

Encephalitis

A plain-English guide for you and your family

WHAT IS HAPPENING

Your brain sits inside a hard, bony skull and is protected by a special wall called the blood-brain barrier. This barrier acts like a strict security gate: it lets oxygen and nutrients through but blocks most germs. Normally, viruses floating in your blood cannot cross into brain tissue, so your brain stays clean and safe. But certain viruses—especially herpes simplex type 1 (the same virus that causes cold sores on your lip), the chickenpox virus hiding in your nerves, or viruses spread by mosquito bites—can break through that barrier and start multiplying inside the brain itself. Sometimes there is no virus at all: the immune system gets confused and makes antibodies that attack the brain's own cells, especially in children and young adults. When either of these things happens, brain tissue swells. Because the skull is rigid and cannot stretch, that swelling has nowhere to go—it squeezes the brain and disrupts the electrical signals that let you think, move, and remember. You or your loved one may suddenly have a high fever, a severe headache, confusion, seizures (shaking or staring spells that you cannot stop), weakness on one side of the body, or strange behavior—like forgetting where you are, saying things that make no sense, or acting completely unlike yourself. These symptoms can start over hours to a few days. Doctors begin acyclovir immediately because untreated herpes encephalitis kills more than 70 out of 100 people, but early treatment saves lives. Tests like an MRI scan of the brain and a lumbar puncture (taking a small sample of fluid from around the spinal cord with a needle in the lower back) help identify the exact cause so the right treatment can continue. With prompt care, many people recover, though some may be left with lasting memory trouble, personality changes, or seizures, depending on how much brain tissue was damaged before treatment started.

What you might feel

- Fever
- Headache
- Confusion or change in behavior
- Seizures
- Weakness or trouble moving one side of the body

- Trouble speaking or understanding words
- Stiff neck
- Sensitivity to light (photophobia)
- Sleepiness or difficulty waking up
- Hallucinations or seeing or hearing things that aren't there

Call the doctor right away if...

- Seizures or repeated jerking movements
- Cannot stay awake or is very hard to wake up
- Sudden weakness or numbness on one side of the body
- Severe confusion or aggressive, strange behavior that is brand new
- Trouble breathing or very slow, irregular breathing

What the care team will do

- Check airway, breathing, and oxygen saturation every 15 minutes until stable; keep oxygen saturation above 94 percent with supplemental oxygen
- Perform and document a full neurological check every hour: Glasgow Coma Scale score, pupil size and reaction to light, arm and leg strength on both sides, and ability to follow commands
- Start IV acyclovir within 30 minutes of the order and give every 8 hours on time; hang each dose over 1 hour and flush the line with at least 100 mL normal saline after each infusion
- Place the patient on continuous seizure precautions: padded side rails up, suction at bedside, IV access secure, and lorazepam 4 mg drawn up and ready; watch for subtle seizures like lip smacking, eye twitching, or staring spells
- Keep the head of the bed elevated 30 degrees, keep the neck straight and midline, and avoid tight cervical collars or neck flexion
- Maintain a quiet, dimly lit room; limit visitors to one at a time; cluster care to allow 90-minute rest periods; avoid sudden loud noises or bright overhead lights
- Monitor strict intake and output every hour; alert the provider immediately if urine output drops below 30 mL per hour or if urine becomes dark or cloudy
- Check temperature every 2 hours and treat any fever above 38.3°C (101°F) promptly with acetaminophen 650 mg oral or rectal; use a cooling blanket if fever does not drop within 30 minutes

Medicines you may be given — and why

Acyclovir (IV)

Acyclovir tricks the herpes virus into using it as a building block when the virus tries to copy its DNA (the instruction manual inside the virus). Once acyclovir gets inside that copying machine, it jams it shut so the virus can't make more of itself. The virus dies out, and your immune system can catch up and clear what's left.

Ganciclovir (IV) or Foscarnet (IV)

These drugs stop cytomegalovirus (CMV) from copying its DNA. Ganciclovir works like acyclovir—it tricks the virus into using it as a fake DNA piece, then jams the copying machine. Foscarnet skips that trick and directly blocks the virus's DNA polymerase (the enzyme that copies DNA). Both stop CMV from multiplying in the brain.

Dexamethasone (IV or oral)

Dexamethasone turns down the immune system's alarm bells. In some kinds of encephalitis—like autoimmune or post-infectious types—your own immune cells attack brain tissue and cause swelling. Dexamethasone tells those immune cells to calm down and stop releasing inflammatory chemicals (cytokines like TNF-alpha and interleukins). This lowers brain pressure and protects brain cells from collateral damage.

IVIG (Intravenous Immunoglobulin)

IVIG is a mixture of antibodies collected from thousands of healthy blood donors. When your own immune system is mistakenly attacking your brain (autoimmune encephalitis), IVIG floods your body with normal antibodies that calm down the rogue immune cells. It also blocks harmful autoantibodies from sticking to brain cell receptors (like NMDA receptors or VGKC) and helps clear those bad antibodies faster.

Levetiracetam (Keppra) or Phenytoin (Dilantin)

These drugs calm overexcited brain cells that are firing out of control and causing seizures. Levetiracetam works by binding to the SV2A protein on nerve terminals, which controls how much neurotransmitter (chemical signal) gets released. When it blocks this protein, cells can't fire as wildly. Phenytoin blocks voltage-gated sodium channels—the doors that let electrical signals rush through a neuron—so cells can't fire rapidly over and over.

Mannitol (IV) or Hypertonic Saline (3% NaCl IV)

When the brain swells inside the rigid skull, pressure builds up and can crush brain tissue against bone. Mannitol and hypertonic saline pull water out of swollen brain tissue and into the blood vessels, like a sponge drawing water. This shrinks the swelling and lowers the

intracranial pressure (ICP), buying time for other treatments—antiviral, anti-inflammatory, or surgery—to work.

Where this information comes from

- IDSA Clinical Practice Guideline for Encephalitis 2008
- American Academy of Neurology Autoimmune Encephalitis Guidelines 2016
- CDC Arboviral Encephalitis
- Cochrane Systematic Reviews

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