

# Haemophilia:

## Information for Schools



### What is haemophilia?

Haemophilia is a disorder where there is a deficiency in a clotting factor in the blood. The clotting factor is like the 'glue' that stops the bleeding from persisting. This is called haemostasis.

Each person is born with a pre-determined clotting factor activity level. People who do not have haemophilia have a clotting factor level of 50 - 150%.

Incidence of haemophilia is approximately 1:10 000

- Haemophilia A is the most common and is a deficiency of the clotting Factor VIII.
- Haemophilia B or Christmas disease is a deficiency of the clotting Factor IX.
- Haemophilia is a lifelong condition, for which there is no cure.

### Myth

It is commonly thought that a person with haemophilia gushes blood from cuts and will rapidly bleed to death. This is not true. A person with haemophilia does not bleed more rapidly than anyone else they just bleed for a longer time. It is the prolonged bleeding and the inability to form a clot that poses potential difficulties.

There are 3 categories of haemophilia. They are mild, moderate and severe and refer to the amount of clotting factor in the blood. Superficial bruising is common and are generally not harmful.

### Types of bleeds

Minor bleeds include simple nose bleeds, minor cuts and abrasions, mouth bleeds and joint bleeds.

Joint bleeds are not life threatening but should be treated promptly. Treat minor injuries as you would for any other child — including using universal precautions for blood handling and ensure pressure is placed on the site.

### First aid

- Rest
- Ice
- Compression (bandage, splint etc. if necessary)



- Elevation (of the limb if possible)

## **NEVER GIVE ASPIRIN OR NUROFEN (Can have paracetamol if necessary)**

If bleeding persists despite applying pressure to the area, the child's parents should be contacted so that they can transfer him/her to hospital or if after an hour of not being able to reach them an ambulance should be called.

Major bleeds include injury to head, neck, chest, abdomen, pelvis, spine, hip, deep lacerations, fractures and dislocations, bleeding into muscle and any sudden severe pain such as abdominal pain or headache. These are usually rare but are considered life threatening and emergency care should be sought immediately.

## **EMERGENCY SITUATIONS- CONTACT AMBULANCE ON 000 & NOTIFY CAREGIVERS**

### **Bleeds – Internal bleeding**

This is the most common type of bleed for boys/girls with haemophilia. Bleeding episodes or 'bleeds' may occur without any apparent cause. These are referred to as spontaneous bleeds. The child may develop a bleed after a playground accident. Sometimes bleeds occur for no reason and these are no one's fault.

Most bleeds occur into the space between joints, most commonly elbows, knees and ankles. A joint with a bleed often swells up and gets stiff and hard to move although this does not always occur. Internal bleeding is very painful. Repetitive bleeding into the one site can cause permanent damage such as arthritis.

If treated within the first few hours, progressive symptoms will be minimised. Delayed treatment causes more oozing of blood into the joint and in turn, more pain. Recovery time is also increased if not treated promptly. From about five or six years of age, a child with haemophilia can detect a bleed. If the child says they is having a bleed, they probably are.

When a bleed is suspected:

- Contact the child's parents
- Let the child rest in a position they finds comfortable
- Put ice on the site and/or elevate if appropriate.
- Call an ambulance on 000 if the child's family cannot be contacted and inform the ambulance service that the child has Haemophilia.

**A head injury or compromised airway is an emergency.**

### *How to assess whether a child is bleeding internally?*

- A limb may be held in an abnormal position
- They may appear uncomfortable or become irritable
- They may hold or support a particular part of his body
- There may be swelling
- There may be unusual warmth in the area
- The area may be more firm than is usual
- They will experience pain when the joint is moved
- If they complain of tingling, pain, stiffness, decreased motion in a limb, ask them if they think they have a bleed

## **Sport and exercise**

Participation is important to build self-esteem and experience a sense of belonging for children with haemophilia. Physical activity is recommended, as exercise is important to maintain a healthy weight, and to develop muscle strength around the joints.

Children with haemophilia have a normal quality of life and can participate in a number of sporting activities. Skills based sporting activities are safe but protective equipment/clothing should be used where appropriate (i.e. shin pads for soccer and cricket). It is recommended that children with haemophilia should not play contact sports such as Football, AFL, Rugby boxing, karate, etc. Instead, appropriate non-contact sports are encouraged such as swimming, cycling, golf, tennis, softball, cricket, etc. For a comprehensive list of sports and risks please visit [http://www.brucecalc.net/activity\\_categories.php](http://www.brucecalc.net/activity_categories.php)

**Remember these are normal children** who should be encouraged to participate in all reasonable sports and activities as this is beneficial for their physical and psychosocial development.

## **Absenteeism**

Absenteeism may occur for some children if a bleeding episode is severe or rehabilitation is prolonged. Children usually should not miss more than 2-3 days due to a bleed, however they may need to attend their local hospital for follow-up care.

## **Return to childcare/school after a bleeding episode**

Please discuss with parents if a child cannot participate in physical activities and when the child can participate again.

If a child returns to childcare/school with a colourful cast on, or with a limb bandaged, the following activities should be **avoided**:

- Swimming or water play(a bandage or cast **cannot** get wet)

- Running
- Jumping activities (includes hopping, high jump, long jump)
- Activities with sand (if sand makes its way inside the cast or bandage this can cause skin irritation and breakdown)

### **Haemophilia treatment**

Some students with haemophilia will receive regular preventative injections of factor replacement at home before attending school. This treatment provides them with some protection against joint and muscle bleeds.

### **Other helpful hints**

Children with haemophilia should be assigned classrooms on lower levels wherever possible. You should also consider whether a locker is available to store extra school books and decrease the amount of weight the child has to carry to/ from classes and school.

If a child has had a bleeding episode they may need to use crutches, slings or sometimes even a wheelchair upon returning to school. This may mean that the child will need more time to get to and from their classes.

### **Special issues for girls with haemophilia or symptomatic carriers**

Girls may experience heavy bleeding with their menstrual cycle. This means that girls may need to be absent from school due to heavy bleeding and/or pain and they may need to leave the classroom frequently to change their tampon or pad.

### **Further information**

Further information is available at the following websites:

<http://www.hnekidshealth.nsw.gov.au/blood>

<https://www.haemophilia.org.au/about-bleeding-disorders/haemophilia>