



KEY POINTS

- Treatment and care for children with haemophilia involves a team of specialist health professionals.
- Factor replacement therapy can be given on demand or regularly ('prophylaxis') and can be administered in the hospital or at home.
- Paracetamol and the PRICE treatment method can help ease the pain of bleeds and reduce ongoing complications.
- If you are unsure whether to take your child to hospital for a bleed, contact your Haemophilia Treatment Centre immediately for advice.
- Do NOT give your child aspirin or ibuprofen as this could worsen their bleeding tendency.

Comprehensive care

Treatment and care for children with haemophilia involves a team of specialist health professionals to cover the range of their care needs. This is known as 'comprehensive care'.

Comprehensive care for your child will be coordinated by your Haemophilia Treatment Centre (HTC).

There is at least one specialist HTC in every state and territory in Australia, which are mostly located in a major public hospital. HTCs have a team of health professionals with expertise in treatment and care for people with bleeding disorders including haemophilia.

The HTC team includes:

- haematologists (doctors specialising in blood disorders)
- specialist haemophilia nurses
- psychosocial workers (e.g. a psychologist, social worker or counsellor)
- physiotherapists
- specialised laboratory services
- access to other specialised health professionals as required.

The team will refer your child to other specialists or health professionals, as appropriate, and liaise with other important partners in your child's care such as your GP or your child's paediatrician.

Key aspects of your child's treatment and care are diagnostic services (such as blood tests, scans and X-rays), factor replacement therapy, rehabilitation and physiotherapy, and psychosocial support.

How can the Haemophilia Treatment Centre team help you and your child?

The HTC team is there to help you and your child every step of the way.

They can:

- work with you to make a treatment plan
- Prescribe and order factor replacement therapy or other treatments that may be required
- help you or your child to learn how to recognise, treat and prevent bleeds
- help make sure any bleeding is treated promptly
- assist with preventing bleeding and joint damage
- manage any complications if they occur
- liaise with other doctors and health services to make sure care is appropriate for your child's haemophilia
- update you on the latest information about haemophilia and treatment
- advise on ways to live well with haemophilia as your child grows, including managing sport, travel, childcare, school, siblings and becoming an adult
- provide care for the social and emotional health of your child and family.

Each child has different needs and their care and treatment will reflect what is best for them as an individual. Your HTC or health professional will advise on the best treatment for your child.

It's okay to ask your HTC lots of questions - your child's health and wellbeing is important and they will be happy to help. Asking questions helps you to be certain that your child is getting the best possible care and provides you with peace of mind.

Factor replacement therapy

New and emerging treatments for haemophilia

Researchers are always looking for new ways to treat haemophilia. The good news is that new treatments are now in development and becoming available. This means that different factor replacement therapy options may become available to treat your child. Some of these new treatments could mean less infusions for your child, or that factor is injected into the "tummy" muscle instead of into your child's veins.

It is important that you are aware of and understand how some of these improvements may benefit your child. There's lots of information out there and it can be difficult to know where to start. Here are two tips for keeping up-to-date with new and emerging treatments for haemophilia:

- *Stay in regular contact with your HTC and your local Haemophilia Foundation - ask lots of questions and request to be kept informed about new and emerging treatments that may be relevant for your child.*
- *Keep an eye on the Haemophilia Foundation Australia (HFA) website www.haemophilia.org.au. Look out for information in the news posts, conference presentations and reports. Also, make sure you're subscribed to HFA e-news and magazines such as National Haemophilia.*

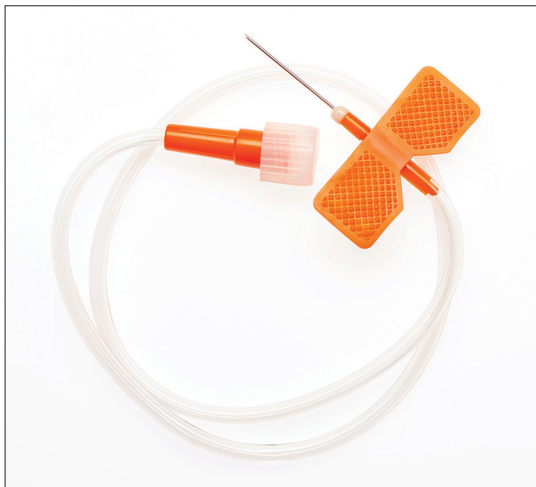
One aspect of haemophilia treatment involves replacing the missing factor in the blood to help the blood to clot. This treatment is also called 'factor replacement therapy'.

The factor usually comes as a powder and is mixed with sterile water (not tap water) or another fluid provided with the factor, to reconstitute it.

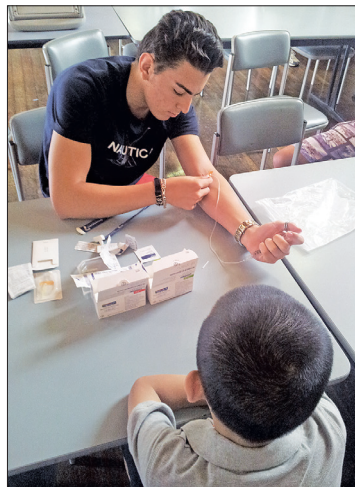
How is the factor given?

Factor is injected (infused) directly into a vein. There are a number of ways to do this:

1. The factor can be infused with a little needle (often called a 'butterfly') into the smaller veins further away from the heart, such as the veins on the arms or legs.



A butterfly needle



Foundation youth leader demonstrating using a butterfly needle to infuse factor

2. Or the factor can be infused through a device that has been placed surgically to connect to a big central vein closer to the heart.
 - Most often this is a small device commonly known as a 'port'. The medical term is an 'implantable central venous access device', so called because it is implanted completely under the skin to access a central vein.

- Less often a central venous line (CVL) is used: a long, thin, soft tube which is inserted into a large central vein and extends from the vein out of the skin on the chest.
3. Other devices may also be used to access veins to infuse factor. Your treating haematologist will discuss the most appropriate devices with you.

What is a port?

A port (implanted central venous access device) is a small device that is surgically placed under the skin, usually on the chest.

Huber needles are special needles used with ports.

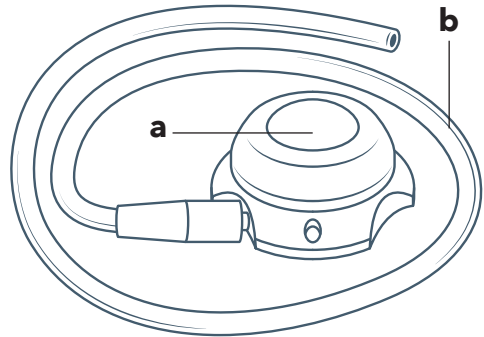


Figure 1: A port with reservoir (a) and flexible catheter (b)

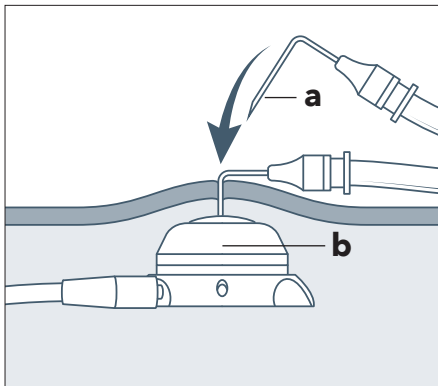


Figure 2: A Huber needle (a) is inserted into the port reservoir (b)

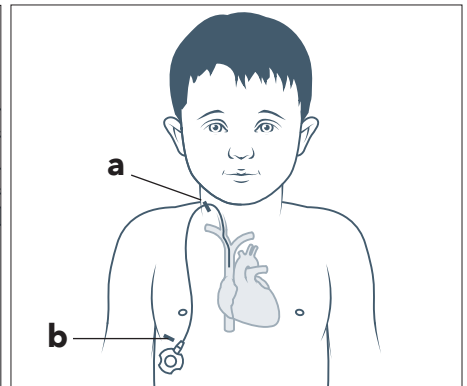


Figure 3: The port is inserted through two small cuts (a,b) and the catheter feeds into a vein (superior vena cava)

Diagrams: Royal Children's Hospital, Melbourne

Children often need a port if the veins in their arms or legs are difficult to find, or if factor is required over a long period of time, for example, when a child starts preventive treatment ('prophylaxis'). A port is a temporary device that makes giving factor to a child easier and quicker, especially while they're young and have small veins.

"It's really a blessing having a port and not having to use veins, especially with little babies. And our son was such a fat little baby you could never hit a vein, so it was really hard."

How does a port work?

A special needle is put through the skin and into the port reservoir. Factor is then pushed through directly into the child's bloodstream via attached tubing called a catheter that goes into a large vein.

The port can remain in place for several years. When the port is not in use it just looks like a small lump on the chest.

The length of time a child has a port depends on their treatment needs and how soon they can manage with the change to using veins again.

Using a port causes very little discomfort. If the child has had a bad experience with infusions into their veins, they may be more comfortable and relaxed with a port.

Your doctor will discuss this option with you if it is required and/or appropriate.

What is a central venous line (CVL)?

A central venous line (CVL) is a long thin soft tube that is inserted into a large vein leading to the heart and can be used for injecting factor rather than the little veins in the arms and legs. It makes it easier, quicker and less painful to give small children their regular dose of replacement factor therapy. A CVL might be used in babies (e.g. under a year old) who need to start regular treatment but are too small for a port. The CVL is inserted under a general anaesthetic.

Where does the needle go?

The most common places for a needle to be inserted are:

- For the smaller veins - the inside of the elbow or the back of the hand, although some people use the veins near the ankles
- For a port: the port is usually placed under the skin on the front of the chest and the needle goes through the overlying skin into the port.
- For a CVL: the factor is connected to the end of the CVL tubing which comes out of the skin on the chest, and there is usually no need to use a needle.

If you will be treating your child at home, you will be shown how to access veins or use the port.

Does treating with factor hurt?

Unfortunately, the needle can be uncomfortable for children. It can also be distressing for parents.

Many hospitals apply an anaesthetic cream to the skin before an injection is given. The cream numbs the area to minimise the discomfort for the child. Children commonly get used to the needles, and no longer need the cream.

Helping your child to cope with needles

There are lots of ways to help your child while they are having needles.

The hospital might have a play therapist available or you could try distracting them with toys or books, watching a DVD, asking questions or holding them in a comfortable position. As children get older, they will learn to self-soothe. Sometimes, extra coping strategies such as tummy breathing or positive self-talk can help to minimise their distress.

While needles can be distressing for you and your child, it's very important to acknowledge how your child is feeling and to create a calming and positive environment during treatment.



Speak with your HTC if your child experiences difficulty coping with treatments. They may be able to arrange for some additional support to help you and your child get through the treatment as comfortably as possible.

What is factor product made from?

There are two main types of factor product. The product that your child uses will depend on the type of haemophilia they have, product availability and which product the HTC identifies as best for your child.

The two main types of product are both concentrates of either clotting factor VIII or IX:

1. Recombinant factor (synthetic)
2. Plasma-derived factor (from the pale-yellow fluid part in human blood).

Recombinant factor

Recombinant factor concentrate is the most common product used for treating for children with haemophilia in Australia. It is genetically engineered in laboratories.

Plasma-derived factor

Plasma-derived factor concentrate is manufactured from the plasma in human blood. This type of product is used in some children with haemophilia if it is more suitable for them individually.



If you have any questions about your child's treatment or the choice of their treatment product, speak with your HTC or health professional.

How often is factor replacement therapy given?

Factor replacement therapy can be given:

- On demand - once a bleed has started, after an injury or accident, or before surgery, medical or dental procedures.
- As 'prophylaxis' or prevention - regularly, from weekly to four times a week, to prevent bleeds or reduce bleeding from an injury.

Where is the factor replacement therapy given?

Initially, factor replacement therapy may be given in hospital or at the HTC.

Over time, many families choose to learn to infuse (inject) the factor themselves. This means factor replacement therapy can be given at home - offering the family freedom from attending hospital and control of their child's treatment. Parents can be taught to administer the factor either into a vein or through a port.

Once your child gets older, they will increasingly become involved in their own treatment. Children can be taught from a young age to administer their own treatment by mixing up products and gradually becoming responsible for the procedure.

The decision to start home therapy should be discussed with your HTC as practices vary across Australia.



Your HTC can tell you what you and your child can expect from home therapy.

What other medications are used to treat bleeds?

Factor replacement therapy is the most common method used to treat bleeds, but it is not the only option available. Every child with haemophilia is different and your HTC will advise on the most appropriate treatment method or medication for your child.

Desmopressin, also known as *DDAVP*, is a synthetic hormone used to treat people with mild haemophilia A. Desmopressin does not affect factor IX levels and is not used to treat people with mild haemophilia B.

Desmopressin can be given as a slow infusion into a vein (intravenously) or injected into the fatty tissue under the skin (subcutaneously). It works by releasing the body's stored factor VIII into the bloodstream to help blood clot.

Desmopressin can help to prevent or treat bleeding in many people but it is not suitable for everyone. The haematologist at your HTC may decide to give a test dose of desmopressin and evaluate whether it will work for your child. This test may need to be repeated at times as people's responses to desmopressin change at different times in their life. It is generally not used for children younger than two-years-old.

Tranexamic acid is a medicine that acts by strengthening blood clots that have formed. This prevents the blood clot from being dislodged and bleeding restarting. It can be used to stop bleeding in the mouth or nosebleeds, gut bleeding, bleeding after dental work, minor surgery or an injury. It is most commonly taken as tablets, syrup or mouthwash. It may be used on its own, or together with factor replacement therapy.

Factor replacement therapy and inhibitors

In some cases, factor replacement therapy is not as effective because the body produces inhibitors.

What are inhibitors?

Inhibitors are antibodies produced by the body's immune system in reaction to factor that is being used to treat or prevent bleeds. Similar to the way the body fights off bacteria or viruses, inhibitors develop when the body's immune system recognises the treatment product as 'foreign' and as a result produces antibodies. The antibodies reduce the effectiveness of the treatment.

Inhibitors are suspected when a bleeding episode does not respond appropriately to the usual factor treatment. A blood test can confirm the presence of inhibitors.



Children who develop inhibitors are at a higher risk of bleeding and can experience difficulties with treatment.

How common are inhibitors?

Inhibitors are most common among people with severe haemophilia, but can also occur in people with mild or moderate haemophilia.

About 30 per cent of children will produce inhibitors or antibodies to the treatment product. This usually occurs within the first 50 treatments with factor product but can occur later.

Is there treatment available for inhibitors?

Some inhibitors are transient and will disappear on their own.

Some inhibitors are at low levels in the blood (“low titre”) and just require an increased dose of factor replacement therapy.

Other inhibitors, most commonly inhibitors at high levels in the blood (“high titre”), require treatment with alternative products to manage bleeding episodes.

Normal factor replacement therapy will not work as well or at all in people with inhibitors. Bleeding episodes in these people need to be treated with special treatment products called “bypassing agents” (because they bypass the need for factor VIII or factor IX).

If a child develops a high titre inhibitor, the best option is to get rid of the inhibitor. This process is called ‘tolerisation’. Tolerisation involves receiving high doses of factor product to try and destroy the inhibitors. If tolerisation is successful, normal factor treatment will again be effective in treating bleeds.



Your HTC will outline treatment options if your child develops inhibitors to their factor product. A haemophilia physiotherapist can also provide guidance on your child’s involvement in sports and physical activity.

Factor product safety



How safe is treatment product?

Many children are now treated with recombinant factor, which is genetically engineered and contains little or no human or animal material. There have been no reports of viruses being transmitted by recombinant products.

Some children are treated with factor products derived from human plasma.

In Australia during the mid-1980s some people with haemophilia acquired HIV from infected clotting factor concentrates made from human plasma. During the early 1990s many people with bleeding disorders also found that they had been exposed to hepatitis C through the clotting factor concentrates they used for their treatment.

Since then new safety measures have been introduced and are reviewed and improved continually.

Is my child at risk of getting a virus?

Some children are prescribed plasma-derived treatment products because this is the most suitable treatment for them.

The risk of new infections from using human blood products, such as factor concentrates made from human plasma, is now extremely low. However, it cannot be entirely excluded, particularly if the risk comes from a new or unknown type of blood-borne virus or other micro-organisms causing disease.

In Australia blood donors are screened and blood donations are tested for Human Immunodeficiency Virus (HIV), hepatitis B and C, human T-cell lymphotropic virus (HTLV) and syphilis.

The manufacture of blood products, such as plasma factor concentrates, is carefully regulated and monitored to make sure that blood products are as safe as possible from infections that can be transmitted by blood, such as HIV, hepatitis B and C and variant Creutzfeldt-Jakob Disease (vCJD).

When they are manufactured, factor concentrates made from human plasma are treated with several processes to remove or inactivate HIV and viral hepatitis and, as far as possible, exclude other known infectious agents that are passed on by blood.



Your HTC will discuss the risks with you when starting a factor replacement therapy. If you have questions about the treatment your child is receiving, speak to your HTC.

Rehabilitation and physiotherapy

Factor replacement therapy is just one component used to treat a bleed. Your child might also require the PRICE treatment as well as rehabilitation, including physiotherapy.

PRICE treatment

If you are told your child does not need to visit the hospital for a bleed, you will likely be advised to give PRICE treatment.

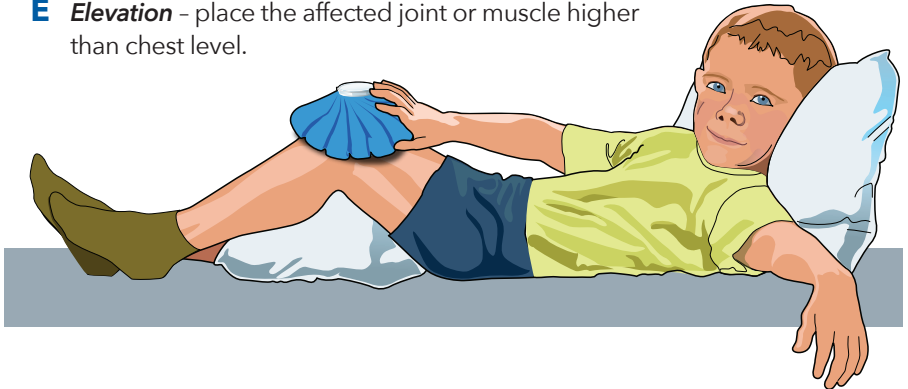


PARENT TIP

If you are unsure whether to take your child to hospital for a bleed, contact your HTC immediately for advice.

PRICE stands for:

- P Protection** - protect the injury from further damage. Stop the activity, minimise weight on the affected joint or muscle.
- R Rest** - rest the affected joint or muscle.
- I Ice** - to reduce pain and swelling apply a cold pack (eg, an ice pack or bag of frozen vegetables wrapped in a towel) or a cool relief gel directly on the skin for about 10-15 minutes, then remove and reapply about every two hours.
- C Compression** - apply pressure to the affected area to slow bleeding. If using a bandage, do not wrap it too tightly.
- E Elevation** - place the affected joint or muscle higher than chest level.



The PRICE method helps to reduce bruising, pain or swelling and speeds up the recovery process. It should be used in combination with factor replacement therapy.



If you are in any doubt about how to treat a bleed or a suspected bleed, contact your local HTC immediately for advice.

Physiotherapy and rehabilitation

Regular exercise and physical activity, when done correctly and safely, is critical to children's health and wellbeing. This is especially true for children with haemophilia. A physiotherapist can discuss how physical activity can help prevent complications from bleeds from an early age.



Balloon exercise

The physiotherapist plays an important role in the prevention of long-term joint and muscle damage. They can assist with the early resolution of bleeding episodes, pain management and getting your child back to their normal activity levels after a bleed. They are able to offer advice to prevent further injury to a susceptible joint and promote involvement in fitness and sporting activities.



Your physiotherapist at your HTC can guide you on appropriate physiotherapy and rehabilitation methods for your child.

Will my child need a mobility aid like crutches or splints?



Soft casts for the elbow and knee of a child with a joint bleed.

Photos: Physiotherapy Dept, Lady Cilento Children's Hospital Brisbane

Your child will need a mobility aid for short periods of time if they develop a joint problem, for example an ankle or knee bleed that affects their ability to walk. Your physiotherapist will be able to advise if your child needs an aid and what is appropriate for their age and type of bleed. For example, when your child is young, they can use a pram or a wheelchair to rest their lower limbs during a bleed. Your child may be recommended to use crutches once they are old enough to manage them safely on their own. This is generally by the age of eight or nine, but will vary depending on your child's development and coordination.

However, sometimes using crutches may exacerbate other problems, for example, if your child has previously had an elbow bleed and now has an ankle or knee bleed. Your HTC will be able to advise you on the best mobility aid for each situation.

When your child gets older, it is recommended that you always have crutches at home so that your child's joints can be protected immediately after a bleed occurs in the lower limbs.

Mobility aids are generally only needed for short periods of time – until the bleed has stabilised or your child can move freely again. Your physiotherapist will guide you on how long to use the aids.

What about scratches and cuts?

Not all of your child's bleeds will need specialist medical attention.

Minor scratches and cuts may only need normal first aid. Minor mouth bleeds can sometimes be treated with a colourless icy pole to help stem the bleeding.

Pain management

Bleeds can be painful. Modern high-quality treatment, including prophylaxis, means that children with haemophilia experience far fewer bleeds – and therefore less pain – than people with haemophilia experienced in the past. However, there will be times when your child experiences pain. Your health professional will be able to assess whether treatment is required and will offer options to manage the pain. As your child gets older, they may be able to identify an early bleed on their own.

To ease your child's discomfort try:

- giving your child paracetamol, (NOT aspirin or ibuprofen, e.g. Nurofen).
- using the PRICE (Protect, Rest, Ice, Compression and Elevation) treatment method



See page 4.15 in this chapter for more information on PRICE).

- using splints or orthotics. These are usually provided by a physiotherapist.

Fear and anxiety can add to your child's discomfort. There's lots you can do while your child is experiencing a bleed or receiving treatment to help ease their pain and anxiety. Try:

- letting your child find their own comfortable way to rest. Beanbags are great and can be moulded into a safe and comfortable nest, creating a good position for your child's joints.
- providing your child with distractions – their favourite books, games, toys – and keeping these close by.
- giving your child a cool bath with a few bubbles and some toys if they don't like ice on a sore limb. This is especially good on a warm day.
- giving your child a colourless icy pole when they have a mouth bleed.
- giving your child a cuddle and providing comfort and reassurance.

"Bleeds and pain are now mostly avoided - prophylactic treatment is pretty amazing. But if he is feeling a little bit sore he'll come and ice pack and we'll put on a movie and he'll put his leg up on a pillow and he's quite happy to chill and relax."



Your HTC can provide you with other pain management techniques. Remember a bleed or suspected bleed into a joint or a muscle that causes pain should be assessed by your HTC team.



Do NOT give aspirin or ibuprofen (e.g. Nurofen) to your child as this may worsen their bleeding tendency

Health management

Surgery

If your child requires surgery, let the treating health professional know that your child has haemophilia (regardless of the severity) and will need appropriate factor coverage throughout the procedure.



It's important that you also let your HTC know well in advance so they can organise the factor coverage and work with the treating health professional to ensure your child has the best possible care.

You may be advised that your child requires surgery in a hospital where a HTC is located to ensure specialist advice is available.

Immunisation

It is important to tell your child and family health nurse, or other health professional who administers your child's immunisations, that your child has haemophilia. This way, they can give your child injections in a way that will reduce the risk of any bruising and excessive bleeding, especially in the muscles.



Talk with your HTC team about the best way for your child to receive their immunisations.

Dental hygiene

It is important that people with haemophilia brush their teeth to keep their gums healthy and prevent gum bleeding. Make sure your child uses a child's toothbrush with soft bristles, and teach them the importance of dental care from an early age. Some clinicians recommend electric toothbrushes, but what is most important is that your child's teeth are cleaned thoroughly. Minor bleeding from the gums may occur but this shouldn't cause a problem.



Poor dental hygiene can cause gum bleeding and this can be made worse by haemophilia. The best way to prevent gum bleeding for your child is to brush their teeth regularly.

When your child visits the dentist, always remember to let them know that your child has haemophilia. If your child is having tooth extractions, fillings or other dental procedures, always discuss appropriate factor coverage with your HTC and dentist in advance to negotiate the best course of action.



Contact your HTC if your child experiences bleeding gums.

Fitness and exercise

Being physically active is essential for a healthy lifestyle. Fitness and exercise helps all children to develop strong bones and muscles and improves their overall health. Sensible exercise and playing sports can be even more beneficial to a child with haemophilia as this physical activity helps to strengthen their muscles and joints and can, in turn, prevent bleeds.



Your physiotherapist can guide you and your child on suitable exercises, activities and sports.



See Chapter 6 for more information on sports and exercise.

Diet and nutrition

There is no special diet for children with haemophilia. All children should have a healthy, well-balanced diet.



Maintaining your child's weight in a healthy range is important. Excess weight places additional strain on joints and can make factor treatment more difficult to administer.

Medicines

Children with haemophilia should NOT be given aspirin or medicines containing aspirin as this could worsen their bleeding tendency. Medicines containing ibuprofen (e.g. Nurofen) should also NOT be given as this also affects the clotting process. Many prescription and over-the-counter pharmacy products contain aspirin or ibuprofen.



PARENT TIP

Speak with your haematologist about medicines to be cautious with or to avoid. Do NOT give your child aspirin or ibuprofen (e.g. Nurofen).

Before your child starts taking anything prescribed by their doctor, naturopath or other health practitioner check whether it is safe for someone with a bleeding disorder.

Some medicines, vitamins and supplements can interfere with blood clotting and healing, or can irritate their mucous membranes such as their nasal passages or stomach lining. This also includes some herbal and homeopathic medicines.



Let your doctor and pharmacist know your child has haemophilia and cannot have anything containing aspirin or ibuprofen or other medicines that interfere with blood clotting when a prescription is required or when buying over-the-counter products.

Ask your pharmacist about bleeding risks with herbal medicines, vitamins and supplements.

Where pain-killers are required, children's paracetamol may be appropriate.



If you are in doubt or have any questions about medication, check with your HTC for advice.

Managing your child's haemophilia

Registering with the Haemophilia Treatment Centre



An important part of managing your child's haemophilia is to register and stay in contact with your local HTC. Let your Centre know if your contact details change.

If you move interstate, contact the HTC in your new area.

Australian Bleeding Disorders Registry (ABDR)

You may also be asked about consenting to have your child's health information entered in the Australian Bleeding Disorders Registry (ABDR). The ABDR is used by HTCs to manage the clinical care of their patients.

With your consent, statistics that do not identify your child can be drawn from the ABDR. These statistics can help improve care for people with haemophilia by assisting researchers to better understand how bleeding disorders affect children.

Statistics about the amount of factor replacement therapy being used also help the government to stocktake and plan for the purchase of future clotting factor product supplies.



**For more information on the ABDR,
visit: www.blood.gov.au/abdr**

MyABDR



MyABDR is a secure smartphone app and website for people with bleeding disorders. It is used to record bleeds and treatments at home.

MyABDR entries are linked to the child's patient record in the ABDR.

Your HTC may ask you to register for MyABDR and use it to keep a record of your child's treatments and bleeds, and the factor product stock you have at home.

MyABDR enables you to share your child's treatment and bleeds information with your HTC securely so you can both keep track of what is happening with your child and manage your treatment stock orders.



PARENT TIP

Download the MyABDR app to keep a handy record of your child's bleeds and treatments and their treatment plan.



**For more information on MyABDR,
visit: www.haemophilia.org.au/myabdr**

As an alternative, there is also a MyABDR paper-based treatment diary.

ABDR patient card

The ABDR patient card is a small, credit-card sized card detailing your child's haemophilia diagnosis, recommended treatment and HTC contact details. You can show it to other health professionals such as doctors or dentists and ask them to liaise with your HTC. This card will help your child get appropriate treatment when you are not at your usual hospital or HTC.



Ask your HTC about organising an ABDR patient card for your child and keep it handy for quick reference.

Medical identity

All people with haemophilia are advised to wear some form of medical identification in case of accidents and emergencies. There are several providers of medical alert or emergency alert identifications.

Some wearable medical identification options include:

'MedicAlert' bracelet

If your child becomes unconscious or is too young to speak for themselves, medical staff and ambulance personnel will identify this bracelet and are immediately informed about your child's condition.

'MedicAlert' is a non-profit organisation sponsored by Rotary and St John Ambulance.

SOS Talisman jewellery

Similar to the **MedicAlert**, the Talisman medical identification jewellery contains all the necessary medical information needed in an emergency. Available as a bracelet, watch band or pendant, medical information is stored within the unit and is available immediately. There is no ongoing expense for a Talisman besides replacement inserts which can be purchased for a small fee.



Ask your HTC for more information on MedicAlerts (www.medicalert.org.au) or SOS Talismans (www.sostalisman.net)

Some pharmacies stock MedicAlerts and/or SOS Talismans and some local Foundations subsidise these for members – check with your local Foundation to see if subsidies are available in your area.

Silicone wristbands

Personalised silicone wristbands are a soft, colourful and waterproof alternative to traditional medical identification jewellery. They are often used for young children. There are several companies online that can personalise the wristband with your child's medical information.



Talk with your HTC for advice on which medical identification is best for your child.

Partnerships for good health



Effective partnerships with health professionals and others who have an important role in your child's life, such as teachers and sporting coaches, can have a positive influence on your child's health and wellbeing.

Establishing respectful relationships that support positive and open communication will help to optimise your child's health and wellbeing, and help ensure that your child receives the care and treatment they need.

If you have any concerns or don't think your child is getting the support they need, begin by speaking directly to the person concerned and consider the following communication tips:

- Say honestly and tactfully what's bothering you. Try to be specific about your concerns.

- Try to avoid criticising the person or the service the person is working for. You're more likely to get a helpful response if you use a cooperative approach.
- Listen to what the professional is saying - the professional should have your child's best interests at heart, just as you do.
- Consider the situation from the professional's perspective - they may have some interesting ideas.

Be proactive with your child's health

There may be times where you encounter a health professional (such as a doctor, nurse, physiotherapist or dentist) that has not treated a child with haemophilia before. You may even find that you know more about haemophilia than the professional.



PARENT TIP

Be an advocate for your child. If you feel that something is wrong, let someone know.



Always speak up and ask as many questions as you need to ensure your child is getting the best care.

Let the professional know they can contact your HTC or a haematologist if they are unsure of the treatment.

If the issue is very serious or you feel uncomfortable raising the issue, seek additional support - your HTC can help you to advocate on your child's behalf.

"Don't allow yourself to be fobbed off. You live with your child and need to be knowledgeable enough to be comfortable and confident in your decisions."

Being assertive and maintaining positive and open communication helps ensure your child receives the most appropriate treatment in their local setting.



Ask your HTC for a treatment plan that you can take with you to all medical appointments or carry your child's ABDR patient card

Further reading

Furmedge, J. Giving factor at home: a guide to using your child's port. Melbourne: Royal Children's Hospital, 2012. Available from your HTC

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This resource was reviewed by:

Dr Moana Harlen from Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group; Janine Furnedger, Anne Jackson, Siew Lee, Joanna McCosker, Robyn Shoemark, James Slade and Helen Starosta from Australian Haemophilia Nurses' Group; Auburn McIntyre, Alison Morris, Wendy Poulsen from Australian and New Zealand Physiotherapy Haemophilia Group; Dr Chris Barnes, Dr Julie Curtin from Australian Haemophilia Centre Directors' Organisation; Sharon Caris and Suzanne O'Callaghan from Haemophilia Foundation Australia; Sandy Breit, grief and loss counsellor; and bleeding disorder community representatives from HFA Parents Consumer Review Group.

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