

Understanding Von Willebrand Disease

A comprehensive guide to the
most common inherited
bleeding disorder.

By William Aird

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digital guide,
audio, and video.



The Big Picture: What You Need to Know



A Spectrum, Not a Uniform Illness.

VWD includes several distinct patterns. Understanding your specific type matters more than the name alone.



Context is Everything.

Laboratory results are interpreted as overarching patterns, not just single numbers.



Type Matters Most.

How the condition is managed depends heavily on your specific subtype.



Most Do Well.

The vast majority of people with VWD live full, active lives with little to no daily treatment.

How Von Willebrand Factor Works

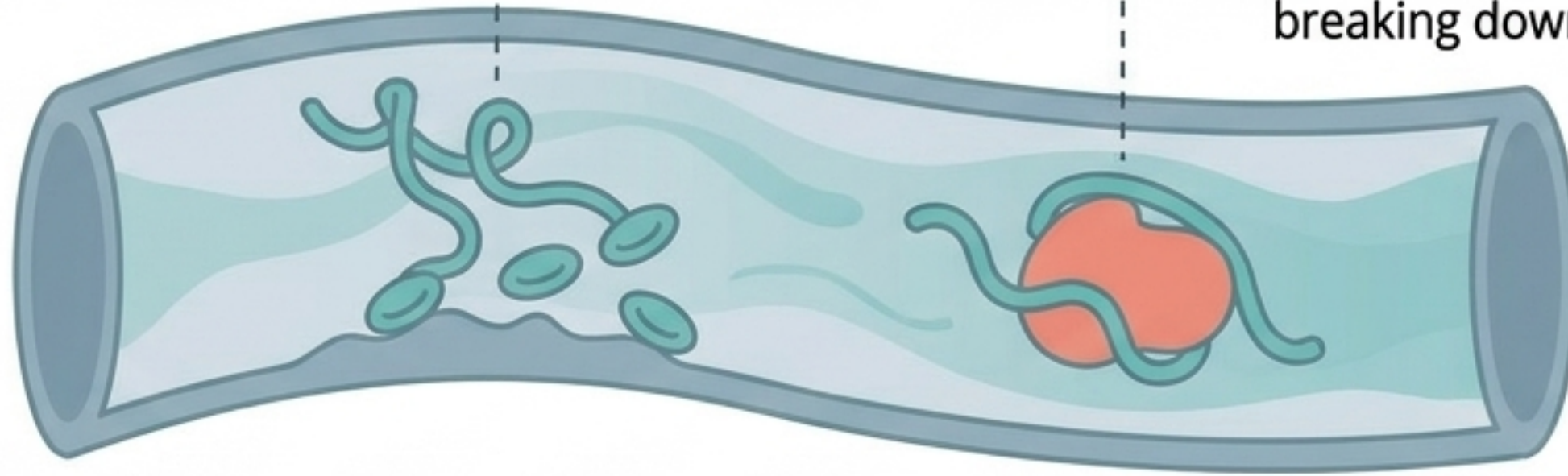
Von Willebrand disease is caused by a problem with von Willebrand factor (VWF), a crucial blood protein that helps clotting work normally.

The "Velcro"

Anchoring small platelets to the injured wall of a blood vessel.

The "Shield"

Protecting other vital clotting proteins, preventing them from breaking down too quickly.



The Result: When von Willebrand factor is low or does not work properly, bleeding can last longer than usual.

Where Does VWD Come From?

Inherited VWD (Most Common)

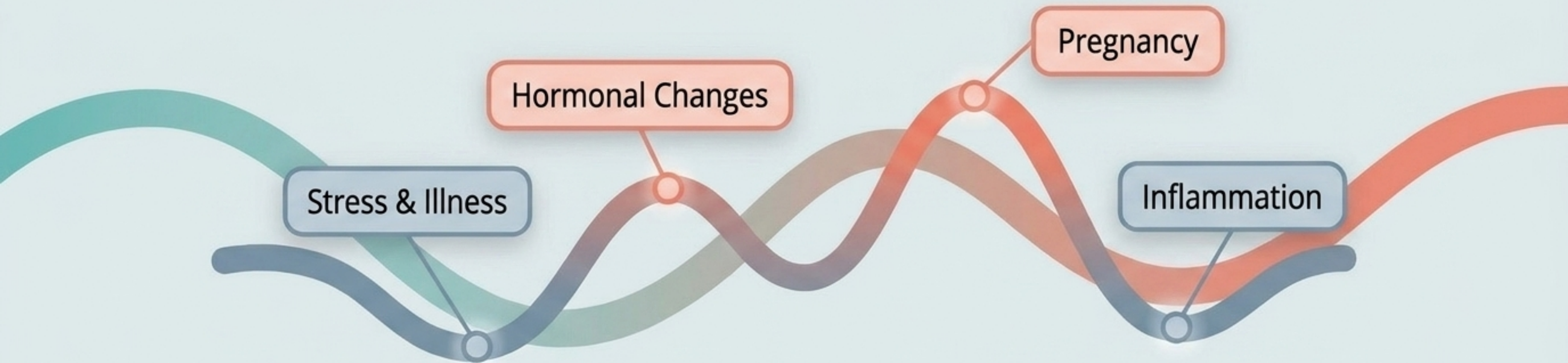
- **Origin:** Passed down in families through genetics.
- **Mechanism:** The underlying gene affects how much VWF is produced or how well it functions.
- **Timeline:** Almost always diagnosed in childhood or young adulthood.

Acquired VWD (Rare)

- **Origin:** Not inherited.
- **Mechanism:** Linked to the presence of other medical conditions.
- **Timeline:** Develops later in life.

The Fluctuation Factor

Von Willebrand factor levels are not static. They can change over time, which is why diagnosis requires careful interpretation rather than a single blood test.



Because levels naturally fluctuate with these triggers, your doctor will look for trends over time rather than reacting to one isolated test result.

The Spectrum of Symptoms

Most People

No noticeable symptoms, or occasional easy bruising.

Heavy menstrual bleeding, frequent nosebleeds, or minor cuts taking longer to stop.

Prolonged bleeding following dental work, major surgery, or childbirth.

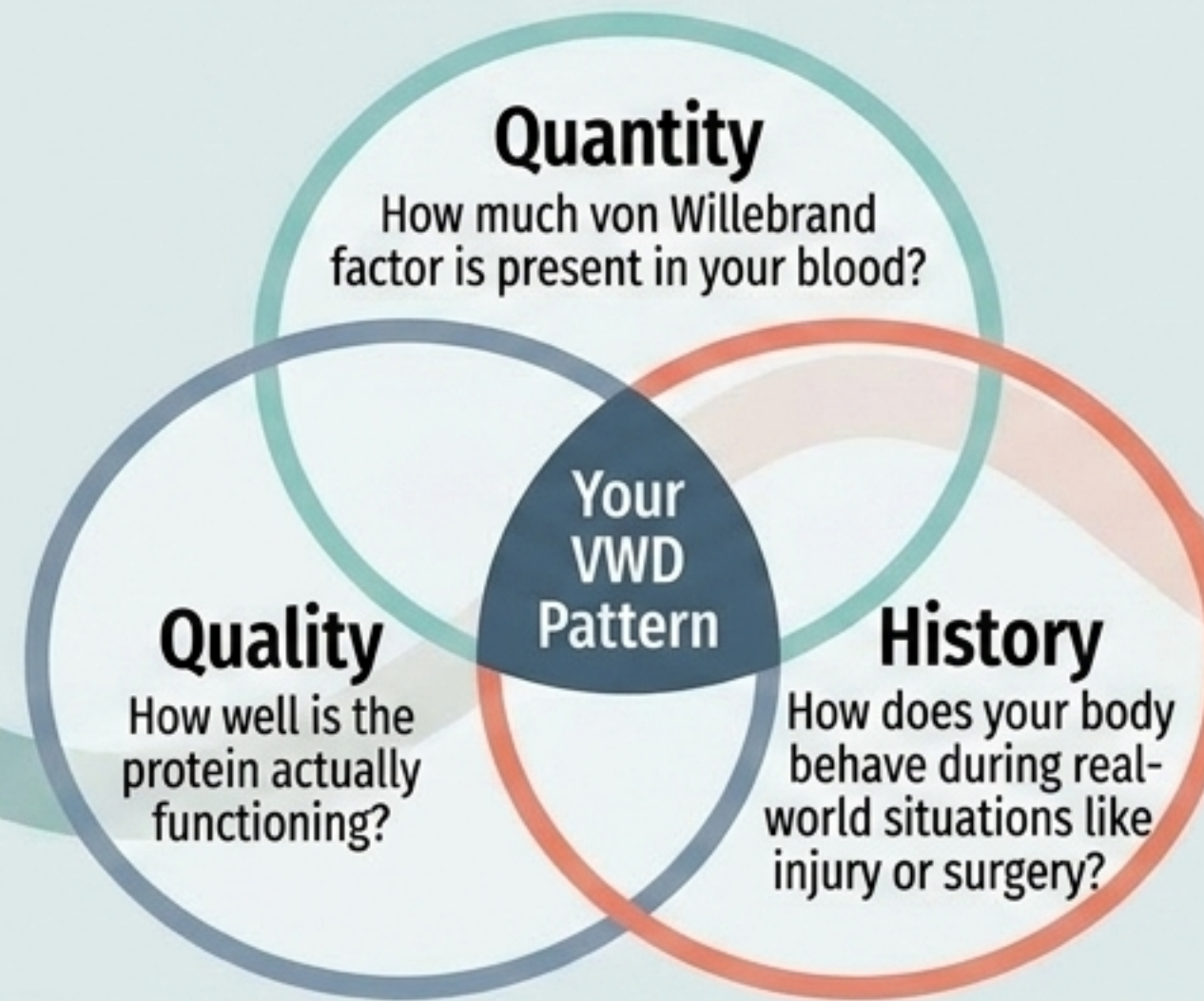
Mild

Noticeable

Crucial Insight: Symptoms do not always match laboratory numbers exactly. Doctors focus on both your real-world bleeding history and your test patterns.

Diagnosing the Pattern

Evaluation isn't about finding a single magic number. Your doctor combines three different pieces of information, often repeating tests over time:



Doctors interpret the complete picture to identify your specific subtype.

Is VWD Dangerous?

For the vast majority of people, von Willebrand disease is not dangerous and does not shorten life expectancy.



- Serious bleeding is uncommon.
- Higher risks usually only apply to more severe forms, or specific situations like surgery, childbirth, or major injury.
- Knowing your specific VWD type allows doctors to anticipate risks and prevent problems before they happen, rather than reacting after the fact.

Personalized Treatment Approaches

Treatment is highly individualized based on your subtype, symptom severity, and current life situation.



No Daily Therapy

Many people require no ongoing or daily treatment.



VWF Boosters

Medications that temporarily raise von Willebrand factor levels when needed.



Clot Stabilizers

Medications designed to prevent clots from breaking down once they form.



Protein Infusions

Direct infusions of clotting proteins, typically reserved for higher-risk situations like major surgery or childbirth.

Daily Life: Awareness Over Restriction

Most people with von Willebrand disease live completely normal, active lives.



Awareness and planning are far more important than ongoing medical therapy.

Knowing your specific subtype is your best tool for guiding everyday decisions.

There is usually no need to avoid routine activities or restrict your lifestyle unnecessarily.

When to Contact Your Care Team

Most bleeding symptoms are not emergencies, but it is important to know when to check in so your team can help reduce risk.

Routine Check-in

You have questions about medications that might affect bleeding.

Plan Ahead

You have upcoming surgery, dental work, medical procedures, or are planning for pregnancy.

Take Action

You notice new or unusual bleeding, bleeding that takes longer or is harder to stop than expected, or menstrual bleeding heavy enough to interfere with daily life.

The Care Cycle Moving Forward

Live Fully
Experience life
without unnecessary
restriction

Anticipate
Understand your
unique pattern

Prepare
Plan for life events
with your doctor



Remember, VWD is a spectrum. Scan the QR code on the cover to access type-specific pages for details regarding your exact subtype. Many patients are followed periodically by a primary care clinician or hematologist.

This information is for general education and does not replace medical care. It applies to people who are medically stable.
If you are experiencing new or worsening symptoms, contact your doctor or seek emergency care.