



## KEY POINTS

- Bruises are common when children start to crawl and walk.
- Bleeds are usually caused by an injury, but sometimes they appear to happen for no obvious reason.
- Some bleeds, including head and throat bleeds, should be treated as emergencies.
- Promptly identifying and treating a bleed helps to minimise pain and reduces complications.
- Do NOT give your child aspirin or ibuprofen as this may worsen their bleeding tendency.

## First signs of haemophilia

Children with haemophilia are usually diagnosed as babies or toddlers. Sometimes this is because there is a family history of haemophilia or a parent or health professional notices unusual bruising or bleeding.

Haemophilia may be suspected if babies have internal bleeding or unusual swelling or bruising after delivery, continue to bleed after a heel prick test, or have excessive bruising or swelling after immunisation.

The most common first signs suggesting haemophilia are:

- unexplainable recurrent bruises and unusual looking lumps
- significant bruising or swelling after injections (e.g. immunisations).  
The bruise may feel quite lumpy and there may be hesitation in using an arm or leg (e.g. limping)
- frequent crying when an arm or leg is touched or moved
- warmth and swelling of a joint
- persistent bleeding after surgery or blood tests.

*Most children with haemophilia do not have bleeding problems at birth. However, some bleeding problems may appear at birth or soon after. If doctors are aware that a child is at risk of haemophilia, a birth plan should be put in place to minimise bleeding problems.*

### Bruises

There are two types of bruises - those close to the surface, which don't need any medical treatment - often called 'superficial bruises' - and deeper bruises that can form lumps - often called 'haematomas'. Deeper bruises may occasionally need to be treated, particularly if they cause tight swelling or discomfort to your child.



*Superficial bruising*



*Bruise with lump/haematoma*

### Will my child get bruises?

Bruising often occurs as your child becomes more active and mobile. They may get bruising on their knees and elbows as they progress to crawling and standing, or if they fall or roll onto a hard toy or surface. Once they begin to stand and walk they may get bruising on their buttocks if they fall or sit down suddenly.

"Our son 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."



**If you have any questions about your child's bruises or bleeds, contact your Haemophilia Treatment Centre (HTC) for advice.**

*People's attitudes*

*Some parents worry about what others will think of their child's bruises, particularly if there is a lot of visible bruising. You may like to consider how to deal with other people's attitudes, particularly those who are not aware that your child has haemophilia.*

## Bleeds

### What causes a bleed?

Bleeds can be caused by an accident such as after a tumble while learning to walk, or a bump while playing. Your child could also have a bleed after a medical procedure, such as an operation, tooth extraction or medical procedure. If your child has severe or moderate haemophilia, they may also have bleeds from no obvious cause.

### Where is my child likely to get a bleed?

Bleeds can occur at a surgery site or at the site of an injury.

However bleeds are also commonly experienced internally, into the joints or muscles.

This can happen as a result of injury or without an obvious cause.

*Bleeds that appear to happen for no obvious reason are sometimes called '**spontaneous bleeds**'. This means that there is no specific identified injury that caused this bleed to occur.*

*Sometimes, on reflection, parents or children can identify an activity that may have contributed to the bleed. When a joint has been damaged in the past, there may be more bleeds into the same joint that cannot be linked to any activity or event beforehand.*

*Spontaneous bleeds are more common in people with severe haemophilia and occur less often in people with moderate haemophilia. They are uncommon in mild haemophilia.*

### Will my child know when they have a bleed?

As your child grows older, they will come to know the sensations associated with bleeds and will usually be able to tell when they are having a bleed. Often, a person with haemophilia can detect a bleed before the more obvious signs appear, for example, swelling, pain, warmth and a reduced range of movement. If your child says they have a bleed, then they probably do.

### Signs of a bleed

Until your child is old enough to recognise what a bleed feels like (or can tell you they are having a bleed), you will need to ask them about their symptoms or look for signs such as your child protecting or not using one arm, suddenly not wanting to take weight on one leg or unexplained crying/irritability.



#### PARENT TIP

***If you're unsure if your child has had a bleed, always check with your HTC. The staff are always happy to investigate suspected bleeds at any time. It will also give you peace of mind even if you just find out it was a false alarm.***

A child experiencing a bleed may describe a warm, tingling or prickly sensation in the affected area. They may also report a feeling of pressure, soreness or pain. These are the very early signs of a bleed.

#### ***Signs of a bleed:***

- *Warm, tingling or prickly sensation in the affected area*
- *Feeling of pressure, soreness or pain (very early signs of a bleed)*
- *Swelling*
- *Reduced range of movement*
- *Not wanting to take weight on one leg*
- *Avoiding using one arm*
- *Unexplained crying or irritability.*

## What if I'm not sure if it's a bleed?



***Always check with your HTC if you suspect a bleed. If it is a bleed - especially an internal bleed - it should be treated promptly with factor replacement therapy. Untreated bleeds can cause long-term problems.***

If possible, bleeds should also be treated with Protection, Rest, Ice, Compression, Elevation (PRICE). This can help to prevent further bleeding and reduce swelling. Although PRICE is valuable to treat your child's bleeds as they grow older, it may be difficult to treat a baby or toddler with PRICE at home: they might resist your efforts to protect the area where the bleed has occurred or not like the ice. Speak to your HTC about what to try at home as part of your emergency treatment plan.

If they have a cut or scratch that is oozing, this can often be managed with normal first aid - a Band-Aid® and some pressure at the site of the bleeding.

Deeper wounds needing stitches will require factor replacement therapy.

You can also administer pain relief medication such as paracetamol.



***See Chapter 4 for more information on factor replacement therapy, PRICE and other treatment options.***



***Doctors usually recommend paracetamol (e.g. Panadol) for managing pain in children with haemophilia. Do NOT give your child aspirin or ibuprofen (e.g. Nurofen) as this may worsen your child's bleeding tendency.***

# Types of internal bleeds

## Joint bleeds

### What is a joint bleed?

A joint bleed occurs when blood seeps into the space in the joints where bones meet. There is no visible bruising or skin discolouration with a joint bleed. The most common joints where bleeds occur are the knees, ankles and elbows, but bleeds can occur in any joint.

Joint bleeds are painful because joints are already filled with fluid, called 'synovial fluid'. When blood enters this space, the pressure increases, making movement difficult and painful.

Repeated bleeding into joints can lead to a deterioration of the joint and can result in arthritis and loss of movement in the long-term. Fortunately, current treatments and prompt action can minimise the risk of damage.



**See Chapter 4 for more information on treatment.**

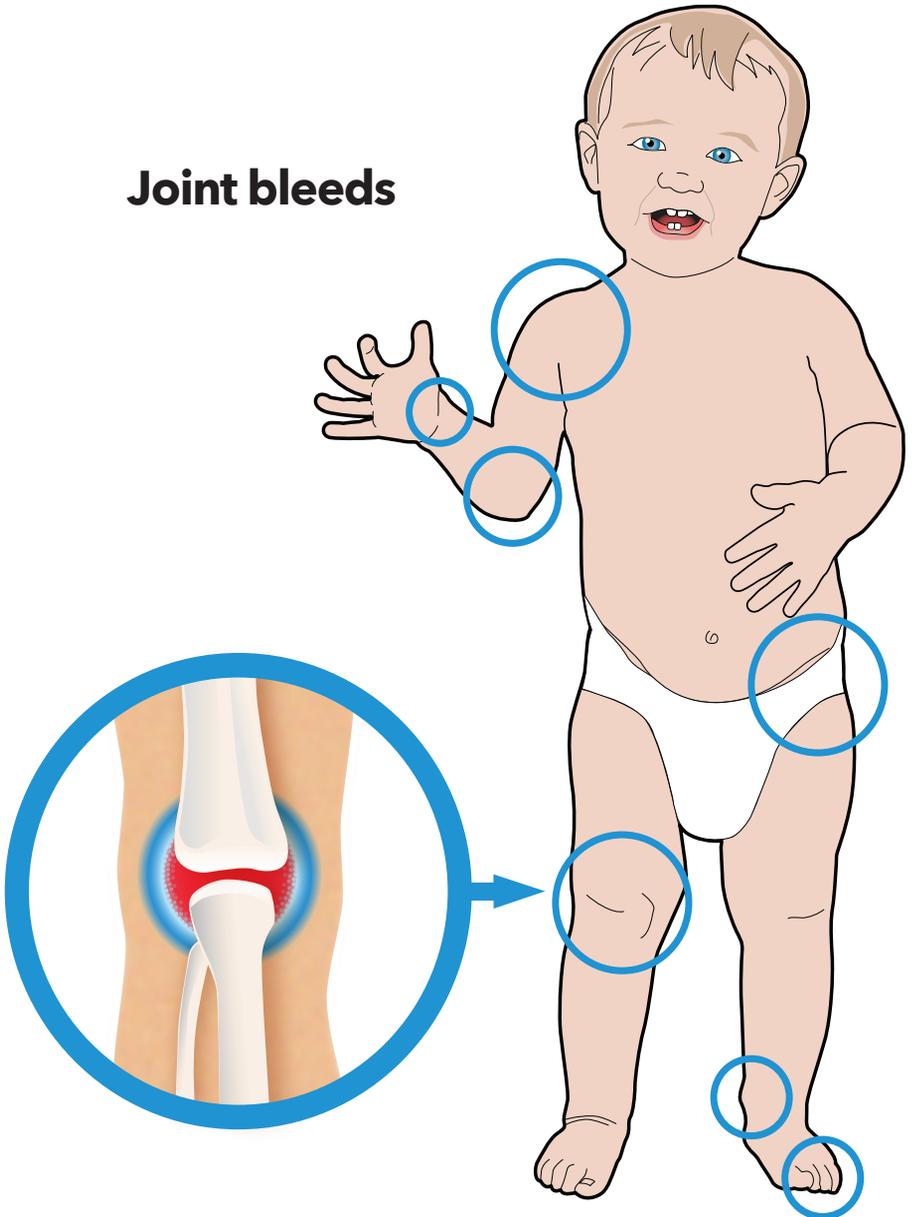
### **Early signs of a joint bleed may include:**

- *pain in the leg or arm*
- *a bubbling or tingling sensation in the joint*
- *reluctance to use a joint fully, holding it in an unusual position or partially using it (e.g. limping)*
- *the affected area becoming warm*
- *pain or unexplained crying or irritability.*

### **Later signs of a joint bleed may include:**

- *the joint is warm to the touch*
- *the joint becomes stiff and/or swollen*
- *reduced movement (mobility) of the joint*
- *reluctance to straighten, weight-bear or use the joint.*

## Joint bleeds



### Target joints

People with haemophilia may find they bleed frequently in the same place in their body, such as one knee or elbow.

The joints where bleeds occur most often are called 'target joints'.

A target joint is a joint that has had three or more bleeds without an apparent cause within a consecutive six-month period.

The most common joints for bleeding are the ankle, knee and elbow. To a lesser extent, the hip, shoulder and joints of the fingers and toes can also have bleeds.

### What should I do about a joint bleed?

Promptly identifying and treating a joint bleed helps to minimise swelling, pain and damage to the joint.



#### PARENT TIP

***Aim to notice the bleeds as quickly as possible so that they can be treated promptly.***

As your child gets older, usually around three to five years of age, they will be able to identify a bleed and let you know.



***If you are unsure about whether there is a bleed or what to do, contact your HTC for advice.***

***If a joint bleed does occur, treatment should be given as quickly as possible. Follow your treatment plan from your HTC. If you live in a metropolitan area the treatment plan will most likely advise you to take your child to the nearest HTC. If you live a long way from your HTC there may be an arrangement to take your child to your local hospital. It is a good idea to phone your HTC and let them know you are coming so they will be ready for your arrival or so they can liaise with your local hospital.***

While this is occurring, you may be able to start Protection, Rest, Ice, Compression, Elevation (PRICE). This can help to stop further bleeding or reduce swelling.

## Complications from joint bleeds

Repeated joint bleeds can lead to arthritis, even in childhood. This occurs when, over time, there is damage to the lining and cartilage that protects the joint. Once this damage occurs, it cannot be repaired.

Symptoms of arthritis include morning stiffness, pain during movement or when still, inflammation and the progressive loss of movement. It can be very difficult for the individual to know the difference between a bleed and what could be 'arthritic' pain. One key difference is that arthritic pain does not respond to factor replacement therapy. A physiotherapist can help with determining if the pain is arthritic or not.

## Can joint bleeds be prevented?

Not all joint bleeds can be prevented, however there are some strategies you can use with your child to reduce the chance of joint bleeds:

- **Follow recommended treatment.** If your child has severe haemophilia and is on prophylaxis treatment, ensure that you follow the treatment as prescribed. It is recommended that factor be given in the morning, especially before your child plays sport. This ensures that the factor level is highest during the day when your child is most active and provides the amount of protection needed.
- **Rehabilitation.** Working with a health professional such as a physiotherapist to fully rehabilitate a joint after a bleed helps to reduce the risk of a rebleed. When done correctly, rehabilitation strengthens muscles and restores movement, allowing your child to get back to their usual activities.
- **Exercise.** Exercise helps to strengthen the muscles that protect the joints. Exercise also helps with general fitness and balance.
- **Safe participation:** Ensure your child is participating in age-appropriate activities and using recommended safety equipment e.g. bike helmets when cycling.
- **Avoid high-contact sports or high-risk activities.** These can increase the risk of bleeding. Ask your HTC for advice about appropriate sports for your child.
- **Maintain a healthy weight.** A healthy weight helps to minimise the stress on joints. (If your child is overweight, your child's doctor may recommend that you consult with a dietician.)

### Muscle bleeds

Deep muscle bleeding has very similar symptoms to joint bleeds.

When bleeding spreads into a muscle it can cause swelling, pain, loss of joint movement and sometimes numbness of the affected area, which can result in the child being unable to move their arm or leg.

#### ***Signs of a muscle bleed may include:***

- *difficulty moving or reluctance to use an arm or leg, e.g. perhaps crawling instead of walking*
- *pain or unexplained crying or irritability*
- *warmth in the muscle*
- *the muscle feeling tense and swollen or tight when touched, even though it is at rest*
- *numbness or tingling*
- *veins appearing larger than normal*
- *in severe cases, the skin may change colour (e.g. be pale or blue) or feel cool.*



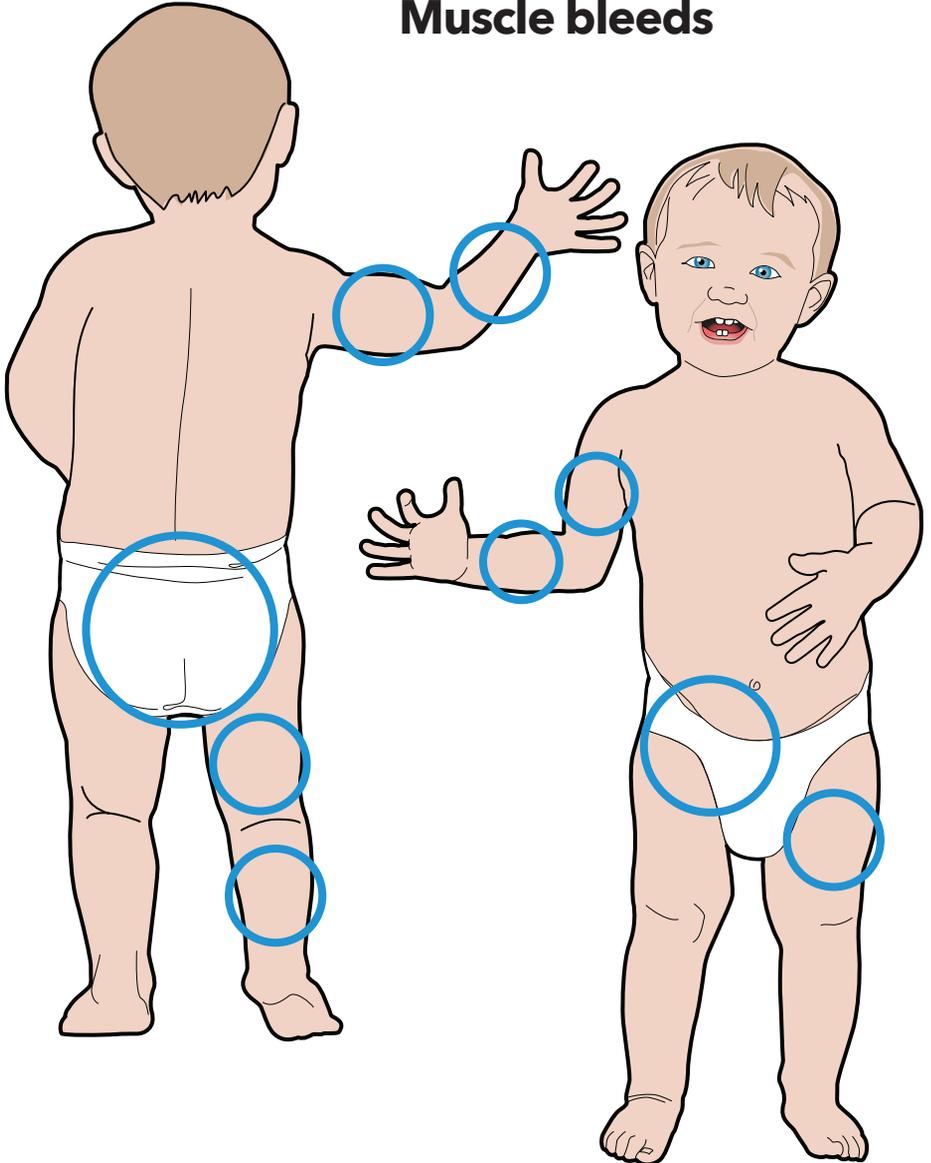
***If you suspect your child is experiencing a muscle bleed, you should contact your HTC or health professional for advice.***

### Where do muscle bleeds occur?

Most muscle bleeds occur in one of the following parts of the body:

- Upper arm
- Forearm
- Upper leg (thigh), front and back
- Large back muscles
- Buttock muscles
- Calf
- Iliopsoas muscle (groin area).

## Muscle bleeds



### ***Groin muscle bleeds***

*Because the iliopsoas is a large muscle, bleeds into the groin area can be serious. There are main blood vessels and nerves near this muscle. Hospital admission may be required. Depending on how severe the bleed is, symptoms can include lower abdominal pain, lower back pain and restricted movement at the hip and often the child will lean forward.*



***A groin muscle bleed is one of the most serious muscle bleeds, takes the longest to rehabilitate and may often rebleed.***

## What should I do about a muscle bleed?



***If you suspect your child is experiencing a muscle bleed, you should contact your HTC or health professional for advice.***

While this is occurring, you may be able to start the Protection, Rest, Ice, Compression, Elevation (PRICE) method. If your child can tolerate it, applying ice for approximately 10-15 minutes at a time to the affected area early on, while you travel to or speak with your child's treating team, can help to stop further bleeding or reduce swelling. Make sure the ice is wrapped in cloth or use a cool relief gel straight on the skin.



***If your child experiences a muscle bleed, you should always see a physiotherapist to help the muscle and nearby joints return to normal mobility and strength.***



***See Chapter 4 for more information on treatment.***

## Complications from muscle bleeds

Repeated muscle bleeds can lead to damage in the muscle cells and nerves. Symptoms of muscle damage include a gradual increase in pain, muscle spasms, swelling, and loss of movement in the surrounding joints.

Repeated muscle bleeds can also cause scar tissue to be formed, which can affect muscle flexibility and strength and can increase the chance of rebleeds.

## Can muscle bleeds be prevented?

To reduce the risk of bleeding in the muscles there are a few things you can do for your child. These include:

- encouraging and supporting your child's physical fitness and exercise to develop muscle strength
- speaking to your child and a physiotherapist to choose age-appropriate activities and sports
- encouraging proper warm-ups and cool-downs when playing sports.



**See Chapter 6 for more information on physical activity and sport.**

*If there are any signs of numbness, tingling, coldness in the limb, weakness, swelling or discomfort after treatment, follow the emergency plan you have made with your HTC. If you live in a metropolitan area the treatment plan will most likely advise you to take your child to the nearest HTC. If you are live a long way from your HTC there may be an arrangement to take your child to your local hospital.*

### Mouth bleeds

Mouth bleeds are common in young children with haemophilia. They can occur when a child accidentally bites their tongue or their cheek, or when they eat something with sharp edges, or lose their baby teeth or have dental work.

Mouth bleeds can bleed a lot and stop and restart after a few hours or days. This is because saliva keeps the wound moist and sometimes washes away the clot, and because the movement involved in eating and using the tongue can knock the clot out of place.

Unless there is excessive bleeding or your child shows other signs of being unwell, there is usually some time to see if the bleeding will stop. Try something cold in the mouth, like an icy pole. Tranexamic acid can also be used to stop bleeding in the mouth.

Contact your HTC:

- If the bleeding persists for several hours in spite of these measures
- Or if your child is pale and lethargic, nauseous or off their food, vomiting blood or has dark stools (poo).

In these cases your child is likely to require factor replacement.

Until the injury heals:

- Avoid giving your child crunchy, chewy or hot food and drink or letting them drink from a straw
- Where possible, babies should drink from a cup not a bottle and not use a dummy.

## Emergency situations



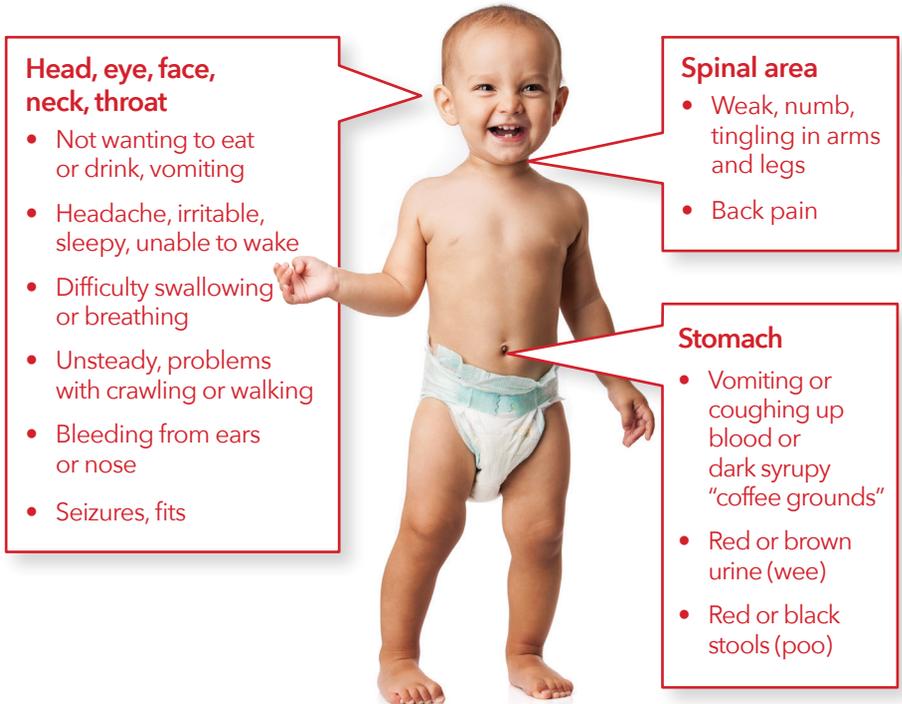
*Some bleeds should be treated as emergencies and require prompt medical attention. Suspected bleeds in the head, throat and stomach should be acted on immediately.*

Sometimes there are no visible signs of bleeding, so being aware of the different types of serious bleeds and their symptoms is important. The illustration below shows areas where serious bleeds can occur.

## Bleeds in these areas are particularly serious

*If you suspect your child has a bleed in any of these areas, go to your HTC or hospital immediately.*

*Phone ahead and let the HTC know you are coming in so they can be ready for your arrival.*



### Seeking help and treatment

No matter what type of 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 call your HTC or go to the hospital. It's always better to be on the safe side.***



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

- In the first instance, suspected bleeds can be treated with the Protection, Rest, Ice, Compression, Elevation (PRICE) method. This can help to prevent further bleeding and reduce swelling while you travel or speak to your HTC.
- If you do not live near a HTC, contact the Centre staff after your child has been treated locally so you can get the best support from your Centre team. Local doctors are encouraged to ring the HTC.

No question is irrelevant or stupid. Haemophilia is an unpredictable condition and what your instincts tell you is often right. As time goes on, you will become more confident in knowing what needs treatment.



#### PARENT TIP

***Make sure you are familiar with the arrangements at your local hospital or HTC for assessment, treatment and management of bleeds after hours as well as during working hours. Keep emergency numbers handy 'just in case'.***



#### PARENT TIP

***The HTC is always there to help you and answer your questions. Contact your Centre whenever you need support.***

## Preventing bleeds and complications

Even the smallest bleeds can cause long-term damage. There are lots of things you can do to help reduce the chances of your child developing a bleed or from experiencing complications from bleeds, including:

- **Prompt treatment.** Whether or not your child is on prophylaxis treatment, ensuring that bleeds are treated promptly will greatly reduce the chance of arthritis developing. This can involve prompt PRICE treatment and factor replacement therapy. Do NOT watch, wait and see. Your HTC will give you advice on how to manage your child's bleeds promptly.



*See Chapter 4 for more information on treatment.*

- **Maintain a healthy diet and weight for your child.**  
This reduces the strain placed on their joints and muscles.
- **Regular exercise and physical fitness help to maintain strong healthy muscles and joints.** Having strong muscles and joints lessens the chance of having a bleed. Regular participation in physical activity provides a better opportunity to maintain a healthy weight and lifestyle.
- **Prophylaxis (preventive) treatment** in children with severe and often moderate haemophilia helps prevent joint and muscle damage by significantly reducing the number of bleeds experienced. Children who have mild haemophilia tend to have bleeds less often and usually do not require prophylaxis. If your child is having prophylaxis treatment, ensure you follow the prescribed treatment.
- **Physiotherapy, treatment and rehabilitation** after a bleed promotes the full resolution of the bleed and its damaging effects. Physiotherapy can take many months, but can lead to a quicker recovery and can ultimately prevent future bleeds.
- **Notify others of your child's medical condition.** Ensure babysitters and your child's teachers at child care, kindergarten or school know how to deal with bleeds. Your HTC or Haemophilia Foundation can assist by providing relevant information. Encourage your child to wear a medical alert bracelet or necklace. Talk to your HTC about getting an Australian Bleeding Disorders Registry (ABDR) patient card for your child. Contact your HTC before you go on holidays to arrange treatment for while you're away.



*See Chapter 5 for more information on notifying others about your child's haemophilia.*

- **Ensure your local doctor 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 local or national Haemophilia Foundation so they can keep up-to-date.
- **Attend all outpatient appointments with the hospital and your HTC as booked.** These usually occur every four to twelve months, depending on your Centre's policy and your child's needs.
- **Keep up-to-date with immunisations and dental appointments.**  
Your child should have a dental check up every six months.
- **Ensure your child uses recommended safety equipment**  
e.g. a seat belt when in the car, a helmet when riding a bike and protective gear when using roller blades or skateboards.
- **Ensure your child wears appropriate footwear** to protect their feet and ankles. Your physiotherapist can advise you on appropriate footwear for your child.

### ***The ABDR patient card and MyABDR***

*The ABDR (Australian Bleeding Disorders Registry) patient card explains your child's diagnosis, what treatment should be given and who should be contacted for further advice. It is the size of a credit card and can be kept on hand for quick reference.*

*You can also record your child's bleeds in MyABDR, an app and website to record treatments and bleeds. This can help the haematologist to review your child's bleeding patterns and adjust the treatment plan to prevent future bleeds.*



*See Chapter 5 for more information on ABDR and MyABDR.*

## References

- Australian Haemophilia Centre Directors' Organisation. Guidelines for the management of haemophilia in Australia. Melbourne; Canberra: AHCDO; National Blood Authority, 2016. <<https://www.blood.gov.au/haemophilia-guidelines>>
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## Important note

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