THE HAEMOPHILIA SOCIETY

Understanding haemophilia

For everyone affected by a bleeding disorder

Contents

Introduction

This booklet is about haemophilia A and B. It gives a general overview of haemophilia and information on diagnosing, treating and living with the condition that we hope will answer your main questions. It has been written for people directly affected by haemophilia and for anyone interested in learning about haemophilia.

If you are a parent and your child has recently been diagnosed with haemophilia you may be feeling quite overwhelmed. Remember, you're not alone and many families are facing the same concerns and issues. Please do get in touch – we have lots of support and information available as well as services for parents and children. You can find out more via our website or Facebook pages, by emailing info@haemophilia.org.uk or calling us on 020 7939 0780.

The outlook is now the best it has ever been for people with haemophilia in the UK. Scientific advances in understanding haemophilia have led to the development of safe and effective treatment. Modern treatment allows children to grow up with the opportunity of a good quality of life and every prospect of fulfilling their potential.

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, though they don't bleed any faster. They may have bleeding into joints and muscles without having had an injury, so treatment is aimed at reducing spontaneous bleeding.

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 and are inherited in the same way, though treatment is different depending on which clotting factor is missing. Specialist blood tests are needed to measure the clotting factors to show whether factor VIII or factor IX is affected and how much is missing.

What causes haemophilia?

Haemophilia is an inherited condition. The genes responsible for producing factor VIII and IX are on the X chromosome.

What is a chromosome?

Each cell of the body contains structures called chromosomes. A chromosome is a long chain of chemicals known as DNA. This DNA is arranged into hundreds of units called genes that hold the instructions for making proteins such as clotting factors and such things as the colour of a person's eyes.

Each cell contains 46 of these chromosomes arranged in 23 pairs. One pair is known as the sex chromosomes because they determine a person's sex.

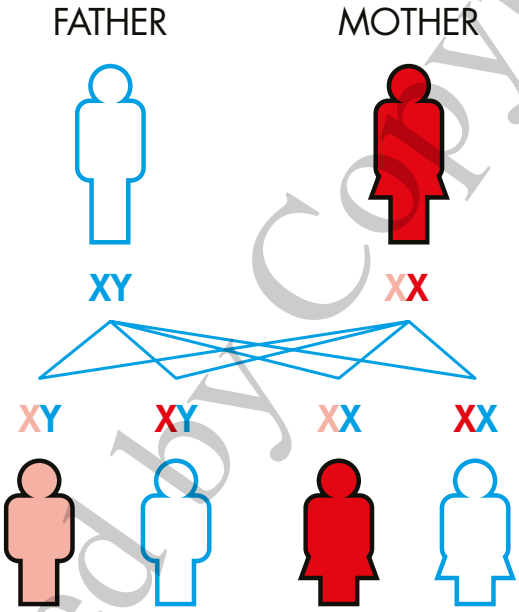
Females have two copies of the X chromosome and males have one X chromosome and one Y chromosome. The mother produces an egg containing one X chromosome. The father produces sperm, which could contain either an X or a Y chromosome. If the father contributes his X chromosome, a girl is conceived. If he contributes his Y chromosome, a boy is conceived.

If a man has an altered haemophilia gene on his X chromosome, then he will be affected with haemophilia. If a woman has an altered haemophilia gene on only one of her X chromosomes, then she is known as a carrier. Some women and girls who are carriers of haemophilia may have slightly reduced factor levels, which means they have a mild form of haemophilia themselves.

In at least 30% of cases of haemophilia there is no known family history. This may be because the alteration to the haemophilia gene is new, known as a spontaneous mutation, or that no affected males have been known in the family. The pattern of inheritance is therefore known as sex- or X-linked recessive. This means that the gene alteration causing haemophilia is on the X chromosome.

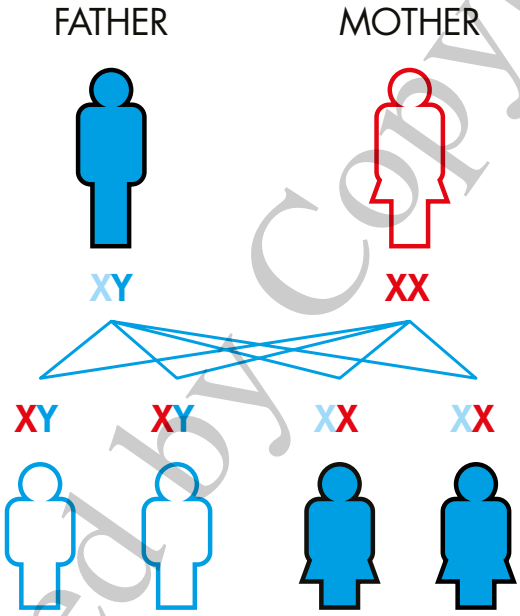
Summary of inheritance chances	
Chance of a carrier having a son with haemophilia	Each of her sons will have a 50% (1 in 2) chance of having haemophilia
Chance of a carrier having a daughter who is a carrier	Each of her daughters will have a 50% (1 in 2) chance of being a carrier
Chance of a man with haemophilia having a son with haemophilia	None – unless the mother of his son is a carrier
Chance of a man with haemophilia having a daughter who is a carrier	All his daughters will be carriers

When the mother carries the haemophilia gene and the father is unaffected



There is a 50% chance at each birth that a son will have haemophilia.
There is a 50% chance at each birth that a daughter will carry the haemophilia gene.

When the father has haemophilia
and the mother is unaffected



None of the sons will have haemophilia.
All of the daughters will carry
the haemophilia gene.

X or X = chromosome with haemophilia gene

‘My son, Jake was diagnosed with severe haemophilia A when he was eight months old. Shortly afterwards I found out that I was a carrier of the gene.

I’ve come to realise that it doesn’t really matter how he got Haemophilia, it’s just something that’s happened that no one had any control over and what’s more important is how we manage it in our lives as a family.

Our genes make up who we are and part of Jake’s genetic makeup is his Haemophilia and you know what, to me he is perfect!’

Hannah

Who might be a carrier of haemophilia?	
Definite (obligate carriers)	**Possible**
The daughter of a man with haemophilia A mother with more than one son with haemophilia A mother with one son with haemophilia and a blood relative with haemophilia	The female relatives of a person with haemophilia on his mother's side of the family (mother, grandmother, sisters, aunts, cousins, nieces, granddaughters)

Carriers of haemophilia

It shouldn't be assumed that a girl who has grown up with a father with haemophilia understands that she is a carrier, or that a sister or cousin of a boy with haemophilia is aware that she might be a carrier. As they grow up girls need to be given information relevant to their age using language they can understand.

There are two different types of blood testing for haemophilia carriers. There are also different issues involved in deciding when they should be done.

Testing factor VIII or factor IX levels

This test is done to find out if a girl has a low factor level and will therefore tend to bleed more than normal. This is important information for her own health and safety if she has an accident or needs an operation. She can then have the right advice and treatment to prevent bleeding. It's also helpful to know before she starts her periods so that advice and support can be in place if she has heavy periods.

Testing the factor level is therefore recommended for all girls who are or may be carriers. A low factor level on its own suggests that a girl may be a carrier but the test doesn't show genetically whether or not she is a carrier. Likewise, a normal level doesn't mean that a girl isn't genetically a carrier. Until the factor level test is done it should be assumed that a girl may have a low factor level and any doctor consulted should be told this as action may need to be taken when having surgery or with a major injury.

Tests to find out if a girl or woman is a carrier

In most cases the type of alteration in the haemophilia gene that has caused haemophilia in any particular family can be found by examining the DNA. This then makes it possible to see whether a girl or woman carries the same gene alteration. If the alteration is found then she is clearly a carrier.

Unlike factor testing, it's less clear when in childhood this test should be done. Views differ on the advantages and disadvantages of knowing at an early age. This is an issue that should be discussed with the haemophilia team. However, it is particularly important for young women to know before there is any possibility of pregnancy.

Who is affected by haemophilia?

Haemophilia A affects about 1 in 5,000 of the male population (boys and men). Haemophilia B is more rare, affecting around 1 in 30,000 of the male population. Around 30-50% of females (girls and women) who are carriers may have milder forms of haemophilia. Haemophilia affects people of all ethnic origins and from all parts of the world.

How severe is haemophilia?

Haemophilia is classed as severe, moderate or mild depending on how much clotting factor is missing. The level of factor VIII or factor IX in the blood is measured by a specialist laboratory. In general, the lower the level, the more bleeding problems the affected person will have if they don't have regular treatment. However, as people with severe haemophilia may be more likely to have prophylactic (preventative) treatment, it isn't unusual for people with mild or moderate haemophilia to experience spontaneous bleeding as often as those with severe haemophilia.

Classification	Level of factor VIII or factor IX in the blood (normal: 45-50 to 150% depending on laboratory)	Typical bleeding tendency
Severe	Less than 1% of normal level	Bleeding into joints and muscles, often with no obvious cause
Moderate	1 to 5% of normal level	Bleeding as a result of minor injury
Mild	Over 5% of normal level	Bleeding usually only occurs following injury, surgery or having a tooth out. Women may have heavy periods

Signs and symptoms of haemophilia

People with haemophilia don't 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 aren't a problem. A little pressure is usually enough to stop the bleeding.

Bruises

Bruises may look serious but they don't usually need any treatment. However, if the bruise is swelling and painful then treatment may be helpful (see Joints and muscles below).

Prolonged bleeding

It's not unusual for people with haemophilia to have prolonged bleeding following larger cuts or minor surgery such as having a tooth out or circumcision. This can last for several days. There's no reason why anyone with haemophilia shouldn't have surgery with the correct treatment (see Medical and dental treatment on page 38).

Joints and muscles

In severe haemophilia the main problem is internal bleeding into joints and muscles. We all damage our tissues in small ways in the activities of everyday life and most people repair that damage automatically. With severe haemophilia, the tiny breaks in the blood vessels in joints and muscles may continue to bleed. These bleeds are sometimes described as 'spontaneous' because it's impossible to identify an obvious reason such as a bump or a fall.

Joint bleeding

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

Bleeding into the joint has a damaging effect on the joint. Once a joint becomes damaged bleeding may occur more frequently and damage can be permanent. This is known as a target joint (see Possible complications on page 29).

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 needs urgent treatment and medical attention as there is a risk of permanent damage.

Possible signs of joint/muscle bleeding in a baby or 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.

Blood in the urine

Blood in the urine may be red or brown. It may go away with drinking plenty of fluid. However, it may be a sign of infection and treatment may be needed to stop the bleeding.

Serious bleeding

Some types of bleeding are serious and need immediate treatment and advice.

Head, face and neck

Any injury to the head, face or neck needs immediate treatment and should be assessed at hospital.

A head injury is always serious if the person is knocked unconscious. Bleeding into the brain is uncommon but can occur without an obvious injury. Symptoms include headache, nausea (feeling sick), drowsiness, fitting, and weakness in an arm or leg.

Rarely, babies with severe haemophilia can develop bleeding in their brain. It's therefore important to be aware that the following are possible signs:

- irritability
- sleepiness
- irregular breathing
- seizures
- vomiting
- difficulty with feeding.

The haemophilia team should be contacted straight away.

Other bleeding

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

How is haemophilia diagnosed?

The diagnosis of haemophilia may be expected or suspected where there is a family history or it may be completely unexpected. The following investigations may lead to the diagnosis:

- the history, signs and symptoms of bleeding
- family history of bleeding
- family history of haemophilia
- blood tests – a general test of blood clotting called a clotting screen which can be performed at all hospitals may suggest haemophilia and lead to referral for specific tests for factor VIII and factor IX.

Known haemophilia in the family

If there is a history of haemophilia in the family it's likely that parents will have had contact with the haemophilia team at their nearest centre and will have had the opportunity to talk about the options available to them. They will also often have known their baby's sex before delivery.

If the haemophilia is severe in the family then the delivery should have been carefully planned and a sample of blood taken from the baby's umbilical cord shortly after birth to measure the factor VIII or factor IX level. Even with the knowledge that there is a 1 in 2 chance of a baby boy having haemophilia, it can take time to get used to the diagnosis. While the baby's mother is likely to have a good understanding of the haemophilia in her family, this will be coloured by family experience and may not be up to date with current treatment. The father's knowledge of haemophilia will be at a different starting point. The haemophilia team will aim to answer questions and give clear explanations to both parents.

If there is a family history of moderate or mild haemophilia, a blood sample can still be taken from the baby's cord. However, since factor VIII and factor IX levels may not reach their normal baseline until the baby is six months old, the blood tests should be done again at that stage. This will give a clearer picture of how the child is likely to be affected by haemophilia.

No history of haemophilia in the family

For at least one-third of newly diagnosed haemophilia there is no family history. The diagnosis may have taken time and can be a traumatic experience for parents and families. Severe haemophilia will tend to be revealed by bruising when an affected baby starts to crawl or is learning to stand. However, it may come to light earlier, such as in these examples.

- The baby may have had bruising with no obvious cause, which led the family to take him to their GP or the hospital for advice. This may have led to blood tests, diagnosis of haemophilia and referral to the nearest haemophilia centre. But as bruising in a baby who is not yet crawling raises concern about the possibility of non-accidental injury (when an adult is harming a child) sometimes the local children's doctors and social workers become involved before the blood tests reveal the haemophilia diagnosis. If there is a delay in reaching the diagnosis and child protection proceedings have started, the family will not only have to come to terms with the diagnosis but also with the anger and distress following the suggestion of non-accidental injury.

- The baby may have needed surgery or a procedure that caused an unexpected amount of bleeding. This may have led to further investigation and a diagnosis of haemophilia.
- The baby may have had bleeding outside his skull or within his brain after he was born, particularly if the delivery was long or complicated. His haemophilia will have been diagnosed during the many tests he had. For the family trying to take in this information while managing their anxieties around his general condition, this will have been very difficult.

Moderate and mild haemophilia may not be diagnosed until later in childhood or in some cases in adulthood. The diagnosis may only be suspected if there is bleeding after surgery or having a tooth out, or after an injury.

Prompt, effective treatment and prevention of bleeding significantly reduces the risk of complications and disruptions to school, work and family life.

Clotting factor concentrate

Bleeding can be controlled or prevented by replacing the missing clotting factor in the blood through an infusion of clotting factor concentrate. The level of factor VIII or factor IX is increased temporarily so infusions need to be repeated. For some minor bleeding episodes one infusion may be enough to stop bleeding. For more serious bleeding or where the first infusion has been delayed, treatment may be needed once or twice a day until the bleeding stops.

Recombinant factor VIII and factor IX concentrates are made using genetic technology and aren't made from blood. Clotting factor concentrates made from plasma from donated blood that has been specially treated to eliminate viruses are still available, though these aren't generally used in the UK.

Treatment will be needed by anyone with haemophilia if they are bleeding. It will also be necessary to prevent bleeding if they need an operation (see Medical and dental treatment on page 38) or have an injury where there is a risk of bleeding.

Bleeding must be treated as soon as possible. Prompt treatment helps relieve pain quickly, shortens recovery time and reduces the chance of permanent damage.

Clotting factor concentrate is given intravenously (into a vein) into the bloodstream through a needle. Children can have anaesthetic cream rubbed onto the skin before an injection to reduce any pain.

Prophylaxis

Treatment with regular infusions of clotting factor aims to prevent the long-term damage caused by bleeding into joints and muscles. Prophylaxis works by stopping the bleeding that occurs without any obvious injury, often called spontaneous bleeding. It also reduces the risk of bleeding from minor injuries. Research has shown that prophylaxis gives children the best chance to reach adulthood without damage to their joints. How often the infusions need to be given is decided for the individual, but is typically every other day for haemophilia A and 2-3 times a week for factor IX, which lasts a bit longer in the blood. New long-acting factors that need to be given less often are now available – these are known as 'extended half-life' or EHL treatments.

Home treatment

Most people with severe haemophilia and some with moderate haemophilia learn to treat themselves/their children with clotting factor at home. Home treatment has many advantages:

- makes regular treatment possible
- treatment can be given as soon as possible after bleeding starts
- less disruption to home, school and working life
- greater independence and control for the parent/person with haemophilia
- reduced need for hospital attendances
- early treatment reduces recovery time and risk of permanent damage.

Treatment can be given in two ways		
On demand	Treatment is given when bleeding occurs such as after an injury	• Very young children • Some adults with severe haemophilia • People with mild or moderate haemophilia
Prophylaxis	Treatment is given regularly to prevent bleeding before it starts	• Children with severe haemophilia • Some adults with severe haemophilia • Some people with moderate haemophilia who have frequent bleeding problems

At first parents are taught by a specialist haemophilia nurse how to give treatment to their child. In time children will learn how to self-treat – most can do this by the time they reach secondary school.

A butterfly needle is inserted into a vein in the arm, the clotting factor is infused and the needle is removed. Alternatively, in very small children or those whose veins are quite difficult to access, an implantable port can be inserted to make having the injections easier. This is a small device inserted under the skin (under general anaesthetic in the operating theatre). Part of the port has a small container called a reservoir and this is placed under the skin. A special needle can be put into the port through the skin so the factor can be injected.

Managing joint bleeds with PRICE

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

- **Protection** Try to keep the weight off the joint or muscle for a couple of days. If it's the ankle or knee, try to use crutches.
- **Rest** Stay off it or don't use it. This helps with healing.
- **Ice** For 15 minutes every two hours. This can help with pain and swelling. Wrap an ice pack in a tea towel or soft cloth so it doesn't 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.

Other treatments

Desmopressin (DDAVP®)

DDAVP® is a synthetic drug that can be suitable for some people with milder forms of haemophilia A. It releases factor VIII stored in the lining of blood vessels, increasing the amount of factor VIII circulating in the blood. This increase can be enough to control minor bleeding episodes and to prevent bleeding from minor operations including dentistry. It is given as a subcutaneous injection (under the skin like a vaccination) or as a nasal spray. It can't 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 as a liquid or tablet and can also be used in a mouthwash. It can be particularly helpful for bleeding in the mouth, nosebleeds or heavy periods. It's often used at the same time as clotting factor or DDAVP® but can be used on its own.

Inhibitors

An inhibitor is an antibody that the immune system (the body's defence mechanism) develops when it recognises the clotting factor being infused as something foreign. The inhibitor removes the clotting factor before it can work to stop any bleeding. Inhibitors usually affect people with severe haemophilia A in early childhood, but they can also occur later in life and in milder forms of haemophilia. They are much more unusual in people with haemophilia B.

Sometimes higher doses of clotting factor can have some effect in stopping bleeding but usually an alternative treatment is needed. The options are called factor VIIa and activated prothrombin complex concentrate. There is also treatment called immune tolerance therapy (ITT) that aims to get rid of the inhibitor so that the person can return to standard haemophilia treatment. People who develop an inhibitor can get specialised advice and support from a haemophilia centre team that has expertise in this area.

‘As a family we’ve adapted our lifestyle to our young son’s needs and try to do the things that make him happy. When we deal with his bleeds it can be tough for the family especially since we’re all so active. Living with an inhibitor has taught us to value the treatment we receive and how important it is to our lives.’

Stephanie

Joint and muscle damage

Bleeding can cause permanent damage to muscles and joints. This is why regular prophylaxis and prompt treatment of any bleeding is so important. When bleeding has affected a joint or muscle, physiotherapy is crucial for good recovery.

Damage to a joint can be caused by one serious bleed, though normally it's a result of repeated bleeding into the same joint over a number of years. The bleeding damages the synovium (the lining of the joint) as well as the cartilage and surrounding tendons and tissues. This leads to arthritic pain and loss of movement and strength in the joint.

In general, the older someone is the more likely they are to have joint damage. Orthopaedic surgery, including joint replacement, can be a successful option when a joint is badly damaged.

Your child with haemophilia

Parents who have just found out that their son has haemophilia can feel shocked and overwhelmed. You may experience many different feelings, including worry and sadness, and you may wonder how you will cope. There's also a lot of information to take in at this time about your son's condition and treatment. You may find it useful to write down questions that you want to ask at your next haemophilia centre appointment.

Your haemophilia team know that this learning takes time and will help you to prioritise the most important information. For example, at first you really need to know the main signs of bleeding that you should be looking out for and who to contact for advice, day and night. With time and experience you will soon learn to recognise the signs of bleeding and judge what to do, though the haemophilia team is always there to offer support.

Because haemophilia is rare, parents may feel isolated and alone and it can be helpful to be put in touch with others in a similar situation. It's important to hold onto the fact that with modern treatment a child with haemophilia has every chance of growing up as an active, fit child who can participate fully in family, school and working life. It's also important to remember that siblings can feel that their brother is receiving more attention than they are, and can become distressed, angry or isolated, so they need to feel included and able to have time with you too.

It's natural to want to protect your child as much as possible, especially when they are very young. But letting them find their own boundaries, within reasonable limits, is essential for building their self-esteem. Most parents find they become more relaxed over time as they learn more about haemophilia and become more confident in managing it effectively.

Brothers and sisters should be included in discussions about haemophilia and trips to the centre. This makes haemophilia less scary for them too, which is important when thinking about home therapy. Sisters may also be carriers and having a good experience with their brother's haemophilia may help them when they come to think about having children themselves.

Call your haemophilia centre if you have any concerns about your son. Make sure you:

- have the contact numbers in your phone
- give the contact information to others involved with your son's care.

School, college and work

With modern treatment, haemophilia shouldn't have a serious impact on a child's education. It's important that the school has a good understanding of the possible problems and knows what to do and who to contact. The child's haemophilia nurse will liaise with the school and if the parent chooses, visit in person to provide advice.

There may be times when a child has to miss school while they recover after a bleed. They may need support to catch up on missed work and get back into the daily routine of classes. Rarely, a child may temporarily need to use a wheelchair or crutches. The school should be aware of this and have the necessary arrangements in place.

In general, most school-based activities are suitable for children with haemophilia. Children should be encouraged to do all the things they can do rather than focusing on minor restrictions. What they can and can't do will not only depend on the severity of their haemophilia, but also on their age, interests and talents. However, there should be discussion between parents and the school about taking part in contact sports. Prophylactic treatment may be beneficial on days when children have PE or sports sessions.

In addition to the information below, parents and teachers may find our *Managing school when a child has a bleeding disorder* booklet helpful. We also have a poster for schools describing the signs of a bleed and what action to take. Visit www.haemophilia.org.uk to order copies.

Nursery, pre-school and primary school

It's important that children join in all play activities with their classmates, especially at this age. Ordinary play activities aren't usually a problem beyond the occasional bruise. Cuts and grazes can generally be managed with standard first aid. Scissors and other sharp instruments don't need to be avoided – all children need to learn to use these safely.

Primary school sport isn't usually particularly competitive or rough. Unless your son has a particular problem or is recovering from a bleed, he should be able to join in with all sports activities.

Secondary school

As young people get older, the range of sports and other activities they want to join in gets wider. The sports and activities they enjoy also tend to get more competitive and rougher. It's important that young people have the right clothing, footwear and equipment for any activity.

The relative risks and benefits of different sports will vary for each individual. If a particular sport does cause a problem, the young person may need to find an alternative and seek advice from their parents, haemophilia centre and the school. Opinions vary about the risks and benefits of different sports – see the next section on Sport and exercise.

College and work

Most young people with haemophilia 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.

College or a job brings new friends and workmates, employers and tutors. A young person with haemophilia has to decide who to tell and what to tell them about haemophilia. This can be daunting – they may be worried that they will be treated differently if people know. This is an individual decision which means thinking about whether telling someone will make life easier or more difficult. It can be helpful to know there is some support and understanding if they have a bleed. One good reason for telling a tutor or employer is so that a safe storage place can be available for some factor concentrate so that it's on hand in case of a bleed. If people don't know, it's worth considering how they will react if they find out later, or from someone else. Most people won't know much about haemophilia, so it can take time to explain and deal with their concerns. It may help to have some accurate written information to give them or refer them to our website.

Sport and exercise

Exercise and sport has many benefits for health and can improve self-esteem, learning and concentration. There are some particular benefits for children and adults with haemophilia 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 involving a lot of physical contact and those where head and neck injuries occur carry the highest risk of injury and therefore risk of bleeding. Prophylaxis can be tailored around days of highest activity so that there is maximum protection from bleeding at these times.

Surgery

People with haemophilia can have any surgery they need but careful planning is essential. The aim of the haemophilia team will be to provide safe management of haemophilia so that there's no greater risk of bleeding than usual for the type of surgery. This is important in making sure there is good healing and for the best possible results from the surgery. This means that clear communication with whoever is carrying out that surgery or procedure is vital. The haemophilia specialist will advise what haemophilia treatment is required. Depending on the type of surgery and the person's condition, planning may include deciding the best place for the surgery to be carried out. If surgery is unplanned, the patient's care team need to know about their haemophilia and speak to their specialist team before the operation.

Dental care

Good dental education and care is particularly important for people with haemophilia to prevent tooth decay and gum disease and avoid the need for dental surgery. Gum bleeding is caused by gum disease but will be worse for someone with haemophilia. Regular brushing will help prevent the build-up of plaque and the development of gum disease. Regular check-ups with a dentist and dental hygiene sessions are also essential. Any dental treatment will need to be planned by the dentist and the haemophilia centre. Haemophilia treatment isn't always necessary before fillings or hygiene sessions but may be before having a tooth out. There's more detailed information in our dentistry action kit – visit www.haemophilia.org.uk

Medicines

Some medicines can affect blood clotting and so may not be suitable for someone with haemophilia. These include aspirin and ibuprofen, which should never be taken unless advised by a haemophilia specialist. Any new medicine, including ones that can be bought over the counter and herbal preparations, needs to be considered for any increased risk of bleeding. Paracetamol is a suitable painkiller for people with haemophilia.

Vaccinations need to be administered under the skin (subcutaneously) rather than into a muscle.

Travel

For anyone planning to travel, important considerations include the following:

- Taking up-to-date written medical information, including diagnosis details and the name and phone number of the haemophilia centre.
- Discussing travel plans with the haemophilia centre, including whether a supply of treatment should be taken and if so, how much.
- Getting a letter from the haemophilia centre explaining about carrying treatment in hand luggage and through security checks.
- Finding out the contact details of haemophilia centres in the places you're visiting. Information is available from the haemophilia centre, the World Federation of Hemophilia (wfh.org), or call us on 020 7939 0780.
- Getting travel insurance that covers haemophilia, including repatriation costs.
- Carrying identification about haemophilia such as a bleeding disorders card or MedicAlert bracelet or necklace.

Our travel insurance fact sheet has lots of tips on travelling with a bleeding disorder – download it from www.haemophilia.org.uk

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 over 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 overleaf.

THE
HAEMOPHILIA
SOCIETY

Willcox House, 140 – 148 Borough High Street, London SE1 1LB
Telephone: 020 939 0780 Email: info@haemophilia.org.uk

www.haemophilia.org.uk

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