



LISA JAMIESON

SPINAL LEAKER STORY

“The weight of my brain was collapsing down on itself under the force of gravity when I was upright...”

www.csfleak.info/profiles/lisajamieson

A bit about me and what life was like before:

Lisa Jamieson began her career working in community pharmacy before moving into medicines management and then NHS planned care service redesign. About a year before she became unwell she had set up her own business working as a consultant pharmacist at the interface between the pharmaceutical industry and the NHS.



How My Leak Started

On 14th April 2014, I developed an absolutely horrendous headache and some hearing loss in my left ear. I felt generally unwell with it, like I had no energy and might collapse, and I thought I might be developing a head cold or an ear infection. By day eight of the now daily headache, I was becoming very puzzled. I still had no sign of an infection (no temperature, head cold, sore throat or cough). The sensations inside my head were worsening and becoming very unsettling. There was a heavy downward dragging sensation, my ears kept popping, I felt weak, nauseous, and had an intense desire to lie down. At one point, I had to hold my head and shield my ears from a loud noise, and I thought that I was going to vomit as a result of the pain and sudden vibration. I considered taking myself to A&E, but it was Easter Monday, and I didn't fancy sitting in A&E for several hours on a bank holiday.

Treatment for my Leak

On day nine, I went to see my GP, who was as equally puzzled as I was. She prescribed two painkillers, in addition to the over-the-counter pain relief that I had already been taking. I told her that I had considered going to A&E the day before, and said that I thought I needed to go to hospital. She booked me in with one of the other GPs for the next day and ordered some urgent blood tests. Later that day, roughly three hours into a dose of the three different painkillers, I bent down to put something away in a kitchen cupboard, and got a terrible surge of pain into the top of my head and my forehead. At that point, as a pharmacist, I knew that there was something very wrong with me. But I still had no idea what it was. The next morning, after being up for about 45 minutes, I felt terrible again. By this time, there was a definite pattern to the pain. I felt relatively well after a night in bed, then upon getting up, the pain would start within about 15-30 minutes of being upright. By 45 mins after being up, I needed to lie down again. Lying down would reduce the headache, and when I got back up, the whole process would start all over again. When I saw the second GP, she too was very thorough, and went through many different possible causes of headache, but was unsure what was wrong with me. I knew I needed to trust my gut instinct, and so I pressed for an admission to the Medical Assessment Unit at my local hospital. To cut a very long story short, all of the junior doctors that I met in hospital, had no clue what might be wrong

with me. Most of the consultants didn't have any idea either. During the eighth night hospital admission, I saw a further twelve different doctors (five consultants and seven junior doctors). I got the impression that some individuals thought that I was either a hypochondriac or a malingerer. One of the nurses even told me, to my face, that I didn't look poorly. At times, it was definitely a case of, "I don't know what's wrong with you, so it must be 'all in your head'". In my case, it really was all in my head - but definitely not imagined! Thankfully, I got to see a neurologist who figured out that I had a 'low pressure headache' also called 'intracranial hypotension' from a spontaneous spinal cerebrospinal fluid (CSF) leak. Even though, as a pharmacist, I had studied all types of primary causes of headache, I had never heard of this relatively rare type of secondary headache before, but my diagnosis made it clear that the heavy dragging downward sensation that I had been describing, was exactly that. It was the weight of my brain collapsing down on itself under the force of gravity when I was upright, which also explained relief from symptoms when lying down. I had a brain and full spine MRI, but the location of the CSF leak wasn't found.

I was advised that resting (in bed) for 1-2 weeks might be enough time for the CSF leak to heal spontaneously. So I left hospital and went home to lie down. As a result of living with my often unpredictable body for 40 years, I knew from experience that I always took longer than 'normal' to heal from anything. So I decided to allow myself 2-4 weeks to recover.

Over the next couple of weeks, whilst lying down pretty much 24/7, I set to reading about spontaneous spinal CSF leaks. I read a medical journal paper, which stated that individuals with Ehlers-Danlos Syndrome (EDS) and Marfan Syndrome are at increased risk of developing a CSF leak. I had never heard of either of these conditions, so first I Googled Ehlers-Danlos Syndrome, which took me to the Ehlers-Danlos Support UK website.

This was probably one of the biggest 'light-bulb moments' of my entire life. I couldn't believe what I was reading! Here was a list of seemingly unconnected symptoms and conditions that explained virtually my entire medical history. I just knew I had EDS, probably hypermobility type. As I read more and more about it, I remember feeling both excited and relieved that I had figured out the underlying cause of practically everything that had ever been wrong with me

In addition to my background in pharmacy, I had also been studying for an MSc in nutritional medicine. So, I began to look for references and clinical papers about how nutrition might influence Ehlers-Danlos Syndrome. As a result of my research I made various dietary tweaks and changes, some more drastic than others, and added in a few nutrient supplements. And I took 'junk foods' and high sugar foods out of my diet. I figured that I had nothing to lose and potentially everything to gain.



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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Gradually, over the weeks after starting the dietary changes, my gut symptoms reduced. I made further dietary tweaks and the autonomic dysfunction gradually subsided also. The CSF leak symptoms also gradually reduced, but it took much longer than the 1-2 weeks I had been told when in hospital. Then one day, about three months after leaving hospital, I developed a new and different headache, which hurt when lying down. I gradually realised over the next few days that the spontaneous CSF leak appeared to have healed, and I had flipped into a rebound high-pressure state. Thankfully, I had read about this in the medical literature and had learned about it from an online patient forum. It is thought that the body increases CSF production to compensate for the leak. Then when the leak heals, there is too much fluid and so a rebound high-pressure state develops. This felt like someone was trying to inflate a ball inside my skull. It was a severe headache that was accompanied by an outward pressure sensation, behind my eyes and sinuses, in my ears and pressing down on my palate in the roof of my mouth. It peaked about a week after it first started, and then gradually reduced over the weeks and months.

Life Now....

I now view the horrendous time with the worst EDS-related symptoms of my life to date, when I couldn't work for several months and had to lie down all day every day with a CSF leak in 2014, as an 'unpaid mid-life sabbatical'. It was one of life's major curveballs, but I learned such a lot from the whole gruesome episode. I wouldn't wish a spontaneous CSF leak on anyone, and I am pretty sure that you wouldn't wish it for yourself. But there is a part of me that is now grateful for the experience. My life has changed in so many positive ways, including changing the direction of my career so that I am now working in research in nutrition in Ehlers-Danlos Syndrome. When I now think about what it was like to live with daily gut symptoms, joint pains, autonomic dysfunction and histamine issues, etc., it seems like I am remembering a completely different version of myself. In fact, learning that I have hypermobile Ehlers-Danlos Syndrome, and discovering what that means mechanistically to help me understand how my body functions, has probably been one of the most positive things that has ever happened to me.

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cerebrospinal fluid leaks
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