

#leakweek 2019

because your dura matters®

June 3 - 8, 2019 - #leakweek - Spinal CSF Leak Awareness Week

This under-diagnosed cause of disabling daily headache can happen to anyone. Experts suspect that this is far more common than limited study would suggest. The hope for a cure exists ONLY if the correct diagnosis is made. Could YOUR daily headache be due to a spinal CSF leak? Could you be cured?

Because spinal CSF leak is unfamiliar to most physicians, it is often misdiagnosed. Patients can suffer for months, years or decades with the wrong diagnosis and the wrong treatments. Medications rarely help. Headache and other neuro symptoms are often much worse when upright, so patients may be largely bedridden.

Our goal with Leak Week is to raise awareness so that more patients might be correctly diagnosed and treated.

What is a spinal CSF leak?

Spinal cerebrospinal fluid (CSF) leak is an important and under-diagnosed cause of disabling daily headache that is curable. Cerebrospinal fluid (CSF) is a special fluid that bathes and supports the brain and spinal cord. When the tough layer called the dura mater (often abbreviated as dura) that holds this special fluid in around the brain and spinal cord has a hole or tear, this results in fluid leak through the defect. Thus our tagline: because your dura matters®

What are the symptoms?

The most common symptom is a headache that is worse after minutes to hours upright and improved with lying flat – but there are many other neurological symptoms and complications. This can be profoundly disabling because patients often have very limited ability to be functional while upright.

What are the causes? – this can happen to anyone!

- 1) out of the blue:
 - a) nerve root cyst can tear and leak
 - b) bone spur along spine can slice the dura mater
 - c) abnormal connection from normal CSF space to veins outside that space
- 2) medical procedures (labor epidural; spinal tap; spinal surgery)
- 3) injuries

How is this diagnosed?

Diagnosis starts with the symptom profile and includes brain and spinal imaging. BUT due to low awareness, frequent negative testing, and so many causes of headache and many other symptoms, misdiagnosis and delayed diagnosis remain common.

How is this treated?

Treatments include bedrest with fluids, spinal injection procedures or surgery to address the leak.

What is the prognosis?

Many patients are cured or much better with treatment but others do poorly, due to the limitations of currently available testing and treatments.

What will make a difference?

Greater awareness means shorter delays to the correct diagnosis and treatment.
More education for health professional to increase familiarity on diagnosis & treatment.
Research to improve testing & treatments; to better understand incidence and underlying causes.