

Factor V Leiden

A plain-English guide for you and your family

WHAT IS HAPPENING

Normally, your blood has a careful balance between forming clots to stop bleeding and breaking down clots when they are no longer needed. Special proteins work like traffic lights—some say 'clot here' and others say 'stop clotting now.' Factor V Leiden is a genetic spelling mistake in the gene for factor V, one of the proteins that helps blood clot. The mistake makes factor V ignore the 'stop' signal, so clots form more easily than they should. Most people with this gene change live normal lives, but they have a higher chance of forming unwanted clots in veins, especially in the legs or lungs, particularly during times of extra risk like surgery, pregnancy, or long flights.

What you might feel

- Leg swelling (unilateral)
- Leg pain or tenderness
- Sudden shortness of breath
- Chest pain with deep breathing
- No symptoms at baseline
- Recurrent miscarriages
- Warmth in affected leg
- Rapid heart rate

Call the doctor right away if...

- Sudden shortness of breath with chest pain suggests pulmonary embolism (a clot lodging in a lung artery) requiring emergent CT angiography
- Leg swelling with warmth and cord-like vein needs urgent ultrasound for a clot in a deep leg vein (deep vein thrombosis)
- Family history of multiple clots before age 50 indicates high-risk thrombophilia requiring testing

- Clot in unusual site (hepatic vein, cerebral sinus) suggests severe combined thrombophilia needing hematology consultation

What the care team will do

- Monitor for signs of a clot in a deep leg vein (deep vein thrombosis) (DVT) and pulmonary embolism (a clot lodging in a lung artery) (PE)
- Educate patient about when to seek emergency care for clot symptoms
- Review all medications and supplements that increase clot risk
- Assess patient understanding of lifelong condition and inheritance pattern
- Ensure proper anticoagulation therapy during high-risk periods
- Teach prevention strategies like mobility and compression stockings
- Monitor for bleeding if patient is on anticoagulant therapy
- Coordinate care between hematology, obstetrics, and primary care providers

Medicines you may be given — and why

rivaroxaban

This medicine blocks Factor Xa, an enzyme in the coagulation cascade (clotting chain reaction). By stopping Factor Xa, the drug prevents conversion of prothrombin to thrombin (the main clotting enzyme). Less thrombin means less fibrin formation, so clots cannot grow.

apixaban

This drug directly attaches to Factor Xa enzyme and blocks its action. Factor Xa normally cuts prothrombin to create thrombin. When apixaban stops this step, the entire clotting cascade slows down. The body's natural clot-dissolving system can then clear existing clots.

warfarin

This medicine blocks vitamin K epoxide reductase, the enzyme that recycles vitamin K in the liver. Without recycled vitamin K, hepatocytes (liver cells) cannot activate clotting factors II, VII, IX, and X. These factors need vitamin K to add carboxyl groups that let them bind calcium and work properly.

enoxaparin

This injectable medicine is a short sugar chain that binds to antithrombin (a natural anticoagulant protein). The enoxaparin-antithrombin complex is 1000 times better at blocking Factor Xa than antithrombin alone. This stops the clotting cascade at an earlier step than warfarin.

fondaparinux

This is a man-made copy of the specific five-sugar sequence in heparin that activates antithrombin. It binds antithrombin and makes it 300 times more effective at neutralizing Factor Xa. Unlike heparin, it is too short to bind thrombin, so it only affects Factor Xa.

early mobilization and hydration

Walking and leg exercises contract calf muscles, which squeeze deep veins like a pump. This muscle pump action moves blood toward the heart and prevents stasis (pooling). Adequate fluid intake keeps blood viscosity (thickness) normal. Lower viscosity means faster flow and less clotting risk.

Where this information comes from

- American Society of Hematology (ASH) 2020 guidelines on venous thromboembolism: diagnosis, treatment, and prevention in adults
- American College of Chest Physicians (ACCP) Evidence-Based Clinical Practice Guidelines on Antithrombotic Therapy and Prevention of Thrombosis, 9th edition (2012, reaffirmed 2019)
- American College of Obstetricians and Gynecologists (ACOG) Practice Bulletin No. 197: Inherited Thrombophilias in Pregnancy (2018, reaffirmed 2022)
- National Institute for Health and Care Excellence (NICE) Clinical Guideline NG89: Venous thromboembolism in adults – reducing the risk in hospital and after discharge (2018, updated 2019)

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