

ROBIN PALMER HOSKING

SPINAL LEAKER STORY



“I spontaneously developed even more symptoms, including ‘end of days’ head pain...”

www.csfleak.info/profiles/robinpalmerhosking

A bit about me and what life was like before:

I'm Robin. In 2008 I suffered a head injury, which caused my leak. Before this, I enjoyed spending time with friends. I loved going clubbing and to music gigs. I played quite a bit of tennis and frequently went to the gym. I continued some of these activities when I was a “slow leaker”, but would often engage in sports and exercise in the morning, reason being I was usually too dizzy and nauseous in the afternoon, not to mention terrible brain fog.



How My Leak Started

Shortly after my head injury, I began to feel nauseous, dizzy and experience problems with my vision on a daily basis. Fast forward to 2017, when I spontaneously developed even more symptoms including “end of days” head pain, worsening of tremors and severe memory problems.

I'd been diagnosed with migraine by a neurologist, and other specialists. My symptoms spontaneously became much worse one-day, and I visited The National Migraine Centre. The doctor there suggested I had low CSF pressure headache.

Treatment for my Leak

Another neurologist later confirmed this diagnosis. I had a 40ml blood patch and continue to make small steps getting my neurological health back.

Reaching a diagnosis involved my parents driving from the North West to London, to pick me up, and driving me back to the North West, whilst I was flat. By this point I was completely unable to look after myself. Unfortunately the doctors I saw in London didn't feel I had a leak so I had to seek care in Staffordshire.

About seven years after my leak symptoms began I learned I had a condition called Hypermobile Ehlers Danlos Syndrome. I found this out following a minor procedure, which took six months to heal, instead of two weeks. My medical history, hypermobile joints and lengthy list of symptoms pointed towards a textbook diagnosis. This diagnosis was reached at a specialist NHS Hypermobility Clinic in London.

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

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Following my hEDS diagnosis, I began to work with The Ehlers Danlos Support UK to improve support services for men with the condition. Men are in the minority of people with EDS, and equally, men seem to be in the minority when it comes to CSF leaks. I recognised that men may prefer to seek support from male peers.

Life Now....

Life now, following my blood patch, is better than it was, but by no means perfect. I now struggle with rebound high-pressure symptoms, which can be confusing as some symptoms overlap with low-pressure symptoms. I lead a more restrained lifestyle in order to continue protecting my patch. I am upright now, with no “end of days” head pain, associated with low CSF, though I do experience some high-pressure symptoms when upright.

There is very little guidance for patients who have been sealed by a blood patch, fibrin patch or surgery regarding the recovery period. I had to adapt, remembering not to bend, twist or lift anything heavy. I had to remember to think about how I was going to move or complete an activity before moving or completing an activity. I enjoyed building up my stamina by going for walks, starting with short distances and building things up slowly.

Lying flat to manage symptoms when I was leaking was isolating, and I lost my mind at points. As a result of my leak, I’ve missed important social engagements such as weddings, spending time with family and friends. I wasn’t able to play the piano, or read. Basic household tasks became impossible as I live alone.

Low CSF pressure is one of the cruelest conditions I have ever known. Most of the medical profession has no clue about it. It is a scary experience to have a condition with no support from your local doctors.

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

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