Living with mild haemophilia: a guide

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UNDERSTANDING MILD HAEMOPHILIA

Mild haemophilia is a very manageable health condition. If you have mild haemophilia it may have little impact on your life as long as you know what to do and how to manage it.

Haemophilia is a rare health condition where a person's body has problems forming blood clots. It means that if this person has an injury causing bleeding, they may bleed for longer or their blood will clot more slowly than other people.

People with mild haemophilia may only have bleeding problems requiring treatment when they have a serious injury or wound, for example, after an accident, surgery or dental extractions. If they have not had any injuries or operations, they might not even be aware they have mild haemophilia and might not be diagnosed until they are older.

Many people with mild haemophilia rarely have problems with bleeding and there may be years between bleeding episodes. Mild haemophilia may only have a minimal impact on the person's life as long as they know what to do and how to manage it.

Important things to know if you have mild haemophilia:

- What type of haemophilia you have
- How to prevent bleeding and how to deal with it when it happens
- When to seek help
- Where to go for help and more information
- What you need to tell other people.

WHAT IS HAEMOPHILIA?

What's your factor deficiency?

If you or your child has haemophilia, it is important to know what type of haemophilia it is:

- Is it haemophilia A/factor VIII (8) deficiency?
- Or haemophilia B/factor IX (9) deficiency?

Each type of haemophilia requires a different clotting factor treatment.

Your Haemophilia Centre will give you a wallet-sized treatment card with brief details about your or your child's diagnosis, recommended treatment and who to contact in an emergency. Keep this card on you and show it to doctors, nurses, ambulance drivers and other health professionals who provide your or your child's care.

Haemophilia is an inherited bleeding disorder where a person's blood doesn't clot properly. It results from not having enough clotting factor in the blood. A clotting factor is a protein in blood that helps control bleeding.

When a person has an injury which causes bleeding, over 20 proteins are involved in the chain reaction to make a clot which stops the bleeding. Two of the key proteins are clotting factor VIII (8) and clotting factor IX (9).

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

Haemophilia A is the most common form and results from having **lower than normal levels of factor VIII** (8).

Haemophilia B, also known as Christmas Disease, results from having **lower than normal levels of factor IX** (9).

Haemophilia is a lifelong condition. It occurs when a person is born with an altered factor VIII or factor IX gene. It is not contagious.

As yet there is no cure for haemophilia. However, there are effective treatments to manage and prevent its symptoms.

In Australia a child born with mild haemophilia today has a similar life expectancy to other Australians.

How common is haemophilia?

Haemophilia is rare. In Australia there are approximately 2,400 people with haemophilia, who are nearly all male. Worldwide 1 in 6,000 – 10,000 males are born with haemophilia.

Haemophilia does occur in females, but this is very rare. However, some women and girls who carry the haemophilia gene also experience bleeding problems. If females have low levels of clotting factor in their blood, with levels falling in the range for mild haemophilia, they are sometimes described as having mild haemophilia or as being a "symptomatic carrier".

Haemophilia is found in all races and socio-economic groups.

WHAT IS MILD HAEMOPHILIA?

Approximately half of all people with haemophilia in Australia have the mild form. People with mild haemophilia generally have between 5% and 40% of clotting factor VIII or IX, which is usually enough to protect them against bruising and minor injury.

The normal level of factor VIII or IX in a person's blood is between 50 and 200%.

Levels of severity

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 • Females may have bleeding problems with menstruation or childbirth • Might not be diagnosed until well into middle age if not taking part in contact sports and have not had any injuries or operations • Might never have a bleeding problem that needs medical attention.
Moderate haemophilia 1 – 5% of normal clotting factor	• Usually have bleeding problems after having teeth taken out, surgery or a bad injury or accident • 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 • More likely to have bleeding episodes than someone with mild or moderate haemophilia • Needs regular treatment to prevent or stop bleeds.

What happens when you have mild haemophilia?

Although haemophilia can't yet be cured, with appropriate treatment it can be managed effectively.

Because a person with haemophilia has lower levels of clotting factor, they will sometimes have bleeding episodes, or "bleeds". There is a common myth that people with haemophilia could bleed to death from a cut. In fact, a person with haemophilia does not bleed any faster than anyone else, but the bleeding continues for longer if it is not treated.

The small knocks, twists and bruises and minor cuts and scratches that are part of everyday living are not usually a problem with mild haemophilia. They can be treated with normal first aid, such as putting on a Band-Aid® and applying some pressure at the site of bleeding.

However, mild haemophilia can sometimes complicate small injuries and medical procedures and if normal first aid does not stop the bleeding, the bleeding can continue for days or there can be internal bleeding.

For people with haemophilia, situations become more serious when there is internal or prolonged bleeding. In mild haemophilia this can often happen when there are deep cuts, for example with surgery, tooth extractions or deep wounds. A more severe injury might result in internal bleeding or "bleeds" into muscles or organs or joints, especially knees, ankles and elbows.

Common physical signs of mild haemophilia

- Can bruise easily
- Having more painful swelling and bruising than you would expect after an injury, eg falling off a bike, car accident, football injury
- Having prolonged bleeding with wounds or after surgery, dental extractions or medical procedures that pierce the skin or mucous membrane.

For girls and women

- Having heavy and/or long menstrual periods
- Having heavy bleeding for an extended time in the weeks after childbirth.

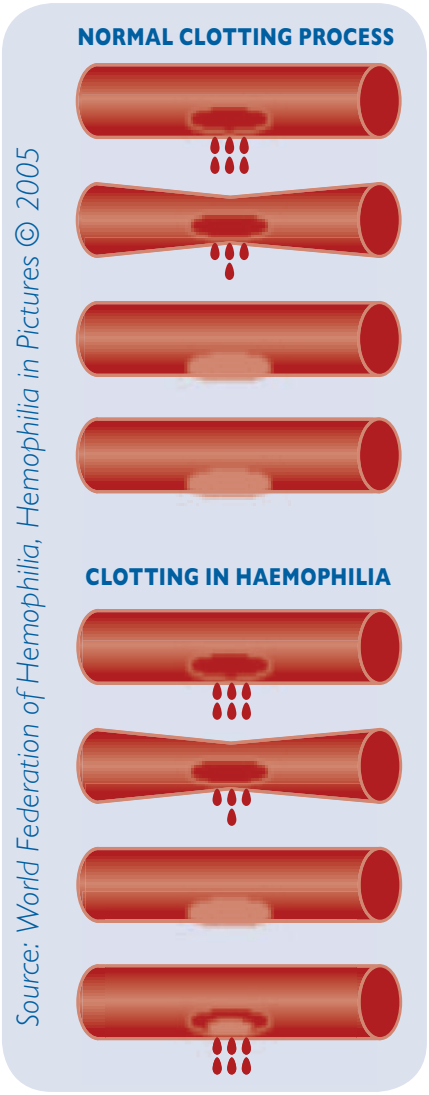
Treatment

Haemophilia treatment enables the blood to clot normally and helps to stop the bleeding.

If internal bleeding is not stopped quickly with treatment, it will result in pain and swelling. Without treatment, bleeding may continue for longer because blood may not form a tough, adherent clot where the blood vessels have been damaged.

If bleeding symptoms, pain or swelling get worse in the first 24 hours or keep you awake overnight, contact your Haemophilia Centre for assessment and advice.

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.

DIAGNOSIS

If you or your child have been diagnosed with mild haemophilia, it is important to see a haematologist who specialises in bleeding disorders. In Australia these haematologists can be found at Haemophilia Centres or Services which are at some major hospitals. Talk to your doctor about a referral.

Haemophilia Centres have a team of doctors, nurses, social workers, counsellors and physiotherapists with expertise in providing treatment and care to people with haemophilia. They also have access to specialist laboratory and diagnostic testing and can give referrals to genetic testing and counselling services.

Although people are born with haemophilia, a person with mild haemophilia may not be diagnosed until they are older when they first experience unusual bleeding problems. This often occurs after an accident or injury or if the person has surgery or tooth extractions. Girls and women may become aware of bleeding problems when they begin to menstruate or after giving birth.

Haemophilia is usually diagnosed by assessing these three things:

- The person has a history of prolonged bleeding, for example, with injury or surgery, dental work or medical procedures
- Checking if there is a family history of haemophilia or bleeding problems
- Laboratory tests on a blood sample for a person's clotting factor levels.

Often further blood tests will be done when the person is reviewed at the Haemophilia Centre to confirm the diagnosis. Sometimes low factor VIII levels can also occur if the person has von Willebrand disorder, which is another type of inherited bleeding disorder. Identifying the people who should have additional testing requires specialised knowledge and expertise in bleeding disorders.

Family history

If someone is diagnosed with mild haemophilia, it is likely that other members of their family also have haemophilia or carry the gene. Diagnosis will also include checking the family history for bleeding problems. Other family members may also need to be tested for haemophilia.

If people who are having a child know that some people in their family have haemophilia, they should arrange with their Haemophilia Centre and obstetric teams to have a male baby tested soon after the baby is born to see whether he has haemophilia. Prior to delivery they may also choose to test for the sex of the baby. Genetic counselling is available to couples and families to discuss options.

This preparation can help with planning for a smooth and safe delivery and care of the newborn baby. Diagnosis at an early age enables both the family and health care teams to manage the child's health care plan safely. It also avoids discovering haemophilia under stressful conditions such as accident or surgery.

See also CARRYING THE HAEMOPHILIA GENE, page 40.

Other issues at diagnosis

Diagnosis with mild haemophilia may also raise other questions:

- Possible implications for employment, personal insurance cover and carrying the haemophilia gene
- Decisions, made in consultation with the Haemophilia Centre or Service, about which treatment options will be the most suitable.

The Haemophilia Centre team is available to help people deal with these issues and questions.

"I'm not sure when I first found out about my mild haemophilia – I think I was around 12-14 years old, because I started getting bleeds."

"When I was told, I didn't really understand the impact of my condition. I just wanted to be just like all the other boys and for a long time I was determined to be so and I largely ignored the condition making excuses for bruises and limps. I would strongly encourage parents to tell their child and siblings about the condition as soon as practicable - in words they understand."

"It's important for parents not to worry, but to educate yourself so you are in the best position to teach your children about their condition."

"My mother was not aware of her carrier status until I was about 12 or 13. My grandfather had gone in for surgery and he had had a bleeding episode - after the procedure the doctors asked him if he had haemophilia and he said yes. He had not told them prior to the procedure as he was ashamed of the condition. Once we found out he had haemophilia the family line was traced - my mother was a carrier, both myself and my brother had haemophilia."

FAMILY AND INHERITANCE

Haemophilia is an inherited condition that occurs in families. The haemophilia gene is passed down from parent to child through generations. Mainly males have haemophilia. Men with haemophilia will pass the gene on to their daughters.

A small number of women also have haemophilia, but usually women who inherit the gene carry it without having the condition, although some have bleeding symptoms. Women who carry the haemophilia gene can pass the gene on to sons and daughters. Sons who inherit the gene will have haemophilia. Daughters who carry the gene can pass it on to their children.

Family members may need to be tested if there is someone in the family who has haemophilia.

When haemophilia is passed down within a family, the males in that family will always inherit the same type and severity of haemophilia, that is, a grandson with mild haemophilia A will have a maternal grandfather with mild haemophilia A. However, the level of severity for females is not related to the form of haemophilia gene they have inherited. For example, a girl whose father has severe haemophilia may have the same factor levels and symptoms as a girl whose father has mild haemophilia – but if she passes the gene onto any of her sons, they will have severe haemophilia.

Cells and chromosomes

The human body is made up of millions of cells. At the centre of each cell there are 46 chromosomes arranged in pairs. The person's genetic information or 'genes' are contained in their chromosomes. These 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 dictate what sex 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, received from their mother, and one Y chromosome, received from their father. There are four possible combinations of sex chromosomes that children can receive from their parents.

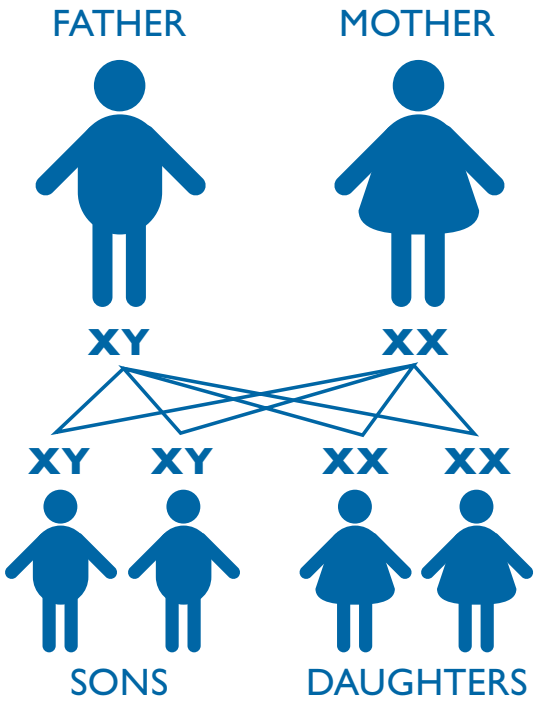
Inheritance

The genes for making factor VIII and IX are located on the X chromosome. Males with an altered factor VIII or IX gene on their X chromosome will have haemophilia. If a male with haemophilia has children, all his daughters will carry the haemophilia gene because he will pass his altered factor VIII or IX gene on to them. His sons will not have haemophilia as the 'normal' Y gene is passed on to them.

If a female who carries the haemophilia gene has children, her sons will have a 50% chance of having haemophilia and her daughters will have a 50% chance of carrying the gene. These percentages are the same with every pregnancy.

No family history of haemophilia

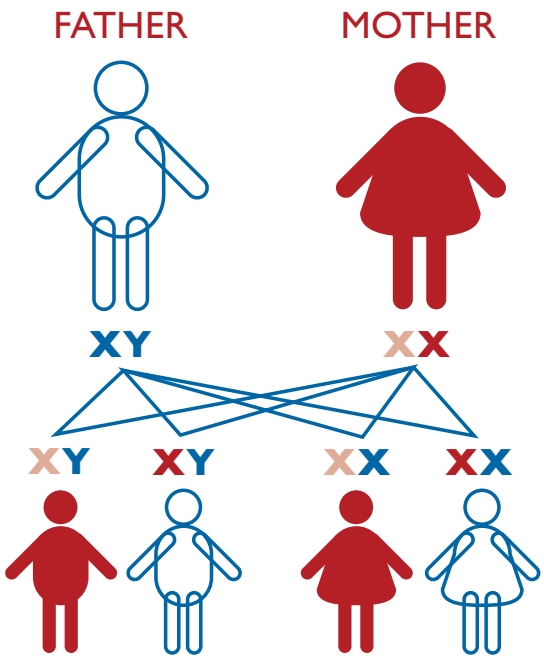
In about one third of people born with haemophilia, there is no history of the disorder in the family. This happens when a person has a genetic mutation in the factor VIII or IX gene on their X chromosome. It is often called a new or spontaneous mutation. Once haemophilia appears in a family the altered gene is then passed on from parents to children following the usual pattern for haemophilia. It is recommended that family members seek genetic counselling and testing if there is someone in the family who has haemophilia.



POSSIBLE CHILDREN

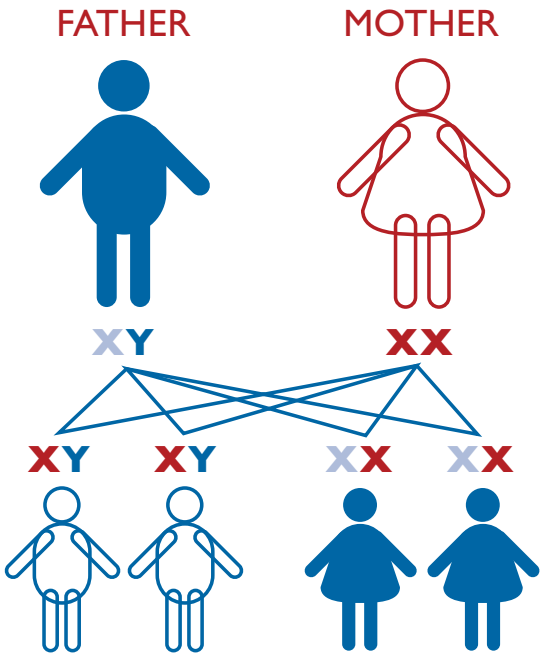
(The sex of the child is determined by the father)

When the mother carries the haemophilia gene 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 haemophilia gene

When the father has haemophilia and the mother is unaffected



None of the sons will have haemophilia
All of the daughters will carry the haemophilia gene

X or X = chromosome with haemophilia gene

WHAT PRECAUTIONS DO I NEED TO TAKE?

It is important to treat bleeds as they occur and prevent bleeds as much as possible.

- Learn how to identify a "bleed" – a bleeding episode related to mild haemophilia
- All bleeds could potentially be serious. Treat a bleed early. Learn when to treat yourself and when to seek help
- Contact your Haemophilia Centre immediately after significant injury or before having medical or dental procedures
- Learn how to prevent bleeds.

Your Haemophilia Centre team will help you with this.

The aim of learning how to manage your bleeds is to enjoy the best quality of life and have as few complications as possible.

HAEMOPHILIA CENTRES

Registering and staying in contact with the local Haemophilia Centre is an important part of managing mild haemophilia.

There is at least one specialist Haemophilia Centre or Service in every state or territory in Australia, located in a major public hospital. Haemophilia Centres have a team of health professionals with expertise in providing treatment and care to people with bleeding disorders including haemophilia.

How can the Haemophilia Centre team help you or your child?

They can:

- Work with you to make a treatment plan
- Help you or your child to learn how to recognise, treat and prevent bleeds
- Liaise with other doctors and health services to make sure care is appropriate for your or your child's bleeding disorder
- Review your or your child's bleeding disorder regularly and adjust the treatment plan
- Update you on the latest information about haemophilia and treatment
- Advise on ways to live well with mild haemophilia, including managing sport, travel, childcare, school, working, relationships and having families.

The team includes:

- Haematologists: doctors who specialise in blood disorders
- Haemophilia nurses
- Social workers or counsellors
- Physiotherapists
- Access to specialised laboratory services
- Other specialist health professionals

Stay in touch with your Haemophilia Centre and check with them regularly about new information and advances in treatment and care. Update the Centre if you change your contact details or move.

WHAT CAN I EXPECT WITH MILD HAEMOPHILIA?

Many people who have mild haemophilia do not experience problems with bleeding, or only have bleeding episodes occasionally. People with severe haemophilia can have spontaneous bleeding - the bleeding that takes place in joints and muscles without any obvious cause. However, in mild haemophilia this is extremely rare.

Usually persistent bleeding will only follow more serious injury or medical and dental procedures or surgery. Some girls and women may have bleeding problems with menstruation and after childbirth, but this can often be prevented or managed with appropriate treatment.

HOW TO RECOGNISE A BLEED

Because people with mild haemophilia have bleeding problems so rarely, they sometimes do not recognise the symptoms and delay seeking treatment.

It is important not to ignore bleeds or think they will be OK if they are left untreated.

Bleeds that are not treated quickly can take longer to stop and to heal. Serious bleeds can be dangerous and need prompt medical attention.

The Haemophilia Centre team will help you with learning how to recognise a bleed and how to deal with it.

When you need to seek advice from your Haemophilia Centre

Mild haemophilia can complicate even small injuries or medical and dental procedures and surgery. If you have any of the following problems, call your Haemophilia Centre who can help you decide whether they can be managed by your local doctor or you need specialist care at the Haemophilia Centre:

- **Bruising:** seems to be growing larger or swelling, is painful and limits movement

- **Mouth, tongue or nose bleeding:** continues to ooze or bleed at times for several days

- **Muscles and joints:** bleeds might occur if a muscle or joint (knees, ankles, elbows, etc) is over-extended, twisted, overworked or receives a hard hit:
  - Feeling of tightness, heat or swelling
  - Stiffness or tingling, difficult to move or extend the limb
  - Pain or movement problems that keep you awake overnight after the RICE procedure (see page 21).
  Contact the Haemophilia Centre if there is still pain in the calf or forearm after several hours

- **Stomach, bowels, urinary tract:**
  - Pink, red or brown urine
  - Urinating more often or difficulty/pain with urinating
  - Abdominal or back pain
  - Bright red bleeding from the bowel
  - Blood in bowel motions or black bowel motions

- **Menorrhagia:** heavy bleeding with menstrual periods

See CARRYING THE HAEMOPHILIA GENE, page 40

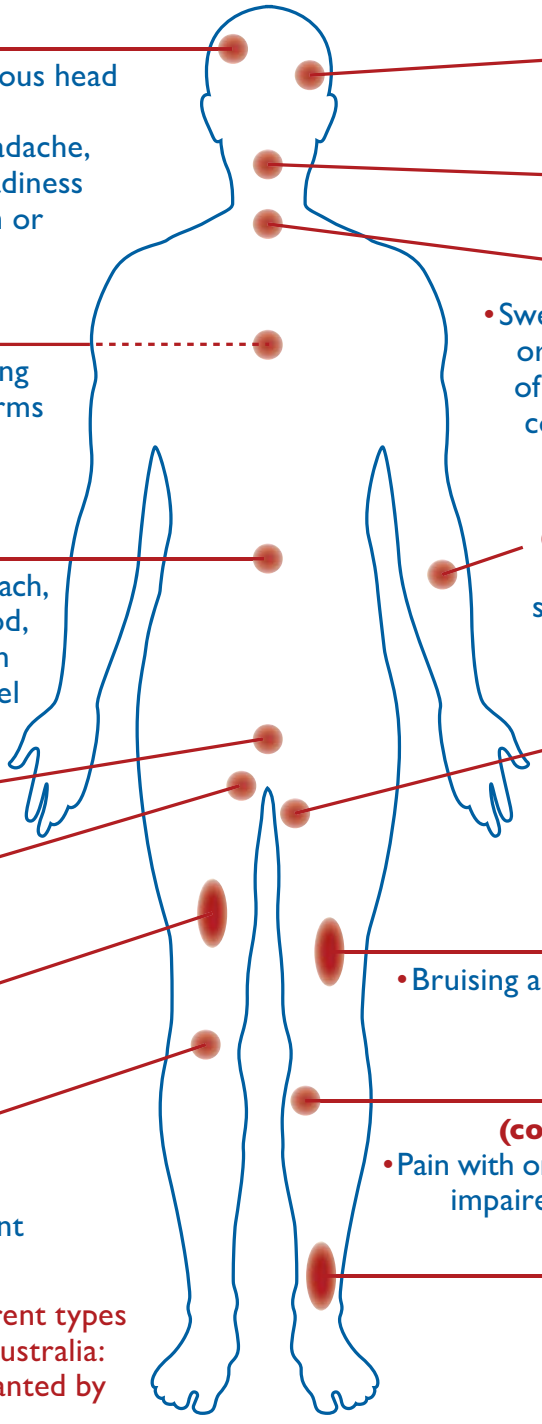
- **Babies and small children:** if you notice these signs, talk to your Haemophilia Centre:
  - Irritability, crying, pain (unrelated to hunger/needing a feed, teething or needing a nappy change)
  - Heat or swelling at a joint
  - Favouring one leg or arm
  - Avoiding some normal actions with one hand, leg or arm, or not wanting to walk.

"A couple of months ago I hurt my leg and did not go for treatment, despite my wife's pleading. A couple of days later I flew four hours on a plane, then spent the rest of the week having to do daily trips to hospital. I had to spend five weeks watching daytime television. It serves me right; it would have been so much easier to seek treatment!"

"It's a really good idea to visit your haematologist or Haemophilia Centre regularly and check treatment procedures before you need them. It's not the best time to negotiate the health system when you're in pain and need prompt attention."

Serious bleeding: injuries requiring prompt medical advice

There may be no visible signs of bleeding in a person with an inherited bleeding disorder, however bleeding episodes can be life and limb threatening. The following bleeds and injuries should be treated as serious and require prompt medical attention.



Head
- Blow to head or spontaneous head bleed
- Loss of consciousness, headache, vomiting, dizziness, unsteadiness
- Treat all head injuries with or without swelling

Spinal
- Back pain, weakness, tingling and numbness of legs or arms

Abdominal
- Swelling or pain in the stomach, vomiting, coughing up blood, unusual weakness, blood in bowel motions, black bowel motions

Urinary
- Blood in urine

Testes
- Blow to the groin

Muscles
- Swelling, lumps, pain, warmth

Joints
- Decreased or no movement

Eye
- Trauma to eye, pain, swelling

Tongue
- Bitten, bleeding

Throat
- Swelling, difficulty swallowing or breathing, discolouration of the skin around the neck, coughing or vomiting blood

Forearm (compartment syndrome)
- Pain with or without swelling, bruising, impaired mobility, tingling in hand

Groin (psoas or iliacus muscle buttock or groin)
- Pain, spontaneous flex, inability to extend the leg without pain

Bruising
- Bruising and significant swelling may require treatment

Calf (compartment syndrome)
- Pain with or without swelling, bruising, impaired mobility, tingling in foot

Skin
- Stitches

Source: adapted from Different types of serious bleeds. Wyeth, Australia: Sydney 2009. Permission granted by Pfizer Australia, 2011.

Contact the Haemophilia Centre for assessment if pain or swelling from an injury keeps you awake overnight after following the Rest Ice Compress and Elevate procedure.

WHAT TO DO ABOUT AN INJURY OR BLEEDING

If bleeding symptoms, pain or swelling get worse in the first 24 hours or keep you awake overnight, contact your Haemophilia Centre for assessment and advice.

All bleeding and bruising should be dealt with promptly to make sure no permanent injuries result.

If you have recurring bleeds into any parts of the body discuss it with your Haemophilia Centre team to investigate the cause, how to manage it and how you might prevent further bleeds.

Minor cuts, scratches and bruises

These can usually be managed using standard first aid techniques.

- To stop bleeding from minor cuts, apply pressure and put a band aid® on it. When the cut has been cleaned, keep it dry until healed
- Small bruises may look unattractive but are not serious and usually fade over a few weeks without treatment.

Larger bruises, strains, sprains, muscle/joint pain and swelling

To reduce bruising, pain or swelling and to recover more quickly, start the **RICE** procedure promptly:

Rest – stop the activity and rest the injured body part

Ice – apply a cold pack (e.g., an ice pack or bag of frozen vegetables or a cool relief gel wrapped in a towel) for about 10-15 minutes, then remove and reapply about every two hours

Compression – after icing, wrap the injury with an elastic compression bandage or firm bandages. Remove the bandage only for icing

Elevate – where practical, raise the injured body part above the level of the heart.

Stopping bleeding into a joint or muscle quickly can help to prevent complications, including permanent injury. Over time repeated bleeds into joints and muscles can lead to problems such as arthritis in joints. This is unusual in someone with mild haemophilia - it occurs more often in people with moderate or severe haemophilia, but can occur if bleeds are unrecognised and untreated in a person with mild haemophilia.

Do not take aspirin or non steroidal anti-inflammatory drugs (NSAIDs – ie, ibuprofen, indomethacin and naproxen) to relieve the pain unless your Haemophilia Centre advises you to do so. These medications can interfere with blood clotting and delay healing.

Nosebleeds

Sit upright and pinch your nostrils together below the bridge of the nose in the soft tissue for 10 -15 minutes. If the bleeding doesn't stop, repeat this procedure a second time. Try to remain calm. A cold cloth on the back of the neck or on the bridge of the nose may also help.

Drinking hot liquids and strenuous exercise can cause the nose bleed to restart. Avoid hot soup, tea or coffee and lifting and straining for 24 hours after a nose bleed.

Bleeding from the bowel or in urine

Contact the Haemophilia Centre for assessment and treatment – untreated bleeds can lead to anaemia or low haemoglobin levels.

Heavy periods (menorrhagia)

Women with heavy periods should consult both their haematologist and gynaecologist as this may also have other causes.

See CARRYING THE HAEMOPHILIA GENE, page 40

Serious bleeding or accidents and injuries/emergencies

Serious bleeding can cause lasting damage and sometimes can be life-threatening.

- Seek emergency treatment
- Where possible, contact the Haemophilia Centre
- The Haemophilia Centre may be able to call ahead to the Emergency Department and prepare for your arrival
- Remember that haemophilia is a rare condition and not many doctors or hospital staff are familiar with it. Ask the health service you are attending to liaise with your Haemophilia Centre about your or your child's treatment
- Not all hospitals will have product for treatment available for emergencies and the Haemophilia Centre may advise on hospitals that hold treatment product or make arrangements to transport it to the hospital
- Talk to your Haemophilia Centre about whether a treatment product will be held in your local hospital in case of emergency.

Consider wearing a medical alert bracelet, carrying a Haemophilia Centre treatment wallet card and having an ICE (In Case of Emergency) number in your mobile phone:
Information about these is available from your Haemophilia Centre or state/territory Haemophilia Foundation. Show the haemophilia treatment card to medical centre or emergency department staff or ambulance drivers.

If you are at all uncertain about when or how to treat injuries or bleeding, contact your Haemophilia Centre. Learning to self-manage treatment for your bleeding disorder happens over time.

TREATMENT OPTIONS FOR MILD HAEMOPHILIA

Your Haemophilia Centre will advise on the best treatment for you.

If you think you need treatment or are not sure, contact your Haemophilia Centre as soon as possible.

There are several types of treatment. Different treatments may be useful in different situations and at different times. The haematologist will look at all of this when they work with you or your child to decide the best treatment option. They will need to reassess the situation each time treatment is needed.

Treatment may be given to prevent bleeding complications:

- In preparation for surgery, medical procedures, dental treatment or childbirth
- Or after an injury or accident
- Or if bleeding does not stop.

Desmopressin (DDAVP) is a synthetic hormone used to treat haemophilia A. It works by releasing the body's stored factor VIII into the bloodstream to help blood clot. These stores are limited, and the body may need time to rebuild stores of factor VIII before another dose is given. If you or your child need more treatment and the body's stores of factor VIII are depleted, clotting factor concentrate may need to be used instead.

Desmopressin 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.

Desmopressin can help to prevent or treat bleeding in many people. It is not suitable for everyone. The haematologist at the Haemophilia Centre may decide to give a test dose of desmopressin and evaluate whether it will work for you or your child. This test may need to be repeated at times as people's responses to desmopressin change at different times in their life.

Tranexamic acid and aminocaproic acid are medicines that act by strengthening blood clots that have formed. This prevents the blood clot from being dislodged and bleeding restarting. They can be used to stop bleeding in the mouth or nosebleeds, gut bleeding, bleeding after dental work, minor surgery or an injury.

Most commonly they are taken as tablets, syrup or as a mouthwash. They may be used by themselves or together with desmopressin or a clotting factor concentrate.

Clotting factor concentrates: there are factor VIII concentrates for people with factor VIII deficiency and factor IX concentrates for people with factor IX deficiency. Both types of concentrates come in two different forms:

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 factor concentrates are also used. These are manufactured from the plasma (pale yellow fluid part) in human blood.

Factor concentrates are infused (injected) into a vein in the arm.

Fibrin glue is a medical gel made from fibrinogen and thrombin, which are proteins in the body that help blood to clot. It can be applied directly onto a wound to stop bleeding.

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

Should you learn to treat at home?

Treatment that needs to be injected, such as DDAVP or factor concentrate, can be given at the Haemophilia Centre or it may be possible to learn to treat at home. This decision will be made by you and your Haemophilia Centre, depending on your situation and how appropriate it is.

Treatment complications

After treatment with a clotting factor concentrate product, a small percentage of people with mild 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.

Like all medicines, treatments for bleeding disorders can have side-effects in some people. These will be discussed with you when they are prescribed. All prescription medicines also have a plain language information leaflet called Consumer Medicine Information (CMI), which includes use, side effects and precautions. Ask your pharmacist for a copy of the CMI for your medicine.

TREATMENT PRODUCT SAFETY

Haemophilia treatment product safety is a high priority for Australian regulatory authorities, blood bank services, manufacturers and the bleeding disorders community.

If they have treatment with clotting factor concentrates, most people with mild haemophilia in Australia use recombinant products, which are genetically engineered and contain little or no human material. There have been no reports that viruses or infectious agents such as vCJD (variant Creutzfeldt-Jakob disease, the human form of "mad cow disease") have been transmitted by recombinant products.

Some people with mild haemophilia may use human plasma factor concentrates.

In Australia manufacture of human plasma factor concentrates is carefully regulated and monitored to make sure the concentrates are now as safe as possible from infections that can be transmitted by blood. This includes steps such as:

- Screening blood donors and testing blood donations
- Strict controls when selecting blood donors
- Treating human plasma factor concentrates with several processes to remove or inactivate HIV and viral hepatitis and, as far as possible, exclude other known infectious agents passed on by blood, such as vCJD.

In Australia before the early 1990s some people with haemophilia acquired hepatitis C through contaminated plasma clotting factor concentrates they used for their treatment. Some also acquired HIV. As a result new safety measures were developed and put in place. Work to prevent the transmission of infections through blood products is ongoing.

The risk of new infections from using human blood products is now thought to be extremely low. In spite of this, the risk 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 organisations such as Haemophilia Foundation Australia (HFA) continue to take a strong and watchful interest in product safety.

Hepatitis B vaccination is recommended for people with bleeding disorders who use plasma derived concentrates.

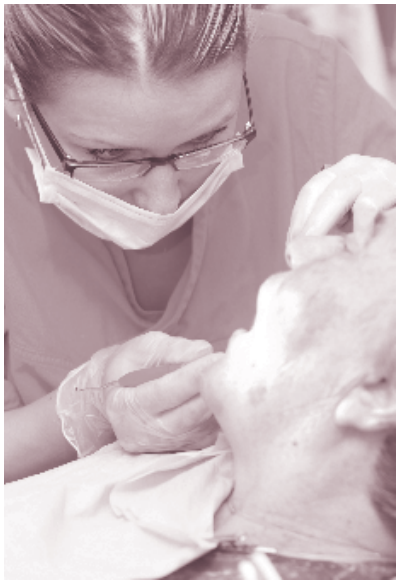
More information: Australian Red Cross Blood Service – http://www.donateblood.com.au

Australian Government. Department of Health & Ageing; National Health and Medical Research Council. Australian immunisation handbook. – http://www.health.gov.au

WHAT DO I TELL MY OTHER DOCTORS OR DENTIST?

Haemophilia is a relatively rare condition. Most doctors and dentists are not familiar with its treatment and will not be aware of your individualised treatment plan.

Ask doctors, dentists and other health care providers to liaise with your Haemophilia Centre about treatment or before having any surgery, dental work or medical procedures.



Make sure you know what type of haemophilia you have and ask the Haemophilia Centre to give you a treatment wallet card: haemophilia A and B require different treatment. The treatment card explains your diagnosis, what treatment should be given and who should be contacted for further advice. Keep the wallet card on you for quick reference.

Show your other doctors, dentist, and other health care providers the treatment card and ask them to liaise with your Haemophilia Centre. This will help with getting appropriate treatment. It will also make it easier to obtain treatment if you need it when you are away from your usual hospital or Haemophilia Centre, for example, if you are travelling or have moved interstate or overseas.

Always inform your doctor, dentist or surgeon that you have mild haemophilia before having any medical, dental or surgical procedures. This includes minor procedures, such as having sun spots or skin growths removed, and screening procedures such as colonoscopy or prostate biopsy.

Before you have any procedures, contact your Haemophilia Centre and discuss the medical support you may need to prevent bleeding complications. Where possible, plan this well ahead of time. The Haemophilia Centre team may also need to liaise with your surgical or dental team or other health professionals involved in your care to discuss the best approach for you individually and any pre- or post-treatment care you may need.

"Consult your Haemophilia Centre prior to any procedure - often your GP may not realise the true implications of a procedure from a haemophilia perspective."

"Ensure your health professionals (physiotherapists, GPs, podiatrists, specialists, optometrists, dentists, etc) are comfortable with the fact that you have haemophilia - if not, find one who is!"

"My local treatment team has issued me with a treatment card. It was really handy when I went interstate. Many of the staff at Emergency had never come across someone with haemophilia before, so it was a novelty for them."

INJECTIONS AND IMMUNISATIONS

Both children and adults with mild haemophilia can have all the normal immunisations. Informing the nurse or doctor giving the immunisation that you or your child has haemophilia is important. Injections may be given subcutaneously, into the fatty tissue under the skin, rather than into the muscle, and pressure put on the skin where you or your child was injected. This reduces the risk of bruising and bleeding.

However, it isn't always necessary to change the way of giving immunisations for children with mild haemophilia. If you or your child have mild haemophilia, contact the Haemophilia Centre for advice on immunisation methods.

Intramuscular injections, such as penicillin, can cause muscle bleeds and are not recommended for children or adults with mild haemophilia.

MEDICATION TO BE AVOIDED

Some medicines, vitamins and herbs interfere with the way platelets promote clotting and may delay healing. If you have mild haemophilia, consult with your haematologist before taking:

- Medicines containing aspirin
- Non-steroidal anti-inflammatory drugs, unless prescribed by a doctor with expertise in haemophilia (i.e., ibuprofen, indomethacin and naproxen – these have many brand names; ask your local pharmacist to check for you)
- Other blood thinners such as warfarin and heparin
- Capsules of fish oil containing omega-3 fatty acids (however, normal serves of fish should not cause a problem)
- Herbal or homeopathic medicines that affect platelet function or clotting, such as ginkgo biloba, ginger, ginseng and chondroitin
- Other medicines that claim to treat bleeding, bruising or improve clotting.

Also check with your doctor when starting new medications that could irritate your mucous membranes such as your nasal passages or stomach lining – any bleeding could be complicated by mild haemophilia.

"There's a line in the poem 'Desiderata' – 'Beyond a wholesome discipline, be gentle with yourself'. I would not be able to express it any better. The key: get on with life; enjoy your wife, children, friends, work, holidays."

"If you get to know other people with mild haemophilia and their families, you can see for yourself that it is a manageable condition and there are people there to help you through this."

"In the last few years I have been involved with a support group and I have derived a great deal of pleasure from it. It's good to be aware that you're not the only one out there with a problem."

CONNECTING WITH OTHERS

Although mild haemophilia may only affect people at certain times in their life, people with mild haemophilia and parents of children often comment that it is helpful to talk to others in a similar situation and know that they are not alone. Haemophilia Foundations are a great way to connect with others and share experiences on managing mild haemophilia.

State and Territory Haemophilia Foundations have:

- Newsletters and web sites to update people with bleeding disorders and their partners, families, friends and carers
- Social activities where people can meet, talk about common experiences and enjoy a meal or a day out, such as family camps, Christmas parties, men and women's groups, grandparents' groups.

Haemophilia Foundation Australia also supports:

- A youth program run by young people affected by bleeding disorders
- Internet-based communities and social networking sites for people affected by bleeding disorders.

TRAVEL TIPS

Plan ahead! Travelling is a wonderful opportunity for activity and adventure, and it can be much more enjoyable if you are prepared for all possibilities:

- Talk to your Haemophilia Centre beforehand if you are travelling interstate or overseas. They can help you prepare depending on your individual situation. They can also advise on documentation, medication and travel insurance
- Discuss with your Haemophilia Centre if you need to take treatment with you
- You may not need them, but just in case, find out the contact details of Haemophilia Centres along your route
- You will need to obtain travel insurance for overseas travel
- Consider telling your travelling companions what to do to help you in case of an emergency
- With airplane and overseas travel you may need further documentation to carry medication and treatment equipment through security and customs – talk to your Haemophilia Centre about this well in advance and allow plenty of time to prepare the documentation.

Useful travel web sites:

- Smarttraveller – www.smarttraveller.gov.au
- World Federation of Hemophilia Passport (global treatment directory) – www.wfh.org
- Medicare Australia (Travelling Overseas section) – www.medicareaustralia.gov.au

MOVING INTERSTATE OR OVERSEAS

Let your Haemophilia Centre know if you are moving interstate or overseas. They can help with making sure your medical information and treatment plans are passed on to the Haemophilia Centre where you will be living. Your Haemophilia Centre or HFA can also advise on the Haemophilia Centres available.

Once you arrive in your new location, it is important to see your new treatment team and register as soon as possible. Your new treatment team will want to understand your particular situation and health needs. They will prepare a new treatment plan and discuss how your treatment can be managed locally. As most people with mild haemophilia do not need treatment very often and may only need treatment in an emergency, it will be immensely valuable to be prepared and prevent delays in getting appropriate treatment if an emergency occurs.

Getting to know other people affected by bleeding disorders in the local community can be important to understand how things work and feel connected. There are State and Territory Haemophilia Foundations in most parts of Australia and haemophilia community organisations around the world. Contact HFA or check the HFA web site for information on local haemophilia organisations.

SPORT AND OTHER ACTIVITIES

Physical activity and regular exercise have great benefits for everyone. For people with mild haemophilia it can be a way to keep muscles and joints strong and even prevent injuries and bleeds.

Being active and healthy can be a balance between taking on physical challenges and preventing injuries. Ask the Haemophilia Centre team for advice on sports and other physical activities and the risks involved, based on your individual health and situation.

If you have mild haemophilia, participation in sport is a positive way to mix with a wide range of people, enjoy the physical aspects of life, control weight and maintain physical fitness which will help to reduce the risk of injuries.

Improving muscle development and increasing skill levels at sport can protect joints and prevent injuries and bleeds. At the same time, individuals may find that for them certain sports or activities are more likely to result in bleeds.

Generally children and adults with mild haemophilia need to try out different sports and physical activities that they enjoy to see what they can and can't do. Many take part in all kinds of sports. In most cases, using current safety guidelines and protective equipment means that people with mild haemophilia can participate in the same sports as their friends – which is especially important for children as they grow up. The main concern is the risk of head injuries. Extreme contact sports, including wrestling and boxing, are a high risk for severe injury and are generally not recommended. If you have questions about the suitability of a sport or activity, check with the Haemophilia Centre.

You may wish to advise a sports coach what to do in case of injury.

Further reading: The book *Boys will be boys: a guide to sports participation for people with haemophilia and other bleeding disorders* by Brendan Egan (Melbourne: Royal Children's Hospital, 2005) has valuable information about participating in sports and preventing injury. Available from HFA and Haemophilia Centres.

WORKING

Most people with mild haemophilia will be able to follow their chosen career.

Mild haemophilia will not usually impact on your work. There may occasionally be problems if jobs are very physically demanding, involve repetitive movements or standing for long periods or cause workers to knock parts of their body. If you find you are having unusual elbow bleeds, aching muscles or neck, swelling and bruising (haematomas) from knocking against equipment, or any other problems, contact your Haemophilia Centre for advice. They may be able to suggest suitable protective equipment or give other suggestions to manage the problems.

An exception to this is the Australian Defence Force (ADF), which has very strict medical entry requirements based on the potential need to send staff to remote locations and for them to be involved in active service. If you have mild haemophilia, you are obliged to disclose your health condition to the medical officer when you apply for entry so that a decision can be made about how relevant it is. If it is not disclosed and causes a problem, you can be discharged from the ADF.

Who should I tell at work?

If your situation changes - you start a new job or are diagnosed with mild haemophilia or have some related health problems – you may find you have to think about telling others in your workplace about your haemophilia. In most cases, whether or not to tell others is entirely up to you.

If mild haemophilia is not going to impact on your work, you may prefer to take your time and think carefully before you tell your employer or work colleagues. You may be in a better position to understand when and where it may be relevant once you are more familiar with your workplace or with your diagnosis – but once you have disclosed, you will have little control over this personal information.

If mild haemophilia is relevant to your work, or questions are asked on your employment application, it may also be worthwhile to look more closely at what the job entails and why the questions are asked.

When you are thinking this through, you may find it valuable to talk it over with the Haemophilia Centre, who can advise you on your situation and provide supporting documentation if necessary. They can also give suggestions on plans to manage emergencies.

"I let HR and Reception know that if I'm injured or unconscious to ring an ambulance. And I'm prepared – I make sure there is an ice pack in the fridge at work."

INSURANCE AND SUPERANNUATION

Some insurance and superannuation companies will ask questions about pre-existing health conditions, including bleeding disorders, in their policy application forms.

You will need to answer questions honestly if questions about health conditions are asked in insurance policies. If you do not provide this information, the company can refuse to pay any claim on the policy where your bleeding disorder is a contributing factor. If you are refused insurance or premiums are higher, you can appeal the decision.

Familiarise yourself with the income protection insurance available under your superannuation. You may decide to take out more cover to provide for a future emergency.

Different companies have different options, so shopping around for your best option could be beneficial. Read the insurance policy carefully and don't hesitate to seek advice before completing it. It may be useful to speak to your Haemophilia Social Worker or Counsellor or HFA for more information.

SCHOOL AND CHILDCARE

Having mild haemophilia will not usually affect your child's ability to attend school. Most bleeding will be the result of normal schoolyard injuries and can be managed with standard first aid. However, it is always possible that a more serious bleed could occur and key staff at the school may need to learn how to identify a more serious situation and how to manage this.

Well-informed day care and school staff can be very helpful. It is important that they have the facts about mild haemophilia, but that the information isn't over-dramatised and any false fears are allayed. You may find it useful to organise information sessions for staff at day care or school – Haemophilia Centre staff are usually very experienced in this and happy to assist you. Your child may or may not want to educate their classmates – most young people want to be treated normally, so the value of this would depend on each individual situation.

- When they are old enough, your child needs to know how to handle their own common bleeding problems, such as nosebleeds. If the child is very young, a staff member will need to learn how to manage them
- Provide the day care centre or school with information on mild haemophilia and how to manage your child's condition
- It is important that the day care or school staff can contact parents or guardians at all times, in case of emergency. It may also be helpful to provide the telephone number of your child's Haemophilia Centre.

What about babysitters?

Generally those taking responsibility for a child with mild haemophilia would need to know what to do in case of an emergency. If bleeding symptoms are rare, you may decide not to tell them specifically that your child has mild haemophilia. However, if your child bruises easily, it may be helpful to be open and talk matter-of-factly about your child's haemophilia with the babysitter: parents of children with bleeding disorders who have bad bruises have occasionally been suspected of child abuse and some accurate information can make this less likely.

FRIENDS AND NEW PARTNERS

It can be valuable if some close friends, partners and family members know about your or your child's health conditions. They can give you or your child support at times of health problems or concerns, or if others are being negative or unhelpful. If they know what to do in emergencies, they can watch out for you or your child and help to deal with accidents or injuries.

However, sometimes there can be negative reactions when you tell friends, family members or new partners. They may be upset or have inaccurate beliefs about bleeding disorders or be overly concerned for your or your child's health. They may tell other people you wouldn't have chosen to tell. New partners may be concerned about what it means for them or any children you may have together in the future.

These negative responses can happen because many people know little about bleeding disorders and sometimes have preconceived ideas about them. It can be worth remembering it is not a reflection on you and you are not responsible for their reaction.

When you are considering whether to tell someone it can be helpful to ask yourself whether mild haemophilia will impact on them and why they need to know.

Preparing to tell others

- Learn about mild haemophilia and your own health situation first, so that you can answer any questions. If you are not sure, talk to your Haemophilia Centre
- Bear in mind that your knowledge and attitude to haemophilia will influence how others understand and accept it
- Have some accurate printed information ready to give them to read in their own time
- Practice telling them first – in your own mind, with a friend or with a social worker or counsellor
- Choose a time and place where you can take some time and talk openly and safely
- Give them the opportunity to talk to your health care team for more information
- Have a supportive person you can contact if you are telling someone important to you
- Think about what might happen if they tell other people – it might be helpful to talk to them about who else knows
- Give the person some time to get used to this new information about you.

New partners

If you are beginning a new relationship, the decision if, when and how to tell your new partner about your bleeding disorder might require some thought.

Your new partner may have a lot to think about, particularly if there is a possibility of having children together in the future. They may appreciate the opportunity to talk to your Haemophilia Centre team or to talk to a partner of someone else with mild haemophilia.

When to tell? It is up to you:

- You may prefer to tell a new partner early on. It may make no difference or even bring you closer together. But if they can't accept the news, it may feel easier to let the relationship go before you both become attached
- You may prefer to wait until the relationship has progressed and looks likely to continue. You may feel you need to know them better to have an idea of how they might react or whether they would respect your privacy.

If you would like to talk this over or get information, you can talk to the Haemophilia Social Worker or Counsellor or ask the Haemophilia Centre to refer you to a counsellor. The Haemophilia Centre, HFA or your local Haemophilia Foundation can also help with finding others in similar situations to talk to.

"Be proud! Haemophilia is nothing to be ashamed of. The more people know about the condition, the less likely they are to panic or make false assumptions based on their fear of the unknown."

"Growing up, I found it difficult to get a grip on my condition without someone like a counsellor to talk about my thoughts and concerns."

CARRYING THE HAEMOPHILIA GENE: SPECIAL ISSUES FOR GIRLS AND WOMEN

CLOTTING FACTOR LEVELS AND SYMPTOMS

Many girls or women who carry the gene causing haemophilia do not have signs or symptoms of a bleeding disorder. If at least one of their X chromosomes has a factor VIII or IX gene that works, their body can usually produce normal or near normal levels of factor and they do not have bleeding problems.

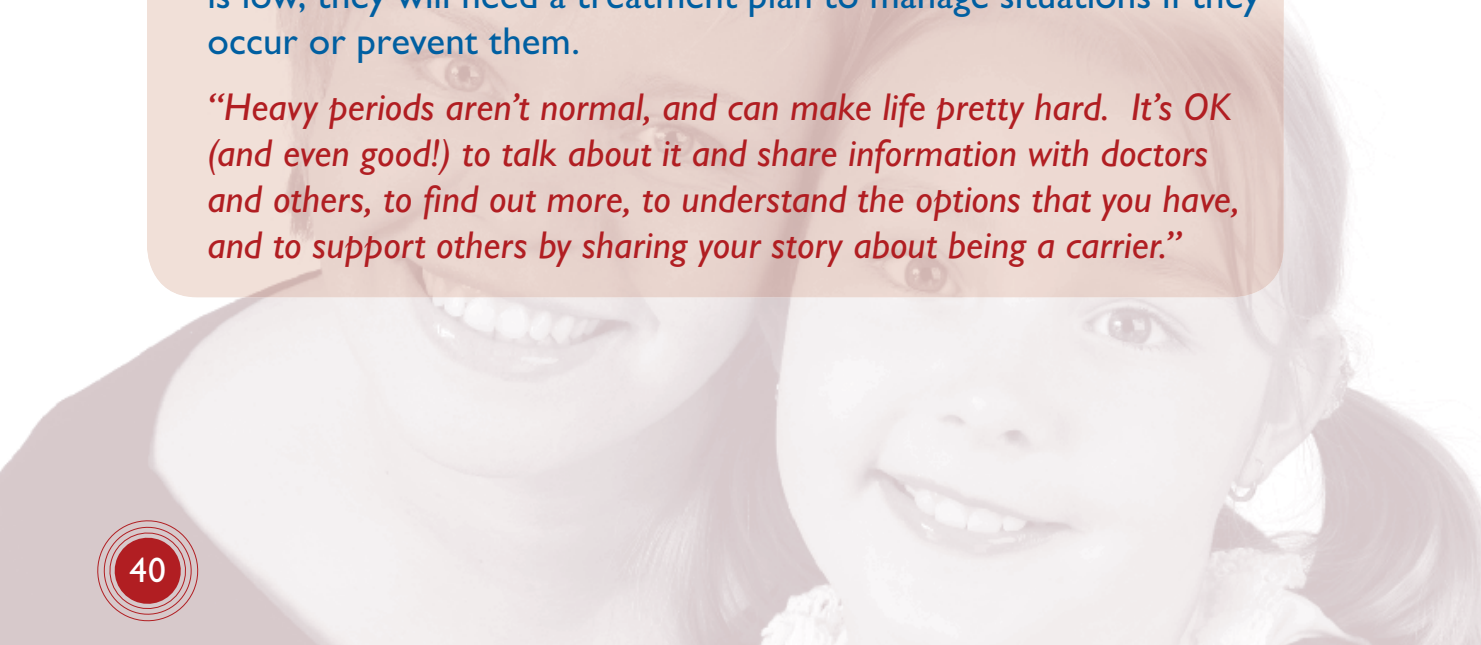
However, some girls or women who carry the haemophilia gene may have a bleeding tendency. Females are often described as "symptomatic carriers". If their factor levels fall in the range for mild haemophilia (5 – 40% of normal clotting factor), they may sometimes also be referred to as having "mild haemophilia".

Examples of having a bleeding tendency may include:

- Bruising easily
- Having heavy menstrual bleeding
- Having excessive bleeding after dental surgery or extractions, other surgery or accidents
- Have prolonged bleeding after childbirth.

All females who carry the gene should have testing for their clotting factor levels 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 manage situations if they occur or prevent them.

"Heavy periods aren't normal, and can make life pretty hard. It's OK (and even good!) to talk about it and share information with doctors and others, to find out more, to understand the options that you have, and to support others by sharing your story about being a carrier."



MANAGING SYMPTOMS

Heavy bleeding with menstrual periods (menorrhagia) may be a symptom of carrying the haemophilia gene and can involve:

- Heavy menstrual periods (e.g., soaking through a tampon and pad around two hourly, or needing to change during the night)
- Menstrual bleeding for longer than normal (e.g., longer than 8 days)
- Bleeding with clots bigger than a 50 cent piece in size.

Heavy menstrual bleeding can lead to anaemia (low red blood cell count/low blood iron levels), with symptoms of fatigue, paleness, lack of energy and shortness of breath.

Although these can be symptoms related to carrying the gene, they can also be symptoms of a gynaecological disorder, so it is important to consult a gynaecologist.

With diagnosis and appropriate treatment, these bleeding problems can usually be reduced or managed.

If you are a woman or girl who carries the haemophilia gene, a holistic or comprehensive care approach to your health care can help you to achieve better health and quality of life. Specialist gynaecological care over your lifetime is important to manage any gynaecological issues that occur. These may not be related to haemophilia, but in some cases the bleeding disorder may make the bleeding problems worse.

At times in their life, some symptomatic women may need to have gynaecological surgery or procedures. If this happens, it is important that this is managed in a team, with discussion between the woman, the Haemophilia Centre and the gynaecologist and/or surgeon.

Ideally your medical care team should work together on your health care and should include:

- A gynaecologist
- A haematologist specialising in bleeding disorders
- A GP or paediatrician or obstetrician, if relevant at the time.

For more information about treatment and managing other bleeding problems, see the TREATMENT AND CARE section, page 15.

GENETIC TESTING

A normal factor VIII or factor IX level test does not mean that a girl or woman does not carry the haemophilia gene.

Finding out whether a girl or woman carries the haemophilia gene is a process which may take some time. This can involve:

- Meeting with a genetic counsellor
- Looking at the family tree to identify other family members who may carry the haemophilia gene
- Blood tests for other affected family members, if known, to identify the particular gene alteration causing haemophilia in her family
- Laboratory tests on a blood sample from the girl or woman to see if she has the same family gene alteration
- A blood test to check clotting factor levels if they are not known.

Genetic counselling is available to girls or women and their parents or partners and many find it helpful. The Haemophilia Centre can help with information and advice about genetic testing and provide a referral to a genetic counsellor.

PREGNANCY AND CHILDBIRTH

With good management, women who carry the haemophilia gene have no more problems with delivering a healthy baby than other mothers.

How to prepare:

- Ideally, if you are planning a pregnancy, contact your Haemophilia Centre for a referral to a genetic counsellor
- When you become pregnant, contact your Haemophilia Centre for advice on local obstetric services they already work with
- Ask your haemophilia and obstetrics teams to consult with each other to plan for a smooth and safe pregnancy and delivery and care for the newborn

- Check with your Haemophilia Centre before having any invasive procedures, such as amniocentesis
- Discuss suitable choices for anaesthesia, especially an epidural, with your Haemophilia Centre and obstetrics teams.

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

PLANNING A FAMILY

If you have mild haemophilia or carry the haemophilia gene, planning a family can raise a number of questions you will need to consider:

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

Your Haemophilia Centre can help you with your questions about having children. It may be helpful to review the information about how haemophilia is passed on to children (see the FAMILY AND INHERITANCE section, page 12).

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 your Haemophilia Centre to see how things have changed. The Haemophilia Centre may also refer you to a genetic counselling service that specialises in bleeding disorders.

For information on genetic testing, pregnancy and childbirth, see the CARRYING THE HAEMOPHILIA GENE section, page 40.

"Treatment is improving all the time - make sure you get the most up-to-date information about your situation and options for having kids, especially if you have a family history of haemophilia and have experienced it in the 'old days'."

LIVING WITH MILD HAEMOPHILIA

"Mild haemophilia makes you unique, rather than different. Be proud of your uniqueness!"

Most people with mild haemophilia find that with awareness and planning their bleeding disorder has little impact on them. They can live full, active and independent lives.

At various stages of life, issues relating to mild haemophilia can arise for a person or their family. It might be about how to help a child play and have fun while dealing with potential bruises or bleeds. Or it could be dealing with situations or emotions like feeling overwhelmed by diagnosis, or that you or your child is somehow different from others, or taking the next step in a personal relationship.

These are some suggestions put together by people with bleeding disorders, parents and Haemophilia Centre teams:

TIPS FOR LIVING WELL

You are not alone

- Stay in regular contact with your local Haemophilia Centre and make sure you keep up with anything new. The Haemophilia Centre team is there to help and can give you advice or talk over any problems or concerns
- Keep in touch with your Haemophilia Foundation for updates on new information and to share experiences and enjoy a chat with others who know what it's like.

Be informed and aware

- Know what type of haemophilia you have: haemophilia A (factor VIII deficiency) or haemophilia B (factor IX deficiency)
- Learn how to prevent bleeding and how to deal with it when it happens
- Make sure you and your family are aware of early warning signs of potentially serious bleeds, such as bleeds in the head

- If you use treatment product, know which one you use
- Your Haemophilia Centre team can help with learning about bleeds and how to manage them
- Ask the Haemophilia Centre team for advice on sports, work and other physical activities and how to manage any risks involved, based on your individual health and situation.

Tell other health professionals that you have a bleeding disorder

- Let your dentist or your doctor know you or your child have a bleeding disorder
- Advise your Haemophilia Centre team in advance of planned medical or dental procedures so that any procedures such as surgery, childbirth or dental procedures that may result in bleeds can be managed in liaison with the Haemophilia Centre team
- Keep the treatment wallet card from your Haemophilia Centre on hand. Show it to your or your child's other doctors and dentist and ask them to liaise with your Haemophilia Centre
- Consider wearing a medical alert bracelet and having an ICE (In Case of Emergency) number in your mobile phone

Control and manage risks

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

Enjoy what life has to offer!

MORE INFORMATION

For more information about mild haemophilia, or to find out how to get in touch with your local Haemophilia Foundation or a specialist Haemophilia Centre, contact:

Haemophilia Foundation Australia
P: 03 9885 7800 Toll free: 1800 807 173
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au

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ACKNOWLEDGEMENTS

Comments quoted in this booklet were contributed by the HFA Mild Haemophilia Consumer Review Panel. Many thanks also to the Mild Haemophilia Consumer and Health Professional Review Panels for their suggestions on topics and content to include.

This booklet was reviewed by Anne Jackson, Penny McCarthy, Megan Walsh and Beryl Zeissink from Australian Haemophilia Nurses' Group; Desdemona Chong, Sharon Hawkins, Kate Lenthen, Leonie Mudge and Maureen Spilsbury from Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group; Nicola Hamilton and Wendy Poulsen from Australian and New Zealand Physiotherapy Haemophilia Group; Dr Chris Barnes, Dr Simon McRae and Dr John Rowell from Australian Haemophilia Centre Directors' Organisation; and community representatives from the HFA Mild Haemophilia Consumer Review Panel.

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