

## 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

<b>Mild haemophilia</b> 5 – 40% of normal clotting factor	<ul style="list-style-type: none"><li>• Usually only have bleeding problems after having teeth taken out, surgery or a bad injury or accident</li><li>• Females may have bleeding problems with menstruation or childbirth</li><li>• Might not be diagnosed until well into middle age if not taking part in contact sports and have not had any injuries or operations</li><li>• Might never have a bleeding problem that needs medical attention.</li></ul>
<b>Moderate haemophilia</b> 1 – 5% of normal clotting factor	<ul style="list-style-type: none"><li>• Usually have bleeding problems after having teeth taken out, surgery or a bad injury or accident</li><li>• Rarely have a bleed for no obvious reason.</li></ul>
<b>Severe haemophilia</b> Less than 1% of normal clotting factor	<ul style="list-style-type: none"><li>• Often have bleeds into joints, muscles and soft tissues</li><li>• Can have bleeds for no obvious reason, as well as after surgery, dental work or injuries including minor bumps or knocks</li><li>• More likely to have bleeding episodes than someone with mild or moderate haemophilia</li><li>• Needs regular treatment to prevent or stop bleeds.</li></ul>

### 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.**