

MILD HAEMOPHILIA FACT SHEET

If you have mild haemophilia it may have little impact on your life as long as you know what to do, how to manage it, and what you should tell the professionals who provide your health care.

Haemophilia is a rare genetic health condition, often inherited, where a person's body has problems forming blood clots. It results from not having enough clotting factor in the blood. A clotting factor is a protein in blood that helps control bleeding.

If a person with haemophilia has an injury causing bleeding, they may bleed for longer or their blood will clot more slowly than other people.

What type of haemophilia?

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

There are two types of inherited haemophilia. Each type needs a different clotting factor treatment. Both have the same symptoms:

- **Haemophilia A** - lower than normal levels of clotting factor VIII (8)
- **Haemophilia B** - lower than normal levels of clotting factor IX (9).

What to tell your doctors

Obtain the wallet-sized **treatment card** from your Haemophilia Centre. This has:

- Brief details about your or your child's diagnosis and type of haemophilia
- Recommended treatment
- Who to contact in an emergency.

Keep this card on you and show it to doctors, nurses, ambulance officers and other health professionals who provide your or your child's care.

What is mild haemophilia?

In Australia about half of all people with haemophilia have the mild form. Many people with mild haemophilia rarely have bleeding problems.

People with mild haemophilia generally have between 5% and 40% of clotting factor VIII or IX in their blood. This is usually enough to protect against bruising and minor injury. The level in a 'normal' person (without haemophilia) is usually between 50 and 150%.

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, people might not be diagnosed with mild haemophilia until they are older.

Who has haemophilia?

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

Common physical signs of mild haemophilia in males and females

- Bruising easily
- More painful swelling and bruising than you would expect after an injury, eg falling off a bike, car accident, football injury
- Bleeding for an unusually long time with wounds or after surgery, dental extractions or medical procedures that cut or scrape any part of the body.

And also for girls and women

- Heavy and/or long menstrual periods
- Heavy bleeding for an unusually long time in the weeks after childbirth.

Treatment

Haemophilia treatment helps the blood to clot normally and 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 and may cause further problems. Treatment can include the drug desmopressin (DDAVP) for haemophilia A, or factor VIII (8) or IX (9) concentrates. You or your child might need testing beforehand with DDAVP to determine the optimal treatment. Not all hospitals have these products, so you might have to wait for treatment or go to a larger hospital. If you have any concerns, ask the doctors to contact the Haemophilia Centre or a Clinical Haematologist directly. Treatment can also include other ways of treating symptoms, rest or physiotherapy.

Where to go for help with mild haemophilia

Register with your local Haemophilia Centre and let them know if your contact details change. Stay in touch regularly for advice and care. The Haemophilia Centre team will develop a treatment plan specific to your or your child's needs and can teach you how to manage your or your child's mild haemophilia. There is at least one Centre in every Australian state or territory, located in a major public hospital. Haemophilia Centres have a team of health professionals who specialise in haemophilia care and treatment, including doctors (haematologists), nurses, social workers, physiotherapists and laboratory services. See www.haemophilia.org.au or phone 1800 807 173 for details.

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When to seek help

Because people with mild haemophilia have bleeding problems so rarely, they sometimes do not recognise the symptoms and delay seeking treatment. Talk to your Haemophilia Centre about how to recognise a bleeding problem and how to deal with it.

If you have followed the Rest Ice Compress and Elevate (RICE) procedure, but bleeding symptoms, pain or swelling get worse in the first 24 hours or keep you awake overnight, or you feel that things aren't quite right, contact your Haemophilia Centre for assessment and advice.

Serious bleeding – seek prompt medical advice

Although it is rare in people with mild haemophilia, serious bleeding can damage muscles or joints and can even be life threatening. **The diagram below shows serious injuries or bleeding problems - if you ever experience them seek medical attention immediately. If in doubt seek medical advice!** Where possible contact your Haemophilia Centre as well.

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.

TIPS FOR LIVING WELL

Suggestions from people with bleeding disorders, parents and Haemophilia Centre teams:

You are not alone

- Stay in regular contact with your local Haemophilia Centre and update them with changes to contact details. The Haemophilia Centre team is there to help you with any questions or concerns
- Join your local Haemophilia Foundation – these are support organisations for people with bleeding disorders. Get updates on new information, newsletters, share experiences, and enjoy a chat with others who know what it's like.

Be informed and aware – Your Haemophilia Centre can help with this

- Know what type of haemophilia you have (ie, A or B)
- 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 bleeding, such as bleeding in the head – if in doubt, seek medical advice
- If you use treatment product, know which one you use
- Treating bleeding symptoms can make a difference
- Ask the Haemophilia Centre team for advice on work, sports, and other physical activities, or to make plans for travelling interstate or overseas.

Tell other health professionals that you have a bleeding disorder – don't assume they already know

- Let your dentist or your doctor know you or your child have a bleeding disorder
- Advise your Haemophilia Centre team before you have planned medical or dental procedures – even if you think they are minor - so that potential bleeding issues can be managed in liaison with the Haemophilia Centre team
- Keep the treatment wallet card from your Haemophilia Centre with you. Show it to your or your child's other doctors and dentists 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!

Important Note: This pamphlet 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.

This pamphlet was reviewed by members of the Australian Haemophilia Nurses' Group, the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group, the Australian and New Zealand Physiotherapy Haemophilia Group, the Australian Haemophilia Centre Directors' Organisation and the HFA Mild Haemophilia Consumer Review Panel.