THE HAEMOPHILIA SOCIETY

Managing school when a child has a bleeding disorder

For everyone affected by an inherited bleeding disorder

'I would say that excellent communication is key. When my son started primary, I discussed his condition with the reception teachers and the teacher who felt most confident with the condition volunteered to have him in her class'

Contents

Introduction

Starting and changing school, whether it is preschool, primary school or secondary school can be a daunting time for any parent. Parents of children with bleeding disorders spend their lives coordinating and planning for both the obvious and the unexpected, working hard to maintain as normal a life as possible. While they recognise the need for someone else to be involved with their child's education this means letting someone else monitor and support their child's needs in relation to their bleeding disorder.

This booklet is designed to help teachers and parents create an appropriate care plan to meet the specific needs of a child with a bleeding disorder. The desired outcome is happy, healthy and safe children and confident teaching staff who know enough to act appropriately and seek advice when they need to. Schools usually have robust policies for everything from bullying to sunscreen application, so medical care is just another part of the school's day-to-day responsibility. However, most teachers will never have come across a child with a bleeding disorder and will therefore need guidance and support to feel confident in meeting their needs while at school. Schools are busy and dynamic places but it is important that several people within the school understand the needs of a child with a bleeding disorder, so there will always be someone available if a child needs help and support.

It is important to remember that the parent, and often the child, is the expert. They will be able to fill you in on the particular details of how the condition affects them. The child will be registered and followed up at a haemophilia centre and the team there can provide advice to support the development of the care plan. The haemophilia nurse will liaise with the school and can visit in person to provide advice. The haemophilia nurses can often help with preparing a care plan too. This can be particularly helpful in ensuring everyone is confident in what to do.

All inherited bleeding disorders are rare and this booklet concentrates on the most common; haemophilia and von Willebrand disease (VWD). With any bleeding disorder, any action you will need to take as a school or nursery will be similar.

Each child should have a small bleeding disorder card that is provided by their haemophilia centre. This will detail their bleeding disorder, treatment required and the contact details of their haemophilia centre.

What is haemophilia?

Haemophilia is a lifelong inherited bleeding disorder. In haemophilia one of the clotting factor proteins that are an important part of how blood clots is either partly or completely missing. People with haemophilia bleed for longer than people with normal amounts of clotting factor but they don't bleed any faster.

There are two types of haemophilia:

- Haemophilia A is a deficiency of factor VIII (8).
- Haemophilia B (also known as Christmas Disease) is a deficiency of factor IX (9).

Both types of haemophilia have the same symptoms. However, the treatment will be different depending on which clotting factor is missing.

Haemophilia is classed as severe, moderate or mild depending on how much clotting factor is missing. In general, the lower the level, the more bleeding problems the affected child will have, but equally the lower the level the more likely the child is to be on a regular treatment programme. Bleeding is generally internal and children with severe haemophilia will typically have a tendency to bleed into joints and muscles, often with no obvious injury. Children with moderate haemophilia will usually only bleed after minor injuries whereas in those with mild haemophilia bleeding problems only tend to occur following major injury, surgery or tooth extraction, although when a bleed does occur it needs urgent attention, whatever the severity of the bleeding disorder.

Haemophilia is an inherited condition that mainly affects males. The genes responsible for producing factor VIII and IX are on the X chromosome. The pattern of inheritance is therefore known as sex or X-linked recessive. If a male has an altered haemophilia gene on his X chromosome, then he will be affected with haemophilia. If a female has an altered haemophilia gene on only one of her X chromosomes, then she is said to be a carrier. Some girls who are carriers of haemophilia may have slightly reduced factor levels, which means they have a mild form of haemophilia themselves.

Some children will develop an inhibitor, which is similar to an antibody to their factor treatment. This means their treatment doesn't has the same effect as it usually would and they have a tendency to have more spontaneous bleeds into joints and muscles, as well as requiring much more intensive treatment. Children with an inhibitor may have more time off school for hospital appointments, and due to bleeds. They may also need more adaptions at school to enable them to attend even if they have a painful bleed. This might include using crutches or a wheelchair at times. Children with inhibitors should still be able to take part in normal school activities, but it is likely they will need a little more flexibility and their haemophilia is likely to have a bigger impact on their day-to-day life.

What is von Willebrand disease (VWD)?

In von Willebrand disease (VWD) the von Willebrand clotting factor is low and may also not work properly. VWD has several functions in blood clotting; one of these is as a carrier of Factor VIII so some people with VWD may also have low factor VIII levels. It is also important for blood cells called platelets to work properly. When a blood vessel is injured, these platelets clump together to plug the hole and form a blood clot, VWD factor sticks the platelets to the clot.

Von Willebrand disease is an inherited disorder. The inheritance pattern is autosomal which means that, unlike haemophilia, males and females are equally affected. It is the most common inherited bleeding disorder in its mild form but rarely can be a severe bleeding disorder. Therefore there is considerable variation in how individuals are affected by the condition.

Because of the way that blood clotting is affected in von Willebrand disease, particular bleeding problems occur from the delicate membranes in the nose and mouth causing nose bleeds, gum bleeds: bruising and in heavy periods in girls. Where the factor VIII is also low, the bleeding problems will also be similar to those seen in haemophilia (joint bleeds).

What are rare bleeding disorders?

The best known and most common bleeding disorders are Haemophilia A (factor VIII deficiency), Haemophilia B (factor IX deficiency) and von Willebrand disease. However there are many more rare bleeding disorders involving blood clotting factors and blood cells called platelets. We have a booklet that explains more about rare bleeding disorders.

Treatment

Prompt, effective modern treatment has significantly reduced the risk of complications and disruptions to school, employment and family life for people with bleeding disorders.

Treatment can be given in two ways		
On demand	Treatment is given when bleeding occurs such as after an injury.	Children with mild or moderate haemophilia and most forms of von Willebrand disease.
Prophylaxis	Treatment is given regularly to prevent bleeding before it starts.	Children with severe haemophilia. Some children with severe von Willebrand disease. Some children with moderate haemophilia who have frequent bleeding problems.

Treatment will be needed by anyone with a bleeding disorder if they are bleeding. It will also be necessary to prevent bleeding if have an injury where there is a risk of bleeding.

Bleeding must be treated as soon as possible.

Prompt treatment helps reduce bleeding and pain quickly, shortens the recovery time and reduces the chance of permanent damage.

Clotting factor concentrate

Bleeding can be controlled or prevented by temporarily replacing the missing clotting factor in the blood through an infusion of clotting factor concentrate. Recombinant factor VIII and factor IX concentrates are made using genetic technology and are not made from blood. There are also clotting factor concentrates containing von Willebrand factor that are made from plasma from donated blood and these have been specially treated to eliminate viruses.

Clotting factor concentrate is given intravenously, into the blood stream through a "butterfly" needle. In young children anesthetic cream can be applied to the skin before an injection to reduce any pain. Parents of children with severe haemophilia, and some with moderate haemophilia, learn to treat their child with clotting factor at home. In time the young people learn to treat themselves. Most children can do this by the time they reach secondary school. It may be sensible to store some factor at school, so a parent, or child can administer this quickly when required, without having to pick it up from home.

Desmopressin (DDAVP)

DDAVP is a synthetic drug that can be suitable for some people with milder forms of haemophilia A and for von Willebrand disease. It releases factor VIII and von Willebrand factor stored in the lining of blood vessels, increasing the amount of these factors circulating in the blood. It is given as a subcutaneous injection (under the skin like a vaccination) or as a nasal spray. It cannot work for severe haemophilia as there are no stores of factor VIII.

Tranexamic Acid

Tranexamic Acid is a medicine that helps to hold a clot in place once it has formed. It comes in tablet and liquid form and can also be used in a mouthwash. It can be particularly helpful for bleeding in the mouth, nosebleeds or heavy periods. It is often used at the same time as clotting factor or DDAVP but can be used on its own.

Other medication

Some medicines can affect blood clotting and therefore may not be suitable for a child with a bleeding disorder. This includes Aspirin and Ibuprofen that should never be taken unless advised by a haemophilia specialist. Paracetamol is a suitable painkiller.

If vaccinations are given at school they need to be administered under the skin (subcutaneously) rather than into a muscle. It is important the school and parent liaise with the haemophilia centre for advice before any vaccination is given.

Question for the care plan: Does this child need to have any treatment stored at school and if so, where will it be kept and how will it be accessed?

Recognising bleeding

Children with bleeding disorders do not cut more easily, bleed more or bleed more quickly than normal. They do bleed for longer.

Cuts and scratches

In most cases minor cuts and scratches are not a problem and a little pressure is usually enough to stop the bleeding.

Bruises

Bruises may look serious but they do not usually need any treatment. However, if the bruise is swelling and is painful then it may benefit from treatment.

Prolonged bleeding after cuts, bites or minor surgery (such as tooth extraction or circumcision)

Nose bleeds

Prolonged nosebleeds are the most common symptom of von Willebrand disease in children, nose bleeds can often be more upsetting for the people who are not used to them than the child themselves, so some privacy can help reduce anxiety in all.

Joints and muscles

In severe haemophilia the main problem is internal bleeding into joints and muscles.

Joint bleeding

- Knees, ankles and elbows are most commonly affected
- Usually starts by feeling stiff, tingly, bubbly or warm – young people with haemophilia have these sensations before there are any external signs
- Becomes increasingly painful as the joint fills up with blood
- May become swollen, warm and difficult to straighten.

Muscle bleeding

- May also happen to someone with mild or moderate haemophilia after an accident or sporting injury
- May not be noticed or be uncomfortable at first
- Bruising near the surface may not be obvious at first
- An affected arm or leg may become swollen, tender and painful
- In deeper muscles swelling can press on nerves or arteries causing numbness and pins and needles – this requires urgent treatment and medical attention as there is a risk of permanent damage.

Recognising possible signs of bleeding in a young child:

- Appearing irritable or crying for no obvious reason
- Avoiding using an arm or leg
- An arm or leg looks bigger or different to the other one
- Swelling which may be warm.

Bleeding into the joint has a damaging effect on the joint. Once a joint becomes damaged bleeding may occur more frequently and permanent damage occurs. This is known as a target joint.

Blood in the urine – may be red or brown

This may go away with drinking plenty of fluid. However, it may need treatment to stop the bleeding and may be a sign of infection.

Periods

Periods may be very heavy from the start for girls with bleeding disorders. It can be challenging to have to leave class frequently to change tampons or pads, so support, understanding and privacy can be very important.

Bleeds and bruises in chi

Muscle and/or joint bleeds

P.R.I.C.E.

P: Protection
- Lower limb: take weight off the joint or muscle
- Upper limb: no carrying using affected arm

R : Rest
- Rest means rest!
- Try not to allow use of the joint or muscle where possible.

I: Ice
- Regular ice packs can help with pain & reduce swelling.
- Put an ice pack over the affected area for 20 minutes. Repeat every two hours.

DO NOT leave the ice pack on for more than 20 minutes

DO NOT place ice pack directly on skin (Use a tea towel/cold pack cover)

C : Compression
- Use an elasticated bandage to compress the affected area to reduce swelling.

E: Elevation
- Elevate the affected limb to help reduce swelling.
- Keep the affected joint or muscle above the level of the heart.

First Aid

Mouth & Gum Bleeds
These can be hard to control because clots that form are washed away by saliva or knocked off by the tongue or food. Try giving the child an ice cube or ice pop to suck. These bleeds may need treatment by parents or the treatment centre.

Nosebleeds
Tilt head forward and pinch the bridge of the nose below the bone for 10 - 20 minutes and / or put an ice-pack on the bridge of the nose for not more than 5 minutes.

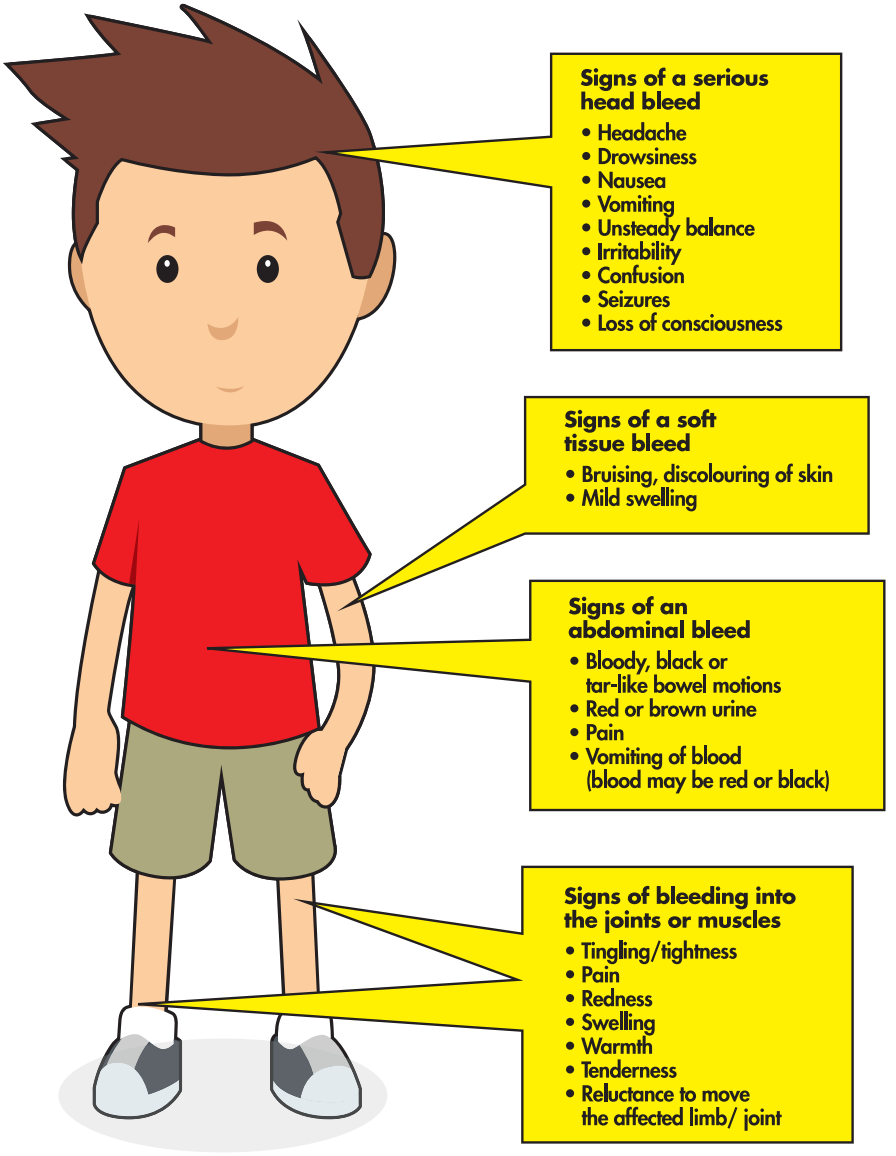
Cuts and Grazes
Cover with a plaster and bandage. Apply pressure for a few minutes. Deep cuts may need stitching, if so contact parents and/or haemophilia treatment centre.

Bruises
Children with haemophilia bruise more easily than children without haemophilia and their bruises will be bigger. Bruises only need treatment if they are very painful.

Bleeds in the following areas are especially
• HEAD • EYE • NECK • AB
Call parents and Haemophilia T

hildren with haemophilia

eds call the parent/guardian



ially serious and require immediate attention:

ABDOMEN • GROIN • HIP •

lia Treatment Centre immediately.

Serious bleeding that requires immediate treatment and advice

Head, Face and Neck

Any injury to the head, face or neck should always be checked as the child may need urgent treatment and should be assessed at hospital.

A head injury is always serious. Bleeding into the brain is uncommon but can occur without an obvious injury. Symptoms include headache, nausea, drowsiness, fitting, and weakness in an arm or leg.

Other bleeding

- Vomiting blood
- Coughing up blood
- Blood in bowel movements – may look like blood or be black and tar-like – is a sign of bleeding in the gastrointestinal tract

Questions for the care plan: Who should be contacted for what types of injuries? What are the parent's contact details? Who is an alternative person if the parent cannot be contacted? How can the child's haemophilia centre be contacted? Does the child have any particular bleeding problems or needs related to his/her bleeding disorder? Does the child use particular words to describe a bleed? What level of understanding does the child have about his/her bleeding disorder? Can the child self-treat and what support does he/she need to do so? The school should have copies of the bleeding disorder card to take on school trips, to A&E etc. – this will give contact details of the haemophilia centre and any treatment the child may need.

What to do if you suspect bleeding

If a child has a bleed into a joint or a muscle they may recognise the sensation and then let their teacher know. Some children might not report the early signs of bleeding for a number of possible reasons: lack of recognition, or not wanting to miss out on a certain activity. Children with milder bleeding disorders will have less knowledge and experience of bleeding. Encouragement needs to be given for a child to say when they have sensations that may be signs of bleeding.

Parents and children may have been taught to manage joint bleeds with PRICE (Protection, Rest, Ice, Compression, Elevation)

Alongside the clotting factor infusion, the following steps help with recovery and comfort.

PROTECTION – Try to keep the weight off the joint of muscle for a couple of days. If it is the ankle or knee, crutches or a wheelchair for a few days may be necessary.

REST – Stay off it or don't use it! This helps with healing and pain.

ICE – for 15 minutes every 2 hours. Can help with pain and swelling. Wrap an ice pack in a tea towel or soft cloth so it does not directly touch the skin.

COMPRESSION – Use the right size of elasticated bandage if this feels comfortable. It can help reduce swelling.

ELEVATION – Raise and support the affected arm or leg to reduce swelling.

Action

- Contact the parent for advice and to arrange for any treatment to be given If the parent or an alternative nominated person cannot be contacted then call the child's haemophilia centre. Older children may be able to treat themselves.
- Remember that if treatment is needed then the sooner it is given the better.
- If a cut or external bleeding such as a nosebleed does not stop with pressure after 10-15 minutes, the parent should be contacted as above.
- As with all children some situations require emergency management. If an ambulance needs to be called then the crew will generally take the child to the nearest A&E department. Take any clotting factor kept at the school if possible. If the haemophilia centre is not too far away and the child's condition permits, then going there will be the best option to get the right treatment. Ultimately this is the ambulance crew's decision but they may find it helpful to speak to the haemophilia centre.
  - Head injury
  - Any major injury such as a broken bone or a serious cut
  - Any sudden, severe pain for example abdominal pain (stomach) or headache.
  - Bleeding into the back of the mouth or under the tongue.
- Any blood spillages should be dealt with according to universal blood and body fluid disposal guidelines that are in place in schools, there is no additional risk from blood from someone with a bleeding disorder.

There may be times when a child has to miss school while they recover after a bleed, or in rare circumstances they may need to use wheelchair or crutches at school. The school should be aware of this and have the necessary arrangements in place. The child who has been absent will need support to catch up on missed work and get back into the swing of classes.

Playgroup, Nursery and Primary school

It is important that children join in all play activities with their class mates, especially at this age ordinary play activities of young children are not usually a problem beyond the occasional bruise. Cuts and grazes can generally be handled with standard first aid. 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 or they are recovering from a bleeding episode, they should be allowed to join in with all activities.

Secondary School

As children get older, the sports they enjoy tend to get competitive and rougher, and the range of sports and other activities they want to join in gets wider. The right clothing, footwear and equipment should be used. If a particular sport does cause a problem, the young person may need to find an alternative and seek advice from parent, haemophilia centre and school. The relative risks and benefits will vary with the individual and opinion differs about the risks and benefits of different sports. (See next section, Sport and Activity)

College and work

Most young people with bleeding disorders will go through school much as the rest of their peer group. This means that choosing to go to college or out to work won't be any different either.

Sport and activity

All children with a bleeding disorder should be encouraged to do all the things they can do rather than focusing on minor restrictions. These will vary not only with the individual's condition, but also with the age, ambitions and talents of the child. In general, most school-based activities are suitable for children with bleeding disorders. However, there should be discussion between parents and school about participation in contact sport. Parents may choose to give prophylaxis on P.E. or sports days.

Activity and exercise have many benefits for health and can help self-esteem, learning and concentration. There are some particular benefits for children with bleeding disorders as strong muscles, good balance and posture can help to protect joints from bleeding. Maintaining a healthy weight helps to reduce stress on joints that have already been damaged by bleeding. The choice of activity or sport will be individual and the specialist haemophilia physiotherapist is a source of advice. The haemophilia team will discuss the risks and benefits of different sports taking account of the person's condition. In general sports with the highest amount of physical contact and those where head and neck injuries occur, carry the highest risk of injury and therefore risk of bleeding for the child with a bleeding disorder. For the child with severe haemophilia prophylaxis can be tailored around days of highest activity so that there is maximum protection from bleeding at these times. Girls with heavy periods may feel nervous about wearing gym kit for fear of bleeding through a tampon or pad.

School trips

Having a bleeding disorder should not limit a child's opportunity to go on school trips. These are a vital part of a child's social development and wherever possible provision should be made to support a child's participation. Once again planning is key.

Day trips

- The child on prophylaxis should have treatment on the day of the trip.

Longer trips

- Older children may be able to give their own treatment. If they need some adult support then this should be discussed and arranged.
- Parents and haemophilia centres will advise whether a supply of treatment should be taken.
- The plan should include any arrangements made with a local haemophilia centre or paediatrician/hospital to see and treat the child.
- A letter from the haemophilia centre with information about the child's condition for any hospital staff consulted should be provided.

Going outside the UK

- A letter from the haemophilia centre for Customs explaining the need for treatment, needles and syringes.
- Ensure that you have travel insurance that covers the bleeding disorder, including repatriation to the UK if necessary.

This booklet is an overview of points important to bear in mind when managing a child with a bleeding disorder. It is not a complete guide; the relationship between the school and the parents is paramount and will ensure that the school, the child and the parents feel confident and supported in managing any difficulties that may arise. The Haemophilia Society is always happy to answer any further questions, provide additional information or refer to an expert if necessary.

About The Haemophilia Society

We are the only UK wide charity for everyone affected by a bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For more than 65 years, we have campaigned for better treatment, been a source of practical information and advice, and enabled people living with long-term conditions to:

- lead fulfilling lives
- make informed choices about their treatment and care
- support and inspire others to do the same.

More than 25,000 men, women and children in the UK have a diagnosed bleeding disorder, and the number rises every year. Membership of The Haemophilia Society is free and open to all.

We bring people together at events like children's activity weekends, information days for women who have a bleeding disorder, and weekends for families with a newly diagnosed child – giving them the knowledge and support they need to feel confident about the future.

Our peer support through local groups around the UK, global family network, and online community offers friendship and a listening ear when needed, as well as enabling people to share their views and experiences. We also support people experiencing particular difficulties or feelings of isolation, such as developing inhibitors which stops their treatment from working, or experiencing a loss of independence as they grow older.

As a health charity, we work alongside the NHS to:

- provide easy access to information and opportunities
- influence national policy and practice to make the care and treatment of bleeding disorders consistent, effective and accessible to all, and
- enable the voices of all people with bleeding disorders to be heard.

As bleeding disorders are fairly rare, many people will never encounter The Haemophilia Society; we are largely invisible outside of the communities we serve. So we have to work doubly hard to raise both awareness and understanding of bleeding disorders and vital funds needed to give those affected the services they deserve and need to live life well.

To find out more, or to become a member for free, visit our website at www.haemophilia.org.uk or call us on 020 7939 0780.

The Haemophilia Society makes every effort to make sure that its services provide up-to-date, unbiased and accurate information about bleeding disorders. We hope that this information will add to the medical advice you have received and help you to take part in decisions related to your treatment and care. Please do continue to talk to your doctor or specialist nurse if you are worried about any medical issues.

Give us your feedback We hope you have found this information helpful. If you have any comments or suggestions about this booklet or any of our other information please write to the Head of Membership and Planning at the address on the back cover.

'I would say that it is important to normalise the condition for the child and school (along the same terms as a child with bad asthma or other condition) and not mark them out as different. Our school wanted our son to wear a green cap so they could watch him in the playground. It only took one playtime for him to work out that if he put the hat on another boy, he could go on the climbing frame unnoticed!'

THE
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