

SARAH HOLLANDS

CRANIAL LEAKER STORY



“As the weeks went by I couldn't look after my son...”

www.csfleak.info/profiles/sarahholland

A bit about me and what life was like before:

I am a single 39-year-old mum with a 2-year-old son. Before I became unwell with my leak we lived a happy, easy going life: enjoying days out to parks, toddler groups and soft play. We were inseparable and I loved everything about motherhood. Before I had my son I had been a support worker for autistic adults.



How My Leak Started

As the summer began to arrive my right nostril suddenly started dripping, I thought it might be the start of a cold although I experienced no other symptoms. At this point it was only a few drops every hour or so. After a few days I began experiencing severe headaches (which were unlike any migraine I had previously experienced) they were so acute when I got up in the morning and I was relieved when I lay down again. Over the next few weeks the headaches increased and my right nostril began to drip more. I thought I may have hay fever or an allergy so took various antihistamines and painkillers, none of which helped at all. I was also being sick 3-4 times a day, every day.

Because I had my son to look after I pushed through the headaches, the nausea and dripping for another few months until they were literally forcing me to retreat to the sofa. I began to feel so embarrassed; by this point the drip became so much that every time I leaned forward or moved my head to eat/change a nappy etc. it poured out of my nose. I was mortified one day when I was shopping in Sainsbury's and leant down to pick the shopping up, and I leaked everywhere. I know the sales assistant saw me and I just wanted to cry. It was impacting on my whole existence and I didn't want to go out where there could be people around. So my son and I went to the park later on in the day, we stopped going to soft play and spent more and more time in the company of close family.

I had been to the GP a few times, each time being treated with antibiotics, nasal steroid drops/sprays, and stronger and stronger painkillers with no effect. I was sent to an eye clinic to see if I had a blocked tear duct with no abnormalities. I was absolutely desperate and began googling causes for this salty liquid coming out of my nose as well as trying to find out the cause of the headaches. It was at this point I read about CSF leaks. Everything related to me: the sickness, the headaches and this salty liquid pouring from my nose. My loved ones, although concerned, told me this was very unlikely but if I was that concerned about it raise it with my GP, I went to him and he arranged for me to see an ENT consultant and have an MRI scan. I also saw a neurologist who sadly didn't believe me and told me my headaches were due to the fact I'd been taking too many painkillers! As soon as I saw the ENT consultant he immediately sent

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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me the same day for a CT scan and took a sample of the fluid. For this I am eternally grateful. As the weeks went by I have become so unwell I couldn't look after my son, fortunately I have the most amazing parents who have well exceeded their grandparents' duties! About three weeks ago my consultant called me and told me that the fluid had come back positive for beta transferrin and CSF fluid - in layman's terms my brain was indeed leaking.

I have never had any head trauma or surgery so had something called a spontaneous leak. The next stage was to find out where it was coming from.... I was sent to a hospital in London where the surgeon was amazing, he was able to show me that I had a hole in the base of my skull and one near my sphenoid sinus and that this hole had pulled the lining of my brain down into it causing the it to leak as it was under too much pressure. I literally burst into tears as finally someone believed me and was able to help fix it!

Treatment for my Leak

I am due to have endoscopic surgery within the month and will have to have a drain put into my spine to drain some of the CSF fluid away so as I have time to heal. Although I'm petrified I am so grateful that I can hopefully go back to being a fully functioning mummy to my son.

Life Now....

At present I am completely bed bound, and on pain patches (morphine) as I am so unwell. My son is unsettled and can't understand why mummy can't play with him. It's been a very tough eight months and although the recovery won't necessarily be easy, I am praying for a successful operation.

I want to be the happy, active mummy my energetic son deserves.

I would really like to raise awareness of this condition. Without the on going support and dedication of my GP I dread to think where I'd be now. Thank goodness for the NHS!!

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

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cerebrospinal fluid leaks**
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