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## Message from the Chairman

Hello and welcome to the inaugural edition of 'Leaker Life', the e-newsletter published by the CSF Leak Association, a new UK charity working to raise the profile of cerebrospinal fluid (CSF) leaks and help facilitate access to improved investigatory techniques and treatment.

The charity was established in early 2016 by a group of CSF leak sufferers who, having struggled to find the support within the UK that they themselves needed, decided that there was pressing need for a charity focused purely on cerebrospinal fluid leaks. We have since established ourselves as an organisation working to raise awareness and promote better understanding of this debilitating and under-diagnosed condition, as well as providing a united voice for sufferers and their families.

The culmination of over 12 months of preparatory work undertaken by six people from across the UK, we are very much a grassroots organisation, run by leakers for leakers, and we rely heavily upon a small, but growing number of passionate and committed volunteers. These are early days. We have big aspirations and while we have made significant progress already, we also know that change takes time and there is much work to do.

We hope that this newsletter will provide a vehicle for updating interested parties on the progress we're making, as well as developing into a valuable, informative asset for the leaker community, both across these islands and further afield. We welcome all with ideas for content, or any other suggestions, to get in contact with us to help make future editions even bigger and better.

On behalf of the Board of Trustees, and everyone else involved in the CSF Leak Association, I would like to thank

### CSF leak factsheets

Our website provides links to a number of useful factsheets. Some have been produced by us; others have been produced by other organisations such as the NHS or the Spinal CSF Leak Foundation in the USA. We have begun work on additional factsheets endorsed by UK doctors, which we hope will assist patients and doctors in both diagnosis and treatment of CSF Leaks.

[Learn more](#)

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### Partnership working

One way in which we are working to raise the profile of CSF Leaks is to link up with other charities and organisations to pool and share resources, where practicable. Since our formation, we have become members of [Genetic Alliance UK](#), [Rare Disease UK](#) and the [Scottish Council for Voluntary Organisations](#).

you all for your support so far, in this our founding year, and we hope that you will enjoy reading both this and future editions of Leaker Life.

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## What is a CSF leak?

A cerebrospinal fluid (CSF) leak is an often debilitating medical condition where a small tear or hole forms in the outer membrane that contains the fluid surrounding the spinal cord and brain (known as the dura mater).

When the fluid leaks out of the dura, the overall volume and pressure of fluid within the skull drops, its cushioning effect is reduced and the brain slumps. This slumping effect, also called 'brain sag', results in severe pain, pressure, blurred/double vision, eye pain, neck pain, hearing impairment, tinnitus, spasm, seizures and a wide range of other symptoms.

A key characteristic of a CSF leak is that the vast majority of symptoms, if not all, worsen markedly upon sitting or standing, but lessen substantially, and in some cases disappear completely, when lying down. The longer a leak goes untreated, the less prominent this orthostatic characteristic of symptoms may become.

Download our comprehensive 'What is a CSF Leak?' factsheet here: [www.csfleak.info/downloads/download-category/csf-leak-association-factsheets](http://www.csfleak.info/downloads/download-category/csf-leak-association-factsheets)

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## The KILT RIDE 2016 raises £1458 for the CSF Leak Association

On Saturday 28<sup>th</sup> May 2016, some 100 tartan-clad bikers arrived on the banks of Loch Ness as part of a two-day 500-mile ride in support of the CSF Leak Association. Called 'The Kilt Ride 2016' the event was the world's first ever large-scale awareness and fundraising event for cerebrospinal fluid (CSF) leaks.

This fantastic two-day motorbike event, organised by Ray Michael, a childhood friend of David Baldwin, Chairman of the CSF Leak Association, saw a convoy of motorbikes of all shapes and sizes, learners and old hands, rally to the support of leakers across the UK by travelling around the country, from the Borders to the Highlands, taking in some of Scotland's most iconic sites and scenery.

The Kilt Ride departed the Leadburn Inn, Midlothian, at 9am on Saturday 28<sup>th</sup> May to the sound of bagpipes and the smell of bacon butties, and made its way to the second rendezvous point at Tesco Extra, Perth, Edinburgh Road for 11:30. Thereafter, the Kilt Ride made its way through Fife, Perthshire through the Spittal of Glenshee and into the Cairngorms.

The overnight stop was at Dores, on the banks of Loch Ness, where there was live music, a BBQ and hugely popular Kilt Ride t-shirts for sale, before travelling back down south the following day via Glen Coe and Bannockburn.

All-in-all, the event was a roaring success and generated significant interest and excitement within the biker community, as well as being warmly welcomed by CSF leak sufferers across the UK, who are in desperate need of support and recognition. Support also came from a number of businesses local to the route, including [The Dores Inn](#), [The Leadburn Inn](#), [Saltire Motorcycles](#) and [Alba Customs](#), to whom we express our genuine thanks.

Ray Michael, a professional photographer originally from Edinburgh and now of Wiltshire, organiser of the Kilt Ride and childhood friend of David, said:

*“Having known David since we were six or seven, it was a massive shock when he fell so ill. When you are faced with a situation where you feel so helpless and it’s someone you’ve known for so long, someone you care about and someone who was always so active and outgoing, you want to do what you can to help.”*

*“I am overwhelmed, after the months of hard work and preparation, at how successful the event was. It has been a true honour to organise the Kilt Ride 2016 and I hope its purpose continues to have the desired effect.”*

The CSF Leak Association is already in discussions with Ray about plans for Kilt Ride 2017, which he hopes to be ‘bigger and better’...watch this space!

For more information, please visit: [www.csfleak.info/kiltride2016](http://www.csfleak.info/kiltride2016)

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## **The Mystery Headache: Migraine, Positional Headache, Spinal Fluid Leak?**

For anyone with an interest in, or working with CSF leaks, this is an absolute must see presentation by Dr Ian Carroll at Stafford Medical. Direct and myth-busting, it lays down a challenge to medical professionals to discard misconceptions about CSF leaks and step up to the plate to help the thousands of leakers worldwide who are not being afforded the care and treatment that they require.

Dr Carroll makes the key point that what so many doctors think they know about CSF leaks - particularly when based upon limited knowledge of acute iatrogenic leaks - is simply not applicable to the vast majority of people suffering from persistent and/or spontaneous leaks.

Crucial links between Heritable Disorders of Connective Tissue (HDCT), such as Ehlers Danlos Syndrome (EDS) and Marfan Syndrome, are also discussed, alongside some of the key indicators for those who may be at risk of suffering from a cerebrospinal fluid leak. This is a lecture not to be missed.

## CSF Leak Association Shop and Merchandise

Well we are very pleased to announce that the CSF Leak Association, in partnership with Teemill, now has an online shop, where you can buy a range of CSF Leak Association-branded clothing and gifts.

Unlike many similar bespoke online clothing platforms, Teemill is located in the UK; printing is carried out in the UK, and items ship from the UK, all within a matter of days. Teemill also ships internationally at very reasonable rates. The quality of the garments is all very good, and production is ethical, low carbon and organic.

For every item sold, the CSF Leak Association will receive a proportion of the profit to go towards the work that we are doing to support sufferers and progress our aims. As an example, for every t-shirt sold at £19, £4.50 will come to the Association; so you help raise the profile of CSF leaks and help us fundraise at the same time!

To visit our online shop, please click on 'shop' in the main menu on the CSF Leak Association website, or visit: <http://csfleakassociation.teemill.co.uk>

PS. Be sure to post a selfie online when you receive your lovely new things, with a brief explanation of what a CSF Leak is and the hashtag **#csfleak** to spread the word even further.

Thank you and happy shopping!

**!! FREE UK POSTAGE THIS WEEKEND (2nd & 3rd July 2016) !!**

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## Leaker's A-Z : A through B

Health-related terminology can be confusing at times, particularly to those without a medical background, with limited experience dealing with doctors or hospitals or who are new to a particular condition or illness.

We have prepared an alphabetical list of some of the most commonly used CSF leak terminology on our website. Below is some of the terminology that start with A or B. We will share further terminology in future editions.

### **Anterior**

Anterior refers to the 'front' of the spine and is synonymous with ventral, other than in the head. When referring to the body as a whole, the term 'ventral' is generally used infrequently in human

### **Low-Volume Patch**

In a low-volume blood patch, normally where the site of a cerebrospinal leak is known, an epidural needle is inserted into the epidural space at the leak site and a small amount of the patient's own

anatomy.

### **Arachnoid Mater**

The arachnoid mater is one of the three meninges, the protective membranes that cover the brain and spinal cord. It is interposed between the two other meninges, the more superficial and much thicker dura mater and the deeper pia mater, from which it is separated by the subarachnoid space. Cerebrospinal fluid (CSF) flows under the arachnoid mater in the subarachnoid space. The arachnoid mater makes arachnoid villi, small protrusions through the dura mater into the venous sinuses of the brain, which allow CSF to exit the subarachnoid space and enter the blood stream.

### **Autologous Blood**

Autologous blood is blood drawn from a patient's body and then injected back into another area of the body for the purposes of healing. It is used in a blood patch.

### **Blind Blood Patch**

A blind blood patch is a blood patch where blood is injected without reference to the specific location of a leak and the placement of the epidural needle is carried out by hand, often without the guidance of fluoroscopy. This is the standard procedure for high volume patches in the lumbar spine. A directed blood patch, using fluoroscopy, is more common for patches in the thoracic and cervical regions of the spine, where incorrect needle placement could have a significant adverse effect, and where a leak location is known.

### **Blood Patch**

An epidural blood patch is a surgical procedure that uses autologous blood in order to close one or more holes in the dura, usually as a result of a previous lumbar puncture or epidural anaesthesia, although hole may also occur follow trauma or spontaneously. Blood is injected into the epidural space. It is the most common treatment for a CSF leak that does not respond to conservative treatment, such as bed rest.

blood is injected (approximately 4-5ml) in order to 'patch' the meninges. The procedure carries the typical risks of any epidural puncture, plus relatively rare complications resulting from blood in the epidural space. While often effective, further intervention is sometimes necessary. A low-volume approach may also be used for blind blood patches in the upper thoracic and cervical spine.

### **High-Volume Patch**

In a high-volume blood patch, normally where the precise location of a cerebrospinal fluid leak is not known, an epidural needle is inserted into the epidural space most commonly around L3/L4 in the lumbar region. A relatively large amount of the patient's own blood is injected (+/- 20ml). The high volume means that the blood can travel around the epidural space in order to 'patch' the meninges. It is thought that this procedure can be successful up to 8 vertebrae from the injection site. The procedure carries the typical risks of any epidural puncture, however due to the additional volume of blood injected, the risks tend to be higher than a low volume patch. Success rates for spontaneous leaks are thought to be in the region of 40% per patch, however even where it is effective, further intervention is sometimes necessary.

One school of thought is that blood patches work by way of the clotting factors of the blood, which close the hole in the dura; another is that the blood, acting as an irritant, encourages the body to scar and heal; while another is that the blood creates a tamponade effect which allows the hole to heal. It is likely that improvement can be a result of all three. It is also postulated that immediate symptom relief following an epidural blood patch may be due to more of a compression effect which raises intracranial pressure than sealing the leak itself (hence why relief can sometimes be short-lived). Epidural blood patches are rarely successful for cranial leaks. Patches used to treat anterior spinal leaks, spinal leaks in the cervical region or leaks to venus fistula may be less effective.

You can view our full A to Z of terminology online, or download it in PDF format here: [www.csfleak.info/csf-leak-terminology](http://www.csfleak.info/csf-leak-terminology).

On September 11<sup>th</sup> 2016, seven brave souls will be taking on the unforgiving challenge of the TOUGH MUDDER North West in order to raise much needed funds, awareness and support for the CSF Leak Association.

Frances Tod, Kate Hubbard and five friends are embarking on this demanding obstacle course spanning 13 miles cross country, because it is a cause very close to their hearts. Kate's Mum has suffered with a CSF Leak for the past 6 years, she has travelled to the States to receive treatment and is committed to helping others with the condition through her role on the CSF Leak Association Board of Trustees.

It's not going to be easy for the Tough Mudders! Apparently the Tough Mudder North West features a mind numbing combination of new obstacles, unrelenting terrain and A LOT of mud. The Mudders are going to need to muster every little piece of mental grit in their quest for the finish line, and on their way they need to be prepared to face obstacles such as:

#### *The Block Ness Monster*

The Block Ness Monster is as epic and tricky as Nessie herself. Mudders have to push, pull, and roll their way through 60ft of slick, rotating barriers.

#### *Arctic Enema 2.0*

Is a highway to brain freeze in all the wrong places. The icy plunge has been updated to include a high-speed entry slide and centre wall that participants must duck under to escape the 10 tonnes of ice that is jammed into this frigid skip dive.

#### *King of the Swingers*

Remember that rope swing you built as a kid? The Tough Mudder version is bigger. Mudders must leap from a 12' platform to catch a swing arm and reach with all their might to tap the bell dangling from above. Many will attempt - few will make that sweet bell-ringing music.

#### *Cage Crawl*

A perfect chance for Mudders to practise their backstroke, under 60' of steel fence with only a few inches of air. In this obstacle, Mudders lie on their back and pull their way through this long, watery trench. It's as easy as breathing..!

#### *Electroshock Therapy*

A field of dangling wires that must be crossed, but it delivers an almighty punch at 10,000 volts. Say no more...eek!

#### *Quagmire*

Shaped like a moon crater filled with treacherous shoe-stealing, unforgiving mud, Quagmire is a mud puddle it'll be easy to step into, but the way back out won't be so simple. Mudders can crawl, scramble, or climb a chain of Mudders back out...

We wish Frances, Kate and friends the very best of luck as they embark on their training for this event and hope you'll update us afterwards! In the meantime, please get behind them and show your support for the CSF Leak Association by pledging

your sponsorship at:

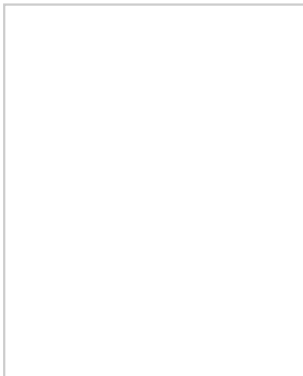
To lend your support or donate, please visit:

[www.totalgiving.co.uk/mypage/csfleaktoughmudder](http://www.totalgiving.co.uk/mypage/csfleaktoughmudder)

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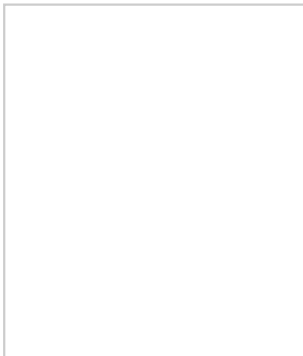
## Meet the Trustees

### David Baldwin - Chairman



David is a founding member and trustee of the CSF Leak Association, and currently serves as chairman. David is a Chartered Town Planner with over a decade worth of experience in the development industry. In 2013, he suffered a cerebrospinal fluid leak due after two osteophytes (bone spurs) punctured the dura in his thoracic spine; ever since, he has been working passionately and proactively to raise awareness of the condition across the UK. David was for many years a keen white water kayaker and volunteer UKCC/BCU Level 2 coach, a mountain biker, hill walker, scrambler and generally busy and active person. He first became involved in the charity sector missions to Romania, where he worked with disadvantaged children, and helped to renovate schools and distribute aid in the north of the country. David played trumpet for many years in a swing band and orchestras, still plays guitar when he can and worked for a spell as a web designer and developer.

### Deborah Ogg - Secretary



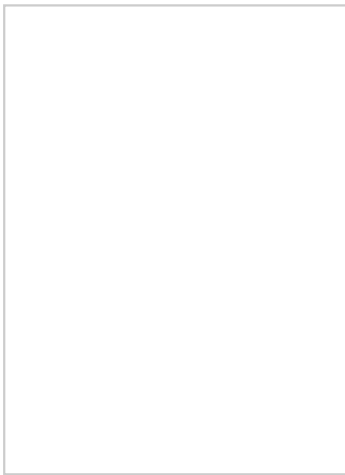
Deborah has spent most of her life working extensively in retail, from Saturday girl to store display design to flagship store manager. She's passionate about art, crafts and design. Her great love of riding motorbikes has been put on hold while she has a CSF leak, however she hopes to get back to that in some form in the future. She feels privileged to be a trustee and secretary of the CSF Leak Association. Being able to help raise awareness, knowledge and work towards better diagnostics and treatments is a fantastic opportunity. She developed a spontaneous spinal CSF Leak in April 2011 and continues to live with this condition. She also has Ehlers Danlos Syndrome (hypermobility type) which she feels is the most likely cause of her CSF leak.

### Cerian Baldwin - Treasurer

Cerian, the CSF Leak Association's treasurer, has been supporting her husband, David, since the onset of his CSF leaks in June 2013. Through being part of David's journey, she has met other CSF Leakers and been humbled by the bravery and determination that they have. She hopes that through the CSF Leak Association we can help to improve the diagnosis and treatment options available to them. In her day job, she works as a Senior Planner for the Scottish Environment Protection Agency. Through her work she's involved in the design and construction of many types of building projects across Scotland. She spends a lot of time analysing and writing reports and is used to liaising with the general public and other government bodies. She's looking forward to using these skills to support the work of the CSF Leak Association.

### Claire Hubbard

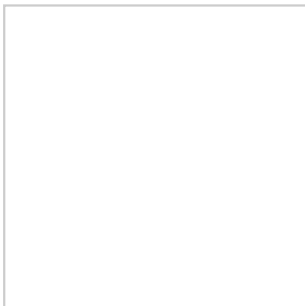




Claire is a trustee and became a Spontaneous Leaker in 2009. She was first diagnosed and treated in June 2014 and has been treated with multiple blood and fibrin glue patches in USA and at Royal Stoke hospital. She is married with two grown up daughters and lives in Staffordshire, surrounded by her extremely supportive family. She enjoys pottering in her greenhouse and preparing resources for children at school, where she can now work again within limited hours. Before leaking, Claire enjoyed exercise and ran the London Marathon in 2009; she would love to exercise again in the future, but for now must be satisfied with walking short distances when she can. As a trustee of the CSF Leak Association, Claire is determined to support leakers in any way she can. She has recently helped to facilitate cutting edge use of

intrathecal gadolinium for detailed MRI scanning at Royal Stoke, by coordinating with doctors in the USA and neurologists here in the UK.

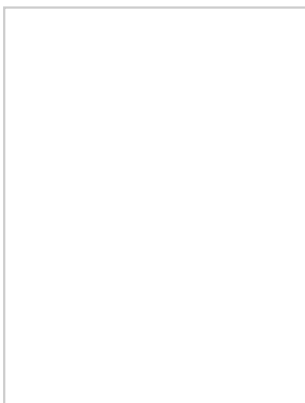
### **Sarah Mead**



Sarah is one of the trustees of the charity. She is married with 3 children and lives in a market town near Cambridge. Sarah trained as a Botanical Illustrator and worked until illness made this no longer possible. Sarah is also a CSF Leak sufferer and her leak started spontaneously in January 2010. She has been treated at the National Hospital for Neurology & Neurosurgery (London), The Royal Stoke University Hospital and The University Medical Centre Freiburg (Germany). Sarah's final treatment in Germany (in September 2015) appears to have solved her low pressure problem, but she is now being treated for rebound high pressure issues.

Sarah, like many leakers, has also been diagnosed with Ehlers Danlos III (an inter-connective tissue disorder), Temporomandibular Joint Disorder, Postural Orthostatic Tachycardia Syndrome and Hypothyroidism. When she is able, Sarah runs a small design company from home and is also a classically trained singer.

### **Pete Marnick**



Pete is a Flight Service Manager for Virgin Atlantic Airways, however has been unable to fulfil this role since the onset of his symptoms. Pete first experienced CSF related problems in 2009 after a spinal fusion operation lead to a CSF leak. This was subsequently patched. He is currently under the care of his third neurologist and has received treatment in both the UK and Germany. He remains under investigation and is yet to have a confirmed diagnosis. Pete has a keen interest in anything aviation related. Gardening is his favourite pastime when symptoms allow. He is determined to make a difference to those affected by CSF related conditions. He recognises there are many challenges ahead but is optimistic for the future. He dares to dream that one day others may not have to experience any of what he has gone through.

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## **A Hole in My Life**

*A Hole in My Life* is a newly published personal account of one woman's life-altering battle with an inner ear disorder (once considered rare, but now more commonly diagnosed), and her protracted struggles with some in the UK's medical community as she sought to access the correct treatment and care. It is an accessible and engaging memoir, which takes the reader from life as it was, to life as it is now, passing through various halts and jumping numerous hurdles along the way. With a chapter on CSF Leak analysis and investigations, honest realism and straight talking, it will strike a chord with many chronic illness sufferers, particularly those living with debilitating neurological symptoms and long-term pain. Providing a



clear and detailed insight into the many facets of chronic illness often known only to sufferers, their family and close friends, this valuable account is also recommended reading for all doctors and medical professionals who strive to understand life-changing health issues from the other side. A Hole in My Life can be purchased from Amazon in both paperback and E-book formats: [www.amazon.co.uk/dp/B01GF3UFBY](http://www.amazon.co.uk/dp/B01GF3UFBY)

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## Free money for the CSF Leak Association!

Yes, you heard right. There are a number of ways that you can generate free donations for our charity when you shop online. The CSF Leak Association is now signed up to Easyfundraising, Give as You Live and The Giving Machine.

Whenever you shop online through qualifying sites such as eBay, Amazon, Tesco, John Lewis etc., the merchants will give a percentage of what you spent to the CSF Leak Association - it's completely free and doesn't cost you a penny.

If you've not signed up already, you can find out more information by following these links:

[www.easyfundraising.org.uk/causes/csfleak](http://www.easyfundraising.org.uk/causes/csfleak)

[www.giveasyoulive.com/charity/csfleakassociation](http://www.giveasyoulive.com/charity/csfleakassociation)

[www.thegivingmachine.co.uk/beneficiary-portal/view/csf-leak-association](http://www.thegivingmachine.co.uk/beneficiary-portal/view/csf-leak-association)

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## Living with a CSF Leak

There is limited published advice on ways to cope with living with a [CSF Leak](#). Below are some hints and tips which may assist with day-to-day life, but as ever, you should always discuss your condition with your doctor and follow their advice.

The key things to remember are: don't bend, twist, or lift in any way that makes you strain. These actions engage what is known as a *Valsalva Manoeuvre*, which puts strain on the dura (membrane containing the CSF) and can make leaks worse.

### *Make Like a Bat*

By keeping your head lower than the rest of your body, the volume of CSF around your brain is maintained, which helps reduce symptoms. Your local council, GP or other NHS services should be able to provide you with a hospital bed to enable you to lie with your head lower than the rest of your body, when needed.

### *Do not bend or twist*

Instead ask your local Occupational Therapist to provide 'grab' sticks to enable you to pick things up, long handled sponges, shoe horns and sock pullers. Be ever mindful of everyday situations in which you might be forced to bend or twist and adapt as much as possible – for example: where is the toilet paper? Check before you sit on the loo, particularly if you're not at home! If it is behind you, put it in front of you before you are seated to avoid twisting to reach it. Ladies – attach a long handle to your razor so that you don't need to bend to shave your legs in the shower and do a leg a day if you're struggling!

### *Log Roll Out of Bed*

Again this stops you twisting and putting strain on your dura and leak site. Ask your local physiotherapist

to show you how or take a look at: <https://youtu.be/1xioiSDHaWM>

#### *Do Not Strain*

Avoid lifting anything heavy or straining when you go to the toilet. Again, this can put strain on the Dura making your leak worse. Maintain a high fibre diet and keep well hydrated to avoid becoming constipated.

#### *Listen To Your Body*

Try and rest as much as you can. The long-term effect of CSF Leaks are poorly understood so it is best to avoid pushing through your symptoms. Bed rest has also been shown to help with some leaks.

#### *Be Rude*

When coughing or sneezing do not try to hold it in. Instead let the air flow unhindered. Holding it in may put strain on the Dura and could make your leak worse. Be mindful of this when blowing up balloons or similar.

#### *Make Mine an Espresso*

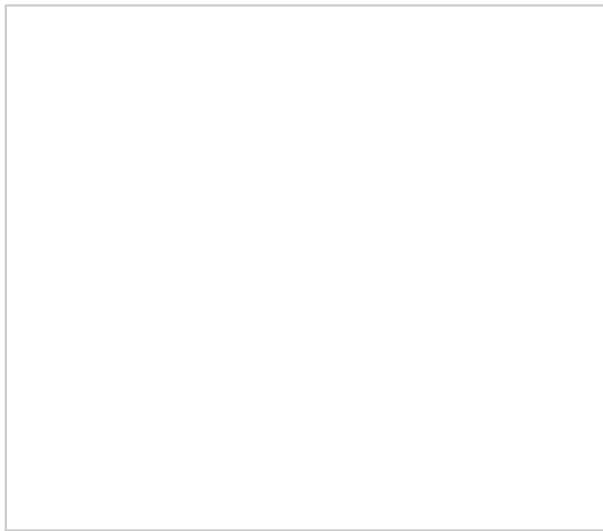
Caffeine can provide temporary relief of some symptoms. Some sufferers drink a lot of coffee or caffeinated drinks to help with this. Check with your doctor before doing so in case it might affect any other medical conditions you have.

#### *Avoid the Gym*

Avoid strenuous activities that might put strain on the dura – including activities that involve spinal stretches and twists such as Yoga and Pilates unless you have a very well educated teacher that can heavily adapt the moves you carry out in order to make them safe. You could use sports tape along your spine to provide instant feedback as to how much you are stretching. If the tape is being stretched, your dura will be too. Be aware of the position of your spine if you decide to swim – the awkward angle of your neck if swimming with your head above water when doing breaststroke may exacerbate a leak in the thoracic or cervical area. Opt for gentle activity and stop if your leak 'declares itself' in any way.

Here are a few more 'Life Hacks' suggested by Leakers to help other Leakers:

- Use a **slow cooker** for making dinner. You can prepare the food early in the day when you are probably feeling your best. Leave **pre-prepared tea or coffee mugs** on the worktop, so you just need to add water when required.
- **Take a camp bed or yoga mat wherever you go.** You can lie down when you need to but still participate in family outings, outdoor fun or other gatherings. **Some leakers have made a sign** saying: 'Why am I lying down? Because I have a Cerebrospinal Fluid Leak and my symptoms are worsened greatly when standing!' to raise awareness and avoid embarrassing or awkward comments and questions, or perhaps carry [a copy of our 'What is a CSF Leak?' fact sheet](#) when you're going places to help folk understand.



- If you have a long way to travel, consider investing in **an inflatable mattress for the car** or ask your Occupational Therapist if they can provide one. If you're heading to a hospital appointment, **book patient transport** and specifically request a stretcher (it's free in the UK).
- Also **when travelling, take a 'survival kit' with you**, tailored to your individual symptoms. Sick bags, anti-nausea medication, ear plus, sunglasses, a flask of coffee etc.
- Consider carrying an emergency **MEDICAL ALERT! card** with detail of contacts on the back in case you get into difficulties. **iPhone and Android smartphones** also have a medical alert button on the passcode page, where you can store emergency details that can be accessed without actually accessing the phone. More info here: <http://goo.gl/GaHwKe>
- **Keep essential items close when lying down** or resting to avoid having to keep getting up. Your phone, a drink, the remote control, a snack, a notebook and pen.
- If you can, invest in **home delivery for your food shopping**. The big supermarkets run brilliant offers to cut the cost of this. You can plan your meals and do your shop in your own time – you can save the contents of your 'trolley' and add to it when you are feeling up to it. When it is delivered, make the most of the helpful delivery drivers and have them bring the shopping into the house and put it on a surface where you can limit how much bending you have to do.
- Find something to help you relax or vent. **Adult colouring** is all the rage at the moment, but it can be very relaxing. You can **keep a diary or a start a blog** to vent, share information or to jot down your thoughts. There are numerous apps available to **keep your mind active** and of course the ever-faithful Netflix for box sets (other internet-based providers are available!). **Listen to relaxing music** or mediation music, or **sign up to Audible** where you can pay to download audio books.

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## It's Competition Time...

Help! We're a new charity and we need a slogan; we'd love for our fabulous supporters to come up with their own ideas – something that represents leakers the

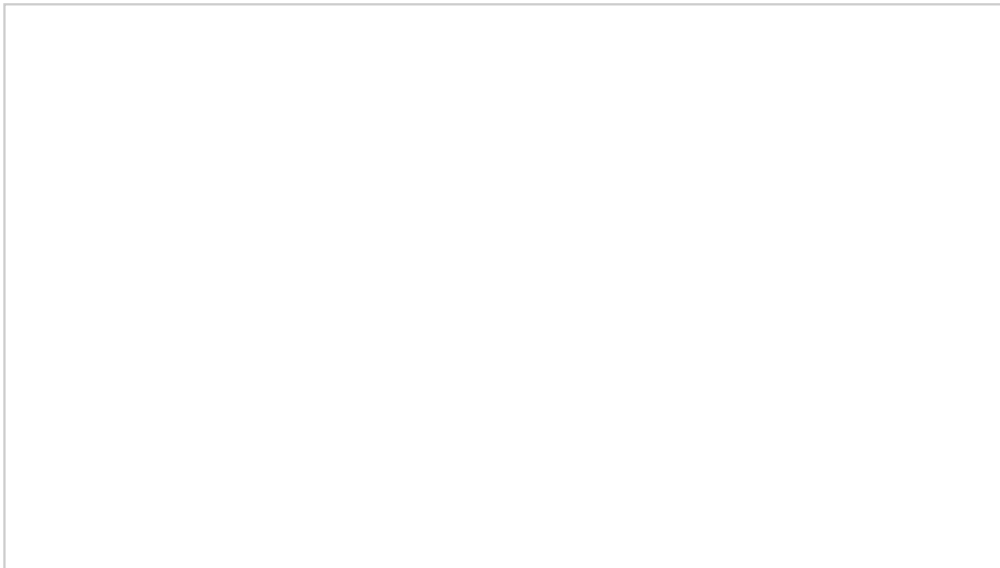
world over - and be part of our work to raise awareness.

The slogan should be no longer than 8 words, should reflect [the general aims of the CSF Leak Association](#) and encapsulate what CSF leaks are about. We hope to use slogans on merchandise, publications and alongside our logo, so if you are able to devise one suitable for all occasions that's great, and it may help nudge you towards the winner's post, but it's not mandatory.

We appreciate that sometimes people come up with similar ideas to others, so should more than one entrant suggest the winning slogan or slogans very similar in wording or meaning to the winning slogan, a prize draw will be carried out to determine the overall winner. May the best line win!

Please email your ideas to [competition@csfleak.info](mailto:competition@csfleak.info) by **31<sup>st</sup> July 2016** and the CSF Leak Association Board will choose their favourite. We need your name, address and email address, alongside your entry. The winning slogan will be announced by the end of August 2016.

The winner will receive a limited edition CSF Leak Association mug, as well as the honour of having your slogan featured in CSF Leak Association work in the coming months.



NB. All entrants should ensure that they have read and understand the terms and conditions for this competition, which can be found here: [www.csfleak.info/competition-terms-and-conditions](http://www.csfleak.info/competition-terms-and-conditions).

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The US-based Spinal CSF Leak Foundation was established in June 2014 as non-profit health advocacy foundation by individuals affected with spinal CSF leaks.

The Foundation has since established a popular online forum for education and support relating to the

condition and they hope to expand their efforts in education to both patients and health care professionals, as well as to raise funds for research.

We have established a good working relationship with the Spinal CSF Leak Foundation and we are looking forward to pooling resources and undertaking collaborative work in the near future.

Further information on the Spinal CSF Leak Foundation can be found at: [www.spinalcsfleak.org](http://www.spinalcsfleak.org)

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## Magnetic Resonance Imaging: Where it all began...

CSF Leak Association chairman, David Baldwin, alongside the world's first ever clinically-used full body MRI scanner at Aberdeen Royal Infirmary in the north-east of Scotland. It is amazing to think that this piece of equipment - cutting edge in the early 1980s - was the precursor to the modern MRI machines with which CSF leak sufferers around the globe will be only too familiar!

Read more about 'Mark-1' here: <https://goo.gl/y5xnwa>

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We're looking for volunteers to help with our work. Whether you have particular experience or skills that you feel may be of use, or just want to muck in and help with anything that needs doing, we'd love to hear from you. We may not have specific job for you immediately, but we have set up a list of volunteers and we will circulate emails as and when projects arise, initiatives begin etc. to see who's interested and able to assist. If you're interested in volunteering, please email: [volunteer@csfleak.info](mailto:volunteer@csfleak.info)

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## To Boldly Go Where No-one Has Gone Before...

It's been a busy few months behind the scene since we became a registered charity. As you may expect, there has been a lot of red tape to cut through, and being the first ever CSF Leak charity in the UK (and one of only two in the world) means there is much to do going forward and little existing groundwork to call upon.

CSF Leaks have been under-diagnosed and regularly misdiagnosed for many decades, with little treatment or support for sufferers, particularly those with spontaneous spinal leaks and those who do not respond well to conservative approaches or basic blood patches. It is a misunderstood condition with little knowledge within the general UK medical community. Raising awareness and improving understanding is crucial element of our work, but it will take time and concerted effort on many fronts.

We have a variety of exciting and ambitious proposals for the short, medium and long term and these will be published as part of our formal strategy in due course; we are, however, extremely keen to also gauge the opinions of leakers and draw upon the thoughts and ideas of those who we aim to help and support.

The diagram below shows a number of ideas we have had, or issues or projects that we are actively considering or currently progressing. Some of these need significant financial investment, whereas others we can start working towards in the near future. We are also considering the creation of a database of CSF leak symptoms on the back of dedicated survey work, which we hope will inform and support both patients and medical staff.

We would warmly welcome suggestions or thoughts you may have on these issues, or for any other initiatives you feel should be considered going forward; all ideas will be added to the mix and considered by the Board.

Please email anything that you'd like us to consider: [secretary@csfleak.info](mailto:secretary@csfleak.info)

You can view the charity's aims and objectives here: [www.csfleak.info/aims-objectives](http://www.csfleak.info/aims-objectives)

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## Feeling social?

If you're active on social media, why not check out our [Twitter feed](#) and [Facebook page](#)? We publish regular updates, news, articles and announcements about CSF Leaks and related conditions. If you wish to post your own content on social media about CSF leaks, why not use the following **#hashtags** in order to maximise exposure and secure awareness across the globe?


**#CSFleak**   **#SpinalCSFleak**   **#headache**   **#IntracranialHypotension**   **#LeakerLife**

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