



## LEAK WEEK / Day Seven

4 March 2018



### Day Seven: The Week That Was

Hi <<First Name>>.

It's Sunday. We made it!

It's final day of Leak Week UK 2018.

The theme for today's activity was 'About the CSF Leak Association' and you can check out the key resources for Day Seven at:

[www.csfleak.info/leakweek2018/dayseven](http://www.csfleak.info/leakweek2018/dayseven)



### The CSF Leak Association

We're a charity for CSF leak sufferers run by people directly affected by CSF leaks. The reality is that although leaks are more common than most of the medical profession appreciate, we are still a relatively small group of patients.

We're a small charity with big ideas and even bigger goals and in order to keep the pressure on and deliver our goals, we need more volunteers.

We will be advertising specific volunteer roles on our website in the future, but we have plans to form a number of focus groups to help us direct our work and review future publications.

Expressions of interest are welcome from current leakers, sealed leakers, carers,

The time required won't be too onerous and since we are ourselves leakers we will understand the need to be flexible.



Do something good for charity  
and support the CSF Leak  
Association:

**[www.csfleak.info/donate](http://www.csfleak.info/donate)**

Find out more about cerebrospinal fluid leaks  
**[www.csfleak.info/findoutmore](http://www.csfleak.info/findoutmore)**

The CSF Leak Association is a Scottish Charitable Incorporated Organisation.  
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If you've found the information, resources and publications of use or interest, please consider making a small donation to help us keep doing what we're doing. Thank you.

## Charity Shop

Don't forget the free UK postage offer with our partner, Teemill, expires tonight. Treat yourself or a loved one to a comfortable and stylish piece of clothing that supports the work of the charity, while also doing your bit to raise awareness. Get your dose of retail therapy at [www.csfileak.info/clothing](http://www.csfileak.info/clothing)



CSF Leak Association Merchandise

You can now support CSF leakers in even more ways, by buying charity merchandise and wearing it with pride!

HOODIES > CLASSIC T-SHIRT >

NEW DESIGN NEW LOGO

FREE DELIVERY  
2-4 MARCH 2018

Teemill is sponsoring **FREE UK** delivery on all CSF Leak Association merchandise from 2-4 March 2018. It will be applied automatically when you check-out - **no promo code needed!**

[www.csfleak.info/clothing](http://www.csfleak.info/clothing)

Find out more about cerebrospinal fluid leaks  
[www.csfleak.info/findoutmore](http://www.csfleak.info/findoutmore)

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## Medical Advisory Committee (MAC)

A lot of work has gone on behind the scenes to gather motivated medical professionals with an interest in CSF leaks together to form the MAC.

The MAC's membership includes specialists from neurology, neurosurgery, anaesthetics and radiology as well as a patient representative and a charity trustee, who acts as secretary.

You can learn more about the makeup of the MAC at: [www.csfleak.info/mac](http://www.csfleak.info/mac)

We're delighted to share with you a summary of what was discussed at the inaugural meeting of the committee earlier this year in January at:

[www.csfleak.info/category/news/medical-advisory-committee-news](http://www.csfleak.info/category/news/medical-advisory-committee-news)

As you can see, the MAC has their work cut out for them!

## CSF Leaker Profiles

Last but not never least, John Jackson and Leah Smith took to the stage today in our last instalment of the Leaker Profile and Life with a CSF Leak video.

John featured in a video earlier in the week, but returned today to talk a little more about his journey. He experienced a spontaneous leak that may be related to an incident while surfing.

He was successfully treated with glue patches but his issues returned with a rare presentation of a leak – a CSF venous fistula. He has surgery for this, thought to be the first of its kind in the UK.

Just this week, he underwent more surgery in an attempt to fix the ongoing leak. You can read his story at: [www.csfleak.info/profiles/johnjackson](http://www.csfleak.info/profiles/johnjackson)



A promotional banner for the CSF Leak Association. The background is dark blue with a light blue and orange wave-like graphic at the bottom. On the left, a circular inset shows a man (John Jackson) wearing a red jacket and a black beanie with a red '0' on it. Above the circle, the text 'SPINAL LEAKER STORY' is written in a white, curved font. To the right of the circle, a quote in white text reads: "Hi, my name's John, and for the past five years I have been a leaker...". Below the quote, the text 'Read my story at:' is followed by the URL [www.csfleak.info/profiles/johnjackson](http://www.csfleak.info/profiles/johnjackson) in a larger font. At the bottom right, in smaller white text, it says 'Do something good for charity and support the CSF Leak Association today: [www.csfleak.info/donate](http://www.csfleak.info/donate)'. The CSF Leak Association logo, featuring a white drop shape with 'csf leak' and 'association' below it, is in the top right corner.

**SPINAL LEAKER STORY**

**"Hi, my name's John, and for the past five years I have been a leaker..."**

Read my story at:  
**[www.csfleak.info/profiles/johnjackson](http://www.csfleak.info/profiles/johnjackson)**

Do something good for charity and support the CSF Leak Association today:  
[www.csfleak.info/donate](http://www.csfleak.info/donate)

csf leak  
association

Leah's leak journey started with an ill-fated diagnostic lumbar puncture last year.

Conservative measures failed to ease her symptoms and she faced repeated obstacles to obtaining definitive treatment of her leak.

She's had three blood patches, only one of which was partially effective, and struggles daily with ongoing symptoms. You can see her video below.





## Bite-sized Facts

Throughout the week, we've been releasing bite-sized facts. We've prepared this special Leak Week UK bite-sized facts poster, which you can download, print off and use.

<b>LEAK FACT #1</b> 5 in 100,000 PEOPLE EACH YEAR ARE AFFECTED BY SPONTANEOUS SPINAL CSF LEAKS	<b>LEAK FACT #2</b> 13 MONTHS FROM THE ONSET OF SPINAL CSF LEAK SYMPTOMS	<b>LEAK FACT #3</b> NOT LOW OPENING PRESSURE	<b>JOIN US FOR:</b> <b>Leak Week UK</b> 25 Feb - 4 March <b>2018</b> Raising awareness of cerebrospinal fluid leaks facebook.com/csflakeassociation @csflakeinfo www.instagram.com/csflakeassociation www.csflakeinfo/leakweek2018
<b>LEAK FACT #4</b> SOME PATIENTS REQUIRE A SINGLE BLOOD PATCH TO SEAL A LEAK WHIST OTHERS REQUIRE MULTIPLE PATCHES	<b>LEAK FACT #5</b> CHILDREN, ADULTS AND MAJOR SPONTANEOUS SPINAL CSF LEAK SURGERIES	<b>LEAK FACT #6</b> 5 in 100,000 1 in 20,000 CASTLEFORD GUARANTEE	
<b>LEAK FACT #7</b> 5 in 100,000 1 in 20,000	<b>LEAK FACT #8</b> 5 in 100,000 1 in 20,000 GARRISON MEDICAL TOWN, ILLINOIS	<b>LEAK FACT #9</b> 46 YEARS*	
<b>LEAK FACT #10</b> 65.7% OF WOMEN 34.3% OF MEN	<b>LEAK FACT #11</b> 10% of people*	<b>LEAK FACT #12</b> 50% of patients*	

Find out more about cerebrospinal fluid leaks  
[www.csflakeinfo/findoutmore](http://www.csflakeinfo/findoutmore)

**csf leak**  
 association

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 Registered Office: 10545518 CSF Leak Association, All Rights Reserved

To download a PDF version, please [click here](#).

## #WearBlueToo

The CSF Leak Association would be nowhere without your support. All week we've been especially impressed with how you took #WearBlueToo to your heart and shared your experiences and photos on social media. Your support meant that Leak Week was a resounding success.

We wish to also applaud the distinguished and laudable manner in which the leaker community welcomes newly diagnosed sufferers of CSF leaks, recognising that many new leakers can be struggling and vulnerable like never before in their lives.

So do yourself a favour and take a moment to feel proud of yourself and the leaker community! Can you spot someone you know in our Leak Week #WearBlueToo montage?





# THANK YOU!



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