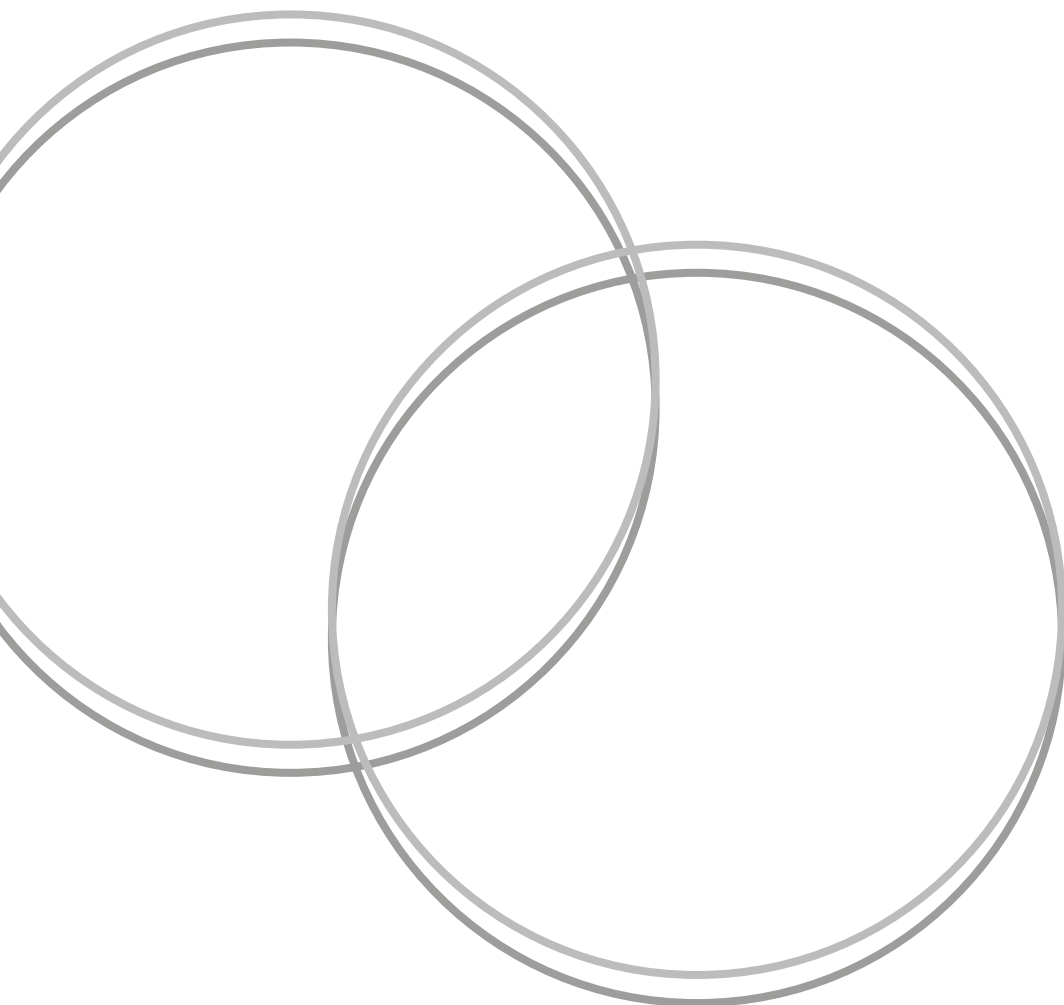


What to do in an Emergency

**Information for patients
with a bleeding disorder**



If you think that you or someone you care for has had a bleed, or is having a bleed, follow these steps

- 1. Stop** what you are doing!
- 2. Assess** the bleed.
- 3. If you are concerned that the bleed is a threat to life or limb: Call 999 for an ambulance, or make your way to the nearest Emergency department if it is safe to do so.**
- 4. Take** Tranexamic acid (unless there is blood in the urine).
- 5. If you are not a self-treater, call the Haemophilia Centre.**
- 6. If you are a self-treater administer your treatment dose of factor and record it on HaemTrack, then call the Haemophilia Centre.**

How to contact The Haemophilia Centre for Adults

Monday to Friday 9.00am to 5.00pm.

Haemophilia Centre Reception

Telephone: **01865 225 316**

Adult Haemophilia Nursing Office

Telephone: **01865 225 308** or **225 309**

Haemophilia Nurses Mobile

Telephone: **07776 135 752**

Weekends, out of hours and Public Holidays

Call the hospital switchboard on 0300 304 7777 and ask the automated system for the operator. Once when connected to the operator ask to speak to the Haematology registrar on-call.

How to contact The Haemophilia Centre for Children

Monday to Friday 9.00am to 5.00pm.

Paediatric Haemostasis Unit Nursing Team

Telephone: **01865 226 562**

If the phone line is engaged or you get the Voicemail facility please call the hospital switchboard and ask the automated service for the operator. Once connected to the operator ask for bleep 5926.

Weekends, out of hours and Public Holidays

Call the hospital switchboard on 0300 304 7777 and ask the automated system for the operator. Once when connected to the operator ask to speak to the Haematology registrar on-call.

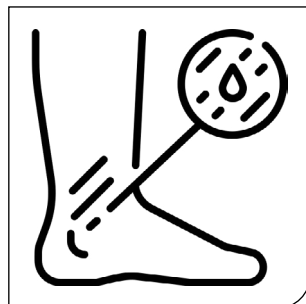
How to assess and manage your bleed

Common bleeds

Soft tissue/Muscle bleeds/Joint bleeds

The following section outlines some of the common signs of a soft tissue, muscle or joint bleed. It is important to note that you may not have all these signs with every bleed. Sometimes, just one sign is apparent, particularly in the early stages. The main thing to remember is that if you are in doubt, please call the Haemophilia Centre because the earlier a bleed is treated, the better. Contact details can be found at the end of this leaflet.

Prompt treatment of joint bleeds helps to prevent long term damage and minimise potential joint changes. Physiotherapy following a bleed will help get your muscles and joints moving again and speed up your recovery.



What to look for:

- A tingling, fizzing, or bubbling feeling in the affected muscle/joint.
- Pain or stiffness in a joint, with or without bruising present.
- Swelling and warmth in a joint, with or without bruising to the area.
- Unusual fussing and crying in an infant or young child and/or refusing to use a limb in a way they previously could (e.g. crawling with one straight leg, when previously both were bent when crawling).
- A bleed that is increasing in size. Use a tape measure to measure the area of concern every few hours. It is important to compare the right and left sides of the body. If you do not have a tape measure, check every few hours to see if the area is growing larger.
- A bruise that is increasing in size. Use a pen to mark the outline of the bruised area and check every few hours to see if the bruise is growing larger.
- A muscle/joint that is becoming more firm, tense, or tight. Compare the right and left sides to assess for differences. Can you feel a specific lump? How big does it feel? Can that limb still be moved normally or is movement limited? There may be increasing stiffness in the limb (arm or leg). Usually there is difficulty with straightening a limb and it tends to be held in a bent position.
- Pain in a particular area that gets worse with time, even without visible signs to help you locate bleeding. This is usually described as constant (even at rest) but can increase when the limb is moved, or if you start to bear weight through that limb.

What to do:

- Stop your activities
- Follow the **P.O.L.I.C.E.** acronym below
 - **P – Protection:** Protect the injured area from further damage. This might involve immobilizing the injured limb or using a splint to prevent unnecessary movement. The use of walking aids or other supports may be recommended. **You need to avoid putting weight on the affected side completely for the first 24 to 48 hours.** A sling may be useful for upper limb bleeds. Your haemophilia team will be able to advise.
 - **O.L – Optimal Loading:** This means providing an optimal amount of stress or loading to the injured tissue during the recovery process. It suggests that, while rest is important initially, some controlled and gradual movement or loading of the injured area can aid in the healing process. This step is often applied in later stages of recovery rather than immediately after the injury. You will be advised by the physiotherapist at the haemophilia centre.
 - **I – Ice:** Apply ice to the injured area to reduce pain, swelling, and inflammation. It's typically recommended to apply ice for 10 to 15 minutes every 2 to 3 hours during the initial stages of the injury. However, it's essential to use a barrier like a cloth between the ice and the skin to prevent ice burns.
 - **C – Compression:** Due to the increased volume of fluid, the more swollen the injury becomes, the more pain you may feel. Use a compression bandage or wrap around the injured area to help reduce swelling and provide support, however not everyone finds compression comfortable. Your physiotherapist can give you an elastic compression bandage. They will make sure these fits correctly, as additional damage may be caused if the bandage is too tight. Try not to allow wrinkles in the bandage and remove at night. Ensure that the compression is firm but not too tight, as excessive compression can impede blood flow. The physiotherapist may also suggest using special tape to help reduce the swelling and help with pain.

- **E – Elevation (raising)**: Elevate the injured area above the level of the heart, if possible. This helps reduce swelling by allowing fluids to drain away from the injury site. For instance, if it's a leg injury, propping up the leg on a pillow can facilitate this elevation.
- Treat with tranexamic acid and factor concentrate (if a self-treater with a treatment dose).
- Take pain killers.
- Record the bleed on Haemtrack if a self-treater and / or call the haemophilia centre!
- Watch closely for signs of improvement, including less swelling, bruises changing colour to green or yellow, and less pain.
- Notify the haemophilia centre if the bleed isn't any better after 24 hours.

If you have pins and needles in the affected limb at any time you must contact the Haemophilia team immediately as this could be a potential sign of reduced blood supply to the nerves and muscles which requires urgent medical attention.

What physiotherapy may I need?

You will require input from your physiotherapy team. This may be provided remotely or at a local physiotherapy service and can be discussed with the physiotherapy team at the Haemophilia Centre. This will depend on your problem but will normally involve an individualised exercise program to help you recover quickly and return to your normal activity as soon as possible. This can involve outpatient appointments and access to the gymnasium or hydrotherapy pool if required.

What should I do if I am worried or not sure?

Please do not worry about bothering us or think “let’s see how it is later.” We would much rather you contact us without any delay.

There is always a doctor, a nurse, or a physiotherapist available to advise you on what to do. Please refer to the contact details at the end of this leaflet.

What do I do once the bleeding has stopped?

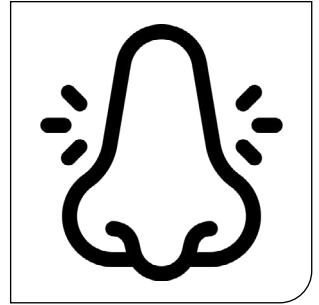
Bleeding usually stops within 24 to 48 hours if adequate factor replacement has been used. It is likely that the bleeding has stopped if you have less pain, more movement and the joint or muscle feels less tense. Once the bleeding has stopped then you can start to become more active. If the bleed is in the leg or hip, begin putting weight through it and increase this within your limits of pain. You may need to use crutches for a few more days. Wear an elasticated support initially if you have one, start moving the joint or muscle gently, trying to increase the movement daily, and try to contract the muscles in the affected area.

If you have pins and needles in the affected limb at any time you must contact the Haemophilia team immediately as this could be a potential sign of reduced blood supply to the nerves and muscles which requires urgent medical attention.

Nosebleeds

What to look for:

- Bleeding from one or both nostrils.
- Blood on paper tissue when blowing nose.
- Continual or very frequent swallowing.
- A salty or metallic taste in the mouth.
- Watch for pale skin, trouble breathing, dizziness, and black or dark bowel movements.



What to do:

- Sit with your head tilted slightly forward.
- Pinch the nose firmly below the bridge (the bony part). Keep pinching for at least 10 minutes after treating with products.
- Put a cold cloth on the back of the neck and replace it when it starts to feel warm.
- Take tranexamic acid.
- Treat with treatment dose factor concentrate according to instructions from haemophilia centre.
- Record the bleed and treatment if taken on Haemtrack if a self-treater and/or call the haemophilia centre!

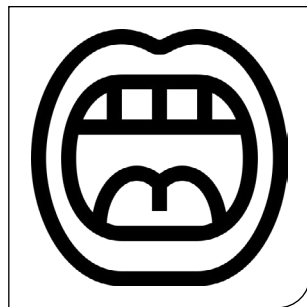
Seek medical attention immediately if the nosebleed happened because of trauma (physical injury), if it doesn't stop within 20 minutes of treatment, or if more nosebleeds occur within a few hours and don't stop within a few minutes.

Occasionally, patients need ENT (Ear, Nose and Throat) doctors to pack the nose or perform cautery on the bleeding blood vessels in the nose.

Mucous membrane/Mouth bleeds

What to look for:

- Obvious bleeding from the gums or tongue.
- Bruising on the gums.
- Continual or very frequent swallowing.
- A salty or metallic taste in the mouth.



What to do:

- Keep calm – if the person is a child, try to distract him or her.
- Have the person eat cold foods, like ice lollies or ice chips.
- Take tranexamic acid: tablets may be crushed and dispersed in water, gargled as a mouthwash and then swallowed.
- Treat with treatment dose factor concentrate according to instructions from haemophilia centre.
- Record the bleed and treatment if taken on Haemtrack if a self-treater and/or call the haemophilia centre!
- Avoid eating spicy foods, as they can irritate gums, especially gums that have already been bleeding.
- Avoid eating foods with sharp edges and using drinking straws, as they can both cause gum bleeds or re-injure gums that have already been bleeding.
- Watch for pale skin, trouble breathing with exercise, dizziness, and black or dark bowel movements.

Seek medical attention immediately if the mouth bleed happened because of significant trauma, if it doesn't stop within 20 minutes of treatment, or if bleeding episodes continue.

Limb threatening bleeds

Compartment syndrome

Muscles contain vast numbers of blood vessels. A tear in muscle tissue results in bleeding from these vessels. Because muscles stretch easily, a lot of blood can leak from injured vessels into surrounding tissues before any signs or symptoms of bleeding are noticed.



Given the amount of bleeding that can happen in some cases, and the location of the bleeding, severe damage can result. A muscle bleed becomes “limb-threatening” when swelling in the injured area causes pressure on blood vessels or nerves supplying the limb.

Pressure on blood vessels prevents normal blood circulation and can lead to tissue death in the affected limb, while pressure on nerves interferes with movement and feeling (sensation). This is known as “compartment syndrome.” If severe, this can lead to needing surgery to release vessel and nerve compression to prevent permanent damage to the limb.

Limb-threatening bleeds are most likely to occur in the forearm muscles, the calf muscles, and the psoas muscle.

What to look for:

- A “tight feeling” in the injured muscle or limping.
- A feeling of numbness, pins, and needles, or tingling at or near the affected area.
- Swelling, shiny, or firm skin.
- Pain.
- Area below bleed pale compared to other side.
- Unusual warmth in the affected area or unusual cold compared to other side.

What to do:

- **Stop** your activities.
- **Call the haemophilia centre!** You will need to come into hospital for urgent assessment. Your haemophilia team will tell you where to go. Otherwise, please dial 999 or go to your nearest Accident and Emergency department if you can safely do so.
- Treat with **P.O.L.I.C.E.**, tranexamic acid, and factor concentrate (if a self-treater with a treatment dose).
- Take pain killers.

Psoas muscle bleeds

The psoas muscles are found deep inside the right and left sides of the lower abdomen at the pelvis.

These muscles are attached to the lower spine at the back of the body, and to the femurs (thighbones) at the front and are very large.



They support your hips when you are standing straight and are also the main muscles you use when you raise your thigh or bend forward at the hip.

Psoas bleeds can occur due to injury, including sexual intercourse in certain positions; or can occur spontaneously.

Some major nerves and blood vessels that supply the legs are located beside the psoas muscles.

As the muscles are large, a lot of blood can be lost into them, which can obviously be serious, but this also means initially it may not appear serious because the pain from bleeding may not be as intense as a joint bleed feels.

Bleeds into psoas muscles can cause swelling, which in turn puts pressure on major nerves and blood vessels. The femoral nerve near the psoas muscles. If this nerve is compressed, it causes loss of sensation and muscle function of the thigh and may take months to resolve, with long-term or even permanent disability if the bleed is not treated in time or adequately.

This type of bleed can quickly become limb-threatening and often needs hospitalization for strict bed rest and intensive physiotherapy involvement.

What to look for:

You may experience some or all of these symptoms:

- Walking or standing in an unusual way, such as up on the toes of one foot, with the body twisted to one side, or with the body bent forward and buttocks raised (i.e. you cannot stand up straight).
- Inability to lay flat on the back with the leg straight out (i.e. the hip remains flexed).
- Pain in the back, hip, groin, or front of the thigh on the person's affected side.
- A sensation of numbness or tingling in the person's outer thigh.
- You will not see swelling, discolouration, or bruising, nor will you feel increased warmth with this type of bleed, because the psoas muscles are located so deep inside the body.

What to do:

Stop your activities and rest in bed whilst you call the haemophilia centre.

- You will need to come into hospital for urgent assessment. Your haemophilia team will tell you where to go. Otherwise **dial 999** or go to A&E.
- Use crutches or a walking aid if you have to mobilise to get to hospital otherwise do not hesitate to call an ambulance.
- Treat with tranexamic acid, and factor concentrate (if a self-treater with a treatment dose).

What treatment will I need and what physiotherapy will I need?

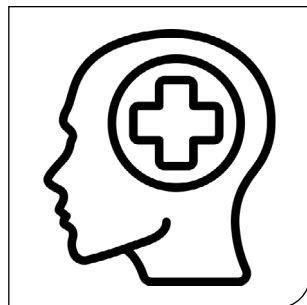
- Treatment of a psoas muscle bleed will be prolonged.
- Factor levels will need to remain raised to a high level for an extended number of days, along with strict bed rest.
- Blood tests for monitoring levels may be needed. For these reasons often a hospital admission is required, so that progress can be monitored closely. A physiotherapist should be involved with your care to provide advice during the acute stage of the bleed, and then to provide ongoing instruction and an exercise regime as improvement is made. Expect progress to a full recovery to be slow.
- It is important to avoid re-bleeding into the muscle – if it occurs it will be more severe and will delay your return to full capacity for everyday activities.

Life threatening Bleeds

Head injury/Head bleeds

The brain controls all the major body functions, so a bleed into the head is very serious.

These bleeds can cause brain damage or even death.



If you experience any of the following symptoms contact the Haemophilia SpR on call or haemophilia centre immediately. They may ask you to go straight to your nearest accident and emergency department.

What to look for:

- Headache.
- Abnormal vision, hearing, or speech.
- Nausea or vomiting.
- Mood or personality changes.
- Drowsiness.
- Loss of balance, problems walking.
- Weakness in one or both arms or legs.
- Weakness of part of the face.
- Loss of fine-motor coordination, clumsiness.
- Loss of consciousness.
- Seizures.
- Specific to infants: increased head circumference in a short period of time (within days), along with increased irritability and bulging fontanelles (the soft spots on the top of an infant's skull).

What to do:

- **Stop** your activities.
- If you are a self-treater: take tranexamic acid and your head injury dose of medication if you can and urgently call the Haemophilia Centre.
- If you are being taken to hospital by ambulance, ask the crew to give you the dose.
- If the ambulance crew are unable to give you the factor, please take it to the hospital and the medical team will give you this on arrival.
- You will need to come into hospital for urgent assessment. Your haemophilia team will tell you where to go. Otherwise, please dial 999 or go to your nearest Accident and Emergency department if you can safely do so.

What will my management plan be?

- Treatment of a head injury will depend on the severity of the injury.
- You may get a CT scan/MRI scan of your brain but factor treatment or treatment to help you clot should be given first.
- If you have a bleed around or in the brain tissue, you will require several days of high doses of factor replacement/medication.
- Occasionally if there is increased pressure around the brain as a result of a bleed, patients need surgery to relieve the pressure.
- If you have not had a bleed, but have had a significant head injury, we ask that if you go home that someone is with you for the first 24 hours and that they also read this advice.

Patients can have delayed bleeds, so it is important to look out for the following:

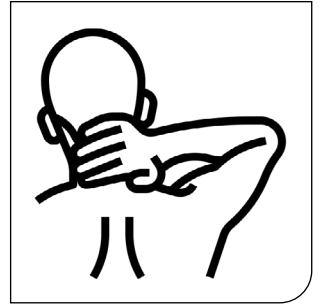
- Headache.
- Abnormal vision, hearing, or speech.
- Nausea or vomiting.
- Mood or personality changes.
- Drowsiness.
- Loss of balance, problems walking.
- Weakness in one or both arms or legs.
- Weakness of part of the face.
- Loss of fine-motor coordination, clumsiness.
- Loss of consciousness.
- Seizures.

Call the Haemophilia Centre urgently if you experience any of the symptoms listed above, and take a head injury dose of factor.

Neck bleeds/injury

Because there are so many blood vessels in the nose, mouth, and throat, bleeds into these areas can easily result in tissue injury or infection.

Also, as tissues in these areas swell with blood, they can press on the airway leading to the lungs. The airway may become narrower, making breathing difficult, or it may be closed completely, making breathing impossible.



What to look for:

- Pain in the neck or throat.
- Swelling.
- Swallowing difficulties.
- Breathing difficulties.

What to do:

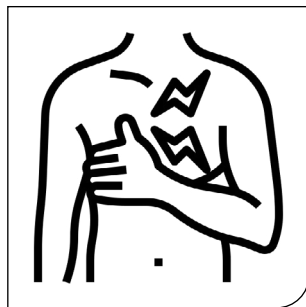
- If any of the above symptoms appear, take tranexamic acid and if you are a self-treater, give a head injury dose of factor and call the **Haemophilia Centre or Haematology SpR out of hours immediately** and they will direct you where to go.

Otherwise, **please dial 999** or go to your nearest Accident and Emergency department if you can safely do so.

Chest

This body cavity contains the lungs, heart, and major blood vessels.

A chest injury may cause bleeding in the lung tissue, forcing blood into spaces that normally contain air. This can result in serious breathing difficulty.



What to look for:

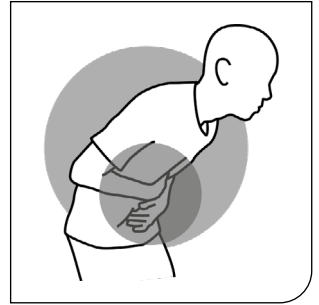
- Pain in the chest.
- Breathing difficulties.
- Coughing up blood.
- Pale skin colour.
- Lack of energy.

What to do:

- If any of the above symptoms appear, especially after trauma, take tranexamic acid and if you are a self-treater, give a 'head injury dose' of factor and call the Haemophilia Centre or Haematology SpR out of hours immediately and they will direct you where to go. Otherwise, please dial 999 or go to your nearest Accident and Emergency department if you can safely do so.

Abdomen

Abdomen organs found in this cavity include the stomach, spleen, liver, kidney, and intestines. Injury to this area can result in massive bleeding from an organ or major blood vessel. Such bleeding can be fatal without treatment and medical care.



What to look for:

- Pain in the abdomen or lower back.
- Nausea or vomiting.
- Blood in urine.
- Black or bloody stool.

What to do:

- If any of the above symptoms appear, especially after trauma, take tranexamic acid if you do not have blood in your urine and if you are a self-treater, give a 'head injury dose' of factor and call the Haemophilia Centre or Haematology SpR out of hours immediately and they will direct you where to go. Otherwise, please dial 999 or go to your nearest Accident and Emergency department if you can safely do so.

Further information

Canadian Hemophilia Organization

hemophilia.ca/files/Home%20Treatment%20Guide.pdf

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Haemophilia and Thrombosis Team
August 2025
Review: August 2028
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

