The Blood Project

UNDERSTANDING VON WILLEBRAND DISEASE

A brief guide for patients with VWD

Von Willebrand disease is a condition that affects how blood clots. It is caused by lower levels or reduced function of a blood protein called **von Willebrand factor**, which helps platelets stick to injured blood vessels and supports normal clot formation. Most people with von Willebrand disease have mild or manageable symptoms and live full, normal lives. The condition is common and varies widely from person to person.

What is von Willebrand disease?

Von Willebrand disease occurs when von Willebrand factor is reduced or does not work properly. When this protein is not functioning as it should, bleeding can last longer than usual after injury, surgery, or dental work. Von Willebrand disease is best thought of as a **group of related conditions**, not a single uniform illness. Some people have only mild changes in clotting, while others have more significant bleeding tendencies. The pattern is usually stable over time.

Why does it happen?

Most forms of von Willebrand disease are **inherited**, meaning they are passed down in families. The underlying gene affects how much von Willebrand factor is made or how well it works.

There is also a separate condition called **acquired von Willebrand disease**, which develops later in life as a result of another medical problem and is not inherited. Most people reading this handout have the inherited form.

Von Willebrand factor levels can change over time. Stress, illness, inflammation, hormones, pregnancy, and aging can all affect test results, which is why diagnosis often involves careful interpretation rather than a single blood test.

Are there different types?

Doctors classify von Willebrand disease into different types based on how much von Willebrand factor is present and how well it functions.

Type 1 is the most common and usually involves lower-than-average levels of von Willebrand factor.

Type 2 involves von Willebrand factor that is present but does not work normally.

Type 3 is rare and involves very low levels of von Willebrand factor, leading to more significant bleeding.

Knowing the type helps doctors plan treatment and prevent bleeding during higher-risk situations.

Does it cause symptoms?

Sometimes.

Some people bruise easily or have frequent nosebleeds. Others may notice heavy menstrual bleeding or prolonged bleeding after dental work or surgery. Bleeding from small cuts may take longer than expected to stop.

Many people with von Willebrand disease have few or no noticeable symptoms, even if blood tests are abnormal. Symptoms do not always match laboratory numbers exactly.

Is it dangerous?

For most people, von Willebrand disease is **not dangerous** and does not shorten life expectancy. More serious bleeding is uncommon and usually occurs during specific situations such as surgery, childbirth, or major injury, particularly in people with more severe forms. Knowing about the condition in advance allows doctors to **plan and prevent problems**, rather than react after bleeding occurs.

How your doctor evaluates it

Doctors diagnose von Willebrand disease by looking at **patterns**, not a single test result. Evaluation often includes:

- blood tests that measure the amount and function of von Willebrand factor
- related clotting tests
- a careful bleeding history
- repeat testing over time to confirm patterns

Because results can fluctuate, one normal test does not always rule out the condition.

What Is the treatment?

Treatment depends on the type of von Willebrand disease, the severity of symptoms, and the situation. Many people do not need daily treatment. Others may receive medications that temporarily raise von Willebrand factor levels, medicines that help stabilize clots, or replacement therapy during higher-risk situations such as surgery, dental work, or childbirth.

Treatment is individualized and focused on **prevention and planning**, rather than constant therapy.

When should I contact my doctor?

You should contact your doctor if you notice changes in bleeding or are planning a procedure. Reach out if you experience:

- new or unusual bleeding
- bleeding that is harder to stop than expected
- heavy menstrual bleeding that interferes with daily life or leads to anemia
- upcoming surgery, dental work, or pregnancy
- questions about medications that affect bleeding

Seek urgent medical care for severe bleeding, head injury, severe abdominal pain, chest pain, or severe shortness of breath.

What is the usual plan going forward?

Many people with von Willebrand disease are followed periodically by a primary care clinician or hematologist. Follow-up usually focuses on **anticipating situations that increase bleeding risk**, rather than frequent testing.

The goal is preparation, not restriction. With awareness and appropriate planning, most people manage this condition without major limitations.

Key points to remember

- **common and variable:** von Willebrand disease affects people differently
- **not a single illness:** it includes several related types
- **often mild:** many people have few or manageable symptoms
- **planning matters:** knowing the diagnosis helps prevent bleeding
- **most people do well:** full, active lives are the norm of life