The Blood Project

UNDERSTANDING VON WILLEBRAND DISEASE TYPE 1

A brief guide for patients with the most common form of von Willebrand disease

Von Willebrand disease type 1 is the most common form of von Willebrand disease. It affects how blood clots because the body has lower-than-average levels of a clotting protein called von Willebrand factor. This protein helps platelets stick to injured blood vessels and supports normal clot formation. Type 1 von Willebrand disease is usually mild, stable over time, and manageable with planning. While symptoms can be more disruptive for some people, particularly heavy menstrual bleeding, many people live full, active lives with few limitations.

What is von Willebrand disease type 1?

Type 1 von Willebrand disease occurs when the body makes **less von Willebrand factor than usual**, but the protein that is present works normally.

Because the protein level is reduced, bleeding can last longer than expected after injury, surgery, or dental work. Day-to-day bleeding is often minimal or absent.

Type 1 is best understood as **having less of a working protein**, rather than a defect in how the protein functions.

Why does it happen?

Type 1 von Willebrand disease is usually inherited, meaning it runs in families. A genetic variation affects how much von Willebrand factor the body produces.

Levels of von Willebrand factor are not fixed. They can rise or fall with stress, illness, inflammation, hormones, pregnancy, and aging. This natural variability explains why blood test results may change over time, even though the underlying condition remains the same.

In addition, people with **blood type O naturally have lower von Willebrand factor levels** (about 20–30% lower than other blood types). This is a normal biologic variation and can overlap with mild type 1.

How common is type 1?

Type 1 is the most common form of von Willebrand disease, accounting for the majority of cases. Many people with type 1 are diagnosed only after a bleeding event, surgery, dental procedure, or evaluation for heavy menstrual bleeding. Others are identified through family testing.

Does it cause symptoms?

Sometimes.

Many people with type 1 have **few or no symptoms**. When symptoms occur, they may include:

- easy bruising
- frequent or prolonged nosebleeds
- heavy menstrual bleeding
- prolonged bleeding after dental work or surgery
- bleeding that takes longer than expected to stop

Symptoms can vary widely and do not always match laboratory numbers exactly. Even when blood tests suggest a “mild” form, symptoms can still meaningfully affect daily life and deserve attention.

Is type 1 von Willebrand disease dangerous?

For most people, **no**.

Type 1 von Willebrand disease is usually mild and does not shorten life expectancy. Serious bleeding is uncommon and typically occurs during specific situations such as surgery, childbirth, or major injury. Knowing about the condition ahead of time allows doctors to **prevent bleeding**, rather than respond to it after it occurs.

How your doctor evaluates it

Doctors diagnose type 1 von Willebrand disease by looking at **patterns**, not a single test result. Evaluation often includes:

- blood tests measuring von Willebrand factor levels
- tests of clotting function
- a detailed bleeding history
- repeat testing over time to confirm consistency

Because levels fluctuate naturally, one normal result does not always rule out type 1.

What Is the treatment?

Many people with type 1 **do not need daily treatment**.

Treatment is used when bleeding risk is higher, such as before surgery, dental work, or childbirth. Options may include:

- medications that temporarily raise von Willebrand factor levels
- medicines that help stabilize clots
- treatment targeted to procedures or high-risk situations
- therapies to manage heavy menstrual bleeding when present

Treatment decisions are individualized and focus on **planning**, not constant therapy.

When should I contact my doctor?

You should contact your doctor if bleeding patterns change or if you are planning a procedure. Reach out if you experience:

- new or worsening bleeding
- heavy menstrual bleeding that interferes with daily life or causes anemia
- bleeding that is harder to stop than expected
- 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?

Most people with type 1 von Willebrand disease are followed periodically by a primary care clinician or hematologist. Follow-up focuses on:

- anticipating situations that increase bleeding risk
- planning ahead for procedures
- reassessing symptoms over time

The goal is **preparation, not restriction**. With awareness and planning, most people manage type 1 without major limitations.

Key points to remember

- **most common type:** type 1 accounts for the majority of von Willebrand disease cases
- **quantity, not function:** the protein works normally but is present in lower amounts

- **often mild, but symptoms still matter:** heavy menstrual bleeding and other symptoms deserve care
- **levels fluctuate:** test results can change without changing the diagnosis
- **planning matters:** advance preparation helps prevent bleeding problems