



# LEAK WEEK / Day Five

2 March 2018



## Day Five: Aftercare

Hi <<First Name>>.

It's Friday. We've reached the end of the working week, but we've still got two days left of Leak Week UK 2018.

The theme for today was 'Aftercare' and you can check out the key resources for Day Five at:

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



## New content

We're acutely aware of the lack of advice for those of us recovering from a CSF leak and this is especially lacking when it comes to sensible steps to take after having an epidural blood patch.

To meet this need, we produced a new resource in the form of a postcard entitled 'If in doubt, Wait it out!' in consultation with doctors on our Medical Advisory Committee. It highlights some of the key precautions to consider after a patch, but you must still always consult with your doctor.

It is worth noting that blood patches can fail for unknown reasons regardless of how 'good' you've been, so following these precautions can be no guarantee to success. There is still so much to learn about leaks and patches, but by following this advice

you're doing the best you can to promote healing.

Our newly-updated collection of resources for aftercare, including general precautions, rebound high intracranial pressure, nutrition and physiotherapy is available at: [www.csfleak.info/aftercare](http://www.csfleak.info/aftercare)

# If in doubt, Wait it out!

**Things to try to avoid after an epidural blood patch**  
Produced in consultation with UK neurologists

**WHAT IS AN EBP?**  
An epidural blood patch (EBP) is a surgical procedure where a patient's own blood is injected into their epidural space in order to close one or more holes in the membrane around the spinal cord. The holes cause a leak of the cerebrospinal fluid (CSF)

- LIE FLAT**  
if possible lie flat for at least 24 hours with only short breaks to use the bathroom
- AVOID STRAINING**  
for at least 6 weeks!
- AVOID BENDING, TWISTING OR STRETCHING**  
for at least 6 weeks!
- AVOID COUGHING OR SNEEZING**  
if you must, don't cover your mouth or hold your nose
- AVOID ANTI INFLAMMATORIES**  
some doctors recommend that you do not take anti-inflammatories for 7 days
- AVOID CAFFEINE OR SALT**  
caffeine and salt can increase CSF pressure, so may worsen any rebound intracranial hypertension, which could 'blow' a blood patch
- AVOID LIFTING**  
anything over 5lbs/2.5kg, for at least 6 weeks!
- TRAVEL**  
Where possible after a blood patch, avoid driving yourself home. Try to recline or lie down and avoid taking public transport

**REMINDER!**  
These are just a few of the precautions to take after an epidural blood patch.  
**Please make sure that you always seek and follow professional advice from your doctor.**

The CSF Leak Association is a Scottish Charitable Incorporated Organisation. Charity No. SC046319 Copyright © 2017 CSF Leak Association. All Rights Reserved

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

To download a PDF of our blood patch postcard for printing, please [click here](#).

To download a lower-resolution copy for sharing on social media, please [click here](#).

## SPINAL LEAKER STORY



**"Progress, no matter how small is positive. Stay strong and keep the faith..."**

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

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

**Leaker Profiles**

Flying the flag of awareness today, we have Rachael Ebeling and Pete Marnick. They've both been sharing their experience of CSF leaks in our Life with a CSF Leak profiles.

Rachael's unlucky start to her leaker journey began with a simple chesty cough, proving that spontaneous spinal leaks can happen in the most seemingly benign ways. She has had two epidural blood patches and although her symptoms have improved she still suffers symptoms.

Read Rachael's story here: [www.csfleak.info/profiles/rachaelebeling](http://www.csfleak.info/profiles/rachaelebeling)

High flyer Pete originally developed a large CSF leak as a complication of spinal surgery. This leak was initially treated and thought to be successful.

Unfortunately Pete suffered persistent headaches that, over time, appeared to have a postural element. These days he suffers daily with symptoms of a leak and cannot work, but tries his best to live as well as he can.

You can watch him talk about this story below:



## Support from our Friends

We were delighted that [EDS UK](#) advertised our Leak Week campaign in their weekly email newsletter this week. In particular, they included coverage of CSF leak and EDS sufferer, [Robin Palmer Hosking](#), who also told [his story of blood patching](#)



yesterday's Leak Week activities.

We are also extremely grateful for the support and exposure given to us by [Rare Disease UK](#), who have been retweeting of tweets and promoting our #LeakWeek through their own channel throughout the week.

And it goes without saying that we appreciate all of the other likes, shares, subscribes, tweets and retweets that everyone out there in cyber space has been giving us since everything began on Monday...we couldn't do it without you!

## Bite-sized Facts

Throughout the week we're releasing bite-sized facts, and today's facts are:



**LEAK FACT #9**

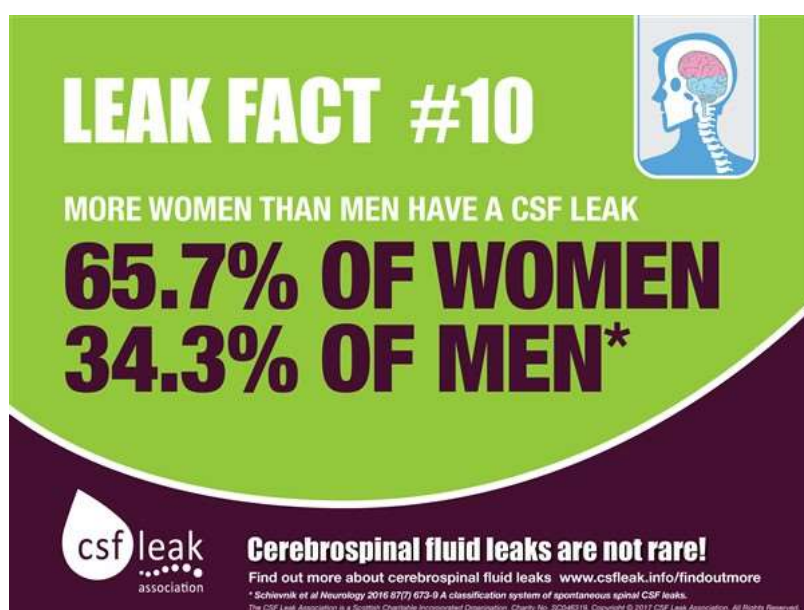
THE AVERAGE AGE TO HAVE A CSF LEAK IS

**46 YEARS\***

**csf leak association**

**Cerebrospinal fluid leaks are not rare!**  
Find out more about cerebrospinal fluid leaks [www.csfleak.info/findoutmore](http://www.csfleak.info/findoutmore)

\* Schievink et al Neurology 2016 87(7) 673-9 A classification system of spontaneous spinal CSF leaks.  
The CSF Leak Association is a Scottish Charitable Incorporated Organisation, Charity No. SC046118. Copyright © 2017 CSF Leak Association. All Rights Reserved.



**LEAK FACT #10**

MORE WOMEN THAN MEN HAVE A CSF LEAK

**65.7% OF WOMEN**  
**34.3% OF MEN\***

**csf leak association**

**Cerebrospinal fluid leaks are not rare!**  
Find out more about cerebrospinal fluid leaks [www.csfleak.info/findoutmore](http://www.csfleak.info/findoutmore)

\* Schievink et al Neurology 2016 87(7) 673-9 A classification system of spontaneous spinal CSF leaks.  
The CSF Leak Association is a Scottish Charitable Incorporated Organisation, Charity No. SC046118. Copyright © 2017 CSF Leak Association. All Rights Reserved.

## #WearBlueToo

We're nearly there with our #WearBlueToo campaign: just a few days more, so go grab something blue and share your snaps!

You all continue to amaze us with your positive attitude and good humour. It continues to be a privilege to work on your behalf.

**#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](http://www.csfleak.info/leakweek2018)

The CSF Leak Association is a Scottish Charitable Incorporated Organisation (Charity No. SC046319)



Copyright © 2018 CSF Leak Association, All rights reserved.

Want to change how you receive these emails?  
You can [update your preferences](#) or [unsubscribe from this list](#).

