

## Supporting a student with haemophilia

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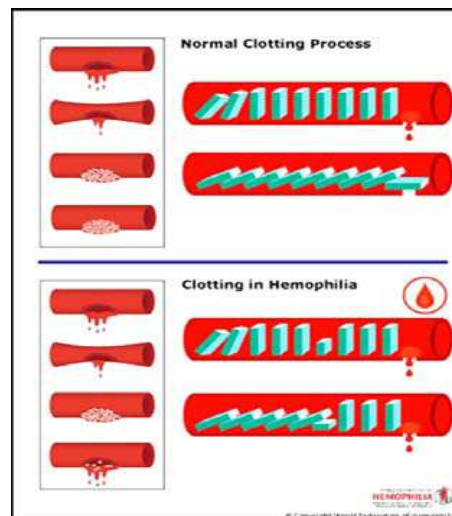
Contacts: RCH Education Institute and the RCH Henry Ekert Haemophilia Treatment Centre

### What is haemophilia?

Haemophilia is a lifelong condition that affects males almost exclusively. It is a disorder where one of the essential blood-clotting factors is lacking. It is helpful to think of this clotting factor as the 'glue' that stops bleeding. There is no cure.

Haemophilia A, the most common form of haemophilia, is due to the deficiency of clotting factor VIII. Haemophilia B is less common and is due to the deficiency of clotting factor IX.

The common belief that a person with haemophilia will rapidly bleed to death if cut is untrue. Bleeding from cuts and scratches *will* eventually stop. A person with haemophilia does not bleed more profusely than anyone else; they just bleed for a longer period of time.



Bleeding episodes ('bleeds') mostly occur internally, usually inside the muscles or inside the joints, and can be very painful. Bleeds are stopped by an intravenous injection of the appropriate clotting factor. Bleeds may occur spontaneously or as a result of trauma or injury. Repetitive bleeding into the one site can cause arthritis and chronic pain. In Australia, clotting factor is now widely used to prevent and treat bleeds.

People with haemophilia can also bruise quite easily; at times the individual may not even know when or how he received the bruises. These bruises can look confronting but are not harmful. Bruises usually last longer for someone with haemophilia; sometimes as long as three weeks.

## Support mechanisms

Schools are encouraged to explore the support mechanisms available to students who have haemophilia. There is a range of resources and community groups to assist schools. Please see the links below or contact the Royal Children's Hospital Education Institute or the Royal Children's Hospital Henry Ekert Haemophilia Treatment Centre for further information.

Haemophilia Foundation, Victoria: [www.haemophiliavic.org.au](http://www.haemophiliavic.org.au)

Haemophilia Foundation, Australia: [www.haemophilia.org.au](http://www.haemophilia.org.au)

Chronic Illness Alliance: [www.chronicillness.org.au/invisible](http://www.chronicillness.org.au/invisible)

National Youth Mental Health Foundation: [www.headspace.org.au](http://www.headspace.org.au)

Positive Youth Mental Health (SA): [www.headroom.net.au](http://www.headroom.net.au)

## Strategies for schools supporting students with haemophilia

The implementation of the whole-school and classroom strategies listed below will assist and support students with haemophilia. While these strategies aim to build the schools' capacity to support students with haemophilia, individual needs will vary depending on the severity of the condition.

### Whole-school approach

- Before educating the whole school about a student's haemophilia, speak with the student and his parents/guardians about their wishes. Some students are happy to discuss their haemophilia openly; others prefer to disclose information only to a select few.
- Discuss and create a care plan with parents/guardians and the student in the event of an emergency.
- Create an *emergency phone numbers list* that includes the RCH Haemophilia Treatment Centre, and display a haemophilia first aid management poster. Position these in a secure (confidential) yet prominent place in the first aid and staff rooms.
- Keep key school contacts informed of regular student absences due to outpatient appointments and/or hospitalisation for more severe bleeds.
- Obtain a copy of *Boys will be boys: a guide to sports participation for people with haemophilia and other bleeding disorders*. This resource discusses sports participation, injury prevention and the wearing of standard, safety gear in more detail.

- Remember that most males with severe haemophilia have clotting factor infusions on a preventative basis (prophylaxis) usually two to three times per week. Infusions involve injecting the clotting factor directly into the vein. Prophylaxis treatment is usually done at home before school. *You will not be expected to give your student an injection.*
- Discuss your student's individual treatment plan with them and/or their parents/guardians. Prophylaxis is encouraged and can often be planned for the days the student plays sport or has physical education.
- Remember that cuts and scratches are not life threatening; bleeding will stop. Ensure pressure is placed upon the site; often a firmly applied band aid is sufficient. Treat these minor injuries with the same care as you would for any other student.
- Be aware that many young boys with haemophilia have port-a-caths or infusa-ports ('ports') as their veins are difficult to access. A 'port' is a small intravenous device surgically implanted under the skin on the student's chest, which assists in accessing the bloodstream directly for infusing treatment product. *You will not be expected to use this device.*
- **DO NOT GIVE A STUDENT WITH HAEMOPHILIA ASPIRIN OR NUROFEN.**

### Classroom approach

- Remember that your student with haemophilia will have his own, unique personality. He will behave – and misbehave – just like any other student in your class.
- Be aware that haemophilia *does not* affect a student's ability to learn or perform academically well at school.
- Involve the student in extracurricular activities, such as school excursions and camps. Discuss and create a detailed care plan with the student and parents/guardian prior to attending excursions and school camps.
- Remember that students with haemophilia can usually participate in most sports; as with their peers, all boys with haemophilia are different and not all sports will be suitable for your student. A discussion with the student's physiotherapist may be appropriate.
- Monitor absences carefully to ensure students do not become disconnected from peers and/or fall significantly behind in their schoolwork.
- If you are concerned about your student's school absences, speak with his parents/guardians about these concerns.
- Maintain communication and provide relevant school work via email or hard copy for the student to complete during hospital stays and recovery periods at home.
- Ensure appropriate educational supports are in place for missed work due to absenteeism, such as catch-up classes, Visiting Teacher Service, Ronald McDonald Learning Program (RMLP).
- Allow for regular intervals during class time where the student may stand up to stretch, go for a walk, move and so on, to alleviate cramping and painful stiffness in muscles and joints from sitting for long periods.
- At Year 12/VCE level, discuss and research options for special exam arrangements and/or SEAS eligibility if relevant.

## Contacts: RCH Education Institute and the RCH Henry Ekert Haemophilia Treatment Centre

*The RCH Education Institute and the RCH Henry Ekert Haemophilia Treatment Centre encourage schools to contact their multidisciplinary teams of educational, medical and allied health staff should they require further information.*

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## References and Acknowledgements

Haemophilia Foundation Victoria 2006, *Haemophilia information for schools; an information kit for teachers*, Haemophilia Foundation, Victoria.

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