



KEY POINTS

- As your child grows, it's important to let them move around and explore their world freely, as any other child would.
- Warm, calm, positive, consistent and caring interactions and messages are at the heart of a child's healthy development.
- Be understanding of other people's feelings and reactions to your child's haemophilia. People will react in different ways.
- Children with haemophilia can be left with babysitters or carers, travel and attend school camps, just like other children.

Letting kids be kids

All parents want their child to be happy, successful and safe. As a parent of a child with haemophilia, it is normal to feel anxious when handling your child as a baby or to be concerned as they become more mobile. You can help your child to become confident and competent as they grow by supporting their healthy development and avoiding being overprotective.

Holding, rocking, cuddling and patting your baby are all ways of letting your child feel safe and loved. These actions won't cause your child any harm. As your child grows, it's important to let them move around and explore their world freely, as any other child would. This is how children learn, grow and begin to make independent decisions. Letting your child move freely also develops their balance and movement and coordination skills which will assist with joint protection while encouraging healthy weight and fitness.

As you learn more about haemophilia, you will become more relaxed knowing that your child will grow and develop just like any other child.



How much should I protect my child?

It is natural to want to protect your child from harm. However, being overly protective can have negative effects such as reducing a child's confidence and removing opportunities for learning and growth. Being fearful and attempting to 'bubble-wrap' your child will not stop bleeds and may end up tiring you out.

"As soon as we found out he had haemophilia, we immediately threw a 'protective blanket' around him. We would follow him everywhere he went (crawled) and we would not let him out of our sight. We found over time that he was still having bleeds, regardless of the fact that we were so careful and protective. We learned to let him be a normal little boy, and nothing has happened due to this."

Some parents try to make their home a little less dangerous and put padding around the sharp corners of furniture like tables, chairs or install padded floor surfaces like carpet while their child learns to crawl and walk. These changes can be sensible, but it will not stop all bleeds.

“We padded all the corners in the house. Our home looked awful, but we felt we were doing the right thing. Besides, our son was our main priority. But over time we learned that no matter what we did, it wouldn’t stop him from having bleeds. We should have been more concerned with treating him normally rather than making him feel different from other kids.”

With your family, friends and community, you can create an environment that encourages your child to learn and grow safely.

Behaviour

It is important to manage your child’s behaviour as you would any other child. If you have other children, compare the way you treat your child with haemophilia with the way you treat your other children. Do you treat them alike?

There are a range of strategies you can use to guide your child’s behaviour and each parent will have a different idea on what approach should be taken.

Like all children, children with haemophilia benefit from:

- praise and rewards for good behaviour
- knowing what behaviour is appropriate and inappropriate
- learning how to understand and express their feelings
- clear consequences for inappropriate behaviour.

“He isn’t any different from his sisters or any other kids as far as I’m concerned, and that’s the best way I feel we could have brought him up.”

Positive parenting

Warm, calm, positive, consistent and caring interactions and messages are at the heart of a child's healthy development. You can show positive attention to your child through:

- smiling
- making eye contact and using caring facial expressions
- being physically gentle and caring
- praising good behaviour (e.g. 'well done for sharing your toy with your sister')
- showing interest in your child's interests, activities and achievements
- giving your child your undivided attention.



The reality is that parenting is not always easy, especially for parents of children with a bleeding disorder. There are days that are really hard work, where it feels like there are more downs than ups, or when you feel challenged by your child's behaviour. It's important to take some time out to look after yourself. If you are experiencing frequent intense emotions then you may need to seek professional help. You can always seek support from your Haemophilia Treatment Centre (HTC), health professional or other parents. You don't have to go through this journey alone.

There are also lots of good books, websites and courses on positive parenting. Talk to your psychosocial professional (psychologist, counsellor or social worker) for advice on local organisations that might be conducting positive parenting courses. Positive parenting principles apply equally to a child with haemophilia.



For more information on child behaviour and parenting, visit the Raising Children Network: raisingchildren.net.au

Promoting healthy self-esteem

Self-esteem is how we value ourselves. Children with good self-esteem will try new things, take healthy risks and attempt to solve problems. Healthy self-esteem provides a solid foundation for children's learning and development.

How you respond to your child and their haemophilia will shape their self-esteem.



Your child will look to you for messages about themselves and their self-image.

When speaking about your child to others, always try to ensure that you speak in a positive manner when discussing their haemophilia, especially when your child is present.

“Simply say ‘come on mate, up you get’ or ‘oops’ and let him decide if there is a problem. This will help him see himself (and other people to see him) as a normal little boy who has haemophilia rather than as a labelled person.”

You can help build your child's self-esteem by letting them find their own boundaries (within reasonable limits), following their interests and building on their strengths and achievements.

Your child may want to participate in activities other children their age do such as sports or leisure activities. By allowing your child to do as much as possible, always within reasonable limits, you will build your child's self-esteem and confidence and they will feel like ‘part of the group’.

If your child is unable to participate in an activity it is important to explain the reason for this.



For more information and tips on building your child's self-esteem, visit the Raising Children Network: raisingchildren.net.au

Learning to manage their haemophilia

When your child is old enough, you could try explaining to them what may cause a bleed and how bleeds are treated. Allowing your child to assist with their treatment in an appropriate manner can increase their confidence with managing haemophilia. Naturally, how much help they give will be determined by their age, ability and motivation.

“We read to our son every night and he will often choose his haemophilia children’s books because they’re relevant to him. He knows he has haemophilia, he knows that he needs his factor so he doesn’t get hurt and he knows that factor makes his blood strong. He’s very proud of his port as well, so he will show strangers his port and spark conversations about it, and about having needles and things like that. He’s quite proud of who he is and the experiences he’s had.”

While your child is still young, you can try letting them help gather supplies and putting on a Band-Aid when they cut themselves. As they get older, they will be able to mix their own factor. Over time, you will gradually be able to hand over more of the treatment responsibility to your child. Eventually your child will be able to administer the entire treatment themselves.

Family and friends

Siblings

Brothers and sisters play a big role in your child's life. Siblings usually treat their brother or sister normally, because they forget about the disorder. However, you may need to spend some extra time with your other children to make up for the additional time your child needs for their haemophilia treatment.



"In the first year, we as parents were very overprotective of our child with haemophilia and often not as patient with the older sister when something went wrong."

"When our second son came back negative to haemophilia, it was a strange feeling. Of course we felt the relief that he wouldn't have to deal with hospitals and needles and all the challenges along the way. However, it also felt a bit strange, as his big brother, two cousins and grandfather all have haemophilia, so in a way he'll be the 'odd one out'."

Haemophilia does not define who your child is. They are all your children, but one simply has a blood clotting disorder. Try to avoid pampering or treating your child with haemophilia any differently to your other children.

It's normal for siblings to have lots of different feelings about their sibling with haemophilia. Brothers and sisters of children with haemophilia can sometimes feel worried, or be jealous or resentful towards their sibling with haemophilia. Some siblings say:

"Even as an adult, I remember all the attention my brother got."

"Just because he has haemophilia, he can do no wrong."

"He gets all the attention. Mum and Dad love him more."

It is important that your other children are given the opportunity to express themselves. Siblings should be given the opportunity to discuss their feelings. Once their feelings have been acknowledged, you can work on ways of coping with them in a positive manner. Let them know that feeling negative emotions is okay, but using them to hurt others is not.



For more information and resources on supporting siblings, visit Siblings Australia: www.siblingsaustralia.org.au

Teaching siblings about haemophilia

Siblings can cope with haemophilia better if they understand what is going on. It is important to explain haemophilia to your child's siblings in age-appropriate ways. For example, a five-year-old might understand that her brother's blood doesn't work properly and that he needs needles to get better, whereas an older child can be taught about how blood clots, what a bleed is and how the factor helps prevent and treat bleeds.

Explaining haemophilia to other children

Preschoolers

Children of preschool age are egocentric and see the world as it relates to themselves. They may blame themselves for causing bleeds and could fear 'catching' haemophilia if they are bad.

At this age, it might be helpful to say things like:

"Your brother has haemophilia. He was born with it. He needs medicine (or needles) to make him better. Don't worry, you won't get haemophilia."

School-age children

School-age children understand things in a concrete way. Their brother has a bleed and needs a needle. The blood doesn't work properly, and so on.

School-age children can understand a more complex explanation:

"Your brother has haemophilia because his blood doesn't work properly. The needles give him medicine which makes his blood work. It can hurt, but your brother is very brave."

Older children

Older children can understand more abstract ideas. They can understand concepts such as how factors work together in blood to form clots, inheritance patterns of haemophilia and so on.

When children are older, you could say something like:

"Your brother has haemophilia because his blood doesn't work properly. There are factors in the blood like ingredients in a cake. Your brother is missing one of his ingredients (factors) so his blood doesn't clot. Sometimes blood goes into his joints (name target joints). The infusion contains the factor he is short on, so he can do normal things."

It may also help to explain haemophilia to each child separately so that you can tailor what you say to each child. Spending time with the siblings individually will also help them feel more important.

Getting siblings involved if they are interested can also make them feel special. Contact your local Foundation about events and activities that you can involve all your children in.

There are children's story books available on haemophilia. You might like to use these when telling your other children about haemophilia. Your HTC can tell you what is available.



For more information and resources on supporting siblings, visit Siblings Australia: www.siblingsaustralia.org.au

Relatives and friends

When you tell relatives and friends about your child's haemophilia, they may not know much about the condition, so be understanding of their reactions. People will react in different ways.

The way you tell other people will influence how they deal with the news. If you are calm and explain it factually, then they can take the information in calmly and gain a clear and realistic understanding of haemophilia.

A simple explanation can help people understand haemophilia and what this means for your child.



Haemophilia Foundation Australia publishes a range of information about haemophilia that relatives and friends may find helpful.

Contact Haemophilia Foundation Australia for details:

T: 1800 807 173 toll free

E: hfaust@haemophilia.org.au

W: www.haemophilia.org.au

Useful websites



Factored In - www.factoredin.org.au - an online community for young Australians with bleeding disorders and their siblings (aged 13-30).



Livewire - www.livewire.org.au - a safe and fun online community for young people (aged 10-20) living with a serious illness, chronic condition or disability, and their siblings.

Babysitters and carers

Finding time for yourself is important for your health and wellbeing. A babysitter or carer can give you the chance to have a break, relax and do some things for yourself.

Children with haemophilia can be safely left with a babysitter or carer. When your child is in the care of others, there are a few things you can do to give yourself peace of mind so you can enjoy your time away:

- Explain to the babysitter or carer what haemophilia is.
- Let the babysitter or carer know how to tell if your child is having a bleed and what to do.
- Leave your contact number/s, your HTC's contact number and other emergency contacts somewhere easily accessible.



See page 5.12 in this chapter for an information sheet that can be used or adapted to provide your child's carers with information about haemophilia.

Information sheet for babysitters or carers

My child is like other children of the same age. He loves the same foods, games and stories. The only difference is that he has haemophilia. Haemophilia is a rare, inherited blood clotting disorder. It is not infectious – you cannot ‘catch’ it.

Like everyone, if my child bumps or cuts himself, he may bleed. He will not bleed faster than anyone else, just for longer. This doesn’t mean he will bleed to death or that he can’t play – in fact, he can do just about everything other children his age do.

I have a few requests while my child is in your care:

1. Please discourage rough play or high contact sports.
2. Minor bumps and cuts are to be expected with any normal active child. However if my child has a hard fall, hits his head or has a significant injury to any vital area (e.g. abdomen, throat, eye), or develops limping or major swelling, please contact me immediately.
3. Even with the best of supervision, bumps and cuts can occur. Please let me know of any injuries or if you have noticed any minor swelling or bruising.
4. Please do not give my child any medication, especially aspirin or ibuprofen (e.g. Nurofen) as these can worsen their bleeding tendency.

Let me know if you have questions, I am happy to talk with you in more detail. Meanwhile, have fun!

Important phone numbers:

Name: _____ Mobile: _____

Name: _____ Mobile: _____

Doctor: _____ Telephone: _____

Haemophilia Treatment Centre: _____

Instructions: _____

Child care, preschool and school

Your child's teachers are accustomed to working with children who have a range of abilities and medical conditions. However, it is important to remember that haemophilia is rare, so your child's teacher may not have come across a child with the condition before.



Staff at your child's child care centre, preschool or school should be well informed and prepared to provide the care and support your child needs.



Contact your HTC about the resources and support available to child care centres and schools - sometimes haemophilia nurses are able to visit your school or centre to teach the staff about haemophilia. You might be asked to provide the centre or school with a health management plan for your child. Your HTC can help with this.

Travel



Travel and holidays are a great way for the family to take a break from the everyday routines and spend time together.

Children with haemophilia can travel just like other children. However, there are some sensible steps you should take to ensure you're well prepared and your trip is as hassle-free as possible.



Before you go:

- **Wherever you are travelling, let your HTC know you are planning a trip well before you leave.** If you are travelling overseas, talk to staff at your HTC **several months in advance.** This allows time to discuss treatment options, arrange letters and get advice on documentation, medication and travel insurance.
- **Request a letter of introduction from your HTC** or health professional, outlining your child's haemophilia and treatment requirements. This will save time in an emergency.
- **Take out travel insurance, especially for overseas travel.** When you take out the cover for your child, you will be asked about pre-existing health conditions and make sure you declare that your child has haemophilia. This usually involves a higher premium. Shop around to find a travel insurance company that will cover haemophilia, check their conditions carefully and compare companies to find the policy that best suits your child's needs.
- **Locate the HTCs and hospitals with emergency departments along your route** for 'just in case' situations. Bear in mind that many hospitals don't have any treatment products or the level of expertise that you are used to.
 - For Australian HTCs, check the HFA website - www.haemophilia.org.au
 - For HTCs overseas, check the World Federation of Hemophilia Global Treatment Centre Directory - www.wfh.org
- **Find out about treatment for the time that you will be away.**
 - If you treat your child at home, discuss the amount of factor to take with your HTC to make sure you have enough treatment product and equipment for the trip and to cover any contingencies. You may be able to make arrangements to access supplies along the way.
 - If your child's treatment is supplied and administered by your HTC, sometimes your HTC will give you factor to take with you just in case.
 - Ask your HTC for a letter to explain your child's diagnosis and treatment and contact details for further information. Make contact with the hospital at your destination in advance to ensure the availability of treatment products and advise them when you will be travelling. Check with your HTC to see if they can do this on your behalf.

- **If you are travelling by plane, you will be subject to airport security and customs checks.** Talk to your HTC about the documentation to explain why you need to carry medication and needles and how to package and store them appropriately.
- **If you are going overseas, be prepared to spend several months organising and planning.**
 - Health systems and services and availability of treatment products will be different in other countries and will take time to understand and negotiate. Treatment supplies and some documentation will need to be organised months in advance.
 - Talk to your HTC about the documentation from authorities you need to take your treatment product in and out of Australia.
 - You will also need to find out if there are any regulations about taking treatment product into the country or countries you are visiting.

Tips for transporting your factor

- Check how long factor can be stored out of the fridge - your HTC can advise you on this.
- Check there is a reliable fridge where you're staying to store your child's factor. Actual room temperature may be too high for "room temperature" factor storage.
- Make sure you take your factor in its original packaging, particularly when travelling overseas.
- Ask your HTC about a suitable travel/cooler bag to carry your factor.
- When flying, carry factor in your hand luggage to avoid having it lost or misplaced or subjected to extremes of temperature in the cargo hold.
- Consider taking a sharps container. You can get travel sized containers.

While you are away:

- Follow the treatment plan as discussed with your HTC. Take a printed copy with you.
- Don't forget your first aid plan and pack! Add in some simple pain relief, e.g. paracetamol (Panadol®)

- If your child goes to hospital for treatment, take your treatment product, ABDR patient card and letter from your doctor or HTC.

When you get back:

- Let your HTC or doctor know if you had any problems while you were away.



Useful travel websites:

- Smartraveller www.smartraveller.gov.au
- World Federation of Hemophilia www.wfh.org, especially the **Tips for travellers** and **Global Treatment Centre Directory** pages.

Camps

Children with haemophilia can attend school camps and participate in most activities.

To help them get the most out of their school camp, there are a few important things to do before they leave:

-  Talk to your HTC in advance to arrange any specific education or support that may be required for your child.
- Check with the school to ensure the adults attending the camp are familiar with haemophilia and know what to do if your child has a bleed while in their care.
- Talk to your doctor or physiotherapist about the types of activities that will be undertaken on the camp and discuss their suitability for your child. With enough notice, modifications can be made to activities to ensure they are appropriate for your child or to your child's treatment plan so they can participate in most activities.

Haemophilia camps

You, your child and your family might also benefit from attending a Haemophilia Foundation family or community camp. These camps are run regularly by local Haemophilia Foundations. Everyone in the family is welcome, including siblings, aunts and uncles and grandparents.



The camps combine haemophilia education sessions with fun activities for the whole family. This can vary from activities such as swimming, climbing on high ropes and bike and scooter riding to parent discussion sessions.

“It was good to be able to sit down during a family group meeting at camp. Our son was the youngest one there. I asked a lot of questions to the older mums about what their experience with school was like.”

They provide a great opportunity for new families to meet others in the same situation and share experiences and to see just what sorts of activities children with haemophilia participate in.

“Our local Foundation does a fantastic job in running the Haemophilia Family Camp to help children and those affected gain self-confidence, form new friendships and develop resilience. There are also educational sessions lead by HTC health professionals and youth mentors. We have attended each year since our son’s diagnosis, and it’s a wonderful opportunity to catch up with other families and just enjoy some recreation time.”



See *Chapter 6* for more information on haemophilia camps.

Further reading

McKay, C. Siblings: the best of friends and rivals. National Haemophilia, September 2015.
<http://tinyurl.com/siblings-rivals>

References

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

Australian Bleeding Disorders Registry (ABDR) Annual Report 2015-16. Canberra: National Blood Authority, 2017. <<https://www.blood.gov.au/system/files/abdr-annual-report-2015-16-final.pdf>>

Wiedebusch S, Pollmann H, Siegmund B, et al. Quality of life, psychosocial strains and coping in parents of children with haemophilia. *Haemophilia*. 2008 Sep;14(5):1014-22.

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