Haemophilia in the classroom
A teacher’s guide to Haemophilia
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Haemophilia is a rare condition. Largely because it is so rare, there are a lot of myths and misconceptions about haemophilia firmly lodged in many people’s minds. Like most such misconceptions, these can make life much more difficult, for both the person with haemophilia and for those around him (or her), than the condition warrants.

This booklet is to help you and your pupils, by giving you the information you require to ensure that the child with haemophilia, or other inherited clotting disorder, enjoys and gains as much from school as any other child.
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What is haemophilia?

Haemophilia is an inherited genetic disorder, affecting only about 6500 people in the UK, which can lead to inadequate clotting of the blood in response to any form of injury. The defective gene responsible controls the production of the proteins in the blood, called clotting factors, which control blood clot formation.

How is haemophilia inherited?

This gene is carried on the X sex chromosome. All females have two X chromosomes, whereas males have one X and one Y chromosome. This difference determines the sex of the person.

Because the haemophilia gene is on the X chromosome, it can be passed to the child by either the father or the mother. A man with haemophilia, married to a woman with normal X chromosomes, would have sons with his Y chromosomes and their mother’s X chromosomes, and would not therefore have haemophilia. His daughters would not either, because although they would have inherited his defective X chromosome, the normal one inherited from their mother would override the defect. However, they would still be carriers of the condition, able to pass it on to their children.

Because a carrier has one normal and one defective X chromosome, there is a 50:50 chance of the haemophilia gene being passed to her children. As a result her sons will have a 50:50 chance of having haemophilia, and her daughters a 50:50 chance of being carriers.

Because of this inheritance pattern, haemophilia runs in families. If you have a child with haemophilia in your school, it is quite possible that any brothers or cousins he has will also be affected. Equally, any sisters could be carriers. Carriers may occasionally show signs of mild haemophilia themselves, but this is unusual.

It is theoretically possible for a girl to have full haemophilia, but this can happen only if she is the child of a carrier mother and a haemophiliac father. As you might expect, this is quite rare.
Female Carrier  

Male with haemophilia  

Female carrier  

Male  

Female  

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Female carrier  

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Male with haemophilia  

Female carrier  

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Female carrier  

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Male with haemophilia
How does haemophilia affect clotting?

Blood clotting is a complex process, involving many factors which are identified by Roman numerals.

These factors are activated in sequence in response to injury, each serving to activate the next, rather like a row of dominoes knocking each other over. The amount of each factor produced can activate a much larger quantity of the next, so there is also a snowball effect, ending up with fibrin which forms the clot.

There are two main types of haemophilia depending upon which clotting factor is affected. About 80% of instances result from a deficiency in Factor VIII which is referred to as Haemophilia A or Classical Haemophilia. The remaining 20% result from a deficiency in Factor IX, called Haemophilia B or Christmas Disease. Because these factors work near the middle of the chain, the clotting process starts as normal, but cannot be completed.

The result of this is that, while people with haemophilia do not bleed any more profusely than anyone else, the bleeding goes on longer.
There are a number of other inherited clotting disorders caused by deficiency of other coagulation factors, most of which are extremely rare, and produce abnormal bruising and bleeding from mucous membranes, such as the inside of the mouth. The only two which are at all common are Factor XI deficiency, which is seen in about 4% of Ashkenazi Jews, and von Willebrand Disease, which may be seen in as many as 1 in 1000 of the population.

Factor XI deficiency may go completely unnoticed until the person with it has to undergo surgery, especially to the mouth and throat or the urinary tract, but sometimes spontaneous bleeding may occur.

The majority of people with von Willebrand Disease, even though they tend to bleed for rather longer than normal, may also go through most of their life without realising there is anything wrong. It is often only when they are found to bleed excessively after having a tooth out or after surgery that the condition is spotted. In the few people with severe von Willebrand Disease there may be haemophilia-like symptoms, and these people need the same sort of precautions as those with haemophilia.
What are the effects of haemophilia?

It all depends on how severe the condition is.

People with mild or moderate haemophilia do not really have many problems. Even though their blood clots more slowly than normal, the difference is only likely to cause concern after serious injuries or during major surgery.

Indeed, many of these people are totally unaware that they have haemophilia, and their condition would almost certainly not be such as to require any special approach on your part.

However, in people with severe haemophilia, the clotting mechanism is so compromised that they can bleed even when there is no obvious sign of injury. The main problem is not from open cuts but from internal bleeding.

All of us damage small blood vessels in the course of everyday life and for most of us, this causes no problem at all, as the bleeding stops and the damage is repaired – often before we even know it has started.

For the person with haemophilia, once bleeding starts, it goes on for longer, meaning that even trivial injuries can lead to bleeding into the muscles and joints, causing them to become inflamed, swollen and painful.

An incident such as this is referred to as ‘a bleed’ and requires treatment with an intravenous infusion of the blood clotting factor which is missing. Because repeated bleeds can also lead to long term damage, particularly to the joints, many people with haemophilia now receive regular infusions of factor, usually twice or three times a week, to prevent bleeds occurring in the first place. This type of treatment, called prophylaxis, is usually effective in preventing bleeding which occurs for no obvious reason (spontaneous bleeds), and will reduce the severity of bleeding as a result of injury to a level close to that of any other child.
How will haemophilia affect schooling?

Fortunately, because of the effectiveness of modern treatment, haemophilia should not have a serious impact on the child’s education. It is important that the school should have a good understanding of the possible problems, and should build a relationship of mutual trust between teachers and pupil. Children with haemophilia are no different from any other in looking for any excuse to get out of lessons and activities they don’t like – if they think they can get away with a fictitious bleed, they may try it.

That said, and although it is just as important for children with haemophilia as it is for any other to attend as much and as regularly as possible, there may be times when they have to miss school while they recover after a bleed, or in very rare circumstances they may require some type of aid such as a wheelchair or crutches.

The school should be aware of this and have the necessary arrangements in place before the event. Naturally, as a teacher you will want to do all you can to help a child who has been absent to catch up on missed work and get back into the swing of classes.

The aim is always to involve the child with haemophilia, and to concentrate on all the things he/she can do rather than the odd one or two that they can’t. These will, of course, vary not only with the severity of individual cases, but also with the age, ambitions and talents of the child.

In general, most school-based activities can be enjoyed by the child with haemophilia, however, it is worth consulting with parents about participation with contact sports – and parents may choose to give prophylaxis on P.E. or sports days.
Playgroup/Nursery, Infants and Primary school

It is important that children join in all play activities with their classmates, especially at this age. The ordinary play activities of young children usually present little problem beyond the occasional ugly bruise. Cuts and grazes are generally easy to deal with (see p12) and children should use scissors and other sharp instruments just the same as other children – they need to know how to use them safely just as much.

Sport at the Primary school level is not usually as competitive or rough as it becomes later, so unless the child has a particular problem like a ‘target joint’ (one which is particularly prone to bleeds) they should be allowed to join in with all activities.

The only time treatment is likely to be required is if they get an injury to the head, joints or genitalia (see p12–14).

Secondary School

As children get older, they get more competitive. The sports they enjoy tend to get rougher, and the range of sports and other activities they want to join in gets wider. This is not a problem. Sport and exercise are good, since they strengthen the joints and build up the muscles which protect them, making bleeds less likely. Provided that they, and the school, are sensible and use the right protective clothing, etc, where appropriate, almost all sports are fine for children with haemophilia. In the event that any particular sport does cause a problem, it is not usually too difficult to find an equally satisfying but safer alternative.

It is not possible to lay down hard and fast rules about which sports are, or are not, suitable for people with haemophilia. The relative risks and benefits will vary from child to child, and opinion differs about the risks and benefits of different sports. As a rule of thumb it may be better to avoid ‘violent’ contact sports, such as boxing, wrestling, rugby, contact martial arts, etc, but there is probably no sport that has not been played and enjoyed by people with haemophilia. If you are in any doubt, it is best to liaise with the child’s parents and Haemophilia Centre.
What should teachers look out for?

Many incidents that you might expect to cause problems can easily be dealt with by simple first aid. Others cannot. These are the ones that cause a bleed. Guidelines for recognising a bleed are included on the tear-off poster at the back of this booklet.

Cuts, grazes and bruises

The minor cuts, grazes and bruises that are an everyday part of childhood do not normally cause any significantly greater problem for a child with haemophilia than for any other, and can be dealt with by normal first aid measures.

**People with haemophilia do not have thinner blood and do not bleed any faster than anyone else – nose bleeds, cuts and grazes will slow and stop with standard, basic first aid measures.**

Obviously, when dealing with any form of open bleeding or blood spillage, all the normal precautions should be observed (eg wearing gloves, cleaning up with dilute bleach solution and paper towels, safe disposal in a sealed polythene bag).

Cuts and grazes should be covered with a plaster and/or bandage and be given direct pressure for a few minutes. Deep cuts, of the sort that might need stitching, should be covered and then referred to your local Haemophilia Centre for treatment.

Bruises are only a problem if they are particularly painful, which may be an indication of a deeper underlying bleed, or if they are the result of a head injury, which is always a cause for concern (see p14). Injuries to the genitalia should also always be taken seriously and referred for treatment.

**Never give any medicine containing aspirin (acetylsalicylic acid). Aspirin slows clotting and will make the problem worse.**
Nose bleeds

These may normally be stopped by applying firm pressure to the affected nostril for 10–20 minutes, or with an ice pack applied to the bridge of the nose for a maximum of 5 minutes, or both, while the child is kept sitting upright. If these measures do not succeed, they should be referred back to their parents or to their Haemophilia Centre.

Bleeding from the tongue, or in the mouth

Any bleeding within the mouth is harder to deal with because any clots that form tend to be either dislodged by the tongue or food, or washed away by the saliva. Sucking an ice cube may work, but usually bleeding inside the mouth will need treating at the Haemophilia Centre.

Joint bleeds

Older children should be able to tell you themselves if they are having a bleed. Younger ones may indicate that there is a problem by appearing upset or by ‘protecting’ a limb by limping or not using it. The commonest sites for joint bleeds are: shoulder, elbow, wrist, hip, knee, ankle and the main signs are:

• Pain or a ‘funny feeling’

• Swelling of the affected joint or muscle

• Heat over the affected joint or muscle

• Loss or impairment of movement

Joint or muscle bleeds should be treated by the parent or Haemophilia Centre as quickly as possible.

Any bleed around the face, neck or throat must be treated as an emergency and treated immediately by either parents or the Haemophilia Centre.
Head injuries

Any head injury may potentially be serious, since there is always the possibility of bleeding within the skull, which would put pressure on the brain. Therefore, even if you judge that the ‘injury’ really is trivial, you should still keep a close eye on the child for the rest of the day and tell the parents, so that you, or they, do not miss any of the signs that the injury may be more serious than it at first appeared.

If in doubt, get help from the Haemophilia Centre.

Minor head injuries

Children often knock their heads. If the child is not distressed and not in pain, the bump is unlikely to have caused a bleed and probably does not need treating. Nevertheless, watch the child carefully, and if in doubt, get help.

However, if the head bump was hard enough to cause bruising or swelling it should always be treated by the parents or the Haemophilia Centre.

Serious head injuries

These are usually the result of a hard blow to the head. Any injury which knocks the child unconscious is always serious. Remember, any head injury may be serious, even if at first sight you might not expect it to be.

If a child shows any of these signs, whatever the injury, they need treatment as soon as possible by your nearest hospital or Haemophilia Centre:

• Persistent or worsening headache
• Nausea and/or vomiting
• Drowsiness or abnormal behaviour
• Weakness in one or more limbs
• Clumsiness or poor coordination
• Neck stiffness or pain
• Blurred or double vision
• Going cross eyed
• Loss of balance
• Fits or convulsions

If in doubt, always contact the child’s parents or the Haemophilia Centre.
Recognising a bleed

At Playgroup/Nursery, Infants and Primary school

If the child is miserable and/or crying for no apparent reason, check for the signs of a bleed.

At Secondary school

As they grow, most children with haemophilia will be well able to identify the signs for themselves and know if they are having a bleed. However, they may sometimes be unwilling to call your attention to any problem, so you need to look out for uncharacteristic quietness or hampered mobility and check for the same signs as in younger children. If in doubt, contact the child’s parents or Haemophilia Centre.

What are the signs of bleeds?

Muscle and joint bleeds

• The area may feel tight, warm or swollen
• The limb is often painful, stiff or difficult to extend
• The limbs may be unequal in appearance

Bumps to the head

• There may be an obvious lump, swelling or bruising
• There may be no obvious mark at all – but always contact the parents or seek help from the Haemophilia Centre

Mouth, gastrointestinal (GI) and urinary tract bleeds

• Visible bleeding from mouth or tongue
• Bloody or black tar like motions
• Red or brown urine

What to do

• Call the child’s parents and/or
• Call the child’s Haemophilia Centre for advice
• If there is swelling or discomfort, apply an ice pack to the affected area. A bag of frozen vegetables or ice cubes wrapped in a towel make an effective substitute
• Never give any medicine containing aspirin (acetylsalicylic acid). Aspirin slows clotting and will make the problem worse

Children with haemophilia should be treated just like any other child. Just be a little extra vigilant so you can learn to recognise bleeds.
Haemophilia in the classroom

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Children with haemophilia should be treated just like any other child. Just be a little extra vigilant so you can learn to recognise bleeds.

If you are worried, unsure or need help, always call the Haemophilia Centre
Haemophilia Centre:
Telephone: Contact:
Haemophilia in the classroom
Detach this poster and put it up where you and the other staff can refer to it quickly and easily in the event of any incident that causes concern.
## A teacher’s guide to Haemophilia

### Haemophilia Centre Details

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### Parent/Guardian Contact Details

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Thanks to the UK Haemophilia Nursing Community for their help with this publication.

Haemophilia Society Helpline – 0800 018 6068

www.haemophiliacare.co.uk