonary embolism.

When flying, we would advise you to move around the plane as often as possible. Try to book an aisle seat, avoid alcohol and stay hydrated drinking plenty of water (not alcohol). Car and train travel can be undertaken as usual but we recommend regular breaks (every 2 hours) for a short walk.

When will I get a follow up appointment?

In Sheffield, patients will be offered an appointment for the Pulmonary Embolism clinic, usually 3-4 months after the PE. You will be seen in clinic by a Consultant Respiratory (chest) doctor and a Consultant Haematologist (expert in thrombosis and anticoagulant treatment). Further investigations will be arranged if required and the choice and duration of anticoagulant treatment agreed.

Useful link

https://www.nhs.uk/conditions/pulmonary-embolism/

Questions for clinic appointment



Sheffield Hospitals Charity

To help support your local hospitals visit sheffieldhospitalscharity.org.uk

Registered Charity No. 116976



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