



RACHAEL EBELING

SPINAL LEAKER STORY

“Progress, no matter how small is positive. Stay strong and keep the faith...”

www.csfleak.info/profiles/rachaelebeling

A bit about me and what life was like before:

I was an active, healthy, wife, mother of two young children and full time Primary School teacher. Then out of nowhere my life changed dramatically due to a spontaneous CSF leak.



How My Leak Started

It was February half term and like most teachers in the country I was recovering from the usual end of term lurgy. I had a terrible chesty cough that I couldn't get rid of and every time I coughed my whole body rattled and jerked. A simple chesty cough turned out to be the cause of my CSF leak. I coughed one morning & felt a pop inside my head and neck.

From this point I felt the most poorly I've felt in my life. I had a relentless high pitched ringing in my ears and my right ear felt full like it was stuffed with cotton wool. The sound was constantly muffled and muted. Every time I swallowed or yawned the pressure would change and my ears would pop like when you're on an aeroplane. My head was throbbing uncontrollably every time I coughed, sneezed, bent down and even when I raised my voice. I couldn't see properly and everything was blurred. I felt dizzy and travel sick all the time. My balance was off, I was confused, had difficulty remembering simple things and getting my sentences to make any sense. The worst feeling of all was the excruciating exploding head feeling. My head felt so heavy on my neck and like it was being crushed in a vice from all angles.

I felt like I was going to die and at times I honestly felt like I wanted to die just to escape the unbearable, relentless pain.

Treatment for my Leak

After a trip to the GP it seemed like a long wait for an MRI scan. I did lots of Googling and worried myself silly. After over a month of feeling horrific and not having any answers, I had an appointment with a consultant in Brighton who showed me my scan results and explained that I had low pressure in the skull due to a spontaneous CSF leak. Somewhere there was a tear in the sack surrounding the brain and spine. The CSF fluid was leaking out of this tear.

This was the point that I was referred to The National Hospital for Neurology and Neurosurgery in London. After lots of bed rest, months waiting, more MRI scans and three sets of caffeine infusion drips it was decided I would have an ICP bolt: Intracranial pressure (ICP) monitoring measured the pressure inside my head, using a pressure monitor inserted through the skull.

In reality this meant that I was awake (but sedated) while a section of hair was shaved off, a hole made in my skull and the bolt inserted. I was then plugged into a laptop for 24 hours to monitor the pressure. I found this procedure completely traumatic but it did definitely confirm that I had low pressure.

As a result of this I then went on to have an epidural blood patch. I was awake in theatre while the surgeon took 60ml of blood from my arm and injected it into the spine (much like an epidural during child birth). The blood was injected in slowly until I couldn't cope with the pressure and pain any longer. I managed to tolerate 40ml.

After bed rest for a number of weeks the blood patch had minimal effect. I then waited over a year for the next one. Again minimal effect but I was then able to get through my working day. During the evenings and weekends I was bed bound and would have to lay flat to get some relief from the pain.

In April 2017 I was able to complete the Brighton Marathon to raise money for the CSF Leak Association. It took me around eight hours but I walked every step with pride.

In August 2017 I went in for another epidural blood patch. This time I tolerated 40ml but with a top up of fibrin glue. This seemed to do the trick and everything felt immediately different.

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.

Do something good for charity and support the CSF Leak Association today:
www.csfleak.info/donate

Life Now...

I have since reduced my work hours to three days part time and I now work every other day so I can rest in between. I am not completely fixed and I'm currently waiting on a date for one last epidural blood patch. For now my quality of life has improved dramatically. I am able to keep on top of the housework. I'm up and about with my husband at the weekends being independent and not laying down flat. I am able to give more time to being a mother of two. I can devote more care to our son who was diagnosed with Autism, ADHD and Anxiety amongst all of this. I am able to go to the gym and exercise regularly to raise my low blood pressure and improve my mental health.

I still get headaches when I'm stressed, dehydrated or when I've had a physically busy day. My ears still ring (although quieter) and they sometimes pop when I yawn. I rest up, drink lots of water, exercise, eat a healthy diet, take Krill oil supplements daily and I find the pain to be much more predictable and manageable.

After almost four years I feel like I've finally have a glimpse of my former life back. My family, friends and colleagues have been so supportive during this journey and I couldn't have got through the dark days without them.

For any fellow CSF leakers reading this, there is hope that you will be fixed even a little piece at a time. Progress, no matter how small is positive. Stay strong and keep the faith.

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



Find out more about
cerebrospinal fluid leaks

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