

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.

Finding your new normal: life after pulmonary embolism (PE)

You have been given this leaflet because of any, or all, of the following reasons:

- You have recovered well from your blood clot
- You have come to a decision with your doctor to stop your anticoagulant
- You do not need further follow-up

This leaflet will go through some of the questions you may have and what to expect going forward.

You may wish to share this leaflet with someone close to you who has played a supporting role in your recovery at home. This may help them better understand what you are experiencing.

When do I need to see a doctor?

If you have any of the following symptoms, please seek **urgent medical help**:



New or worsening symptoms of breathlessness that occur at rest or during exercise



Chest pain



Rapid heart rate



Light headedness or passing out



Pain, tenderness, swelling, warmth, and/or redness of an arm or leg

If you do have reason to see or speak with a healthcare professional, it is important to mention your history of blood clots. If you have regular health checks scheduled, you should make sure to attend these.

Will I have another blood clot?

You have come to the decision with your doctor to stop your anticoagulant because your risk of another blood clot is low or – in a small number of cases – your risk of bleeding is high.

Your own risk of having another blood clot is individual to you and will depend on other risk factors. The following list will include some of the risk factors that have been taken into account when deciding whether you continued on anticoagulation. 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

In cases where a blood clot was associated with a major temporary or reversible risk factor, it is usual to consider stopping anticoagulants after 3 to 6 months. In cases where a blood clot was associated with risk factors that are not temporary or reversible, it is common to consider continuing anticoagulant to prevent further blood clots (if the risk of bleeding is acceptable). In cases where risk factors are thought to be minor, or weak, then other factors may be taken into account – in these cases, you and your doctor will have had a discussion about the risks and benefits of stopping or continuing anticoagulation.

Now that you have stopped anticoagulation, if any of these risk factors become relevant for you, then please discuss these and your previous history of blood clots with your doctor. Your doctor may consider preventative (prophylactic) anticoagulation for a period of time.

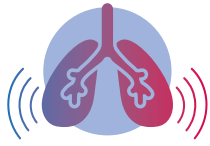
What can I do to lower my risk of blood clots in the future?

If it has been decided to stop your anticoagulation, then your risk of having another clot is low, but not zero, just like the rest of the population. We can all find ways to reduce our risk of having another clot. An important thing you can do to lower your risk of blood clots is to maintain a healthy lifestyle.

It can feel difficult to get back into exercise following a lung clot, and it is not uncommon for patients to be worried about doing too much. However, getting or staying active is good for you and it is key to leading a healthy lifestyle. Here are some important points on exercise after a lung clot:



Start gently with exercise and gradually build up



Remember that experiencing shortness of breath for a while during and after exercise is a normal response to exercise, especially if you are unfit



During exercise, you should be guided by your body – if the exercise starts to become painful, take a break

For more helpful tips and advice, please follow the link or scan the QR code:



Thrombosis UK leaflet on getting active after a blood clot



Thrombosis UK video on getting active after a blood clot



If you have any questions or concerns relating to getting active after a lung clot, please speak with your doctor or physiotherapist. You may also wish to share your fitness journey with someone who has also experienced a blood clot.

What happens now?

You are at the beginning of your journey to finding your new normal and there are lots of materials and networks to support you on this journey.

It is not unusual to feel anxious after a lung clot. Lung clots can have a big psychological impact on the lives of those affected and will factor into many decisions you make from now on.

It is important to know that you are not alone:

If you have concerns about your health, please do voice these to your doctor (your GP or your VTE [venous thromboembolism] team) so they can help you and direct you to further support



Mind

Mind are a mental health charity who provide lots of helpful resources and support for anyone struggling with their mental health



Thrombosis UK - dealing with the psychological impact of blood clots

Thrombosis UK have a webpage dedicated to resources for dealing with the psychological impact of blood clots including several videos and leaflets with advice on coping with worries and getting to sleep



Find an NHS talking therapies service

If you are in England, you can refer yourself directly to a psychological therapies service (IAPT) without seeing your GP – anyone who is registered with a GP can access this service on the NHS

It can be very helpful to simply to talk to someone about your experience. If you would like to connect with someone who has had a blood clot, consider searching for Thrombosis forums or ask your medical team.

If you are struggling with your mental health, please do speak with a healthcare professional and seek support.



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.

