

How to recognise a bleed

Information for parents and carers from the Haemophilia Centre

Having your child diagnosed with haemophilia A or B means having to learn how to live with haemophilia. Part of doing this includes taking the time to adjust and to learn how to recognise when there is a bleed. It is very hard for parents when your child is small and cannot talk and tell you where the pain is. This information sheet has been developed to help you recognise the signs of bleeding.

If you are in doubt about whether your child has a bleed, please call the Haemophilia Centre on the emergency line 01227 78 31 66, between 8:30am and 5pm Monday to Friday (excluding Bank Holidays). Outside these times call the hospital switchboard on 01227 78 31 90 and ask for the on-call haematologist for haemophilia.

The sooner we treat a bleed, the more likely it is to improve quickly, and the less likely it is to need more treatment over the following days.

What are the signs of a bleed?

Bleeding in haemophilia most commonly involves joints and muscles. This causes pain and sometimes swelling at the site of the bleed.

Your child may be miserable or crying for no apparent reason and not because they are hungry, thirsty, need their nappy changing, or just want a cuddle.

Signs of bleeding in to either a joint or a muscle

Early signs of a bleed (babies and toddlers)

- Walking with a limp, not wanting to stand or walk on their painful leg, going back to crawling.
- Not wanting to reach for things with their painful arm or use it to play.
- Generally upset and irritable.



Early signs of a bleed (older children)

- Some children may tell you they have a tingling, fizzing, or bubbling feeling in their affected joint or muscle.
- Pain in the affected joint or muscle, which is usually described as constant (even at rest) but can increase when the limb is moved or they are weight-bearing.
- Limping.

Later signs of a bleed (older children)

- The area may feel tight, warm, or swollen.
- There may be increasing stiffness in their limb (arm or leg). Usually there is difficulty with straightening their limb and it tends to be held in a bent position.
- The limb may look different when compared to their other one.

Bruising does not normally happen with joint or muscle bleeds because bleeding is inside the joint or the muscle and not underneath the skin. There may be bruising as well as a muscle bleed, particularly if there has been an injury with a blow to the arm or leg.

It is important to note that your child may not have all of 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.

Bumps to the head

- There may be obvious swelling, lumps, or bruising.
- There may be no marks at all.

Always call the Haemophilia Centre for advice as soon as possible.

Signs of bleeding in the mouth, gastrointestinal (GI), or urinary tract

- You may see bleeding from their mouth or tongue.
- You may notice bloody or black tar like stools (poo) (not in newborn babies).
- Red or brown urine.

Always call the Haemophilia Centre for advice as soon as possible

Is there anything I should look out for?

At changing or bath time

- Look closely at their skin. Are there any new bruises?
- Are their legs and arms equal in size?
- Are all their limbs moving normally?
- Are there any bruises or swelling in their nappy area?

After a fall or bump

- Are there any signs of a bleed?
- Have they bumped their head?

General

- Do they avoid reaching for things with their nearest hand?
- Do they avoid particular actions?
- Do they favour one leg or do they limp?

What should I do if I notice any of these things?

Call the Haemophilia Centre for advice. There is always a doctor, a nurse, or a physiotherapist available to advise you on what to do. The Haemophilia Centre is open Monday to Friday from 8:30am until 5pm (excluding Bank Holidays).

We have an emergency number you can ring if you think your child is having a bleed. This should be answered quickly by a member of the reception team. They will contact a member of the team. If they are not available to talk to you straightaway they will call you back as soon as possible.

**Monday to Friday 8:30am to 5pm (excluding Bank Holidays)
please call 01227 78 31 66**

If something happens outside of these times, there will still be someone you can speak to. One of the haemophilia consultants will be on call and available when the Haemophilia Centre is closed. We have a designated telephone number that a member of switchboard will answer. This is not an automated response.

**It is important that you ask for the doctor looking after haemophilia.
Please call 01227 78 31 90 out of hours**

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. If your child has only recently been diagnosed with a bleeding disorder, it can take some time to recognise a bleed.

**Even if you are not sure, please ring one of the above phone numbers.
We are here to support you and your child.**

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation