Royal United Hospitals Bath
NHS Foundation Trust

Patient information leaflet:

Cancer-Associated Thrombosis (Blood clots)

Departments: Oncology, Haematology (cancer services)

Introduction

This leaflet provides you with information about cancer and the associated risk of blood clots.

It includes:

- how to identify a potential blood clot
- how we can try to prevent blood clots from forming
- how a blood clot may be diagnosed and treated
- what some of the long-term complications can be

The leaflet doesn't replace the discussion between you and your clinician but may act as a starting point for discussion. It is also a source of information for you to refer back to if needed. If after reading this leaflet, you have any concerns or require further explanation, please discuss this with a member of the healthcare team caring for you.

If you are already on blood thinners, please make sure the team treating you is aware.

What is Cancer-Associated Thrombosis?

When a blood clot develops in a patient with cancer it is known as **cancer-associated thrombosis**, commonly known as **CAT**.

CAT is not caused by anything you have or have not done. Some people are more likely to develop blood clots than others.

Cancer and its treatments are well known risk factors for the development of blood clots. Other risks include having surgery, being less active and having a long line in a vein placed in the neck,

chest or arm such as a peripherally inserted central catheter (PICC) line.

Certain types of cancer are also more likely to be associated with CAT. Your clinician can give you an idea of the risk that you may have of developing a clot with your type of cancer and while you are on cancer treatment.

Deep Vein Thrombosis

Deep vein thrombosis is a blood clot that forms in a vein deep in the body. Most deep vein thromboses will form in the lower leg or thigh, however, they can occur in other parts of the body. In many cases there may be few or no symptoms.

A blood clot in a deep vein can break off and travel through the bloodstream, this is known as an embolus. It can travel to the lungs and become lodged resulting in a pulmonary embolism. If left untreated, about 1 in 10 people with a deep vein thrombosis will develop a pulmonary embolism.

Pulmonary Embolism

Pulmonary embolism is a blood clot in the lungs that occurs when a piece of a blood clot breaks loose into the bloodstream and travels to the lungs. This causes a blockage in a blood vessel in the lungs.

Why is this important?

About 1 in 5 people with cancer will develop a blood clot. Clots can be very serious and, if not identified early, can be a significant cause of death in patients with cancer. However, there are effective medicines which can treat or prevent clots. Therefore, it is important to be aware of the signs and symptoms of a blood clot so that you can seek prompt help.

What are the signs of a blood clot?

It is important to be aware of the possible signs of a blood clot.

Signs you may be developing a blood clot in the leg (a deep vein thrombosis) may include one or more of the following:

- Tenderness in the leg
- Swelling
- A feeling of tightness – the skin may feel stretched
- Pain in the leg (usually in the calf)
- A heavy ache in the affected area
- Warmth and / or redness of the skin (particularly at the back of the leg, below the knee)

Similar symptoms may occur in your arm or neck and possibly indicate a clot, especially if you have a line in place such as a PICC or you are receiving cancer treatment such as chemotherapy.

Signs you may be developing a blood clot in the lungs (a pulmonary embolism) include:

- Light-headedness or feeling faint
- Shortness of breath – which may come on gradually or suddenly
- Chest pain – particularly when you take a deep breath
- Coughing up blood
- Sweating
- Sudden collapse

It is important to note that symptoms such as feeling faint, being short of breath and chest pain are also similar to having anxiety. These symptoms would likely pass once anxiety has passed or settled down, but would persist if they were caused by a blood clot.

Some patients may not have any symptoms of a blood clot on the lung at all and the clot may be picked up on a routine scan done for other reasons, for example a scan done to assess the effect of cancer treatment. This is called an incidental pulmonary embolism. In most cases this will be treated the same way as a regular blood clot on the lung.

What to do: If you develop any symptoms of a blood clot or suspect you may be developing a blood clot, please seek immediate medical attention. You can do this by contacting the emergency numbers you have been given for your cancer treatment (24 hour helpline: 01225 821884), your GP, calling 111 or 999 or going to the nearest Emergency Department.

What is the treatment for a blood clot?

If you develop a blood clot whilst being treated for cancer, there is an effective treatment which may help manage your clot and prevent further blood clots from forming.

The treatment is usually given in one of two ways, and uses anticoagulants – also known as blood thinners. Your doctor will inform you of the treatment you will be receiving.

1. Low-molecular weight heparin (sometimes written as LMWH) is a type of blood thinner which is given every day, usually for 6 months in the first instance, as an injection under the skin.

If you are given low molecular weight heparin, you will be shown how to give the injections yourself at home. If you are unable to do this, we will show a family member how to give the injections or arrange for a District Nurse to come to your home. You should also be provided with a sharps bin for the safe disposal of the needles after use.

2. Direct oral anticoagulants (sometimes written as DOAC). These are a group of blood thinners which are taken in tablet form. These would also be prescribed for 6 months in the first instance.

It is important that you keep taking your treatment every day for 6 months or as long as your clinician advises.

In some cases, you may need to be on blood thinners for longer than 6 months and some patients may have to stay on these for life. This will be a discussion you will have with your GP or consultant.

If you are already on blood thinners, this will reduce the risk of a blood clot, but you may still develop a clot. In this case, your doctor will identify the best treatment. Even if you are already taking blood thinners, or have been given blood thinners because you have a clot, you should still look out for signs of a blood clot developing, as blood thinners do not offer absolute protection.

For further information about your medication please read the patient information leaflet that comes with the medicine, or you can consult a member of the healthcare team caring for you.

What are the risks of treatment?

Although blood thinners are generally safe medications, they can have some side effects. Any bleeding, for example if you accidentally cut yourself - may be heavier than normal. If you cut yourself, apply firm pressure to the site for at least five minutes using a clean, dry dressing.

You should make your GP or consultant aware if you experience any of the following:

- Increased bruising
- Severe or spontaneous bruising
- Any unusual bleeding or dark ulcers at injection sites
- Prolonged nosebleeds (more than 10 minutes)
- Unusual headaches
- Passing blood in your wee (urine)
- Heavy or increased bleeding during a period or any other vaginal bleeding

You should report to the Emergency Department of your nearest hospital if you experience any of the following symptoms as uncontrolled bleeding may lead to death. **Please ensure that someone else drives you to the hospital.**

- Coughing up blood
- Blood in vomit
- You have soft black tarry poo (stools)

- Any bleeding that you cannot control or explain (e.g. uncontrollable nosebleed)

You should seek immediate medical attention by calling 111 or 999 or attending the nearest Emergency Department if you:

- Are involved in a serious accident
- Suffer a significant blow to the head

How can I reduce the risk of a clot?

First of all, discuss with your consultant or a member of the healthcare team looking after you:

- whether your cancer puts you at a higher risk of getting a blood clot
- whether this risk can be calculated
- whether a blood thinner to prevent a clot happening is appropriate.

You can also help to reduce your risk of developing CAT by:

- Exercising little and often as this will help to keep the blood flowing.
- Changing your position and moving your legs regularly, particularly if you are sitting or lying down for long periods of time.
- Drinking plenty of fluids but avoiding coffee and alcohol where possible, unless you have been told to restrict your fluid intake.
- Being smoke free. Your healthcare team can help and support you to stop smoking should you require more information.

Can a blood clot happen again?

Some patients who have had a deep vein thrombosis or pulmonary embolism can develop another blood clot even if they are still on blood thinners. This is known as recurrent venous thromboembolism. It is important to still look out for symptoms even if the first blood clot has been resolved.

There are a number of risk factors for developing another blood clot such as:

- having a previous deep vein thrombosis
- having to stop treatment with blood thinners
- the cancer has progressed (got worse)
- having a condition called heparin-induced thrombocytopenia (HIT)

What to do: If you develop any new or worsening symptoms related to blood clots, even while on a blood thinner or suspect you may be developing another blood clot, please seek immediate medical attention. You can do this by contacting the emergency numbers you have been given for your cancer treatment, your GP, calling 111 or 999 or going to the nearest Emergency Department.

Long-term effects of blood clots

Symptoms of the blood clot should start improving soon after starting blood thinners. Further scans to prove this are not needed. However, in some cases the symptoms may persist.

It is also possible that, even though you are getting the best possible blood thinning treatment for the blood clot, long term damage can occur to the leg if the clot was a deep vein thrombosis or to the lungs if the clot was a pulmonary embolism. These complications are called post-thrombotic syndrome (PTS) and chronic thromboembolic pulmonary hypertension (CTEPH) and they may need long-term specialist management.

Post-thrombotic syndrome

Deep vein thrombosis can sometimes cause damage to deep veins in the leg. This can then cause damage to valves in the leg which usually stop blood from going back down the leg. Blood can then pool in the foot and lower leg causing pain, swelling and leg ulcers.

This is known as post-thrombotic syndrome, sometimes called post-phlebitic syndrome.

- Up to 30% of people who have had a blood clot in the leg will develop some form of post-thrombotic syndrome within five years.
- Post-thrombotic syndrome may develop 6 months to 2 years after the initial blood clot.
- People who have had more than one deep vein thrombosis in the same leg are at higher risk of developing post-thrombotic syndrome.
- People who have had a deep vein thrombosis in the upper body may develop post-thrombotic syndrome in the upper body, but this is much less common than in the lower body.

Signs of post-thrombotic syndrome include:

- A heavy ache in the calf and ankle, particularly after standing or walking
- Swelling of the ankle and leg
- Persistent itching, tingling or pins and needles
- Discolouration or hardening of the skin
- Varicose veins
- Venous ulcers – ulcers on the legs that are hard to heal

What to do: If you develop any symptoms related to post-thrombotic syndrome, please seek medical attention by contacting your GP or consultant.

Chronic thromboembolic pulmonary hypertension

Pulmonary embolism can rarely lead to a condition called chronic thromboembolic pulmonary hypertension.

This is where blood clots in the lungs have not fully gone despite treatment with blood thinners. The clot blocks the blood flow in the lungs, leading to an increase in blood pressure.

Around 2-4% of patients that have a pulmonary embolism will go on to develop chronic thromboembolic pulmonary hypertension. Symptoms may include continual issues with shortness of breath or chest pain.

Patients with confirmed or suspected chronic thromboembolic pulmonary hypertension will usually need continued treatment with blood thinners and referral to a specialist.

What to do: If you develop any new or worsening symptoms related to chronic thromboembolic pulmonary hypertension, please seek medical attention by contacting your GP or consultant.

Who can I talk to?

We understand that being told you could develop a blood clot or being diagnosed with a blood clot can be distressing for some patients. Please feel free to show this information leaflet and / or discuss your diagnosis with:

- a family member
- a friend
- a carer,
- your GP
- a member of the healthcare team caring for you.

Please also see below for useful contact information.

Useful contact numbers and more information

Should you require further advice about the issues contained in this leaflet, please do not hesitate to contact the:

- CAT Clinic Team: 01225 825812. Monday-Friday 09:00-17:00 (closed on bank holidays).
- E-mail ruh-tr.AnticoagulationTeam@nhs.net or the haematology secretaries on ruh-tr.haematologysecs@nhs.net.
- Oncology 24 hour helpline: 01225 821884.

For more information about blood clots, the charity Thrombosis UK has resources which you can access here: https://thrombosisuk.org/index.php

Including downloads and factsheets which you can access here: https://thrombosisuk.org/information-fact-sheets.php

General advice and consent

Most of your questions should have been answered by this leaflet but please feel free to ask any unanswered questions to your healthcare team.

Consent to treatment

Before any doctor, nurse or therapist examines or treats you, they must seek your consent or permission. In order to make a decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. **You should always ask them more questions if you do not understand or if you want more information.**

The information you receive should be about your condition, the alternatives available to you, and whether it carries risks as well as the benefits. What is important is that your consent is genuine or valid. That means:

- you must be able to give your consent
- you must be given enough information to enable you to make a decision
- you must be acting under your own free will and not under the strong influence of another person

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Please contact the Patient Support and Complaints Team (PSCT) if you require this leaflet in a different format or would like to feedback your experience of the hospital.

Contact the Patient Support and Complaints Team – ruh-tr.psct@nhs.net

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