

# UNDERSTANDING VON WILLEBRAND DISEASE TESTING

## *A brief guide to making sense of von Willebrand blood tests*

Testing for von Willebrand disease can feel confusing. Results may change over time, different tests may appear to conflict, and symptoms do not always match a single number. This guide explains what von Willebrand disease tests measure, why results can vary, and how doctors interpret patterns rather than relying on one test alone.

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### **Why testing can be confusing**

Von Willebrand factor is a dynamic protein. Its levels and function change naturally in response to stress, illness, inflammation, hormones, pregnancy, and aging.

Because of this, von Willebrand disease cannot usually be diagnosed or ruled out based on a single blood test. Doctors look at trends, combinations of tests, and bleeding history together.

It is common for people to have:

- results that fluctuate over time
- “near-normal” values despite real bleeding symptoms
- different results depending on when testing is done

This does not mean testing is unreliable. It means interpretation requires context.

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### **What do von Willebrand tests measure?**

Von Willebrand disease testing usually looks at two broad questions:

1. **How much von Willebrand factor is present?**
2. **How well does it work?**

Some tests measure the amount of von Willebrand factor in the blood. Others measure how well the protein functions during clotting.

Both types of information are important

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### **What are the main tests?**

Common tests may include:

- tests that measure von Willebrand factor level (amount)
- tests that measure von Willebrand factor activity (function)
- tests comparing function to amount
- factor VIII level
- other clotting studies

Different combinations of results help doctors distinguish between:

- normal variation
- inherited von Willebrand disease
- different von Willebrand disease types
- acquired von Willebrand syndrome

Patients do not need to memorize test names. What matters is how the results fit together.

## Why do results change over time?

Von Willebrand factor levels can rise temporarily with:

- stress or anxiety
- infection or inflammation
- pregnancy or estrogen exposure
- physical exertion

Levels may be lower at other times, especially when the body is at rest.

Because of this natural variability:

- one normal test does not always rule out von Willebrand disease
- repeat testing is often necessary
- results are interpreted as patterns, not absolutes

This variability is expected and does not mean the diagnosis is uncertain.

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## Why do symptoms and numbers not always match?

Bleeding symptoms reflect how the body behaves in real-world situations, not just what a single lab value shows.

Some people bleed more than expected despite “near-normal” numbers, especially when von Willebrand factor does not function properly. Others may have low numbers but few symptoms.

For this reason, doctors place strong weight on:

- bleeding history
- surgical and dental bleeding
- menstrual bleeding patterns
- family history (for inherited forms)

Lab tests support the diagnosis, but they do not replace clinical experience.

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## How do doctors interpret the results?

Doctors look for consistent patterns rather than isolated values.

They consider:

- multiple test results together
- trends over time
- how function compares to amount
- bleeding symptoms and history
- age, hormones, pregnancy status, and medical conditions

This approach helps avoid over- or under-diagnosis and guides safe treatment planning.

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## Does testing determine the type of von Willebrand disease?

Yes.

Testing helps distinguish between:

- type 1 (lower amount, normal function)
- type 2 (normal or near-normal amount, impaired function)
- type 3 (very low or absent von Willebrand factor)
- acquired von Willebrand syndrome

Subtyping matters because treatment choices and bleeding risk differ.

Patients do not need to understand subtype details. The care team uses this information to plan safely.

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## When is repeat testing needed?

Repeat testing is common and expected.

Doctors may repeat tests:

- to confirm a pattern
- when results are borderline
- if symptoms change
- before surgery or pregnancy
- when evaluating treatment response

Repeat testing does not mean something was done wrong the first time. It reflects how von Willebrand factor behaves in the body.

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## What should I do if results seem inconsistent?

If results feel confusing, ask your doctor:

- what pattern they see over time
- how the results match your bleeding history
- whether repeat testing is planned
- how the results affect treatment decisions

In most cases, bleeding can be managed safely even while testing continues.

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## Key points to remember

- **testing looks at patterns:** single numbers rarely tell the full story
- **amount and function differ:** both matter for diagnosis
- **results fluctuate naturally:** this is expected, not a mistake
- **symptoms matter:** bleeding history guides interpretation
- **repeat testing is normal:** it improves accuracy and safety