

Upright headache? Think CSF leak!



A cerebrospinal fluid (CSF) leak is a serious and often incapacitating medical condition stemming from a tear or hole in the membrane that contains the fluid surrounding the spinal cord and brain. It can occur in the head or spine as result of trauma, surgery, an underlying disorder or spontaneously. When fluid leaks out, intracranial pressure and CSF volume reduces (known as intracranial hypotension) which allows the brain to sag within the skull. As a result of this 'brain sag', sufferers may experience severe and unrelenting head pain, pressure, visual disturbances, hearing impairment, tinnitus, muscle twitches, spasms and a wide range of other symptoms.

VERTICAL POSITION

Intracranial hypotension is responsible for many CSF leak symptoms. It normally has a prominent postural element; pain and other symptoms are worse when upright. Sometimes onset may occur immediately, but symptoms can build slowly over a number of hours to become a 'second half of day headache'.



HORIZONTAL POSITION

Symptoms may be entirely relieved or significantly reduced by lying down (often with head lower than feet). The postural element may, however, reduce over time, and lying down may then provide less relief.

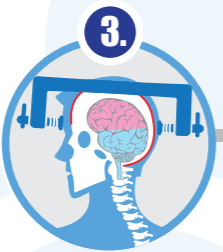


LEAK FACT

Research shows that at least **5 in 100,000** people each year are affected by spontaneous CSF leaks, with many more suffering from iatrogenic or traumatic CSF leaks. **They are not rare**, yet are generally under-diagnosed; misdiagnosis of migraine, sinusitis, NPDP, tension and other headache disorders is common place, and on average correct diagnosis takes **13 months** from onset.

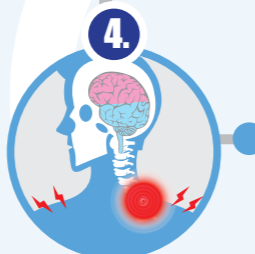
HEADACHE PRESSURE AND SENSATIONS

- Pressure feeling within the skull
- 'Pulling' sensation from the head to neck
- Facial numbness, jaw pain and toothache
- 'Crawling' or dripping liquid sensations around top of head.



NECK AND BACK PAIN

- Neck pain, aches and stiffness
- Interscapular pain (stiffness between shoulder blades)
- Generalised back pain (occasionally at nerve roots)
- Rarely, localised pain at the site of the CSF leak.



HEADACHE AND HEAD PAIN

- Often experienced at the front or back of the head, although can vary a great deal in severity and characteristics
- It is often worse when sitting or standing and relieved when lying, but may become less positional over time.



SPINAL AND CRANIAL CEREBROSPINAL FLUID LEAK

- Rarely, pockets of leaked CSF may be visible under the skin, however majority of spinal leaks cannot be seen externally
- Cranial leaks may present as fluid leaking from nose, ears and drainage to throat.



EYE PAIN AND PHOTOPHOBIA

- Pain behind eyes
- Pain when moving eyes
- Sensitivity to bright light (photophobia)
- Visual field changes.



DOUBLE AND BLURRED VISION

- Vision can become blurred or double vision may be experienced, often worsening after a period sitting or standing
- For glasses and contact lens users, prescription changes may occur.



BRAIN FOG AND FATIGUE

- Cognitive impairment (including memory loss, loss of concentration and/or inability to maintain train of thought)
- Chronic fatigue, lack of stamina and exhaustion.



NAUSEA AND TASTE

- Nausea and vomiting (often worse when sitting or standing)
- Changes in taste (sometimes metallic or salty)
- Cranial leaks may result in fluid discharge to throat.



DIZZINESS AND IMBALANCE AND HEART RATE

- Dizziness (particularly when upright or changing position)
- Sense of imbalance and ataxia (unsteady gait)
- Rarely, quadriplegia, parkinsonism or other movement disorders
- Elevated heart rate and occasionally shortness of breath.



TINNITUS AND HEARING CHANGES

- Tinnitus – high pitched, buzzing and/or pulsatile
- Ear pressure, popping or feeling of liquid in ears
- Hearing loss and dulled hearing
- Sensitivity to sound (phonophobia).



Find out more about cerebrospinal fluid leaks

www.csfleak.info/findoutmore

The CSF Leak Association is a Scottish Charitable Incorporated Organisation. Charity No. SC046319

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