# Women living with bleeding disorders

The Haemophilia Society

# Contents

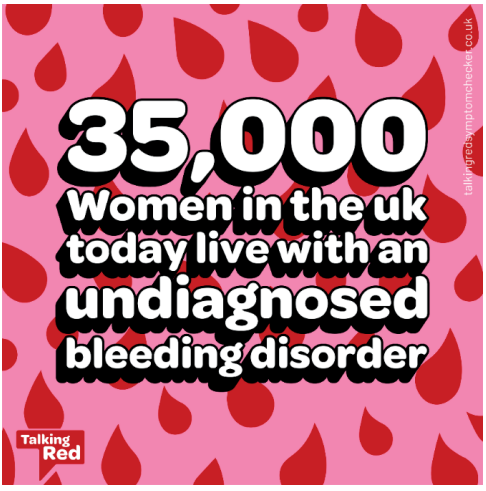
# Introduction

Living with a bleeding disorder can be challenging to manage and affects relationships, education and work. It can also have a huge impact mentally, physically and financially. It can be emotional living with conditions that some people find hard to talk about.

As a woman with a bleeding disorder, you need to understand your condition and the impact it may have. This booklet covers various bleeding symptoms, and it's important to note that bleeding disorders do not affect everyone in the same way.

Depending on your life stage and your particular bleeding disorder, you'll need different information at different times. The booklet is divided into sections on different topics so you can dip in and out of it. There's also a helpful list of medical words in the glossary at the back.

We hope you find the information in this booklet helpful. If you have any questions about anything you read, you can call the Haemophilia Society on **020 7939 0780** or email **info@haemophilia.org.uk**




We recognise that not everyone who has periods identify as a woman and that not all women have periods.

# Section 1 – Bleeding disorders

## What are bleeding disorders?

Bleeding disorders are conditions where the blood doesn't clot properly. Most are inherited and are caused by either a blood clotting factor or platelets not working correctly or being reduced or even missing altogether.

Clotting factors are proteins in the blood that control bleeding. They are written in 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 many other proteins (factors) are involved in normal blood clotting.

These are bleeding disorders caused by problems with clotting factor deficiency:

| | | |
|---|---|---|
| Factor I (one) [fibrinogen] | Factor II (two) [prothrombin] | Factor V (five) |
| Factor VII (seven) | Factor VIII (eight) | Factor IX (nine) |
| Factor X (ten) | Factor XI (eleven) | Factor XIII (thirteen) |
| von Willebrand factor (VWF) | | |

Your doctor may call your disorder a 'deficiency'. You may hear your bleeding disorder called factor XI deficiency, for example.

Platelets are small cells in the blood that clump together to start the process of forming a clot. When this doesn't work properly you have a 'platelet function disorder'.

**Haemophilia**

Haemophilia is a lifelong inherited bleeding disorder. In haemophilia one of the clotting factor proteins important for blood clotting is either partly or completely missing. People with haemophilia take longer than normal for bleeding to stop. 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 (nine).

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. Haemophilia is classed as severe, moderate or mild depending on how much clotting factor is missing.

**von Willebrand disorder**

The most common bleeding disorder is von Willebrand disorder (VWD), also known as von Willebrand disease. This is an inherited condition that can make you bleed more easily than normal. People with VWD have a low level of von Willebrand factor (VWF) in their blood, or it doesn't work very well. VWF works closely with factor VIII to help blood cells stick together (clot) when you bleed. If there's not enough of it or it doesn't work properly, it takes longer for bleeding to stop. There's currently no cure for VWD, but it doesn't usually cause serious problems and most people with it can live normal, active lives.

There are three types of VWD:

- Type 1 is the most common. There is a reduced amount of von Willebrand factor (VWF) in the blood.
- Type 2 is the next most common. The VWF protein is abnormal and doesn't work properly. Type 2 includes several sub-types.
- Type 3 VWD is the rarest and the most severe form. People with type 3 VWD have almost no VWF. As VWF transports factor VIII in the bloodstream, people with type 3 VWD have very low levels of factor VIII as well.

**Platelet function disorders**

Platelet function disorders affect a small percentage of the population. Most of these disorders are mild and many go undiagnosed. Some platelet function disorders, such as Glanzmann thrombasthenia, are associated with more severe bleeding.

Depending on the type of platelet function disorder, platelets may not stick to the walls of damaged blood vessels or form a proper surface so that other clotting factors can form a clot at the site of an injury.

All clotting factor and platelet disorders can affect women.

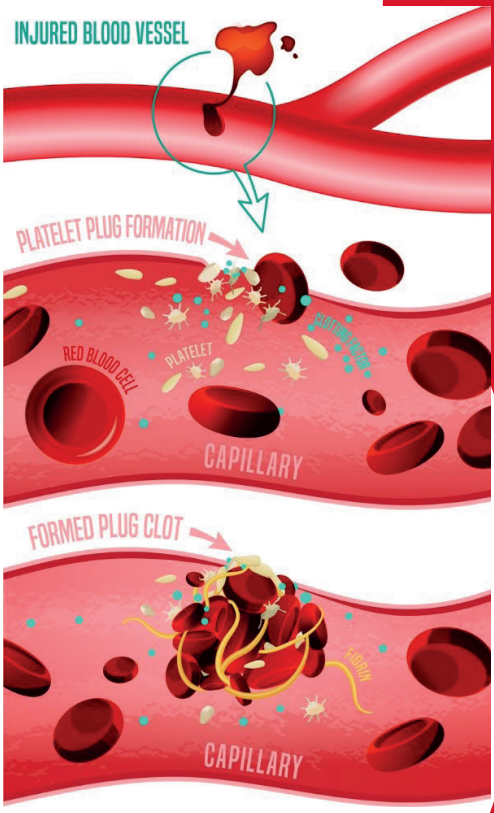
**We have a range of booklets available on the different types of bleeding disorders on our website.**

## 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 blood flow 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 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 as a mesh to hold the platelets together and stop the bleeding.




Normally, clotting factors circulate in the blood in an inactive form to prevent clots forming in the body when not needed. The picture above shows the stages in clot formation to make 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 that you 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 adults can pass on to their children. For most bleeding disorders, you must inherit a specific gene fault from a parent before you develop the condition. People who inherit a gene fault from one parent may be called 'carriers' but may also have the condition. Usually though, they will not have the condition but could pass the gene fault to their children. Carriers may have lower clotting factor levels than normal and may have symptoms (but also may have no symptoms at all).

Bleeding disorders are inherited by one of two patterns of inheritance:

- autosomal inheritance
- sex linked inheritance

**Autosomal inheritance**

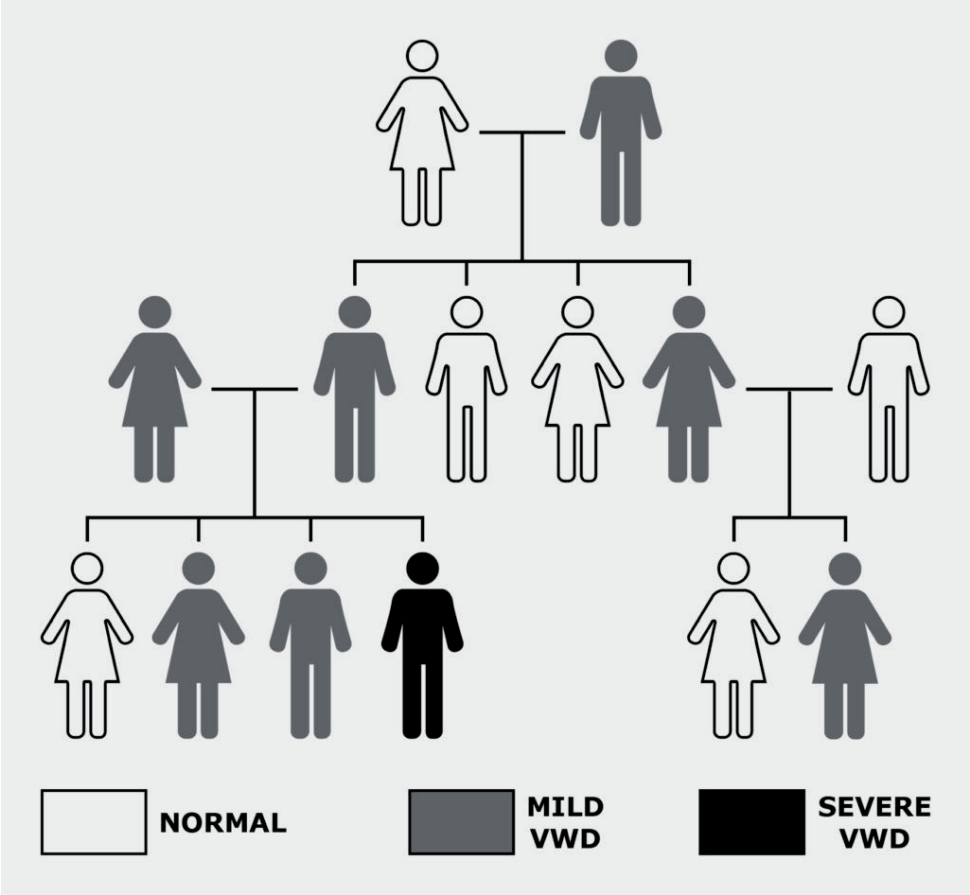
Autosomal inheritance pattern is when the faulty gene that causes a bleeding disorder is on a chromosome which does not decide the sex of the child. It means the bleeding disorder is inherited in an autosomal manner. Bleeding disorders inherited in an autosomal manner affect girls as well as boys.

Most bleeding disorders have autosomal inheritance patterns, for example deficiencies of factors I, II, V, VII, X, XI, XIII, VWD and some platelet function disorders. There are two types of autosomal inheritance patterns: autosomal recessive and autosomal dominant.

**Autosomal dominant** means that only one defective gene, from one of the child's parents, is required for the disorder to affect the child.

**Autosomal recessive** means that two defective genes, one from each parent, are required for the disorder to affect the child. This means both parents must be carriers. A carrier of an autosomal disorder is someone who carries the defective gene without being affected by the disorder. The carrier of a factor deficiency may have a factor level just below, or at the lower limit of, the normal range.

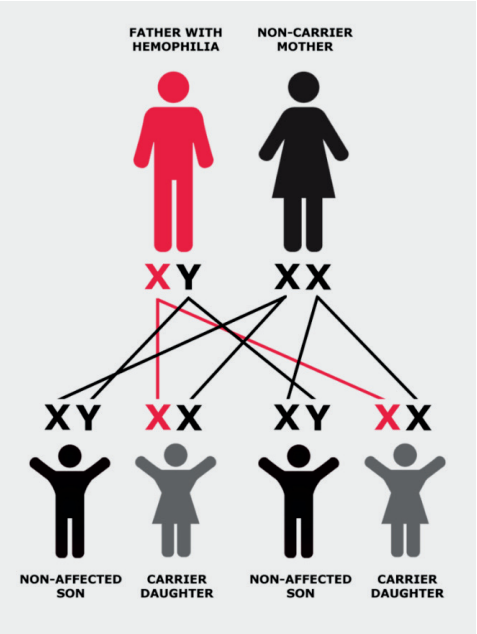
Example below is von Willebrand Disorder

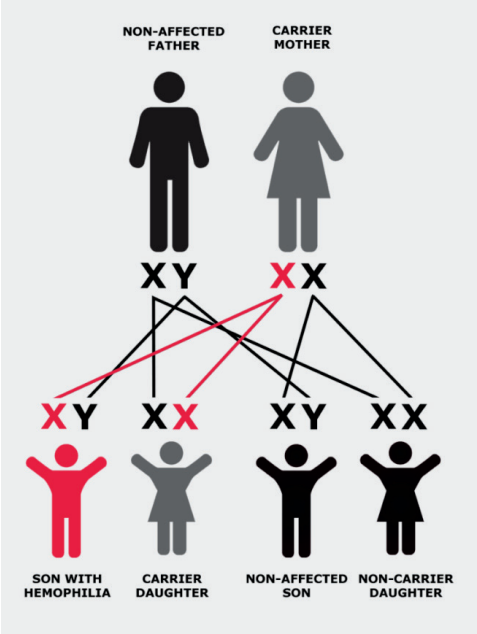



(image from https://elearning.wfh.org/wp-content/uploads/2016/06/VWD-Inheritance2-1024x946.jpg)

**Sex-linked inheritance pattern**

When the defective gene that causes a factor deficiency is on the chromosome that does decide the sex of a child, inheritance is said to be sex linked. The factor VIII and IX genes are on the X chromosome so haemophilia A (factor VIII deficiency) and haemophilia B (factor IX deficiency) are inherited in a sex-linked manner.

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**Bleeding disorders don't run in my family, so can I have one?**

Up to a third of bleeding disorders result from a 'spontaneous mutation' caused by a change in a person's genes at conception, so there won't be a history of bleeding disorders in these cases. Also, some people may not be aware of a bleeding disorder within their family if other relatives are undiagnosed or if their symptoms are different.

## Symptoms and diagnosis of a bleeding disorder

**Symptoms of a bleeding disorder**

Heavy menstrual bleeding is a common condition that has a significant impact on the lives of many women. Women may feel they are expected to cope and suffer in silence. Because of the taboos and stigma associated with periods, many are hesitant to discuss this with family or seek medical advice. However, increased awareness and multidisciplinary management is essential to ensure to best outcome for women with a bleeding disorder.

Symptoms will vary depending on the exact type of bleeding disorder you have but some symptoms are common to all of them. You may:

- bruise more easily
- have prolonged bleeding after surgery
- have serious bleeding after trauma
- have heavier and more prolonged bleeding during your periods (menorrhagia) and be more likely to need an iron supplement;
- be more likely to have postpartum bleeding following childbirth
- be more likely to have a hysterectomy.

If you have one or more of the bleeding symptoms above and/or a family member with a bleeding disorder (such as VWD, haemophilia, or clotting factor deficiency) you should be tested to find out if you have a bleeding disorder. If you have heavy periods as well as other bleeding symptoms or needed iron, admission to hospital, or a blood transfusion in the past, you should also be referred for testing.

**What are some of the consequences and issues of untreated bleeding disorders?**

- Poor quality of life and restrictions around work, sport and exercise, and social activities due to heavy periods.
- Period poverty due to inadequate access to and cost of sanitary products.
- Anaemia which leads to fatigue and further negatively impacts quality of life.
- Need for blood transfusion.
- Bleeding in other parts of the body such as the joints, head or ovaries.
- Hysterectomy and other surgery to control heavy periods.
- Fear of stigma associated with having an inherited disorder can be a barrier to testing and treatment.

## Heavy menstrual bleeding

Women with bleeding disorders tend to have more symptoms because of their monthly periods. Heavy, prolonged periods are the most common symptom for women with bleeding disorders. This is called heavy menstrual bleeding (HMB), which doctors used to call menorrhagia.

If your period lasts for more than seven days, you are soaking through sanitary protection (pads and tampons) every two hours or less, or you have clots that are bigger than the size of a 10p coin, then you should contact your GP or haemophilia centre. Every woman is different, and what is considered 'normal' bleeding during a period for one woman may be 'excessive' for another. When measured by laboratory methods, the average amount of blood lost during a 'normal' period is 30 to 40ml. Blood loss of 80ml or more is considered to be 'heavy' and may cause anaemia (see page 14). But there is no easy way to measure the exact amount of blood you lose during your periods, so it's important to keep a record of number of days you bleed, how many pads/tampons you use and how bloodstained they are, or the amount of blood in the menstrual cup if you use one.

Keep a diary of your periods (track your blood loss during your period) and bring this with you when you attend your haemophilia centre. There are mobile phone apps you can use to track your periods such as Flo Period Tracker & Calendar, Period Tracker, or Eve by Glow.

**What is a normal period?**
Gynaecologists often define a normal period as:

- bleeding for around 5 to 6 days up to about 7 days
- losing about 30 to 40ml of blood per month (around 2 to 3 tablespoons)
- bleeding every 25 to 35 days
- average cycle is 28 days.

**What is an abnormal period?**
An abnormal period may be defined as:

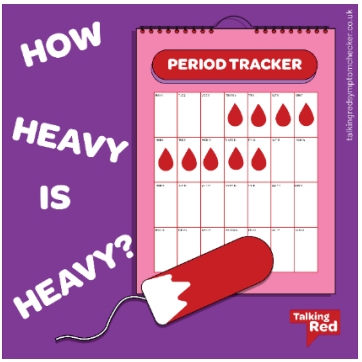
- losing 5 to 6 tablespoons (about 80ml or more) of blood
- bleeding lasting longer than 7 days
- passing lots of large clots and flooding
- erratic periods
- interfering with your physical, social, emotional and/or material quality of life.

You may experience heavy periods if you have been diagnosed with the following:

- VWD
- factor deficiencies – ( haemophilia A and haemophilia B)
- other rare factor deficiencies (II, V, VII, X, XI, XIII)
- thrombocytopenia (including congenital or acquired) including ITP and TTP
- other rare bleeding disorders e.g. Glanzmann thrombasthenia, Bernard-Soulier syndrome.

If you have always bled a lot during your monthly periods, and because other women in your family also bleed a lot, you may not realise the amount of blood lost during your period is more than is normal in most women.

Living with heavy periods shouldn't be dismissed as a minor issue. Heavy periods can dramatically affect your health, your sense of wellbeing and your ability to work. Personal relationships can also be affected. But there are treatments that can help – find out more on page 19.




## Talking Red symptom tracker

Talking Red is a campaign by the Haemophilia Society to encourage women and girls to talk about their periods and consider whether they might have heavy periods. Some women with heavy periods may have an underlying bleeding disorder. This tool is designed to ask you questions about your period as well as other symptoms of a bleeding disorder which may help you to discuss your symptoms with a GP. While a bleeding disorder may be the cause of your symptoms not all women with heavy periods have a bleeding disorder and other causes are common. Whatever the cause, your GP can signpost you to the right specialist care and may be able to offer immediate help through a prescription to help heavy menstrual bleeding. This symptom tracker will give you guidance and empower you with information so that if you do go on to visit your GP, you receive the right treatment.

You can use our symptom tracker on our website link:
**https://haemophilia.org.uk/support/talking-red/checkyoursymptoms/**

## Other bleeding issues

### Anaemia

Having heavier and longer monthly periods can mean that women have low levels of iron in their blood. This is known as anaemia. Anaemia causes weakness and tiredness. Women with bleeding disorders should be checked regularly for anaemia. Iron supplements may be prescribed for this.

### Ovulation bleeding

Ovulation bleeding is light spotting that occurs when your ovary releases an egg. It can happen during the middle of your menstrual cycle. For some women, changes in hormone levels can trigger light vaginal spotting during ovulation. Ovulation doesn't go on for very long, and neither does the bleeding – a day or two at most. Bleeding tends to be very light and you may only need to use a panty liner. The blood is usually pale pink; that's because the blood is mixed with cervical fluid, which increases during ovulation.

Ovulation can also be associated with slight bleeding from the ovary as it releases the egg and can cause abdominal pain called mid-cycle pain. In women with severe bleeding disorders this bleeding can be severe and need immediate medical attention. If you have a severe pain or bleeding or feel faint, you should contact your haemophilia centre.

**Bleeding after sex**

Vaginal bleeding can occur during and after sex. The amount of bleeding varies for each woman. If it persists for more than a couple of days or you need to use more than two sanitary pads a day, call your local haemophilia centre for advice.

**What should I do if I think I may have an inherited bleeding disorder?**

The first thing to do is to seek medical help. This may be from your GP or your obstetrician/gynaecologist if you have one. Talk to them about your concerns and ask to be referred to a haematologist (a doctor who specialises in blood diseases). Many doctors and healthcare providers may not be familiar with bleeding disorders so if you have access to a computer or mobile phone, you can download information, take it with you and share it with your healthcare team. It can be intimidating to let medical professionals know that you suspect that you have a bleeding disorder but don't be afraid to speak out.

You can find out more about how bleeding disorders are diagnosed in the next section of this booklet.

**Did you know?**

**Women have on average 400 to 450 menstrual cycles in a lifetime and 6.4 years of periods**

# Section 2 – How is my bleeding disorder diagnosed?

## Diagnosing a bleeding disorder

Depending on the type of bleeding disorder, 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 an operation.

Some rare bleeding disorders can develop later in life because you have another medical condition, such as liver disease. You may hear this called an acquired bleeding disorder.

Blood tests are used to make a diagnosis. These tests can't be done in GP surgeries and need special laboratories. The blood tests you have may include:

- full blood count (FBC) to check the haemoglobin and platelet count
- prothrombin time (PT), activated partial thromboplastin time (APTT), thrombin time (TT) and fibrinogen activity to check for factor deficiencies
- von Willebrand factor investigations
- platelet studies.

Diagnosing bleeding disorders is complex, particularly if you have no known family history. Diagnosis can be even more complicated in women due to other causes of bleeding (usually heavy menstrual bleeding), changes in blood clotting levels during menstrual cycles, and a lack of awareness of women's bleeding in non-specialist healthcare professionals.

You may have to attend more than once to have blood tests repeated as many levels can be affected by stress, your menstrual cycle and any medicines you may be taking. Although this can be frustrating it's nothing to worry about and you can be sure that full investigations are being done to find out what's causing your bleeding. Your hospital will contact you as soon as they have the results back from the blood tests.

Once you have a diagnosis other family members can be offered testing. It's easier for them to get a diagnosis as the haemophilia team know what condition they are looking for.

**Genetic counselling and testing**

Genetic counselling is an essential but complex part of proper care for individuals and families with a bleeding disorder. Genetic counselling should consider your experiences and perceptions, as well as the social, cultural, and religious factors and contexts that may influence your decisions and the options you have.

Genetic testing can work out the exact genetic mutation causing a certain condition. For bleeding disorders, genetic tests may answer the following questions:

- If you know you have a bleeding disorder, what is the genetic change that has caused your condition?
- Are you a carrier of a bleeding disorder?

Depending on the type of disorder and the reason for testing, the genetic test results can take weeks or months. Your haemophilia centre may be able to give you an estimate of the time it will take.

**Carrier testing**

Unlike factor testing, it's less clear when genetic tests should be done. Views differ on the advantages and disadvantages of testing at an early age and this is something families should discuss with their bleeding disorders team.

However, it's important for young women and girls to know if they are carriers well before they have any thoughts of having children. Knowing this will make planning pregnancies easier. There are two tests that can be done to find out if you are a carrier:

- First, there is a genetic test to work out carrier status.
- Second, there is a factor level test to measure factor levels. This can help work out whether you have a greater than normal risk of bleeding.

It's important to know the factor level in a potential carrier because of the increased risk of bleeding that women with low factor levels can experience, such as bleeding after having a tooth out or an operation, or heavy menstrual bleeding.

If you have very low factor levels you may need medical treatment, such as for very heavy bleeding during your period or for nosebleeds. Where factor levels are low, precautions can be taken to prevent many of these complications.

As a carrier, you may experience a range of emotional and psychosocial impacts related to having your own family or the consequences of passing on a genetic disorder. Your experience of being a carrier may change with different life stages, and you may need genetic and/or psychosocial counselling and support more than once in your life.

**Please remember that if you are diagnosed with a bleeding disorder, it might at first seem overwhelming. But we want to reassure you that with ever better treatments and care available, people with bleeding disorders usually manage their conditions very well and can get on with living and enjoying their lives.**

# Section 3 – What are my treatment options?

Bleeding such as bruising, minor cuts and some nosebleeds can often be controlled using simple first aid measures such as PRICE (Protection, Rest, Ice, Compression and Elevation).

If bleeding continues in cases like heavy or long-lasting nosebleeds, heavy menstrual bleeding, some dental procedures, during or after surgery or after injury, other treatment options may be needed. Bruising may also need treatment, especially if it's extensive or painful, or there are raised haematomas (where blood collects in the tissues under the skin).

## Non-hormonal treatments

**Tranexamic acid (Cyklokapron)**

Tranexamic acid is an anti-fibrinolytic agent. This means that it slows the breakdown of blood clots. It is often used to prevent or treat bleeding from mucous membranes such as the inside of the mouth, nose, gut or womb. It is usually taken as tablets, three or four times a day, but may also be given as an intravenous infusion (drip into a vein). You will be able to get a repeat prescription for tranexamic acid from your GP or haemophilia centre.

Tranexamic acid may be given before some dental treatments, for nosebleeds or prolonged or heavy periods. It may be used alone or in combination with DDAVP® and factor replacement therapy. Tranexamic acid doesn't replace or increase clotting factor levels. This means it can't be used instead of DDAVP® or factor VIII/VWF concentrate, but for some minor procedures it may be the only treatment needed.

It can sometimes have side effects including:

- nausea (feeling sick)
- dizziness
- diarrhoea (loose, watery poo)
- stomach pain.

For heavy periods, you should take tranexamic acid as soon as your period starts. This reduces the breakdown of a pre-formed blood clot, which reduces bleeding. You may need to take it three times a day for around 3 to 5 days (or longer if needed) to reduce blood loss.

**Desmopressin (DDAVP®)**

DDAVP® is a synthetic drug that can be suitable for some people with milder forms of haemophilia A or VWD. 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. For some women, desmopressin is a helpful treatment for heavy periods.

**Clotting factor replacement**

For some women with severe factor deficiencies that don't respond to other treatments, regular treatment (known as prophylaxis) with clotting factor replacement may be needed to control heavy menstrual bleeding.

This treatment may also be needed when the risk of severe bleeding is high, such as during childbirth, before major surgery or if someone has a head injury.

**Iron supplements**

You may be advised to take iron supplements to boost iron levels in the blood. If your iron levels don't improve, you may need an intravenous infusion (drip into a vein) of iron. This is given in a hospital clinic as there is a risk of an allergic reaction with intravenous iron.

## Hormonal treatments

**Combined hormonal contraception (CHC)**

Hormones in CHCs work by preventing the ovaries from releasing an egg. They also thin the lining of the womb which often makes periods lighter and less painful. These can come as pills, a patch or a vaginal ring. In this situation, CHCs are used to treat heavy bleeding, not as contraception. You may be advised to use this continuously for a few months so that you don't get a period.

**Progestogen-only pill or cyclical progestogens**

Some progestogens can be used to make periods lighter and less painful. These include cyclical progestogens (e.g. norethisterone or medroxyprogesterone acetate), a desogestrel progestogen-only pill and the depo injection.

The progestogen-only pill needs to be taken every day to work. You need to take one pill every day within either 3 or 12 hours of the same time each day, depending on which type you are taking.

**Intrauterine system (IUS)**

An IUS is a small T-shaped plastic device that releases the hormone progestogen directly into the womb, which thins the womb lining to reduce heavy periods. Brand names include Mirena and Levosert. It can give you some erratic bleeding at first but this device lasts for up to five years, depending on the brand.

Advantages

- The IUS is inserted by a doctor or nurse in a clinic and doesn't need an operation.
- If you are having sex, the IUS is an effective method of birth control, though you can still get pregnant after it's removed.
- You don't have to remember to take pills on a regular basis.

Disadvantages

- Some women experience discomfort and cramping when the IUS is put in.
- Periods can be irregular for the first 3 to 6 months after the IUS is put in.

**If one treatment doesn't suit you, there are others you can try.**

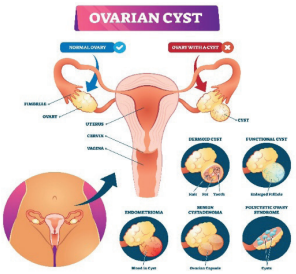
# Section 4 – Gynaecological conditions

Women with bleeding disorders may also have gynaecological complications. For these women, gynaecological procedures, including surgery, may be considered. It is essential to have all the relevant information before making decisions.

**Dysmenorrhoea (period pain)**

Period pain from your first period or shortly after, and without a specific cause, is known as primary dysmenorrhoea. It is a common and normal part of your menstrual cycle. Most women get it at some point in their lives. It can cause painful cramping, vomiting, nausea, diarrhoea, fatigue, irritability, dizziness, headache, lower back pain and pain usually in the lower abdomen, which occurs shortly before or during your period, or both. The pain sometimes comes in intense spasms, while at other times, it may be dull but more constant. If it's severe, dysmenorrhoea can adversely affect your quality of life and wellbeing, restrict daily activities and mean time off work.

Less commonly, period pain can be caused by an underlying medical condition such as endometriosis (see below), fibroids, pelvic inflammatory disease and adenomyosis (see glossary). This is known as secondary dysmenorrhoea. Your GP can refer you for further investigation and treatment if necessary.



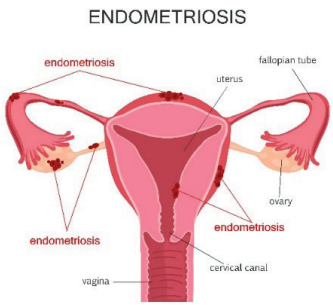

**Ovarian cysts**

When a woman ovulates, a small amount of bleeding may occur when the egg follicle breaks as the egg is released from the ovary. There may also be abdominal and pelvic pain. Women with bleeding disorders are more likely to have significant bleeding at ovulation with resulting pain, haemorrhagic ovarian cysts (fluid-filled sac that develops on an ovary) or even bleeding into the abdominal and pelvic cavity.

These gynaecological complications can be treated surgically, but for women with bleeding disorders, treatment with clotting agents is preferable. Options include tranexamic acid (Cyklokapron), desmopressin (DDAVP®) and clotting factor

replacement – see pages 20. Combined hormonal contraception (see page 20) suppresses ovulation and may be used to prevent recurrences.

**Endometriosis**




Endometriosis is when the cells like the ones in the lining of the womb (uterus) are found elsewhere in the body, e.g. the bladder or bowel.

Symptoms include heavy periods (with or without clots), prolonged bleeding, irregular periods, painful when you poo, back pain and leg pain. It's important to note that these symptoms may not necessarily be caused by endometriosis. Contact your haemophilia centre to discuss any concerns you have about managing bleeding caused by your bleeding disorder.

**Menopause**

Menopause is the time in a woman's life when menstrual periods permanently stop, usually between the ages of 45 and 55. Perimenopause is the 3 to 10-year period before menopause when hormones are 'in transition'.

For all women, symptoms of perimenopause can include heavy menstrual bleeding, irregular periods and spotting. Women with bleeding disorders are likely to be at much higher risk of unpredictable and heavy bleeding.

There are other conditions that can cause heavy bleeding, so you should have a full medical investigation to rule these out. Doctors, which might include a gynaecologist and haematologist, need to work out what is causing the abnormal menstrual bleeding before any treatment is given.

You can still get pregnant during perimenopause. You should keep using contraception for two years after your periods stop if you are under 50 years old or one year if you are over 50 years of age.

**Post-menopausal bleeding**

Post-menopausal bleeding is common and occurs a year or more after your last period. The bleeding can range from spotting, a pink or brownish discharge, to heavier, period-like bleeding. Bleeding after menopause is rarely a cause for concern. Mostly the cause will be something very simple and treatable but occasionally it's a sign of a more serious problem so it does need to be investigated by your doctor.

## Surgical procedures

Sometimes gynaecological conditions may need to be treated with surgery. If this is an option for you, your doctors will discuss the advantages and disadvantages with you before you make any decision about treatment.

**Hysterectomy**

This is the surgical procedure to remove your womb (uterus) so that your menstrual bleeding stops. Sometimes your fallopian tubes, cervix or ovaries are removed as well. A hysterectomy isn't the first-line treatment for heavy menstrual bleeding (HMB) in women with bleeding disorders, but it may be an option if you don't respond to medical treatment and you have completed your family. A hysterectomy is a significant operation with an increased risk of bleeding during and after the surgery.

There are three ways to carry out a hysterectomy:

- laparoscopic hysterectomy (keyhole surgery) – where the womb is removed through several small cuts in the tummy
- vaginal hysterectomy – where the womb is removed through a cut in the top of the vagina
- abdominal hysterectomy – where the womb is removed through a cut in the lower tummy.

Recovery time depends on the type of hysterectomy that's done. If your gynaecologist recommends a hysterectomy, you should contact your haemophilia centre for advice.

Advantages

- Hysterectomy stops menstrual bleeding once and for all.
- It may be the only option if you don't respond to medical treatment or the Mirena IUS (see page 21) and endometrial ablation (see below) doesn't work for you.

Disadvantages

- Hysterectomy means you can no longer have children.
- Hysterectomy is a major operation with increased risk of bleeding both during and after the operation. This can be managed with clotting factors recommended by your haemophilia team.
- The operation requires a stay in hospital.
- The recovery time is much longer than with endometrial ablation.
- Women who have a full hysterectomy (removal of the uterus and the ovaries) need long-term hormone therapy afterwards.

**Endometrial ablation**

Endometrial ablation is now widely used as an alternative to hysterectomy. It can be effective in reducing menstrual blood loss in women with bleeding disorders. Endometrial ablation removes a thin layer of the lining of the womb (uterus). For many women it stops menstrual bleeding, while for others bleeding doesn't stop but is reduced to normal or lighter levels. Compared with hysterectomy, the procedure has a shorter operating and recovery time, and fewer complications. Possible complications are:

- cramping, like menstrual cramps, for 1 to 2 days
- thin, watery discharge mixed with blood, which can last a few weeks
- frequent peeing for 24 hours
- nausea.

Advantages

- The operation is done through the vagina so no surgical cutting is needed.
- There is much less chance of bleeding and other complications compared with a hysterectomy.
- The operation can be done as an outpatient procedure, so you don't have to stay in hospital.
- Recovery time is much shorter than with a hysterectomy.
- Success rates are high.

Disadvantages

- Endometrial ablation means you are unlikely to have children afterwards.
- The operation may have to be repeated.
- In a small percentage of women, this operation doesn't reduce bleeding.

**Surgery for endometriosis, or endometrial tissue outside the uterus**

This operation is to remove endometrial tissue that has formed outside the womb (uterus) – see page 23 (endometriosis section). It is usually done using keyhole surgery. Two small incisions are cut in the abdomen. Two tubes are inserted – one for a tiny camera, the other for the instruments to cut out the endometrial tissue.

Advantage

- This operation can reduce pain and bleeding if you don't respond to hormonal therapy or other medical treatment.

Disadvantage

- While not a major operation, you will need appropriate preparation with factor VIII/VWF concentrates.

**Your haemophilia centre or gynaecologist will discuss the best treatment options for you.**

# Section 5 – Planning and managing pregnancy

If you have an inherited bleeding disorder, you may want to see a genetic counsellor before getting 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. Your antenatal care should be provided by a multidisciplinary team with haematologists and obstetricians who are experts in bleeding disorders.

## Planning your pregnancy

Ideally, you should begin planning for pregnancy before you get pregnant because depending on your bleeding disorder, there may be an increased risk of bleeding complications during pregnancy. You should have an evaluation with a haematologist and a high-risk obstetrician, both skilled in managing bleeding disorders. You may be referred to a centre where specialist obstetricians in high-risk birth work alongside experts in haemostasis (stopping blood flow) for prenatal care, delivery, termination of pregnancy, or managing miscarriage.

For women having in vitro fertilisation (IVF) treatment, the process of egg collection and embryo transfer can be associated with bleeding.

## Prenatal diagnosis

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 isn't always possible – it depends on the exact type of bleeding disorder.

Prenatal diagnosis is an important part of the care of mothers affected by an inherited bleeding disorder. It's mostly considered in carriers of haemophilia because of the severity of the disorder. In von Willebrand disorder (VWD) the option of prenatal diagnosis should be offered when the baby is at risk of being affected by severe forms of the disorder, principally type 3 in a sibling. Similarly, in factor XI deficiency, prenatal diagnosis is offered when there is a risk of severe factor XI deficiency in the baby.

Prenatal diagnosis will help with planning and risk assessment at delivery. Knowing whether a male foetus is affected by haemophilia helps parents and healthcare providers make decisions around managing the pregnancy and the delivery.

## What tests can I be offered during pregnancy?

**Free foetal DNA (ffDNA**) is a blood test arranged by your haemophilia centre to find out the sex of your baby during the early stages of pregnancy. As early as nine weeks of pregnancy, cells from your baby (foetal cells) can be detected in your blood, and these are analysed to work out the baby's sex. Your haemophilia centre will take a small blood sample – about 10ml (around a tablespoon) – and send it to the laboratory for analysis. The scientists in the laboratory look for the Y chromosome. This is how your doctors know whether the foetus is male or female, as women don't have a Y chromosome.

The test results take about a week, and your haemophilia centre will contact you as soon as they have them. This test is only suggested for haemophilia A and B. If you don't want to know the sex of your baby, your haemophilia centre can still do the test but inform your obstetric team without telling you the results.

The ffDNA test allows your haemophilia centre to identify the sex of the foetus early in pregnancy. This can help avoid further invasive testing if the foetus is female, which carries a risk of miscarriage. Knowing the results earlier rather than later may also relieve stress for you and your partner. If you are having a boy, then further prenatal diagnosis options are available and your haemophilia centre can discuss these with you. If your centre knows that you are having a boy, they can ensure that plans are put in place to manage a safe delivery.

**Chorionic villus sampling (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 pregnancy. The doctor puts a fine needle through the wall of your abdomen through to the placenta. They can then take a small sample of cells from the placenta for genetic testing. A miscarriage can occur up to three weeks after the CVS and it is hard to predict if a pregnancy will miscarry. CVS is carried out in the early stages of pregnancy when the risk of miscarriage is more common anyway.

**Amniocentesis** is a test where a sample of fluid is taken 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 15 to 20 weeks, but you can have it later if necessary. During the test, a long, thin needle is inserted through your abdominal wall, guided by an ultrasound image. The needle is passed into the amniotic sac that surrounds the foetus and a small sample of amniotic fluid is removed for analysis. The test itself usually takes about 10 minutes, although the whole consultation may take about 30 minutes. Amniocentesis can feel uncomfortable but isn't painful.

There is a risk of breaking the amniotic membranes that surround the baby and a small risk of introducing infection into the amniotic fluid.

There is an increased 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. Results for the tests can take around 3 to 5 working days.

## Miscarriage

There is no evidence of a higher rate of miscarriage in carriers and women with the most common bleeding disorders than in the general population. Around 20% of all pregnancies are complicated by at least one occurrence of bleeding, so bleeding in pregnancy may not be due to an underlying bleeding disorder.

But women with certain rare factor deficiencies (such as factor XIII deficiency and fibrinogen deficiency) have a greater risk of miscarriage and placental abruption. This is where the placenta comes away from the wall of the womb so the baby gets less blood flow and oxygen. These women may need factor replacement throughout pregnancy to prevent these complications.

Women with factor XI deficiency may have excessive bleeding after miscarriage.

## Pregnancy and childbirth

**Precautions for pregnant women with a bleeding disorder**
Women who have factor XIII (thirteen) deficiency or the factor I (one) disorder afibrinogenaemia have a greater risk of miscarriage and a complication of pregnancy called placental abruption (see page 29). You will need treatment throughout your pregnancy to lower these risks. You should 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 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 and your family's history of bleeding symptoms, how severe your bleeding disorder is and how you have your baby. Some women may need factor replacement treatment. You need to discuss your pregnancy and delivery with your haemophilia team, even if you have your baby in another hospital.

Women with bleeding disorders can bleed with procedures such as caesarean section and surgery to remove any remaining products of conception inside the womb (uterus) following a miscarriage or termination of pregnancy. They are also at risk of bleeding with invasive medical interventions such as prenatal diagnostic tests (chorionic villus sampling [CVS] and amniocentesis).

**Do factor levels normalise during pregnancy?**
**Factor II (two) and factor V (five)** – factor II and factor V activity doesn't change significantly during normal pregnancy and usually remains insufficient for delivery in women with severe FII and FV deficiency.

**Factor VII (seven)** – FVII activity increases in normal pregnancy; women with mild FVII deficiency may achieve FVII activity within normal range by the time of delivery. This is unlikely in women with severe FVII deficiency.

**Factor VIII (eight)** – during pregnancy, FVIII levels can increase significantly in carriers and may completely normalise in the later stages.

**Factor IX (nine)** – FIX levels don't increase during pregnancy.

**Factor X (ten)** – FX activity increases during normal pregnancy and levels usually remain insufficient for haemostasis at delivery in women with severe factor X deficiency.

**Combined factor V (five) and factor VIII (eight)** – during normal pregnancy FV remains unchanged but FVIII increases progressively.

**Fibrinogen** – fibrinogen activity increases during normal pregnancy. But this doesn't prevent potential complications such as venous thrombosis, miscarriage, antepartum haemorrhage (APH) and postpartum haemorrhage (PPH) in women with afibrinogenaemia and hypofibrinogenaemia.

If you have a bleeding disorder or are a carrier of haemophilia, you should have your factor levels checked in the third trimester of pregnancy to assess your bleeding risk during delivery and in the postpartum period.

**Caesarean or vaginal delivery**
Your doctors will discuss your delivery options with you. They will aim to avoid prolonged labour and to deliver your baby by the least traumatic method.

**Managing labour and delivery**
Managing childbirth will depend on your and your baby's needs at the time of delivery. Women with a mild bleeding disorder should have shared antenatal care between their local obstetric unit and haemophilia centre with a delivery planned at the local unit. Women with severe or rare inherited bleeding disorders and those carrying an affected, or potentially affected baby, should deliver at a hospital with an on-site haemophilia centre.

Invasive monitoring techniques (e.g. fetal scalp electrode, fetal scalp blood sampling) and instrumental deliveries (ventouse, mid cavity or rotational forceps) should be avoided in pregnancies with potentially affected babies, as serious head bleeding may result from these procedures. If your baby has been diagnosed with a bleeding disorder, a cranial ultrasound should be carried out before discharge from the hospital.

There should be a clear plan for managing labour and delivery in your case notes and you should also have a copy of the plan.

As soon as your baby is delivered, a sample of blood from the umbilical cord may be collected to measure clotting factor levels. If you are planning to have your son circumcised shortly after birth, this should be avoided until the results of these blood tests are known.

**Postpartum haemorrhage**

Women with bleeding disorders are also at risk of bleeding days after delivery. This is called secondary postpartum haemorrhage (PPH). After you have had a baby it's normal to have vaginal bleeding similar to a period. This is called a lochia and is usually red in colour for the first 1 to 2 weeks, gradually changing to dark red and lightening before completely tapering off. For some women, their lochia will decrease by 2 to 4 weeks after childbirth, but it's normal for lochia to last up to 6 weeks.

Women with inherited bleeding disorders are typically at risk of secondary PPH 2 to 3 weeks after delivery or experiencing a prolonged period of bleeding (up to 12 weeks). This is because clotting factors may increase during pregnancy and then return to their low baseline levels by 2 to 3 weeks after delivery. This return to low clotting factor levels may be accompanied by increased vaginal bleeding. If this occurs, medicine such as tranexamic acid (see page 19) may be helpful. If you are concerned about your bleeding, you should contact your obstetrician and haemophilia centre.

**Breastfeeding**

Breastfeeding increases factor VIII and von Willebrand factor (VWF) levels in response to pregnancy hormones. Women who breast feed may maintain the high hormone levels they had during pregnancy. This protects them from bleeding in the weeks following delivery.

# Section 6 – Living with a bleeding disorder

In this section we cover some of the common areas that might cause concern if you are living with a bleeding disorder such as work, exercise, dental and mental health.

## Bleeding disorders and the workplace

If you have problems with your bleeding disorder, your employer must make 'reasonable adjustments' so that you are not put at a disadvantage. This could be, for example, adjusting your working hours or giving you flexibility to allow for a treatment regime or hospital visits. Whether or not you tell your employer about a bleeding disorder is your choice, though not doing so may not be in your best interests.

If you need to take time off work for hospital, dentist or doctor's appointments, there is no automatic right to take paid time off. You should check whether there are any terms in your employment contract which allow you to take time off work in these situations and whether such time off is paid. Even if your contract doesn't cover this, your employer may still give you the time off. If not, you may have to use part of your holiday entitlement.

For advice on employment law, human resources (HR) processes and good practice at work contact the ACAS helpline on 0300 123 1100.


## Managing periods at work

Heavy menstrual bleeding affects approximately 1 in 5 women, and 43% take time off work due because of it. It's one of the most common reasons for being referred to a gynaecologist.

Heavy bleeding and painful cramps can affect how productive you feel and you might feel too unwell to go into work. Currently, there are no laws for menstruation leave in the workplace. Some workplaces in the UK have introduced their own HR policies based on employee menstrual cycles, including flexible working and an allowance for sanitary products.

Experiences of periods can be very debilitating. If you're worried about leaking, you can't concentrate on your work; you can't get up to go to meetings or to colleagues' desks because you're afraid to move in case something happens. This doesn't help productivity and adds to your stress. Having a conversation about periods at work can be daunting but can also be extremely helpful. You could ask about the possibility of flexible work depending on your needs. Possible options include:

- working from home
- staying at work with circumstances that help employees to be comfortable, such as being able to rest in a quiet area
- taking a day's paid leave.

There are lots of different resources out there, so don't be afraid to speak to a friend, family member, haemophilia centre or GP if you're finding it hard to cope. If you notice any changes to your monthly cycle, or you're finding the pain or bleeding unmanageable, make an appointment with your haemophilia centre or your GP. They can take you through different options that can help relieve your symptoms.

## Positive mental health

Having a bleeding disorder places extra demands on individuals and families. Sometimes it helps to talk to someone outside your usual circle of family and friends.

You are not alone. Everyone goes through times of stress and pressure, and everyone deals with this differently. If you're feeling the strain, ask your haemophilia centre if they can refer you for support locally. Everyone needs someone who will listen and give them extra support at different times in their life.

Haemophilia centres are increasingly taking steps to help women with bleeding disorders look after their minds as well as their bodies because doing so is likely to improve health and wellbeing for the long term. Many now have their own 'in-house' psychologists who work alongside the haemophilia doctors, nurses and physiotherapists, offering various support and 'talking therapies' which help women and their families to cope at difficult times.

There are also lots of ways you can help yourself to feel better. Try using simple techniques like relaxation and mindfulness to slow your body and mind down whenever you feel pressured. Our website has more information to help: **https://haemophilia.org.uk/support/day-day-living/positive-mental-health/**

## Exercise

Exercise and sport have many benefits for health and can improve self-esteem, learning and concentration. There are some particular benefits for women with a bleeding disorder: strong muscles, good balance and posture can help protect joints from bleeding. Maintaining a healthy weight helps to reduce stress on joints that have already been damaged by bleeding.

Your choice of activity or sport will be individual, and your haemophilia team will discuss the risks and benefits of different sports taking account of your 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 risk of bleeding. Any treatment you have can be tailored around days when you're most active so that you have maximum protection from bleeding at these times.

**Tips about exercise**

- Be ready for accidents, just in case: always have your first aid kit on hand (this might include emergency treatment product); wear a medical alert bracelet; and tell someone with you what to do if you hurt yourself.
- Treat injuries, bruising or bleeding promptly and give yourself time to recover fully.
- Common sense is very important – set your own achievable limits.

## Joint bleeds

Although it's rare, women whose conditions are severe may have joint and muscle bleeds.

Bleeding into a joint damages it. Once a joint is damaged bleeding may occur more frequently and damage can be permanent. This is known as a target joint. Minor bleeds can often be controlled with PRICE (Protection, Rest, Ice, Compression and Elevation) – see below.

You may need treatment to stop the bleeding and physiotherapy, so contact your haemophilia centre for specialist advice.

**Managing joint bleeds with PRICE**

It's very important not to ignore the signs of a joint bleed. Early treatment with factor concentrate is crucial to reduce the risk of joint damage.

Alongside the clotting factor infusion and pain relief (paracetamol), the following steps help with recovery and comfort.

- **Protection** – Try to keep the weight off the joint of muscle for a couple of days. If it's the ankle or knee, try to use crutches.
- **Rest** – Stay off it or don't use it. This helps with healing.
- **Ice** – For 10 to 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 because it can cause ice burns.
- **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.

You will come to know the sensation associated with bleeds and will usually be able to tell when you are having a bleed. If you are unsure whether you have a bleed, check with your haemophilia team. It will give you peace of mind even if you find out it was a false alarm.

## Dental care

It's essential 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.

You should:

- brush your teeth at least twice a day
- floss your teeth daily
- use toothpaste that contains fluoride
- have regular dental check-ups.

If you have a mild bleeding disorder, it's okay for you to attend your dentist for routine care such as check-ups and fillings. More invasive treatment such as having a tooth out, root canal work or gum surgery can cause prolonged or excessive bleeding.
If your local dentist plans any dental work, they must contact your haemophilia team beforehand. They can advise on any risks or precautions that need to be taken. They may ask you to take tranexamic acid (Cyklokapron) beforehand to minimise bleeding.

**Major dental surgery should be carried out in the hospital as a precaution for people with severe bleeding disorders.**

### Dental care during pregnancy

Women who are pregnant can find they bleed more from their gums, regardless of whether they have a bleeding disorder. Gingivitis (a mild form of gum disease) can cause swollen, red, tender gums that bleed when you brush or floss. So it's important to see a dentist during your pregnancy and for the first year after you have had your baby.

You are entitled to free NHS dental treatment if you are pregnant when you start your treatment and for 12 months after your baby is born. Contact your health centre as you will need to apply for a medical exemption certificate.

## Preparation before medical, surgical and dental procedures

It's important to inform your doctor, dentist or surgeon that you have a bleeding disorder before undergoing any procedures. Without proper management, wound healing may be delayed as bleeding that occurs with surgery or procedures may last much longer in people with a bleeding disorder.

Before having surgery or medical or dental treatment, talk to your haemophilia centre about what medical support you may need to prevent excessive or unnecessary bleeding from the procedure. Where possible, plan this well ahead of time.

Your haemophilia centre team may also need to liaise with the surgeon, dentist or other health professionals involved in your care to discuss the best approach for you individually and any care you may need before or after your treatment.

## Frequently asked questions

**What painkillers can I use?**

**Paracetamol** is a suitable painkiller if you have a bleeding disorder. You should talk to your haemophilia centre before taking:

- Medicines containing Aspirin
- Non-steroidal anti-inflammatory drugs (NSAIDs). Sometimes they are called 'topical non-steroidal anti-inflammatory drugs' or just 'topical anti-inflammatories'. They contain an anti-inflammatory medicine such as ibuprofen, diclofenac, felbinac, ketoprofen, piroxicam or naproxen etc. and come in various brand names.

- Pain relief gels containing NSAIDs e.g. voltarol, ibuprofen, ibuleve, nurofen, deep relief and deep heat.
- Analgesic creams, rubs, and sprays containing NSAIDs.
- Other medicines that claim to treat bleeding, bruising or improve clotting.

Before you start taking anything prescribed by your doctor or other health practitioner check with them whether it is safe for someone with a bleeding disorder. Some medicines, vitamins and supplements can interfere with blood clotting and healing or can irritate your nasal passages or stomach lining. This includes some herbal and homeopathic medicines that you can buy over the counter.

**If you are uncertain about whether any medicine may affect blood clotting, it's important to check with your haemophilia team before taking it.**

**Do I need a bleeding disorder card?**

You should always carry a 'bleeding disorder card', which is provided by your haemophilia centre. This will detail the bleeding disorder you have, treatment needed and the haemophilia centre's contact details. Haemophilia centres should be able to provide you with as many cards as you need, for example, so that one can always be left at work (with medicines if appropriate).

Not all doctors are familiar with the specific needs of women with bleeding disorders, so do not be afraid to advocate for yourself. Inform your haemophilia centre that you are attending the hospital so they can communicate with local doctors and provide advice.

**Can I have tattoos and piercings?**
If you are thinking of getting a tattoo or piercing, the type of bleeding disorder and the severity you have may mean you need treatment before and after, particularly if you have a severe bleeding disorder. Speak to your haemophilia nurse to ensure that you take the necessary precautions beforehand.

You may be discouraged from getting tattoos or piercings because of the associated medical risks, such as infection. If you decide to go ahead, it's crucial to find a reputable tattoo and piercing shop to avoid the risk of getting an infection. You should tell the person doing your piercing or tattoo that you have a bleeding disorder so they are aware of any potential complications.

There are other issues to be aware of too. Tongue, lip or cheek piercings can result in gum problems and tongue piercing can damage the enamel on your teeth. And some parts of the body take longer to heal than others – for example it can take up to a year for a belly button to heal properly following piercing. This means you are susceptible to infections for up to a year after the piercing is removed.

**I can't get a dentist locally. What should I do?**
You may face difficulty accessing dental care due to the lack of understanding by the dentist of your bleeding disorder. Some local dentists may refuse to do any major dental work because of your bleeding disorder. If this is the case, your haemophilia centre team can speak to the dentist to offer specific guidance, or they may have access to a dentist on site, or they may be able to give you details of local dentists who specialise in treating patients with a bleeding disorder. Ask your haemophilia centre for advice.

**What do I tell other doctors or dentists about my bleeding disorder?**
Bleeding disorders are relatively rare conditions. Most doctors and dentists are not familiar with the treatment and will not be aware of your individualised treatment plan. Understanding the impact of bleeding disorders on women is quite a new area and many doctors, nurses and health professionals don't know about bleeding

disorders. This can be an added challenge when you are using services outside of the haemophilia centre. Always carry your bleeding disorder card with you as this explains your diagnosis, what treatment should be given and who should be contacted for further advice.

Always tell your doctor, dentist or surgeon that you have a bleeding disorder before having any medical, dental or surgical procedures, no matter how minor.

**What are maternity exemption certificates?**
A maternity exemption certificate entitles you to free prescriptions and can be used to prove your entitlement to free NHS dental treatment. You can apply for a certificate if you are pregnant or have had a baby in the last 12 months. To apply, you need to speak to your midwife, doctor or health visitor. They will complete the application for you. You can apply as soon as they confirm that you are pregnant.

If you miscarry or your baby is stillborn, you can continue to use your certificate for free NHS prescriptions until it expires.

It's your responsibility to check the expiry date on your certificate. If you claim free prescriptions and your certificate has expired, you may have to pay a penalty charge.

# You are not alone

Many women tell us that it's helpful to talk to others in a similar situation and know that they are not alone, even though bleeding disorders may only affect them at certain times in their life.

**Talking Red** is The Haemophilia Society's campaign that urges everyone – women and men – to talk about women's bleeding.

We started the **Talking Red** to empower women, share knowledge and spread the word that help and support are out there.

Women's bleeding disorders can have a significant impact mentally, physically and financially. Yet many people still don't know that women can be affected by bleeding disorders.

Thousands of women struggle with common symptoms – such as heavy periods and frequent bruising – unaware that they can ask to be tested for a bleeding disorder. There is no cure for a genetic bleeding disorder, but there is effective treatment available. That's why it's so important to get the right diagnosis.

**"I've had to deal with very heavy periods, and so worrying about embarrassing leaking, all my life. But I just thought that that was normal."**

Talking Red

Living with a bleeding disorder can be challenging to manage and affects relationships, education and work. It can be lonely living with a condition that some people find hard to talk about.

No woman should go through this alone. **Talking Red** is here to bring people together and share knowledge and experience to empower women to get their treatment and care.

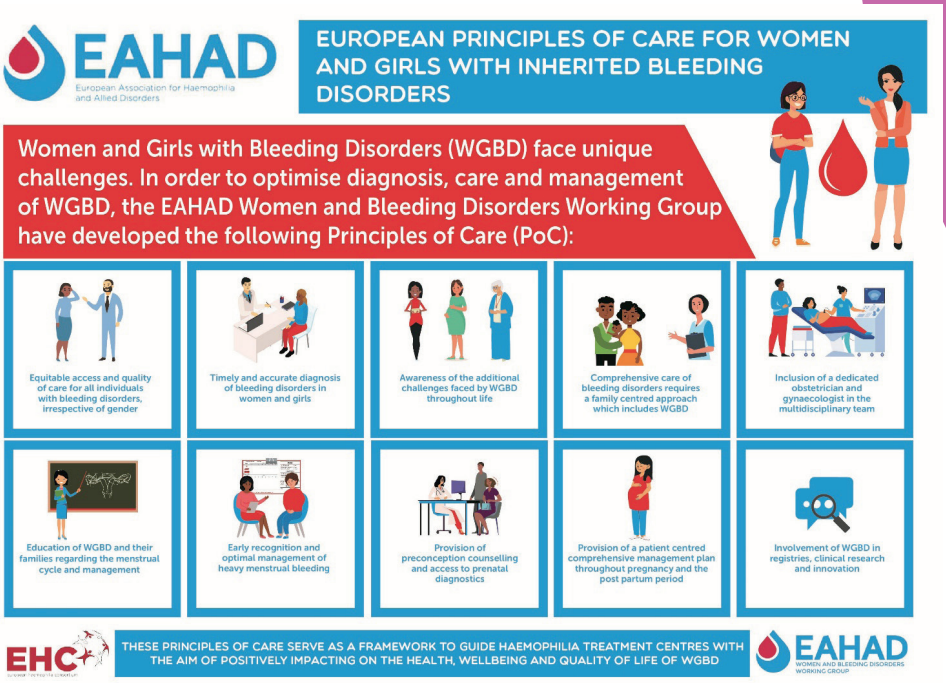
Why don't you join our community and help get everyone **Talking Red?**

**"My periods were horrific. I'd wake up stuck to the bedsheets. On days that I knew were going to be bad I wouldn't go out. My whole life revolved around my periods."**

Talking Red

# European Principles of Care for Women and Girls with Bleeding Disorders

The 10 principles of care listed below are a benchmark for diagnosis and management of women and girls with bleeding disorders. They aim to improve awareness of their unique challenges and have a positive impact on their health, wellbeing and quality of life.




You can read more about the 10 principles of care on our website at: **https://haemophilia.org.uk/bleeding-disorders/women-with-bleeding-disorders/european-principles-of-care-for-women-and-girls-with-bleeding-disorders/**

## Glossary

**Adenomyosis**
The tissue that normally lines the womb starts to grow within the muscular womb wall, making periods particularly painful.

**Bernard Soulier syndrome**
A disorder caused by a missing or non-working protein on the surface of a platelet called the glycoprotein Ib/IX/V.

**Carrier**
A person who has the gene for a condition but doesn't always have the symptoms of the condition.

**Cervix**
The lower, narrow end of the womb (uterus) that links the womb to the vagina.

**Chromosomes**
Structures made of nucleic acids and proteins found in the nucleus of a cell that carry genetic information in the form of genes.

**Dysmenorrhoea (period pain)**
Painful cramping, usually in the lower abdomen, occurring shortly before or during menstruation, or both.

**Endometriosis**
A condition where cells that normally line the womb grow in other places, such as in the fallopian tubes and ovaries. These cells can cause intense pain when they shed.

**Factor I (one) deficiency**
A bleeding disorder in which the body doesn't have enough of the blood protein fibrinogen or none at all or the protein doesn't work correctly.

**Factor II (two) deficiency**
A bleeding disorder in which the body doesn't have enough of the blood protein prothrombin or none at all or the protein doesn't work correctly.

**Factor VII (seven) deficiency**
A bleeding disorder in which the body doesn't have enough of factor VII or none at all or factor VII doesn't work correctly.

**Factor XI (eleven) deficiency**
A bleeding disorder in which the body doesn't have enough of factor XI or none at all or factor XI doesn't work correctly.

**Factor XIII (thirteen) deficiency**
A bleeding disorder in which the body doesn't have enough of factor XIII or none at all or factor XIII doesn't work correctly.

**Fallopian tube**
The part inside a woman's body that carries the eggs from the ovaries to the uterus.

**Fibroids**
Benign (non-cancerous) tumours that can grow in or around the womb and can make your periods heavy and painful.

**Glanzmann thrombasthenia**
A condition caused by a missing or non-working protein on the surface of a platelet called the glycoprotein IIb/IIIa.

**Gynaecologist**
A doctor who specialises in the female reproductive system, including menstruation (periods), reproductive medicine (fertility problems and recurrent miscarriage), contraception (birth control) and menopause.

**Gynaecology**
The care of women with problems of the female reproductive system (ovaries, tubes, womb, cervix, vagina).

**Haematologist**
A doctor who specialises in researching, diagnosing, treating and preventing blood disorders.

**Haemophilia A (factor VIII deficiency)**
A genetic disorder caused by missing or non-working factor VIII, a protein needed for the blood to clot.

**Haemophilia B (factor IX deficiency)**
A genetic disorder caused by missing or non-working protein called factor IX, making it difficult for the blood to clot. Haemophilia B is also known as factor IX (FIX) deficiency.

**Haemorrhagic ovarian cyst**
An ovarian cyst is a fluid-filled sac that develops on an ovary

**Heavy menstrual bleeding (HMB)**
Menstrual periods with abnormally heavy bleeding that limits daily activities and places women at increased risk of health problems if left untreated.

**Intrauterine system (IUS)**
A small, T-shaped plastic device that's put into your womb (uterus) by a doctor or nurse to stop you getting pregnant.

**Menstrual cup**
A small, flexible cup that is inserted into the vagina to collect period blood. Also known as a moon cup.

**Menstrual cycle**
The number of days from the start of one period to the start of the next period. On average, the menstrual cycle is 28 days but can range from 21 to 35 days.

**Menstruation**
The medical term for a period.

**Obstetrician**
A doctor who deals with problems that arise in maternity care, treating any complications of pregnancy and childbirth and any that arise after the birth. Obstetricians work alongside midwives, whose speciality is usually normal pregnancy and delivery. Obstetricians may see some women before conception to plan their pregnancy.

**Ovaries**
The part inside your body that makes eggs.

**Pelvic inflammatory disease**
A condition where the womb (uterus), fallopian tubes and ovaries become infected with bacteria, making them severely inflamed.

**Period**
The time of the month when the womb (uterus) lining sheds and blood comes out of your vagina. Normal periods usually last 2 to 7 days.

**Placenta**
An organ that develops in the womb (uterus) during pregnancy and provides a growing baby with oxygen and nutrients through the umbilical cord.

**Prophylaxis**
Treatment given or action taken to prevent illness. For bleeding disorders, this might mean having factor replacement therapy before you have a bleed or to make a bleed less serious if it does happen.

**Progestogen**
A type of medication which produces effects similar to those of the natural female sex hormone progesterone in the body.

**Vagina**
A muscular tube connecting the womb (uterus) to the outside of the body.

**von Willebrand disease (VWD)**
A disorder that is caused by a lack of or a problem with the von Willebrand factor (VWF) in the blood.

**von Willebrand factor (VWF)**
A clotting protein that helps platelets stick together to stop bleeding; factor VIII is attached to VWF.

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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.

**Your Society: getting in touch**
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