



## Imaging and Investigation (cont.)

CT Myelography, MR Myelography and/or Digital Subtraction Myelography (for spinal leaks) may be used to locate a suspected leak that has not been identified through more conventional imaging.

These are invasive scans which require a lumbar puncture to enable contrast to be injected into the CSF. They are not available at all hospitals, but if performed and interpreted by a radiologist with suitable experience, can often return good results.

For cranial CSF leaks, radionuclide cisternography remains a relatively common test. Pledgets are normally placed in the nose and ears to detect any leaked contrast. Beta 2 Transferrin testing can also be used with cranial leaks to test the composition of any nasal drip or other discharge collected.



## Treatment and Prognosis

In many cases, a CSF leak will heal on its own following **conservative treatment**, including bed rest, increased fluid intake and caffeine.

Not all leaks will respond to such an approach and surgical or other interventions may be necessary.

Spinal leaks may require a procedure known as a **blood patch**, where blood is injected into the epidural space in order to promote healing.

Where a blood patch is not successful, a surgical sealant, known as **fibrin glue**, may be injected into the same space, providing a stronger fix.

For more complex spinal cases or unresolved cranial leaks, **neurosurgery** can be used to good effect, if the site of the leak is known.

In a lesser, but not insignificant number of cases, CSF may continue to leak despite repeated repair attempts, leading to **long-term disability**.

# Who we are






The CSF Leak Association is a UK-based charity working to raise awareness of **cerebrospinal fluid leaks**, with a particular focus on spinal CSF leaks.

We are passionate about improving access to **quality information and resources**, and securing swift access to the most appropriate **diagnostic techniques and treatment** options.

We advocate the development of **clear and consistent patient pathways** within the NHS, and support research into CSF leak aetiology, investigation and resolution.

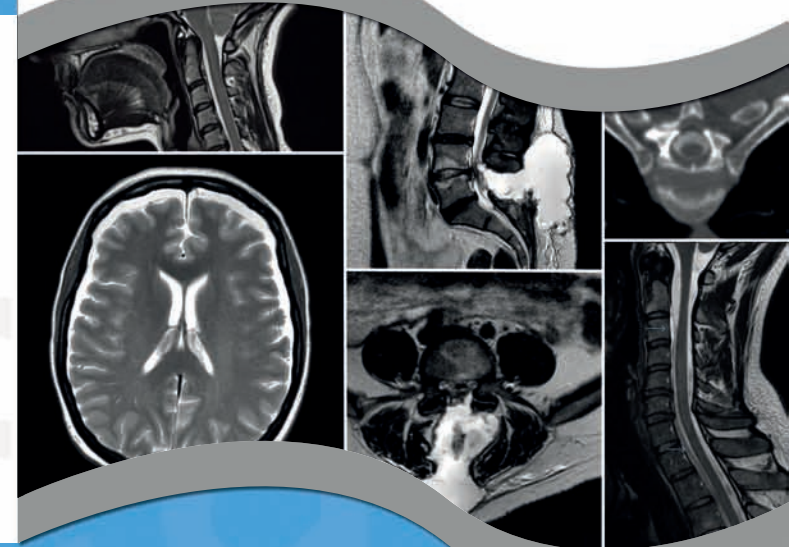
### More Information

If you would like to find out more about CSF leaks, keep up-to-date with charity news, join us in membership or offer much-needed support, you can find us at:

-  [www.csfleak.info](http://www.csfleak.info)
-  [csfleakassociation](https://www.facebook.com/csfleakassociation)
-  [csfleakinfo](https://twitter.com/csfleakinfo)



This leaflet has been produced in consultation with UK neurologists, Dr Simon Ellis and Dr Manjit Matharu. It has been prepared in good faith in order to raise awareness and inform discussion. It cannot, however, be guaranteed error-free and is not a substitute for professional healthcare advice. You must consult your doctor and discuss healthcare options with them. The CSF Leak Association is a Scottish Charitable Incorporated Organisation (Charity No. SC046319). Copyright © 2017 CSF Leak Association. All Rights Reserved. [v3.00/2017]



## Cerebrospinal Fluid Leaks

### An Overview

## ? What is a Cerebrospinal Fluid Leak?

A cerebrospinal fluid (CSF) leak is a potentially incapacitating medical condition where a hole, tear or defect forms in the dura mater.

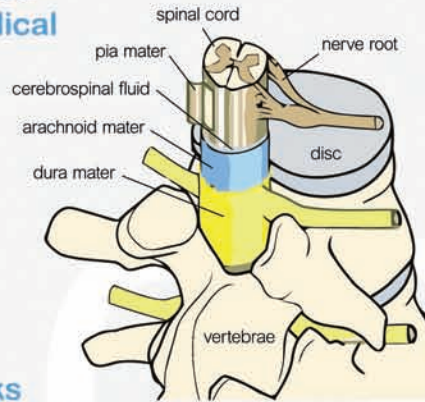
The dura mater is a membrane which holds in the CSF, a clear and colourless fluid that supports, bathes and protects the brain and spinal cord.

When CSF leaks out, the volume of fluid around the brain reduces. This can cause it to sag, impacting upon nerves and the brain stem, and causing pain.

A CSF leak can occur as a **result of medical intervention, trauma, an underlying disorder or spontaneously.**

At least **5 in 100,000 people** suffer from **spontaneous leaks**

alone, and many more from iatrogenic leaks; misdiagnosis remains common.



## Spinal CSF Leak Symptoms

Common symptoms of a spinal leak, and closely associated intracranial hypotension, can include:

- ❖ Headache (worse when upright, relieved when lying down)
- ❖ Neck pain, ache or stiffness
- ❖ Interscapular pain (between the shoulder blades)
- ❖ Pain, tingling or numbness in the arms
- ❖ Nausea and vomiting
- ❖ Ear ache and hearing changes (incl. muffled and popping)
- ❖ Tinnitus (pulsatile and high-pitched)
- ❖ Photophobia (sensitivity to light)
- ❖ Phonophobia (sensitivity to sound)
- ❖ Dizziness, vertigo or a sense of imbalance
- ❖ Cognitive impairment or 'brain fog'

Less common signs or symptoms can include:

- ❖ Visual changes (incl. blurring and double vision)
- ❖ Facial numbness or pain (incl. jaw pain/ache)
- ❖ Changes in taste (incl. metallic taste)
- ❖ Pain or numbness at various nerve root levels

Rare signs or symptoms can include:

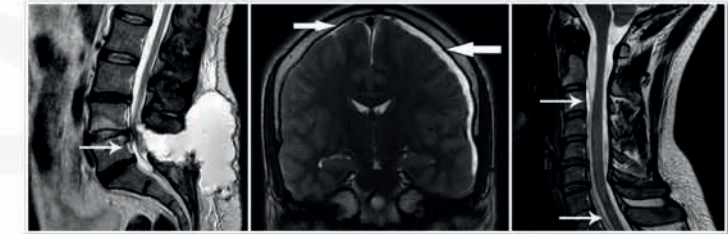
- ❖ Quadriplegia, seizure, stupor or coma
- ❖ Subdural haematoma or subarachnoid haemorrhage

## CSF Leak Diagnosis

CSF leaks are uncommon, but they are not rare. Statistically speaking, each year in the UK, you are more likely to suffer from a leak than die in a road traffic accident; yet CSF leaks remain mis- and underdiagnosed, and diagnosis delay is common.

Where a CSF leak is suspected, diagnosis will begin with an assessment of patient history, onset and potential triggers, including consideration of any underlying disorders, such as Marfan or Ehlers-Danlos Syndrome.

A positional (orthostatic) component to symptoms is a key characteristic of many CSF leaks (although it may diminish over time). A lumbar puncture may be performed to measure CSF pressure, but is not required to make a diagnosis; readings within 'normal range' are not uncommon despite a leak.



## Cranial CSF Leak Symptoms

The most common cranial leak symptoms are:

- ❖ Drainage from the nose (rhinorrhea)
- ❖ Salty or metallic taste in the mouth
- ❖ Sense of drainage down back of throat
- ❖ Drainage from the ear (otorrhea)
- ❖ Cutaneous sinus tract drainage
- ❖ Anosmia (loss of sense of smell)
- ❖ Change in hearing or ringing in the ears
- ❖ Cognitive changes (less common)



Cranial leaks may increase the risk of meningitis.

## Intracranial Hypotension

Low pressure within the skull (intracranial hypotension), a result of CSF volume loss, is common with a spinal CSF leak. It causes many of the symptoms experienced. Some key indicators on imaging can be remembered by the mnemonic:

**S**ubdural fluid collections  
**E**nhancement or pachymeninges  
**E**ngorgement of venous structures  
**P**ituitary hyperaemia  
**S**agging of the brain



**Note:** The absence of these findings cannot rule out a CSF Leak.

## Imaging and Investigation

A variety of imaging studies are normally used to evaluate and investigate suspected CSF leaks. It is, however, not uncommon for imaging to appear normal, which can lead to delays in terms of achieving an accurate and timely diagnosis.

Cranial CT may disclose sinus or subdural fluid collections and haematomas. MRI with/without gadolinium contrast (T1 and T2 weighting with STIR sequences) is preferred for spinal leaks and may disclose cranial meningeal enhancement, 'brain sag' or extradural fluid collections in the spine.