

JOHN JACKSON

SPINAL LEAKER STORY



“Hi, my name’s John and for the past five years I have been a leaker..”

www.csfleak.info/profiles/johnjackson

A bit about me and what life was like before:

Hi, my name is John and for the last five years I have been a leaker - sounds like the sort of thing people say at support groups for well known conditions, right. . . ? Well, this is not.

Life before I developed a leak in my spine was action-packed. I had a young family, busy job, physical hobbies and an infectious enthusiasm for fun.



How My Leak Started

I started to notice a pain in my head every time I leant over to change my youngest daughter’s nappy; the pain was enough to drop me to my knees. This continued to worsen over the next few weeks to the point my whole body would sweat trying to endure the pain.

I made a doctor’s appointment, fearing a brain tumor or something similar, the GP also had the same concern! I was given a Cancer leaflet, an emergency MRI and advised to have a difficult conversation with my wife. I thought I was going to die.

I met with the Neurosurgeon the next day and, after examining me, he immediately diagnosed me with Intracranial Hypotension. I was relieved it wasn’t a brain tumor, and also relieved he knew what it was – that means I’ll be fixed, right?

Treatment for my Leak

In the following two and half years, various attempts to heal my leak with blood patches, glue patches and directly injecting glue into the site were made. The multi-site glue patch fixed me – although, this was so painful I nearly passed out as all my nerves were crushed. This resulted in every part of my body experiencing the maximum level of pain, from burning to crushing.

About 6 months later, the symptoms came back, but this time much worse resulting in me having to stop working. After various scans failed to find a leak I spoke to the Neuroradiologist, who has a keen interest in this condition; He mentioned patients in America who had been diagnosed with a CSF Venous Fistula – the body grows a rogue vein that siphons Cerebral Spinal Fluid. He suspected this is what could have happened in my case and re-examined the area with a more complex CT myelogram. The results confirmed his suspicions – this is exactly what my body had done.

CSF LEAK

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, NPDH, tension and other headache disorders is common place, and on average correct diagnosis takes 13 months from onset.

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The symptoms are slightly different – I still suffer from pain, but have also developed extreme fatigue, some long and short-term memory loss, decreased cognitive ability and, more recently, Trigeminal Neuralgia – known by the NHS as one of the most severe pains one can experience (not what I needed!). This is because my brain has sunk to the back of my skull in the lack of Cerebral Spinal Fluid and is crushing nerves.

My Neurosurgeon did the first operation of its kind in the UK on my spine, and rightly did it conservatively. He's opening me up again in the next few weeks to potentially cut my nerve off and remove parts of my spine, hopefully for the last time, fingers crossed.

Life Now....

I still try to live life and pretend its not there; I do as much as I can, in fact exercise makes me feel better at the time, but immediately after I stop the pain is exponentially worse – this is due to the increase of intracranial pressure. It is frustrating at times as many people do not understand this 'hidden' illness, they see me trying to enjoy what I can in life, however they do not see the debilitating pain I endure in doing so. Only people close to me will see the suffering I exchange for trying to have a normal life and have witnessed the devastating impact it's had on my career, personal life and the ability to be the dad I imagined I'd be.

I'm so grateful for the team at the Royal Victoria Infirmary, if it wasn't for them I'd still be in a bed screaming with pain.

You can read more leaker profiles at: www.csfleak.info/profiles



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cerebrospinal fluid leaks

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