Spinal CSF Leak Fact Sheet

spinal csf leak FOUNDATION

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WHAT IS SPINAL CSF LEAK?

Cerebrospinal fluid (CSF) bathes and supports the brain and spinal cord and is held in place by a tough connective tissue called the dura mater. When the dura mater has a hole or tear in it along the spine, the result is a spinal CSF leak. This loss of CSF volume, known as intracranial hypotension, can cause pain and other neurological symptoms. Because spinal CSF leak is unfamiliar to most physicians, it is often misdiagnosed. Patients can suffer for months, years, or even decades with the wrong diagnosis and the wrong treatments.

WHAT ARE THE SYMPTOMS?

The most common symptom is positional head pain that is worse after minutes to hours upright and improved when lying down, but there are many other neurologic signs and symptoms. Head pain severity varies enormously from mild to severe and may not correlate well with findings on imaging. Patients may be quite disabled by their inability to be functional while upright. Recognition of the head pain pattern and other symptoms is important in leading physicians to suspect the diagnosis of intracranial hypotension.

HOW IS IT 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 head pain and many other symptoms, misdiagnosis and delayed diagnosis remain common.

HOW IS IT TREATED?

Treatments include bedrest with fluids, epidural blood patch, procedures or surgery to address the leak.

WHAT ARE THE CAUSES?

A spinal CSF leak can be **spontaneous** due to:

- pre-existing spinal pathology such as a bone spur
- pre-existing weakness of the dura mater due to heritable disorders of connective tissue
- CSF-venous fistula (an abnormal connection from CSF space to epidural veins)

It can be **iatrogenic,** caused by medical procedures such as:

- Lumbar puncture (spinal tap)
- Epidural injection (spinal injection)
- Spinal or other surgery

And it can be **traumatic:**

- caused by an injury

WHAT IS THE PROGNOSIS?

Many patients improve with proper treatment, but others do poorly, due to the limitations of currently available testing and treatments.

WHAT WILL MAKE A DIFFERENCE?

Greater awareness will help shorten delays to the correct diagnosis and treatment. **More education for health professionals** will increase familiarity with diagnosis & treatment. **More research** is key to advancing our understanding of all aspects of the disorder and to improve testing and treatments.