

What is a bleeding disorder?

Bleeding disorders are rare health conditions where a person's blood doesn't clot properly.

This means that if someone with a bleeding disorder starts to bleed, for example from an injury, surgery or from having their period, they might bleed for longer than other people because their blood takes longer to clot (stop running).

This can happen because there is a problem with the blood clotting - for example, not enough clotting factor in the blood or it doesn't work the way it should.

The clotting process

A clotting factor is an ingredient (a protein) in the blood that controls bleeding.

Many different clotting factors work together in a chain of chemical reactions to stop bleeding. This is called the clotting process or 'haemostasis'.

There are over 20 different proteins and other substances involved in the clotting process.

Types of bleeding disorders

The most common inherited bleeding disorders are von Willebrand disease (VWD) and haemophilia.

Von Willebrand disease (VWD)

Von Willebrand disease (also called *von Willebrand disorder* or VWD) is caused by low levels of von Willebrand factor or because the von Willebrand factor doesn't work properly.

Haemophilia

There are two types of inherited haemophilia:

- Haemophilia A - caused by low levels of clotting factor VIII (8)
- Haemophilia B - caused by low levels of clotting factor IX (9).

Rare clotting factor deficiencies

Rare clotting factor deficiencies are another group of inherited bleeding disorders.

They are caused by low levels of other factors and include:

- Factor I (1) deficiency – often called *fibrinogen deficiency*
- Factor II (2) deficiency
- Factor V (5) deficiency
- Combined factor V (5) and VIII (8) deficiency
- Factor VII (7) deficiency
- Factor X (10) deficiency
- Factor XI (11) deficiency
- Factor XIII (13) deficiency.

Inherited platelet function disorders

Inherited platelet function disorders are conditions where platelets, rather than clotting factors, don't work the way they should, resulting in a tendency to bleed or bruise. Platelets are very small cells circulating in the blood, which stick to the walls of damaged blood vessels to promote clotting. Inherited platelet disorders include Bernard-Soulier syndrome, Glanzmann thrombasthenia and storage pool deficiencies.

These bleeding disorders - von Willebrand disease (VWD), haemophilia, rare clotting factor deficiencies and inherited platelet disorders - are caused by changes to the genes responsible for blood clotting. The changed genes are passed down from parent to child and so the bleeding disorders are referred to as genetic or inherited disorders. People with bleeding disorders are nearly always born with them.

The exceptions are acquired haemophilia and acquired VWD, which mostly occur in adulthood. These conditions are different to inherited bleeding disorders and are very rare (see page 21).

Symptoms

Common symptoms of bleeding disorders in females are:

- Bruising easily
- Heavy periods
- Pain with periods
- Pain with ovulation (when an egg is released from the ovary half-way between periods)
- Bleeding or oozing that lasts for a long time after surgery, dental procedures including tooth extractions, medical procedures, injuries or accidents
- Bleeding from the gums, usually after trauma/injury (more common with VWD)
- Frequent nosebleeds, or nosebleeds that are difficult to stop (more common with VWD)
- Heavy bleeding that lasts longer than expected after childbirth (particularly when bleeding increases 3 days or more after giving birth)
- Bleeding that lasts longer than expected after cuts
- Anaemia (low red blood cell count/low blood iron levels)

“ I mainly experience issues during dental surgery - excessive bleeding, swelling and bruising. Occasionally I come up with bruises and I’m not sure why! But on a daily basis, haemophilia doesn’t affect my life. ”

Rarely, females with very low clotting factor levels (such as severe haemophilia or VWD or rare clotting factor deficiencies) may also have:



- Joint and muscle bleeds which can occur often and cause swelling and pain
- Bleeding episodes that seem to happen for no obvious reason.

“ I have always had heavy periods from a young age, and breakthrough bleeding, which I now know to be ovulation bleeding, but I also get regular gum and throat bleeding episodes as well as the occasional nose bleed. I've also always bruised easily, and often without injury. ”

Because girls start having periods in puberty, symptoms of a mild or moderate bleeding disorder are often more obvious from an earlier age in girls than in boys.

For more information visit factoredin.org.au

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