TREATMENT

Conservative Measures

Conservative measures may be trialed for 1-2 weeks, and involve bedrest, oral analgesics, caffeine, “overhydration”, application of abdominal binders and avoidance of valsalva maneuvers. Conservative treatments may be effective for some patients but will not be effective for most.

Epidural Blood and/or Fibrin Glue Patch or a combination of both

- **Blind or Non targeted Epidural Blood Patch (EBP)*:** patient’s own blood is injected into the spinal epidural space (usually in the lumbar region for the first EBP), without knowledge of the leak site.

*Further EBPs (possibly with higher volume or higher level in lumbar and/or thoracic spine) could be considered before proceeding to specialized imaging to find the exact leak site.

- **Targeted (EBP):** if the leak is identified, targeted EBP and/or fibrin glue may be performed.

Other treatment techniques for leaks with identified sites include:

- **Endovascular treatment** (treatment using a catheter threaded through the blood vessels) for CSF-venous fistulas).
- **Spinal Surgery:** spinal surgery may repair all types of leaks if feasible.

AFTER CARE AND PROGNOSIS

In general, patients should lie flat as much as possible for 24-72 hours following procedures such as EBP, and based on surgeon advice for spinal surgery. Patients should also avoid or minimize bending, straining, constipation, stretching, twisting, closed-mouth coughing, sneezing, heavy lifting, and strenuous exercise or other exertional activities for 4–6 weeks following all procedures. Recovery typically unfolds over weeks to months.

Some patients may experience a change to their headache following treatment. One possibility may be rebound intracranial hypertension, which often presents with headache that is worse lying down and more notable in the morning. It is important for patients to notify their physician of this headache change, as it may warrant reassessment and treatment.

Spinal CSF leaks are often treatable, may be curable, and have a better prognosis if treated early.

Patients suspected of having this condition should be referred to a specialist or center with expertise in this condition.

References:

- Schievink WI. Spontaneous Intracranial Hypotension. N Engl J Med. 2021 Dec 2;385(23):2173-2178.
- Cheema S et al. Multidisciplinary consensus guideline for the diagnosis and management of spontaneous intracranial hypotension. J Neurol Neurosurg Psychiatry. 2023 Oct;94(10):835-843.
- This brochure has been created by Spinal CSF Leak Canada and medical content has been reviewed by a member of the medical advisory team.

For more information, visit:
www.spinalcsfleakcanada.ca

WHAT IS SPINAL CEREBROSPINAL FLUID (CSF) LEAK?

CSF is a clear fluid that surrounds, nourishes, and protects the brain and the spinal cord, and one of the elements that cushions them from injury. **When there is a tear or defect in the dura mater, the fibrous tissue that overlies CSF, or there are abnormal connections with blood vessels, CSF can leak out, causing a loss of CSF volume. This is known as spinal CSF leak or intracranial hypotension.**

Incidence

Nearly 5 in 100,000 people

This incidence is comparable to some other neurological disorders such as Multiple Sclerosis (MS) or Amyotrophic Lateral Sclerosis (ALS).

The peak age for this condition is in the 40’s, and women are affected more commonly. However, spinal CSF leaks can affect people at any age. Once considered a rare disorder, recent studies suggest a higher actual incidence with increasing awareness of providers and increased sensitivity of diagnostic tests.

Brain MRI with Contrast

There are five classic qualitative findings typically seen on brain imaging that can be remembered by the mnemonic "SEEPS":

Subdural fluid collections
E nhancement of pachymeninges
E ngorgement of venous structures
Pituitary hyperemia
Sagging of the brain

There also other findings that involve measurements (quantitative findings) on MRI brain.

Full Spine MRI

A special MRI sequence of the spine called non-invasive myelogram or heavily T2-weighted MRI spine with fat saturation, is helpful to determine the type of spinal leak a patient may have. This can help direct further specialized imaging of the spine, if needed, to pinpoint the exact location of the leak.

Specialized imaging is usually done in the form of:

- **Dynamic CT Myelography:** involves injection of contrast dye via lumbar puncture and computed tomography (CT) images of the spine
- **Digital Subtraction Myelography (DSM):** involves injection of contrast dye via lumbar puncture but it is performed under fluoroscopy

COMMON NON-HEADACHE SYMPTOMS**

- Nausea and vomiting
- Dizziness or vertigo
- Disequilibrium (Trouble with balance and walking)
- Hearing abnormalities (fan-like sound, muffled hearing, ear fullness, plugged ears, tinnitus, reduced hearing)
- Posterior neck pain
- Cognitive impairment
- Fatigue
- Photophobia (sensitivity to light) or phonophobia (sensitivity to sound)
- Visual blurring
- Facial numbness, paresthesia or pressure

**For a list of other symptoms and rare complications, please visit: www.spinalcsfleakcanada.ca

DIAGNOSIS

Diagnosis starts with a careful history and neurological exam, followed by imaging of the brain. Although a CT scan of the brain is often completed first, an MRI of the brain with enhancement*** provides more information.

***Approximately 20% of patients with a spinal CSF leak may have a normal brain MRI.

CAUSES

1. Spontaneously*:

- Spinal pathology such as a bone spur or calcified disc that tears the dura
- Weakness or abnormality of the dura mater, creating a defect. Connective tissue disorders such as Ehlers-Danlos syndrome (EDS) and Marfan syndrome may be a predisposing factor.
- CSF-venous fistula (an abnormal connection between the CSF space and surrounding veins), spilling CSF into the venous system.

2. Head or neck trauma

3. Iatrogenic causes (following spinal procedures such as lumbar puncture, epidural injection and spinal surgery)

*Also referred to as Spontaneous Intracranial Hypotension (SIH).

SYMPTOMS

Spinal CSF leak is a neurological condition that may cause a number of disabling symptoms. One of the most common symptoms is an orthostatic headache (partial or complete relief when lying down and worsening considerably when upright). On occasion, the headache may not be orthostatic. It is also not unusual for the headache to become less orthostatic over time. There are several other possible symptoms.