

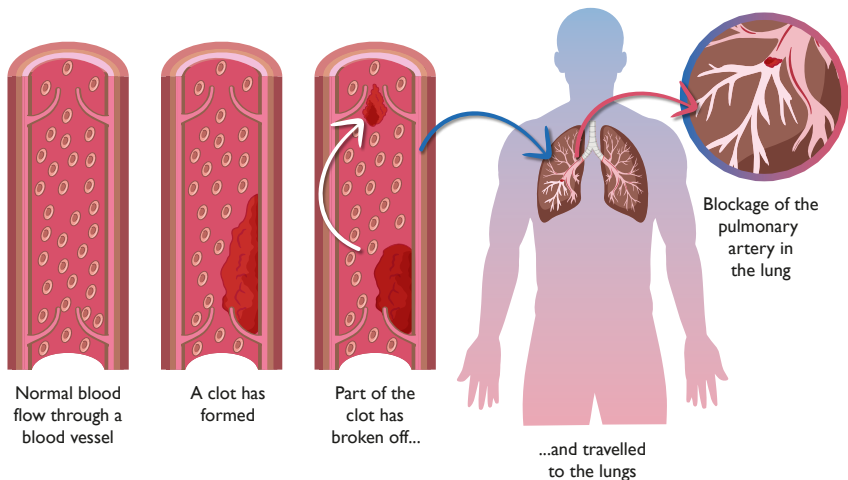
This material has been developed and produced by Janssen-Cilag Ltd with input from the CONNECT steering committee, Thrombosis UK and a patient representative. This material is intended for use by people diagnosed with pulmonary embolism.

Information for patients with a confirmed diagnosis of pulmonary embolism

This booklet will explain what blood clots are, why they happen and what to expect and look out for over the next few months. You may wish to share this leaflet with someone close to you who will play a supporting role in your recovery at home. This may help them better understand what you have experienced and your aftercare.

What is a pulmonary embolism (PE)?

A PE, or lung clot, is a blood clot (or a collection of blood clots) that gets trapped in the blood vessels (arteries) in the lungs and stops the normal flow of blood in that area. This blockage can make it difficult for your lungs to provide the rest of your body with oxygen. This is why people with a lung clot feel short of breath and may have chest pains.



Where do blood clots come from?

It is not fully clear, but in most cases, the blood clot first forms in a vein in the leg and then travels to the lung. This is why you may have had some swelling in one of your legs, but there are often no clear signs of where the blood clot came from.

Once the lung clot has formed, it cannot move to other areas of the body. The blood vessels in the lung are like a tree: they branch into smaller and smaller tubes like twigs so that only one blood cell can pass through at a time. In this way, the lung acts like a sieve, stopping the clot from travelling any further in the body.

What causes blood clots?

Most blood clots have no clear cause. There are factors that can increase the risk of someone having a blood clot. These risk factors can be divided into those that are temporary/short-term and reversible and those which are not. Temporary risk factors can also be divided into whether they are major (associated with a bigger risk of blood clots) or minor (associated with a smaller risk of blood clots).

Major temporary or reversible risk factors



- Surgery with general anaesthesia* for more than 30 minutes (*totally unconscious and unaware during the surgery)



- Bed rest in hospital for several days



- Injury, with broken bones

Minor temporary or reversible risk factors



- Surgery with general anaesthesia for less than 30 minutes



- Short stays in hospital (less than 3 days)



- Long-haul flights



- Pregnancy



- Not being able to move due to a leg injury (without broken bones)

Other risk factors



- Family history or previous history of blood clots



- Older age



- Medical conditions such as inflammatory bowel diseases (e.g., ulcerative colitis, Crohn's disease), cancer, acute infection and acute heart failure



- Being overweight

How are lung clots treated?

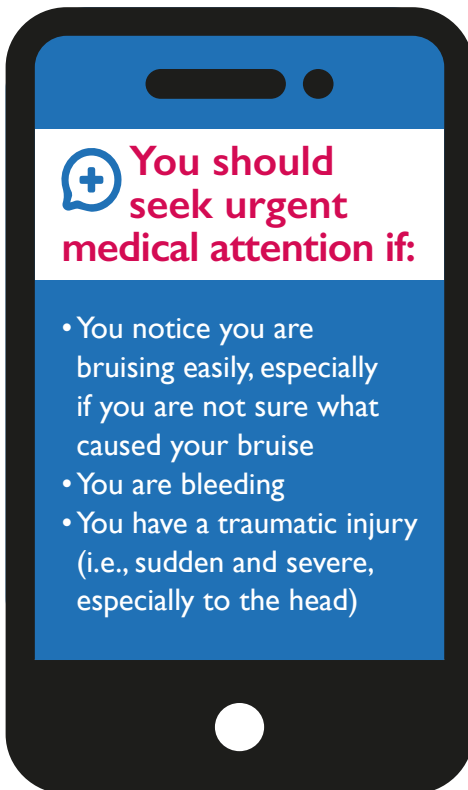
Lung clots are treated with medicines called anticoagulants. They are commonly called “blood thinners”, but this is not an accurate term. Anticoagulants do not actually thin your blood – they make your blood less sticky and stop it from clotting too easily. Anticoagulants do not dissolve your blood clot; they stop it from getting bigger, so your body can break the clot down naturally.

Someone who has a large lung clot may be given stronger, ‘clot-busting’ treatment (called thrombolysis), but this is much less common.

Talk to your doctor if you have any questions about medicines for your lung clot.

What are the side effects of anticoagulants?

The package insert for your anticoagulant will describe common, less common and uncommon side effects of the anticoagulant you have been given.



There are some safety precautions you should take while you are on an anticoagulant:

- You should carry an anticoagulant alert card so that any healthcare professionals who treat you are aware that you are on an anticoagulant.
 - This will be given to you when you are prescribed your anticoagulant.
 - It is very important to keep this card on your person.
 - Some people chose to wear a medical alert bracelet while they are exercising, as it is easy to keep on your person.
 - It is important that you carry either the anticoagulant alert card or bracelet at all times.
- If you have a dentist appointment, you should also inform your dentist if you are on an anticoagulant.

What are the side effects of anticoagulants? Continued

- There may be some medicines or supplements that you cannot take while you are on an anticoagulant:
 - You should tell your doctor, nurse or pharmacist that you are on an anticoagulant if you are prescribed a new medication, or if you buy over-the-counter medications, herbal remedies or supplements.
 - You should not take aspirin unless it is prescribed by your doctor and they are aware that you are also taking an anticoagulant
 - You should avoid non-steroidal anti-inflammatory drugs (NSAIDs, e.g., ibuprofen, diclofenac, indomethacin, naproxen) unless prescribed by your doctor and they are aware that you are also taking an anticoagulant.
 - Some antidepressants may increase your risk of bruising and bleeding when taken with an anticoagulant and your doctor will talk through this with you, if you are taking antidepressants.

Some anticoagulants such as warfarin are affected by diet and you may be advised to stick to a regular diet. Scan the QR code or visit [the link](#) to the NHS for more information. However, if you have any questions or concerns about this, please speak with a pharmacist.



How long will I need to take my anticoagulant?

You will need to take your anticoagulant for at least 3 months. After 3 months of taking your anticoagulant, your body will have removed most, if not all, of the clot.

The decision on whether to stay on the anticoagulant after 3 months will depend on your risk of having another clot if the anticoagulant is stopped. You should have a follow-up appointment 3 to 6 months after your lung clot. At this appointment, you and your doctor will talk about how you are getting on and whether you can stop taking your anticoagulant or if you should continue to take it. You should keep taking your anticoagulant as prescribed until you are told to stop or change by your doctor.

Your doctor may say it is fine for you to stop your anticoagulant at 3–6 months if this was your first blood clot and it was caused by a risk factor that is no longer around (a broken leg, for example).

Your doctor may talk through the option of continuing anticoagulants beyond 3 months if:

- Your blood clot had no obvious cause
- Your blood clot was caused by a risk factor that is still settling down (e.g., still not able to move normally after a broken bone)
- Your blood clot was caused by a risk factor that is still around (e.g., cancer)

Sometimes the risk of someone having another clot is not fully clear. You should talk to your doctor about the pros and cons of staying on anticoagulants versus stopping, and take a decision that you both feel comfortable with.

Will I have another clot?

The chances of you having another lung clot are very low while you are on an anticoagulant. Once you have stopped taking the anticoagulant, your risk of having another clot depends on other risk factors. Two examples are given below.

Example 1: A person whose lung clot was caused by a major surgical operation (a major temporary risk factor).



- Once they are feeling better and have fully healed from the surgery, their risk of having another blood clot off anticoagulant is low (around 2–3 in 100 chance of having another blood clot in the next year).^{1,2}

Example 2: A person whose lung clot had no obvious cause.



- The risk of this person having another blood clot off anticoagulant in the next year can be higher than the first example, up to 1 in 10.^{3,4}
- The risk increases over time and may be as high as 1 in 3 at 10 years.³

Your own risk of having another blood clot and the final decision on whether you continue or stop anticoagulation is individual to you and needs to be discussed with your doctor.

Do my family have a higher risk of having a lung clot?

If your blood clot had no obvious cause, then your immediate relatives (parents, siblings or children) may be at a higher risk of blood clots, although the overall risk will be low. You should talk to your doctor about this, as they may advise certain things. For example:

- The combined oral contraceptive pill increases your chances of having a clot. If you have a daughter on the combined oral contraceptive pill, your daughter may be advised to switch to another method of contraception.
- If you have an immediate relative who is having surgery, your relative should inform their surgical team about your blood clot. The surgical team will follow their local practice on thrombosis prevention.

When should I call my doctor?

Before you are discharged from hospital you should identify a phone number to contact, in case you have any questions before you are scheduled to see your doctor. You can note it down here or in the notes page at the end of this booklet.

- **Contact number:**

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It is not unusual to experience symptoms (such as shortness of breath) for a while after the lung clot, while the treatment takes effect. If your symptoms do not get any worse, then it is unlikely you will need any additional treatment. *However, if you experience any new or worsening symptoms, you should seek medical advice.*

Your road to recovery: what will happen over the next 3 months?

The key things for you to do over the next few months, to help your recovery, are shown below:



Take your medications as prescribed

It is important to take medicine as advised by your doctor or nurse, and to talk to them if you have any worries



Follow your doctor's advice on lifestyle changes

e.g., stopping smoking



Gradually build up exercise/movement

Thrombosis UK has a helpful leaflet with more advice on getting active after a lung clot

Your follow-up appointment should be scheduled for 3–6 months after your lung clot. There are two sections at the end of this leaflet to help you get the most from this consultation:

- A questionnaire, which you can complete and share with your doctor, to help give your doctor a good idea of how you are doing.
- A space to note down your questions and any concerns you have, so that you can bring this to your consultation.

The next page includes links to where you can find more information about blood clots. After that page, the next section includes frequently asked questions (FAQs) on what to expect between now and your follow-up visit

Other helpful resources

[Thrombosis UK](#) is also a good source of further information on blood clots, particularly the following leaflets:



[Thrombosis UK](#)



[General overview of blood clots](#)



[Getting active after a lung clot](#)



[Information on a type of anticoagulants called 'Direct Oral AntiCoagulants' or DOACs](#)

Thrombosis UK leaflets on the impact of a lung clot on your mental health:



[Post-thrombotic panic syndrome](#)



[Coping with worries: meditation and mindfulness](#)



[Coping with worries: active distraction](#)

Please click the links or scan the QR codes to find out more. However, these materials are not a substitute for talking to your doctor – if you have any other questions or any concerns, please be sure to contact your doctor.

FAQs: What will happen over the next 3 months?

When should I go back to work?



- The time needed to get better after a lung clot will vary from person to person.
 - For example, someone with a large clot and other conditions (e.g., heart disease) may take longer than someone with a small clot and no other medical conditions.
- Many people start to feel better a few days after they have started anticoagulation. If you are one of these people, you may be able to return to work around one week after your diagnosis of lung clot (pulmonary embolism).
- How quickly you go back to work also depends on the type of work you do and how well you feel.

Am I fit to drive?



- Most people can drive once they feel well enough to go back to their normal daily activities.
- There are some rare cases where you must contact the Driver and Vehicle Licensing Agency (DVLA) to check if and when you are able to drive:
 - If you have a blackout you must contact the DVLA to let them know and not drive until you have heard back from the DVLA.

What kind of sports can I play?

It is best to focus on gradually building up your physical activity, rather than playing sports. You will need to avoid full-contact sports, especially those that risk injury to the head (e.g., rugby and boxing) at least until you attend your 3–6 month follow-up visit. You should be able to play non-contact sports once you feel well enough to do so and have no shortness of breath or chest pains – but it is important to speak with your doctor first.

When can I travel by plane?



- It is best to delay air travel for *at least 2 weeks* after your lung clot.
 - You may need to wait even longer if you still feel unwell.
- This is because oxygen levels are lower on the plane than they are on the ground.
- If you are planning to take a flight in the first 3 months after your lung clot, it is important that you:
 - Talk to your doctor about any scheduled flights
 - Tell your travel insurance company that you are on an anticoagulant
 - Make sure you have enough medication with you
 - Make sure you know where you can access emergency services while you are abroad

What should I do if I have heavy periods?

It is very important that you do not stop taking your anticoagulant. You should speak with your GP. Your doctor may wish to do some additional tests and advise hormone treatment, tranexamic acid or a change in anticoagulant.

What contraception can I use?



- You should not suddenly stop taking hormonal contraception when you start on an anticoagulant. You should speak with your doctor.
- If you are taking the combined oral contraceptive pill, your doctor may discuss whether to switch you to an alternative.
- Some anticoagulants (known as DOACs or Direct Oral AntiCoagulants) are not safe for pregnant women to use, so pregnancy should be avoided while you are on DOAC anticoagulant. Other options are available.

What kind of hormone replacement therapy (HRT) can I use?

There is an increased risk of blood clots with most oral HRT (given in pill form). You should speak with your doctor if you are taking HRT so they can advise which type is best for you.

Can I get a tattoo if I am on an anticoagulant?

You should avoid getting a tattoo during the first 3 months of anticoagulant treatment. After 3 months you should talk this through with your doctor and tell the tattoo artist you are on an anticoagulant.

Getting the most out of your follow-up consultations

Questionnaire

If you are concerned about how you are feeling, you might find the questionnaire below helpful to monitor how you are doing. You could then take the completed questionnaire to your follow-up appointment to share with your doctor. Please note that this questionnaire is to help you and your doctor assess how you are doing *once your blood clot has started breaking down*. This means that you should only complete it once you have been taking your anticoagulant for at least 1 month. After that point, you may find it helpful to complete every few weeks or a month, or you may wish to simply complete it just before your consultation.

Question	Your answers:			
	1	2	3	4
	month(s) after blood clot			
Please tick any answers that apply				
Do you become breathless while:				
Walking on the flat?				
Walking up the stairs?				
Do you have any chest pain?				
Do you have any ankle swelling?				
Have you experienced any exercise bruising or any bleeding (including heavy periods) while on your anticoagulant? <i>Please seek urgent medical attention if you experience any of these side effects</i>				
Have you experienced any of the following symptoms since you were first discharged from hospital?				
Panic attacks				
Anxiety				
Please enter a number from 1 to 10 into the box				
On a scale of 1 to 10 (with 10 being your normal feeling of wellness before the lung clot, and 1 being your feeling of wellness when you were first admitted to hospital), how do you feel?				



If you have any questions or concerns, please speak to your healthcare professional. This leaflet does not constitute, and should not be used as a substitute for, professional medical advice from your doctor or nurse. It is important to talk through any questions or concerns with a medical professional.

References

1. Konstantinides et al. *Eur Heart J* 2020;41:543–603; 2. Agnelli et al. *Ann Intern Med* 2003;139:19–25; 3. Khan et al. *BMJ* 2019;366:14363; 4. NICE. *Clinical Knowledge Summary for pulmonary embolism*, available at: <https://cks.nice.org.uk/topics/pulmonary-embolism/background-information/prognosis/> [last accessed Nov 2023].

