

the

STUDENT

with haemophilia



HAEMOPHILIA FOUNDATION AUSTRALIA

There is one guiding principle to remember if you have a child with haemophilia in your class:

“The child is a person first: then a person with haemophilia.”

Haemophilia is an hereditary disorder of the blood clotting mechanism - primarily affecting males, being transmitted through unaffected females. Females are affected only in very rare cases. It strikes all racial, national and socio-economic groups, and often occurs without any previous family history of the condition.

Approximately one in 5,000 males in Australia is born with haemophilia in its severe, moderate or mild form. The variation in severity of the clotting factor deficiency produces a wide range of bleeding experiences. Severe haemophilia usually causes frequent bleeding episodes either spontaneously (apparently without cause) or as a result of minor or major trauma, while very mild haemophilia may only cause bleeding after surgery or major injury. However, when bleeding does occur, it all requires the same treatment.

Haemophilia is a physical condition, not a psychological one. Nevertheless, different expectations of a child because of his medical problems can complicate a physical condition by introducing a psychological one.

It is important that teachers recognise that the child with haemophilia does have a few special needs because of the condition. It is the responsibility of the parents to see that the school has all the necessary information concerning their child's needs. If it is felt that insufficient information is forthcoming, contact can be made with the relevant

what special information should be supplied by the parents for the school's records?

A copy of "Haemophilia Information For Schools", which includes: -

- Phone numbers where parents can be reached.
- The type and severity of the haemophilia.
- The physician responsible for treating the child's haemophilia.
- The place of treatment.
- Any necessary consent statements needed for treatment.

what is the procedure if a child cuts himself?

The child with haemophilia does not gush blood. Small, superficial wounds will bleed no more than in a non-haemophilic person. A firmly applied bandaid will stop the bleeding. Pressure on the wound can be applied, or elevation as necessary. Deep cuts will also appear to bleed in the same manner as a non-haemophilic person, but if left the bleeding may persist. First apply a dressing with sufficient pressure to stop bleeding. The child's parents

should then be contacted so that treatment which involves infusion of clotting factor may be given.

As with all blood, care must be taken to protect against bloodborne virus infections. When applying first aid it is recommended that disposable plastic or latex gloves be worn, especially if people have open sores or abrasions on their hands. All surfaces should be cleaned afterwards with a 25% solution of bleach and water.

The more frequent and the more serious bleeding is internal rather than external.

what is the procedure when a child is bleeding internally?

At about five or six years of age a child can usually recognise internal bleeding. Even though there may not be any visible sign of internal bleeding the child's opinion should be heeded. While bleeding episodes are rarely an emergency, the parent or caregiver should be contacted as soon as possible. The child should not go home alone.

If the bleed is treated within the first few hours progressive symptoms will be minimised, and recovery will be quick. If treatment is delayed, more blood oozes into the joint, causing increasing pain. This is followed by a prolonged recovery period and subsequent loss of class time.

what is the procedure in an emergency?

In the rare case of an emergency the school should have written instructions and authority to take the child to hospital if the parents cannot be contacted.

what situation constitutes an emergency?

- Any major injury (as with any other child) such as broken bones or severe cuts.
- Head injury. A bump to the head can trigger internal bleeding. Prompt attention is therefore necessary, especially if the injury has been hard enough to induce headache, nausea or giddiness.
- Bleeding into the nose or throat cavity. (Minor nose bleeds are generally not a problem).
- Any sudden, severe pain, e.g. abdominal pain or headache.

All of the above require prompt intravenous infusion of clotting factor and attention by staff at the Haemophilia Treatment Centre.

do emergencies occur frequently at school?

No. Emergencies are rare, and children tend to have less problems with bleeding at school than at home.

what should the school do in the interim between injury or bleeding episode, and getting the child to a treatment centre?

- Allow the most comfortable position to be assumed.
- Apply a protected ice pack to the area of the bleed. This can decrease the pain and lessen the bleeding.
- Keep the child in a quiet environment.
- If a pain killer is necessary, offer Panadol.

Never give Aspirin or any medication containing aspirin. Aspirin affects the blood clotting process and could cause a more serious bleeding problem.

does a bleeding episode mean a long absence from school?

The length of absence will usually depend on the site and the severity of the bleed. The student should be absent only for as long as is absolutely necessary. If the bleed is not severe, the child may not miss any school or may return to school within 24 hours.

The student will sometimes return to school in a wheelchair, with crutches or a sling to take pressure off the affected area. If this is the case, the teacher may

need to help him feel comfortable socially. A brief question or comment is sufficient to acknowledge the bleed without drawing too much attention to it, such as, "How's it coming along?"

After a bleeding episode, activity should be resumed gradually. Vigorous activity can cause the area to bleed again. As each bleeding episode may differ it may be helpful to ask parents if any changes need to be made to the agreed guidelines regarding restrictions at this time.

what is the role of the class or form teacher?

- Inform the staff who have contact with the student about his haemophilia. Pass on copies of this leaflet, and share the copy of "Haemophilia Information For Schools" which includes a record of where to find details of the procedure if treatment is needed.
- Be aware of absences as a result of the haemophilia, especially if they become so frequent that academic progress is being hindered.

Frequency of absence will usually depend on the severity of the haemophilia. If absenteeism becomes a problem, the school may want to contact the family. If further information is needed, the social worker or Haemophilia Coordinator associated with the Haemophilia Treatment

Centre can clear up misconceptions on either side and facilitate co-operative solutions to the problem.

what is the role of the subject teacher?

The subject teacher's role lies mainly in dealing with absence following bleeding episodes:

- Being flexible in work requirements and approach. (This does not mean decreased work requirements.)
- Ensuring that work missed is completed or compensated for by completion of work which can be done at home.
- Expecting and encouraging performance according to academic ability.

Such requirements for individual students are often onerous for the subject teacher, who is pressured enough by regular student needs. However, this attention is of immense value. Children with haemophilia can present as under-achievers (even though they have normal to above average intelligence) due to absence from school and decreased expectations arising from their physical and medical problems.

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

should there be preparation for specific career areas?

There are no hard and fast rules about what career a student should choose. The plans made should be their own, as with any other young person.

A sound education is nevertheless of primary importance because a career may need to be chosen in keeping with any limitations imposed by the bleeding disorder. Career goals should be geared to individual needs, interests and abilities. Some people with haemophilia can cope with a vocation involving more physical stress than others.

are there activities in which a child with haemophilia should not participate?

Only contact sports such as football, boxing, judo, karate, and those sports which use hard balls (cricket, baseball) are contra-indicated for the student with haemophilia. Otherwise, activities should be restricted as little as possible. It has been recognised that if bleeding is to occur, it will happen whether or not restrictions are applied.

These students can attempt what other children do according to their physical abilities. Like all children and adolescents, it is important that they

explore their capabilities and learn their limitations for themselves.

what activities can be particularly helpful?

Contrary to popular belief, exercise is vital for the child with haemophilia. Good physical condition reduces the frequency and the severity of bleeding episodes and helps the muscles and the joints to resist damage.

Exercise also improves balance and sharpens reactions so that injury can be avoided. Swimming is excellent for the development of muscle tone, and should be encouraged.

Alternative interests to sports should also be encouraged. These may include musical interests, or hobby groups such as photography, model aeroplanes or crafts such as wood work and metal work.

Normal safety measures appropriate for all students are sufficient.

should a child's peers be informed about his haemophilia?

It is not usually necessary to inform a child's peers about his haemophilia. The requirement of special treatment can result in alienation. Most children are able to handle their own

explanations about their haemophilia.

Allow discussion to take place if it is initiated by the student, or if it arises in a natural context - along with other, for example, life-long conditions such as diabetes or epilepsy. These should be seen as conditions that need to be dealt with rather than as inhibiting diseases.

should disciplinary measures be modified for the child with haemophilia?

Discipline should be the same for the child with haemophilia as for any other student. It is emotionally and psychologically unhealthy for a student to feel "different" from their peers in this area, or to receive any special privileges.

Corporal punishment is, of course, out of the question.

do primary school children with haemophilia have special needs?

Yes, in the primary years these children will need some special watching. Even when they know they are bleeding, they may not tell the teacher because they are involved in a particular activity or because they know the treatment

involves being stuck with a needle, and this is something they may prefer to avoid. Eventually the young children learn that venipuncture means relief from the pain in their joints and the need to watch them decreases.

how does the teacher assess whether the child may be bleeding internally?

- Loss of function (limitation of movement) in a limb. Knees, elbows and ankles are the most common sites of bleeding.
- The child may appear uncomfortable or become irritable.
- They may hold or support a particular part of the body.
- There may be swelling (though not necessarily).
- There may be unusual warmth in the area.
- The area may be more firm than is usual.
- The child will experience pain when the joint is moved.
- Ask the child if he thinks he's bleeding.

It is not the responsibility of teachers to make a diagnosis. If in doubt, always ask. It is better to err on the side of caution than to ignore a potential problem.

conclusion

Most children are knowledgeable about their disorder and will deal well with its effects. If school personnel are informed about haemophilia, they too can manage it without fear or apprehension. Your reassurance and understanding can be of great support to the student and the family.

It should be noted that emergency situations are rare, and a balance must be achieved between protection and the aim of allowing the child to grow into a well adjusted, healthy adult.

Children with haemophilia must be regarded as normal individuals who happen to have a chronic, variable problem which sometimes can interfere with their education.

"Accent the pluses - disregard the minuses."

Extreme care should still be taken in handling blood, blood products and equipment, irrespective of their source. These can be the cause of a range of blood borne infections such as the hepatitis viruses and HIV.

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