The Haemophilia Society

Understanding VWD

Contents

Introduction

This booklet is for anyone who has been diagnosed with a bleeding disorder called von Willebrand disorder (VWD) (also known as von Willebrand disease). It gives a general introduction to VWD and information on diagnosing, treating and living with the condition. There's also a helpful list of medical words in the glossary at the back of the booklet. You may also find the information useful if you are concerned that you might have a bleeding disorder.

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

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

We use the current guidelines for the diagnosis and management of bleeding disorders when producing our resources. These guidelines help improve accurate diagnosis to ensure access to care and minimise inappropriate testing and harms caused by over-diagnosis.

In 2021, 32 VWD experts worldwide, including people with VWD, created clinical practice guidelines for the diagnosis and management of Von Willebrand disorder. The diagnosis, evaluation, and management of VWD guidelines can be found on our website: haemophilia.org.uk/resources/guidelines/

Don’t suffer in silence

VWD does not discriminate. It is an inherited condition that affects both males and females. It also does not discriminate according to ethnicity. Many of our members are from varied backgrounds.

We at the Haemophilia Society understand that people with bleeding disorders within certain communities are unable to open up about their lifelong condition due to the stigma and shame attached to a disorder that can affect your or your child’s care. You mustn’t feel isolated; we are here to ensure that this does not happen, and discretion is a key foundation to our work. We have a lot of experience in dealing with these specific issues. We are here to provide the bespoke support and assistance needed for people from different backgrounds.

Sunny Maini, our UK Ambassador for VWD, suffers from Type 3 VWD. He is from an Indian background and understands the difficulties that may arise.

Please do not suffer in silence. We are here to help you.

About von Willebrand disorder (VWD)

What is VWD?

von Willebrand disorder (VWD) , also known as von Willebrand disease is a bleeding disorder. It is a common inherited condition that can sometimes cause heavy bleeding. It is caused by a deficiency of von Willebrand factor (VWF), a type of protein that helps your blood clot.

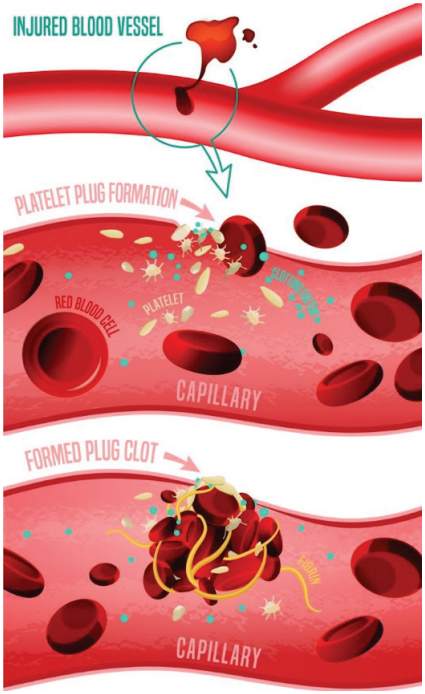
The von Willebrand factor (VWF) protein in the blood helps blood to clot. In VWD, either the level of VWF is low or the VWF does not work very well, or both. Normally, when a blood vessel is injured, you start to bleed. Small blood cells called platelets clump together to plug the hole in the blood vessel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

VWF is also responsible for carrying the blood-clotting factor called factor VIII (eight), another essential protein that helps your blood clot. Factor VIII is the protein that is missing or does not work well in people who have haemophilia, another bleeding disorder. As a result, some people with VWD also have low factor VIII levels and may share some bleeding symptoms with people who have haemophilia.

Because VWD affects the blood's ability to clot, people with the condition can bleed more than most people and have symptoms such as easy bruising, frequent or long-lasting nosebleeds or bleeding from their gums. It may also be hard to stop bleeding after an injury, dental treatment or surgery. More women than men show symptoms of VWD because of menstruation and childbirth. Men can also have serious symptoms, especially those with very low levels of VWF.

VWD affects men and women equally, from all racial backgrounds. It is the most common inherited bleeding disorder, affecting thousands of people in the UK. It is thought that around 11,100 people in the UK are registered with VWD but many more have low levels of VWF that may contribute to bleeding problems.

Although there is currently no cure for VWD, most people with VWD can live normal, active lives – the condition is mild and manageable and does not usually cause serious problems. However, people with the most severe form of the condition (type 3) have very low levels of VWF. This makes episodes of bleeding difficult to control, particularly because their factor VIII is likely to be low as well.



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 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 as a mesh to hold the platelets together and 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.

The picture on page 7 shows the stages in clot formation in a way that makes it easier to understand.

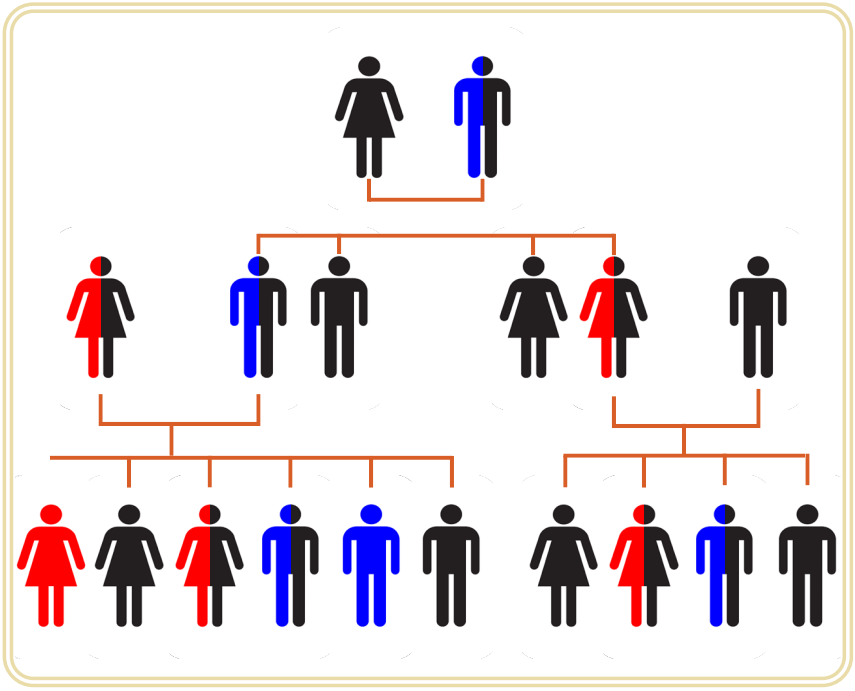
How serious is VWD?

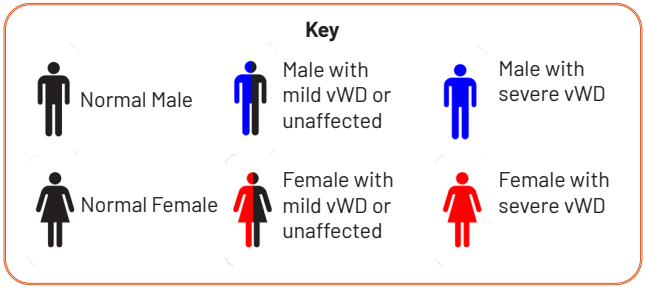
It depends on the type of VWD and the level of VWF in the person's blood. Most people have such mild symptoms that they are not aware they have the disorder. Others only realise they have a bleeding problem when they have heavy bleeding after a serious accident, dental treatment or surgery. However, all forms of VWD cause some bleeding problems.

Some people with VWD bleed quite often, e.g. with nosebleeds, bruising and heavy periods. A small number of people who have very low levels of VWF may also experience joint and muscle bleeds, similar to haemophilia.

How is VWD inherited?

VWD is caused by a mutation (change) on the gene responsible for producing von Willebrand Factor (specifically at 12p13). In most cases, this mutation is passed on from parent to child but the manner in which this occurs depends on the type of VWD. The type of VWD people are born with mostly depends on whether they inherit copies of this faulty gene from one or both parents.





The son or daughter of a parent with VWD has a 50% chance of having VWD. The 'type' of VWD indicates how the condition is passed down. In type 1 and 2, if one parent has VWD and passes it to their child, then that child will have the condition. In type 3, the child usually inherits the condition from both parents. Even if both parents have VWD, the child could get either a mild or severe form of VWD based on how the condition is passed on. People with VWD can have different experiences of bleeding, depending on their type, and even within types, some people may experience bleeding more than others.

Low von Willebrand factor (Low VWF)

Some people have low VWF levels which may contribute to bleeding but are not low enough to be called VWD. This applies to people with levels of VWF between 30–50% of normal.

VWF levels can be reduced for other reasons, such as when the body clears VWF from the blood more quickly as happens in people who have blood group O.

If you have low VWF levels and have bleeding symptoms you may need treatment if you are having a tooth taken out or an operation. However, many people with VWF in the 30-50% range do not have any bleeding problems, even after surgery.

No family history of VWD

Sometimes there is no family history of VWD. A baby can have a genetic mutation or change in one of their genes before they are born. Although their parents, brothers, and sisters do not have the VWD gene, the child will pass the VWD gene on to their children in the future.

Can you acquire VWD?

Some people develop a form of VWD later in life due to other medical problems that affect their von Willebrand factor. This is called acquired von Willebrand syndrome (AVWS) and is very rare. It can arise in a variety of ways and is suspected when a patient's bleeding symptoms and laboratory results suggest 'new onset' VWD. It can occur because of narrowing of one of the heart valves, or because of hypothyroidism (underactive thyroid gland) or myeloma (a blood

cancer). Rarely, it has been associated with drugs including sodium valproate, ciprofloxacin and griseofulvin.

AVWS will respond to treatment of the underlying cause where this is possible. People with AVWS may also be treated with VWF concentrates and desmopressin.

Types of von Willebrand disorder (VWD)

The three main types of VWD are called type 1, type 2 and type 3. Different gene faults cause each type. The severity of symptoms depends partly on the type of VWD a person has. Types 1 and 2 are generally mild, but people with type 3 VWD can have severe bleeding episodes. Even within each type of VWD, symptoms can be quite variable.

Type 1 VWD

Type 1 VWD is the commonest form of VWD. It results from simple reduction in the amount of VWF in the blood (but not a complete absence as in type 3). It varies widely in severity, from near normal to near absence of VWF. In most cases the problem is mild and bleeding is only a problem if people have surgery, injure themselves, or have a tooth removed.

People who have type 1 VWD may have low levels of factor VIII. A diagnosis of type 1 VWD is harder to establish when the VWF level is not markedly low but instead is near the lower end of the normal range.

About 3 in 4 people who have VWD have type 1.

Type 2 VWD

In people with this type of VWD, VWF does not work correctly. Bleeding tends to be more frequent and heavier than in type 1. About 1 in 4 people who have VWD have type 2.

As well as not working properly, the level of VWF may also be low and sometimes factor VIII is low too. The important difference is that the quality of the VWF is affected. This means it is less effective in helping the blood to clot.

There are four main subtypes of type 2 VWD. These are: 2A, 2B, 2M and 2N.

- **Type 2A**

The VWF multimers are too small.

- **Type 2B**

The VWF multimers are small and the VWF becomes too active. It attaches to the platelets in the blood when it is not supposed to. The body quickly gets rid of the platelets with the attached VWF. This causes a shortage of both platelets and VWF in the blood.

- **Type 2M**

Low or absent binding to a specific VWF receptor. VWF is not able to stick to the platelets. Factor VIII binds as normal.

- **Type 2N (Normandy)**

Factor VIII levels reduced to 5-25%, as VWF has a reduced affinity to factor VIII.

Type 3 VWD

This is the most severe and rarest type, affecting about 1 in 500,000 people.

People who have type 3 VWD have virtually no VWF. If you have this type, your body will not produce any VWF, or only very small amounts. As a result, your platelets will not be able to form a clot and your factor VIII levels will be low as well.

This will put you at risk of severe bleeding that is difficult to stop. Bleeding from the mouth, nose and gut is common, and joint and muscle bleeds can occur after an injury.

Signs and symptoms of VWD

Sometimes VWD will show up when the person is a child. Others don't find out until they are adults and have a bleeding problem, or until a relative is diagnosed and it is suggested that they are tested as well.

Many people have such mild symptoms in day-to-day life that they do not know they have VWD. In many cases, the condition is so mild that there are no noticeable signs or symptoms until the problem is revealed through an accident or surgery. Other people have frequent and heavy bleeding that affects their everyday life and need regular treatment to manage their condition.

The symptoms of VWD vary greatly from person to person. Even members of the same family may have different symptoms. Women are more likely to show symptoms of VWD than men.

Type 1 or type 2 VWD or Low VWF

When you have VWD, bleeding can stop and start over a number of days. It may not seem to be a lot at any one time, but it can be excessive over several days.

Common symptoms include:

- frequent large bruises from minor bumps or injuries, particularly on the arms and legs
- frequent or hard to stop nosebleeds
- prolonged bleeding from gums after dental procedures
- heavy or prolonged bleeding from a cut
- prolonged or heavy bleeding after injury
- bleeding after surgery

Bleeding in people with VWD usually involves the mucous membranes, the delicate tissues that line body passages such as the nose, mouth, uterus (womb), vagina, stomach and intestines.

More serious, but uncommon complications can include:

- gastrointestinal bleeding
- blood in faeces (bowel motions/poo) from bleeding in the intestines or stomach
- blood in urine from bleeding in the kidneys or bladder
- solid swellings of congealed blood (hematomas)
- bleeding into the muscle and joints (haemarthrosis), which can cause progressive joint damage and degeneration. Eventually, in these cases, there may be a limit the range of motion of an affected joint.

Also for women:

- heavy bleeding after childbirth.
- heavy or prolonged menstrual bleeding (periods).

Type 3 VWD

People who have type 3 VWD may have any of the symptoms listed above. They may also have bleeding into muscles or joints. Bleeding may happen for no obvious reason; this is called spontaneous bleeding.

The symptoms a person with VWD experiences can change over their lifetime.

For example, they may have nosebleeds and easy bruising as a child and find this occurs less often as they grow older. However, their type of VWD will not change.

Anaemia and VWD

Excessive bleeding and heavy periods can lead to anaemia (low levels of red blood cells). Blood contains iron, so the blood loss can cause the body to lose iron.

Diet is important to help with anaemia. Eat plenty of iron (e.g. red meat and green vegetables) or take iron supplements to keep your iron level up. If your diet is partly causing your iron deficiency anaemia, try to eat more foods that are rich in iron, e.g.:

- dark-green leafy vegetables like watercress and curly kale
- cereals and bread with extra iron in them (fortified)
- red meat
- dried fruit like apricots, prunes and raisins
- pulses (beans, peas and lentils).

If this persists, speak to your GP or haemophilia team for prescribed tablets as these are stronger than the supplements you can buy in chemists and supermarkets. You may need to take supplements for up to six months.

If you are not sure if you have VWD but have one or more of the symptoms listed, you should see your GP. It may be helpful to take this booklet with you.

Diagnosing VWD

Because symptoms can be mild, VWD often goes undetected and because it fluctuates in the blood it may require a couple of tests to be sure of the diagnosis. Most GPs will not have met anyone with VWD, so getting a diagnosis can take persistence, repeated visits and referral to a hospital. Your diagnosis will usually take place in a haemophilia comprehensive care centre or a haemophilia treatment centre, where you will see a haematologist (doctor specialising in blood disorders) or a specialist haemophilia nurse.

How is VWD diagnosed?

VWD is often hard to diagnose and usually involves a couple of visits to a haemophilia centre for repeat tests.

People with type 1 or type 2 VWD may not have day-to-day bleeding problems. This means it is quite common for people not to be diagnosed until they have heavy bleeding after surgery, dental treatment or injury. For women, giving birth may be the first time that VWD is suspected.

Type 3 VWD can cause major bleeding problems in babies and children. This means people with type 3 VWD are usually diagnosed during their childhood.

Diagnosing VWD involves:

- a personal history of bleeding or bruising more than normal
- a family history of bleeding more than normal
- specialised laboratory test results for VWD.

A clinical history of which symptoms are present and when will also help with the diagnosis. At your appointment with the haemophilia doctor, you may be asked questions such as:

- Do you have a blood relative with a bleeding disorder, such as VWD or haemophilia?
- Have you ever had prolonged bleeding from minor wounds, lasting more than 15 minutes or recurring spontaneously during the seven days after the injury?
- Have you ever had heavy, prolonged, or recurrent bleeding after surgery, such as having your tonsils out?
- Have you ever had bruising, with minimal or no apparent injury, especially if you could feel a lump under the bruise?
- Have you ever had a spontaneous nosebleed that needed more than 10 minutes to stop or needed medical attention?
- Have you ever had heavy, prolonged, or recurrent bleeding after having a tooth out that needed medical attention?
- Have you ever had blood in your stool (poo) that couldn't be explained by a specific condition (such as an ulcer in the stomach, or a polyp in the colon), that needed medical attention?
- Have you used any medicines that might cause bleeding or increase the amount of bleeding; like non-steroidal anti-inflammatory drugs (NSAID's some examples e.g. Aspirin, Nurofen, Naproxen and Diclofenac).
- Have you ever had anaemia needing treatment or had a blood transfusion?

- For women, have you ever had heavy periods, with clots larger than an inch in diameter and/or changing a pad or tampon more than hourly, or resulting in anaemia or low iron level? You could even take your results from the Talking Red symptom tracker with you (see below).

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 and girls 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 get the right treatment.

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

Physical examination

Your doctor may examine you to look for any unusual bruising or recent bleeding.

Blood tests for VWD

The diagnosis of VWD can be complex and no single diagnostic laboratory test is available. Diagnostic testing to confirm VWD may have to be repeated because levels of VWF fluctuate and having these tests more than once to confirm or exclude a diagnosis is vital.

VWD can only be diagnosed with specialised blood tests. Your doctor will need to collect a sample of your blood, which they will send to a laboratory for testing. Due to the specialised nature of these tests, it may take up to two or three weeks to get your results. Many people need multiple tests over a period of time to make a clear diagnosis, including which type of VWD they have.

Your doctor may request several laboratory tests on blood samples:

- **von Willebrand factor (VWF) antigen:** to measure the amount of von Willebrand factor in your blood.
- **von Willebrand factor ristocetin cofactor activity and/or the collagen binding assay:** to show how well the von Willebrand factor works.
- **Factor VIII clotting activity:** to measure how well the von Willebrand factor (VWF) binds to the factor VIII protein and maintains the level of factor VIII in the blood. Some people with VWD have low levels of factor VIII, while others have normal levels.
- **von Willebrand factor multimers:** if some tests suggest you have VWD, this test is used to show the make-up or structure of the von Willebrand factor and helps to diagnose the type of VWD.
- **Platelet function test:** to measure how well your platelets are working.

Routine blood tests often give normal results, which is why the person's history of bleeding is so important. Testing is often repeated because a person's VWF and factor VIII levels can vary at different times. For example, several common experiences can cause the level of VWF to rise in the blood and appear to be normal:

- stress (such as struggling or crying in children or anxiety in adults)
- exercise
- pregnancy
- normal hormonal changes during a woman's monthly menstrual cycle
- hormone treatment.

People with type O blood often have lower levels of VWF.

Family screening

After the diagnosis of VWD has been made, testing should be offered to first-degree relatives (with or without a positive bleeding history).

Recognising the signs of a bleed

Whether you have a mild, moderate or severe VWD, it is important that you know the signs of a bleed so you can spot it quickly, get the right treatment and minimise any complications. People with mild VWD 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.

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 stool 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 or kidney bleeds

Bright blood in the urine is easy to see. But a more minor bleed may make the urine 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 (for more than 24 hours), feel or be 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.

Joint bleeds

Joint bleeds are uncommon. When they occur the elbows, knees and ankles are more frequently affected, 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.

Self-management

All bleeding and bruising should be dealt with promptly to make sure no permanent injuries result. Some minor bleeding episodes can be managed at home without a visit to the doctor. It is important to know how to treat yourself or your child correctly for bleeds and injuries until you can get expert help – see Standard first aid techniques on page 45. Talk to your haemophilia centre team for advice on what would work best for you or your child.

Preparation before medical, surgical and dental procedures

It's important to tell your doctor, dentist or surgeon that you have VWD 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 VWD.

Before having surgery or medical or dental procedures, consult with your haemophilia centre so that you can discuss the 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 healthcare professionals involved in your care to discuss the best approach for you individually and any pre- or post-treatment care you may need.

How is VWD treated?

The recommended treatment for VWD can depend on the type of VWD you have and how severe it is. Usually, people with mild VWD will only need treatment if they have surgery, dental treatment or an accident or injury. Minor bleeds such as nosebleeds, bruises and minor cuts can often be controlled using simple first aid measures (see page 45).

If you need treatment, there are several available. The particular treatment used will depend on your medical needs, what works best for you, and the situation. Your haematologist will consider all of this when they talk with you to decide the best treatment option.

It is important you contact your haemophilia centre for advice before treatment if you:

- need to have a tooth out
- need intramuscular injections
- need surgery
- are injured.

Also for women, if you:

- are pregnant
- are having a hysterectomy.

Treatment options are:

- desmopressin (DDAVP)
- tranexamic acid (Cyklokapron)
- factor replacement therapy.

Also for women:

- hormonal contraceptives
- intrauterine system (IUS)
- surgery.

Desmopressin (DDAVP®)

DDAVP® is a synthetic drug modelled on a hormone found normally in the body. It is not used in children under two years old as it can cause fluid retention that is hard to control.

How does it work?

DDAVP® stimulates release of your own clotting factors (factor VIII and VWF) from storage sites in the body into the blood. Levels of the clotting factors are increased by three to six times your baseline level for 12-24 hours. If necessary, you may have a repeat dose after 24 hours.

DDAVP® trial

As some people do not respond to DDAVP® you will need to have a trial infusion. This is to see how well you respond to the treatment before it is needed for a bleeding episode or an emergency.

You are given a dose of DDAVP® and then blood samples are taken at set time points after the injection for up to six hours. Occasionally a blood test will be needed on the following day. This helps the doctors understand how your body responds to the drug.

The response to DDAVP® will be reported as one of the three following categories:

- DDAVP® responsive: DDAVP® is the treatment of choice for all procedures and bleeding episodes except major surgery or injury.
- Partial response: DDAVP® can be used only for minor procedures and minor bleeding episodes. An alternative treatment will be necessary for major procedures and major bleeding episodes.

- No response: an alternative treatment will be necessary for all procedures and all bleeding episodes.

How is DDAVP® given?

DDAVP® can be given:

- by intravenous infusion (a drip into a vein) over 30 minutes to an hour
- as an injection under the skin (tummies and thighs can be good places for this; the needles are similar to those used by people with diabetes)
- in a nasal spray. (Always use desmopressin nasal spray exactly as your doctor has told you.)

Your haemophilia centre will advise which method is best for you.

Before you have DDAVP®

It is important you tell your nurse or doctor the following before you have DDAVP®:

- if you have any known reaction to this or any other medication
- if you take diuretics (drugs that increase urine production), medication for high blood pressure or any other medicines, including over-the-counter medicines and herbal remedies
- if you are pregnant or breastfeeding
- if you have any significant medical problems including heart disease, kidney disease, cystic fibrosis, epilepsy.

Side effects of DDAVP®

Occasional side effects of DDAVP® include:

- headache
- facial flushing
- stomach pain and nausea (feeling sick)
- allergic reactions
- decrease in blood pressure
- increase in heart rate.

Treatment with DDAVP® without reducing fluid intake may lead to fluid retention (see below) and dilution of salt in the blood. Very occasionally, in more severe cases it can lead to epileptic seizures. If these side effects occur, your doctor may advise an alternative treatment to DDAVP®.

Fluid intake

As DDAVP® can cause the body to retain fluid you will be asked to restrict fluid intake after having the drug. Your haemophilia centre will advise you on how much you should drink.

Adults should not drink more than 1 to 1.5 litres (approximately 8 to 10 cups) in the 24 hours following DDAVP®. Children should only drink 75% of normal daily fluid requirement in the 24 hours following DDAVP®.

You will pass less urine in the 24 hours after the infusion. If you find you are passing little urine in 24 hours following the DDAVP® treatment you should contact your haemophilia centre.

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).

A liquid form is also available for children, though you will usually need to get this from your 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 VWF replacement therapy. Tranexamic acid does not help to form a clot.

This means it cannot be used instead of DDAVP® or factor VIII/VWF replacement therapy, 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 stools)
- stomach pain

Factor replacement therapy

People can be given VWF replacement into a vein to replace the missing VWF and allow clotting to take place.

There are two types of factor replacement available for VWD. The first is made from pooled human plasma, first screened for blood-borne viruses such as HIV and hepatitis and also treated to destroy viruses. This also contains FVIII.

The newest option is recombinant VWF (rVWF) which is engineered in a laboratory. The type of product used can depend on the type of bleeding that you are being treated for, as well as the type of VWD you have.

Your haemophilia centre will advise you which product is used to treat your condition.

Hormonal contraceptive therapy

Heavy or prolonged menstrual bleeding is often the main bleeding symptom in women who have VWD. However, it may be a sign of a gynaecological disorder rather than VWD. Therefore, a complete gynaecological evaluation is needed before hormonal contraceptive therapy is started.

Hormonal contraceptives reduce menstrual bleeding by thinning the lining of the womb (endometrium) and possibly increasing FVIII and VWF levels. They have an added advantage of controlling ovulation bleeding and mid-cycle pain. For any woman who doesn't want to get pregnant but may wish to in future, hormonal contraceptives should be the first treatment choice.

Hormonal contraceptives currently available include the combined oral contraceptive pill (COC), progesterone-only contraception (mini-pill or implant) and transdermal contraceptive patches.

Most women and girls who use hormonal contraceptives have very few or no side effects.

- Side effects can include nausea, headaches, dizziness, breast tenderness and mood changes. Some of these side effects improve over the first three months. If the side effects continue, your doctor may prescribe a different brand of hormonal contraceptive.
- Though rare, serious side effects of hormonal contraceptives include high blood pressure, liver abnormalities and clots. Women with inherited bleeding disorders may have a lower risk of clotting.

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 cause some erratic bleeding at first but this device lasts for up to five years. This is sometimes put in under anaesthetic, depending on your age and whether you have had a baby.

Advantages

- The IUS can be inserted by a doctor or nurse in a clinic and does not require an operation.
- The IUS is an effective method of birth control, though you can still get pregnant after it is 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 three to six months after insertion.

Special issues for men

Circumcision

Circumcision is the surgical removal of the skin covering the tip of the penis. It is quite a common procedure and may be done for medical, social, cultural, personal or religious reasons. It is often the earliest surgery performed in a boy's life and may lead to a diagnosis of VWD.

Circumcision is associated with complications including prolonged bleeding, infection and delayed skin healing. Some males will bleed when stitches are removed. Early diagnosis and treatment are key to stop bleeding. Baby boys with a family history of VWD should not be circumcised until a treatment plan has been discussed with the haemophilia centre team.

Special issues for women and girls

Women with VWD tend to have more symptoms than men because of menstruation and childbirth. Without treatment, women and girls with VWD often have longer or heavier periods. Some women with VWD also have heavy bleeding a few days or weeks after having a baby and some have a lot of period pain or irregular periods. These symptoms are not always related to VWD and may have other causes. An assessment by a gynaecologist is an important part of understanding and treating these symptoms effectively.

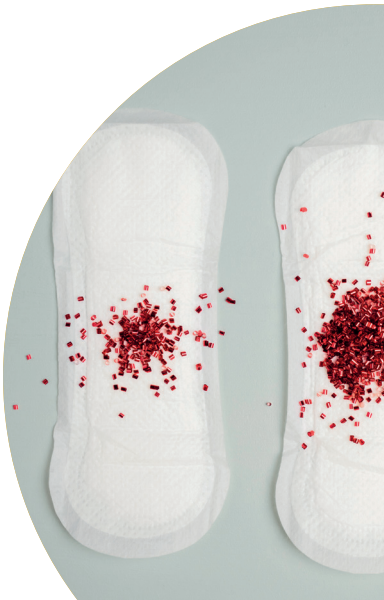
Periods

Periods can be especially heavy when a girl first starts having them. When a girl knows she has VWD or there is a family history of VWD, she should be followed closely by her medical team during puberty and may need treatment if she has heavy bleeding.

Women with VWD often have heavier and/or longer periods. This can cause anaemia (low levels of red blood cells), which can lead to weakness and fatigue. Women with VWD should be checked regularly for anaemia.

You may find it difficult to know if your periods are heavier or longer than normal. Comparing yourself to other women or girls in your family can be misleading, as they may also have VWD without knowing it. These signs may be useful in assessing a potential problem:

- Bleeding that lasts longer than seven days.
- Bleeding that affects daily life, such as bleeding so heavily that you don't want to leave the house or worry about flooding and it showing through your clothes.



- Tiredness and lethargy (lack of energy) or shortness of breath due to anaemia caused by heavy bleeding.

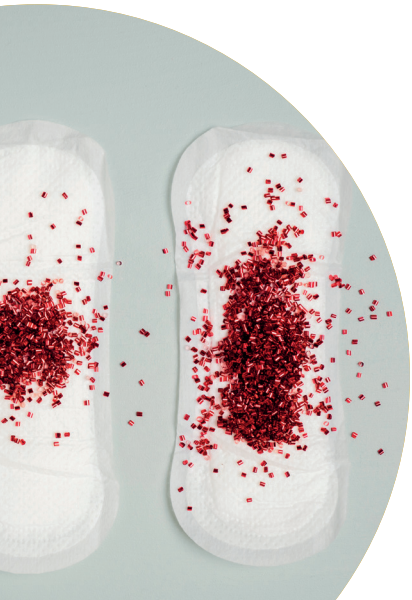
You don't need to just accept that you have heavy periods and adapt your life to fit around them, as treatment is available. Talk to your haemophilia centre as oral contraceptives, other hormone therapy and anti-fibrinolytic drugs can all be effective (see page 27).

Dysmenorrhea and mid-cycle pain

Some women and girls with VWD have pain during their periods. This is called dysmenorrhea. Dysmenorrhea is usually worse in women and girls who have heavy periods, such as those with VWD. They can also have pain at mid-cycle when they ovulate. With ovulation slight bleeding of the ovary is common.

Endometriosis

Some women may have a separate condition called endometriosis. This is where endometrial tissue (tissue that's like the lining of the womb) forms outside the uterus (womb), for example, around the abdomen. When a woman has a period, endometrial tissue, wherever it is in the body, bleeds. If these women also have VWD, the bleeding may be heavy.



The blood can irritate the abdominal wall, causing pain. Typically, this pain starts a few days before a period starts. You may also have heavy periods. You might use lots of pads or tampons, or you may bleed through your clothes. Endometriosis can affect women of any age. It's a long-term condition that can have a significant impact on your life, but there are treatments that can help.

Sexual intercourse

Some women with VWD may experience bleeding if there are small tears in their vagina after sexual intercourse. This can happen during their first sexual experience when the hymen is broken. It can also occur after childbirth and menopause when the vaginal wall may be thinner and dryer due to a drop in oestrogen levels. Oestrogen creams for the vaginal wall and/or lubricants can help with this.

Pregnancy

You can have children if you have VWD, even if it is severe, although there is risk of your child being born with VWD and/or you having heavy bleeding during or after labour. Talk to your haemophilia centre doctor about your VWD before you get pregnant.

As soon as you know you are pregnant, contact your haemophilia centre. You should be monitored closely throughout your pregnancy by your obstetrician (doctor specialising in pregnancy and childbirth) under the guidance of your haemophilia centre.

Working together in this way will help the doctor who delivers your baby take special safety measures to avoid injury. These safety measures include not using forceps or a vacuum extractor to assist in the delivery of your baby, if possible.

During pregnancy, women experience an increase in VWF and FVIII levels. This provides better protection from bleeding during delivery. However, after delivery, these clotting factor levels fall quickly and bleeding can continue for longer than normal.

Women with Type 3 VWD seem to have more frequent miscarriages, especially in the first trimester of pregnancy. However, it is possible that these miscarriages are simply more noticeable in women with VWD, because there is more bleeding. Bleeding after miscarriage can also be more severe for women with VWD.

Labour and delivery

It is important for the doctors and midwives looking after you to be aware of your VWD; not just for your sake but for your baby's too. It should be assumed that the baby may have VWD and delivery methods should be as gentle as possible. It is also important that everyone knows about your VWD if you need a caesarean delivery. Women with VWD whose VWF does not rise to normal levels during pregnancy will need specialist assessment and multidisciplinary team management.

If you continue to bleed heavily during the days and weeks after the birth, you should remind your midwife or health visitor about your VWD and seek treatment. Remember that most healthcare professionals may be unfamiliar with VWD. Always let your haemophilia centre know if you are pregnant or are experiencing bleeding so that they can advise the team looking after you about the risks and how best to care for you both. It is important not to presume your maternity team have contacted your haemophilia team, even if they're based in the same hospital, as this can sometimes be missed.

We have more information about women's issues in our Women and bleeding disorders booklet.

VWD and your child

Finding out your child has VWD can leave you feeling shocked and overwhelmed. You may experience many different feelings, including worry and sadness, and you may wonder how you will cope. There's also a lot of information to take in, often all at the same time, about their condition and treatment. You may find it useful to write down questions that you want to ask at your next haemophilia centre appointment.

Your haemophilia centre team know that this learning takes time and will help you to prioritise the most important information. For example, at first you really need to know the main signs of bleeding that you should be looking out for and who to contact for advice, day and night.

With time and experience, you will soon learn to recognise the signs of bleeding and judge what to do, though the haemophilia centre team is always there to offer support.

It's important to remember that with modern treatment a child with a bleeding disorder like VWD has every chance of growing up as an active, fit child who can participate fully in family, school and working life. It's also important to remember that your child's siblings can feel they aren't getting as much attention, and can become distressed, angry or isolated, so they need to feel included and able to have time with you too.

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

Children and young people with VWD need lifelong monitoring and treatment, so as your child approaches their teenage years, your haemophilia centre team will start to talk to them about getting ready to move on to adult health services.

This is a planned process so that they become more independent as they grow older and able to manage their own health.

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

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

Educating your child about VWD

Involving your child in learning about their bleeding disorder is an important part of their growth and development. As your child grows up, you can teach them about their type of VWD, the treatment they use, medicines they should avoid, when to seek treatment, how VWD is inherited/passed on, and how to speak out and get help to achieve what they need.

The type of information and how you teach it will depend on their stage of development – your haemophilia centre can help you with this.

It will be a gradual learning process throughout their childhood, which gives them an opportunity to understand and adapt to their VWD and take responsibility for managing their bleeding disorder.

When they reach adulthood and take on the management of their own health, they will then have enough information and the confidence to make independent decisions about their health and life choices.

VWD and school

Starting or changing school, whether it is nursery, primary or secondary school, can be a daunting time for any parent.

As a parent of a child with VWD, you will put lots of effort into coordinating and planning for both the obvious and the unexpected, working hard to maintain as normal a life as possible. You will also recognise that while your child is at school, you have to let someone else monitor and support their needs in relation to their VWD.

Most school staff will never have come across a child with a bleeding disorder and will need guidance and support to feel confident in meeting their needs. Schools are busy and dynamic places, but it is important that several people within the school understand the needs of your child, so there will always be someone available if your child needs help and support.

As the parent, you – and often your child too – are the experts, so talk to the school about your child and how their VWF affects them. It might help the school to know that:

- Children with bleeding disorders like to be treated as 'normal' at school especially when with friends.
- They will be able to participate in most of the same activities as other children.
- Many have had their bleeding disorder diagnosed since birth and have had time to be aware of their disorder.
- Older children should be able to identify if they are having a bleed even before any symptoms are detected.
- The haemophilia centre team can provide advice and support. The haemophilia nurse will liaise with the school and can visit in person to provide advice in developing a care plan if requested. This can be particularly helpful in ensuring everyone is confident in what to do.

You can also give the school a copy of our Bleeding disorders and school booklet, which concentrates on the most common bleeding disorders: haemophilia and VWD. The information in the booklet aims to help teachers and parents create an appropriate care plan to meet the specific needs of a child with a bleeding disorder. The desired outcome is happy, healthy and safe children and confident teaching staff who know enough to act appropriately and seek advice when they need to.

We have more information on bleeding disorders and school on our website:
For parents
haemophilia.org.uk/support/school/parents/
For teachers and carers
haemophilia.org.uk/support/school/teachers-and-carers

Living with VWD

Tell your doctor, dentist, pharmacist and other health professionals that you have VWD. Many health professionals will not know anything about VWD as it is a rare disease, so having some information to give them or asking them to contact your haemophilia centre is a good idea. Your dentist can ask your haemophilia centre whether you need treatment before dental work to reduce bleeding.

You also may want to tell other people about your condition, like an occupational health nurse or sports coach. Anyone who cares for a child with VWD (e.g. teachers, childminders, nursery staff) should be told about the condition. This will allow them to act quickly and appropriately if you or your child has an injury. It can be helpful to explain that you have a full understanding of your or your child's VWD and are competent in managing it in daily life.

Consider wearing a medical ID bracelet or necklace if you have a serious form of VWD (e.g. type 3). In case of a serious accident or injury, the healthcare team treating you will then know straightaway that you have VWD.

Do I need to tell others?

There is no single answer to this question. It depends on a number of factors, including:

- the age of the person with VWD and whether they can look after themselves
- how severe the symptoms are
- relationship to the person with VWD

Generally, those taking responsibility for someone with VWD (babysitters, sports coaches, carers, etc.) need to know what to do in case of bleeding. If bleeding symptoms are extremely rare or the person can take care of any problems themselves, telling them may not be necessary.

Consider whether you might want to tell your work manager, close friends or travelling companions in case of an emergency.

If the question is asked on an insurance form you must answer it. This could mean you are refused insurance or have to pay a higher premium.

Parents have occasionally been suspected of child abuse when their child has bad bruises because of a bleeding disorder. Being open in talking matter-of-factly about VWD with babysitters, neighbours and others may lessen the chance of this happening. It is a good idea to let health professionals and key school staff know as they are obliged to report suspected child abuse.

Positive mental health

Having VWD places extra demands on people and families. Sometimes, it helps to talk to someone outside of your usual circle of family and friends.

You are not alone. Everyone goes through times of stress and pressure, and we all deal with this differently. However, 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 throughout different times in their life.

Haemophilia centres are increasingly taking steps to help people with a bleeding disorder look after their minds and 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 children, adults, individuals and families to cope at difficult times.

There are also lots of ways you can help yourself to feel better, 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: **haemophilia.org.uk/support/day-day-living/positive-mental-health/**

Medication to be avoided

Some medicines, vitamins and herbs interfere with clotting and may delay healing. If you have VWD, talk to your haematologist before taking:

- Medicines containing aspirin.
- Non-steroidal anti-inflammatory drugs (NSAIDs), unless prescribed by a doctor with expertise in VWD. Examples are ibuprofen, indomethacin and naproxen – these have many brand names, so ask your pharmacist to check.
- Blood thinners such as warfarin and heparin.
- Capsules of fish oil containing omega-3 fatty acids. (Eating fish as part of your diet should not cause a problem.)
- Herbal or homeopathic medicines that affect platelet function or clotting, such as ginkgo biloba, ginger, ginseng and chondroitin.
- Other medicines that claim to treat bleeding, bruising or improve clotting.

Also check with your doctor when starting new medicines that could irritate your mucous membranes such as your nasal passages or stomach lining – any bleeding could be complicated by VWD.

Exercise

It's a really good idea to keep fit and active. People with VWD generally have to find out what physical activities they can and can't do. Many people with VWD participate in all kinds of sports, including active sports like football and tag rugby.

Talk to your haemophilia centre if you are thinking about a new sport. If you are starting a new exercise programme, slowly build up and if necessary, discuss more intense programmes with your haemophilia centre.

As a parent, it's important to think about what activities are safe for your child. As your child grows up, they will want to take part in the same sports as their friends. Your haemophilia centre will discuss the risks and benefits of different sports taking account of your child's condition.

In general, sports involving a lot of physical contact and those where head and neck injuries occur carry the highest risk of injury and therefore risk of bleeding should be avoided. If you child is on treatment for VWD this can be tailored around days of highest activity so that there is 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 are injured.
- Treat injuries, bruising or bleeding promptly and give yourself time to recover fully.
- Common sense is very important – children need to understand what VWD is all about and realise they have to set their own limits as their parents will not always be watching over them.

Dental care

It's important that you take good care of your teeth and gums to reduce the chance of future problems such as extractions or mouth infections, which can lead to further problems. You should visit your dentist at least twice a year for advice on interventions such as fluoride treatments and fissure sealants (special coatings on the teeth) to prevent dental problems.

Dental procedure treatment options will depend on the type of VWD you have and the severity. A treatment plan prior to any dental procedures will focus on your bleeding management strategies. Your dentist will liaise with your haemophilia centre to discuss how to minimise a bleed during and after dental procedures. Following dental extractions your dentist may use oxidized cellulose and stitches to aid clotting.

College or work

Most young people with VWD will go through school much as the rest of their peer group. This means that choosing to go to college or out to work won't be any different either. College or a job brings new friends and workmates, employers and tutors.

As a young person with VWD, you have to decide who to tell and what to tell them about VWD. This can be daunting – you may be worried that you will be treated differently if people know.

This is an individual decision which means thinking about whether telling someone will make life easier or more difficult. It can be helpful to know there is some support and understanding if you have a bleed. If people don't know, it's worth considering how they will react if they find out later, or from someone else.

Most people won't know much about VWD, so it can take time to explain and deal with their concerns. You may find it helpful to have some accurate written information to give them or refer them to our website.

Career choices

Having a bleeding disorder like VWD brings risks; you might not want to take on a physically demanding career role that causes you to have more bleeds.

Think about if the work is physically demanding and will put more stress on your joints, such as jobs that involve a lot of heavy lifting or bending.

It's important to think carefully about how your VWD may affect your chosen career and vice-versa, not just now but in the years to come.

Some institutions and professions still limit access to some career paths by restrictive recruitment requirements, including the armed forces, police, front-line prison service, airline pilot, or lifeboat volunteer. Depending how severe your VWD is and how it affects your day-to-day life, there may be barriers to pursuing certain career paths.

You will need to think laterally; we have members working in the prison service as a facilities manager and the fire service in an office/risk management role. These employers decide on a case by case basis, rather than having a blanket exclusion policy, as with the armed forces.

There is also more information on our website about career choices:
haemophilia.org.uk/support/day-day-living/career-choices/

Travel

Travelling is an excellent opportunity for activity and adventure. It can be much more enjoyable if you are prepared for all eventualities – pre-planning can make all the difference. If you plan to travel, it is essential to find out the contact details of the haemophilia treatment centres near where you are travelling. Information is available from your haemophilia centre, the World Federation of Hemophilia (wfh.org), or on our website. Make sure you take up-to-date written medical information with you, including your diagnosis and the name and phone number of your haemophilia centre.

It is very important to have travel insurance that covers your VWD. You may find our travel insurance factsheet helpful – find it on our website together with lots of other top travel tips: **haemophilia.org.uk/support/day-day-living/travel/**

Standard first aid techniques

- Bruising easily is common with VWD. Small bruises may look lumpy and unattractive but are not serious and usually fade over a few weeks.
- Larger bruises or minor bleeding into muscles and joints can often be controlled by applying a cold pack (e.g., an ice pack wrapped in a towel or a cool relief gel) and elevating the leg or arm. Apply the cold pack for about 10-15 minutes, then remove and reapply every two hours or so
- Bleeding from minor cuts can be stopped by applying pressure and keeping the cut dry until healed.
- To treat a nosebleed, sit upright and pinch your nostrils together below the bridge of the nose in the soft tissue for 10-15 minutes. If the bleeding doesn't stop, repeat this a second time. Try to remain calm. A cold cloth on the back of the neck or on the bridge of the nose may also help.
- Drinking hot liquids, hot baths/showers, swimming and strenuous exercise can cause nosebleeds to restart. Avoid hot soup and drinks, and lifting and straining for 24 hours after a nosebleed.
- Bleeds in the mouth or tongue can be treated at home with tranexamic acid. This is available on prescription from your doctor.

If you are at all uncertain about when or how to treat bleeding, contact your haemophilia centre team.

When to seek medical attention

In general, seek medical attention if:

- The nostril pinching procedure doesn't stop a nosebleed and severe bleeding continues for more than 20-30 minutes.
- There is blood in the urine or stools (poo).
- Bleeding is excessive or lasts for hours.
- There are broken bones.
- There are cuts that do not stop bleeding with pressure and may need stitches.
- There is a suspected bleed into a muscle or joint.
- There has been a blow to the head or a head injury.

Glossary

Acquired
Acquired bleeding is not inherited, or passed through families, like most bleeding disorders.

Comprehensive care
A way of giving health care in which a team of professionals works with the patient to improve his or her physical, emotional, and mental wellbeing. The care is usually given in one place; either at a haemophilia comprehensive care centre (HCCC) or haemophilia treatment centre (HTC), so the experts can work together.

Factor VIII (Factor 8)
One of the clotting factors that is essential to prevent bleeding. The clotting factor protein that is decreased in people with haemophilia A.

Factor VIII clotting activity
Shows whether you have abnormally low levels and activity of factor VIII.

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

First-degree relative
A person's parent, sibling, or child.

Fissure sealant
A protective layer that keeps food and bacteria from getting stuck in the tiny grooves in the teeth.

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

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

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

Joint
The place where two or more bones come together.

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 technical term for a period.

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

Menorrhagia
Heavy or prolonged menstrual bleeding.

Multimers
The form in which VWF is circulated in the blood. Formed by many von Willebrand factor protein units joined together.

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.

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

Platelet function tests
Determine how well the platelets work.

Ristocetin cofactor activity
This test is used to evaluate the function of the protein von Willebrand factor (VWF), which helps blood to clot.

von Willebrand factor antigen
Determines the level of von Willebrand factor (VWF) in your blood by measuring the amount of protein.

von Willebrand factor activity
A variety of tests to measure how well the von Willebrand factor (VWF) works in your clotting process.

von Willebrand factor multimers
Evaluates the structure of von Willebrand factor (VWF) in your blood. This information helps identify the type of von Willebrand disease you have.

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.

About the Haemophilia Society (THS)

We are the only UK-wide charity and free membership organisation for everyone affected by a genetic bleeding disorder.

We aim to empower people affected by a bleeding disorder to live life to the fullest; offering support, including events and local groups, the latest news and in-depth information resources, and campaigning and advocacy to demand the best possible care, safe and effective treatment, and equitable access for everyone affected by a bleeding disorder.

There are over 4,500 members of the Haemophilia Society, including people and families living with bleeding disorders, as well as healthcare professionals.

The charity's supporters help fundraise the costs that are vitally needed to be able to offer membership – and services such as events and printed publications – entirely free to all members.

What we do:

Support each other
We understand each other. We offer advice and support from personal experience. Our growing community is there for each other because we're in it together.

Raise awareness
We rally together because every little thing we do makes a difference and gives hope to people living with a bleeding disorder.

Make a lasting difference
We influence and advocate on what matters to our community. Health and social care policy, access to treatment and much more.

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

Notes

The Haemophilia Society

This booked was reviewed by doctors from our Medical and Scientific Advisory Group.

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
The Haemophilia Society
52b Borough High Street
London SE1 1XN
Phone: 020 7939 0780
Email: info@haemophilia.org.uk
Web: haemophilia.org.uk

HaemophiliaSocietyUK
HaemoSocUK
thehaemophiliasociety

Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia

Review date 2024