

Vasculitis

A plain-English guide for you and your family

WHAT IS HAPPENING

Blood vessels are the body's delivery highways—they carry oxygen and food to every organ. When they are healthy, their walls are smooth and open. In vasculitis, the immune system (the body's defense army) makes a terrible mistake: it decides the vessel walls are the enemy and attacks them. This attack causes swelling, which can narrow or block the highway. It also makes the walls fragile, so they can leak blood or even tear. The first clues are often fever (the immune fight heats the body) and weight loss (the body is burning fuel to fight). Then you may see red spots on the skin (tiny bleeding), blood in the urine (kidney vessels leaking), coughing up blood (lung vessels breaking), weakness in hands or feet (nerves starving from no blood), or severe belly pain (gut losing its supply). Which organs get hit depends on the size of the vessels under attack. Giant cell arteritis hits the big arteries in the head and can cause sudden blindness. Takayasu arteritis hits the big trunk arteries. Medium-vessel types (like polyarteritis nodosa) damage kidneys, gut, and nerves. Small-vessel types (like granulomatosis with polyangiitis) often hit lungs and kidneys together. The key is to recognize the pattern early, confirm it with blood tests (ANCA, ESR, CRP) and sometimes a tissue sample, and then calm the immune attack with steroids and stronger immune-quieting medicines before permanent damage happens.

What you might feel

- Fever that won't go away
- Weight loss you didn't try for
- Purple or red spots on the skin (purpura)
- Numbness, tingling, or weakness in hands or feet
- Blood in the urine (hematuria)
- Jaw pain when chewing (jaw claudication)
- New, severe headache (often at the temples)
- Sudden vision loss or double vision
- Cough, wheezing, or shortness of breath
- Joint pain and swelling (arthralgia or arthritis)

Call the doctor right away if...

- Sudden vision loss or new severe headache in someone over 50 (possible giant cell arteritis — needs urgent steroids to save sight)
- Blood in the urine plus swelling or high blood pressure (kidney damage can spiral quickly)
- Coughing up blood or fast-worsening shortness of breath (lungs may be bleeding or severely inflamed)
- Numbness, weakness, or stroke-like symptoms (brain blood vessels may be involved)

What the care team will do

- Check vision in each eye separately every 4 hours and report any new blurry vision, blind spots, or vision loss to the provider immediately
- Monitor oxygen saturation continuously and listen to lung sounds every 2 hours; report oxygen saturation below 92 percent or new crackles
- Measure urine output every hour and check urine color; report output less than 0.5 mL per kilogram per hour or dark urine
- Administer high-dose corticosteroids exactly on time (usually prednisone 40 to 60 mg daily or IV methylprednisolone 1000 mg daily for severe cases) and never hold the dose without provider order
- Check blood pressure in both arms and both legs at admission and then every 4 hours; report differences greater than 10 mmHg between arms
- Monitor blood glucose (finger-stick) every 6 hours and give insulin per sliding scale if glucose is above 180 mg/dL
- Assess skin, nose, and extremities for new purple bleeding blotches (purpura) (purple spots), ulcers, or black discolored areas (necrosis); photograph and measure any skin changes
- Test hand grip strength and foot dorsiflexion (ability to lift toes up) every shift and ask about new numbness or tingling

Medicines you may be given — and why

Prednisone (corticosteroid)

Prednisone quiets down the immune system's attack on blood vessel walls. It works like a dimmer switch: it turns down the production of inflammatory chemicals (cytokines like TNF-alpha and IL-1) that white blood cells release when they're fired up. By cooling the inflammation, it stops the swelling and damage inside the arteries and veins so blood can flow normally again.

Cyclophosphamide (Cytoxan)

Cyclophosphamide shuts down the immune cells (B cells and T cells) that are attacking the blood vessels. It works by damaging the DNA inside rapidly dividing immune cells so they can't multiply. Because the immune army can't keep growing, the attack on the vessel walls stops and inflammation fades.

Rituximab (Rituxan)

Rituximab targets and removes B cells, the immune cells that make harmful antibodies (like ANCA) that tag blood vessels for attack. It works like a smart eraser: it sticks to a marker (CD20) on the surface of B cells and flags them for destruction. Once the B cells are gone, the production of damaging antibodies stops and inflammation in the vessels quiets down.

Methotrexate

Methotrexate slows down immune cells by blocking an enzyme (dihydrofolate reductase) they need to build DNA. Think of it like cutting off the supply of bricks to a construction crew—without enough building blocks, immune cells (especially T cells) can't multiply as fast. This calms the immune attack on blood vessel walls and keeps inflammation low after the initial flare is controlled.

Azathioprine (Imuran)

Azathioprine tricks immune cells by mimicking a building block (purine) they need to copy their DNA. When immune cells (especially T and B cells) try to use azathioprine as a brick, they can't finish building new DNA, so they stop multiplying. This keeps the immune attack on blood vessels under control and helps prevent relapses after the initial treatment.

Tocilizumab (Actemra)

Tocilizumab blocks a specific inflammatory signal called interleukin-6 (IL-6), which is one of the main alarm bells that keep the immune attack going in giant cell arteritis. It works by attaching to the IL-6 receptor on immune cells, so IL-6 can't deliver its 'keep fighting' message. Without that signal, the inflammation in large arteries (especially the temporal artery and aorta) cools down and symptoms improve.

Aspirin (low-dose, 81 mg daily)

Low-dose aspirin keeps platelets (the sticky blood cells that form clots) from clumping together too easily. It works by blocking an enzyme (cyclooxygenase-1, or COX-1) inside platelets that makes thromboxane A2, a chemical that tells platelets to stick and form a plug. By preventing clots, aspirin lowers the risk of stroke and heart attack in patients with inflamed arteries (especially in giant cell arteritis).

Plasma Exchange (PLEX, plasmapheresis)

Plasma exchange is like doing a partial oil change on the blood. A machine filters the patient's blood, removing the liquid part (plasma) that contains harmful antibodies (like ANCA) and inflammatory proteins. The blood cells are mixed with fresh donor plasma or a replacement fluid and returned to the body. This quickly lowers the level of antibodies attacking the kidneys and lungs in severe ANCA-associated vasculitis.

Where this information comes from

- ACR/EULAR 2022 Classification Criteria for Vasculitis
- Chapel Hill Consensus Conference (CHCC) 2012 Nomenclature
- Cochrane systematic reviews on vasculitis treatment
- UpToDate clinical guidelines (Rheumatology)

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