THE HAEMOPHILIA SOCIETY

Bleeding disorders and school

Contents

This booklet is an overview of important points 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. This 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 suggest an expert if necessary.

Introduction

Starting or changing school, whether it is nursery, primary 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 also means letting someone else monitor and support their child's needs in relation to their bleeding disorder.

Children with bleeding disorders like to be treated as 'normal' at school especially when with friends. They will be able to participate in most of the same activities as other children. Many have had their bleeding disorder diagnosed since birth and have had time to be aware of their disorder. Older children should be able to identify if they are having a bleed even before any symptoms are detected. **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 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 and support. **The haemophilia nurse will liaise with the school and can visit in person to provide advice in developing a care plan if requested** (see page 13). 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 that needs to be taken at a nursery or school will be similar.

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.

Most teachers will never have come across a child with a bleeding disorder and will 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.

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 are 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. Most children with haemophilia can live normal, active lives.

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 is 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 of clotting factor, the more bleeding problems the child will have. 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 tend to bleed into joints and muscles, often with no obvious injury. Frequent bleeding into the same site can cause permanent damage such as arthritis.

Children with **moderate** haemophilia will usually only bleed after minor injuries and as with mild haemophilia can also bruise easily. They may also have internal bleeding in their joints, especially if they have a knock or fall.

Children with **mild** haemophilia only tend to bleed following major injury, surgery or having a tooth out, although when a bleed does occur it needs urgent attention.

Bleeding from scratches or cuts will stop with normal first aid measures. Children with mild haemophilia rarely have any problems but it is important to know what to do in an emergency.

Haemophilia is an inherited condition that mainly affects males. The genes responsible for producing clotting 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, then he will be affected with haemophilia.

Girls can also be affected with haemophilia. If a female has an altered haemophilia gene on only one of her X chromosomes (females have two X chromosomes, while males have an X and a Y chromosome), then she is said to be a carrier.

Some girls who are carriers of haemophilia have reduced factor levels, which means they have a form of haemophilia themselves. They can also have symptoms such as frequent and prolonged nose bleeds, heavy or prolonged periods (menorrhagia), prolonged bleeding from cuts and easy bruising.

Inhibitors

Some children, usually those with a severe bleeding disorder, will develop an inhibitor, which is like an antibody to their factor treatment. This means their treatment does not have the same effect as it usually would and they tend 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 as their bleeding disorder is likely to have a bigger impact on their day-to-day life.

What is von Willebrand disease (VWD)?

von Willebrand disease (VWD) is a bleeding disorder that affects males and females equally. It is more common than haemophilia and can sometimes cause heavy bleeding. It is caused by a deficiency of von Willebrand factor (VWF), which is a type of protein that helps blood to clot.

There is currently no cure for VWD but for most people it does not usually cause serious problems, as the condition is mild and manageable. Most people with it can live normal, active lives. However, the lower the level of VWF, the more likely you are to have bleeding problems. In the most severe form, the body does not make any VWF at all.

VWD affects the blood's ability to clot. If your blood does not clot you can bleed more than most people and have symptoms such as easy bruising, frequent or long-lasting nosebleeds or bleeding from your gums. Women are more likely to experience symptoms and complications due to the increased risk of bleeding during menstruation, pregnancy and childbirth. It may also be hard to stop bleeding after an injury, dental procedure or surgery.

A protein in the blood called von Willebrand factor (VWF) helps blood to clot. In VWD, either the level of VWF is low or the VWF does not work very well, or both. Normally, when a blood vessel is injured you start to bleed. Small blood cells called platelets clump together to plug the hole in the blood vessel and stop the bleeding. For most people, VWF acts like glue to help the platelets stick together and form a blood clot. When you have VWD the glue does not stick the platelets together, so clots do not form as easily.

VWF also carries a blood clotting factor called factor VIII (eight), another important protein that helps your blood to clot. Factor VIII is the protein that is missing or does not work well in people who have haemophilia. Some people with VWD also have low levels of factor VIII and may share some symptoms with people with haemophilia.

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 (VWD). However, there are many more rare bleeding disorders involving blood clotting factors and platelets. Rare clotting factor deficiencies include factor I, factor II, factor V, factor VII, factor X, factor XI, factor XII and

factor XIII. Platelet function disorders include Bernard-Soulier Syndrome and Glanzmann Thrombasthenia. Parents must liaise with their haemophilia centre with regards to activities their child can do.

We have separate booklets that explain more about haemophilia, VWD and rare bleeding disorders. Contact The Haemophilia Society for more details or look on our website at haemophilia.org.uk/

Treating bleeding disorders

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

Children with severe haemophilia and some with moderate haemophilia will be receiving regular treatment to prevent bleeding before it starts, called 'prophylaxis'.

Children with mild haemophilia will usually only need treatment when bleeding occurs, such as after an injury, and this is called 'on demand'. Treatment will be needed by anyone with a bleeding disorder if they are bleeding, even those on prophylaxis.

Bleeding must be treated as soon as possible. Prompt treatment helps reduce bleeding and pain quickly, shortens recovery time and reduces the chance of permanent damage. Sometimes it may be necessary for children to have treatment where there is a particular risk of injury or bleeding.

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

Types of treatment

Clotting factor concentrates

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 into a vein or through a port-a-cath (see page 9). In young children anaesthetic 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.

Subcutaneous treatment

Emicizumab (or Hemlibra®) is a subcutaneous (under the skin) treatment used to prevent or reduce bleeding in people with haemophilia A that is given only once weekly, once every two weeks or once a month.

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 (VWF) 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) 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 other treatments but can be used on its own.

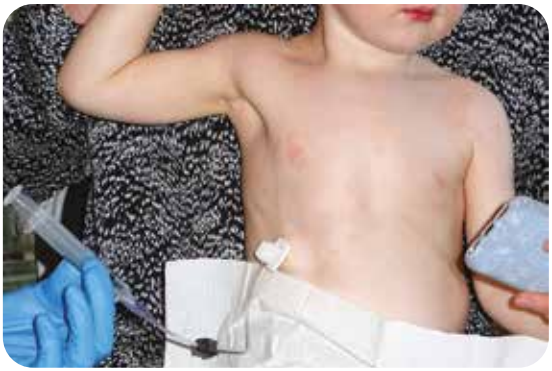
Other medication

Some medicines can affect blood clotting and so may not be suitable for a child with a bleeding disorder. Aspirin and ibuprofen should never be taken unless advised by a haemophilia specialist. Paracetamol is suitable for treating pain and fever.

Vaccinations

If vaccinations are given at school they need to be administered subcutaneously (under the skin) rather than into a muscle.

It is important the school and parents liaise with the child's haemophilia centre for advice before any vaccination is given.



Port-a-cath

Port-a-caths are increasingly used in children with severe bleeding disorders. This is a small device surgically inserted under the skin, usually in the upper chest above the heart. This device is a more comfortable way for children to receive their treatment rather than into a vein.

Haematomas or bruises can occur on the surface of the port after treatment is given. Children with ports are closely monitored if they have a fever, especially if it is not due to a childhood illness, as there is a small risk of infection. If a port infection is identified, the child will be given a course of antibiotics. The infection is likely to be treated in hospital for a few days.

Children can play sports with a port, though it is best to avoid contact sports as a knock to the port could be painful or could cause damage. Swimming is allowed with a port-a-cath.

Stages of schooling

Playgroup, nursery and primary school

It is important that children join in all play activities with their classmates, especially at this age as 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 primary school level is not usually as competitive or rough as it may become later, so unless a child has a problem or is 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 with gets wider. The right clothing, footwear and equipment should be used.

If a sport does cause a problem, the young person may need to find an alternative and seek advice from parents, their haemophilia centre and their school. The relative risks and benefits will vary with the individual and opinion differs about the risks and benefits of different sports.

College and university

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 university won't be any different either.

Young people planning to move away to college or university can continue to receive care from their haemophilia centre during the holidays. However, they may choose to register at a haemophilia centre close to where they are studying. Whatever they decide, they will need know where their nearest haemophilia centre is, in case they need emergency treatment during term time.

Medication at school

Some schools are happy to store medication at school; if so it is important to identify where it will be kept and how will it be accessed. A named member of staff whose responsibilities include overseeing medication procedures should be agreed. However, for legal reasons some schools are not happy to store certain mediations on site due to concerns about expiry dates and who will be responsible for the treatment.

It is the parents' responsibility to provide the school with the medication required. The medication must be as dispensed, in the original container and clearly labelled. Precise information must be supplied ('taken as directed' does not provide sufficient information). It is the parents' responsibility to ensure medication is replenished when needed. The school should work in partnership with the parents to ensure medication is still in date. The school should develop a policy on the administration of medication and have an emergency aid policy.

Should a child need to receive medication during the school day, a parent may be asked to come into school to administer it.

Illness and education

Parents, with support from the haemophilia centre, must tell the school about their child's medical needs. It is important that the school medical form includes details of the child's bleeding disorder and severity. The school must also be informed of special educational needs (SENs) and/or disabilities.

By law, schools must provide a space for children who need:

- treatment for sickness or injury
- first aid or medical examinations.

If a child cannot attend school

If a child cannot go to school for a while because of illness or injury, the school and local council will provide support to make sure their education does not suffer.

The child's school will:

- inform the local council if the child is likely to be away from school for more than 15 school successive days

- give the local council information about the child's needs, capabilities and the programme of work
- help the child reintegrate at school when they return
- make sure the parents are kept informed about school events and clubs
- encourage the child to stay in contact with other pupils, e.g. through visits or videos.

The role of the local council

If a child is away from school for a long time, the local council will make sure they get as normal an education as possible. This could include arranging:

- home teaching
- a hospital school or teaching service
- a combination of home and hospital teaching

The local council must make sure the child continues to get a full-time education – unless part time is better for their health needs.

The local council should also:

- have a senior officer in charge of the arrangements and a written policy explaining how they'll meet their responsibilities
- make sure the child is not without access to education for more than 15 school days
- arrange education from the start of the child's absence if it is clear the child is going to be away from school for long and recurring periods.
- If a child needs an education, health and care (EHC) plan parents must discuss this with their haemophilia centre.

Illness and exams

If a child becomes unwell due to illness, injury or unavoidable circumstances beyond their control at the time of the exam or when they complete their coursework/controlled assessment special consideration applies. Parents must contact their child's school or college exams officer who will be able to provide with more details about special consideration. The school or college must support the child's application for special consideration.

Absenteeism

Parents, with the support of the child's haemophilia nurse, should tell the school about their child's medical needs. Children with bleeding disorders are likely to

be absent from education if an injury occurs and rehabilitation is required. They may also need to attend their haemophilia centre for follow-up care.

If a child with a bleeding disorder sustains an injury, they may need crutches, slings or even a wheelchair when returning to education. This may mean that they will need more time getting to and from classes.

Girls who experience heavy bleeding with their periods may need to be absent from school due to heavy bleeding and/or pain. They may also need to leave the classroom regularly to change their tampon or pad.

If a child is going to be absent from education (e.g. due to injury or for a hospital appointment) then parents should let the school know as soon as possible.

Bleeding disorder card

Each child should have a 'bleeding disorder card' that is provided by their haemophilia centre. This will detail their bleeding disorder, treatment required and the haemophilia centre's contact details. Haemophilia centres should be able to provide the child with as many cards as required so that one can be left at school at all times (with medicines if appropriate).

School care plan

Individual care plans help to ensure that schools effectively support children with their medical condition. They provide clarity about what needs to be done, by whom and when. It is important that a school care plan is in place for children with bleeding disorders. A school care plan can be obtained from the child's haemophilia centre. Parents should also provide the school with sufficient and up-to-date information about their child's medical needs.

Questions for the care plan:

- Who should be contacted and for what types of injuries?
- What are the parents' contact details?
- Who is an alternative person if a parent cannot be contacted? How can the child's haemophilia centre be contacted?
- Does the child have any bleeding problems or needs related to their bleeding disorder?
- Does the child use particular words to describe a bleed?
- What level of understanding does the child have about their bleeding disorder?
- Can the child self-treat and what support do they 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 details of any treatment the child may need.

Arranging for parents to meet with the key members of staff in school is vital. This might include their class or form teacher, head of year, PE staff, medical staff/first aiders and head of SEN inclusion.

This will ensure that everyone is educated about the child's bleeding disorder, can support the child and know what to do in an emergency. It is advisable that the head of SEN is responsible for making sure all staff in school are aware there is a care plan and can access it easily. It is also essential that lunchtime supervisors are made aware there is a care plan or have access to it.

It is paramount that parents build trusting, supportive relationships with school staff and ensure that staff know they are always contactable, no matter what.

The following advice was given by a mother of a child with a bleeding disorder:

- Before a child starts school find out which teacher is responsible for working out care plans.
- Meet the staff member so they understand what the bleeding order is and how it can be managed.
- Offer to make fact sheets or give a talk about the bleeding disorder. Give staff the chance to ask the parents what they need to know.
- Speak directly to PE teachers as the child will be at greatest risk of injury and potential joint bleeds in their class.
- Do not assume all the child's teachers will have seen the care plan. Work with the school to make sure this happens.
- Try to build trusting, supportive relationships with staff at the school.
- Make it clear that parents can always be contacted, whatever the circumstances. Ensure that the school has up-to-date contact details.
- Look for support from other parents via The Haemophilia Society's social media. This is a very stressful time and being able to talk about it can help a lot.
- Try to encourage the child to be assertive to staff when they feel they need to attend the medical room.

Managing a bleeding disorder at school

It is essential that the school has a good understanding of the possible problems associated with a bleeding disorder. The child's haemophilia centre team will be more than happy to carry out an education session at school if requested.

All teachers/staff responsible for the child should be aware of the diagnosis, treatment and any precautions that may need to be taken.

Recognising bleeds

Children with bleeding disorders do not cut more easily, bleed more or bleed more quickly than normal. They do bleed for longer. Children with bleeding disorders can enjoy a normal, active lifestyle. If there are any concerns about recognising a bleed refer to the child's school care plan for guidance.

The common signs of bleeding into joints and muscles are:

- tight feeling in the affected area
- decreased movement in the affected limb – the child may be reluctant to move or use the limb
- swelling
- bruising or redness – this may not always be immediately evident
- the child may not be their usual self because of pain.

Observation and awareness are essential. Compare the affected area to the same area on the other limb and see if it looks or feels different.

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

What to do if you suspect a joint or muscle bleed

If a child has a bleed into a joint or a muscle, they may recognise the sensation and let their teacher know. Some children might not report the early signs of bleeding for several possible reasons: lack of recognition, or not wanting to miss a certain activity. Children with milder bleeding disorders will have less knowledge and experience of bleeding.

- Check for any signs of major injury.
- Normal first aid measures – raise and rest the affected area, apply ice or cold pack for 10 minutes and repeat every 10 minutes if symptoms persist.
- If symptoms continue or get worse, the child may need treatment; contact the parents and/or the child's haemophilia centre.

What to do if injuries occur

First aid advice provided by the haemophilia team at Evelina Children's Hospital:

Head injury	**Minor bump** Watch and observe for increasing swelling/bruising **First aid** • Apply cold compress If increasing swelling/bruising occurs • Contact parent and haemophilia centre **Major injury** • Call an ambulance • Treatment will be required • Contact parent and haemophilia centre immediately • Inform ambulance crew that child has a bleeding disorder **First aid** • Apply cold compress • Give tranexamic acid if available
Swelling/ pain in any joint	**First aid** • Apply ice (10 mins on and 10 mins off – do not let ice have direct contact with skin) • Contact parent and haemophilia centre • Give tranexamic acid if available • Treatment may be required
Traumatic injury to: **Neck** **Chest/Axilla** **Back** **Abdomen** **Groin** **Legs/arms**	**First Aid** • Apply ice (10 mins on and 10 mins off – do not let ice have direct contact with skin) • Watch and observe area for developing pain and swelling • Watch for limp, guarding and immobility **If pain, swelling and limp/immobility occurs** • Contact parent and haemophilia centre • Give tranexamic acid if available • Treatment may be required
Cut deep enough to need stitches	**First aid** • Apply dry dressing and pressure • Contact parent and haemophilia centre • Treatment may be required

Nosebleed	**First aid** • Apply dry dressing and pressure • If bleeding does not stop pinch the bridge of the nose and lean forward slightly • Contact parent and haemophilia centre • Give tranexamic acid if available
Bleeding **Skin discolouration, Purple, red, pink, yellow** **Head lump surrounded by bruising**	The child will have more bruises than other children • some bruises will cause skin discolouration only • bruises that do not increase in size and do not cause a lot of discomfort can be treated with: **First aid** • Apply ice/ice pack (10 minutes on the bruise and 10 minutes off the skin). Do not let ice have direct contact with skin – place a towel or cloth between the ice pack and the skin • Rest and raise an injured limb to help reduce pain and swelling **First aid** • Apply ice (10 mins on and 10 mins off – do not let ice have direct contact with skin) • Contact parent and haemophilia centre • Treatment may be required

If an ambulance is called, emergency services should be informed of the child's bleeding condition. Also, the child's haemophilia centre should be informed if an ambulance is required so they can give advice on necessary treatment.

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 administered 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 the crew will generally take the child to the nearest A&E department. Take any treatment kept at the school if possible. If the haemophilia centre is not too far away and

the child's condition permits, then going there may 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.

- 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 must miss school while they recover after a bleed or injury and 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.

Following the child's absence from school they will need support to catch up on missed work and get back into the swing of classes.

Managing periods in the classroom

Girls just starting their periods may have heavy bleeding (menorrhagia). Heavy menstrual bleeding is also common among girls with bleeding disorders and varies in what is considered to be 'normal' blood loss or pain during periods. Signs that could signal problem periods include:

- bleeding for longer than seven days
- bleeding that affects daily life (e.g. staying home due to fear of bleeding)
- changing sanitary protection frequently
- headaches, dizziness, fatigue, swollen limbs and bruising
- leaking or flooding (soiling clothes or underwear with blood)
- need to use two types of sanitary product together (e.g. tampons and pads)
- passing blood clots larger than 2.5cm (about the size of a 10p coin).

Heavy periods and excessive bleeding can also lead to anaemia. Blood contains iron, so the blood loss can cause the body to lose iron. Anaemia can make girls feel tired so iron supplements may be prescribed to boost iron levels.

Periods can be heavy and require additional treatment prescribed by a doctor, such as tranexamic acid during a girl's period to manage blood loss.

Girls experiencing heavier blood loss may require use of the toilet or medical facilities more regularly, which may mean they need to leave lessons more often. A toilet pass should be issued and teachers aware that a girl may frequently leave the classroom during her period.

Understanding and privacy is important, especially as leakage may show through clothing. Girls should keep a small bag at school with spare clothing in case they need to change and a have a good supply of tampons/pads.

If a girl seems tired and pale during her period she should not take part in physical activities at school at that time. She can be involved PE lessons in a positive way by allowing her to umpire sports games or assist with timing of games, cross country running etc.

Light exercise may help relieve the tension in the muscles and ease the pain caused by cramps. Swimming should be avoided if a girl is concerned about leaking blood even when wearing a tampon.

No two girls experience the same period so it is important to remember that a girl with a bleeding disorder may be embarrassed to talk about hers.

It is important that the school shows understanding during this difficult time. A nominated person or first aider could help to ensure her needs are being met and staff respond appropriately.

More information is available on females with bleeding disorders at **haemophilia.org.uk/support/womensawareness/talking-red/**

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 their age, ambitions and talents.

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.

Children with severe bleeding disorders should avoid contact sports. Before undertaking risky sporting activities, discuss this with the child's haemophilia centre as some activities may be done safely when the bleeding disorder is mild or moderate.

Parents may choose to give treatment on PE 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. The choice of activity or sport will be individual, and the haemophilia physiotherapist is a good source of advice.

The haemophilia centre clinical team will discuss the risks and benefits of different sports taking account of the child'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. Children with severe bleeding disorders need to avoid contact sports.

For children with severe bleeding disorders treatment can be tailored around days of highest activity so that there is maximum protection from bleeding at these times.

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: school trips should be discussed with the parents and/or the haemophilia centre in advance.

Teachers can be nervous of taking children with bleeding disorders on residential trips, as can parents. This means it is essential to have meeting with the parents to discuss if and how the trip can be managed effectively. Parents could offer to stay in a hotel nearby should they be required in an emergency.

Furthermore, parents should contact their haemophilia centre to get details of the nearest haemophilia centre to the child's planned trip. If necessary, they could ask their haemophilia centre to provide a letter for 'in case of emergency' that they have can have with them throughout the trip.

Day trips

- A child on prophylaxis should have treatment on the day of the trip, preferably given before attending school.
- If a child is on on-demand treatment, this can be taken with them in case it's needed.

Longer trips

- Older children may be able to self-treat. If they need some adult support, then this should be discussed and arranged in advance.
- Parents and haemophilia centres will advise whether a supply of treatment should be taken.
- A 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 should be provided with information about the child's condition for any hospital staff consulted.

Going outside the UK

- A letter from the haemophilia centre for customs explaining the need for treatment, needles, syringes etc. will be provided.
- A letter from the haemophilia centre with information about the child's condition for any hospital staff consulted will be provided.
- Ensure that the child has travel insurance that covers the bleeding disorder, including repatriation to the UK if needed.

Glossary of terms

Anaemia
Lack of red blood cells

Bleeds
Bleeding into the muscles and the space between joints

Joint
The place where two or more bones come together

Haemophilia
A lifelong hereditary blood disorder in which bleeding lasts longer than normal. It is caused by a defect in a protein needed for blood clotting

Hereditary
Passed in the genes from parent to child. The basic unit of heredity is the gene

Inhibitor
Antibody to factor treatment

Menorrhagia
Heavy menstrual flow (periods) with severe cramping

Prophylaxis
Treatment given regularly to prevent bleeding before it starts

About The Haemophilia Society

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

For 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

We want to ensure that everyone affected by a bleeding disorder:

- Has equality of opportunity
- Has the opportunity to connect with others in the community
- Has the knowledge to feel empowered

We do this by:

- Raising awareness about bleeding disorders
- Providing information and support throughout our members lives
- Influencing and advocating on health and social care policy and access to treatment

More than 36,000 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.

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. By bringing people together for information and support at events tailored to all life stages, we amplify their voices to reduce isolation and influence government, welfare and health care policy.

Our community are at the heart of everything we do – we work collaboratively with members and health professionals to ensure we make decisions influenced by their valued input and direction.

As bleeding disorders are rare, many people will never encounter The Haemophilia Society; we are largely invisible beyond 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 the best life they can.

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

Notes

THE HAEMOPHILIA SOCIETY

This material has been sponsored by Sobi – Liberate Life: https://liberatelife.co.uk

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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
If you have any comments about this booklet or any of our other information, please write to the Head of Services at the address below.

Everything we do is free because of fundraising and donations of our incredible supporters. If you would like to fundraise for us or find out more about how you can get involved send us an email to fundraising@haemophilia.org.uk

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thehaemophiliasociety

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Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia

President: Baroness Meacher

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