

MERCHANDISE

A selection of awareness merchandise is available to purchase via the website.

T-Shirts & Vests: from £14.00

Baseball Cap: £12.00

Mug: £10.00

Medical Accommodation Cards: £1.00 for 5



MEMBERSHIP

Membership of Target CSF Leaks is open to individuals who are looking to join a community dedicated to raising awareness about CSF leaks, supporting those affected by this condition and share an interest in our mission.

By becoming a member, you will play a vital role in helping our charity achieve its objectives. Join us and be part of something meaningful and impactful.

Annual membership subscription rates:

Standard Membership: £8.00

Joint Membership: £10.00

Young Persons Membership: FREE

Organisation Affiliation: £30.00

MEMBER BENEFITS:

PATIENT SUPPORT SERVICES

Target CSF Leaks is dedicated to providing exceptional Patient Support Services to individuals affected by CSF leaks. Our commitment extends to advocating for patients in ways not currently offered anywhere else. We will actively support the patient by helping them through their healthcare appointments by prepping them accordingly, to question the consultant, and advocate the needs of the patient. By doing this, we strive to ensure patients receive the highest standard of care and support.

We also offer personalised support plans tailored to meet the specific needs and circumstances of each person we assist. This extends to the assistance of writing support letters for patients to use in their PIP claims and offer help in composing letters of complaint to PALS departments; or general letter writing to communicate with healthcare providers.

Other member benefits include exclusive resources, member newsletter and more..!

Target CSF Leaks

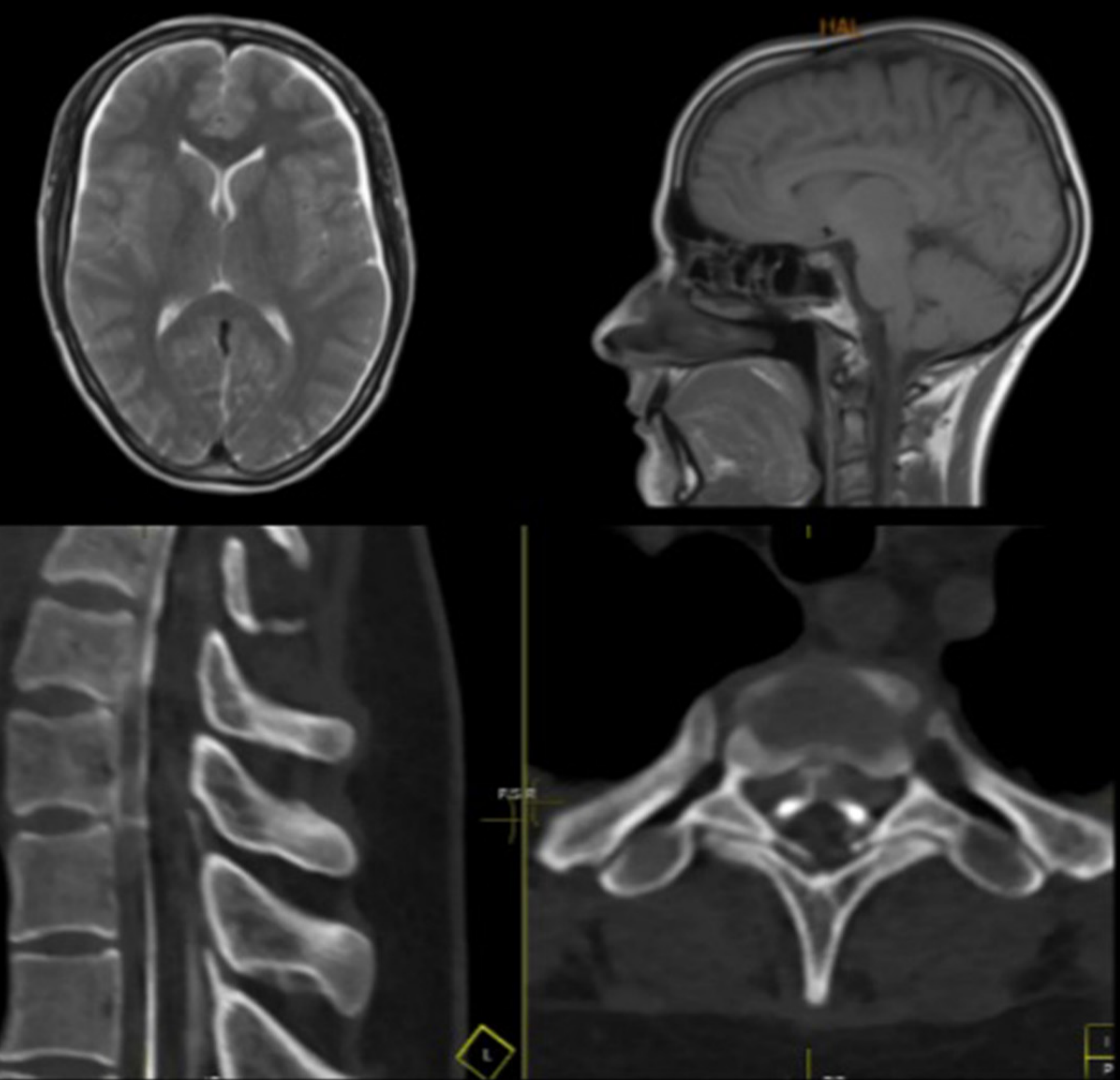
Defending your Dura

Leaky Café
Coffee House

Target CSF Leaks is registered as a
Charitable Incorporated
Organisation with the Charity
Commission.

Registered charity no.1209509

Leaky Café (Coffee House) is our
virtual online support group. Please
visit our website for details:
targetcsfleaks.uk



OUR MISSION

Our mission at 'Target CSF Leaks' is ambitious yet simple: to help as many people as possible who are battling with CSF leaks.

Through pioneering support and unwavering advocacy, Target CSF Leaks endeavours to mend the invisible wounds of CSF leaks, ensuring no one has to navigate the path to wellness alone.

Target CSF Leaks

Defending your Dura

CSF LEAKS General Information

This leaflet has been produced in good faith in order to raise awareness of CSF leaks. It is not a substitute for professional healthcare advice. You must always consult your own doctor with regards your diagnosis and treatment options.

More Information

If you would like to find out more about Target CSF Leaks you can find us via the following channels:

targetcsfleaks.uk
targetcsfleaks@gmail.com



@targetcsfleaks

Target CSF Leaks

Defending your Dura

Leaky Café
Coffee House

Target CSF Leaks
Defending your Dura

Charitable Incorporated Organisation (Registered Charity No. 1209509)

WHAT IS CSF AND HOW CAN IT LEAK?

CSF means cerebrospinal fluid. This is the fluid that surrounds our brains and spinal cord. It is very important as it cushions our brains which floats in it. When there's a defect or abnormality of the dura mater, this fluid leaks out draining the fluid causing 'spontaneous intracranial hypotension' (SIH).

TYPES OF CSF LEAK: SPINAL SPONTANEOUS

Type 1 – Dural tear

1a – ventral CSF leaks

1b – posterolateral CSF leaks

Type 2 – Meningeal Diverticula

Type 3 – CSF-venous fistulas

Type 4 – Indeterminate

CRANIAL

Cranial leaks are usually caused by head injury, sinus surgery, increased pressure in the brain, or malformations of the inner ear. Cranial leakers will drip CSF from their nose or ear. Other symptoms may include hearing loss, a metallic / salty taste in the mouth, or loss of sense of smell. The diagnosis and treatment for cranial leaks vary slightly to spinal leaks as features of SIH are not usually present.

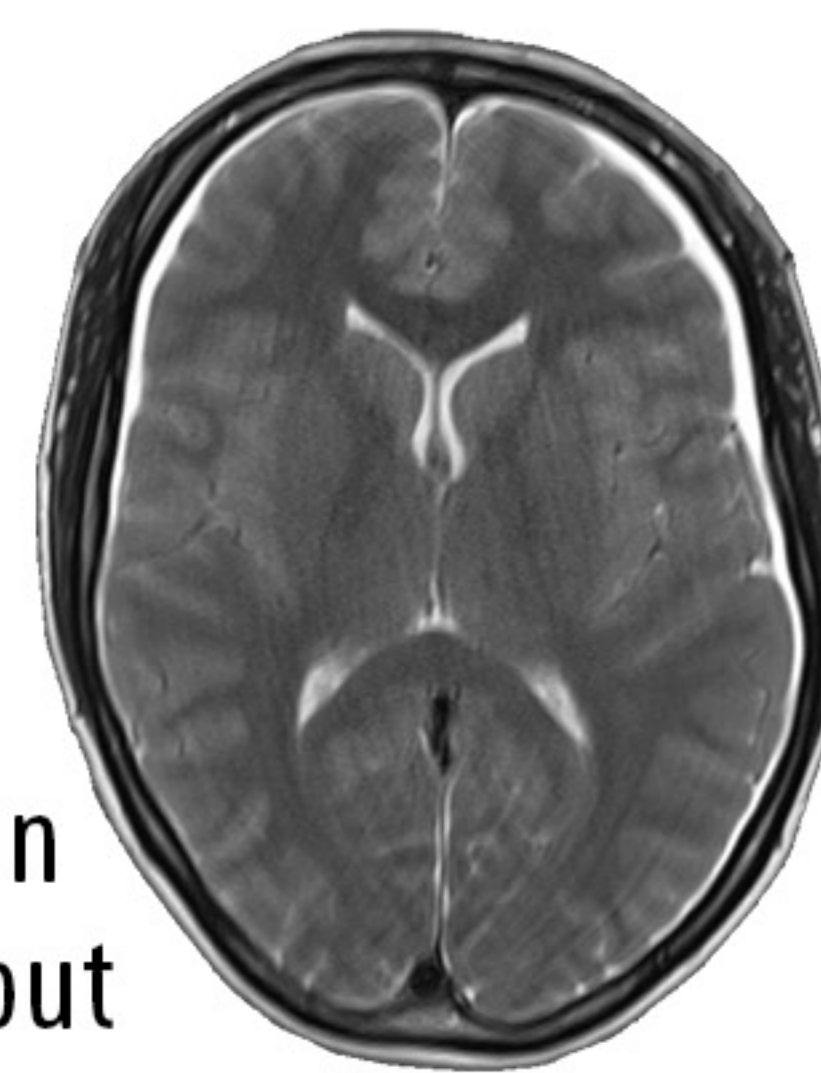
IATROGENIC

Iatrogenic means the leak was caused by an intervention such as lumbar puncture, epidural injections, or surgical procedures. It is crucial to be aware of the risks associated with these procedures and to discuss them thoroughly with your healthcare provider before proceeding.



DIAGNOSIS

Investigations for diagnosing a CSF leak would begin with assessing the patient's symptoms and history. A red flag for recognising a CSF leak is the orthostatic nature of the head pain being worse when upright and improves when lying down; but imaging will play an important part of the diagnosis.



IMAGING:- BRAIN MRI

A MRI scan of the brain is used to find indications of spontaneous intracranial hypotension (SIH). It is preferred this is done with contrast, however, it is acceptable to have this done without as most signs of SIH can be seen without it. SIH signs include:

- Diffuse Dural Thickening (although please note, this has a time dependence associated with it, as the longer the patient has been leaking, the more likely this appearance will diminish over time)
- Subdural fluid collections, which are usually bilateral and over time can get progressively worse.
- Dural Enhancement (only seen with contrast)
- Brainstem displacement
- Brain sag
- Venous Distension

IMAGING:- SPINE MRI

It is important to understand the reason for doing a spine MRI is not to localise the leak, but categorise the type of leak, although on rare occasions you can see where the leak is coming from, but this should be used as a guide, with the preference being to confirm via myelography.

The key finding investigated on a spine MRI is a fluid collection and whether the collection is:

- Ventral (front of the spine) – more commonly associated with type 1 – bone osteophyte caused leaks, or:
- Dorsal (back of the spine) – more commonly associated with nerve root sleeve tears.

Finding this fluid collection means there is a dural defect somewhere. The fluid can spread a long way.

If there is no fluid collection, it does not mean the patient isn't leaking, it might mean it is a CSF venous fistula, which means the leak is going straight into a vein. For this type of leak, the meningeal diverticula is what you are looking out for, although it is impossible to know which one the culprit is on MRI.

IMAGING:- NEGATIVE MRI

1 in 5 patients will have negative MRI's. This is probable the longer the patient has been symptomatic as some findings can disappear over time. When a brain MRI is completely normal, the spine MRI becomes more important as if there's diverticular and a good clinical syndrome, you're looking at a venous fistula. If both brain and spine are completely normal, then it means the likelihood of finding the leak at myelography is reduced.

IMAGING:- MYELOGRAPHY

The findings from the spine MRI is what dictates the next step for localisation of the leak, which will be in the form of a CT Myelogram (CTM), or Digital Subtraction Myelogram (DSM), depending on the type of leak being investigated and the resources available at the hospital. Primarily, CT Myelography is used. This is a CT scan which requires contrast dye to be injected into the spinal canal. There are different approaches that can be taken with performing a myelogram and this will depend on the type of leak suspected. More information is given in our separate leaflet.

TREATMENT OPTIONS

Some CSF leaks will heal on their own following conservative approaches. When this fails, a procedure called an epidural blood patch can be considered depending on the leak type. This is a procedure which involves your own blood being drawn from a vein in your arm and injected into the epidural space to cover the defect, encouraging the dura to heal. These are best done "targeted", as close to the defect as possible, and early. Fibrin Glue is increasingly being used to help seal venous fistulas and can work with some dural tears. In cases where blood patching is unlikely to work, surgery should be offered.

! Targeted treatment requires precise leak localisation !

PROGNOSIS

When targeted interventions are used, prognosis in sealing the leak is very positive. Some patients require more than one blood patch; and the surgery outcome is very good when done by an experienced surgeon.