

Haemophilia Information For Schools

An Information Kit for Teachers.

2010 Edition



Haemophilia Information for Schools

Published by

Haemophilia Foundation Victoria Inc.

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About the Royal Children's Hospital Treatment Centre

The Henry Ekert Haemophilia Treatment Centre is a comprehensive treatment centre for haemophilia and other bleeding disorders. The centre provides services such as clinical support, social work, physiotherapy and education advice.

Centre Director is Dr Chris Barnes who has international and local Haemophilia treatment experience. He leads a team of dedicated health professionals:

Janine Furmedge: Haemophilia Nurse Coordinator

Julia Ekert: Data/Office Manager

Cecilia Schreuder: Social Worker

Enquiries should be directed to Janine Furmedge or Julia Ekert by calling the Haemophilia Treatment Centre office on 9345 5099.

HAEMOPHILIA FOUNDATION VICTORIA INC.



February 2010

Dear Educator,

Teachers sometimes worry about having a student with haemophilia. You don't need to panic. There is nothing special you need to do and 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.

This pack is an initiative of HFV and has been compiled in collaboration with the Royal Children's Hospital Haemophilia Treatment Centre to inform teachers about haemophilia and how it relates to schooling. We suggest you read it now and then put it in a safe place for future reference.

You may also like to make it available to other teachers at your school so they are aware of how to handle an accident involving a student with haemophilia. Extra copies are available from Haemophilia Foundation Victoria and on the Haemophilia Foundation Victoria website.

If you have any questions about your student's haemophilia, ask the student or their parents/guardians. You can also contact the Haemophilia Treatment Centre at the Royal Children's Hospital on (03) 9345 5099.

You are also welcome to contact the Haemophilia Foundation Victoria on 9555 7595 or email info@hfv.org.au. We are located at 13 Keith Street, Hampton East 3188 and our office hours are usually Monday to Thursday, 8.30am to 4.30pm.

More information/ resources

Haemophilia Foundation AUSTRALIA www.haemophilia.org.au
Haemophilia Foundation VICTORIA www.hfv.org.au

Thank you again for taking the time to become familiar with haemophilia.

Committee of Haemophilia Foundation Victoria

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February 2010

Dear Educator

Thank you for your interest in the care of boys with haemophilia and children with other bleeding disorders.

Progress in the medical management of boys with haemophilia and children with other bleeding disorders over the last 20 years has been dramatic. Children with bleeding disorders in 2010 experience a very different quality of life compared to previous generations. In the absence of effective treatment, past generations of these children were discouraged to participate in active past-times for fear of precipitating bleeding episodes. Participation in most sports was not possible. As a result, these children missed out on the health and social benefits of being able to share in play and sporting activities.

With the modern treatment available today, the majority of these children in Australia are expected to lead normal lives. Taking part in active play and sporting pursuits is now encouraged and today's generation of children with bleeding disorders are experiencing the full range of benefits of involving themselves in the broad range of recreational activities.

School remains an extremely important part of these children's lives. Although these disorders have the potential to cause serious medical problems, successful integration of these children into the school community is extremely important. The information contained in this teachers' package, produced with the generous support of the Haemophilia Foundation of Victoria, will provide you with all the information required to maximize the school experience for boys with haemophilia and children with other bleeding disorders. If you require further information please feel free to contact me on the telephone number listed below.

Thank you once again for your interest.



Dr Chris Barnes
Director
Henry Ekert Haemophilia Treatment Centre
Tel: 9345 5099

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About Haemophilia

Haemophilia is a blood clotting disorder in which one of the essential clotting factors in the blood is deficient. It is helpful to think of these clotting factors as 'glue' that stops bleeding. This is called haemostasis.

Approximately one in 5,000 males is affected and the gene responsible is transmitted by women. While haemophilia in females is extremely rare, females who carry the gene responsible for haemophilia may have some symptoms themselves.

While haemophilia is hereditary, approximately one third of people with haemophilia have no prior family history of the condition. Their haemophilia is the result of a gene mutation (change).

Gender References in this Guide

As haemophilia predominantly affects males, masculine pronouns are used in this text for ease of reading. However, females can have haemophilia and other related coagulation disorders too. The information in this document is relevant to females also. Females with haemophilia (and other related bleeding disorders) who are old enough have menstruation to consider too.

Symptoms

The common belief that a person with haemophilia gushes blood from cuts and will rapidly bleed to death is a myth. A person with haemophilia bleeds no more profusely than anyone else, just for a longer time. Bleeding from cuts and scratches *will* stop. First aid for minor and more serious injuries will be covered later in this information pack.

Bleeding is mostly inside the body (internal), usually inside muscles or into the space between joints. Internal bleeding is very painful. Bleeding episodes, or 'bleeds', may occur without any apparent cause (spontaneously), after surgery or trauma. Repetitive bleeding into the one site can cause permanent damage such as arthritis. This pack contains information about what to do if you suspect that your student with haemophilia has an internal bleed.

Easy bruising is also common in people with haemophilia. Quite often the individual will not even know how he received the bruises. They last longer than most people's – often lasting as long as three weeks – but are not harmful. Sometimes parents are wrongly accused of child abuse because of these bruises, which is devastating for the parents.

Severity of Haemophilia

There are three degrees of severity; mild, moderate and severe. These refer to the amount of clotting factor in the blood. The more severe the haemophilia, the less clotting factor is present in the blood. People who do not have haemophilia have a factor VIII (eight) or IX (nine) level of 50-150%.

The factor level often acts as a guide as to what to expect. Generalisations are listed below. However it is important to remember that your student's experience of haemophilia is unique and may vary from the generalisations listed. Your student, his parents or last year's teacher will be able to give you a better idea of what to expect.

Mild Haemophilia (>5- 40%)

People with mild haemophilia rarely have bleeds that affect schooling. Most difficulties arise after an accident or surgery. However, it is important to know what to do in an emergency.

Moderate Haemophilia (1-5%)

Similar to mild haemophilia, boys with moderate haemophilia will bleed after a trauma or surgery. They may require treatment to stop their bleeds. The term for this course of treatment is 'on demand' (as necessary).

Severe Haemophilia (<1%)

Severe haemophilia is, obviously, the most serious type of haemophilia. Bleeds occur easily and sometimes for no apparent reason at all. These are called 'spontaneous' bleeds. To prevent this happening, your student will have a personalised prophylactic treatment plan. This means he is given the clotting factor he is deficient in by injection two to three times a week.

Treatment minimizes the problems your student will have by raising his factor level and allowing him to lead a more 'normal' active life.

Treatment

Haemophilia is a lifelong condition, for which there is no cure. Fortunately, effective treatment is available.

Treatment involves injecting the clotting factor that is deficient directly into the vein, thereby raising the amount of clotting factor in the blood to a more normal level. This is usually done at home by his parents before he comes to school. Older boys administer their own treatment. 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's best cover is for the first eight hours after it has been given. We encourage him to choose the days he plays sport or has PE. Usually the treatment days are Monday, Wednesday and Friday, but the families can vary this to suit the week's activities. Do ask them what days he has treatment.

Ports

Because children's veins 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 student's 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.

What to Expect

Just as every student in your class is unique, every person with haemophilia has a different experience. There is no 'normal'. The best person/people to ask about what you can expect is the parent/s or guardian/s and the student himself.

We can, however, make a few generalisations.

The Student with Haemophilia

The student with haemophilia will behave – and misbehave – just like any other student of a similar age. He will have his own unique personality.

Your student has had haemophilia since birth. He has had time to become used to it. He will therefore be able to tell you if he is having a bleed – even before there are any symptoms you can detect. If he says he is having a bleed, he probably is!

One of the Crowd

No student likes to feel 'different'. Being part of the crowd is especially important for a student with haemophilia. Many adults with haemophilia report going to great lengths as children to be seen as normal by their peers.

Today's treatment helps students participate in all class studies and activities, including most sports. Your student will appreciate and respect your effort to treat him normally and let him be seen as 'normal' by his peers.

Maintaining a balance between letting your student be 'normal' and being sensitive to his haemophilia can sometimes be difficult. Ask the student's parents how they strike this balance. If the student is old enough, you can ask the student himself to provide guidance about his wishes.

Schooling

Academic Achievement

Haemophilia does *not* affect a student's ability to learn or perform at school. A student with haemophilia can reasonably be expected to reach the same academic levels as his classmates.

He will have no particular learning difficulties due to haemophilia.

However if the student misses a lot of school, he may fall behind and require special assistance to catch up.

“A sound education is important for the employment prospects of a person with haemophilia.”

Source: 'The Student with Haemophilia', Haemophilia Foundation Australia

If you are concerned about your student's achievement or absences, speak with his parents/guardians.

Talking about Haemophilia at School

Some students are happy for their teachers to tell the class about their haemophilia. Other students prefer to tell only a select few. There are as many reasons for these choices as there are students with haemophilia.

Before talking with your class about haemophilia, speak with your student and his parents/guardians about their wishes.

Haemophilia & Sport

For many years people with haemophilia were not actively encouraged to participate in sport or physical activity in an attempt to minimise the number of bleeding episodes they experienced.

Prophylaxis

In most developed countries, including Australia, many boys and men with severe haemophilia are given clotting factor concentrate on a preventative basis (called prophylaxis). By having regular infusions of clotting factor, severe haemophilia can be changed to moderate and on the day of infusion to its mild form.

Boys who have grown up with prophylaxis experience markedly reduced numbers of bleeds. This has in turn reduced the joint and muscle changes so common in the older haemophilia population. The joint does not get damaged if a bleed does not occur.

Benefits of physical activity

Receiving prophylaxis is not the only reason that bleeds have decreased. As prophylaxis has allowed more participation in physical activity, boys with haemophilia have stronger muscles and are more able to accommodate the stresses placed on their bodies.

Within the group of boys who have grown up with prophylaxis it is those who are active, fit and strong who have the least problems. Even with prophylaxis, boys who are not active, do not participate enthusiastically in sport and leisure activities and who are possibly overweight all seem to have more trouble with their bleeds.

Physical activity has many physical and social benefits for everybody. The benefits are even more pronounced for people with haemophilia, who often have reduced fitness levels compared to their peers without a bleeding disorder.

Choice of sport

The choice of sport and activity is individualised to each child with haemophilia. A sport that is appropriate for one child may not be for another. Sports and activities at school that are controlled and supervised are strongly encouraged.

If you are unsure if your student should participate in a particular activity please discuss this with the boy's parents in the first instance. Families and teachers are able to obtain advice about sports participation from a Royal Children's Hospital physiotherapist specialising in haemophilia (Tel 9345 5099).

As for everyone, students with haemophilia are strongly encouraged to wear the standard safety gear for their chosen sport. (e.g. bike helmets when cycling, standard gear for skateboards, etc.)

More information

Further information can be found in "Boys will be boys. A guide to sports participation for people with haemophilia and other bleeding disorders."

This publication has been produced by the Royal Children's Hospital Physiotherapy Department and the Henry Ekert Haemophilia Treatment Centre.

Copies can be obtained by telephoning 9345 5099.

Minor Accidents (Cuts & Scratches)

All children get cut and scratched on the playground. Children with haemophilia are no exception. Your student with haemophilia will have as many cuts and scratches as other children his age.

Cuts and scratches are not life threatening and bleeding will stop. Often a firmly applied band aid is sufficient.

Treat these minor injuries as you would for any other child – including using universal precautions for blood handling - and ensure pressure is placed upon the site.

Treating minor cuts & scratches

1. Wash hands
2. Put on gloves
3. Apply firm pressure until bleeding stops
4. Clean the wound with antiseptic
5. Apply dressing or band-aid
6. Seek appropriate medical/ambulance treatment depending on type and severity of bleed. If cut requires stitches, call the ambulance or parents to take the child to the local medical officer who knows the child or to the hospital/ haemophilia treatment centre.
7. Clean up all blood spills with water.
8. Dispose of blood stained equipment in a safe and appropriate manner.

An older student will be able to attend to cuts and scratches himself. If you are concerned about bleeding from a cut or scratch, contact the student's parents.

Bleeds (Internal Bleeding)

Your student might develop a bleed after a playground accident. Sometimes bleeds occur for no reason and these are no one's fault. 'Spontaneous' bleeds are more common with severe haemophilia. The photo (right) shows an advanced knee bleed. Fortunately, today's treatment prevents most such bleeds.

From about five or six years of age, a child with haemophilia can detect a bleed *before* swelling and other signs are visible. He will feel a tingling sensation in the affected area. If your student says he is having a bleed, he probably is.



How do you assess whether a student is bleeding internally?

1. The student will tell you,
2. A limb may be held in an abnormal position,
3. He may appear uncomfortable or become irritable,
4. He may hold or support a particular part of his body,
5. There may be swelling,
6. There may be unusual warmth in the area,
7. The area may be more firm than is usual,
8. The student will experience pain when the joint is moved,
9. If he complains of tingling, pain, stiffness, decreased motion in a limb,
10. Ask the student if he *thinks* he has a bleed.

When a bleed is suspected:

1. Contact the parents/guardians
2. Let the student rest in a position he finds comfortable. (Bean bags are great, especially for younger children)
3. Put ice on the site and/or elevate if appropriate. If he does not want ice on, do not worry. Some boys report it hurts too much.
4. If you have been given permission to offer him Panadol, this will help.
5. Contact the hospital/medical officer who treats the student for advice if the family cannot be contacted.
6. Bleeds must be treated promptly. A bleed is not a medical emergency; however bleeding will not stop unless he has his treatment. Head injuries or a compromised airway is an emergency. Please see over the page.

In an Emergency

Emergencies are rare. However, it is strongly encouraged that you discuss what the parents expect you to do in event of an emergency. If you have any questions about what you need to do, it is prudent to resolve them early and it will increase your confidence to handle situations effectively.

What should I have?

Because we can't schedule an emergency, it's best to have everything together 'in case'. Some items you/your school may want to keep in a safe, convenient place are:

- This kit
 - Emergency phone numbers (you can use the list in the back of this kit)
 - Haemophilia First Aid poster (page 20) completed and prominently place in the first aid room.
 - Written instructions and authority to take the student to hospital if the parents cannot be contacted.
 - Any notes about what the parents/guardians expect in an emergency.
- You may like to keep everything together in this kit for easy reference.

What is an emergency?

- Any head injury. This does not mean knocking his head on the table, for example. A fall from a height and landing with a whip lash effect is to be treated as a serious bleed. Falling from the monkey bars is a good example.
- Bleeding in the nose or throat cavity. (Minor nose bleeds are not generally a problem).
- Any sudden, severe pain, such as a headache or abdominal pain.

What if I'm not sure?

If in doubt whether a situation constitutes an emergency, contact the parents or guardians promptly for advice. If unavailable, contact the student's medical officer or the Royal Children's Hospital Haemophilia Centre for advice on **9345 5099**. If you're still in doubt err on the side of caution.

What is the procedure?

First Aid

Ice, Rest, Sling, Bandage, Splint, etc.
if necessary, using universal precautions including wearing gloves when
handling blood spills.

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



Call Ambulance (if necessary)

Advise that the student must go to the Royal Children's Hospital (if in
Melbourne metro area) as he has haemophilia and is on the register at RCH.

No other hospital stocks the treatment product he needs.



Contact RCH Emergency Department

 **9345 6139**

Student's UR Number _____

State who you are, what has happened, the student's unit record (UR) number
and that the student has haemophilia.



Call the parent/guardian



Alternative Number:  _____

An adult must stay with the student if he travels in an ambulance and/or goes to
hospital.

Common Myths about Haemophilia

MYTH 1 If a person with haemophilia cuts himself, he will bleed to death.

This is probably the most common myth. People with haemophilia have blood which does not always clot properly so it will keep oozing for a longer time, but with appropriate treatment it will definitely stop. The person does not bleed any faster. It just takes more effort to stop the persistent bleeding.

MYTH 2 It is a royal disease and therefore the student must have royal heritage.

Just because it was present in the royal family in the 1800s does not mean that only royalty may have the disorder.

MYTH 3 A child with haemophilia cannot play any sports.

The child (or adult!) can participate in most sports, providing he does not endanger himself by playing too roughly or by knocking himself about too much. Boxing and heavy contact sports are potentially dangerous and should be avoided by boys who have haemophilia.

Encourage participation in the wide range of suitable activities. Warm up and safety equipment for ALL students helps prepare them for safe sport.

Remember, he is a boy first. His haemophilia always comes second!

MYTH 4 Children with haemophilia must constantly wear protective clothing and helmets.

This is definitely NOT TRUE.
However, people with haemophilia are strongly encouraged to wear any protective gear generally recommended for their sport. E.g. wear helmets for cycling, pads for cricket etc.

MYTH 5 Students with haemophilia need to go to special schools.

Boys with haemophilia participate, grow and learn naturally and happily in the normal school environment. Teachers are alert to the special needs of children with a variety of physical, emotional and intellectual disabilities.

MYTH 6 Haemophilia is due to the mother having done something wrong during her pregnancy.

This is absolute nonsense, as haemophilia is a disorder which is genetically inherited. It is something over which no-one has control, and for which no-one should be blamed.

MYTH 7 Haemophilia is contagious.

There is absolutely no way that this disorder can be passed on from the affected student to anyone else. It can only be passed on through pregnancy.

MYTH 8 Children with haemophilia have a shorter life span than so called “normal” children.

The life span for people with haemophilia is usually very similar to that of the average person in the community

First Aid Room Notice (Enlarge, complete & display in first aid area)

Haemophilia First Aid



Student's Name: _____

Teacher: _____

Grade/Year: _____

EMERGENCIES INCLUDE:

- Any head injury,
- Major injuries such as broken bones and severe cuts,
- Bleeding in the nose/throat cavity *Minor nose bleeds not usually a problem,*
- Any sudden, severe pain, such as headache or abdominal pain, and
- Difficulty breathing

IN AN EMERGENCY:

First aid

Ice, Rest, Sling, Bandage, Splint etc
If necessary, using universal precautions



Call Ambulance

If necessary. Be sure to advise that the student must go to the Royal Children's Hospital (if in metropolitan Melbourne area) as he has haemophilia and is on the register at RCH.



Contact RCH Emergency Department

☎ 9345 6139

Student's UR Number _____

State who you are, what has happened, the student's unit record (UR) number and that the student has haemophilia.



Call the parent/guardian

Name: _____

☎ _____

Alternative: ☎ _____

INTERNAL BLEEDING ('Bleeds')

Students with haemophilia can often detect bleeding before any signs are visible. If the student says he has a bleed, or *thinks* he *might* have a bleed, he probably does. The class teacher also knows how to detect bleeds.

If a bleed is suspected,

- Contact parents/guardians
- Let the student rest in a position he finds comfortable
- Put ice on the site and/or elevate if appropriate
- If unable to contact the parent/guardian contact the hospital/local medical officer who treats the child for advice,
- Keep the student still and relaxed to avoid further injury while waiting for parents/ambulance.

MINOR INJURIES

Cuts and scratches may take longer to stop bleeding but are not life threatening. Often a firmly applied bandaid is sufficient. (Use standard precautions used for all children if blood is involved – e.g. gloves, thoughtful disposal of bloodied items etc.)

NOTES

DO NOT GIVE STUDENT ASPIRIN OR NUROFEN

Important Information

About the Student:

Student's Name: _____ Year: _____

Diagnosis: _____

Parents' (or Guardians') Contact Details:

Home ☎ _____

Mother's Work ☎ _____

Father's Work ☎ _____

Other Emergency Contact _____ ☎ _____

Royal Children's Hospital:

Haemophilia Treatment Centre ☎ 9345 5099

Haematologist on call (for out of hours advice) ☎ 9345 5522

Emergency Department Triage Nurse ☎ 9345 6139

Student's Hospital UR Number: _____

Medical Information:

Family Doctor's Name: _____ ☎ _____

Drug Allergies: _____

Normal Treatment: _____

Other information: _____

Ambulance ☎ Dial 000

Letter to Teachers

Student's Photo

(In uniform)

Hi! I'm _____ (name) from grade _____.

I am a regular kid who happens to have haemophilia. I can do almost anything other kids can. There are just a few things you need to know about my haemophilia.

- ✂ Haemophilia is a bleeding disorder. There is an ingredient missing in my blood so it doesn't clot as quickly as other people's does.
- ✂ When I get cut on the playground, I will not bleed faster than any other child. It will just take a little longer to stop bleeding.
- ✂ Sometimes I bleed inside my body, usually into joints (e.g. elbows and knees). These are called 'bleeds' and hurt. A joint with a bleed swells up and gets stiff and hard to move. I can often tell if a bleed is coming before anyone else because it feels funny.
- ✂ I can get bleeds by being knocked or hit. Sometimes bleeds just happen (this is rare if my haemophilia is mild). If I have a bleed, please let my parent/guardian know and get advice on what to do next. I might need an injection to make the pain and swelling stop faster.
- ✂ If I get knocked on the head I might bleed inside my brain. If this happens please call my parents/guardians straight away. I might need to go to the hospital in an ambulance.
- ✂ I have haemophilia because it's in my genetic 'blueprint' just like hair colour – only having haemophilia isn't as good as having brown hair. You can't catch my haemophilia.

My class teacher has a poster for the first aid room so you will know what to do if I have an accident. He/she also has an information pack too. You can look at that or ring Haemophilia Foundation Victoria (☎ 9555 7595) and ask for a copy of the 'Information Pack for Teachers'.

Thanks for reading this.

Signed _____

Glossary of Terms

Arthritis	A group of related conditions involving inflammation of the joints
Bleeds	A bleed is bleeding into muscles and the space between joints
Clotting factor	See factor
Factor	An 'ingredient' in the blood that is part of the normal blood clotting process
Genes	Genetic 'blueprints' for the body
Haemophilia	A rare bleeding disorder
Hereditary	Passed on from parent to child through genes
Mutation	Change
Ports	Devices that are surgically implanted beneath the skin to make accessing veins easier. Ports are most often used in young children as their veins tend to be more difficult to access.
Prophylaxis	A preventative treatment. In haemophilia, prophylactic treatment is given three times a week, usually Mondays, Wednesdays and Fridays, to help prevent most bleeding episodes
UR Number	Stands for Universal Record Number. A system the Royal Children's Hospital uses to identify patients.

Notes

Permission Letters from Parents

Other Relevant Items