Upright headache?  Think CSF leak!

1. Causes of the condition:
A cerebrospinal fluid (CSF) leak is a potentially 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 a result of trauma, surgery, an underlying connective tissue 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 in particular whenever they sit or stand.

2. Symptoms:

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 round top of head.

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.

3. Treatments:
• Bed rest
• Epidural blood patch
• Epidural glue patch
• Neurosurgical repair

4. Impact of the condition:
Imagine trying to live your life lying down; it’s all-but impossible. Yet, due to the extreme pain and debilitation, this is what many CSF leak sufferers are forced to do. Stuck in a body that they’re unable to utilise.

All leaks, irrespective of how they occur and how long they persist can be life-changing and extremely distressing, however, where a leak becomes chronic, either through unsuccessful treatment or delayed diagnosis, long-term disability is not uncommon due to severe pain, visual disturbance, seizures and nerve damage.

Accordingly, sufferers may be unable to work, socialise, undertake any form of physical exercise or carry out basic day-to-day functions that able-bodied people would take for granted. Life as they knew it can be turned on its head.

5. Hopes and aspirations for the future:
1. To work with medical professionals to advance understanding of the causes, symptoms, diagnosis and treatment of CSF leaks through research, education, publications and practical advice.
2. To improve the availability of and access to the correct and most up-to-date investigatory tests and treatments required by people suffering or suspected to be suffering from CSF leaks, irrespective of where in the UK they live.
3. To standardise treatment pathways for all sufferers and speed up diagnosis and treatment.
4. To help to establish a specialist centre for the care and treatment of CSF leakers in the UK.