



## Why do we need your help?

- **Greater awareness and education** is needed to improve familiarity of spinal CSF leaks among health care professionals and the general public. This will help to shorten delays to diagnosis and treatment.
- The full range of specialized diagnostic imaging is not available in all centers and even in expert hands may still fail to identify a leak.
- While a cure is possible for many, a few patients do suffer for years despite currently available treatments.
- **More research** is needed to advance our understanding of all aspects of the disorder and to improve testing and treatments.

## How can you help?

### Get involved

[www.spinalcsfleak.org/get-involved](http://www.spinalcsfleak.org/get-involved)

### Volunteer

[volunteer@spinalcsfleak.org](mailto:volunteer@spinalcsfleak.org)

### Donate

- support education of general public and medical professionals
- support research

## Who we are

**Spinal CSF Leak Foundation** is a 501(c)(3) non-profit health advocacy organization.

Our mission is to reduce the suffering of those affected by spinal CSF leaks.

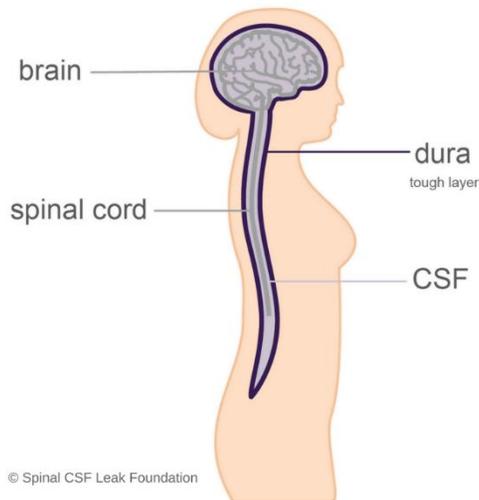


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**INTRACRANIAL  
HYPOTENSION**

**SPINAL CSF LEAK**



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## What is a spinal CSF leak?

**Spinal cerebrospinal fluid (CSF) leak is an important and under-diagnosed cause of new onset headache that is treatable.**

CSF is a special fluid that bathes and supports the brain and spinal cord. When the tough layer known as dura that holds CSF in around the spinal cord has a hole or tear, the result is a loss of CSF volume, known as **intracranial hypotension**.

The most common symptom is a positional headache that is worse after minutes to hours upright and improved when lying down, but there are many other signs and symptoms. Patients may be quite disabled by their inability to be functional while upright.

## What are the causes of spinal CSF leaks?

### Medical Procedures

- lumbar puncture (spinal tap)
- epidural injection (spinal injection)
- spinal or other surgery

### Injuries

- fall
- motor vehicle accident

### Spontaneous

- associated with 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 spinal bone spur or calcified disc may be the cause of a seemingly spontaneous dural tear



Lori has Ehlers-Danlos syndrome and Chiari as well as spinal CSF leaks. Bailey, her kitty, comforts her.

## How is a spinal CSF leak diagnosed?

### Symptoms

The diagnosis is suspected on the basis of the patient's symptoms.

### Brain imaging

MRI of the head without and with contrast should be performed in most cases. There are several typical findings seen in about 80% of cases although normal imaging does not rule out the diagnosis.

### Spinal imaging

Specialized spinal imaging is used to locate the CSF leak. MRI, CT and digital subtraction imaging are used.

## How is a spinal CSF leak treated?

### Initial treatment

Bedrest, fluids and extra caffeine may allow some cases to resolve without any further treatment.

### Spinal Injection Procedures

For those that require treatment, a type of spinal injection procedure called epidural patching is commonly performed. This can be repeated a number of times.

### Surgery

Some patients require surgical repair by a neurosurgeon. A few patients will require a number of procedures.