

1. PRIVACY

Epilepsy Foundation Privacy Statement

The Epilepsy Foundation (referred to as the Epilepsy Foundation, we, us or our) is strongly committed to protecting the privacy of its members, clients, supporters and donors, volunteers, staff and all members of the public who deal with the Epilepsy Foundation, and has implemented the Epilepsy Foundation Privacy Policy, which includes this Privacy Statement, to provide you with information about how we collect, hold and use personal information you provide to us.

The Epilepsy Foundation may, from time to time, review and update our Privacy Policy, including to take into account new laws, regulations, practices and technology. All personal information held by the Epilepsy Foundation will be governed by our most recent Privacy Policy (including this Privacy Statement). We will post on our website that changes have been made to the Privacy Policy and publish on our website the effective date when the Privacy Policy is updated. From time to time we may use the personal information already collected to identify new products/services we believe may be of interest to you or use personal information in new ways. We will generally only do this where we are permitted to do so under the relevant privacy laws.

To the extent applicable, the Epilepsy Foundation will comply with the relevant Acts covering the legitimate use of an individual's personal information. The relevant Acts are:

- Privacy and Data Protection Act 2014 (Vic) [Click_here/](#)
- Health Records Act 2001 (Vic) [Click Here](#)
- Freedom of Information Act 1982 (Vic) [Click Here](#)
- Public Records Act 1973 (Vic) [Click Here](#)
- Australian Privacy Principles (APPs) of the Privacy Act 1988 (Cth) [Click here](#)
- [Notifiable Data Breaches \(NDB\) scheme of the Privacy Act 1988 \(Cth\) Click here](#)

Risk Management

The Epilepsy Foundation takes a risk management approach to collecting, storing and using your personal information and data. We know the risks and take steps to mitigate them as the most important element of best practice charity governance. Our Board is highly aware of and sensitive to its legal responsibility in managing personal information and data. Where a data breach occurs, and meets relevant regulators' specified harm thresholds, the Epilepsy Foundation follows mandatory data breach notification procedures of the relevant regulator.

What is personal information?

Personal information means information or an opinion about an identified individual, or an individual who is reasonably identifiable:

- whether the information or opinion is true or not; and
- whether the information or opinion is recorded in a material form or not.

This includes information such as:

- name, including the name of an authorised parent, guardian, carer or other representative who you have nominated as your representative,
- date of birth and gender,
- the name, address and contact details of your organisation or business (if applicable),

- contact information (such as a home address, email address and phone number),
- credit/debit card and bank account information,
- signatures
- employment details
- details of products or services purchased or received from the Epilepsy Foundation and Epilepsy Foundation suppliers (such as products from the Epilepsy Foundation Shop, counselling and support services, professional development events, training programs, fundraising activities, education, peer support and networking and information services),
- **details of service and product preferences**
- details of the products or services purchased, received or in which individuals have participated (such as the name and date of the fundraising activity or professional development/training program),
- health information and other sensitive information (as set out in further detail under "Health information and other sensitive information", below), and
- other information about your history with, or relationship to epilepsy.

Whose personal information does the Epilepsy Foundation collect?

The Epilepsy Foundation collects personal information from people who are connected to its operations and activities – including:

- employees,
- volunteers,
- donors,
- supporters,
- customers,
- clients,
- research study participants,
- recipients of support services,
- participants in advocacy campaigns or health promotion projects,
- health professionals, and
- suppliers and service providers.

We also collect information about you if you are a user of our website.

How does the Epilepsy Foundation collect your personal information?

Where possible, the Epilepsy Foundation will collect your personal information directly from you. This may be:

- in person (for example, where you purchase a retail product in-store, when you make a donation to a doorknock collector or attend an event),
- on the telephone (for example, if you contact the Epilepsy Foundation by phone, including the Epilepsy Helpline, or if you answer a telephone-based research questionnaire conducted by or on behalf of the Epilepsy Foundation),
- by mail (for example, if you complete research study documentation or a survey, if we mail a donor appeal to you) or
- online (for example, if you sign up for an event online).

Where it is unreasonable or impracticable to collect personal information about you directly from you, we may also collect your personal information from third parties such as:

- contractors (including fundraising service providers),
- list vendors,

- parent/carer
- health professionals, and
- social and community workers.

Where we engage with you multiple times over a short period in relation to the same matter, we may not provide you with a separate notice about privacy each time we engage with you.

Research studies with ethics approval from an Australian Human Research Ethics Committee (HREC) may have additional obligations in relation to collection of personal information. Such projects will comply with the conditions of the ethics approval by the relevant HREC. In particular, collection of health information from health professionals and health record databases must be provided for in a peer-reviewed protocol that is approved by the relevant HREC, and consent must be obtained from the relevant individuals.

Why does the Epilepsy Foundation collect your personal information?

The Epilepsy Foundation may collect your personal information for a number of purposes, including:

- Marketing: to communicate with you about donations, products, services, campaigns, causes and events;
- Fundraising operations: to administer fundraising events (including to process receipts and conduct those events) and to communicate with you in relation to those events;
- Dealings with suppliers and medical and health professionals: to administer our dealings and potential dealings with suppliers of our products and services, including medical and health professionals;
- Support services: to provide you with information, our products and support services, and to evaluate and report on these services;
- Service partners and their staff;
- Research: to conduct research studies on the psycho-social issues of living with epilepsy;
- Health promotion: to provide you with information about epilepsy risk factors, such as seizure first aid, epilepsy management, and to seek your support for campaigns;
- Employment: to process any job application submitted by you, conduct employment activities with staff and for other employment-related purposes;
- Volunteering and other support: to enable you to assist us with volunteering, community fundraising, advocacy and other activities where we seek the community's assistance; and
- Other issues: communicating with you in relation to our operations, activities and objectives, to verify your identity, to improve and evaluate our programs and services and to comply with relevant laws.

In some cases, the Epilepsy Foundation may collect your personal information as an agent for Epilepsy Australia or other state and territory epilepsy organisations that are members of Epilepsy Australia (e.g. where we are the lead State on a national fundraising campaign). In those circumstances, your personal information will be collected, used and disclosed by both the Epilepsy Foundation and those organisations in accordance with their separate privacy policies.

We will provide you with a collection notice which explains the primary purpose for which we are collecting your personal information.

Unless required or authorised by law to use or disclose your personal information, the Epilepsy Foundation will not use or disclose personal information that was provided for a particular purpose for other purposes unless:

- (a) you have consented to the use or disclosure of the information for that other purpose; or
- (b) the purpose for which the information is used or disclosed is directly related to the purpose for which the personal information was obtained. If you would like to change any consents you previously provided us, or you have any questions about how we use and disclose your personal information, please contact the Epilepsy Foundation using any of the details set out at the end of this Privacy Statement.

Health information and other sensitive information

As part of administering the Epilepsy Foundation's services, we may collect health information and other sensitive information about you. For example, we may collect medical history information from you, if you are participating in an epilepsy program or research study. Sensitive information is defined by law as the following type of information:

- racial or ethnic origin;
- political opinions;
- membership of a political association;
- religious beliefs or associations;
- philosophical beliefs;
- memberships of a professional or trade association, or of a trade union;
- sexual orientation;
- criminal record;
- health information;
- genetic information;
- biometric information; or
- biometric templates.

We will only collect these types of information if it is necessary to deliver a service to you, or where it is required for research purposes and you have specifically consented to the collection of that information.

What happens if you don't provide all this information?

You are free to provide (or not provide) any information you choose. However, if you do not provide some or all of the personal information requested, we may not be able to offer you services or products, allow you to participate in the Epilepsy Foundation's events or fundraisers, or provide you with information about our cause, events, programs and projects.

Website usage information and cookies

When you access our website, we may use software embedded in our website (such as Javascript) and we may place small data files (or cookies) on your computer or other device to collect information about which pages you view and how you reach them, what you do when you visit a page, the length of time you remain on the page, and how we perform in providing content to you.

A cookie does not identify individuals personally, but it does identify computers. You can set your browser to notify you when you receive a cookie and this will provide you with an opportunity to either accept or reject it in each instance. If you disable the use of cookies

on your browser or remove or reject specific cookies from our website or linked sites then you may not be able to gain access to all of the content and facilities in those websites.

We may gather your IP address as part of our business activities and to assist with any operational difficulties or support issues with our services. This information does not identify you personally.

How we handle email and "Contact us" forms and messages

The Epilepsy Foundation may preserve the content of any email, completed "Contact us" form or other electronic message or form that we receive. Any personal information contained in those messages will only be used or disclosed in accordance with this Epilepsy Foundation Privacy Statement. The message content may be monitored by our service providers or Epilepsy Foundation employees for purposes including trouble shooting, compliance, auditing and maintenance, or where email abuse is suspected, which means that your personal information may be disclosed to third party service providers.

Links

The Epilepsy Foundation website and its social media channels may, from time to time, contain links to the websites and social media sites/profiles of other organisations or individuals which may be of interest to you. These third party websites or profiles themselves may facilitate collection of information by those third parties, through your interaction with the websites or profiles and sometimes even if you do not interact directly with them. We are not responsible for the technical operation of these websites or profiles or the collection and use practices of the relevant third parties. Linked websites and social media sites/profiles are responsible for their own privacy practices and you should check those websites and social media sites/profiles for their respective privacy policies to understand their privacy practices and options they may make available to you in relation to their collection of your personal information.

Social media

The Epilepsy Foundation uses a range of social media accounts to inform, engage, communicate with and learn from stakeholders and the world wide epilepsy community. The Epilepsy Foundation social media team may choose to follow organisations and individuals involved with, or actively discussing relevant issues. Individuals and organisations choosing to follow the Epilepsy Foundation may be followed, friended or your posts shared or connected to in return, but the Epilepsy Foundation only contacts individuals who have initiated the communication through social media.

You may request that the Epilepsy Foundation stop following you by a request to the account, emailing epilepsy@epilepsyfoundation.org.au or by blocking the Foundation's account using the block function in the relevant social media account. You are reminded that social media operates in a public space on the internet and most interactions are publicly viewable and searchable over time. For more information on how best to manage your interactions visit the social media account's host website (e.g. www.facebook.com).

The Epilepsy Foundation social media team responses should be considered as comparatively informal especially when they are dealing with enquiries and direct messages sent via our social media accounts. The Epilepsy Foundation has formal procedures for providing support and can only respond to emails, post and phone.

The Epilepsy Foundation social media team periodically monitors accounts during business hours (Australian Eastern Time). The accounts may also be intermittently monitored outside business hours subject to staff availability; we reserve the right to remove any posts not complying with acceptable use.

Third party sites or profiles linked from our social media accounts are not controlled, maintained or endorsed by the Epilepsy Foundation. To the extent permitted by law, the Epilepsy Foundation is not responsible or liable for any content posted on or uploaded to our social media accounts by a user or any content on third party sites linked to by our social media accounts.

Opting out of direct marketing communications

From time to time, the Epilepsy Foundation may send you information, including promotional material, about us, our products and services, fundraising activities and events. You consent to us using your Personal Information for sending you such information, now and in the future. You also consent to us sending you such information by means of direct mail, phone or email.

If you do not wish to receive or if you wish to modify how you receive or how much direct marketing communication you receive from us, please contact us in any of the ways set out under "Contact, complaints and further information", below.

To whom does the Epilepsy Foundation disclose your personal information?

- We may need to disclose your personal information to others in order to carry out our activities, including in connection with the purposes described in this Privacy Statement. Depending on the nature of your engagement with us, the Epilepsy Foundation may disclose your personal information to: External support services: to health care professionals, lawyers, other professionals, counsellors, funders, financiers, co-ordinators, volunteers, service providers, agencies and not-for-profits that provide support services;
- Researchers: to conduct research studies on the psycho-social issues of living with epilepsy;
- Third parties for marketing purposes: we may provide your contact details to other like-minded organisations to contact you with information that may be of interest to you, where you have consented to us doing so. From time to time, we participate in data collectives where we share your personal information (other than sensitive information) with other like-minded organisations;
- Contractors and service providers: who perform services on our behalf, such as mailing houses, printers, information technology services providers (including offshore cloud computing service providers), database contractors and telemarketing agencies;
- Corporate partners: who may wish to provide special offers to the Epilepsy Foundation supporters; and
- Epilepsy Australia and state and territory epilepsy organisation that are members of Epilepsy Australia.

Where is your personal information stored?

Your personal information will be stored on a password protected electronic database, which may be an Epilepsy Foundation database, a database maintained by a cloud hosting service provider or other third party database storage or server provider. Backups of electronic information are currently written to tapes and are stored securely offsite.

Hard copy information is generally stored in our offices, which are secured to prevent entry by unauthorised people. It may be stored for a time with a third party for specific purposes, for example at a mailing house. Any personal information not actively being used is archived, usually for 7 years, after which time it is securely destroyed.

Where personal information is stored with a third party, we have arrangements which require those third parties to maintain the security of the information. We take reasonable steps to protect the privacy and security of that information, but we are not liable for any unauthorised access or use of that information.

Your personal information will stay on the database indefinitely until you advise you would like it removed, unless we de-identify it or destroy it earlier in accordance with privacy law requirements.

Due to the complexity of the Epilepsy Foundation's operations, your personal information may be stored simultaneously in more than one database or location.

We comply with the Payment Card Industry standards when handling payment card transactions. This means that we handle payment card information extremely securely while transactions are made, and do not retain payment card details afterwards.

Your direct debit or credit cards; or bank account details

We use Secure Socket Layer (SSL) certificates which is the industry standard for encrypting your credit card and debit card numbers, bank account details, your name and address so that it cannot be viewed by any third party over the internet. Your financial information is encrypted on our servers and access to this information is restricted to authorised Epilepsy Foundation staff or authorised personnel at supplier agencies (for example, our telemarketing agency, which receives and processes donations and raffle payments on our behalf).

Access to your personal information

The Epilepsy Foundation will, upon your request, and subject to applicable privacy laws, provide you with access to your personal information that is held by us. However, we request that you identify, as clearly as possible, the type/s of information requested. We will endeavour to deal with your request to provide access to your personal information within 30 days and you agree we may charge you our reasonable costs incurred in supplying you with access to this information. If we refuse your request to access your personal information, we will provide you with reasons for the refusal where required by law.

Your rights to access personal information are not absolute and in certain circumstances, privacy laws dictate that we are not required to grant access such as:

- access would pose a serious threat to the life, safety or health of any individual or to public health or public safety
- access would have an unreasonable impact on the privacy of other individuals
- the request is frivolous or vexatious
- denying access is required or authorised by a law or a court or tribunal order
- access would be unlawful, or
- access may prejudice commercial negotiations, legal proceedings, enforcement activities or appropriate action being taken in respect of a suspected unlawful activity or serious misconduct

Participants in research studies should note that access to personal information is not generally granted. This is notified to participants where applicable, at the time of committing to the research study.

Updating your personal information

You may ask us to update or delete the personal information we hold about you at any time. We will take reasonable steps to verify your identity before granting access or making any corrections to or deletion of your information. We also have obligations to take reasonable steps to correct personal information we hold when we are satisfied that it is inaccurate, out-of-date, incomplete, irrelevant or misleading for the purpose for which it is held. To assist us in this, you need to provide true, accurate, current and complete information about yourself as requested, and promptly update the information provided to us to keep it true, accurate, current and complete.

If you require access to, or wish to update your personal information, please contact us in any of the ways set out under "Contact, complaints and further information", below. We will generally not charge you for obtaining your information in an electronic format, but if you would like a hard copy of your information you may be charged a reasonable fee to cover expenses incurred. We will use all reasonable efforts to correct the information. You may be required to authenticate your identity by providing your personal information or the personal information of others, such as your authorised representative or the person for whom you are an authorised representative.

Anonymity or pseudonymity

Sometimes a person may deal with the Epilepsy Foundation anonymously or by using pseudonym, such as when making a general enquiry. The nature of these calls may be recorded for evaluation purposes (for example assessing a particular issue of living with epilepsy). However, in most circumstances the Epilepsy Foundation will not be able to deal with persons in this way for practical or regulatory reasons.

A donor may request to remain anonymous for publication or recognition purposes but generally speaking donations of a material nature must be identified to be used for a tax deduction.

Contact, complaints and further information

If you:

- have any questions in relation to the Privacy Policy, including this Privacy Statement or the information handling procedures of the Epilepsy Foundation,
- wish to make a complaint regarding the treatment or a breach of your privacy,
- would like to access your personal information held by us,
- would like to opt out of direct marketing, or
- would like to correct your personal information held by us,

please contact the Privacy Officer in any of the following ways:

- By telephone: (03) 8809 0600 or 1300 852 853 (regional)
- By email: epilepsy@epilepsyfoundation.org.au
- By ordinary mail addressed to: Privacy Officer, Epilepsy Foundation, 587 Canterbury Road, Surrey Hills, VIC 3127

We may need you to provide more information about your concern. If your concern is bona-fide, we will investigate the issue and endeavour to provide you with a written response within 28 days of receipt of your written query. Sometimes we might not be able to provide you with a written response within the timeframe specified. If that is the case, we will contact you and explain the reason for the delay and give you a new timeframe for a written response.

If you are not satisfied with our response, please notify the Privacy Officer in writing. We can escalate your matter and review the response that you were given. This may involve an escalation to the next level of management or referral to the CEO. You may also direct your issue to the Office of the Australian Information Commissioner's website at:

www.oaic.gov.au/privacy/privacy-complaints/

You are entitled to make an anonymous complaint or inquiry in relation to the Privacy Policy (including this Privacy Statement) or your privacy rights. However, we may require you to identify yourself if required by law or if it is impracticable for the Epilepsy Foundation to deal with your matter otherwise.

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