

This guide has been produced by the CSF Leak Association, a Scottish Charitable Incorporated Organisation working to raise the profile, promote awareness and support sufferers of Cerebrospinal Fluid (CSF) Leaks. The content is checked regularly to ensure it remains current; it was last updated on **10 January 2017**. If it is some time since you obtained this document, please visit our website to check if a newer version is available for download: www.csfleak.info

CSF Leak Association Membership

[Membership Overview](#) | [Membership Benefits](#) | [Charity Governance](#) | [Join Us Today!](#)

Membership Overview

Hello! Thank you for your interest in becoming a member of the CSF Leak Association.

As an organisation, our aim is to provide support to all sufferers of Cerebrospinal Fluid (CSF) leaks and, in addition, their family, friends and medical advisers. Whether the leak is caused by injury, accident, a pre-existing medical condition, be it a spinal or cranial leak, we will do all we can to supply you with the information you need to know.



CSF Leak Association Membership Card



Our Android App

If you think you may have a CSF leak but have not yet received a positive diagnosis, we can help you find a consultant that may have experience of treating patients with CSF leaks. If you already have a diagnosis, we can help explain all the medical terms and procedures that you may encounter during your journey towards treatment and resolution.

Questions? Need more information?
www.csfleak.info | info@csfleak.info

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This information is provided in good faith and in order to raise awareness, inform discussion and aid research. It cannot, however, be guaranteed error-free and is not a substitute for professional healthcare advice. You must consult your doctor and discuss healthcare options with them.

We understand that this condition can be debilitating, life-changing and sometimes frightening. We hope that the information contained within our membership resources, publications and on our website will help to take the edge off some of these worries and reassure you that you are not alone.



Exclusive members' window sticker



CSF Leak awareness wristband

The CSF Leak Association is run by people who all have personal experience of CSF leaks. Many of our trustees and volunteers have suffered, or are still suffering, with the effects of a leak, while others are partners or family of a 'leaker' (as we like to be known!). We firmly believe that it is vital that those offering support understand what you are going through, and we know how important it is to know that support is out there.

As a membership organisation, we rely heavily on the fantastic support and generous encouragement of our members and volunteers in the work that we do. Without this dedicated help, we could not function and would be unable to continue in our work to raise awareness of CSF leaks and push for positive change.

If you share [our aims and objectives](#) and benefit from the work that we do, why not [join us](#) and get involved?

» [Top of page](#)

Membership Benefits

As a new member of the CSF Leak Association, you will be sent a welcome pack, which includes:

- Welcome letter
- Membership card
- Medical accommodations cards
- Window sticker

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- Awareness wrist band
- A copy of our latest factsheet
- Printed copies of our *Cerebrospinal Fluid Leaks: An Overview* leaflet



Our Leaker Life e-newsletter is available hot off the press to all members

Membership benefits also include:

- Access to our membership mailing list
- Access to our online membership system
- Access to our members' network directory
- Access to our members' library
- Right to attend and vote at members' meetings

You will also be eligible to receive a full copy of our quarterly e-newsletter, Leaker Life, as soon as it is published (non-members have access to limited new content and back-issues only).

Online Membership System

Our online membership system allows our members to manage their subscription (incl. updating personal information), contact preferences and mailing list memberships. It also provides access to membership directories and our members' library, where you can download CSF Leak Association policies and resources.

You can access our online membership system at: www.csfleak.info/members

» [Top of document](#)

Governance of the Charity

General

The CSF Leak Association is governed in accordance with [our constitution](#) and Scottish charity law. While the day-to-

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day management of the charity is the responsibility of the Board of Trustees, members have the right to attend members' meetings (including any annual or extraordinary general meeting) and have important powers under our constitution; in particular, the members appoint people to serve on the board and take decisions on changes to the constitution itself.

Membership of the charity is open to anyone aged 16 years or older, unless they are a current employee of the organisation, in which case they are ineligible for membership. Junior Supporter status is available to those under the age of 16, and junior supporters enjoy many of the same benefits as members, but due to their age, cannot vote at meetings or become charity trustees.

Your support and involvement as a member allows us to continue our work to raise awareness of CSF leaks within the medical and non-medical communities, to campaign for recognition and support of this condition and to support you through the information on our website.

Register of Members

We are required by legislation to keep a register of members. The register includes, for each member or former member (up to six years after they ceased to be a member):

- his/her/its full name and address;
- the date on which he/she/it was registered as a member of the organisation; and
- where a member is a body corporate:
- any other name by which the member is, or makes itself, known;
- the principal contact for the member.

You may request a copy of the register of members at any time. If you are an ordinary member and not a charity trustee, a copy will be provided with addresses (and any other personal information) of other members redacted.

Withdrawal from Membership

While we hope that you'll want to be part of our work for a long time to come, if at any point you wish to withdraw from membership, you must advise us in writing; you will cease to be a member on the date when the notice is received by us.

Expulsion from Membership

While it is extremely uncommon, very occasionally the membership may decide to expel a member by way of a resolution passed by not less than two thirds of those present and voting at a members' meeting, providing the following procedures have been observed:

- at least 21 days' notice of the intention to propose the resolution must be given to the member concerned, specifying the grounds for the proposed expulsion; and
- the member concerned will be entitled to be heard on the resolution at the members' meeting at which the resolution is proposed.

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If you fail to renew your membership with eight weeks of the date upon which it is due, you may automatically be expelled from membership; however, this will only occur after at least one reminder letter has been issued to you. Under such circumstances, you are always free to re-join again in the future – indeed we would welcome it!

Termination

Membership of the organisation terminates on death; or (in the case of a corporate body) on the liquidation, receivership, winding-up or dissolution of that body; or (in the case of an individual admitted to membership on the basis of nomination by an unincorporated body) if the unincorporated body is dissolved.

Members Meetings

The board of trustees will arrange an Annual General Meeting (AGM) each year. Special members' meetings can also be called under certain circumstances. At least 14 clear days' notice will be given of any AGM or any special members' meeting and papers (including an agenda and details of key resolutions), and will be distributed by email to the members' mailing list. **If you have not joined this list, you will not receive copies of the papers.**

All members may attend the meeting and are entitled to vote. Meetings will generally be held at the charity's registered office, however given the distances involved, and in recognition of the implications that a CSF leak can have on our members' ability to travel, up to 25 teleconference slots will be available via Skype (service status permitting). Slots must be booked in advance; booking details will be issued with the notice of the meeting.

Proxy voting is also available to members, and should be arranged in advance in accordance with the guidelines outlined in our Decision-Making Protocol. Members wishing to use a proxy vote must complete the official proxy vote form in full and return it to us within the prescribed timescales. Both of these items can be downloaded from the members' library or are available on request.

Written Resolutions by Members

While decisions are normally made at members' meetings, occasionally a decision may require urgent attention and a resolution may be circulated for the written approval of the membership. A resolution agreed to in writing (incl. electronically) by all the members will be as valid as if it had been passed at a members' meeting; the date of the resolution will be taken to be the date on which the last member agreed to it. If such a resolution is circulated, and



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you agree with it, please ensure that you respond within the prescribed timescale.

Minutes

The Board of Trustees is required to ensure that proper minutes are kept in relation to all members' and board meetings. Copies of the members' or board meeting minutes may be requested by any member or member of the public on request, but the board may exclude confidential material.

Election to the Board of Trustees

Any member may stand for election to the Board of Trustees. Our constitution outlines many of the key roles, responsibilities and requirements for Trustees, however please feel free to contact any of our current Trustees if you have any queries or are interested in getting involved.

Being a charity trustee can be extremely rewarding, but it also carries with it legal responsibilities and does require a certain amount of time to be committed every year. Trustees must comply with application legal frameworks and national guidelines, as well as our own Code of Conduct and Conflict of Interests policies.

Liability of Members

Members of the CSF Leak Association have no liability to pay any sums to help to meet the debts (or other liabilities) of the Association if it is wound up; accordingly, if the charity is unable to meet its debts, the members will not be held responsible. This is outlined in Clause 7 of our constitution.

Members, in addition to the charity trustees, do have certain legal duties under the [Charities and Trustee Investment \(Scotland\) Act 2005](#); Clause 7 does not, however, exclude (or limit) any personal liabilities they might incur if they are in breach of those duties or in breach of other legal obligations or duties that apply to them personally.

Further Information

If you require any further information or advice on matters relating to governance or membership of the CSF Leak Association, please feel free to contact our Membership Secretary at: membership@csfleak.info

Further information can also be found in our constitution, which is available in our members' library and can be accessed via our [online membership system](#), and at the Office of the Scottish Charity Regulator: www.oscr.org.uk

» [Top of document](#)

Join Us Today

We have a variety of membership categories available, ranging from single adult to corporate. In accordance with Scottish charity law, anyone over the age of 16 can join us in membership, irrespective of where they live.

- **Adult (18 years of age or older) – £15.00**

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- **Adult (ages 16-17)** – £5.00
- **Junior Supporter (ages 0 – 15)** – £5.00*
- **Family (a family group living at the same address)** – £30.00
- **Incorporated Body or Organisation** – £50.00
- **Unincorporated Body or Organisation** – £50.00

*Junior Supporter status, while not constituting a formal member, carries all of the benefits of membership, with the exception of voting rights or the ability to stand for election as a trustee.

Membership lasts for 12 months from the date of application, unless you have selected automatic renewal, in which case it will renew each year and will only expire if you manually cancel the subscription yourself through PayPal.

You can submit your membership application online (individual applications only) or via postal application (individual, family and corporate membership).

Please visit www.csfleak.info/membership to apply online or download and application form.

» [Top of document](#)

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