

First signs of haemophilia

The main initial signs of haemophilia are:

- Persistent bleeding after circumcision, other surgery or blood tests
- Unexplainable recurrent bruises and unusual looking lumps
- Hesitation to use a limb
- Bleeding from cuts and scratches taking a long time to stop
- Frequent crying when a limb is touched or moved
- Swelling of a joint
- A lot of bruising after injections (e.g. immunisations). The bruise will feel quite lumpy.

Bruises

When will my child get bruises?

Bruising usually occurs when the child starts to crawl and becomes more active and mobile.

“Xavier had the biggest, ugliest bruise that made me want to cry every time I looked at it. Our Haematologist said ‘It’s just a bruise.’ And he’s right. They look ugly but my son keeps telling me they don’t hurt, so I got over it.”

There are basically two types of bruises – those close to the surface which don’t need any medical treatment and deeper bruises that can form lumps but only occasionally need to be treated.

If you have any questions about your child’s treatment or any bruising or bleeds experienced, contact your Haemophilia Centre for advice.

People’s attitudes

Some parents worry about what others will think of their son’s bruises, particularly if he has a lot of visible bruising. You may like to think about how to deal with the attitudes of other people, particularly those who are not aware that your child has haemophilia. Whatever you choose, ensure that you and your son are comfortable with the decision.

Bleeds

What causes a bleed?

Bleeds can be caused by an accident. Your child might have a bleed after a tumble while learning to walk, falling from a swing, or be involved in an accident. Your child could also have a bleed after an operation or a tooth extraction.

“In the first year we as parents were very over-protective of our child with haemophilia.”

Sometimes bleeds just happen for no obvious reason. These are called ‘spontaneous bleeds’ and are more common in people with severe haemophilia and less frequent in people with moderate haemophilia. Spontaneous bleeds are uncommon in mild haemophilia.

Will my child know when he has a bleed?

Yes. With time, your child will come to know the sensations associated with bleeds and will be able to tell when they are having a bleed. Often, a person with haemophilia can detect a bleed before any outward signs become obvious. If your child says he has a bleed, then he probably does.

Symptoms to ask about

Until your child is old enough to recognise what a bleed feels like, you may need to ask about his symptoms.

A child experiencing a bleed may report a warm, tingling or prickly sensation in the affected area. The child may also report a feeling of pressure.

What if I'm not sure?

It is better to have a suspected bleed checked. If it is a bleed, it can be treated promptly, avoiding problems associated with untreated bleeds. It will also give you peace of mind – even if you just find out it was a false alarm.

Don't worry that the Haemophilia Centre staff might think you are worrying for nothing, or overreacting. They are caring people who want what's best for you and your child and are happy to investigate a suspected bleed.

*If in doubt,
contact your
Haemophilia
Centre or
treating
hospital.*

Where is my child likely to get a bleed?

A bleed may occur at an injury or surgery site if treatment is not given. Spontaneous bleeds (bleeds with no apparent cause) occur in the joints and the muscles. These are discussed in detail on the next few pages.

Joint bleeds

What is a joint bleed?

A joint bleed occurs when your child's blood seeps into the space where bones meet (in his joints). For example, a joint bleed might occur in the ankle or elbow.

Joint bleeds are painful because the space is already filled with lubrication (synovial fluid) and is surrounded by muscles, cartilage, tendons and ligaments. There is not enough space for blood too. As the synovial capsule swells, it presses against muscles, cartilage and so on, making it harder to move.

Repeated bleeding into joints can lead to a deterioration of the joint and may result in arthritis. Fortunately, current treatments and prompt action can minimise the risk of arthritis. Chapter 4 discusses treatment in more detail.

Early symptoms include¹:

- Pain in the joint
- A bubbling or tingling in the joint
- Reluctance to use a joint
- The affected area becoming warm
- In a baby, crying that cannot be explained by other reasons such as thirst, hunger, a need to be held, stomachache, wetness or coldness².

NB: there is no visible bruising or skin discolouration with a joint bleed.

If not detected or treated early, other signs may develop¹:

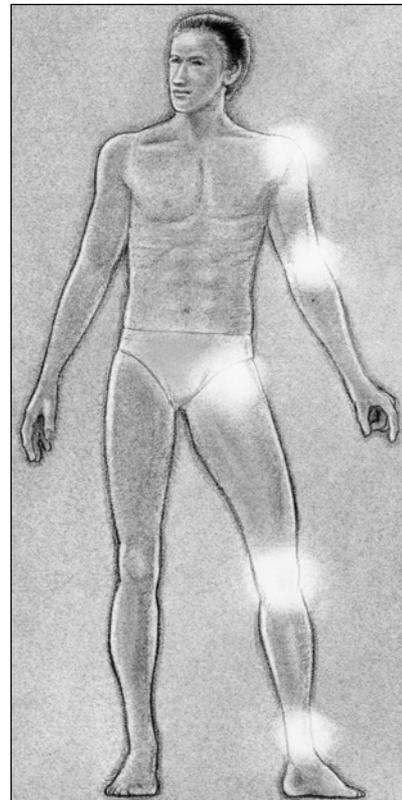
- The joint is warm to the touch
- The joint becomes stiff and/or swollen
- Limited movement (mobility) of the joint
- In a young child, refusal to straighten, weight-bear or use the limb

Target joints

People with haemophilia find they tend to bleed frequently in the same place, such as one knee or elbow. The joints where bleeds seem to occur most often are called 'target joints'. The most common joints for bleeding are the²:

- Ankle
- Knee
- Elbow
- Hip
- Shoulder

The latter two are much less common.



(Image Source: Haemophilia in Pictures, WFH 1998)

What should I do?

The earlier a bleed is detected the less pain your child will endure and the easier it is to treat.

The main aim for you as a parent is to notice the bleeds as quickly as possible, so that treatment can be given to eliminate any pain and the possibility of arthritis. If a joint bleed does occur, take your child to the nearest Haemophilia Centre as quickly as possible.

If you aren't sure whether there is a bleed, phone your Haemophilia Centre for advice.

Do NOT give your child aspirin as this encourages bleeding.

Can joint bleeds be prevented?

There are a number of things you and your child can do to prevent joint bleeds, including¹:

- Exercise to strengthen the muscles that protect the joints.
- Maintain healthy weight levels to minimise the stress on joints. If your child is overweight, your child's doctor may recommend that you consult with a dietician.
- Avoid activities which increase the risk of causing bleeding, such as playing contact sports.

Muscle bleeds

Deep muscle bleeding is very similar to joint bleeds in terms of symptoms.

When bleeding spreads into a muscle it can cause swelling, pain and sometimes numbness of the affected area, which can result in the child being unable to move the limb.

Symptoms

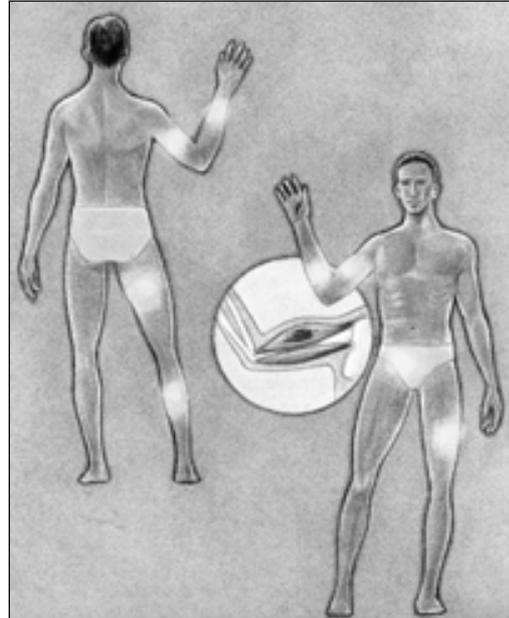
Symptoms of a muscle bleed include¹:

- Difficulty moving an arm or leg
- Pain
- Avoiding use of an arm or leg, perhaps crawling instead of walking
- Warmth in the muscle
- When touched, the muscle feels tense or tight even though it is at rest
- Numbness or tingling (*seek assessment if numbness is significant*)
- Veins appear larger than normal
- In severe cases, skin may change colour or go blue

Where do muscle bleeds occur?

Most muscle bleeds occur into one of the following parts of the body²:

- Upper arm
- Forearm
- Upper leg, back and front
- Calf
- Iliopsoas muscle (groin area)



Because the iliopsoas is a large muscle, bleeds into it can be serious and may require hospital admission. The usual signs are lower abdominal pain and restricted movement at the hip.

(Image Source: Haemophilia in Pictures, WFH 1998)

What should I do about a muscle bleed?

Contact your Haemophilia Centre or treating health professional for advice. Your child may need to be given treatment.

Initially treatment is given at the hospital. However, you may wish to treat your child at home. See the section on treatment for more details or speak with your treating health care provider.

Can I prevent muscle bleeds?

There are a few things you and your child can do to prevent muscle bleeds, including encouraging your child to be physically fit.

If there are any signs of numbness, tingling, coldness in the limb, swelling or discomfort after treatment, contact your hospital or health care professional again.

Emergency situations

Some bleeds should be regarded as emergencies.

If there has been, or even if you only suspect that any of the following have occurred, take your son to the Haemophilia Centre immediately:

Head Injury/Bleeding

- HEAD INJURY BLEEDS
- THROAT/NECK BLEEDS
- ABDOMEN & CHEST BLEEDS
- INTERNAL BLEEDING

It is a good idea to phone ahead and let the Haemophilia Centre know you are coming in and the reason so they can be ready for your arrival.

Make sure you are familiar with the arrangements at your local hospital or Haemophilia Centre for assessment, treatment and management of bleeds after hours as well as during working hours.

All head injuries must be assessed in hospital as soon as possible.

For your child's sake...

No matter what bleed your child has, or what concerns or questions you have, there are a few things to always remember.

- If you are unsure about an injury or a bleed, don't hesitate to ring or go to the hospital. It's always better to be on the safe side.
- Don't ever feel as though you are wasting the Haemophilia Centre staff's time. They are there to help you.
- Never feel that anything you ask or suspect is irrelevant or stupid. Haemophilia is very unpredictable and what your instincts tell you are often right.
- If you do not live near a Haemophilia Centre, phone or email Centre staff after your child has been treated locally so you can get the best support from your Centre team.
- As time goes on, you'll be able to judge for yourself what needs treatment.
- Always remember you are not alone. There are many parents going through or have gone through exactly the same feelings and uncertainty as you may be experiencing.

Things you can do to prevent complications

- Treat bleeds promptly.
- Make sure your local doctor, GP and/or hospital staff is up to date on haemophilia care. You can ask your haemophilia specialist to keep in touch with your GP. Your treating health professionals may also like to become a member of the Haemophilia Foundation, if they have not already done so.
- Keep emergency numbers by the phone 'just in case'.
- Make sure your child's school or day care centre knows how to deal with bleeds and so on. Your local Haemophilia Centre or Haemophilia Foundation can assist by providing information.
- Attend all outpatient appointments with the hospital and your Haemophilia Centre as booked. These usually occur every four to six months, depending on your Centre's policy and your child's needs.
- Dental checkup every six months.
- Brush his teeth twice a day and follow your dentist's advice.
- Eat a balanced, nutritious diet and maintain a healthy weight.
- Keep your child's immunisations up to date.
- Wear seat belts, helmets when riding bikes, and standard safety gear where recommended for all children such as when on roller blades and skateboards etc.
- Encourage your child to wear a medical alert bracelet or necklace.
- Contact your Haemophilia Centre before you go on holidays to arrange treatment for while you're away.
- Ensure your child wears appropriate footwear.

Holidays and school camps

Children with haemophilia can go on holidays and school camps. To minimise complications and get the most out of the trip:

- Contact your Haemophilia Centre or treating health professional before you leave and request a letter to take on the trip that explains your child's condition and treatment needs should your child require medical attention while you are away.
- If your child hasn't had a checkup in a while, do so before the trip.
- Discuss holiday treatment with your treating health professional. Who will administer it?
- You may need to arrange to have additional supplies of treatment product for your child to take away.
- You or your Centre may wish to make contact with the local hospital before the trip.
- If travelling interstate or overseas, find out where the nearest Haemophilia Centre is located. Haemophilia Centres are listed at the back of this guide. Confirm that the contact details have not changed; they do vary from time to time. For international Haemophilia Centre details, contact Haemophilia Foundation Australia.
- Contact your Haemophilia Centre while away if there are any issues.