

New VWD fact sheet

Looking for some simple information about von Willebrand disease (VWD) to share with others?

Our new **Von Willebrand disease (VWD) fact sheet** has answers to a range of FAQs with the very latest information:

- What is VWD? How do you get it?
- What are the symptoms and types?
- How is it diagnosed and treated?

Share it with your family – or keep it on hand for new doctors or school or other situations where you want to give a quick explanation.

And don't forget to talk to your Haemophilia Treatment Centre (HTC) to keep up-to-date with treatment options for VWD.

Download the fact sheet from the HFA website:
www.haemophilia.org.au/resources

Or contact HFA for print copies:

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Our thanks to the health professional experts and the HFA VWD consumer focus group for their contributions and advice.

FACT SHEET

Von Willebrand disease (VWD)

What is von Willebrand disease?

Von Willebrand disease (VWD) – also known as von Willebrand disorder – is a bleeding disorder that affects both females and males. VWD is the most common hereditary bleeding disorder worldwide. It is estimated that 1 in 1,000 people have a form of VWD that needs medical treatment. More than 1,000 people have been diagnosed with VWD in Australia, but many more are thought to be undiagnosed.

People with VWD have a problem with a clotting protein in their blood called von Willebrand Factor (VWF), which works with another protein called FVIII (F8) to help control bleeding. They do not have enough VWF or it doesn't work the way it should. As a result it takes longer for blood to clot and for bleeding to stop.

What are the symptoms of VWD?

Bleeding problems can vary a bit between people with VWD, even in the same family. Some people experience little or no disruption to their lives unless they have serious injury or surgery, and others bleed quite often.

There can be bleeding problems with all forms of VWD. Any bleeding that occurs with VWD needs to be assessed and treated promptly.

Bleeding in people with VWD usually involves the mucous membranes, the skin, and joints.

- Nose (nose bleeds that occur often or are difficult to stop)
- Mouth (bleeding in the mouth)
- Menstrual and intermenstrual (spotting/bleeding)
- Menstrual and vaginal (during menstrual periods, heavy bleeding for longer than usual after childbirth)

Other common symptoms are:

- Easy bruising, bleeding for a long time with minor cuts
- Bleeding after surgery, surgery or dental work that continues for a long time
- Anaemia (low red blood cells, especially in females)

Some VWD is a mild form of the disease and some people with VWD have the severe form. Without preventive treatment they may also have bleeding associated with muscle and joint pain and 'spontaneous' bleeds (bleeds that occur for no obvious reason). Over time repeated bleeding can damage joints and muscles, causing arthritis and osteoarthritis.

How do you get VWD?

How is VWD diagnosed?

Diagnosing VWD needs specialist medical and laboratory experience in VWD. A screen disorder but more specific tests and sometimes repeated testing will be needed. If you have questions about bleeding symptoms, speak to your doctor. If your doctor is not sure you can be referred to a haemophilia or haemophilia treatment centre. Blood test Haemophilia Treatment Centres have a team of specialist clinicians, nurses, social workers, laboratory services with expertise in bleeding disorders. There is at least one in a public territory and private health care and support.

What are the different types of VWD?

There are three main types of VWD. Bleeding symptoms can vary from person to person. It is important to know which type of VWD a person has to make sure they

Type 1 VWD	The most common form. Usually low levels of VWF.	
Type 2 VWD	Divided into 2A, 2B, 2C, 2M	The level of VWF may be normal but the VWF doesn't work.
Type 3 VWD	Very rare. Very little or no VWF and low FVIII. Symptoms are	

What is the treatment for VWD?

Treatment for VWD is individualised to each person, depending on their bleeding and the reason for the bleeding.

Some people with VWD who do not bleed often will only need treatment if they are to have surgery or dental or medical. Some will however may need special treatment of bleeding or to prepare for childbirth.

People with the severe form of VWD or who bleed often may need treatment to prevent types of haemorrhage.

New VWD fact sheet
Quick info about von Willebrand disease (VWD), its symptoms, and how it's treated.