

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.

Recovering from a pulmonary embolism (PE): information for patients with ongoing breathlessness

You have been given this leaflet because you have ongoing breathlessness and you will need further follow-up care. This leaflet will help answer any questions you may have on what happens next. For any other questions or concerns you may have, please speak with your doctor.

Why am I still breathless?

Recovery after a lung clot (pulmonary embolism) varies and it can take many months to return to your pre-clot level of wellness and fitness. After a lung clot, it is very common for people to have persistent or ongoing breathlessness (i.e., their breathlessness does not improve over time), but often this does not require further treatment. In most cases, persistent breathlessness is related to either a pre-existing lung and/or heart condition, de-conditioning (doing less) or understandable anxiety. It is also common for people to have some long-term (chronic) blockages in the blood vessels of the lungs following a lung clot. Often these chronic blockages are minor and do not cause any problems, as the lungs have a lot of reserve and these blockages will not move anywhere. In rare cases (around 2% or 1 in 50 people who have had a lung clot),^{1,2} these chronic blockages are major and increase the blood pressure in the lungs. High blood pressure in the lungs is called pulmonary hypertension (PH), and the type of PH caused by chronic blood clots is called chronic thromboembolic pulmonary hypertension (CTEPH).

What happens now?

Tests can be done to look for blockages in the lungs. Each of these tests has pros and cons, and your doctor or nurse will talk with you about which test(s) are best for you. The tests that are most often used to look for blockages are V/Q SPECT scans (ventilation/perfusion single-photon emission computerized tomography scans) and CT scans (computed tomography scans). Below you will find a brief overview of what to expect and the main risks involved with each test. Your doctor may also give you additional information or material on these tests that can complement the brief overview in this leaflet. If you have any questions, please speak with your doctor.

V/Q SPECT scan

What is a V/Q SPECT scan?

This test is made up of two scans:

1. One scan looks at air flow (V) in the lungs
2. Another scan looks at blood flow (Q) in the lungs

How does it work?

In both scans, the patient is given a small amount of radioactive material so that your doctor can trace the flow of either blood or air in the lungs. If there are no blockages in the blood vessels in the lungs, the substance will send out radioactivity, which is detected by the scanner. If there are blockages in the lungs, less radioactivity will be detected. In many cases you may only have the blood flow scan (Q) scan and it is often not necessary to perform the air flow (V) scan.

How long will it take?

In total, a V/Q SPECT scan can take 30 minutes to an hour.

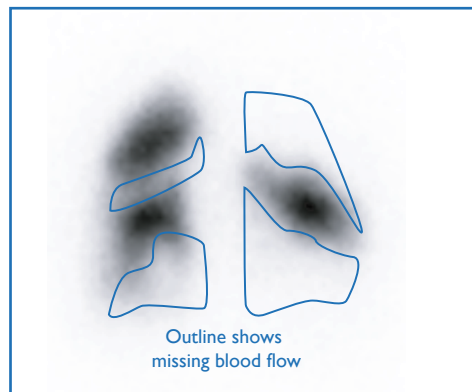
What are the risks?

The amount of radiation used in this test is safe for most adults. In the blood flow (Q) scan, the radioactive material is administered by injection, and the injection may cause some discomfort. In a small number of people, the injection can cause a skin reaction.

Example of a ventilation scan image of the lungs



Example of a perfusion scan image of the lungs



CT scan

What is a CT scan?

A CT scan is a special type of X-ray that creates a detailed image of the inside of your body. Lung clots (pulmonary emboli) are usually diagnosed with a CT scan. CT scans can also be used to look for long-term (or 'chronic') blockages in the same way.

How does it work?

The CT scanner looks like a large polo mint and uses X-rays to create a detailed image of the patient's lungs. During the test, dye will be injected into the patient. The dye travels to the blood vessels in the lung and makes them bright, allowing the clots to be seen.

How long does it take?

A CT scan usually lasts around 10 to 20 minutes.

What are the risks?

Patients are exposed to X-ray radiation as part of this test. Your doctor will talk with you about the benefits and risks of you having a CT scan. You may feel some discomfort due to the injection. A small number of people can have a reaction to the injection. If you have diabetes or your kidney function is not normal you may be asked to withhold certain medication or drink more water around the time of the scan, to help flush the dye out of your system.

Having a CT scan



Echocardiogram

Your doctor will also consider performing an echocardiogram. This test does not usually let you see blockages in the lungs but it can check the likelihood of you having high blood pressure in the lungs and the health of your heart. An echocardiogram can help your doctor decide if you may have CTEPH.

What is an echocardiogram?

The echocardiogram is an ultrasound scan, like the scan used in pregnant women.

How does it work?

A small probe is used to send out sound waves that create echoes when they bounce off different parts of the body. The echoes are picked up by the probe and turned into a moving image on a monitor while the scan is carried out.

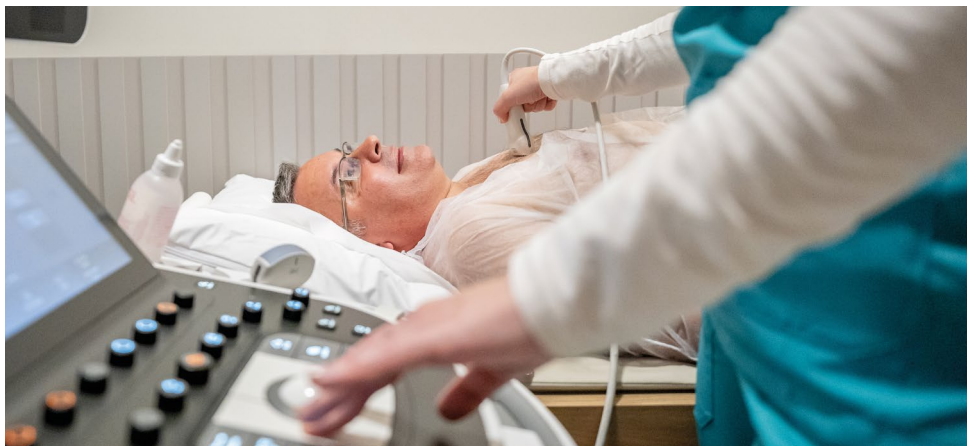
How long will it take?

An echocardiogram can take anywhere from 15 minutes to an hour.

What are the risks?

No radiation is used during an echocardiogram and no injections are needed. It is a safe procedure and there are no side effects from the test. Occasionally you may feel some discomfort when the probe is pressed on your chest.

Having a chest echocardiogram



Other tests your doctor may consider are:



A blood test – there are ‘biomarkers’ in the blood that can tell us if there is a deterioration in heart function, for example.



An exercise test – this test is not as common as the tests mentioned above.

If the results of these tests suggest that you may have major chronic blockages and high blood pressure in the lungs, you may be referred to a specialist pulmonary hypertension/CTEPH clinic for more specialized tests.

You can find more information about each of these tests:



By searching the NHS A–Z of health for CT scan, MRI scan or echocardiogram

By visiting the Pulmonary Hypertension Association website, which provides information on V/Q scans and other tests that might be used to investigate unexplained breathlessness



It is important to highlight that these tests are used to investigate many symptoms and conditions – they are not only used to investigate for pulmonary hypertension or CTEPH. If you are breathless they may help to identify another cause for your breathlessness, and it can often take several tests to determine the cause of your breathlessness. Your doctor will review your test results to see if you need further tests or additional treatment and if you should be referred to a specialist.

What can I do to help my recovery?

The key things for you to do to help your recovery are illustrated 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

Scan the QR code below for more advice on getting active after a lung clot

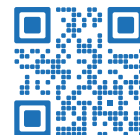
In most cases, increasing your fitness and activity can do a lot to help your recovery. Here are some important points on exercise after a lung clot:

- Start gently with exercise and gradually build up
- Avoid full-contact sports, where there is a risk of injury and bleeding
- During exercise, you should be guided by your body – if the exercise starts to become painful, take a break



Take a look at the Thrombosis UK leaflet on getting active after a blood clot for more helpful tips and advice.

Making the most of your consultations



Take a look at this video from Thrombosis UK for more advice on getting the most from your consultations.

If you are concerned about how you are feeling, you might find the questionnaire below helpful to monitor how you are doing. You could take this to your appointment to share with your doctor, and help you get the most out of 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, please speak with your doctor – this leaflet should not be used as a substitute for medical advice, and it is important to talk through any questions or concerns with a medical healthcare professional.



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.

