



# Confidentiality Policy



# HOPE for Epilepsy Confidentiality Policy

## Purpose of this Policy

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HOPE for Epilepsy (also referred to in this document as 'us', 'we' and 'the charity') recognises the importance of confidentiality as central to the work we undertake. It forms the basis of the trust that the families attached to our charity place in us and ensures compliance with Data Protection laws. In relation to safeguarding issues, it is not a breach of confidentiality to pass safeguarding concerns on to the safeguarding lead or appropriate authorities.

This Confidentiality Policy should be read in conjunction with the Data Protection Policy, Privacy Policy, Social Media Policy, and Safeguarding Policy.

## Definitions

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Personal Information:

By personal information, we mean both:

- a) The data protection definition is any information that enables a living person to be identified (eg name, address, phone number, email address, NHS number etc or Special Categories of Personal Data which require the individual's explicit consent for it to be held by the Charity, eg ethnicity, sexual life, political interests, religious beliefs, trade union affiliations etc.
- b) Information, written or verbal, about an individual that relates to their health, circumstances, family, or experiences that is either provided to us for context so that we can provide a service and/or information we gather directly as a result of our contact with that individual.

## Context

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HOPE for Epilepsy hosts monthly support sessions in person, a general advice/support phone line, and facilitates contact between families and medical-trained epilepsy specialists. We also receive contacts over email and social media.

Another service the charity provides is the provision (free of charge) of anti-suffocation pillows to families where a child/young person has nocturnal convulsive seizures. This is a service based on need not means where we request a copy of a medical letter outlining the presence of these types of seizures to process the request for the pillow. Once the request has been processed, we no longer hold onto the letter or any copy of it.

## Information about individuals

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In the course of the above activities, confidentiality is of central importance. Only people who need to know medical information specific to the individual have access to or knowledge of it. The medically trained and other professionals associated with our charity will regularly receive confidentiality training in connection to their roles outside of HOPE, and the principles of that training are directly applicable to the services they help HOPE for Epilepsy provides.

When medical letters are given by parents/carers for the provision of anti-suffocation pillows, details of these are not shared with any third party or the supplier of the pillows. Only the Chair of Trustees processes the medical letters, which are deleted after the pillow is received.

Individuals whose information is collected are made aware of their right of access to their records. They will also be made aware of their right to complain if they feel confidentiality has been breached.

To be clear, all personal information will be treated as confidential. Information will only be collected that is necessary and relevant to the purpose it is required. It will be stored securely, accessible only on a need-to-know basis to those members of the board, trustees, and volunteers duly authorised. The retention periods of personal information are covered in the retention section of the Data Protection Policy which should be read in conjunction with this policy.

## Information supplied by children and young people

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If a child or young person under the age of 16 directly contacts HOPE for Epilepsy either by email or telephone, the information they provide will only be used to process their enquiry.

Unless it is a safeguarding concern, express permission from their parent/carer may be required to talk to them, and this will be made clear to anyone under the age of 16 who directly contacts the charity.

Age-appropriate signposting, information, and advice must be given in the response, and if appropriate, the parent/carer should also be advised about what was discussed and the advice given.

## The use of images/videos of children

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When information or life stories about the children attached to HOPE for Epilepsy are used on our website, social media, or promotional materials; full names are not given. The child shall only be identified by their first name or a pseudonym. No information that may give away the exact area they live, or specific address details will be divulged.

Full and informed permission is required for pictures of those who attend HOPE for Epilepsy sessions before they can be used. Pictures of a child/young person with an anti-

suffocation pillow that we may receive likewise can only be used once this permission is obtained. The same for any video footage.

The use of these images will not exceed the original permission unless new permission is requested and granted on each occasion the image is used.

On occasion, HOPE for Epilepsy will use licensed, available stock images for illustrative purposes on social media posts. If these images are used, it is made clear they are stock images.

## **Duty to disclose information**

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There is a legal duty to disclose some information including:

Drug trafficking, money laundering, or acts of terrorism will be disclosed to the police.

It is the responsibility of all trustees, board members, and volunteers to ensure that any concerns arising from situations they observe, allegations (or reports from third parties), or disclosures (reports from someone about themselves) relating to potential abuse or where an indictable offence may have been committed, are reported to the safeguarding lead and/or relevant authorities even if they are unsure whether the concern is justified. It is not a breach of confidentiality to pass this concern on in the appropriate way.

In addition, if a board member, trustee, or volunteer believes an illegal act has taken place, or that a user is at risk of harming themselves or others, they must report this to the chair who will report it to the appropriate authorities.

Individuals should be informed of this disclosure unless this would put at risk the safety of any individual or jeopardise a potential criminal investigation. Details about the disclosure of information and who has been informed will always be kept on record and stored securely with restricted access

Please refer to the Safeguarding Policy.

## **Breaches of confidentiality**

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All trustees, board members, and volunteers should guard against breaches of confidentiality. This includes, but is not limited to:

- Discussing matters in public where an individual or family can be identified by what is being said/overheard
- Unauthorised access to person-identifiable information where a member of staff, or third party, does not have a need to know
- Incidents of information lying around in a public area
- Theft and loss of information should also be reported directly to the Chair of trustees

When reporting any breaches, a full account as possible must be given by those concerned. Any breaches will be evaluated on a case-by-case basis and dealt with accordingly.



<b>Date</b>	<b>Action</b>	<b>By whom</b>
November 2022	Completed and edited	Louise Miller (Trustee)
November 2022	Reviewed and checked	Dr Nadine Gurr (Cahier of Trustees)
November 2023	Reviewed	Louise Miller (Trustee)
November 2024	Name changed from 'HOPE for Paediatric Epilepsy: London' to 'HOPE for Epilepsy' as per rebrand	Louise Miller (Trustee)
<i>November 2024</i>	<i>Date of next review</i>	