



LEAK WEEK / Day Three

28 February 2018



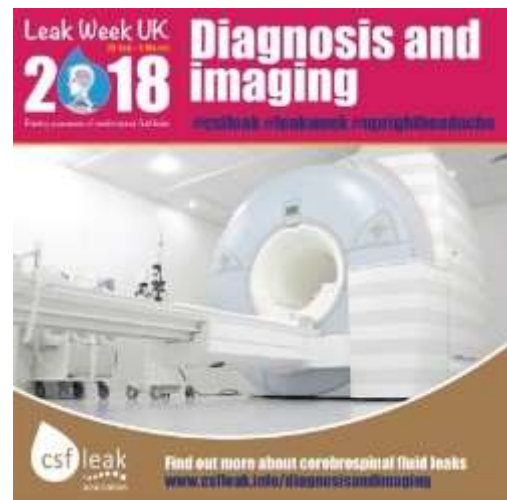
Day Three: Diagnosis & Imaging

Hi <<First Name>>. The theme for Day Three was Diagnosis & Imaging, but we also joined forces with Rare Disease UK for Rare Disease Day.

Rare Disease Day is a global initiative that aims to bring together patient organisations and charities like ours, for one day a year to raise awareness for all rare diseases.

We have received even more positive feedback today and we're absolutely delighted to hear that friends and family are becoming more aware and informed of the trials and tribulations of being a 'leaker'.

You can check out the key resources for Day Three here: www.csfleak.info/leakweek2018/daythree

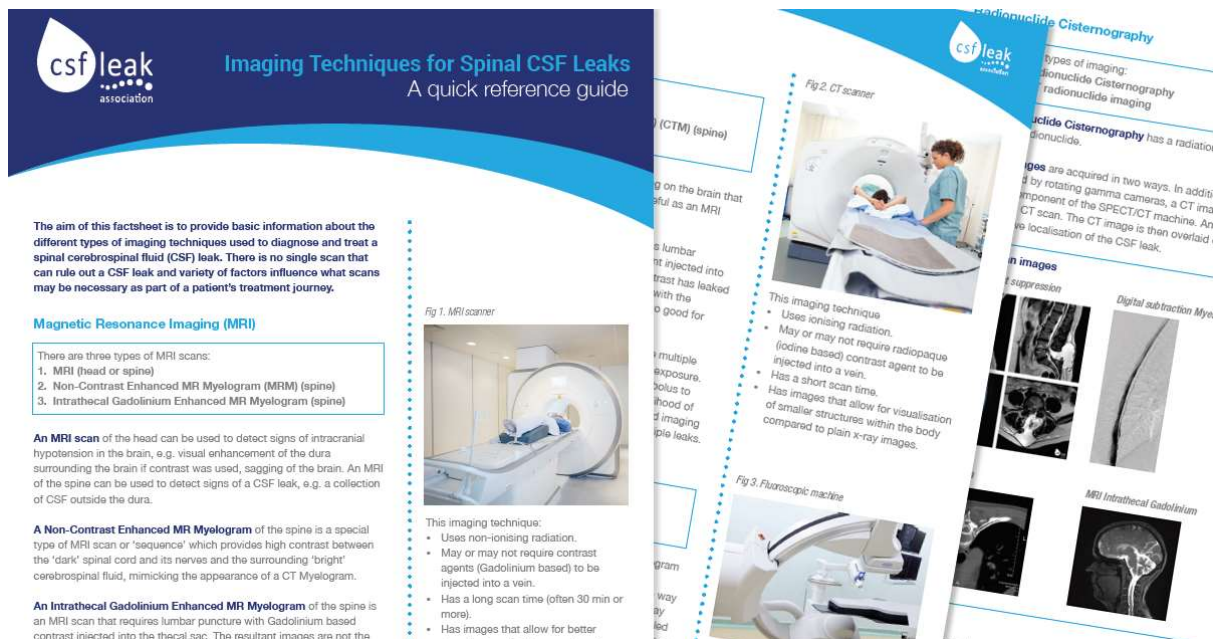


New content

CSF leak diagnosis can be tricky because not all leaks appear on imaging; sometimes patients are sent for a multiple types of imaging as part of the diagnostic process.

If you've got questions about the types of imaging machines used and the pros and cons of different scans, we've got the answers in our newly released factsheet: 'Quick Reference Guide to Imaging Techniques for Spinal CSF Leaks'.

We don't have one for cranial CSF leaks yet, but it's in the pipeline, so keep tuned in to our social media channels and future emails where we'll announce new factsheets as and when they're published.



To download our new factsheet, please [click here](#).

The banner features a circular portrait of Robin Palmer Hosking, a man with glasses and a goatee. The text on the banner includes the CSF Leak Association logo, the title 'SPINAL LEAKER STORY', a quote from Robin: "I spontaneously developed even more symptoms, including 'end of days' head pain...", the website address 'www.csfleak.info/profiles/robinpalmerhosking', and a call to action: 'Do something good for charity and support the CSF Leak Association today: www.csfleak.info/donate'.

Leaker Profiles

Today's volunteers for a few moments in the limelight are Robin Palmer Hosking and our very own, Polly Walker, who is also a charity Trustee.

Robin's leaker journey began with a traumatic head injury and a diagnosis of migraine. A sudden worsening of his symptoms some years later raised the suspicion that he was actually suffering from a CSF leak.

Robin has recently had a blood patch and is currently living life gently but positively.

You can read his story at: www.csfleak.info/profiles/robinpalmerhosking

Polly is what we call a 'functional' leaker who's been dealing with a spontaneous spinal CSF leak for the last three years. She's not had any invasive treatment to-date.

A long road to diagnosis led Polly to suspect connective tissue issues and bone spurs. She continues to struggle with symptoms associated with her CSF leak.

You can watch Polly's his video below:



Bite-sized Facts

Every day this week we're releasing a few bite-sized facts, and today's facts are:

LEAK FACT #5

STUDIES SHOW THAT CONNECTIVE TISSUE DISORDERS SUCH AS **EHLERS-DANLOS AND MARFAN** ARE COMMON AMONGST **SPONTANEOUS SPINAL CSF LEAK SUFFERERS**

csf leak association

Cerebrospinal fluid leaks are not rare!
Find out more about cerebrospinal fluid leaks www.csfleak.info/findoutmore
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LEAK FACT #12

The location of a spinal CSF leak is **undetectable in 50% of patients***

csf leak association

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* Shima et al Acta Neurochir Supp 2008 102 153-6 Pathophysiology and diagnosis of spontaneous intracranial hypotension. The CSF Leak Association is a Scottish Charitable Incorporated Organisation. Charity No. SC048319. Copyright © 2017 CSF Leak Association. All Rights Reserved.

#WearBlueToo

Don't forget to keep on wearing blue this week and start some conversations with your friends and colleagues. Each day, more and more people are using our [Facebook Frame](#) and [Twitter twibbon](#).

As it's Rare disease Day, it's even more important to get out there wearing some blue and join our sister charities by adding **#ShowYourRare** and **#RareDiseaseDay** to all our usual hashtags:

#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

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



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