

Haemophilia treatment

The type of treatment, how often it is needed and the size of each dose will vary from child to child. Your Haemophilia Centre or health professional will advise which is best for your child.



Feel free to ask questions of your Haemophilia Centre staff, even if you think you may sound silly. It's your child's health and you have a right to be certain that he is getting the best possible care. Having answers to your questions will also give you peace of mind.

What is the treatment?

Haemophilia treatment involves replacing the missing or faulty factor in the blood stream. This sort of treatment is called 'replacement therapy'. The factor usually comes as a powder in little bottles. This is reconstituted with sterile water (not tap water).

How is the treatment given?

Factor is injected directly into a vein.

Does treatment hurt?

The needle can be uncomfortable for young children. Many hospitals have a 'magic' cream, a topical anaesthetic, that is applied a while before the needle is given. This cream numbs the area so the child does not feel the needle go in. After a while, children get so used to the needles that they do not need the cream.

Speak with your Haemophilia Centre staff if your child has a particular problem coping with receiving treatments. They may be able to arrange for some occupational therapy to help your child deal with the situation.

Where does the needle go?

The most common places for a needle to be inserted are the inside of the elbow, back of the hand or into an implantable venous (vein) access device, often called a port-a-cath, infus-a-port, or simply called a port.

If you will be treating your son at home, you will be shown how to access veins or use his implantable venous access device.

Why do children have ports?

A port is a small disc with tubing that is surgically implanted beneath the skin of the chest when veins in the arms or legs are difficult to find, or if factor is required over a long period of time (e.g. when a child starts prophylaxis).

Ports are implanted under a general anaesthetic. The port remains permanently in place and when not in use just looks like a small lump on the chest.

Using the ports causes very little discomfort. If the child has had a bad experience with infusions into his veins, he 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's treatment product made from?

There are a few different products. The treatment your son receives will depend on the type of haemophilia he has, availability, and which product the Haemophilia Centre believes is best for your child.

There are two main types of product used. One is a concentrate of either factor VIII or IX. It is made from blood plasma from blood collected by the Australian Red Cross Blood Service. Concentrates undergo multiple viral inactivation processes to remove known viruses including HIV and hepatitis C.

The second type is recombinant factor. Recombinant factor is made in laboratories and uses either very little or no human material. Recombinant products are considered safer than plasma derived ones, with no known cases of viral transmission from using these products.

Recombinant factor has been standard treatment for most children in Australia over the past few years.

If you have any questions about your child's treatment or the choice of his treatment product, speak with your Haemophilia Centre staff or treating health professional.

Who gives the treatment?

Initially, treatment may be given in hospital or at the Haemophilia Centre.



Another option is home therapy. Over time, many families choose to learn to infuse (inject) the factor themselves. This means treatments can be given at home – offering the family a great deal of freedom from the hospital. Parents can be taught to administer the factor themselves at home, either into a vein or through a port. Older children like to be involved in their own treatment. Children can be progressively taught to administer their own treatment, starting at a young age by mixing up products and gradually taking on total responsibility for the procedure.

The decision to start home therapy involves many factors. Home therapy practices vary between Haemophilia Centres around Australia. Your Haemophilia Centre will be able to tell you what you and your child can expect.

Is there anything else I can do to treat bleeds?

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

RICE stands for:

- R** **Rest** – rest the affected joint or muscle.
- I** **Ice** – use an icepack, cool cloth or other cooling agents to reduce pain and swelling. (Do not apply for more than 10-15 minutes at a time.)
- C** **Compression** – apply pressure to the affected area to slow bleeding. If using a bandage, do not wrap too tightly.
- E** **Elevation** – place the affected joint or muscle higher than chest level.

This can also be used with factor replacement treatment. If you are in any doubt about how to treat a bleed or a suspected bleed, contact your local Haemophilia Centre immediately for advice.



What about scratches and cuts?

Depending on the type of injury, your child may not need to go to hospital. Minor scratches may only need normal first aid.

Mouth bleeds can be difficult to treat even if they are mild. Giving the child a colourless icy pole can often help stem bleeding.

Not all of your child's bleeds will need specialist attention, but if there is any uncertainty be sure to contact staff at your Haemophilia Centre immediately. They are there to help.

Will my child need crutches?

Your child may need crutches for short periods of time if he develops a joint problem that affects mobility, for example an ankle bleed which may not allow him to walk.

There are different aids that the physiotherapist can provide for your child including crutches and splints to immobilise the joint. Your physiotherapist will be able to tell you more about these if your child needs them.

The use of aids is generally only necessary for short periods of time, i.e. until the bleed has stabilised or mobility has been regained.

Children under the age of six are not usually coordinated enough to use crutches. Alternatives may be used that are more appropriate to their level of coordination.

Pain management

Bleeds can be very painful. With prophylaxis and the high quality of treatment products available today, your child will have far fewer bleeds – and therefore less pain – than his counterparts of just decades ago. There will, however, be times when he could experience pain. Your treating medical adviser will be able to assess whether treatment is required. As time passes, you will be able to tell this yourself. There may be times when you want to do more to ease discomfort. Tessa Speller, Haemophilia Nurse at the Royal Children’s Hospital in Melbourne, offers these suggestions:

- Paracetamol (NOT Aspirin).
- RICE (Rest, Ice, Compression and Elevation).
- Instead of using an ice pack, try using a bag of frozen peas, which is light and flexible or “Cool Relief” patches which can be obtained from some sports shops.
- If your child doesn’t like ice on a sore limb, try a cool bath with a few bubbles and some toys. This is especially good on a warm day.
- Lemonade (not coloured) icy poles are good for mouth bleeds.
- Splints. These are usually provided by the physiotherapist.
- Children find their own comfortable way to sit/rest rather than being told to rest on their bed. Beanbags are great and can be molded into a comfortable position. Tessa often suggests to kindergarten and prep teachers that if a child has a bleed at school, this is a great place to put them until parents arrive.
- Distractions – favourite videos, computer games, books etc.
- A small child with a lower limb bleed tends to stop walking and crawl again – or just sit. If they are put in a safe area with toys nearby they can also be distracted.
- And, of course, the all-important cuddle!

Never give aspirin to a person with haemophilia.

General health management

Surgery

Should your child require surgery, let the health provider involved know that your child has haemophilia and will need appropriate factor coverage throughout the procedure. Let your Haemophilia Centre staff know well in advance so they can organise the coverage and work with the surgeon/health professional concerned to ensure your child has the best possible care.

It may be best for your child to have surgery in a hospital where a Haemophilia Centre is located to ensure specialist advice is available.

Child immunisation

It is always wise to tell your infant welfare nurse, or any other personnel who administer your child's immunisations, that your child has haemophilia. This way they can give him the injections in a way that will reduce the risk of any bruising and excessive bleeding.

Dental hygiene

This should be a concern for all your children as proper dental hygiene will improve dental health and lessen dental treatment.

People with haemophilia must brush their teeth. Minor bleeding which may occur shouldn't be a problem. Make sure your child has a proper toothbrush (i.e. a child's toothbrush with soft bristles), and start teaching the importance of dental care from an early stage. Some clinicians recommend electric toothbrushes, but what is most important is that the teeth are cleaned thoroughly.

When your child visits the dentist, be sure to let the dentist know that he has haemophilia. If your child is having tooth extractions or other dental procedures, discuss appropriate factor cover with your Haemophilia Centre AND dentist in advance to negotiate the best course of action.

Fitness and exercise

Just because your child has haemophilia doesn't mean he can't exercise and be fit. A strong and fit body will help prevent bleeds as well as improve his overall health! See the lifestyle and sport section (chapter 7) for more information.

Nutrition

There is no special diet for haemophilia. Healthy, WELL-BALANCED diets such as those recommended for everyone are appropriate. Maintaining your child's weight at a healthy level for his height is also recommended: excess kilos are hard on tender joints.

Medication

People with haemophilia should NOT be given aspirin or medications containing aspirin as this encourages bleeding.

Many prescription and over-the-counter pharmacy products contain aspirin. Let your doctor know your child has haemophilia and cannot have anything containing aspirin when a prescription is required. When buying over-the-counter products, check with the pharmacist whether an item is suitable.

Where pain-killers are required, children's paracetamol may be appropriate. If you are in doubt or have any questions, speak with your Haemophilia Centre, pharmacist or treating health professional.

NEVER give your child aspirin

Medical identity

All people with haemophilia should wear some form of medical identification in case of accidents and emergencies.

'MedicAlert' - bracelet

If a person is unconscious or unable to speak for themselves (e.g. too young), medical staff and ambulance personnel will identify this bracelet and are immediately informed about your child's condition by the information available.

'MedicAlert' is a non-profitable organisation sponsored by Rotary and St John Ambulance. Ask your Haemophilia Centre for more information.

SOS Talisman - bracelet or locket

Similarly, the Talisman medical ID contains all the necessary medical information needed in an emergency. The information is stored within the unit and is available immediately. There is no ongoing expense for a Talisman. (Replacement inserts are available for a small fee.)

Some pharmacies stock MedicAlerts and/or SOS Talismans. Your Haemophilia Centre may also be able to advise where you can purchase these units.

Assertiveness

There may be times when you feel your child is being treated incorrectly, or that he should be treated for a bleed when the doctors and nurses don't agree with you, or it could be that you have been waiting in the casualty department for a long time and you think your son needs immediate attention. It is at times like these that you need to be assertive and speak up for yourself, and most importantly, for your son.

Even though the doctors and nurses have the medical expertise, you have the instincts and knowledge about your son that all parents have about their children – and parents' instinct is usually right.

Inexperienced doctors or nurses may not have seen a child with haemophilia before. Doctors and nurses are human and can make errors as well, so if you feel that something is wrong, speak up for your son's sake. A doctor or nurse unfamiliar with haemophilia may need to contact your haemophilia clinicians or the haematologist on call.

“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.”

If you do not receive haemophilia care from a Haemophilia Centre, ask the Centre in your State/Territory to contact your local doctor or hospital. Local staff can learn a lot about haemophilia through this contact.

Maintaining good and open communication helps ensure your child receives the most appropriate treatment in their local setting. Ask your Haemophilia Centre for a treatment plan that you can carry with you.

Assertive versus aggressive

Being assertive is not the same as being aggressive.

Aggressive behavior can make it more difficult to work effectively with your treating health professionals. In some instances, aggression may backfire on

you – health professionals may take little notice of what you are saying if you appear aggressive and angry.

Being assertive means saying what you need to say in a calm, reasonable manner. Be as helpful as you can. Use a helpful tone and don't shout.

Advocacy

If you have had difficulty communicating with local staff or you feel you are not getting your point across on your own, you may wish to have someone advocate for you. Your counsellor, Haemophilia Foundation or Haemophilia Centre can help you to advocate for your child's needs.