

## WHAT IS HAEMOPHILIA?

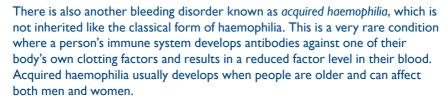
Haemophilia is an inherited bleeding disorder where blood doesn't clot properly. It is caused when blood does not have enough *clotting factor*. A clotting factor is a protein in blood that controls bleeding.

There are two types of haemophilia. Both have the same symptoms.

Haemophilia A is the most common form and is caused by having reduced levels of clotting factor VIII (8).

Haemophilia B, also known as Christmas Disease, is caused by having reduced levels of clotting factor IX (9).

Haemophilia is not contagious.



# How common is haemophilia?

Haemophilia is rare. In Australia there are more than 2,800 people with haemophilia, who are nearly all male. Approximately one in 6,000 males has haemophilia A. Haemophilia B is less common and approximately one in 25,000-30,000 males has it. Haemophilia is found in all races and all socio-economic groups. Haemophilia in females does occur but is very rare. However, some females who carry the genetic alteration that causes haemophilia can also have bleeding problems.

# What happens when you have haemophilia?

Haemophilia is a lifelong condition. It can't be cured, but with current clotting factor treatments it can be managed effectively.

The common belief that people with haemophilia could bleed to death from a cut is a myth. A person with haemophilia does not bleed any faster than anyone else, but the bleeding continues for longer if it is not treated and may lead to a delay in healing. Minor cuts and scratches are not a problem and need only



a Band-Aid® and some pressure at the site of bleeding. With deeper cuts or injuries, bleeding continues for longer if blood does not form a tough, adherent clot where the blood vessels have been damaged. Specialised treatment will then be needed so blood can clot normally.

Internal bleeding episodes or 'bleeds' are the main problem for most people with haemophilia. Bleeds are most commonly into joints or muscles. They can happen without an obvious cause (sometimes called 'spontaneous'), or as a result of injury.

If internal bleeding is not stopped quickly with treatment, it will result in pain and swelling. 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, the person with haemophilia should attend an emergency centre immediately and the Haemophilia Centre should also be contacted.

There is at least one specialist Haemophilia Centre in every Australian state or territory, located in a major public hospital. The Haemophilia Centre has a team of health professionals, including doctors, nurses, physiotherapists, and social workers or counsellors, who specialise in the treatment and care of people with bleeding disorders.

# **HOW BLEEDING STARTS AND STOPS**



- The **capillary** (small blood vessel) is injured and blood leaks out.
- The capillary tightens up to slow the bleeding.
- Then blood cells called **platelets** make a plug to patch the hole.
- Next, many clotting factors in plasma (part of the blood) knit together to make a clot over the plug. This makes the plug stronger and stops the bleeding.
- In haemophilia, there is not enough factor for the clot to stay together, so bleeding continues for longer than usual, but not faster.

## LEVELS OF SEVERITY

There are three levels of severity in haemophilia: mild, moderate and severe. The level of severity depends on the amount of clotting factor in the person's blood. A person with haemophilia will have the same level of severity over their lifetime, eg a person with severe haemophilia will always have severe haemophilia. Within a family, males with haemophilia will also have the same level of severity, eg if a grandfather has severe haemophilia and his grandson has inherited haemophilia, his grandson will also have severe haemophilia.

The normal range of factor VIII and factor IX in a person's blood is between 50% and 150%

### Mild haemophilia

5 – 40% of normal clotting factor

- Usually only have bleeding problems after having teeth taken out, surgery or a bad injury or accident
- Might never have a bleeding problem.

## Moderate haemophilia

I – 5% of normal clotting factor

- Might have bleeding problems after having teeth taken out, surgery or a bad injury or accident
- May have bleeding problems after minor injuries, such as sporting injuries
- Rarely have a bleed for no obvious reason.

# Severe haemophilia

Less than 1% of normal clotting factor

- Often have bleeds into joints, muscles and soft tissues
- Can have bleeds for no obvious reason, as well as after surgery, dental work or injuries including minor bumps or knocks

# SIGNS AND SYMPTOMS OF HAEMOPHILIA

# How is haemophilia diagnosed?

Haemophilia is usually diagnosed through:

- The physical signs that a person has unusual bleeding problems And
- Checking the family history for bleeding problems And
- Laboratory tests on a blood sample for a person's clotting factor levels. If a male has low factor VIII levels, he has haemophilia A. If he has low factor IX levels, he has haemophilia B. The laboratory tests will show whether he has mild, moderate or severe haemophilia.

## First signs

Children with severe haemophilia are usually diagnosed in the first year when their parents or health professionals notice unusual bruising or bleeding problems or there is a family history of haemophilia. Most babies with haemophilia do not have bleeding problems at birth. However, some bleeding problems may appear at birth or soon after. Haemophilia may be suspected if babies have internal bleeding or unusual swelling or bruising after delivery, continue to bleed after a heel prick or after circumcision, or have excessive bruising after immunisation.

If there is a family history of haemophilia, a sample of the baby's blood can be tested after birth to check the factor VIII or IX levels and see whether the baby has haemophilia. Testing should be repeated when the baby is six months of age to confirm the results. Testing can also be done during pregnancy to determine if the baby has haemophilia (see CARRYING THE GENE, page 9).

When all babies begin to crawl and walk, they can knock into hard objects as well as having twists, falls or sitting down with a bump. Small bruises are common in children with severe haemophilia and are not usually dangerous or painful – the padding of "baby fat" is a natural protection. Bruising easily might be the first sign they have a bleeding problem. As with anyone, a knock or bang or bruise on the head needs some extra attention. In a child with severe haemophilia, these might become serious and should be checked by a haemophilia specialist. Sometimes toddlers or children may have a bleed into a joint. Painful swelling or reluctance to use an arm or a leg can be a sign that a bleed has taken place. The specialist nurses and physiotherapists at the Haemophilia Centre can advise on haemophilia issues during these normal childhood stages.

Children with haemophilia can have all the normal immunisations at the usual age. Informing the nurse or doctor giving the immunisation that the baby or toddler has haemophilia is important. Injections can be given subcutaneously, into the fatty tissue under the skin, rather than into the muscle, and pressure put on the skin where the child was injected. This reduces the risk of

bruising and bleeding. However, changing the way of giving immunisations isn't necessary for all children with haemophilia. If you have a child with haemophilia, contact the Haemophilia Centre for advice on how your child should be immunised.

As children grow they learn to recognize that bleeding may be occurring. Even before pain or swelling becomes obvious they may recognize a "funny feeling" which is one of the earliest signs of a joint bleed.

Mild or moderate haemophilia might not be diagnosed until children are older, or sometimes until they are adults. If they have mild haemophilia, minor injuries may heal normally because there is enough clotting factor activity in the blood. The bleeding problem might not be noticed until the person has surgery, a tooth taken out or a major accident or injury.

## Growing up with haemophilia

With treatment and support from their Haemophilia Centre, most people with haemophilia can live relatively normal healthy lives. Haemophilia treatment has changed a great deal in recent years. Unless there are complications, young people can expect to grow up with fewer or no joint problems from their haemophilia. With sensible precautions, they can play most sports, exercise and look forward to a full and productive life.

Although the level of haemophilia severity usually doesn't change during a person's lifetime, people tend to have more bleeding episodes as children than as adults. The reasons for this are not clear. Sometimes also the factor VIII level rises in later adult years in people with mild haemophilia A. This rarely occurs in people with haemophilia B.

# INHERITANCE AND HAEMOPHILIA

Haemophilia is an inherited condition and occurs in families. Haemophilia is caused by a mutation or alteration in the gene making factor VIII or IX, and this altered gene is commonly called the "haemophilia gene". This altered gene is passed down from parent to child through generations. Men with haemophilia will pass the altered gene on to their daughters but not their sons. Women who carry the altered gene may pass it on to their sons and daughters. Sons with the altered gene will have haemophilia. Daughters with the altered gene may have normal or reduced factor VIII levels and some will not have symptoms, while others may have a bleeding tendency.

#### Cells and chromosomes

Every person has millions of cells that make up their body. At the centre of each cell are 46 chromosomes arranged in pairs. The chromosomes contain the person's genetic information or 'genes', which determine the person's individual characteristics, such as the colour of their hair or their eyes.

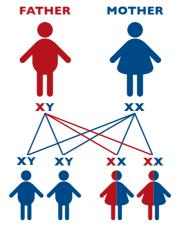
#### Sex determination

Everyone has a pair of 'sex' chromosomes, which decide what gender they are. Each parent contributes one of these chromosomes to their children. Females have two X chromosomes, and receive one from each parent. Males have one X chromosome, which they receive from their mother, and one Y chromosome, which they receive from their father. There are four possible combinations of sex chromosomes that children can receive from their parents.

### **Haemophilia Genetic Inheritance**

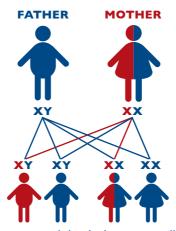
or = has an X chromosome with the "haemophilia" genetic alteration
or = has an unaltered X chromosome

## When the father has haemophilia and the mother is unaffected



None of the sons will have haemophilia. All of the daughters will carry the gene. Some might have symptoms.

# When the mother carries the altered gene causing haemophilia and the father is unaffected



There is a 50% chance at each birth that a son will have haemophilia. There is a 50% chance at each birth that a daughter will carry the gene. Some might have symptoms.

#### **Inheritance**

The genes for making factor VIII and IX are located on the X chromosome. Because females have two copies of these genes, one inherited from each parent, women with an altered factor VIII or IX gene usually have another copy that is not altered. This helps factor VIII and IX to work properly in the blood clotting process and is often enough to control bleeding.

However, the Y chromosome does not have a gene to produce these factors. Males with an altered factor VIII or IX gene on their X chromosome do not have another factor VIII or IX gene to help with blood clotting and will have haemophilia. If a male with haemophilia has children, all his daughters will carry the haemophilia gene because he will pass the altered factor VIII or IX gene on to them on his X chromosome. His sons will not have haemophilia as his 'normal' Y chromosome is passed on to them and they receive their X chromosome from their mother.

Women can carry the genetic alteration causing haemophilia even if they don't have symptoms. A woman who carries the altered gene can pass it on to both her sons and her daughters. With each pregnancy, there is a 50% chance her male baby will have haemophilia or a 50% chance her female baby will carry the altered gene.

## No family history of haemophilia

In about one third of people born with haemophilia, there is no history of the disorder in the family. This happens when a genetic mutation in the factor VIII or IX gene occurs for the first time in the family during reproduction and is passed on at conception. It is often called a new or spontaneous mutation. Once haemophilia appears in a family the altered gene is then passed on from parents to children following the usual pattern for haemophilia.



# CARRYING THE GENE

# Clotting factor levels and symptoms

Many girls or women who carry the altered factor VIII or IX gene causing haemophilia (the "haemophilia gene") do not have signs or symptoms of a bleeding disorder.

However, some girls or women who carry this gene have a bleeding tendency. They are often described as "symptomatic carriers". If their factor levels fall in the range for mild haemophilia (5-40% of normal clotting factor), they may sometimes also be referred to as having "mild haemophilia". In very rare cases, some girls or women have particularly low factor levels causing them to have moderate or severe haemophilia.

Examples of having a bleeding tendency may include:

- Bruising easily
- Heavy menstrual bleeding. This may lead to low iron levels or anaemia
- Excessive bleeding after dental surgery or extractions, other surgery and medical procedures, injuries or accidents
- Prolonged bleeding after childbirth
- Females with very low clotting factor levels may also have joint or muscle bleeds.

All females who carry the gene should have testing for their clotting factor levels. Unlike males with haemophilia, where the factor level is the same within the same family, the factor level in females who carry the gene is unpredictable and varies between family members. Women and girls with lower levels should have theirs checked periodically, as their factor levels may change with age, pregnancy and hormonal medications. If their factor level is low, they will need a treatment plan to prevent bleeding problems and manage any situations that occur.

### **Genetic testing**

A normal factor VIII or factor IX level test will not tell women or girls whether they carry the altered gene causing haemophilia. Some women or girls may have normal factor levels, but still carry the gene.

A common time for testing whether a girl or woman carries the gene is when she reaches childbearing age and can understand the process and implications fully and make the decision for herself. Finding out whether she carries the gene is a process which will take time, sometimes many months. This may involve:

- Discussion with a haemophilia specialist and/or genetic counsellor
- Weighing up the pros and cons of genetic testing with advice and support from specialists, counsellors and other experts - for example, the role of genetic testing in understanding her bleeding disorder; its effect on her perception of herself and on her relationships; her personal understanding of what it's like to have haemophilia; the impact on children and other family members; her personal religious and cultural beliefs; future disclosure obligations and implications for life or income protection insurance; any costs involved; and other issues relevant to her personal situation
- Looking at the family tree to identify other family members who may carry the gene
- Blood tests for other affected family members (eg, a man with haemophilia) to identify the particular genetic mutation causing haemophilia in her family
- Blood tests for the woman to see if she has the same family genetic mutation.

Many people find that undertaking these tests gives them a lot to think about. The Haemophilia Centre can help with information and advice about genetic testing and can provide a referral to a genetic counsellor, if needed. Women, their partner, parents or family can talk to the Haemophilia Centre or genetic counsellor individually or together prior to testing and many find it helpful.

If a person starts exploring genetic testing but decides against it, there is no obligation to complete the process.

For more information about genetic testing, see the Policies and Position Statements on the Human Genetics Society of Australasia web site – www.hgsa.org.au.

## Planning a family

For people with haemophilia or women who carry the gene, planning a family can raise a number of questions:

- Will their children have haemophilia or carry the gene?
- If so, how will this affect them?
- How can they find out?
- What are the options for planning a family?
- How can a mother who carries the gene plan for a safe pregnancy and delivery?
- Who will help with all of this?

Haemophilia Centres can help with questions about having children. It may be helpful to review the information about how haemophilia is passed on to children (see INHERITANCE AND HAEMOPHILIA, page 6).

Often people have a particular view of haemophilia based on their memories of their brother, father or grandfather's experience. Treatment for haemophilia has improved a great deal over the years and it can be valuable to learn more about how haemophilia is treated now and to speak to other people with haemophilia or parents of children with haemophilia or the Haemophilia Centre to see how things have changed. The Haemophilia Centre can also give a referral to a genetic counselling service that specialises in bleeding disorders.

## **Pregnancy and childbirth**

With good management, women who carry the altered gene causing haemophilia have no more problems with delivering a healthy baby than other mothers. However, it is very important to plan and prepare as much as possible.

#### This involves:

- Ideally, if planning a pregnancy, discussing this with a haemophilia specialist who may refer to a genetic counsellor
- When the pregnancy is confirmed, contacting the Haemophilia Centre for advice on local obstetric services with experience of haemophilia
- Asking the haemophilia and obstetrics teams to consult with each other to plan for a smooth and safe pregnancy and delivery and care for the newborn

- Checking with the Haemophilia Centre before having any invasive procedures, such as chorionic villus sampling or amniocentesis
- Discussing suitable choices for anaesthesia, especially an epidural, with the Haemophilia Centre and obstetrics teams.

A normal vaginal delivery is usually recommended unless there are obstetric complications.

## Identifying the sex of the baby

If a pregnant woman knows she carries the altered gene causing haemophilia, it is advisable to determine the sex of the baby before birth, preferably with a non-invasive test with minimal risk to the foetus, such as ultrasound. A male baby is more likely to be affected by haemophilia than a female. The woman and her partner can choose if they want to be told the sex of the baby or not before delivery even if the haemophilia and obstetric teams are aware. If neither the couple nor the medical staff know the sex of the baby and no other genetic testing of the foetus has been carried out, the pregnancy and birth will be managed as if the baby is a male with haemophilia to ensure the baby is delivered safely.

## Testing for haemophilia before birth

For a woman or couples who wish to test for haemophilia before birth, there are two main testing options:

- Prenatal diagnostic testing: a test during the pregnancy to check the sex of the baby. If it is male, further testing can check for the family gene mutation or alteration, which will show if the baby has haemophilia
- IVF with pre-implantation genetic diagnosis (PGD): using IVF technology to test embryos for the family gene alteration, before embryo implantation and pregnancy.

For these options to be available the gene alteration in the family must be known.

A genetic counsellor can explore these reproductive options with the woman or the couple in further detail, along with any implications (see "weighing up the pros and cons" under GENETIC TESTING, page 10). There may also be substantial costs involved for these tests and procedures and it may be valuable to clarify this and options for support beforehand.

If a pregnant woman has a history of haemophilia in the family and does not know whether she carries the gene, it is important to let the obstetrics team know so that they can plan a safe delivery of the baby with the haemophilia team.

## **TREATMENT**

There are a variety of treatment products used to treat haemophilia.

## • Clotting factor concentrates

**Recombinant factor** is the most widely used type of concentrate. This is made by genetic engineering and contains little or no material from human blood or animals. There are several brands available manufactured by different pharmaceutical companies.

**Plasma-derived factor concentrates** are also used by some people. These are made from the plasma (pale yellow fluid part) in human blood.

Clotting factor concentrate can be given:

- "On demand" before surgery, childbirth or dental treatment, or after an injury or accident, or once a bleed has started.
- As "prophylaxis" taken regularly, two to three times a week, to prevent bleeds or reduce bleeding from injury.

Factor concentrates are infused (injected) into a vein at home by parents trained to treat their child, or by people themselves when they are confident enough to do it, or at the Haemophilia Centre.

# Desmopressin (DDAVP)

This is a synthetic hormone which releases the body's stored factor VIII into the bloodstream to help blood clot. It is used for treating some people with mild haemophilia A and some women with bleeding disorder symptoms. DDAVP can be given as a slow injection into a vein, but may also be given as an injection subcutaneously (into the fatty tissue under the skin), or in special circumstances as a nasal spray.

#### • Tranexamic acid

This slows blood clots from breaking down after they have been formed. It can help to treat mouth or nosebleeds, gut bleeding or bleeding after dental work. Most commonly it is taken as tablets, syrup or in a mouthwash.

Hormone treatment, such as oral contraceptives (birth control pills), can help women who have heavy menstrual bleeding. The hormones can increase factor VIII levels.

#### **Inhibitors**

After treatment with a clotting factor product, some people with haemophilia may develop antibodies – known as 'inhibitors' - which make treatment less effective. There are a number of ways to treat inhibitors and many people are successful in overcoming them while others have ongoing problems.

## How often do people need treatment?

Current treatment for people with moderate or severe haemophilia aims to prevent bleeding, pain and joint damage. In Australia the usual treatment for most children and young people with severe haemophilia is prophylaxis, where factor concentrate is injected twice to three times a week to keep factor levels high enough to prevent 'spontaneous' bleeds. Many children and young people have benefited from prophylaxis, which reduces the risk of developing the arthritis and joint problems often experienced by those older people who grew up without adequate treatment due to limited product. Treatment also involves exercise guided by a haemophilia physiotherapist. This helps to prevent bleeds and protect joints as well as maintaining a healthy body and mind.

Even when treating with factor replacement regularly, bleeding into joints and muscles may still occur. To recover fully from a bleed, people with haemophilia are advised to apply the RICE principles (Rest, Ice, Compression, Elevation) when they have a bleed and to work with their Haemophilia Centre team, including their haemophilia physiotherapist, to rehabilitate the joint or muscle back to full function.

Most people with haemophilia will need treatment for injuries apart from minor cuts and scratches or in preparation for surgical and some dental procedures.

People with mild haemophilia will not need prophylaxis and will only need treatment for a bleed when it occurs, usually after trauma or injury, or when they are preparing for surgery or some dental work.

The local Haemophilia Centre team will help with learning how to recognize a bleed and deal with it promptly, and how to prevent and rehabilitate injuries and bleeds.



## **Treatment product safety**

Haemophilia treatment product safety is a high priority for the Australian Red Cross Blood Service, government agencies such as the National Blood Authority and the Australian government regulator, Therapeutic Goods Administration, manufacturers, and the bleeding disorders community. Manufacture of blood products, such as plasma factor concentrates, is carefully regulated and monitored to make sure that blood products are now as safe as possible from infections that can be transmitted by blood, such as Human Immunodeficiency Virus (HIV), hepatitis B and C and variant Creutzfeldt-Jakob Disease (vCJD):

- In Australia blood donors are screened and blood donations are tested for HIV, hepatitis B and C, human T-cell lymphotropic virus (HTLV) and syphilis
- 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
- Most people are now treated with recombinant clotting factor, which is genetically engineered and contains little or no human or animal material.
   There have been no reports that viruses have been transmitted by recombinant products.

In Australia during the mid-1980s some people with haemophilia acquired HIV from contaminated 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.

The risk of new infections from using human blood products is now thought to be extremely low. However it cannot be entirely excluded, particularly if the risk came from a new or unknown type of blood-borne virus or other micro-organisms causing disease. Because of this, people using these products and patient advocacy organizations such as HFA continue to take a strong and watchful interest in product safety.

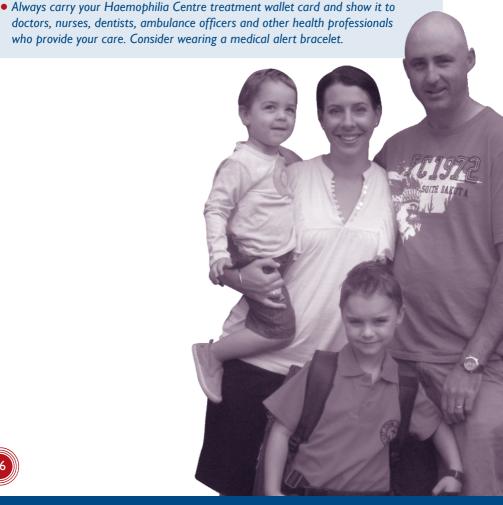
# What about those already affected by HIV or hepatitis C?

- Ongoing support is needed to help with the social, emotional and health impacts
- People with hepatitis C are advised to keep a regular check on their hepatitis C and their liver health
- People with HIV need care from a doctor and health care team specializing in HIV as well as from the Haemophilia Centre team
- HFA continues to provide advocacy, education and support.

# Tips for people with haemophilia or girls/women who carry the gene:

- Stay in regular contact with your local Haemophilia Centre team and make sure you keep up with anything new
- A regular review may be recommended by your Haemophilia Centre, depending on the severity of your bleeding disorder and your individual needs
- Report all joint or muscle bleeding to your Haemophilia Centre team so that each episode can be properly assessed and rehabilitated
- Let your dentist or your doctor know you have a bleeding disorder so that any
  procedures such as surgery or dental procedures that may result in bleeds can be
  managed in liaison with your Haemophilia Centre team

• If you use treatment product, know which one you use and your usual dose



# LIVING WELL WITH A BLEEDING DISORDER

Health and wellbeing are important to keep in mind. This can mean taking the opportunity to enjoy what life has to offer, maintaining a healthy lifestyle and good relationships and participating in all sorts of activities, including play, travel, sports, career and other activities that are sustaining or inspiring.

At the various stages of life, issues can arise for a person with a bleeding disorder or their family that impact on their ability to enjoy their life. It could be as simple as knowing how to arrange the necessary documents and treatment product to travel. Or for parents, how best to help a child to play and have fun while dealing with the potential for bruises and bleeds. Or it could be dealing with more complicated situations and emotions such as feeling overwhelmed by diagnosis, or that you or your child is somehow "different" from others, or taking the next step in a personal relationship.

Haemophilia is part of life but doesn't need to dominate it.

# What do people with bleeding disorders suggest? You are not alone

- Stay in contact with the Haemophilia Centre. The Haemophilia Team is there to help and can give you advice or talk over any problems or concerns
- Keep in touch with your Haemophilia Foundation. State and Territory
  Haemophilia Foundations have newsletters to keep members updated
  and social activities such as family camps, men and women's groups and
  grandparents' groups where people can meet, talk about common
  experiences and enjoy a meal or a day out. Haemophilia Foundation Australia
  also has a Youth Program run by young people affected by bleeding disorders.

#### Be informed and aware

- Know about your or your child's condition and how best to manage it
- Develop a relationship with the Haemophilia Team to keep in touch about your or your child's wellbeing and any health issues that might arise.
- Keep up with the latest information on treatments and services

# **Control and manage risks**

 You or your child can live a normal active life, but everyone's experience is different. Know about your limits and plan around them.

With knowledge and planning most people live well with haemophilia and lead active and independent lives.



# MORE INFORMATION

For more information about haemophilia, talk to your doctor, your local Haemophilia Centre or contact Haemophilia Foundation Australia (HFA).

#### How to find out more about:

- Your State/Territory Haemophilia Foundation?
- Your local specialist Haemophilia Centre?

# For up-to-date contact details:

- See the HFA web site www.haemophilia.org.au
- Or phone HFA on 1800 807 173

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## SOURCES AND ACKNOWLEDGEMENTS

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**Important Note:** This booklet was developed by Haemophilia Foundation Australia for education and information purposes only and does not replace advice from a treating health professional. Always see your health care provider for assessment and advice about your individual health before taking action or relying on published information.

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