

Patient Guide to Acquired Von Willebrand Disease

Understanding the clues, managing the symptoms, and moving forward.

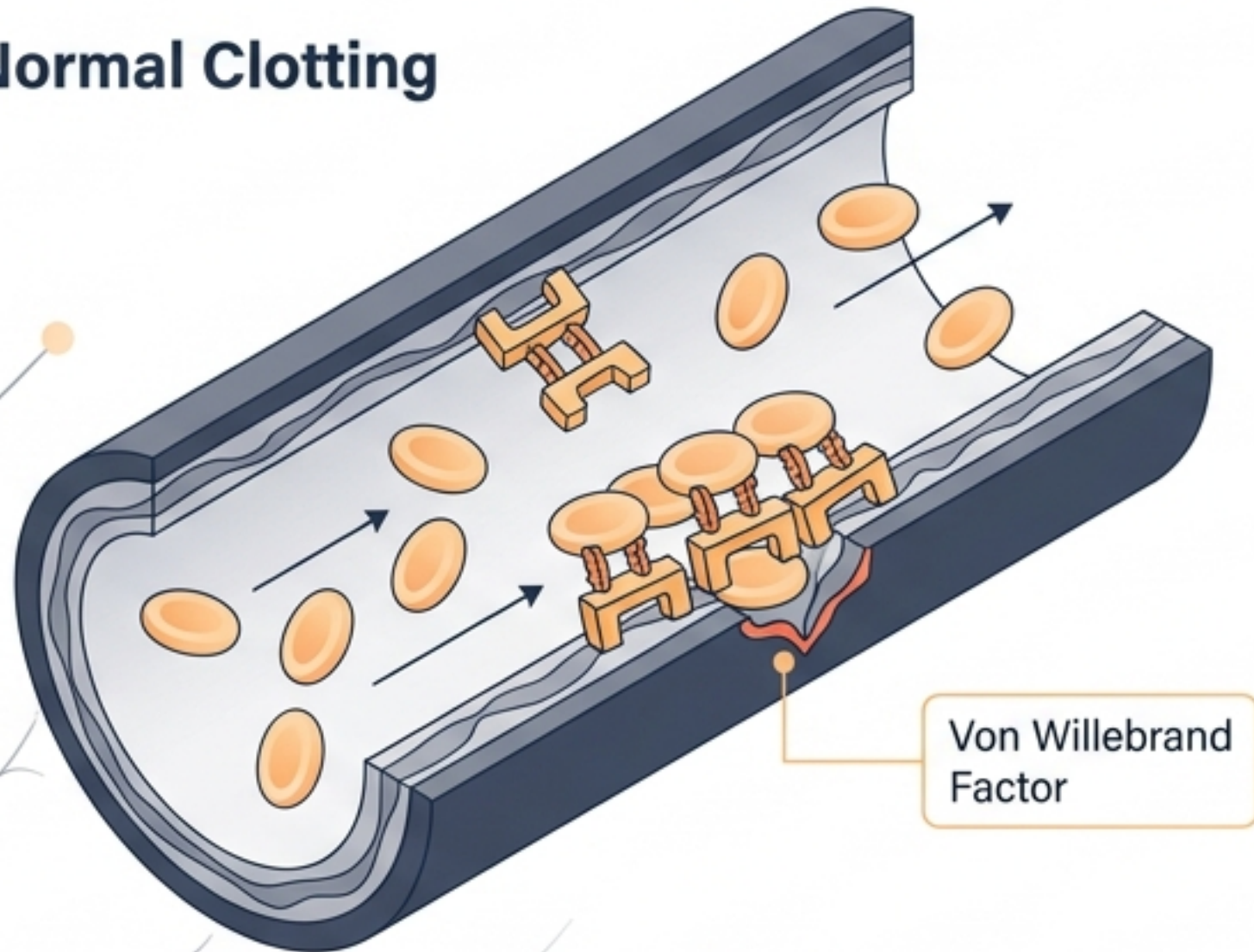


The Connected Clues

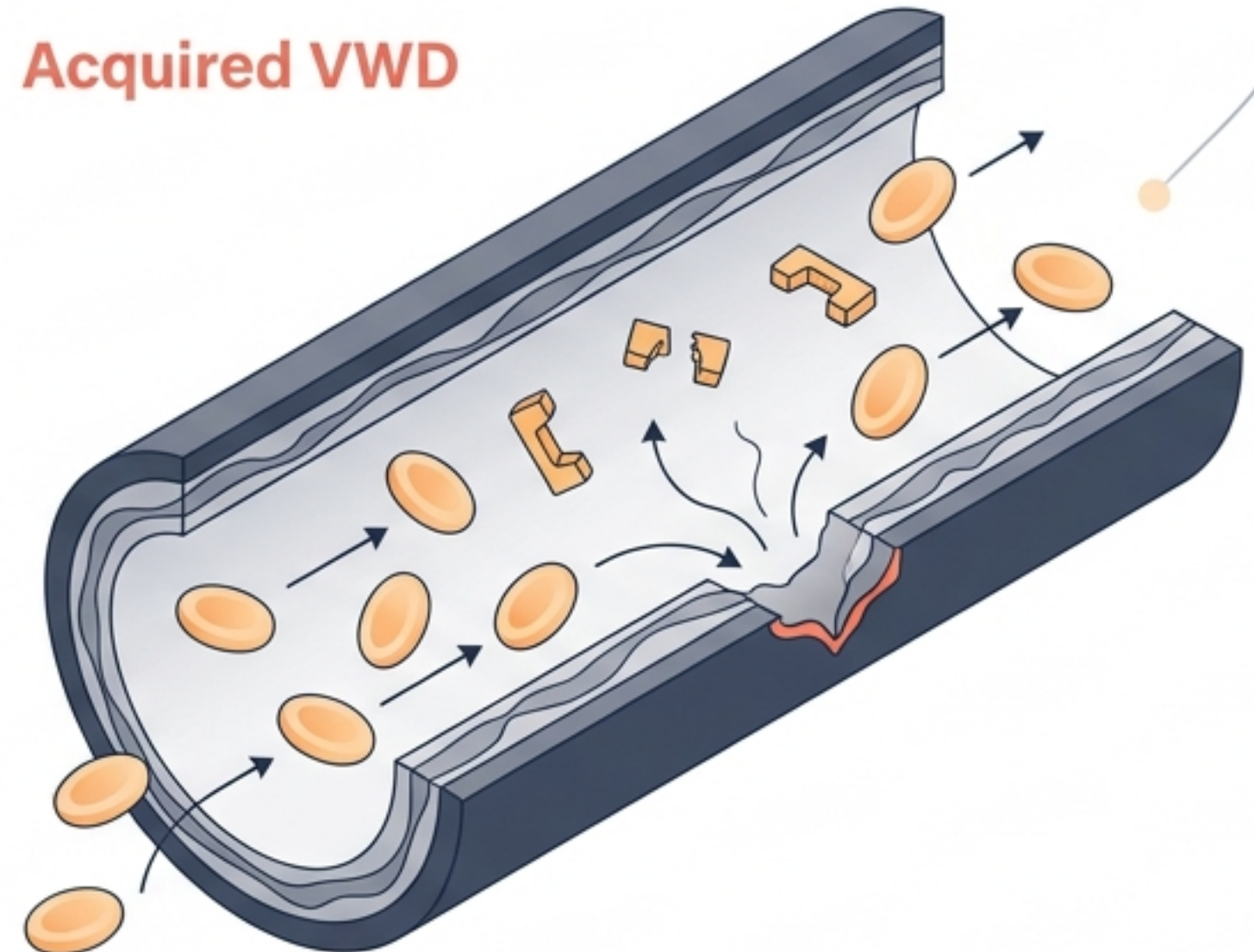
Von Willebrand Factor Acts as the Blood's 'Platelet Glue'

In acquired von Willebrand disease (aVWD), this crucial factor becomes low or stops working normally. Something in the body changes how it is made, how it circulates, or how quickly it is removed from the bloodstream.

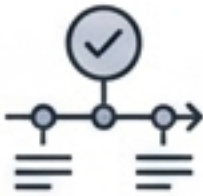
Normal Clotting



Acquired VWD



A Crucial Distinction: Acquired vs. Inherited

		Inherited VWD	Acquired VWD
Onset		Present from birth.	Develops later, often in adulthood.
Past History		Lifelong history of bleeding issues.	Usually had completely normal bleeding earlier in life.
Root Cause		Genetic trait passed down through families.	Caused by a separate, underlying medical condition affecting the von Willebrand factor.

The Bleeding is Usually a Clue to Something Else



The diagram features a stylized iceberg floating in a light blue-grey water. The tip of the iceberg, which is above the water line, is colored in shades of orange and yellow. A line points from this tip to the text 'Acquired Von Willebrand Disease'. The much larger, submerged part of the iceberg is a dark navy blue. A line points from this submerged part to the text 'The Underlying Medical Condition'. The background of the slide includes faint, decorative grey lines with small orange circles at the top right and bottom left corners.

Acquired Von Willebrand Disease

The visible bleeding symptoms.

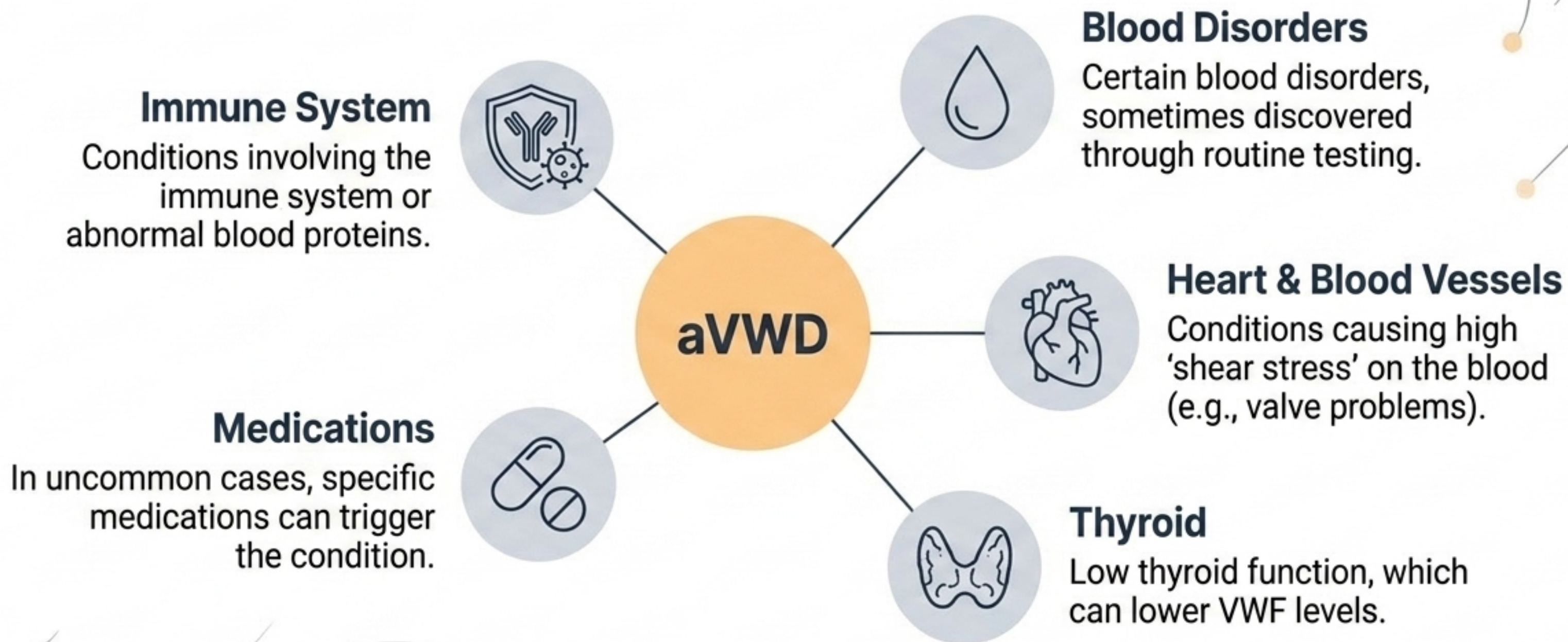
The Underlying Medical Condition

The true root cause hiding beneath the surface.

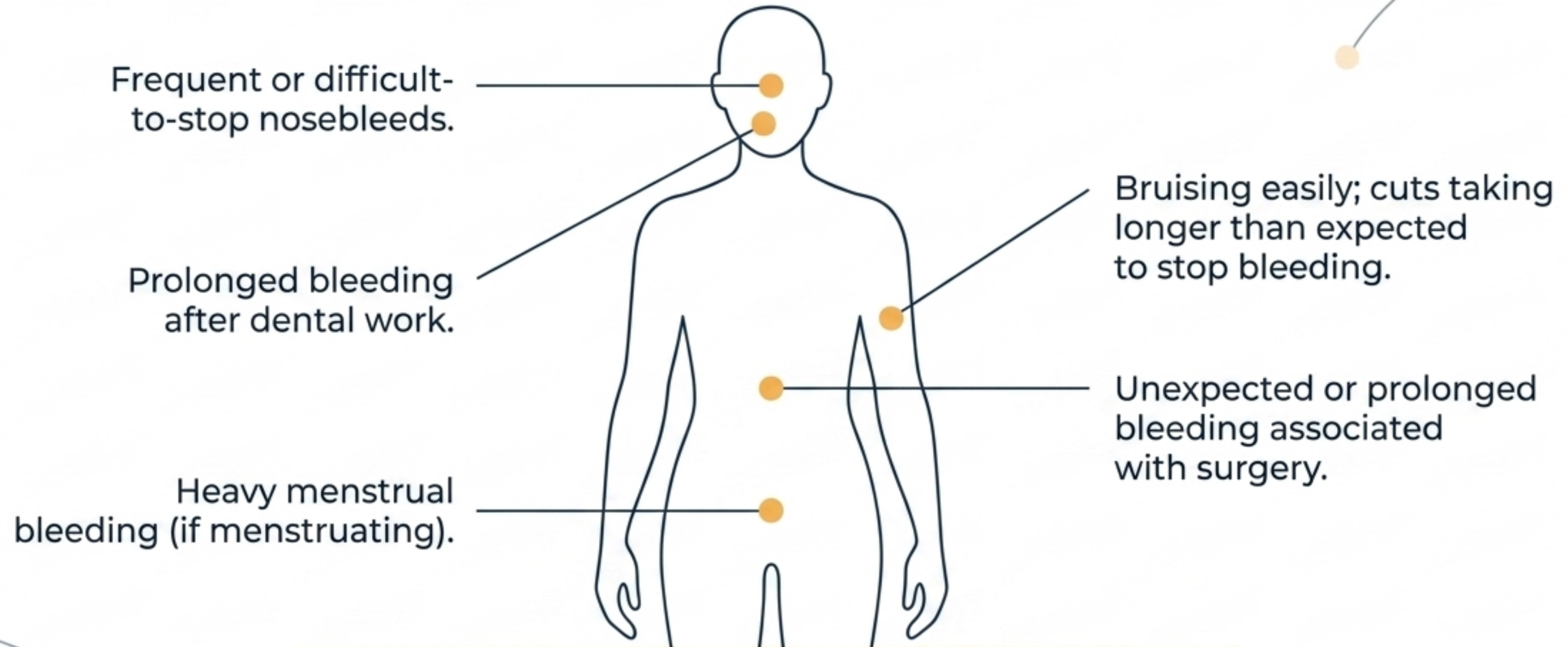
This diagnosis raises an obvious question: **'What is causing it?'**

The aVWD is a clue pointing your care team toward an underlying issue. Identifying this hidden condition is the key to effectively managing the bleeding risk.

Where the Clinical Investigation Leads



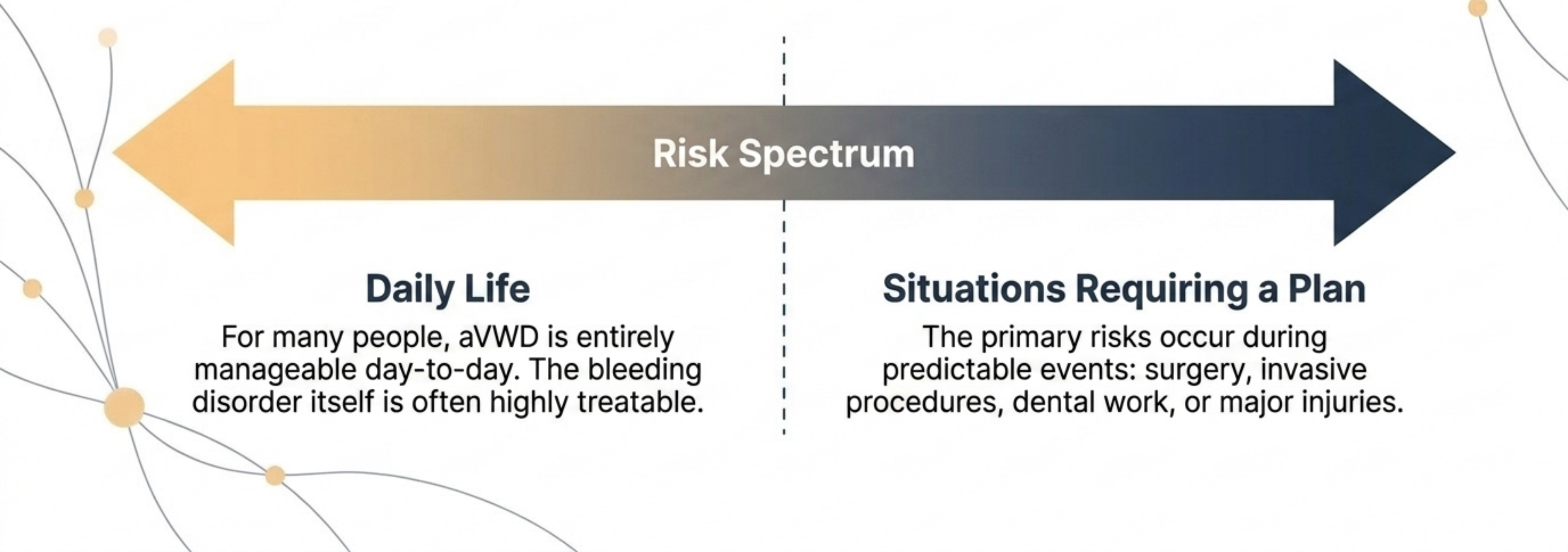
How the Condition Shows Up in Daily Life



Note: Many people are diagnosed only after an unexpected bleeding event or during routine pre-procedure testing.

Understanding Your Bleeding Risk

Depending on how low the von Willebrand factor becomes, some may experience bleeding without a clear trigger. The most important safety step is creating a **clear clinical plan** for predictable procedures.



Connecting the Dots for a Diagnosis



- 1. Measuring VWF:** Blood tests to measure both the amount of von Willebrand factor and how well it functions.



- 2. Seeking the Pattern:** Doctors do not rely on a single number. They interpret results as a pattern, which is why testing may be repeated.



- 3. The Underlying Workup:** Specific tests targeting the patient's history to find the root cause (checking immune health, abnormal proteins, heart valves, and thyroid function).



The Dual-Goal Treatment Strategy

**Manage
Bleeding
Risk Now**

Focuses on **immediate safety and symptom control.**

Goal: Keep the patient stable during daily life and planned procedures.

**Address the
Root Cause**

Focuses on the **underlying medical condition.**

Goal: Treat the immune, thyroid, or cardiac issue driving the disease.

In many cases, successfully treating the underlying cause **significantly improves**, and **sometimes entirely resolves**, the bleeding risk and VWF test results.

The Clinical Toolkit for Managing Bleeding



Clot-Stabilizers

Medicines designed for specific localized bleeding (nosebleeds, mouth, heavy menses) or used around surgical procedures.



Activity Improvers

Specific medications or temporary infusions that boost the activity of existing von Willebrand factor in the blood.



VWF Concentrates

Direct infusions containing von Willebrand factor, reserved for higher-risk situations and surgeries.



Root-Cause Therapies

Treatments directed entirely at the underlying condition (e.g., adjusting a medication, fixing a heart valve, correcting low thyroid). Treatment plans are always individualized.

Living Normally: Daily Life and Self-Care



Communicate Proactively

Always let clinicians and dentists know about the acquired VWD diagnosis before any procedures are scheduled.



Carry Your Summary

Keep a short, written summary of your exact diagnosis and medical treatment plan with you.



Check All Medications

Ask your doctor before starting any new medications, especially over-the-counter drugs that may increase bleeding risk (like aspirin or ibuprofen).

Triage Guide: When to Seek Medical Care

 Non-Emergency Check-Ins	 Immediate Emergency Care
• New or unusual bleeding • Heavy bleeding interfering with daily life • Upcoming dental or surgical work • Bleeding taking longer than expected to stop • Questions about anti-inflammatory meds	• Head injury or trauma • Severe abdominal pain • Black stools or vomiting blood • Heavy bleeding that is worsening and not responding to standard first-aid measures

Your Clinical Roadmap Going Forward

Confirm

Confirming the precise diagnosis and analyzing the specific pattern of testing.

Evaluate

Running targeted tests to discover the underlying cause.

Plan

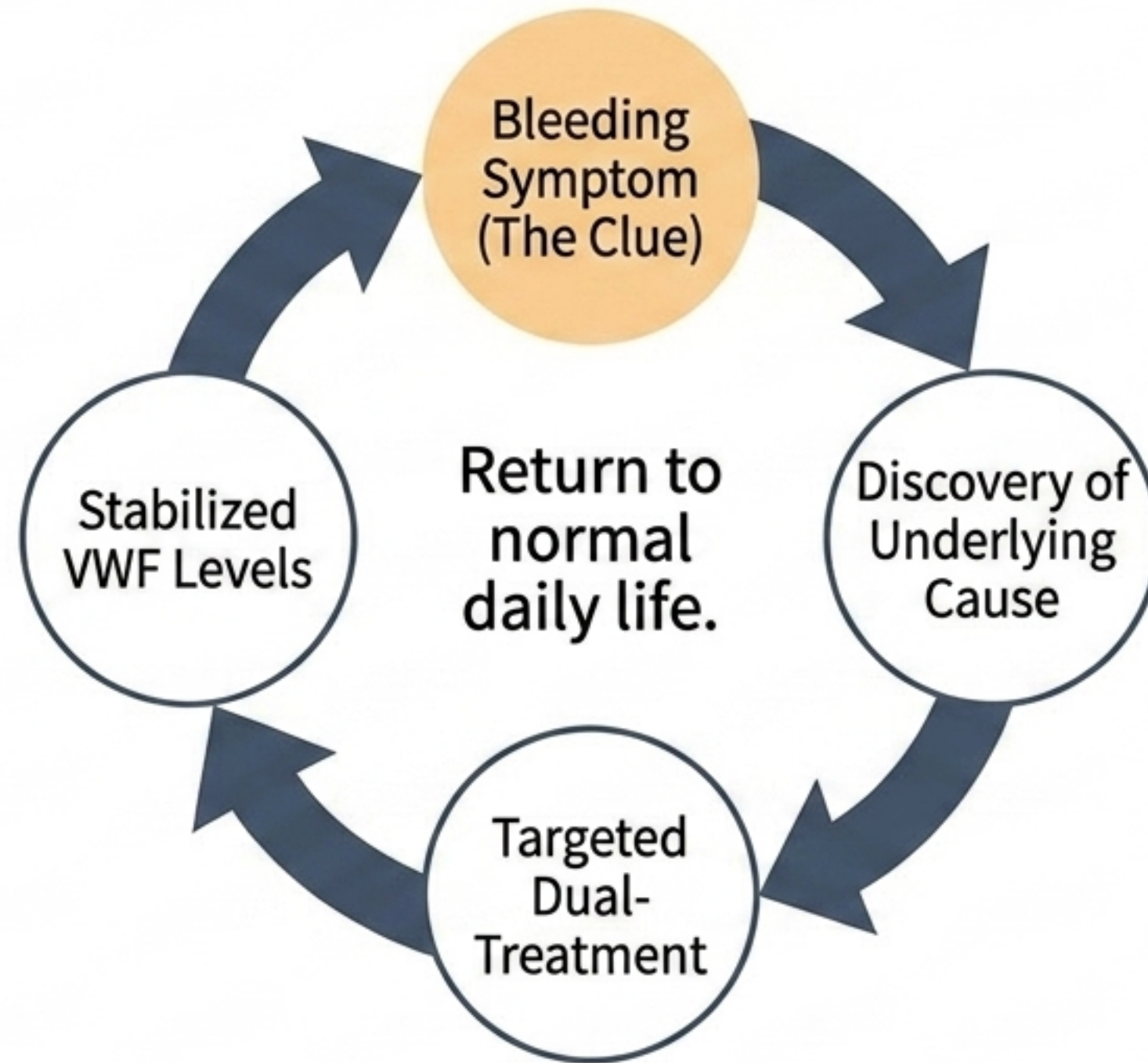
Creating a formal, written safety plan for any future procedures and potential emergencies.

Reassess

Monitoring over time, as treating the underlying condition may naturally improve VWF tests and lower bleeding risks.

(Note: Some require only temporary precautions; others need long-term hematology follow-up).

From Uncertainty to Action



An acquired diagnosis can feel like an extra layer of uncertainty at first. The reassuring point is that acquired von Willebrand disease is often a problem your care team can act on: identify a cause, plan ahead, and use effective treatments.

Five Things to Remember



1. **It is not inherited:** Acquired VWD develops later in life.



2. **It is usually a clue:** Finding and addressing the underlying cause can dramatically improve bleeding risk.



3. **Bleeding is situational:** Procedures, dental work, and injuries are the most common triggers.



4. **Testing is a puzzle:** Doctors interpret multiple test patterns together over time, not just single numbers.



5. **Planning prevents problems:** Having a clear procedure and emergency plan is your main safety tool.



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