



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



HAEMOPHILIA Entry

Organisations who wrote / approved the information

Haemophilia Foundation Victoria Inc.

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***Chronic Illness Alliance
www.chronicillness.org.au
03 9882 4654***

HAEMOPHILIA

A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

Haemophilia is a rare blood clotting disorder caused by a deficiency of clotting factor in the blood. It affects males almost exclusively. Clotting factors are like dry ingredients in a cake—helping the cake set. Without enough, the cake will take longer to set and will not have the desired result.

When there is not enough of a particular factor in the blood, bleeding takes longer to heal. Scratches and cuts take a little more effort to stop bleeding. Internal bleeding, however, is the biggest problem. Bleeding can be triggered by surgery or trauma, or, in people with severe haemophilia, it can happen for no apparent reason.

Haemophilia A, or Classical Haemophilia, is a deficiency of blood clotting factor VIII. This is the most common form of haemophilia.

Haemophilia B is also called Christmas disease, after the first patient in whom the disorder was discovered. Haemophilia B is caused by a factor IX deficiency.

Although haemophilia A and B are caused by a deficiency of different clotting factors, symptoms are very similar. Haemophilia A and B are often referred to simply as 'haemophilia' because the two disorders are similar.

Symptoms

Many people think that a person with haemophilia will bleed to death from a minor cut. This is NOT true. Bleeding will stop, though it takes a little longer.

Bruising is common in people who have haemophilia, particularly severe haemophilia. (People with mild haemophilia may have little or no unusual bruising.) At times, the individual may not know when or how they received the bruises. These bruises can often look confronting and usually last longer than the bruising of someone without haemophilia.

Sometimes parents have been wrongly accused of child abuse because of these bruises, which is devastating for the parents.

Internal Bleeding

The biggest problem for people with haemophilia is internal bleeding into joints and muscles. During a bleed, blood enters muscles or the space between joints, depending on whether it is a muscle or joint bleed. These bleeding episodes ('bleeds') are extremely painful as blood does not belong in these areas. Bleed sites become swollen. Even slight movement can be extremely painful.

A person with mild haemophilia may only experience a bleed following surgery or trauma. A person with severe haemophilia, however, may have a bleed after being hit, falling etc. Some bleeds occur for no apparent reason. These bleeds are called 'spontaneous bleeds'. Enough bleeds into the one spot can cause long-term damage, leading to arthritis and immobility.

Prevalence

Haemophilia affects people from all over the world, from all socioeconomic backgrounds and of all religious beliefs. Approximately one in 5,000 males is affected. Haemophilia in women is extremely rare, though it does happen. It is more common for females to be 'carriers' of the gene responsible for haemophilia; this may result in the female having some symptoms themselves, such as menorrhagia, heavy menstrual flow.

Continued on page 3

Gender references

As few females have haemophilia, masculine pronouns are used in this document.

Severity

Haemophilia is said to be mild, moderate or severe. The severity is linked to the amount of clotting factor in the blood. People with mild haemophilia have a slight factor deficiency and have minimal trouble. Severe haemophilia is the result of a significant factor deficiency (less than 5% of normal). People with severe haemophilia are more prone to 'bleeds'. People with moderate haemophilia have an experience somewhere between that of a person with mild haemophilia and one with severe haemophilia.

While the severity of haemophilia is a good guide, it is also important to remember that each individual's experience is unique. A person with moderate haemophilia may have more difficulty with their disorder than a person with severe haemophilia. For a better insight into what you can expect, talk with the young person with haemophilia, his parents and/or last year's teacher.

2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

Haemophilia is a lifelong condition for which there is no cure. Fortunately, effective treatment is available which minimises bleeds and bruising. Young people can participate in most activities including sport, and can expect to lead a normal life.

Treatment and Prevention

In Australia, clotting factor is now widely used for the prevention and treatment of bleeds. Treatment consists of injections of the missing clotting factor, either factor VIII or IX. These injections, or infusions, are given directly into the vein, thereby raising the amount of clotting factor in the blood to a more normal level. Today's treatment is highly effective and significantly reduces the number of incidents.

People with haemophilia have a personalised treatment plan, which is determined by the Haemophilia Treatment Centre or haematologist. Most individuals with severe haemophilia will have clotting factor treatment on a preventative basis (prophylaxis) usually two to three times per week. Treatment is usually given at home by parent or the student himself before he comes to school. People with less bleeding incidents may only receive treatment when required. Your student or his parents can tell you about his personal treatment plan.

You will NOT be expected to give your student an injection.

The treatment provides the best cover for the first eight hours following administration. Usually treatment days are Monday, Wednesday and Friday, though families can vary this to suit the week's activities. People with haemophilia are encouraged to have treatment on the morning of the days they are most physically active. Ask which days your student has treatment.

Ports

Because children's veins are small and can be difficult to access, many children with haemophilia have port-a-caths or infusa-ports, often just called 'ports'. A port is a small intravenous device surgically implanted under the skin on the chest. Your student may have a port to assist in accessing the bloodstream for infusing treatment product. You will not be expected to use this device.

Specialists

While most people with haemophilia are treated at home, they have regular checkups with a haematologist. Haemophilia nurses and the Haemophilia Treatment Centre team works together to provide the best possible care for the person with haemophilia.

HAEMOPHILIA

Pain Relief

Pain relief is often required during a bleed. People with haemophilia use a variety of pain management techniques including meditation, relaxation techniques and pain killers. Resting the affected area is important.

Ice packs are sometimes used, though children tend to find these too cold.

Paracetamol is commonly used for pain management. Your student's parents will tell you what you may do to alleviate pain, including when paracetamol may be taken.

Aspirin

Aspirin has properties which thin the blood and promote bleeding. These properties are not helpful to people with haemophilia and can further complicate a bleed.

A number of pharmacy products contain aspirin as an ingredient, such as Nurofen, etc. Always check medication labels before administering to a person with haemophilia. If it contains aspirin, do not administer.

Never give a person with haemophilia aspirin.

B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

A boy first...

Parents of boys with haemophilia often say, 'He is a boy first. Haemophilia comes second.' And boys do seem to live by this motto.

People with haemophilia are interested in getting on with their lives. While haemophilia must be respected, it does not need to dominate life. Students with haemophilia get up to the same mischief and participate in the same interests as their peers. They have their own dreams and aspirations. This is perfectly normal and the student will significantly benefit by participating with his peers.

Academic Achievement

Haemophilia does not affect a student's ability to learn or perform academically. A student with haemophilia can reasonably be expected to reach the same academic levels as his classmates. However, if the student misses a lot of school, he may fall behind and require special assistance to catch up.

Sport

People with haemophilia can participate in most sports. In fact, exercise is encouraged as it promotes healthy growth and development, and helps prevent bleeds. Cycling and swimming are particularly recommended. Contact sports and 'adventure' sports (e.g. bungee jumping) are discouraged as the risks outweigh the benefits. Your student, his parent/s or guardian/s can tell you which sports he should avoid. With permission, a discussion with your student's physiotherapist may also be appropriate.

'I Don't Have Haemophilia!'

Because today's prophylactic (preventative) treatment is so effective, there are a growing number of young people who cannot remember having a bleed. (Their last bleed might have been when they were diagnosed as infants.)

These young people do not realise the impact of haemophilia because the treatment masks it. They might not believe they 'really' have haemophilia and rebel against having treatment. This feeling of 'invincibility' can sometimes lead to reckless actions.

2. Effects on those close to the child/young person

Parents

Finding the balance between protecting a young person with haemophilia and allowing him to get on with life is not easy. This becomes even more difficult as the young person starts questioning why they need treatment when their friends do not. Parents worry about their child refusing treatment and the possible consequences of doing so.

Siblings

Brothers and sisters can feel left out, especially if their sibling with haemophilia seems to get more attention than they. They may feel that parents do not love them as much as the sibling with haemophilia and may resent that sibling.

Sometimes, a child with haemophilia will play on the fact that he has a bleeding disorder to achieve some end, much to the frustration of his brothers and sisters.

Continued on page 6

HAEMOPHILIA

3. "In Their Shoes" - stories from children/young people with the condition

"Hello, my name is Jarrad and I'm writing how haemophilia can't stop me. I was diagnosed with haemophilia A at 8 months.

" My mum had taken me to swimming lessons when I was little. I kept going to the swimming lessons and got better as I got older. I was beaten in events when I first joined the Geelong Swimming Club, but after a lot of hard training I got better and better. My best is backstroke. Kids that used to beat me, now, I can beat them because of a lot of hard work.

" This year I reached the state final for under 14 100m backstroke and came 10th, state final for under 14 50m backstroke came 6th, broke the Geelong District record and Geelong All-Course record. I have won a lot of medals for swimming and other sports like netball, umpiring and tennis. I don't let haemophilia stop me from participating in sport."

Continued on page 7

C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

Knowledge

Teachers sometimes worry about having a student with haemophilia in their class. You don't need to panic. It is unlikely to impact on your classroom practices. However, it is important to know a few basics, including what to do in the event of an emergency. Knowledge will help you relax and become more comfortable with haemophilia.

Teacher Attitude

The teacher has a significant impact on the student. A positive and realistic attitude towards haemophilia and not using it to define the student can help create a positive attitude in the student towards haemophilia, himself and his abilities. Your positive attitude will also 'rub off' onto other students and teachers.

Talking About Haemophilia - with the class

Some students, particularly younger children, are happy for their teachers to tell the class about their haemophilia. As a student gets older, he may prefer that only a select few know. Before talking with your class about haemophilia, speak with your student and his parents/guardians about their wishes. They may want you to address certain issues or avoid others.

Talking About Haemophilia - with teachers

All members of staff should have some understanding of haemophilia and know which student has the disorder so they know what to do in the event of a playground accident. Create an 'Emergency Care Plan' together with parents/guardians and the student; this should consist of an emergency phone numbers list. It is important for parents to be present during these meetings to provide information about their child.

There is no need for staff to panic - it is unlikely that they will need to use this knowledge. However, everyone concerned will feel happier and safer knowing what to do 'in case'. Display the 'Care Plan' and haemophilia first aid management poster in a secure (confidential) yet prominent place in the sick bay and staff room.

First Aid - Minor Accidents

Your student with haemophilia will have as many cuts and scrapes as any other child his age. Shallow cuts and scratches are not life-threatening and bleeding will stop. Often a firmly applied band aid is sufficient.

Treat minor injuries as you would for any other child. Ensure pressure is placed upon the site to curb bleeding.

Bleeds

Your student's parent or guardian will speak with you about what to do if the student has a bleed at school; this can be included in the student's 'Emergency Care Plan'. You may be asked to contact the parent or guardian, put ice on the site, and/or let the student rest. If you have permission to offer him Panadol, this will help (**DO NOT GIVE ASPIRIN/NUROFEN TO A PERSON WITH HAEMOPHILIA**).

Emergencies

Emergencies include head injuries such as falling from the monkey bars, bleeding into the nose or throat cavity (minor nose bleeds are not generally a problem) and any sudden, severe pain such as a headache or abdominal pain. Blood into these regions can be life threatening and should be checked immediately.

Emergencies are extremely rare. However, it is strongly encouraged that you discuss and create and 'Emergency Care Plan' with the parent/guardian around what they expect you to do in the event of an emergency. If you have questions about what you need to do, it is prudent to resolve them early. Knowing what you need to do will increase your confidence to handle situations effectively.

Be Prepared

Keep permission forms, notes about the parent's/guardian's wishes, phone numbers and other information together in a safe place so you can easily find it in an emergency. Plan what you will do in an emergency. You will probably never need to use this plan, but it is invaluable in an emergency. As the boy scouts say, Be Prepared!

2. Link(s) to useful other online resources for schools on strategies in responding to a child/young person with this condition

There is little information on the web specifically for teachers - most of it is in book format.

However there are some general information sites:

Haemophilia Foundation Victoria www.haemophiliavic.org.au

Haemophilia Foundation Australia www.haemophilia.org.au

RCH Education Institute www.rch.org.au/edinst/support.cfm?doc_id=10315

Also look in the *Helpful Resources* section of the [Further Resources](#) section (next page).

D: FURTHER INFORMATION

1. Organisations, including services and resources available

Haemophilia Foundation Victoria (HFV) is a member of Haemophilia Foundation Australia and provides education, support and advocacy for people with bleeding disorders. HFV also offers information and education to the wider community.

Haemophilia Foundation Victoria
13 Keith Street
Hampton East VIC 3188
Phone: (03) 9555 7595
Fax: (03) 9555 7375
Email: hfvic@vicnet.net.au
Web: www.haemophiliavic.org.au

Services include:

Information: books, booklets, brochures, articles, internet and video

Library: members can access this library free

Counsellors: 2 professional counsellors who understand haemophilia, bleeding disorders and associated complications (free service to members/individuals affected by bleeding disorders)

Speakers: Speakers are available free to community groups and schools around Victoria

Workshops: Workshops, seminars and conferences are held periodically and are advertised in the HFV newsletter

Newsletter: Contains information about bleeding disorders, treatment and associated complications, details of upcoming events, personal stories, services available to members and more. Quarterly.

Social events: Several events are held each year, including the Christmas Picnic, camps, golf group and other social functions

Peer support: Includes a Men's Group (meets approx 8 times a year), Women's Group (meets annually), Golf Group (meets every few months) and a Youth Group (meets occasionally).

Subsidies: HFV subsidises ambulance subscriptions, SOS talismans, MedicAlerts and some reference books. Details printed in Newsletter or contact the office.

Helpful Resources:

While some material may be available from your library, we suggest you ensure it is recent as haemophilia care has progressed considerably over the past few decades.

Getting the Facts: Haemophilia, Arthritis and Your Student, 1999, Haemophilia Foundation Australia (booklet)

Haemophilia, 2000, Haemophilia Foundation Australia (booklet)

Haemophilia Information for Schools, 2003, Leah Lonsdale, Haemophilia Foundation Victoria

Teacher Information Pack, 2003, Haemophilia Foundation Victoria (pack)

The Student with Haemophilia, 1995, Haemophilia Foundation Australia

What Do You Know About Haemophilia?, 2002, Haemophilia Foundation Australia (poster)

Boys will be boys. A guide to sports participation for people with haemophilia and other bleeding disorders, 2005, Royal Children's Hospital Physiotherapy Department & Henry Ekert Haemophilia Treatment Centre, Royal Children's Hospital Melbourne (booklet)