



Your child has haemophilia. These four words have most likely echoed through your mind over and over again since your child was diagnosed.

There are so many things to know about haemophilia - what it is, what the symptoms are, how it's treated and who's there to help.

Here's three things you need to know right now:

- 1. Your child will be okay.**
- 2. With appropriate treatment and care, haemophilia is manageable.**
- 3. Your child will have a normal life expectancy and will be able to do most things that other children their age can do.**

You will need to make some adjustments to your life but most things you do with your family will remain the same. While haemophilia can't be ignored, it does not have to rule your life - or your child's. Remember always to treat your child as a little boy or girl first, and a child with haemophilia second.

Rest assured that as your child grows, so will your understanding of haemophilia and your confidence in how to manage it - and it will be the same for your child.

Your Haemophilia Treatment Centre (HTC) is always available to offer advice whenever you need it. Haemophilia Foundations can also provide information and support and connect you to other parents. You are not on your own.

Haemophilia - what you need to know now

"Once I learnt more about haemophilia I became more comfortable."

What is haemophilia?

Haemophilia is a rare bleeding disorder in which there are low levels of one of the essential clotting factors, factor VIII (8) or factor IX (9). These factors are components (proteins) that help blood to clot.

There are two types of haemophilia, both with the same symptoms:

- Haemophilia A - factor VIII (8) deficiency
- Haemophilia B - factor IX (9) deficiency

When factor levels are significantly low, bleeding problems can occur. Your child may have more bruising and bigger bruises, often lumpy, and may have bleeding (e.g. from the mouth) that stops and restarts. They may also experience internal bleeding into joints and muscles (commonly referred to as 'bleeds').

How serious is it?

While haemophilia is not curable at present, it is most certainly treatable. Your child will have a normal life expectancy and be able to do most things that a child without haemophilia enjoys.

Your HTC team will guide you and your child throughout life to manage factor levels and discuss their development and their involvement in sports and activities as they grow.



Some bleeds can be very serious - even life threatening - if not treated appropriately. Bleeds to the head, throat and stomach should be treated as emergencies. If you suspect your child has a head, throat or stomach bleed, take your child to hospital for immediate medical attention and contact your HTC.



See Chapter 3 for more information on serious bleeds.

How did my child get haemophilia?

Haemophilia is caused by a change (mutation) in the genes. Once a gene has altered, the change may be passed on to future generations. Often people with haemophilia have a family member who also has haemophilia. However, around a third of children born with haemophilia have no previous family history of the condition.



See Chapter 2 for more information on inheritance.

Did I do something wrong during pregnancy to cause this?

No, certainly not. Haemophilia is caused by changes in the genes that are beyond our control. There is nothing you or your partner could have done to prevent your child having haemophilia.

What does mild, moderate and severe haemophilia mean?

Haemophilia can be mild, moderate or severe. The level of severity is directly related to the percentage of factor VIII (8) or IX (9) in the blood.

Knowing the factor levels helps to determine the appropriate treatment and can give you a guide as to what you can expect. In general, people with severe haemophilia can expect more frequent bleeds.

Each person's experience with haemophilia is unique. Over time, you will become familiar with your child's bleeding patterns and be able to predict what is likely to cause a bleed. As they get older, you can ask them about their symptoms.



See Chapter 2 for more information on mild, moderate and severe haemophilia.

Is haemophilia contagious?

No. People do NOT get haemophilia from living with or being near a person with haemophilia. It is only passed on through genetics.

Will it go away or change?

Haemophilia is a lifelong condition. However, it can be managed effectively.

The severity of haemophilia (mild, moderate or severe) does not change over a lifetime.

Within a family, males with haemophilia will nearly always have the same level of severity.

However, the factor level for females who 'carry the gene' is unpredictable and the level of severity can vary between family members. For example, a man with severe haemophilia who passes it on to all his daughters may have one daughter with mild haemophilia and another daughter who has inherited the gene but has normal factor levels and no bleeding problems.

Will my other children have haemophilia?

If you are a woman, you may carry the altered gene that causes haemophilia. In this case, some of your children may also inherit haemophilia or some of your daughters may carry the gene.

A man with haemophilia will pass the gene on to all his daughters, but not his sons.



See Chapter 2 for more information on inheritance patterns.



There are tests available to determine whether you or your partner have the gene for haemophilia. Your HTC can provide you with more information and advice about these tests. You can also be referred to a genetic counsellor if required.

What is the treatment?

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

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

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.



See Chapter 4 for more information on treatment.

What is factor replacement therapy?

Factor replacement therapy involves injecting the missing clotting factor into a vein or 'port' (a temporary device inserted under the skin to access the vein). Depending on how severe your child's haemophilia is, treatment may be required up to a few times per week to prevent bleeds from occurring (this is called 'prophylaxis') or whenever they have a bleeding episode (this is called 'on demand'). Your haematologist or Haemophilia Treatment Centre will discuss the appropriate treatment for your child with you.



See Chapter 4 for more information on treatment.

How will I know when my child has a bleed?

Your HTC or treating health professional will provide you with individual medical advice on how to recognise and manage a bleed.



See Chapters 3 and 4 for more information on bruises and bleeds and treatment.



If you are ever uncertain whether your child is having a bleed, contact your HTC for advice and support

What can I expect?

Every child will have their own individual experience with haemophilia.

- Babies usually have very few problems, with the exception of babies who require a medical procedure or have surgery such as circumcision. As your child becomes mobile, there may be more bruises and bleeds.
- Your child will be able to do most things that other children their age can do.
- Your child will be able to be cared for by babysitters, attend child care, preschool and participate in the normal school environment. You will just need to make sure that whoever is in charge knows about your child's haemophilia and what to do in an emergency.
- Your child can travel.
- Bleeds need to be treated promptly.
- The frequency of treatment with factor (factor replacement therapy) depends on the severity of your child's haemophilia, their tendency to bleed and the type of factor replacement therapy.
- Treatment is initially given in hospital. If your child requires regular treatment (prophylaxis) and you are comfortable to do so, you can learn to provide treatment at home.

If you have questions at any time, don't hesitate to contact the team at your HTC. They are happy to help you.

Who can help me, my family and my child?

Your HTC team has expertise in dealing with haemophilia and helping patients and their families at various stages of a child's life. The team includes the haematologist (specialist doctor), nurse, physiotherapist and a psychosocial professional who could be a psychologist, social worker or counsellor.



Read more about the HTC at the end of this chapter and in Chapter 4.

Haemophilia Foundations are national and state/territory community organisations that provide information and support and can connect you to other parents.



Read more about Haemophilia Foundations at the end of this chapter and in Appendix 1.

Frequently asked questions

What is a bleed?


The main problem for most people with haemophilia is internal bleeding, called 'bleeds'. Internal bleeds are most commonly into joints or muscles. They can happen as a result of an injury or without an obvious cause (sometimes called 'spontaneous bleeds'). If internal bleeding is not stopped quickly with treatment, it will result in pain and swelling.

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 or dental procedure, such as an operation, tooth extraction or skin biopsy.

Bleeds from minor cuts and scratches are usually not a problem and only need general first aid and some pressure at the site of bleeding. With deeper cuts or injuries, bleeding continues for longer if blood does not form a clot. Specialised treatment will then be needed so blood can clot normally.



Over a period of time, repeated bleeding into joints and muscles can cause permanent damage, such as arthritis in the joints and chronic pain.

 **Bleeds into the head, spine, neck, throat, chest, stomach or abdominal area are much less common but can be life threatening. If this happens, take your child to an emergency centre immediately and contact your HTC.**

How will I know when my child has a bleed?

Until your child is old enough to recognise what an internal bleed feels like (or can tell you they are having a bleed), you will need to look out for signs such as pain, unexplained crying or irritability, swelling, warmth in the area, not using one arm or not wanting to take weight on one leg. As they get older, you can ask them about their symptoms or they will be able to tell you when there is a problem.



If you are unsure whether your child is having a bleed, contact your HTC promptly for advice.

What do I do when my child has a bleed?

Your HTC or treating health professional will provide you with individual medical advice on how to assess and manage a bleed. If you are ever uncertain, contact your HTC for advice and support. Your HTC will give you information on who to call and what to do if you need advice after hours.



See Chapters 3 and 4 for more information on bleeds and treatment.

Does the bleeding stop?

People with haemophilia will bleed for a longer period of time, but not any faster, than people without haemophilia. This is because people with haemophilia are missing or have low levels of clotting factor in their blood.

It is a common myth that people with bleeding disorders will bleed to death from a cut or scratch. With appropriate first aid and treatment, bleeding from a cut or scratch will stop.



If normal first aid does not stop the bleeding from a cut, call your HTC. They will help you decide whether the bleeding can be managed by your local doctor or if your child needs specialist care at the HTC.

Internal bleeds into the joints and muscles require prompt treatment. This involves a combination of Protect, Rest, Ice, Compression, Elevation (PRICE) treatment, factor replacement therapy, and physiotherapy and rehabilitation.



See Chapter 4 for more information on treatment.

How common is haemophilia?

Haemophilia is rare, which explains why you may not have known much about it before you found out your child has the disorder.

Approximately 1 in 6,000 males has haemophilia A. Haemophilia B is less common and approximately 1 in 25,000–30,000 males has it.

The number of females affected by haemophilia is still being researched.

Condition	Occurrence in general population
Asthma	1 in 4
Diabetes	1 in 52
Spina Bifida	1 in 500
Down Syndrome	1 in 1,000
Haemophilia A	1 in 6,000 males
Haemophilia B	1 in 25,000-30,000 males

Can girls have haemophilia?

Females can 'carry' the gene responsible for haemophilia. Most females do not have symptoms of a bleeding disorder, but some may have a bleeding tendency. These females used to be described as 'symptomatic carriers'. If their factor levels fall in the range for mild haemophilia, they are now recognised as having mild haemophilia. In very rare cases, some females have particularly low factor levels causing them to have moderate or severe haemophilia. Some females with factor levels at the lower end of normal also experience abnormal bleeding.



See Chapter 2 for more information on haemophilia and females and inheritance.

Is haemophilia a 'royal disease'?

Haemophilia is caused by an alteration in the factor VIII or IX gene and can occur in any family.

Haemophilia has often been associated with European royal families and is sometimes called 'The Royal Disease'. This is because several members of the European royal families had haemophilia or carried the gene in the nineteenth and twentieth centuries. Queen Victoria of England (1819-1901) carried the altered factor IX gene causing haemophilia B. One of her sons had haemophilia and the gene was passed on through some of her children to the English, Prussian, Russian, and Spanish royal families. No living member of the current royal families of Europe is known to have haemophilia or carry the gene for it.

Does my child need to wear protective gear?

Current treatments mean that protective gear for everyday living isn't necessary. Everyone - whether they have haemophilia or not - should wear protective gear when participating in certain activities or sports; for example, a helmet should be worn when riding a bike or scooter, or standard safety gear when playing cricket.



Can my child exercise and play sports?

A good level of fitness can help reduce the number of bleeds. Your child should be encouraged to participate in a range of activities suited to them and that they enjoy.

There are some sports that are particularly good for people with haemophilia, such as swimming which develops strong muscles without causing impact to the joints. There are other sports, such as boxing, that are riskier for anyone whether or not they have haemophilia. People with haemophilia have been world champions in sports ranging from cycling to darts. Ultimately people with haemophilia can play most sports and their bleeding risk can be managed in consultation with their doctor. By the time your child is old enough to play sports you will be in a better position to judge what sort of sports you are happy for your child to play. Your HTC will be able to help you with information and guidance about sports.



See Chapter 6 for more information on exercise and sport.

How safe is factor product?

Haemophilia factor replacement therapy is essential to preventing or stopping life- and limb-threatening bleeding episodes. Making sure that this essential treatment product is safe from infections that can be transmitted by blood is a high priority for Australian governments and regulators, manufacturers and the bleeding disorders community. Manufacture of blood products, including plasma-derived factor concentrates, is carefully regulated and monitored to make sure that blood products are as safe as possible.

Many people with haemophilia are now treated with recombinant (synthetic) products which contain little or no human or animal material. There have been no reports of viruses being transmitted by recombinant products.

Some children and adults with haemophilia use plasma-derived treatment products. Before 1993 some people with bleeding disorders acquired HIV and hepatitis C from clotting factor treatment products made from human plasma. The blood supply is now tested for a number of bloodborne infections and there are several viral inactivation processes when these

treatment products are manufactured. As a result the risk of new infections from human blood products is now extremely low.



See Chapter 4 for more information on factor.

Are there any medications my child can't take?

Children with haemophilia should avoid medications such as aspirin or ibuprofen (e.g. Nurofen) that interfere with platelet function. Platelets are also important for clotting and these medications may worsen your child's bleeding tendency. Paracetamol (e.g. Panadol) is a suitable alternative.

Before you give your child anything prescribed by a health professional or complementary therapist (eg, naturopath), check with them whether it is safe for someone with a bleeding disorder. Apart from aspirin and ibuprofen, there are other medicines, vitamins and supplements that can interfere with blood clotting and healing. Your pharmacist may also be able to help with this.

However, in some circumstances your haemophilia doctor might recommend using some of these or similar medications, but will work it in carefully with the treatment plan to prevent bleeding. This is more likely in adults with haemophilia, for example, if they have heart disease and have a stent put in.



If you are unsure which medications are safe for your child, check with your HTC for advice.

What to expect

Each person with haemophilia has their own experience with the disorder. What happens with your child may be different to another child's experience.

Over time you will become skilled at recognising your child's patterns and when there are problems.

It is important, where possible, to be guided in your child's development by your HTC team. For example, the team can explain how physical activity can help prevent complications from an early age.

- Babies usually have very few problems, with the exception of babies who require a medical procedure or have surgery such as circumcision. As your child becomes mobile, there may be more bruises and bleeds. This is normal and your HTC will advise you on the appropriate care. Encouraging babies to roll, sit up and balance is essential for their physical development.
- Your child will be able to do most things that other children their age can do.



PARENT TIP

If your baby needs to have a medical procedure or surgery, your HTC will provide a plan to prevent bleeding.



- Your child will be able to be cared for by babysitters, attend child care and preschool. You will just need to ensure that whoever is in charge is aware of your child's haemophilia and knows what to do in an emergency. The HTC can provide an appropriate care plan for your child.

- Children with haemophilia participate, grow and learn in the normal school environment. Teachers are alert to the special needs of children with a variety of physical, emotional and intellectual needs. Talk to your child's teacher about haemophilia, your child's treatment program and what to do in an emergency. Your Haemophilia Foundation and HTC can provide information for teachers or talk to them directly.
- Your child can travel. Children with haemophilia can holiday with the family, go overseas, and spend time away from home, including school camps. There are a few things you should do if your child is travelling far from your HTC.



See Chapter 5 for more information on travel.

- Your child may sometimes have a lot of bruises, which may take weeks to fade. They may be a bit lumpier than usual and don't look very nice, but they are usually not harmful. Over time, you will get to know your child's bruising patterns and what's likely to cause them.



See Chapter 3 for more information on bruises.

- Older children may get bleeds from rough play or high-contact sports. Sometimes it can appear that they have bleeds for no reason at all ('spontaneous bleeds'). These bleeds can be a result of a minor injury that went unnoticed. Your HTC will advise on the appropriate management of these bleeds.
- Bleeds need to be treated promptly.



See Chapter 3 for more information on handling emergency situations. Prompt medical attention is required in the event of a serious bleed.

- The frequency of treatment with factor (factor replacement therapy) depends on the severity of your child's haemophilia and their tendency to bleed. Treatment is initially given in hospital. If your child requires regular treatment (prophylaxis) and you are comfortable to do so, you can learn to provide treatment at home.



Chapter 4 for more information on treatment.

- Factor replacement therapy is one element used to treat a bleed. There is also the PRICE treatment method and rehabilitation which are used to prevent complications to the joints and muscles. Your HTC team will guide you on the appropriate methods for your child.



See Chapter 4 and 6 for more information on physiotherapy and rehabilitation.

- As haemophilia is a rare condition, you may find that some health professionals outside of your HTC have limited experience with the condition. You might even find that you know more about haemophilia than some of these health professionals and, as a result, you may need to advocate for your child's needs.



See Chapter 4 for tips on advocating for your child.



If you have questions at any time, remember you can always contact your HTC. The team is happy to help. No question is too silly to ask. The team understands that you are learning about haemophilia and respect that you want what is best for your child. You are entitled and encouraged to ask questions and by doing so you will become more confident and informed about your child's condition.

Support for you and your child

Parents can feel isolated and may begin looking for support during this difficult time. You are not alone. There are many people and services available to help you and your child. These include:

- The Haemophilia Treatment Centre (HTC)
- Haemophilia Foundation Australia and local Haemophilia Foundations.
- Other parents of children with haemophilia
- Older children with haemophilia
- Trusted websites. (see page 1.22)

The Haemophilia Treatment Centre (HTC)

When you have a child with haemophilia, you will meet a wide range of health and medical professionals who are all there to support your child's needs.

Many of the health professionals you will encounter are part of the haemophilia team at the Haemophilia Treatment Centre (HTC). There is at least one HTC located in a major public hospital in all states and territories in Australia. The haemophilia team includes specialists in dealing with haemophilia and helping patients and their families. The HTC provides a comprehensive range of services, from medical treatment and advice to emotional support for your child and your family.



PARENT TIP

Build up a relationship with your Haemophilia Treatment Centre. If you are far away from a HTC, choose a GP you can trust and who can liaise with the HTC.

The HTC team generally includes:

- **Haematologists** – doctors with specialist expertise in blood and bleeding disorders such as haemophilia. These doctors provide explanations and guidance and will recommend the treatment that is appropriate for your child. They will review your child regularly, monitor their progress and adjust your child's treatment accordingly.
- **Specialist haemophilia nurses** – are in a dedicated role to provide nursing care and education to people with bleeding disorders. In most cases, haemophilia nurses will help you coordinate all your child's different needs at the HTC. Haemophilia nurses may also administer your child's treatment.
- **Psychosocial workers (a psychologist, social worker or counsellor)** – can assist you and your family in coming to terms with the diagnosis and help you understand the options available for your child.

The psychologist, social worker or counsellor can also assist you to work through other decisions such as whether to have another child.

The psychosocial professionals do not tell you what to do: they ensure you understand all the options available and help you decide what is best for you and your family.

- **Physiotherapists** – will guide and support you through your child's growth and physical development. The physiotherapist plays an important role in the prevention of long-term joint and muscle damage. The physiotherapist 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. Physiotherapists are also a good sounding board if your child is thinking of starting a new sport or fitness regime.

The HTC also has access to specialised laboratory services and to other specialised health professionals as required.

GPs, paediatricians and other health professionals will also be important in the care of your child. They will need to be aware that your child has haemophilia before undertaking any medical, dental or surgical procedure.

The way these health care professionals work varies slightly between HTC's. You will quickly become familiar with the way things are done in your Centre.

If you are treated outside of the HTC, the staff at your medical centre can consult with your treating doctor through videoconferencing (telehealth), email or phone consultation.

If you are unsure about how something works at your Centre, ask the staff. They are more than happy to assist.

What if I live in the country?

If you do not live in the city where your HTC is located, you will develop links with all the staff in the HTC team and they will refer you to your local hospital or medical centre and keep in touch with your local care team. You will likely have to make trips to the city to visit your HTC occasionally. Some HTC's make outreach visits to country areas, others may be able to organise some appointments by video link up. Check with your HTC to see what's available in your area.

Government support

Government financial assistance may be available to help you take care of your child if they have severe haemophilia.



***To see if you qualify for a carer's allowance, visit the Department of Human Services website and check the eligibility criteria:
www.humanservices.gov.au***

The psychosocial worker at your HTC may also be able to provide information on the allowances you may be eligible for and to help you with the application process.

Haemophilia Foundation Australia and local Haemophilia Foundations

You can recognise Haemophilia Foundations in Australia by their distinctive red 'H' logo. All Australian Haemophilia Foundations work cooperatively to provide the best possible service for your child and family.

The Haemophilia Treatment Centre can only pass your details on to the Haemophilia Foundation with your permission. However, you can always contact the Foundation yourself. Your call is most welcome and your Foundation is happy to be of service.

Haemophilia Foundation Australia (HFA)

Haemophilia Foundation Australia (HFA) is the national haemophilia body representing the Australian bleeding disorders community. All state and territory Foundations in Australia are members of HFA. HFA is based in Melbourne.

HFA is committed to inspiring excellence in treatment, care and support through representation, education and the promotion of research for haemophilia, von Willebrand disorder (VWD) and related bleeding disorders.

HFA publishes a regular magazine, e-news and other educational material and is involved in organising the biennial Australia/New Zealand Conference on Haemophilia and Rare Bleeding Disorders. Members of local Foundations are automatically entitled to a free magazine subscription and e-news from HFA and are welcome to contact HFA.

For more information on Haemophilia Foundation Australia visit:

www.haemophilia.org.au

Your local Foundation

There is a local Haemophilia Foundation in most Australian states and territories. Local Foundations provide support to people with haemophilia throughout their lifetime, and to their families and carers.

State/Territory Haemophilia Foundations:

Haemophilia Foundation ACT - www.hfact.org.au

Haemophilia Foundation New South Wales - www.hfnsw.org.au

Haemophilia Foundation Queensland - www.hfq.org.au

Haemophilia Foundation Tasmania - www.hft.org.au

Haemophilia Foundation Victoria - www.hfv.org.au

Haemophilia Foundation Western Australia - www.hfwa.org

If you live in South Australia or the Northern Territory, contact HFA for advice on local activities and support.

Local Foundations provide a range of educational materials, regular newsletters, social and educational gatherings such as meetings, women's, men's and grandparent groups, and community camps.

Some local Foundations offer subsidies to their members, such as discounted ambulance memberships and medical identification jewellery (e.g. MedicAlerts). Subsidies vary between states and territories and are determined by the needs of the local members.

Contact your local Foundation to find out what benefits are available for you. Contact details are listed at the back of this guide.

Other parents

There are many parents of children with haemophilia who have been through, or are going through, experiences and feelings to similar to yours. You don't need to feel alone.

Although each child's experience with haemophilia is unique, hearing other parents' stories can be a great source of support. Do not hesitate to make contact, as most of these parents are very eager to talk to you and help you in many different ways. This can often be arranged through your local Foundation.



PARENT TIP

It can help to speak to other families. Everybody remembers what it was like at the time of diagnosis and are happy to share with others.

"I think you learn most from just talking to other parents... it's really important to build up a network of people who know what you are talking about, and it's nice to know you are not alone."

Older children

Many parents find that meeting older children with haemophilia can be inspiring and encouraging. Children with haemophilia usually grow up going to regular schools, participating in most activities, getting a job and having a family of their own. Children and family members can also benefit from meeting other children with haemophilia



and sharing their experiences, feelings and challenges. Often older children can play a 'mentor' role to younger children with haemophilia.

Your HTC or local Foundation may be able to help introduce you to older children with haemophilia.

Trusted websites

The internet offers a wealth of information and some information is more reliable than others. It's normal to feel overwhelmed with where to start.

"I didn't know anything about haemophilia. It was really overwhelming, it was scary, our precious baby boy. We were determined to learn as much about haemophilia as we can. I did a couple of Google searches and got off that pretty quick! I decided to just go with the information from the HTC."



When searching for information on haemophilia, it's a good idea to start with the Haemophilia Foundation Australia website: www.haemophilia.org.au

The HFA website publishes information about haemophilia, useful resources, research, services and events as well as links to local and international haemophilia organisations and other trusted groups. It also has links to HFA's social media platforms. You will find a lot more detailed information in the articles in *National Haemophilia*. Just click on the *National Haemophilia* section and search the magazine on the topic of your choice.

Your local Haemophilia Foundation website will keep you up-to-date with the latest news, activities, newsletters and local services and support groups.

A list of local Haemophilia Foundation websites are listed above on page 1.20.

Your HTC can also direct you to relevant and appropriate information on the internet to help answer your questions. They may also have print publications they can give you.



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



For information and support for your emotional health and wellbeing, visit beyondblue: beyondblue.org.au

Understanding your feelings

When your child is diagnosed with haemophilia, you might feel a whole rollercoaster of emotions. It's common for parents to feel shocked, in denial, angry, scared, stressed, guilty or sad. Some parents are relieved their child has a diagnosis or optimistic that it will all be okay. This is normal. There is no right or wrong way to feel. Every parent is different and deals with things in their own way.



PARENT TIP

It can be tough at times, but you don't have to try and manage your feelings alone. It's okay to reach out to others for support.

Allow yourself time to adjust.

"Everyone deals with it differently. Some people cry, some learn everything they can. Others shut down. Whatever way is you is okay, as long as you are dealing with it."

Over time, most parents will find it easier to deal with their feelings about their child's haemophilia diagnosis. You will learn to manage your child's haemophilia and will have other people you can speak to who understand what you are going through.

It is important to take the time to care for yourself and keep healthy.

"It took a couple of years for us to accept our son's diagnosis and get a real handle on it. We immersed ourselves in the hospital appointments and monitoring his every move.

But as time went on, our confidence in ourselves rose and we began to feel positive about the future. Now it's not often that haemophilia impacts our lives. Through our experiences we have grown from the nervous and anxious parents of the past into the confident advocates of today."

Common reactions to a haemophilia diagnosis

Shock

Understandably, finding out their child has haemophilia can shock parents, particularly if this is the first time haemophilia has appeared in the family.

One parent said:

“We were devastated when we first found out. It was pretty upsetting.”

Denial

Denial is marked by thoughts such as:

“It isn’t possible. He can’t have haemophilia.”

“Maybe he doesn’t really have haemophilia. Maybe they mixed the tests up. Maybe...”

Sometimes parents try to deny the fact that their child has haemophilia and as a result might pay less attention to the symptoms.

Anger

Some parents might feel angry or frustrated. These feelings can be directed at others or towards oneself, particularly if you carry the gene and feel responsible for passing it on to your child. Just remember that if you carry the haemophilia gene, there was nothing you could have done to change this, so don’t be too hard on yourself.

You may also be thinking, ‘Why my child?’

Fear

Finding out your child has haemophilia can be scary, especially when you don't know much, if anything, about it. You will find there are plenty of people who can give you the information and assistance you want, from sophisticated medical information to friendly chats over the phone. An excellent place to start is your HTC or local Haemophilia Foundation. They can put you in touch with other families going through similar experiences - but remember, everyone's journey with haemophilia is different.

Guilt

Many mothers say that they felt guilty, because in many cases the mother transmits the gene responsible for haemophilia. Fathers or grandfathers may feel guilt too.

It is not uncommon to feel guilt when you need to go to the hospital for treatment or a check-up.

You did not choose for your child to have haemophilia, just as you cannot choose hair or eye colour.

Guilt can make some parents want to compensate their child for their haemophilia. These parents may try to do too much. Doing too much can wear you out quickly. Taking good care of yourself will help you to take good care of your child.

Grief and sadness

It is common for parents to feel grief and sadness about their child's haemophilia, particularly if the diagnosis was unexpected. Parents may mourn for the 'normal' child they had hoped for, and be sad about the pain their child may endure.

Sadness is a normal part of coming to terms with the situation and is a sign that parents are learning to accept the diagnosis. However, if these feelings become difficult to manage over time, you should seek help from your GP or your psychosocial worker at your HTC.

Stress

Receiving a haemophilia diagnosis can be very stressful for parents, particularly if their child has had to go to hospital for treatment. At the same time as dealing with the diagnosis, parents often find themselves juggling other responsibilities such as arranging care for their other children or just learning how to look after their new baby. As their child gets more mobile, parents can feel like they have to constantly keep an eye on their child, leaving them feeling overwhelmed.



If you are feeling overwhelmed or stressed, please keep in mind that things will get easier over time. There is support available for you. Speak to your GP or the psychosocial worker at your HTC.

Optimism

Some parents look on the bright side and think how fortunate their child is compared to some other children or how lucky they are that treatment options are so good these days.

Relief

When parents get the diagnosis of haemophilia, they might feel relieved, especially if they have been worried for some time. Now that there is a diagnosis, parents can start to understand the condition and get help for their child.

If you have had any of these feelings, be assured that they're all perfectly normal emotions. It's also normal to feel some of these emotions as time progresses. Over time, you will learn to deal with your child's haemophilia and readjust.



If you feel you are 'stuck', that these feelings are not going away or are becoming more intense and frequent, it may be a good idea to seek professional help. It's okay to ask for support if you need it. Your HTC or GP can provide you with emotional help and advice for coming to terms with your child's haemophilia diagnosis.

Tips for helping you get through the tough times

The time when you receive a haemophilia diagnosis, and the early days following diagnosis, are likely to be very stressful for you and your family.

Remember you are not alone. Your HTC is always there to support you.

“Thinking back over the last years, it was important to us to see that our boys now can live life and do things like any other child. As parents, you get through. Kids with haemophilia are resilient and surprise you every day. Our boys don’t want to be treated any differently, they are just like their friends (with a few limitations). We don’t sweat the small stuff anymore.”

Anxiety and worry are commonly experienced feelings for parents of newly diagnosed children. Here are some tips to help reduce anxiety or worry:

- Try relaxation exercises such as yoga, meditation or deep breathing.
- Recognise your thinking. Are you only focusing on the worst case scenario? Instead, ask yourself “how would someone else think about this?”
- Put some time aside to worry about things and save your worries up for then.
- Learn about how mindfulness can help – bring your attention to something in the present moment. When your mind is busy worrying about the future you are losing precious moments with your child in the present.
- Contact your local Haemophilia Foundation and find out about support and activities for parents and families. Many parents comment on how much they really value the opportunity to make friends and share



PARENT TIP

It’s important to remember to take care of yourself so you can take good care of your child. Try to ensure you’re getting enough sleep, eating a balanced diet and exercising.

experiences and tips on managing haemophilia from others in the same situation.

If you are feeling down, try:

- Stimulating your mind and body. Get active, walk, run, swim, cycle or take the stairs. All these activities increase your heart rate and makes your brain release 'feel good' hormones.
- Taking time out for yourself doing something you enjoy. Try going out for a coffee with a friend, playing music, going to a movie, playing with your child or going out with your partner.
- Recognising your thoughts. Are you thinking negatively about things? If so, it can help to identify your main concern and then ask yourself these questions to come up with a more realistic thought:
 - Is this thought based on fact or an opinion?
 - What evidence am I overlooking that doesn't support this thought?
 - Is this thought helpful?
- Trying to think of as many things as possible that you are grateful for.
- Practising some self-compassion. Forgive yourself for whatever you feel guilty about.



For more information and strategies to maintain your emotional wellbeing, visit [beyondblue: www.beyondblue.org.au](http://www.beyondblue.org.au) or refer to the tip sheets from the Australian Psychological Society: www.psychology.org.au

Your partner's reaction

Learning your child has haemophilia may be stressful for the whole family. Everyone will handle the news in their own way, including your partner.

When you're ready, try to talk with your partner about how each of you are feeling about your child's haemophilia. Try to understand that your partner may be handling the diagnosis differently from you and try not to place unrealistic expectations on them.

“(My child’s) Dad internalised his emotions while I wanted to talk it through. The old different sexes from different planets - it made it difficult.”

“I knew very little about haemophilia...It was all I could think about for weeks. I was still in denial for ages. I would cry every time a new bruise appeared. My husband was very down to earth and accepting. He would say ‘He has a bleed and we treat it...’ How simple!”



If you or your partner are feeling withdrawn or depressed over an extended period of time, you may wish to seek professional help.

Grandparents and extended family

Grandparents and extended family members often play an important role in supporting children and these relationships can have a very positive influence on children’s development.

It is also normal for grandparents and other family members to be concerned for their children and grandchildren.

As haemophilia is an inherited condition, a grandparent may also have haemophilia themselves, or carry the haemophilia gene. In this instance, a grandparent may feel a sense of guilt when their grandchild is diagnosed with haemophilia.



Grandparents and extended family might find it helpful to learn more about haemophilia, the treatments that are available, and how they can help.

They may also find it valuable to connect to other grandparents or families through local Haemophilia Foundations and to share experiences.

"My husband's mum came to a Foundation afternoon tea and saw my friend's son who has haemophilia and was just beside herself, because he was scootering around, and he was just a little boy, totally normal, he wasn't covered in bruises and he wasn't in a wheelchair. It was a really important moment for them."



Your HTC is a good place for family members to start learning more about how they can help. A chat on the phone or a meeting with a haemophilia nurse, psychologist, social worker or counsellor can be a reassuring first step for them.

References

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This resource was reviewed by:

Dr Moana Harlen from Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group; Janine Furmedge, 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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