



## **LIVING WITH HAEMOPHILIA**

### **ATTENDING SCHOOL: CONSIDERATIONS FOR THE LEARNER WITH HAEMOPHILIA**

#### **INTRODUCTION:**

The aim of this communication is to dispel the myths and fears teachers and personnel may have in the care of a child with a bleeding disorder. Teachers and school nurses without previous experience of haemophilia may feel anxious and fearful that they might bleed to death from a cut or bump!

Severe bleeding is a rare condition, and it is important for a learner with haemophilia to have a balance between protection and allowing them to participate in normal school activities. In the past youngsters with severe haemophilia were placed in schools for the handicapped because they were crippled by their disease. Today, thanks to dramatic medical advancements in treatment products and "Home Therapy" the outlook is bright for even the most severely affected learner.

The following information is to help you understand the condition, the treatment, the psychological needs of the learner and how to deal with a bleed at school. This will help the learner grow into a well-adjusted, healthy adult. As with any learner school attendance is important to promote intellect and interaction with their peers

#### **THE CONDITION:**

A bleeding disorder occurs when a plasma protein clotting factor is missing in your blood. The main types of Haemophilia are known as Haemophilia "A" or "B" and occur in males. Von Willebrand's Disease (VWD) is another bleeding condition that can affect both males and females. This can result in bleeding episodes that if not controlled can result in severe bruising and bleeding into joints and muscles. The bleeding problems are generally the same for both types. In addition, females may also experience heavy menstrual bleeding. Haemophilia and VWD are found equally in all racial and socio-economic groups.

A person with a bleeding condition will not bleed faster than a person with normal clotting factors, but they may bleed longer unless they receive appropriate treatment. Bleeding disorders are a relatively rare condition and those with a severe condition will need to be constantly managed.

Severity of the clotting problem differs greatly amongst individuals. In some it is pronounced and causes frequent bleeding episodes. In others it is less severe and some individuals only experience bleeding episodes following surgery or major injury.

Since most bleeding disorders are diagnosed before the learner starts school, the teacher and the school nurse should have a record of the diagnosis and the severity of the disorder from the Haemophilia Treatment Centre (HTC).





### **TREATMENT OF BLEEDING:**

The treatment of bleeding disorders requires an intravenous infusion which temporarily replaces the missing blood clotting factor and raises it to normal. The infusion can stop bleeds already in progress or prevent them from starting. The clotting factor is gradually cleared from the blood by circulation so a follow-up infusion may be needed later for a bad bleed.

The person with a bleeding disorder does not gush blood; this is an old myth. They will bleed internally, slowly and steadily. Most often bleeds occur into joints (knees, elbows, wrists or ankles). Early treatment stops the bleeding before blood escapes into the joint space. If treatment is delayed, more blood oozes into the joint causing pain and requiring more time and treatment to return to normal activity.

When a person with a bleeding disorder sustains injury, the first aid treatment is the same as for anyone else but may be followed by an infusion of the missing blood clotting factor. Head injuries are potentially dangerous and life-threatening and should be treated with an infusion of the factor even if there are no signs of intracranial bleeding. Injuries in the neck and throat area can also be serious and swelling may obstruct the airway. Complaints of pain and swelling in this area usually require immediate referral to a doctor.

Treatment of bleeding disorders has greatly improved in recent years. Products are now available in concentrated form so that large amounts of the missing factor can be given in a relatively small volume. The majority of children attending the Haemophilia Treatment Centre (HTC) will be receiving "Home Therapy". This enables parents and also the child, when they are a little older, to administer the required treatment. Although periodic check-ups at their HTC are required, frequent trips to the hospital are no longer necessary, meaning fewer absences from school.

### **CURRICULUM:**

The learner with a bleeding disorder should participate in the regular school programme. Intelligence is unaffected and they should be encouraged to follow their passions. If a learner is capable of higher education, they will have as much success as an unaffected learner. They can join class outings, participate in the school play, dance, run and join in activities around the playground. When they have had a bleeding episode they should limit some activities for a few days to recover.

### **EXERCISE:**

Exercise is vital for a learner with a bleeding disorder. This will help to reduce the frequency and severity of bleeding episodes and protect muscles and joints from permanent damage. Learners with haemophilia should be allowed to run and play with other learners, ride bikes and exercise.

Exercise programmes may need to be modified and contact sports such as rugby or soccer are not advisable. Swimming, calisthenics, cycling, tennis and table tennis are popular. As one expert physiotherapist observed, "Although track and field events may precipitate ankle, knee and calf problems, they should not be excluded arbitrarily". The learner himself is usually the best judge of his own limitations regarding physical activity.





A learner with a bleeding disorder who wishes to participate in activities and teams can be a manager, score keeper, referee or some other such position. The learner with a bleeding disorder, just like any other student, needs to belong to his peer group and to be accepted as "one of the guys". School personnel should encourage this participation.

### **PSYCHOLOGICAL AND SOCIAL CONCERNS:**

A child with a chronic disease, such as a bleeding disorder, requires some adjustment on the part of his family. Some parents adjust very well, while others may have more difficulty coping with this added stress. The parent's acceptance of the child and their bleeding disorder greatly influence the child's self-image, their attitude towards their condition and ability to function normally. The attitudes and actions of the school personnel and the learner's peers can be crucial in promoting optimal adjustments and a healthy self-image.

Over-protection is common and can be very detrimental. Parents, friends, neighbours and teachers often try to protect the child from getting hurt. This usually does not decrease the number of bleeding episodes but prevents the child from learning how to determine their own limitations.

Parents and teachers may feel sorry for the learner with a bleeding disorder and therefore make exceptions for them. It is important to treat the learner with a bleeding disorder the same as the other learners. If they are recovering from a bleeding episode they may not be able to participate in physical activity but no other exceptions should be necessary.

The learner who misses a lot of school naturally gets behind in his assignments, making it very difficult and discouraging when they return to school. This discouragement results in poor school progress and a dislike for school. With well managed treatment protocols frequent absences can be avoided.

The advent of "Home Therapy" has made this possible. If a learner with a bleeding disorder has poor attendance due to bleeding, the parents should be encouraged to consult their HTC regarding a possible change in the treatment programme. All efforts should be made to keep the learner with a bleeding disorder up to date with his schoolwork. This may require the understanding and co-operation of the school personnel.

### **BLEEDING IN SCHOOL:**

Emergencies are extremely rare and a standing arrangement for contacting the learner's parents/guardian should be made so that he/she can be taken for treatment. Parents should provide all emergency contact numbers to the school.

Following a heavy fall, blow or any head injury, the learner will need medical attention. They should be allowed to rest with a cold wet towel on the injured part. Complaining of a headache or pain in their throat must be treated as a genuine crisis. Should this ever occur, the school nurse should immediately notify his/her parents/guardians or, if they are not available, contact the HTC.





The application of an ice pack to the affected bruised muscle or swollen joint has proved to be beneficial. The ice pack should be applied for 5 minutes and then removed for 10 minutes. This process can be repeated for an extended period of time.

If there is bleeding into joints, the learner will normally tell the teacher. Past experience has taught them to recognize this type of internal bleeding before pain sets in. Parents/guardians should be contacted and the learner should not be allowed to find his own way home.

After a bleeding episode a learner may not be able to write or run on the playground. School personnel should make allowances for this. As soon as the affected area has recovered, they can resume their usual activities.

**NB: NO ASPIRIN OR MEDICATION CONTAINING ASPIRIN SHOULD BE GIVEN FOR PAIN RELIEF, NOR SHOULD ANTI-INFLAMMATORIES BE ADMINISTERED.**

These drugs prolong bleeding times because they ‘thin’ the blood. Aspirin substitutes, such as Panado (Paracetamol) should be used instead for pain.

### **VOCATIONAL GUIDANCE:**

With new treatment methods and products, a learner with a bleeding disorder should be capable of engaging in most occupations with the exception of heavy manual labour. However, employers may still be reluctant to hire them because of inaccurate preconceptions about their condition. Despite this, learners with a bleeding disorder and a good education and training in a specific field should be able to find employment. For this reason, it is important that parents, school personnel and the HTC work together to provide a positive school experience for the learner.

If any further information regarding a particular learner is required, please do not hesitate to contact the HTC or The South African Haemophilia Foundation.

(Adapted from literature made available by the World Federation of Hemophilia.)

### **Telephone numbers:**

Please contact The South African Haemophilia Foundation (021) 785 2140 for the Haemophilia Comprehensive Care Centre (HTC) near you.

For further information, visit: <http://www.haemophilia.org.za/>

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