We need your help!

- Spinal CSF leak and intracranial hypotension cause profoundly disabling neurological symptoms in a majority of patients. Many patients lose the ability to work.
- Although outcomes improve with early treatment, many spinal CSF leak patients face misdiagnosis and delays in accessing care. Greater awareness and education are needed to increase recognition of the condition among healthcare professionals and the general public.
- More research is needed to advance the field and improve spinal CSF leak diagnostics, testing, and treatment.
- While most spinal CSF leak patients see positive outcomes, some continue to suffer from ongoing symptoms despite currently available treatments. We need a better understanding of why this happens.

Who we are:

Spinal CSF Leak Foundation is a 501(c)(3) non-profit heath advocacy organization. Our mission is to reduce the suffering of any person affected by spinal CSF leak or intracranial hypotension.

We strive to close information gaps, support and fund research, raise awareness, and educate patients, medical professionals, and caregivers.

Get involved!

Volunteer with us:
spinalcsfleak.org/get-involved/volunteer

Make a tax-deductible donation:
spinalcsfleak.org/donate

Fundraise for awareness & education:
spinalcsfleak.org/get-involved/fundraise

Join ileak registry℠ for spinal CSF leak:
ileakregistry.org

Follow us online:

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A patient's guide to

SPINAL CSF LEAK

and

SPONTANEOUS INTRACRANIAL HYPOTENSION

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What is spinal CSF leak?

Spinal cerebrospinal fluid (CSF) leak is a debilitating and underdiagnosed neurological condition caused by leakage of CSF through the spinal dura mater. The dura mater is a membrane that holds CSF in and around the brain and spinal cord.

Leakage of CSF can occur through a tear or other defect in the dura mater, or through an abnormal connection to a paraspinal vein. The resulting loss of CSF volume can lead to reduced CSF pressure around the brain, referred to as intracranial hypotension.

What are common symptoms of spinal CSF leak?

The following are common symptoms:

- Headache or head pain that is worse when upright and better when horizontal (though other patterns do occur)
- Nausea and vomiting
- Neck pain or stiffness
- Changes in hearing (muffled, tinnitus)
- Sense of imbalance
- Photophobia (light sensitivity)
- Phonophobia (sound sensitivity)
- Pain between the shoulder blades
- Pain or numbness of arms
- Cognitive changes (“brain fog”)
- Dizziness or vertigo
- Fatigue
- Visual changes (blurring, double vision)

What are the causes of spinal CSF leak?

Medical Procedures

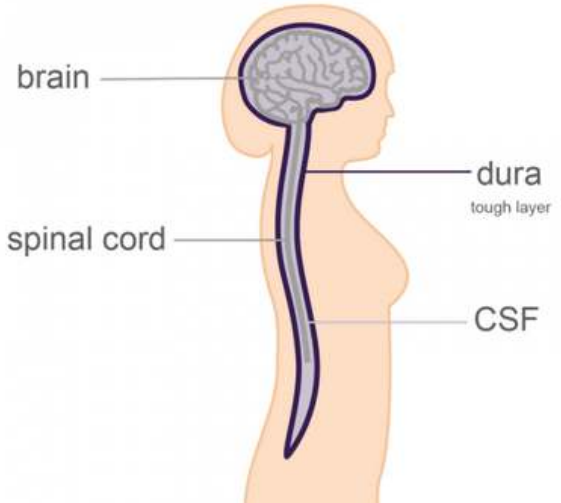
- Lumbar puncture (spinal tap)
- Spinal anesthesia
- Labor epidural
- Epidural steroid injection
- Spinal surgery

Injuries

- Fall
- Motor vehicle accident

Spontaneous Intracranial Hypotension

- Associated with an abnormally thin or weak dura as may be seen with a number of genetic connective tissue disorders, such as Marfan syndrome or Ehlers-Danlos syndrome.
- A dural tear may result from a bone spur, a calcified disc, or other causes.
- An abnormal connection between the normal space containing CSF and veins outside the dura mater, called a CSF-venous fistula, can form.



How is spinal CSF leak diagnosed?

Symptoms

The diagnosis can be suspected on the basis of the patient’s symptoms.

Brain imaging

MRI of the brain without and with contrast should be performed when a spinal CSF leak is suspected. Specific brain imaging findings are found in 80% of cases, although normal imaging does not rule out a diagnosis.

Spine imaging

Several types of specialized spinal imaging called myelography may be used to locate a CSF leak. Types include MRI, CT, and Digital Subtraction Myelography.

How is spinal CSF leak treated?

Conservative treatment

Bedrest, fluids, and extra caffeine may allow some cases to resolve fully.

Epidural Blood Patching

Epidural blood patching is a commonly performed treatment where a doctor injects a small amount of the patient’s own blood (and/or fibrin glue) into their epidural space.

Transvenous Embolization

Transvenous embolization is a minimally invasive procedure where a doctor accesses a CSF-venous fistula via the patient’s vein, and seals it with a liquid embolic agent.

Surgery

Some patients require direct surgical repair by a neurosurgeon.