

# CSF Leak Consultation Aid

## Target CSF Leaks

Defending your Dura

### Patient-held communication support

This consultation aid is designed to help patients clearly describe symptoms that may be associated with a suspected cerebrospinal fluid (CSF) leak.

It supports calm, accurate communication during healthcare appointments and may be shared with clinicians to aid discussion and understanding.

This aid does not diagnose a CSF leak and does not replace clinical judgement.

### Using clear, measured language

How symptoms are described can influence how they are understood during a consultation. Strong or alarming language can sometimes distract from the clinical features that matter most, while vague descriptions may lead to important details being missed.

This consultation aid encourages the use of **clear, measured language** that focuses on observable symptoms and patterns, rather than fear, speculation, or worst-case outcomes.

The aim is to support shared understanding and productive discussion.

### Language to avoid

Patients may find it helpful to avoid language that is:

- Catastrophic or frightening
- Absolute or predictive
- Based on online descriptions rather than lived symptoms
- Focused on outcomes rather than current experience

Examples include phrases that imply serious or dramatic consequences.

Using this type of language can increase anxiety and may make it harder for clinicians to identify relevant clinical features.

### Language that is often more helpful

Clear, descriptive language focused on what is happening, when it happens, and what changes symptoms is often easier to interpret in a clinical setting.

Some patients find it helpful to describe symptoms by stating what is happening, giving a brief example, and explaining how it affects daily function. For example:

Instead of saying:

*“My head feels like it’s collapsing”*

It may be clearer to say:

*“I have a headache that worsens when I am upright and improves when I lie down which limits how long I can remain upright.”*

Instead of saying:

*“I’m worried something terrible is happening to my brain”*

It may be clearer to say:

*“I have developed neurological symptoms, such as visual disturbance and difficulty concentrating, that change with position”*

Instead of saying:

*“My symptoms are unbearable and getting worse all the time”*

It may be clearer to say:

*“My symptoms have become more persistent over the past few weeks/months and are affecting my ability to function day to day”*

## The purpose of this approach

Using calm, accurate language does not minimise symptoms or concerns.

It helps ensure that what you are experiencing is understood as clearly as possible, particularly in busy or time-limited appointments.

This consultation aid is designed to support that process by helping patients describe symptoms in a way that prioritises clarity, safety, and shared understanding.

## Symptoms patients may wish to highlight

It is often more effective to focus on a small number of **key symptoms** rather than providing a long or exhaustive list.

Patients may find it helpful to highlight **five or six main symptoms** that are:

- most **consistent**
- having the **greatest impact** on daily function
- most **relevant** to how symptoms change with position

This approach can make it easier for clinicians to identify important patterns, particularly during time-limited appointments. When describing these key symptoms, some patients find it helpful to briefly explain what is happening, when or how it occurs, and how it affects daily function.

Focusing on key symptoms does **not** mean that other symptoms are unimportant. Additional symptoms can be discussed once the main pattern has been clearly established.

Patients may experience one or more of the following. Symptoms can vary between individuals and may change over time in how they present or are experienced.

Changes in symptoms do not necessarily indicate improvement or resolution. For some patients, symptoms may fluctuate, spread, or become less clearly positional, while still reflecting an underlying CSF leak. Others may experience new or different symptoms over time, particularly if diagnosis or appropriate treatment is delayed. This may occur as the body adapts over time, symptoms fluctuate, or the clinical presentation becomes less typical.

- **Orthostatic headache**  
Headache that worsens when upright and improves when lying down
- Neck pain or stiffness
- Head pressure or a sensation of heaviness
- Nausea, dizziness, or visual disturbance
- Cognitive symptoms such as difficulty concentrating or mental fatigue
- Symptoms beginning after injury, medical procedures, or without a clear trigger

#### *Why positional symptoms matter*

Orthostatic headache is a recognised clinical feature that may warrant further consideration of a CSF leak, particularly when symptoms are persistent or progressive.

Positional changes may not always be obvious unless specifically described, especially during brief or pressured appointments.

#### **Safety considerations for awareness**

In some patients with an existing CSF leak:

- Lumbar puncture may worsen symptoms
- Opening pressure may be within the normal range

These considerations help explain why a CSF leak may not be confirmed through lumbar puncture alone, and why symptoms should be considered alongside the clinical history described above.

#### **Patient notes** *(to complete before the appointment)*

You may find it helpful to note what is happening, when or how symptoms occur, and how they affect daily function.

**When did your symptoms begin?**

**Do symptoms improve when lying flat?**

**Do symptoms worsen when upright or active?**

**Have symptoms changed over time?**

**Previous investigations or procedures:**

**Impact on daily function (work, mobility, cognition)**

## How to use this aid

- Complete this document in advance of your consultation
- Bring it to appointments as a reference
- Share it with clinicians to support discussion
- Update it if symptoms change

*This aid is intended to support clearer communication and shared understanding.*

## About this resource

This consultation aid was developed by **Target CSF Leaks**, a UK charity focused on reducing harm associated with delayed recognition, misdiagnosis, and unsafe early management of cerebrospinal fluid (CSF) leaks.

Target CSF Leaks works to improve understanding of CSF leaks at the earliest points of care, where patients are most vulnerable to dismissal, misinterpretation, or avoidable harm. Our approach centres on patient safety, clearer communication, and earlier recognition, rather than fear-based messaging or sensationalised descriptions.

We prioritise accurate, measured language that reflects recognised clinical features, respects clinical judgement, and supports informed, productive conversations between patients and healthcare professionals.

This consultation aid forms part of our wider work to improve care **before specialist referral**, recognising that early interactions can significantly influence patient experience and outcomes.

For more information about our work and resources, visit:

**[targetcsfleaks.uk](https://targetcsfleaks.uk)**