



LEAK WEEK / Day Six

3 March 2018



Day Six: Living with a CSF Leak

Hi <<First Name>>.

It's Saturday. The theme for today was 'Living with a Leak' and you can check out the key resources for the day at: www.csfleak.info/leakweek2018/daysix

And while you're living with a leak or enjoying a sealed life, you could be doing so in style with a CSF Leak Association branded t-shirt or hoody.



We're delighted that our partner, Teemill, is offering free UK postage on all items in our clothing shop this weekend: www.csfleak.info/clothing

CSF Leaker Profiles

In keeping with today's theme, we shared three different Leaker Profiles instead of the usual two. Sarah Hollands, Lisa Jamieson and Deborah Lunnon share their experiences.

Sarah is a cranial leaker whose leaker journey began suddenly with dripping fluid from her right nostril, followed by severe headaches. She struggled to get a correct diagnosis, but finally an ENT consultant sent a sample of the fluid away for a beta transferrin test and it tested positive for CSF.



CRANIAL LEAKER STORY



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

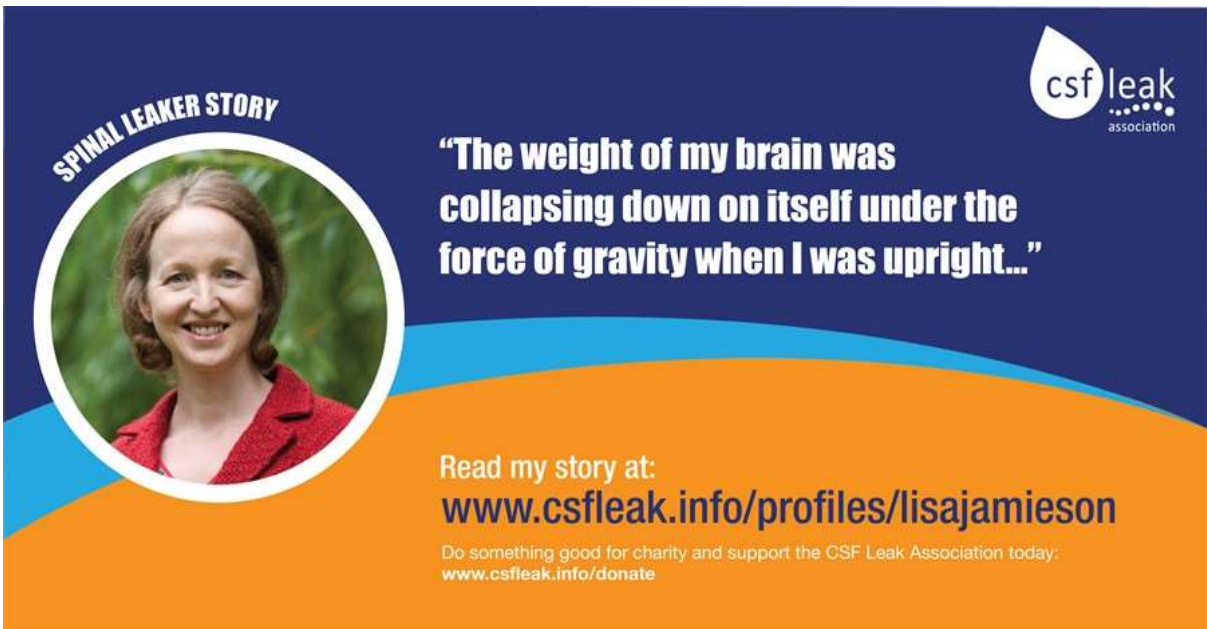
Read my story at:
www.csfleak.info/profiles/sarahhollands

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


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Read Sarah's story here: www.csfleak.info/profiles/sarahhollands

Our second leaker, Lisa, is a spinal leaker whose symptoms started with a bang one day in 2014. During an inpatient stay undergoing many tests and confronted by the clinicians who were stumped, she met a neurologist who figured out she was suffering with a low pressure headache. She has tried conservative treatment and dietary changes and found some success.



SPINAL LEAKER STORY



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

Read my story at:
www.csfleak.info/profiles/lisajamieson

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

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Read Lisa's story here: www.csfleak.info/profiles/lisajamieson

Deborah is a spinal leak who is also one of the Charity’s trustees. She’s been in the unfortunate position of having experienced three leaks since 2007. Her first two leaks responded favourably to blood patches, but her third required targeted glue/blood patches. Along her journey she also discovered she has EDS and Tarlov cysts.

You can watch her talk about her journey over on our YouTube channel:



We also produced this eye-catching flow diagram to document Deborah's journey. It complements her video and we are sure that it'll be of real interest to many leakers. As you'll see, there were many ups and downs and even though she is sealed, she continues to suffer daily pain.

Cerebrospinal fluid leaks. A leakers journey!



2007

My journey with cerebrospinal fluid leaks by Deborah Lunnon in conjunction with the CSF Leak Association

After suffering a whiplash-type injury in September 2007, I began to suffer from excruciating head pain, vomiting, neck pain and photophobia whenever I was upright, but all of which were alleviated when I lay down.



Treatment also involved an emergency admission to hospital. Treatment was an **Aspirin** but this was ineffective.



Over an **8 week** period I made many visits to the Doctors and was treated by every method possible for severe migraine.



Initially, I was put on bed rest with caffeine drinks to boost my CSF pressure/volume. I later had an MRI scan with IV contrast and a leak was evident below C6. This resulted in a lumbar Epidural Blood Patch being performed in theatre



Then, during a chance appointment with a private specialist, my symptoms were recognised as 'classic' CSF Leak and I was admitted immediately.

No-one could explain why I was so ill and doctors seemed unable to help. I was unable to get an appointment with Neurology, despite the severity of my symptoms, because A&E did not recognise them.

During this time I was unable to remain upright. This meant that I was unable to work or function normally, eat or maintain my fluid intake, focus my eyes correctly or sleep. I was severely debilitated



The effect was immediate. Apart from residual neck and shoulder pain and tinnitus, the debilitating symptoms were gone. However, it took a long time to reach this stage.

2014

Suffered another spontaneous CSF leak. Diagnosed privately and patched within a week.

THE END?
Not quite

2016

Another leak! This time a slow leak over a 5 month period, culminating in an emergency admission to hospital and another blood patch. This time it was unsuccessful.

2017

Underwent a CT Myelogram and 3 leaks were found in the thoracic spine. A high volume targeted blood patch with Fibrin glue was administered. Diagnosis of Ehlers-Danlos Syndrome (Type H) with chronic pain and Tarlov Cysts was also made.

Prognosis

Potential for recurrent spontaneous cerebrospinal fluid leaks due to Ehlers-Danlos Syndrome; a connective tissue disorder that can leave sufferers predisposed to leaks.

Find out more about cerebrospinal fluid leaks www.csfleak.info/findoutmore

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To read more about Deborah's journey, please visit our special 'A CSF Leaker's Journey' web page [here](#).

Bite-sized Facts

Throughout the week, we've been releasing bite-sized facts. Today's facts (and the last ones for this year's Leak Week) are:

LEAK FACT #6

5 IN 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS, THIS IS **1 IN 20,000** PEOPLE WHICH IS 2 PEOPLE IN A TOWN IN ENGLAND THE SIZE OF:

**CASTLEFORD
BRAINTREE
RAMSGATE**

Cerebrospinal fluid leaks are not rare!
Find out more about cerebrospinal fluid leaks www.csfleak.info/findoutmore

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LEAK FACT #7

5 IN 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS, THIS IS **1 IN 20,000** PEOPLE WHICH IS 2 PEOPLE IN A TOWN IN SCOTLAND THE SIZE OF:
**GLENROTHES
 COATBRIDGE
 AIRDRIE**

csf leak association **Cerebrospinal fluid leaks are not rare!**
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LEAK FACT #8

5 IN 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS, THIS IS **1 IN 20,000** PEOPLE WHICH IS 2 PEOPLE IN A TOWN IN WALES THE SIZE OF:
**CAERPHILLY
 MERTHYR TYDFIL
 LLANELLI**

csf leak association **Cerebrospinal fluid leaks are not rare!**
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#WearBlueToo

The (friendly) competition has heated up in the last 24 hours, with ever more ingenious pictures being shared. Let's push this to the limit for tomorrow, the last day of Leak Week UK. Bring it on!

#WearBlueToo #CSFleak #LeakWeek #Headache #UprightHeadache



Click here to visit our Leak Week UK webpage

GET INVOLVED!

1. Add the Leak Week UK logo to your social media profile or page.
2. Share our Leak Week posts across social media using the hashtags #CSFleak & #LeakWeek.
3. Download our leaflets, factsheets & infographics and share them with your friends, GP and other medical specialists, like your neurologist.
4. Wear your CSF Leak Association wristband or dress in blue & make it a conversation starter with friends & colleagues at work.
5. Add a fundraiser for the CSF Leak Association to your Facebook page & help us fight for CSF leaks.

Leak Week UK

26 Feb - 4 March

2018

Raising awareness of cerebrospinal fluid leaks

www.csfleak.info/leakweek2018

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