The Blood Project

UNDERSTANDING ACQUIRED VON WILLEBRAND SYNDROME

A brief guide for patients with an acquired bleeding disorder

Acquired von Willebrand syndrome is a bleeding condition that develops later in life, usually in association with another medical condition. It affects how blood clots because von Willebrand factor, a protein that helps platelets stick to injured blood vessels and supports normal clot formation, is reduced or does not work properly.
Common associated conditions include heart valve or circulatory problems, immune system disorders, and certain blood conditions. Unlike inherited von Willebrand disease, acquired von Willebrand syndrome is not present at birth and does not run in families. In many cases, bleeding improves when the underlying condition is treated.

What is acquired von Willebrand syndrome?

Acquired von Willebrand syndrome occurs when von Willebrand factor becomes low or dysfunctional because of another medical problem, rather than a genetic condition.
The clotting protein itself is normal, but it may be removed from the bloodstream too quickly, blocked by antibodies, or altered by abnormal blood flow. As a result, bleeding can last longer than expected after injury, surgery, or procedures.
Because this condition develops later in life, it is often recognized when new or unexpected bleeding occurs in someone without a prior bleeding history.

What is acquired von Willebrand syndrome?

Inherited von Willebrand disease is present from birth and usually runs in families.
Acquired von Willebrand syndrome:

- develops later in life
- is not inherited
- is often linked to another medical condition
- may improve or resolve if the underlying cause is treated

This distinction matters because management focuses not only on controlling bleeding, but also on identifying and addressing the underlying problem. Family members do **not** need testing for this condition.

Why does it happen?

Acquired von Willebrand syndrome can occur in association with a variety of conditions, including:

- heart valve or circulatory conditions that affect blood flow
- disorders of the immune system
- some blood or bone marrow conditions, including those involving abnormal protein
- rare tumors or other chronic medical illnesses

These conditions can reduce von Willebrand factor levels or interfere with how the protein functions. In some cases, the body produces antibodies that block or remove von Willebrand factor from circulation.
Many causes are **benign and treatable**, and not everyone with these conditions develops bleeding. The severity of symptoms varies widely.

Does it cause symptoms?

Sometimes.

Symptoms may include:

- easy bruising
- frequent or prolonged nosebleeds
- bleeding that lasts longer than expected after dental work or surgery
- gastrointestinal bleeding (such as black or bloody stools)
- heavy menstrual bleeding (if applicable)

Symptoms often appear later in life and may feel new or unexpected. As with other bleeding disorders, symptoms do not always match lab values exactly.

Is acquired von Willebrand syndrome dangerous?

For most people, bleeding is manageable, especially once the condition is recognized.

Bleeding risk is most relevant during surgery, procedures, or when bleeding occurs in sensitive areas such as the gastrointestinal tract. Serious bleeding can occur, but prompt recognition and planning greatly reduce risk.

Outcomes usually depend more on the underlying medical condition than on the bleeding disorder itself.

How your doctor evaluates it

Doctors diagnose acquired von Willebrand syndrome by combining blood tests with clinical context.

Evaluation often includes:

- tests measuring von Willebrand factor level and function
- clotting studies
- review of bleeding history
- assessment for associated medical conditions
- repeat testing to confirm patterns over time

Because lab patterns can resemble inherited von Willebrand disease, the absence of a lifelong bleeding history and the presence of another medical condition help guide the diagnosis. Identifying the underlying cause may take time, but bleeding can usually be managed safely during the evaluation period.

What Is the treatment?

Treatment focuses on two goals: controlling bleeding and addressing the underlying cause.

Management may include:

- treatments to control bleeding during procedures or active bleeding
- medications that help stabilize clots
- von Willebrand factor replacement in selected situations
- treatment of the underlying medical condition, which may lead to improvement or resolution

Not everyone needs long-term treatment. In many cases, bleeding improves once the associated condition is treated or stabilized. Even when the underlying condition is chronic, bleeding risk can often be managed effectively with planning

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When should I contact my doctor?

You should contact your doctor if you experience:

- new or worsening bleeding
- bleeding that is harder to stop than expected
- gastrointestinal bleeding (such as black or bloody stools)
- planned surgery, dental work, or invasive procedures

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?

Follow-up depends on the underlying cause and the severity of bleeding.
Care often involves:

- monitoring bleeding symptoms and blood tests over time
- coordinating care before procedures or surgeries
- treating or managing the associated medical condition
- reassessing whether the bleeding disorder improves or resolves

In many cases, acquired von Willebrand syndrome is not permanent. With appropriate evaluation and treatment, bleeding risk can often be reduced and, in some people, eliminated.

Key points to remember

- **not inherited:** this condition develops later in life and does not run in families
- **often linked to another condition:** identifying the cause is essential
- **bleeding is usually manageable:** especially with planning and awareness
- **treatment is targeted:** both bleeding and the underlying problem are addressed
- **sometimes reversible:** bleeding may improve when the cause is treated