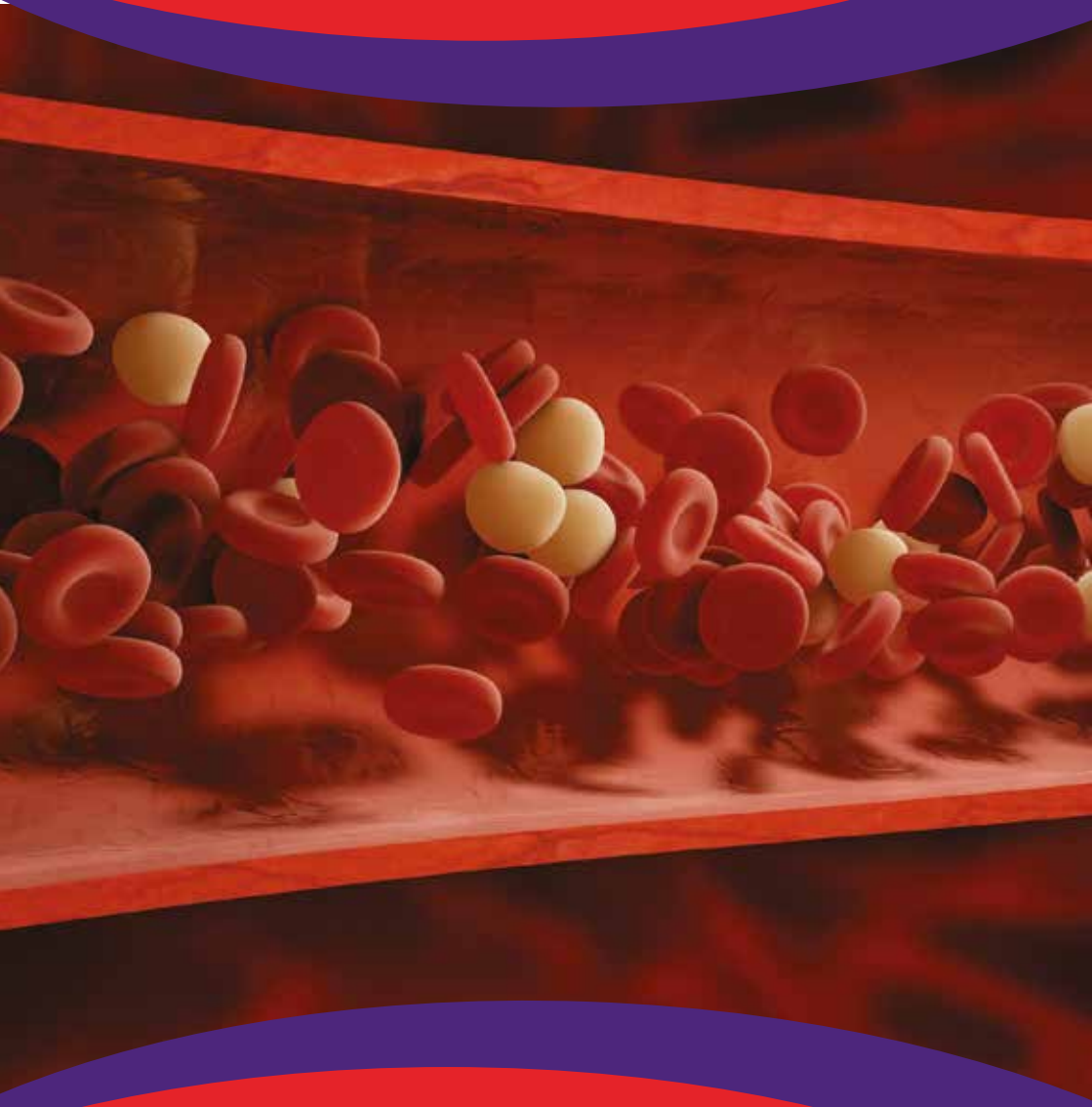
THE HAEMOPHILIA SOCIETY



Rare bleeding disorders

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Introduction

The best-known and most common bleeding disorders are haemophilia A (factor VIII deficiency), haemophilia B (factor IX deficiency) and von Willebrand disease. But there are many more rare bleeding disorders involving blood clotting factors and blood cells called platelets.

The outlook is now the best it has ever been for people with bleeding disorders. Medicine has made huge advances. There are still no cures, but with modern treatment children born now with a bleeding disorder can live a normal lifespan and enjoy the opportunities in life that anyone else has.

There is a series of factsheets that go along with this booklet, providing specific information about each bleeding disorder.

This booklet does not cover haemophilia or von Willebrand disease (these are covered in separate booklets by The Haemophilia Society).

What are bleeding disorders?

Bleeding disorders are conditions where the blood fails to clot properly. They are rare and nearly always inherited. Most are caused by a blood-clotting factor that doesn't work properly or is missing altogether. There are also conditions caused by a problem with platelets – small cells in the blood involved in clotting.

Clotting factors are proteins in the blood that control bleeding. They are named with Roman numerals, and each related bleeding disorder is named after the clotting factor that is lacking. There are many different types of bleeding disorders because there are many different proteins (factors) involved in normal blood clotting. which can have a reduced number, not work properly or both.

There are bleeding disorders caused by problems with clotting factors I (one), II (two), V (five), VII (seven), VIII (eight), IX (nine) X (ten), XI (eleven) and XIII (thirteen). Your doctor may call your disorder a 'deficiency'. You may hear your bleeding disorder called factor XI deficiency, for example.

More than 36,000 people in the UK are registered with a bleeding disorder. The exact incidence varies, depending on the type. About one in every 100,000 males has a factor IX deficiency. But only about one in two million people have a factor XIII deficiency.

How does blood clot normally?

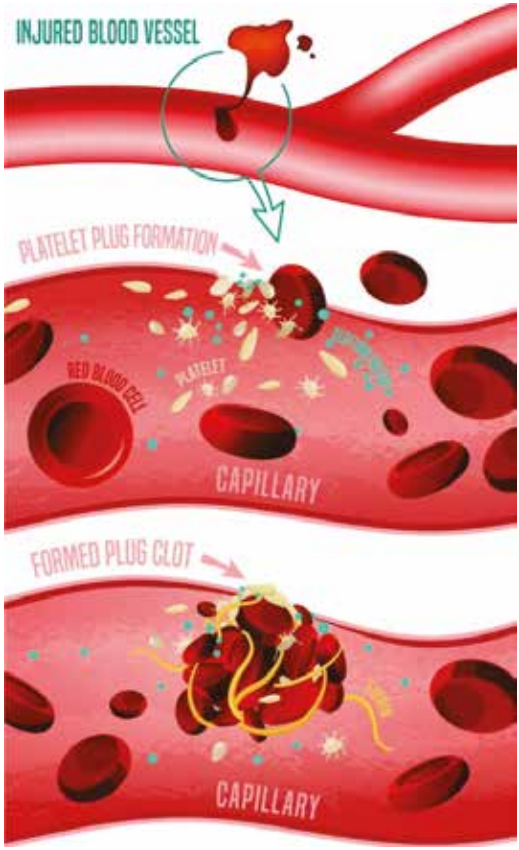
Blood is carried throughout the body in a network of blood vessels – arteries, veins and capillaries. When part of the body is injured, damage to blood vessels can cause holes in the vessel walls, where blood will leak out. The vessels can break near the surface, as in the case of a cut. Or they can break inside the body, causing a bruise or internal bleeding.

When a blood vessel is injured, the vessel walls contract to limit the flow of blood to the damaged area. Small blood cells called platelets are activated. They stick to the site of injury and spread along the surface of the blood vessel to stop bleeding.

The activated platelets release chemical signals that attract more platelets to the area. These clump together to form what is called a platelet plug. On the surface of the platelets, many different clotting factors work together in a series of chemical reactions. This is known as the clotting (or coagulation) cascade – it's like a chain reaction. The result is a fibrin clot, which acts like a mesh to hold the platelets together and to stop the bleeding.

Normally, clotting factors circulate in the blood in an inactive form, because it can be dangerous for a clot to form in the body where it is not needed.

This picture shows the stages in clot formation in a way that makes it easier to understand.



How do you get a bleeding disorder?

Bleeding disorders are generally inherited, meaning they are passed from parent to child in their genes, so you would have the condition from birth. There are some bleeding disorders that you can develop later in life because of another illness or condition, but this is quite rare. These are known as acquired bleeding disorders.

When a baby is conceived, two sets of genes are brought together, one from each parent. Genes are small sections of DNA within the genome that code for proteins. Everything about us, from our eye colour to our height, is coded in our genes. Different sets of genes carry information for different characteristics.

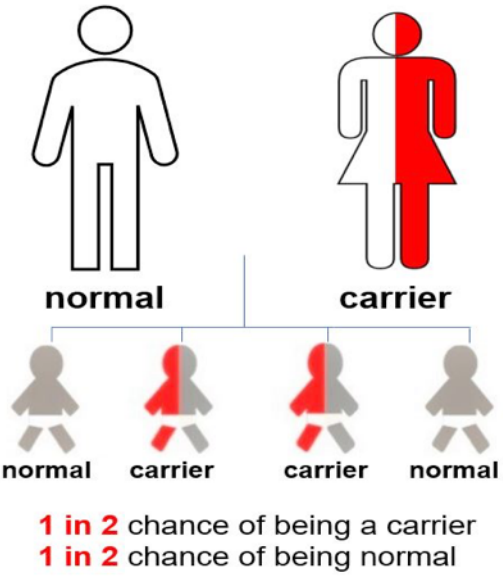
Sometimes genes carry faults that can be passed on to our children. For most bleeding disorders, it is necessary to inherit a specific gene fault from both parents before you develop the condition. People who inherit a gene fault from one parent are called carriers. In most bleeding disorders, they will not have the condition but could pass the gene fault on to their children. Carriers may have lower levels of the clotting factor than normal and may have mild symptoms (but also may have no symptoms at all).

The best-known bleeding disorder, haemophilia, is caused by a gene fault on the X chromosome, one of the two sex chromosomes. This means that it is far more common in boys, because they only have one X chromosome so only need to inherit a gene fault from one parent to have the disease. This is not the case with most bleeding disorders, which are not linked to the sex chromosomes and affect men and women equally.

There are five possible situations that can arise with parents passing on a clotting factor gene or platelet fault:

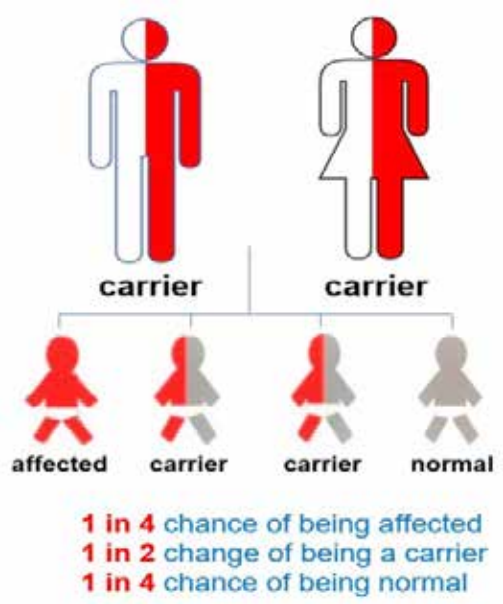
1. **one parent is a carrier and the other has 'normal' genes**
2. **both parents are carriers**
3. **one parent has the condition and the other has 'normal' genes**
4. **one parent has the condition and the other is a carrier**
5. **both parents have the condition.**

The following show how children will be affected in each situation.



1. One parent is a carrier and the other has 'normal' genes

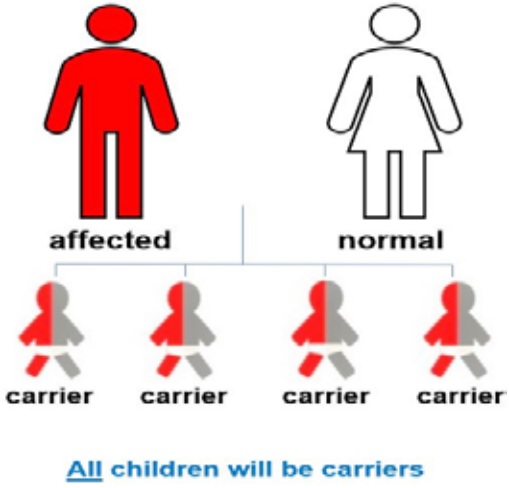
There is a one in two chance that each child will be a carrier and a one in two chance that each child will be a carrier and not have the condition.



2. Both parents are carriers

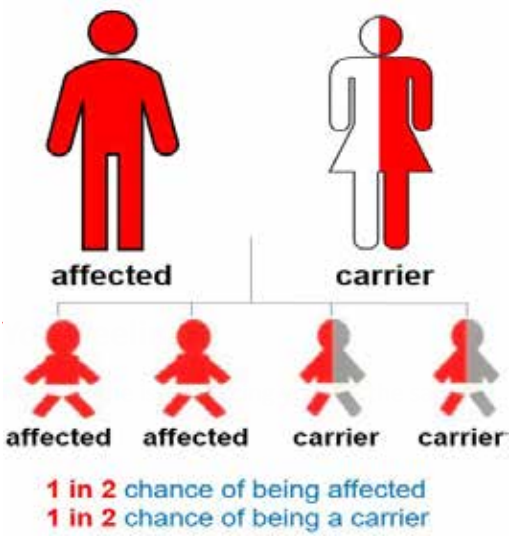
There is a one in four chance of each child being completely unaffected and a one in four chance of each child having the condition.

There is a two out of four chance of each child being a carrier.



3.One parent has the condition and the other has normal genes

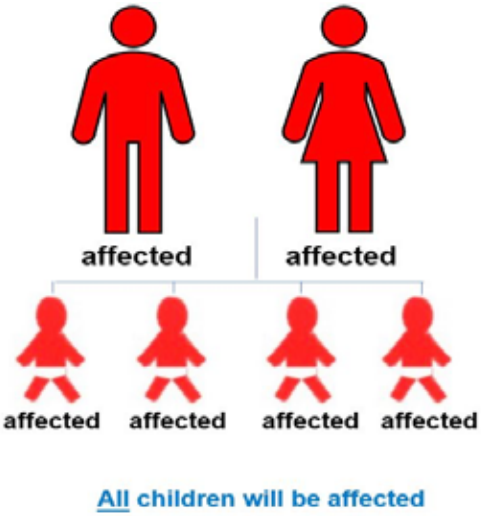
All the children will be carriers, but none will have the condition.



4. One parent has the condition and the other is a carrier

There is a one in two chance of each child having the condition and a one in two chance of each child being a carrier.

No children will be unaffected.



5. Both parents have the condition

All children will have the condition.

General symptoms

The symptoms will vary, depending on the exact type of bleeding disorder you have. But there are some symptoms that are common to all of them. You may:

- bruise easily
- have heavy, painful periods lasting longer than a week.

There are other symptoms that don't happen in all bleeding disorders but can in most. You may have bleeding:

- into joints
- into muscles
- for longer than normal after minor or major surgery
- after dental work.

You can find the exact symptoms for each bleeding disorder in our factsheets that go along with this booklet.

We have included information about preventing bleeding episodes later in this booklet.

Being diagnosed with a bleeding disorder

Depending on the type of bleeding disorder and your family history, you may know you have one from birth, or you may be diagnosed as a young child.

Some bleeding disorders can have mild symptoms, or no symptoms at all. So you may not find out until you are an adult, perhaps after having abnormally heavy bleeding when having a tooth out or after having an operation. It is usual to do blood tests before surgery these days, so it may be picked up during routine pre-surgical screening.

How bleeding disorders are diagnosed

You need to have blood tests to get a firm diagnosis of a bleeding disorder. These are not generally routine tests and may have to be carried out in a specialist centre. You may also have a genetic test to look for the exact mutation in your genes that is causing the condition.

Diagnosis before birth

If you know that a bleeding disorder runs in your family, you may wish to have a test during pregnancy to find out if your baby has the condition. This is not always possible – it depends on the exact type of bleeding disorder.

You may be able to have a test called chorionic villus sampling (CVS), if the gene mutation causing the bleeding disorder in your family is known. CVS is a test where the doctor takes a sample of cells from the placenta. It is usually carried out between 11 and 14 weeks of a pregnancy. To do the test, the doctor puts a fine needle through the wall of your abdomen or a thin tube into your vagina and up into the womb. They can then take a small sample of cells from the placenta for genetic testing.

An additional possible test is amniocentesis. This means taking a sample of fluid from the womb, from inside the membrane holding the baby. The fluid contains cells from the baby that can be genetically tested. Amniocentesis is usually done later in pregnancy than CVS, at between 15 and 20 weeks.

There is a risk of miscarriage with CVS and amniocentesis – about 1 in 100. Your doctor will talk you through all the possible risks and what the test can show before you decide whether you want to go ahead.

Treating bleeding disorders

There are many different types of treatment for rare bleeding disorders. Which is appropriate for you will depend on the disorder you have. There is information in our factsheets on the exact treatment that doctors use for each one. This section contains a summary of all treatments that are used. Following that, there is information about how to manage a bleed if you have one.

Factor concentrates

This is the ideal treatment for a bleeding disorder as it replaces the missing or faulty factor. Unfortunately factor concentrates are not available for all bleeding disorders but more research is being carried out to try and manufacture other treatments.

You have the treatment into a vein, usually as an injection but sometimes as a drip (an intravenous infusion). Depending on your condition and how severe it is, you may have factor concentrates to try to prevent bleeding (prophylactic treatment) or only after you have had a bleed.

Factors I, VII, VIII, IX, X, XI and XIII are available in replacement factors for bleeding disorders. They can all be made from human blood plasma – the straw-coloured liquid that carries the clotting factors. The plasma is treated during the process to make sure it cannot spread HIV or hepatitis.

For bleeding disorders involving factors VII, VIII, IX and XIII there are man-made factor ('recombinant') concentrates available. These are made in a laboratory.

There is another factor replacement treatment called prothrombin complex concentrate (PCC). This is also made from human plasma and contains a mixture of factors II, VII, IX and X, although not all PCC products contain all of these. It is used to treat deficiencies of factors II and X, and inherited combined deficiency of vitamin K dependent factors (VKCFD).

Fresh frozen plasma

You may have treatment with human plasma if there is no factor concentrate available for your condition. You have the treatment through a drip into a vein. It is frequently used as treatment for factor V deficiency and is a straw-coloured liquid.

Platelet transfusions

You may have this if you have a platelet disorder. Platelets are small blood cells, found in human blood, that are important for clotting, they stick to each other

to form the platelet plug, which is important for the clotting factors to stick on to. These are given through a drip into a vein and looks very much like blood plasma.

Cryoprecipitate

This is made from blood plasma. It contains factor I, factor VIII, VWF and FXIII that are important for blood clotting. You have the treatment through a drip into a vein. It is more concentrated than FFP, so you have a smaller volume through the drip.

Desmopressin

Also known as DDAVP, this is a manufactured hormone that boosts factor VIII and VWF levels in people with mild haemophilia, some forms of VWD and will raise FVIII in combined factor V and VIII deficiency (F5F8). You can have this treatment as an injection under the skin or into a vein, or through a nasal spray.

Tranexamic acid (Cyklokapron)

This drug helps to stop clots breaking down. It is useful if you need to have a tooth out, before planned surgery or if you have nosebleeds or heavy periods. It can be used alongside factor replacement for other bleeding symptoms. It comes either as a tablet or liquid that you swallow or as an injection given into a vein.

Fibrin glue

You have this to treat an injury, rather than your condition. It is mostly used if you have 'open' bleeding such as a cut or wound. Your doctor or dentist will apply it directly to the bleeding site.

Vitamin K treatment

This is a treatment for some forms of inherited combined deficiency of vitamin K dependent factors (VKCFD). You may have it if you have a bleed or need surgery. It comes as an injection or in a tablet. If it doesn't help you will need factor replacement treatment.

Hormonal contraceptives

This means either the birth control pill or mirena coil. Any woman with a bleeding disorder can take this to help control heavy periods.

Treating a bleed

If you have a bleed, there are steps you can take to treat it. This is not a substitute for medical treatment, such as factor replacement, but can help. To help you remember what to do, think P.R.I.C.E.

Protection
Rest
Ice
Compression
Elevation

Protection – make sure you do not make the injury any worse. Contact your haemophilia team if you think you need a brace, splint or crutches.

Rest – walk as little as possible if you have an injury to a leg. You may need to use crutches or a wheelchair. Rest an affected arm in a sling.

Ice – apply ice to the injured area for about 15 minutes every two hours. Never put ice directly onto the skin – use an ice pack or bag of frozen peas wrapped in a damp towel. Ice lollies are good for mouth bleeds.

Compression – wrap an injured joint in an elastic bandage using a figure of eight pattern. Look out for signs that the bandage is too tight and cutting off the circulation. These are numbness, cold, a sharp pain or a change of colour in fingers or toes. If any of these happen, take the bandage off and rewrap using less tension.

Elevation – keep the affected limb above the level of your heart to limit swelling and improve the circulation.

Your haemophilia team will support you during any bleeding episodes. A major bleed into a muscle or joint can be very painful and cause permanent damage if not treated. So do contact your team if you are concerned that you have had a joint or muscle bleed.

Preventing and recognising bleeds

Preventing a bleed

You can't always prevent bleeding but there are some things you can do to make having one less likely.

- Only take medicines that have been approved for you by your doctor and haemophilia team. Paracetamol (or Calpol for children) is the only over-the-counter painkiller you should take.
- Never take aspirin unless your haemophilia team has agreed that you can take it for a heart condition, for example. This is particularly important if you have a platelet disorder because aspirin blocks platelet function.
- Don't take ibuprofen (e.g. Nurofen) or similar over-the-counter anti-inflammatory drugs. These can irritate the stomach lining and cause bleeding; they also affect platelet function. You may be advised to take this by your haemophilia team if you are on regular treatment.
- Always speak to your haemophilia team before taking any herbal medicines, vitamin sup-plements or alternative remedies.
- If you need to have surgery or dental treatment, contact your haemophilia team before-hand in case you need any treatment to prevent or minimise bleeding.

Being prepared

- If you are planning any trips, let your haemophilia team know. They will tell you if you need to take any precautions. There is a list of haemophilia centres worldwide on the World Federation of Hemophilia website: **www.wfh.org**
- Always stay in touch with your haemophilia team.

Recognising the signs of a bleed

Whether you have a severe or mild bleeding disorder, it is important that you know the signs of a bleed so you can spot it quickly, get appropriate treatment and minimise any complications. People with mild bleeding disorders may be more at risk of missing a bleed as they won't be so used to the signs. Some bleeds are more obvious than others, of course. Nosebleeds, bleeding from the gums, heavy periods or bright red blood in the urine are all easy to spot. But other types of bleeding may be more difficult.

Nose bleeds

Nose bleeds are very common in all children, they tend to get less as children get older. As a rule of thumb, normal first aid precautions should stop nose bleeds in people with bleeding disorders. If after 15-20 minutes this isn't the case you should contact your haemophilia centres.

Joint bleeds

Bleeds are most common in the elbows, knees and ankles, but they can happen anywhere so look out for signs if you've had a blow or sprain. The signs are pain, swelling, and stiffness. The joint may feel warm or hot. An early sign can be tingling or a bubbling feeling inside the joint. A bleed into a joint can cause permanent damage if not treated so do contact your haemophilia team.

Muscle bleeds

This may happen if you have had a blow or a sprain. The muscle may feel tight, hot or stiff. You may have trouble moving an arm or leg. More serious signs are pins and needles, tingling, a change of colour in the skin over the muscle or swollen veins. Contact your haemophilia team straightaway if you have any of these.

Gastrointestinal bleeding

This is not common but can be serious if it happens. You may have abdominal or stomach pain, feel faint, clammy or look pale. Signs of a gastrointestinal bleed include black, tarry bowel movements or passing fresh blood. Signs of a stomach bleed include vomiting blood or vomit that looks like coffee grounds. Contact your haemophilia team immediately if you see this.

Blood in the urine

Bright blood in the urine is easy to see. But a more minor bleed may cause the urine to look pinkish or dark brown. A kidney bleed may cause low back pain; contact your haemophilia team for advice.

Bleeds into the eye

This may be a result of a blow or injury near the eye. The area may swell, be painful, or change colour. You may have double vision, blurred vision or see spots. An ice pack may slow the bleeding, but you should still contact your haemophilia team.

Bleeding inside the skull

This can happen after a blow to the head or for no obvious reason. You may have a bad or worsening headache, feel or are sick, become confused, drowsy or sluggish, have slurred speech, stiffness in your neck or muscle weakness. You may also be unable to bear bright light or have double or blurred vision. **This is a medical emergency** – contact your haemophilia team immediately if you have a head injury.

Bleeding between periods

Women may have a small amount of internal bleeding when they release an egg (ovulate) between periods. A niggling pain on one side, low down in the abdomen is normal. But if pain becomes severe or you feel faint or dizzy, contact your haemophilia team. You may have a bleed into a cyst in your ovary.

Heavy periods

Girls often have heavy periods when they reach puberty. However women with bleeding disorders can have periods that are heavier or last longer than 'normal'. Anything more than 7 days is NOT usual. You should keep a diary and discuss with your haemophilia team especially if this is affecting your lifestyle or you are very tired - (see page 18 for more information)

Living with a bleeding disorder

How much your bleeding disorder affects your daily life will depend on the type you or your child have and how severely you have it. Bleeding disorders are very variable. You can have a mild form of some types and if so, you may not have any symptoms at all. It may only be an issue if you are having major surgery, having a baby or have an accident. But you need to be able to spot the signs of a bleed and know how to deal with it if it happens.

Coping with your diagnosis

Finding out that you or your child have a bleeding disorder can be upsetting and bring on a range of different emotions. Some people are frightened and anxious. Others may be relieved that they finally have a diagnosis for symptoms they've had for some time. Parents may feel guilty that their child has been born with an inherited disorder and feel that they have caused it.

All this is perfectly normal. You have had a bit of a shock. Talking to other people with a similar condition, as well as your haemophilia team, can be a real help.

Finding out as much as you can about your condition can help you to deal with it, so do ask as many questions as you need to. Your haemophilia team will be more than happy to answer your questions no matter how many times you ask.

You may also get support from talking to your friends and family. Passing on information to them about your condition can help them to support you. Get in touch with your treatment centre, or call The Haemophilia Society on **020 7939 0780** or email **info@haemophilia.org.uk**

Dental care

It is very important to look after your teeth and pay attention to mouth hygiene. This will help to lower your risk of gum disease and tooth decay and minimise the need for dental treatment later in life. Dental procedures can cause prolonged or excessive bleeding if you have a bleeding disorder.

- Brush your teeth at least twice a day.
- Floss your teeth daily.
- Use toothpaste that con contains fluoride.
- Have regular dental check-ups.

Having a tooth out or root canal work can cause bleeding. Your dentist will need to contact your haemophilia team before you have any dental work done. They can advise on any risks or precautions that need to be taken. They may ask you to take Tranexamic Acid (Cyklokapron) or other treatment beforehand to minimise bleeding.

Carrying medical information with you

In an emergency, it is important that anyone giving you medical treatment knows that you have a bleeding disorder. You should carry with you:

- information about your disorder
- information about any treatment you are on
- the name and phone number of your doctor and haemophilia centre.

If you are registered with the National Haemophilia Database, you will have a 'Bleeding Disorder Information Card' with the name of your disorder and contact details for your haemophilia centre. It is very useful to have this with you in case you need to go to another hospital. If you're going away, find out where the nearest haemophilia centre is and take the address and phone number with you.

If you prefer, you can get a MedicAlert disc or piece of jewellery. You must buy these but as you wear them, they are a good way of making sure your medical details are always to hand. Visit **medicalert.org.uk** to find out more.

Special issues for girls and women

Women have added issues to deal with if they have a bleeding disorder, because they can affect periods, pregnancy and childbirth.

Girls just starting their periods may have heavy bleeding. Women of any age may have heavier periods that last longer than normal. This can make you anaemic – a lower than normal level of red blood cells that can cause tiredness and breathlessness.

If you have an inherited bleeding disorder, you may want to see a genetic counsellor before you become pregnant. They can talk through the risk of having an affected child and tell you whether prenatal testing is available. You will need to see an obstetrician earlier than most women – as soon as you know you are pregnant. The obstetrician will need to be in contact with your haemophilia centre throughout your pregnancy.

If you have factor XIII (13) deficiency, or the factor I (1) disorder afibrinogenaemia, you have a greater risk of miscarriage and a complication of pregnancy called placental abruption. This is where the placenta comes away from the wall of the womb, meaning that the baby gets less blood flow and oxygen. You will need treatment throughout your pregnancy to lower the risk of miscarriage and placental abruption. Contact your haemophilia centre before planning a pregnancy and as soon as you think you might be pregnant.

All bleeding disorders carry a greater risk of bleeding for you during delivery and after the baby has been born. Treatment can lower the risk of bleeding and minimise it if it does happen. Treatment is different for each woman and will depend on your own and your family's history of bleeding symptoms, how severe your bleeding disorder is and how you deliver your baby. Some women may need factor replacement treatment. You need to discuss your pregnancy and delivery with your haemophilia team even if you are delivering in another hospital.

General guidance

If you have bleeding disorder, it is a good idea to:

- Tell your surgeon or dentist about your bleeding disorder if you are due to have a proce-dure or operation – you may need to take medication to reduce the risk of bleeding before and afterwards. Your surgeon or dentist may also need to contact your doctor to discuss the procedure.

- Tell your doctor or nurse about your bleeding disorder if you need a vaccination. They can give the injection just under your skin to avoid painful bleeding in your muscles.

- Avoid aspirin and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen unless your specialist advises you it is safe to use them, as these can make bleeding worse. Use other medicines such as paracetamol instead.

- Ask your haemophilia doctor or nurse if there are any activities you need to avoid – you should be able to take part in most sports and activities, but it is best to check first.

- Ask your haemophilia centre to provide you with a Bleeding States Information Card – you always need to keep this card with you so if you are involved in an emergency you can show the card and give attending staff the relevant information and phone numbers to call for advice.

- Boys at risk of a bleeding disorder should not be circumcised without first speaking to your haemophilia centre, due to the risk of excessive bleeding.

If you prefer, you can buy a MedicAlert disc or piece of jewellery. As you wear them, they are a good way of making sure your medical details are always to hand. Visit **medicalert.org.uk** to find out more.

Glossary

Carrier
People who inherit a gene fault causing a recessive disorder from one parent only.

Chromosome
A threadlike structure of nucleic acids and protein found in the nucleus of most living cells, carrying genetic information in the form of genes. Humans have 22 chromosome pairs and two sex chromosomes. Females have two X chromosomes; males have an X chromosome and a Y chromosome.

Factor concentrate
A factor protein that has been made into a powder.

Fibrin
Strands of protein that weave around and through a platelet plug to form a blood clot.

Gene
The basic unit of heredity. Each gene has a certain position on a chromosome.

Genetics
The type of science that studies heredity.

Haemophilia
A lifelong, hereditary blood disorder in which bleeding lasts longer than normal. It is caused by a defect in either factor VIII or IX proteins needed for blood clotting.

Hepatitis
Inflammation of the liver sometimes caused by a virus.

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

HIV
Human immunodeficiency virus; the virus that causes AIDS.

Menstrual period
Also called menstruation or just a 'period'. The shedding of the lining of the uterus through the vagina. On average, it occurs every 28 days and lasts from three to five days.

Placenta
An organ attached to the lining of the womb during pregnancy. It keeps the unborn baby's blood supply separate from the mothers.

Platelet
A small disk-shaped particle in the blood that is used in the clotting process. Also called a thrombocyte.

Platelet function tests
Blood tests to determine how well the platelets work.

Platelet plug
A weak fix of a leaking blood vessel. It is made when platelets begin sticking to each other at the site. Platelet plug formation is part of the blood clotting process.

Tranexamic acid
An antifibrinolytic agent available as tablets, a mouthwash or an injection.

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

With special thanks to Dr Mary Mathias, Haemophilia Consultant, Great Ormond Street Hospital for reviewing this booklet and the accompanying fact sheets.

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 Policy and Programmes 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

Your Society: getting in touch
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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

Review date January 2022