



A guide for women with von Willebrand disease

Answers to common questions, to help you understand your condition



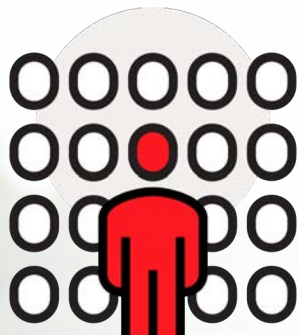
What is von Willebrand disease (VWD)?

VWD is the most common inherited bleeding disorder, affecting up to 1 in 100 people.

In VWD, blood is unable to clot normally, so when people with VWD bleed, it takes longer to stop.

VWD occurs when people don't have enough of a substance called von Willebrand factor (VWF) in their blood, or if their VWF doesn't work properly. VWF is an essential component for blood clotting.

When we bleed from a cut, small blood cells called platelets clump together in a clot to plug the injury. Normally, VWF acts like a glue to stick the platelets together and strengthen the clot. But in VWD, this 'glue' effect is reduced, so clots take longer to form or are weak.



What types of VWD are there?

There are different types of VWD. Your doctor will be able to tell you which type you have:



- **Type 1 VWD**

This is the most common and least severe form. Around three-quarters of people with VWD have type 1. People with type 1 VWD have low levels of VWF. They may also have low levels of factor VIII (spoken as ‘factor 8’), which is another substance involved in blood clotting.

- **Type 2 VWD**

Around one quarter of people with VWD have type 2. Here, the amount of VWF in the blood may be low or normal, but the VWF does not work as well as it should.

There are four main subtypes of type 2 VWD: 2A, 2B, 2M and 2N. Each relates to a specific fault in the way VWF behaves.

- **Type 3 VWD**

This is the rarest and most severe form of inherited VWD, affecting one person in every half a million. People with type 3 VWD have virtually no VWF in their blood. They also have low levels of factor VIII.

- **Acquired VWD**

In extremely rare cases, VWD can occur as a result of other medical conditions, such as lupus, heart disease and some cancers.

What are the symptoms of VWD?

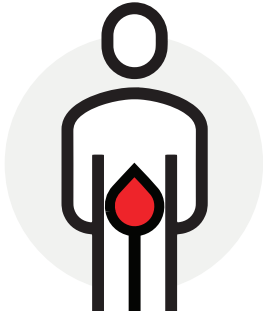
Many people with type 1 and type 2 VWD may have mild or no symptoms. Symptoms can vary between people, and they can change over time. Management options are available to help with all aspects of VWD, so be sure to tell your healthcare team about any symptoms you experience.

Some of the common symptoms include:

- frequent hard-to-stop nose bleeds
- bruising more easily, and having significant bruising from minor bumps
- bleeding for longer than most people after injuries, surgery or dental procedures
- heavy or prolonged periods (see 'Will VWD affect my periods?' on next page) and excess bleeding in childbirth

In severe cases and in type 3 VWD, internal bleeding – such as in the gut, muscle or into joints – can occur in addition to all or some of the above symptoms. This can happen even without an obvious trigger, like a fall or bump to the body.





Will VWD affect my periods?

VWD affects bleeding, so it can contribute towards heavy or prolonged periods. However, menstrual flow varies widely between women, so it can be difficult to know for sure if your period is being affected by your VWD.

If you bleed for more than seven days, or your daily life is impacted by your period (e.g. you stay at home for fear of bleeding) it could signal that your VWD is having an impact.

Tiredness, lack of energy and shortness of breath are other things to watch out for, as these could point to a lack of red blood cells (anaemia) due to heavy bleeding.

If you have any concerns about your periods, talk to your healthcare professional. If you can, prepare for your appointment by keeping a record of your periods in a bleeding diary. Ask your doctor or nurse for a bleeding diary if you don't have one.



Does VWD affect pregnancy and childbirth?

During pregnancy, the amount of VWF in the body often increases, which reduces the likelihood of bleeding problems during this time. However, careful monitoring is vital in case of heavy bleeding after giving birth. There is also the possibility of delayed bleeding when the amount of VWF in your body returns to pre-pregnancy levels; any time up to six weeks after delivery.

If you're having a baby, be sure to tell all of your midwives and doctors that you have VWD. You should discuss with your obstetric team and haematology specialists what type of delivery is best for you and your baby. Always tell your bleeding disorder team that you are pregnant too. Don't assume that your maternity team will have told them, even if they are in the same hospital.

If you are bleeding heavily in the days and weeks after the birth, you should contact your haematologist or nurse specialist for advice.



How do people get VWD?

VWD can affect both males and females and it is usually inherited, when one or both parents pass a faulty VWF gene to their children.

Humans have two copies of most genes. Sometimes a normal gene can reduce the impact of its faulty partner, but if both copies are faulty the effects are more severe. This is the case with the VWF gene:

- If one parent passes a faulty VWF gene to their child, but the other parent passes on a normal VWF gene, the child may have no symptoms or develop the milder forms of VWD
- If both parents pass on a faulty VWF gene, their child is likely to have more severe VWD

Some people are born with VWD even if neither of their parents have it. That happens if the VWF gene developed a fault (or 'mutation') in the embryo.

In extremely rare cases, other medical conditions in later life, such as heart disease and some cancers, can cause VWD.

It is impossible to 'catch' VWD of any type, so it can never be passed on like a cold or flu.





Will my children get VWD?

Although VWD is passed down through families, children of a parent with VWD may not necessarily inherit the condition themselves. In fact, there are **three possibilities**:

- the child may have VWD
- the child may not have VWD
- the child may be a carrier without symptoms

Genetic counsellors are trained to help people understand the likelihood of passing VWD to their children, as well as to offer advice and support. If you would like to know more, ask your healthcare professional about genetic counselling services in your area.





Is there a cure for VWD?

VWD cannot be cured, but there are a range of ways that the condition can be managed. These enable most people with VWD to live full and active lives, with a normal life expectancy.

Your doctor or nurse will discuss management options with you. Together, you can decide the most appropriate course of action for you, based on your type of VWD, lifestyle and symptoms.



Can I still be active and play sports?

Being physically active is important for health and wellbeing, and people with mild or moderate VWD can participate in most sports and exercise.

For some people it will be advisable to avoid high-contact sports and dangerous pursuits. The sports or activities that suit you best will depend on your type of VWD and symptoms, so check with your doctor or nurse specialist before taking part.

Can I shave with a razor?

Although electric shavers are a wise choice to avoid nicks and bleeding while shaving, some people still prefer to use a razor. Talk to your doctor or nurse specialist about shaving practices.

Can I have body piercings and tattoos?

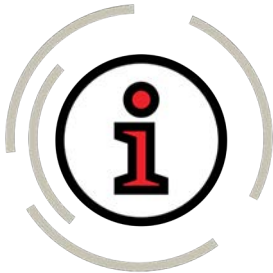
Body piercings and tattoos can cause bleeding, so talk to your doctor or nurse specialist if you are considering having one.



Who should I tell about my VWD?

When you see a healthcare professional, be sure to tell them you have VWD. This includes doctors, surgeons and dentists, physiotherapists, opticians and chiropractors.

When a diagnosis of VWD has been confirmed, you will be given an alert card to keep with you and show to any healthcare professionals you are in contact with. Some people also like to wear a medical alert bracelet or have their medical information stored on their mobile phone in case of emergency.



Where can I find out more?

Your doctor or specialist nurse will be able to answer any questions that you may have.

The Haemophilia Society provides help and support to people with bleeding disorders, including VWD. Find out more by calling **020 7939 0780**.

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CSL Behring UK Ltd
Phone: 01444 447 400
Email: medinfo@cslbehring.com
www.cslbehring.co.uk

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