

Guillain Barr Syndrome

A plain-English guide for you and your family

WHAT IS HAPPENING

Your peripheral nerves are like electrical wires that carry signals from your brain and spinal cord out to every muscle and patch of skin. Each nerve fiber is wrapped in a fatty insulation called myelin, just like the plastic coating on a wire, so the signal travels fast and clear. Your immune system normally patrols for germs and leaves your own tissue alone. In Guillain-Barré syndrome, something flips that switch: a few days to weeks after an infection—often a stomach bug from *Campylobacter* bacteria, or sometimes a respiratory virus—your immune system gets confused and starts attacking the myelin wrapping on your peripheral nerves. The attack usually begins in the longest nerves first, the ones running down to your feet, so weakness and tingling start there and then climb upward over hours to days—into your legs, then your trunk, arms, and sometimes your face. Because the myelin is damaged, signals cannot jump quickly, so your muscles get weak and your reflexes disappear. In severe cases the weakness reaches the diaphragm and the muscles between your ribs, making it hard to take a deep breath, and that is when a breathing tube may be needed. The good news is that most people stop getting worse within four weeks, and then the nerves slowly rebuild their myelin wrap over months—about two out of three people recover fully, though it takes time and sometimes rehab to get strength back.

What you might feel

- Weakness that starts in the legs and climbs up
- Tingling or numbness in the hands and feet
- Trouble walking or standing
- Loss of reflexes (like the knee-jerk reflex)
- Pain in the back, legs, or muscles
- Trouble breathing or swallowing
- Fast or uneven heart rate, or blood pressure swings
- Recent infection one to four weeks before weakness started

Call the doctor right away if...

- Trouble breathing, shortness of breath, or feeling like you cannot take a deep breath
- Trouble swallowing, drooling, or choking on food or water
- Weakness spreading to the chest, neck, or face within hours
- Heart racing, slowing, or skipping beats; blood pressure swinging high and low
- Cannot stand or walk at all, or weakness has reached both arms

What the care team will do

- Check forced vital capacity (FVC) or negative inspiratory force (NIF) every 4 hours and watch for shallow breathing, trouble speaking full sentences, or using neck muscles to breathe.
- Place patient on continuous cardiac monitor and check blood pressure every 2 hours, watching for heart rate below 50 or above 120, and blood pressure swings greater than 40 mmHg.
- Turn patient every 2 hours, keep heels off the bed with pillows, and apply sequential compression devices (SCDs) to both legs unless patient has clots already.
- Assess swallow safety before any food or pills by mouth; keep suction at bedside and head of bed elevated 30 to 45 degrees at all times.
- Perform passive range-of-motion exercises to all joints twice every shift and position arms and legs in neutral alignment with splints if needed.
- Assess pain level every 4 hours using 0-to-10 scale and give scheduled gabapentin or pregabalin, not only as-needed opioids.
- Monitor urine output every shift and check for bladder distension (swollen bladder) above the pubic bone; consider bladder scan or straight catheterization if patient has not urinated in 6 hours.
- Provide eye care every 4 hours with artificial tears and tape eyelids closed during sleep if patient cannot blink fully.

Medicines you may be given — and why

IVIG (intravenous immunoglobulin)

IVIG floods the bloodstream with normal antibodies from thousands of healthy people. These good antibodies crowd out and block the rogue antibodies that are attacking the nerve coating. They also calm down the overactive immune cells and help the body stop the attack on its own nerves.

Plasma exchange (plasmapheresis, or PLEX)

A machine takes blood out of your body, spins it to separate the liquid part (plasma) from the cells, throws away the plasma (which contains the attacking antibodies), and returns the clean cells mixed with fresh donor plasma or a replacement fluid. This physically removes the rogue antibodies so they can't keep damaging your nerves.

Gabapentin

Gabapentin attaches to calcium channels on nerve endings and dials down the pain signals that fire when nerves are damaged or irritated. It does not heal the nerve, but it quiets the 'alarm bells' so the pain is less intense.

Opioid analgesics (e.g. oxycodone, morphine)

Opioids attach to opioid receptors on nerve cells in the spinal cord and brain. This blocks pain signals from traveling up to consciousness and changes how the brain interprets pain, making severe nerve pain more bearable in the short term.

Low-molecular-weight heparin (e.g. enoxaparin) or unfractionated heparin

Heparin attaches to a natural protein in your blood called antithrombin and supercharges it. Antithrombin then shuts down clotting factors (especially Factor Xa and thrombin), making your blood less sticky. This prevents dangerous clots from forming in the legs or lungs when you are lying still and paralyzed.

Where this information comes from

- American Academy of Neurology (AAN) Guillain-Barré Syndrome Guidelines 2021
- Cochrane Systematic Review on Guillain-Barré Syndrome
- National Institute of Neurological Disorders and Stroke (NINDS)
- New England Journal of Medicine Clinical Practice Review

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