

## **Privacy Policy**

SUDEP Action is dedicated to prevention of epilepsy deaths and specialises in supporting and working with families after a sudden epilepsy-related death. When we refer to “we” or “our”, we are referring to SUDEP Action. When we refer to “this website” we are referring to [www.sudep.org](http://www.sudep.org)

SUDEP Action (registered charity 1164250 (England and Wales); SC047223 (Scotland) is the data controller of any personal information you give us. Epilepsy Bereaved (founded 1995) is part of SUDEP Action.

This Privacy Policy explains what to expect when SUDEP Action collects and uses your personal information. We encourage you to read this notice carefully and if you’d like to learn more about our data protection and privacy policies or get further clarification, please contact our friendly team and we will be happy to assist.

### **Contact: SUDEP Action Data Secretariat**

**Address: SUDEP Action, 12a Mill Street, Wantage, Oxfordshire, OX12 9AQ.**

**Phone: 01235 772852**

**Email: [info@sudep.org](mailto:info@sudep.org)**

### **Our Promise**

SUDEP Action is committed to respecting your privacy, which we monitor to help keep personal information secure and to ensure that SUDEP Action complies with its obligations under the Data Protection Act 1998 (the DPA); the Privacy & Electronic Communications Regulations 2003 and the General Data Protection Regulation (the GDPR) from May 2018.

By using our website, you agree to the collection, use and transfer of the information you share with us in line with the terms of this Privacy policy.

## **Our Principles**

We'll only collect and use personal information where we have lawful grounds and legitimate reasons to do so.

We'll be open with you and tell you how we'll collect and use your information:

- Information given for a particular purpose will only be used for that purpose, unless you've been otherwise informed and given your permission where relevant
- We won't ask for more information than we need for the purposes for which we're collecting it
- We'll update our records when you tell us that your details have changed
- We'll periodically review your personal information to ensure we don't keep it for longer than is necessary
- We'll ensure that your information is securely disposed of at the end of the appropriate retention period
- We'll observe your rights under applicable privacy and data protection laws and will ensure that queries relating to privacy issues are dealt with promptly and transparently
- We'll train our staff on their privacy obligations.
- We'll ensure we have appropriate physical and technological security measures to protect your information regardless of where it's held

In this policy, the following sections have been outlined:

<b>1. Information you give us</b>	<b>10. Security and safe storage of your personal data</b>
<b>2. We may use this information</b>	<b>11. People who contact us through social media</b>
<b>3. Sensitive personal information</b>	<b>12. Children's data</b>
<b>4. Information we receive from other sources</b>	<b>13. How long we keep your data</b>
<b>5. Marketing permissions</b>	<b>14. Third-party websites</b>
<b>6. Fundraising</b>	<b>15. Cookies</b>
<b>7. Job applicants and SUDEP Action employees</b>	<b>16. Reporting your concerns or complaints</b>
<b>8. Who we share your information with</b>	<b>17. Changes to the Privacy Policy</b>
<b>9. Information, rights and choices</b>	

## **1. Information you give us**

You may give us information about yourself by filling in forms on our website, providing feedback or corresponding with us by phone, email or otherwise. This includes, for example, the information you provide when you do any of the following:

- Use, or visit or provide feedback on our website
- Make an enquiry
- Participate in, access or sign up for a SUDEP Action service
- Sign up for our e-news
- Use our support service
- Sign up to a campaign
- Make a donation
- Give your taxation status (for Gift Aid purposes)
- Make a purchase
- Enter survey(s) or participate in research projects(s)
- Offer to help as a volunteer or fundraiser
- Apply for a job

If you use any of the email facilities or forms on any of our sites, we will capture your email address, your name and, where relevant, your postal address. This means we can respond to your request, enquiry or order. We will then invite you to opt-in to future contact by email, phone or post if you wish to do so.

Other information on your browsing behaviour, through the use of cookies, on our sites does not enable us to identify you personally. However, it does allow us to track usage of our sites, so that we can improve them.

The personal information you provide may include your name, email address, telephone number, mobile number or date of birth and details regarding your involvement with the charity. This may also include details about a person who has died.

SUDEP Action uses cookies and collects IP addresses of visitors to this website and collect statistics on website visits both at a web server level and using Google Analytics.

## **2. We may use this information:**

- to provide you with services and information that you request from us
- to allow you to participate in interactive features of our service
- to monitor and improve our service to you (via research activities)
- to notify you of changes to our website or service
- administer the charity as per our legal obligations with the charity commission and other regulators
- to provide you with information that you have consented to receive
- to monitor the traffic on the website in accordance with our cookie policy
- as part of a recruitment process or employment, when applicable

Where we collect information by way of feedback, a survey, or research activities, this will only ever be published anonymously as a combination of responses, rather than individually, unless otherwise agreed with you.

We may use profiling and screening techniques to communicate with you better helping us to communicate in a relevant and timely way.

We may analyse geographic, demographic and other information relating to you so that we can target invitations where you would reasonably expect to be invited, for example, to a local coffee club or local campaign.

Unlike many other charities, we do not use third parties to provide information about earnings.

## **3. Sensitive personal information**

Sensitive Personal Information includes information which reveals your religious beliefs, health issues, race or ethnicity.

SUDEP Action will always treat any sensitive personal data we process with the greatest care and process the information in accordance with the Data Protection Act.

Personal information about health, from people contacting our support line, will be held for the purpose of that call unless exceptionally there is an obligation or legal reason to keep or disclose e.g. to help keep someone safe.

#### **4. Information we receive from other sources**

We do not buy or use mailing lists from third parties.

We work closely with a small number of third parties in order for us to provide a specific service to you. They are contracted as our data processors and may receive information about you from them when you have agreed for this to be shared with us:

- Just Giving
- Much loved
- Virgin Money
- Tiger Fish

In addition, we may use Royal Mail postcode checker or Google to check the accuracy of the postcode for the address we hold.

#### **5. Marketing permissions**

We love sharing news about how supporters are making a difference and changing people's lives.

This includes sending you information about our work, news, research campaigns, appeals, events, information on volunteering.

Email marketing: We will ask for your permission to contact you by email for marketing purposes. We gather statistics around email opening and clicks using industry standard technologies.

Postal marketing: From time to time we may send you information about our work if you have shared your address with us, unless you have told us you would prefer not to receive this information by post.

Telephone marketing: We may call to update you on the work we are doing if you have given us your telephone number. SUDEP Action is committed to respecting your choices to receive marketing communication.

You can update your permission and contact preferences by calling our friendly team on 01235 772850 or emailing [info@sudep.org](mailto:info@sudep.org) and this will be dealt with the same working day and before any other communication is sent. You can also click the 'unsubscribe' link included in each email communication we send.

## **6. Fundraising**

SUDEP Action delivers vital services to the bereaved, and through our Prevent21 campaign, is working to prevent more than 21 deaths a week from epilepsy.

Fundraising is essential for SUDEP Action to make a lasting difference. To fundraise more efficiently and steward our resources with integrity and excellence, we conduct research to gain a better understanding of our supporters. This helps us to personalise our funding requests for supporters with the interest and ability to support. This may involve:

- Sharing information, you have given us within the SUDEP Action staff team. This would only be with relevant staff members who are liaising with you. This does not include information that you have shared with our specialist support, counselling and casework service or with the Epilepsy Deaths Register
- Include information that is already public information, for example a news story. You may give permission already for your information to be viewed publicly depending on your settings for social media and messaging sites such as Facebook and Twitter and LinkedIn. We will only do this, where appropriate, for events you have registered for

or expressed an interest in or on relevant social media sites where you would reasonably expect SUDEP Action to be active. To control these adverts, you should amend your social media platform settings

You can contact us at any time to opt-out of your personal information being processed in this way.

As well as the organisations already listed in point 4, supporters have used other trusted organisations to facilitate fundraising, Skyline, Action Challenge, Life Changing Challenges and BT My Donate - all of which have implemented adequate privacy policies, compliant with the new GDPR regulations.

Where organisations are not recommended by SUDEP Action, we are not able to ensure that they are GDPR compliant. We would recommend that the supporter would need to check the chosen organisation's privacy policy to see if they are compliant. It is therefore the supporter's preference, as to whether or not that organisation is used, SUDEP Action cannot take responsibility for that decision.

## **7. Job Applicants and SUDEP Action employees**

We use information supplied to SUDEP Action to process applications and monitor recruitment statistics.

We may need to take up a reference or obtain a 'disclosure' from the Disclosure and Barring Service. We will not do so without telling you in advance unless the disclosure is required by law.

Personal information about unsuccessful candidates will be held for six months after the recruitment exercise has finished. It will then be securely destroyed or deleted. We keep de-personalised statistical information about applicants to help inform our recruitment activities. However, no individuals can be identified from that data.

Once a person has taken up employment with the SUDEP Action, we will hold a personnel file about their employment. The information in this file will be kept secure and will only be used for purposes directly relevant to that person's employment. We will keep this file as required by our retention policy and then securely destroy or delete it.

## **8. Who we share your information with**

We don't sell, share or exchange your data with another organisation for funding or marketing purposes. The only times when we share your information are:

- Where you have consented to us doing this, for example:
  - you have consented to sharing your story with us and expressed your preferences regarding this
  - or you have expressed your preferences regarding sharing information, recordings or photographs for SUDEP Action publicity
  - or told us your preferences regarding the media.

Please note - we pride ourselves on our care of people helping us raise awareness in the media and would always liaise with you, check your consent, and offer support before and after personally identifiable information is shared with the media

- Exceptionally we may need to disclose personal information to comply with legal and regulatory obligations for safeguarding or other regulatory reasons. This could be to investigate, prevent, or take action regarding illegal activities, suspected fraud, or situations involving potential threats to the physical safety, property or rights of any person
- We sometimes need to use selected and trusted third parties to handle some of our services on our behalf. These organisations are only allowed to use your personal information for the specific purpose they have been contracted to provide. For example, processing your direct debit or sending a letter. Be assured



that when we outsource any data processes we ensure that any supplier or contractor has adequate security measures in place. We'll also require them to comply with privacy principles as part of our contract with them

We monitor information security compliance and have written contracts which obligate our partners or third-party providers to process your personal information only on our instructions and in accordance with applicable data protection and privacy laws.

We use standard third-party web analytics services (such as Google Analytics) so we can monitor and report on the effectiveness of our website, so we can improve it. This involves collecting anonymous information about your computer, including your IP address, operating system and browser type and includes, for example, the number of users viewing pages on the site, but it does not identify you individually to us.

We use third-party providers to host our websites, supporter database, our data storage and to deliver our e-newsletters. These third-party providers are:

- Tiger Fish
- Salesforce
- Ring24
- MailChimp
- Microsoft and Office 365

## **9. Information rights and choices**

You can contact the SUDEP Action Data Secretariat at [info@sudep.org](mailto:info@sudep.org) to:

- correct the information we hold about you
- change your preferences relating to marketing communications from SUDEP Action and withdraw your consent at any time
- make a request to access your personally identifiable information that's held by us and maintained in our database

From 25 May 2018, depending on the circumstances, you may also have the right to:

- request removal of personal information we hold about you

- request restriction of processing of such information
- object to the processing of such information
- request a copy of such information in a portable format

Very simple requests such as correcting information on our database or changing preferences, will be dealt within the same working day if possible. In most other cases, we will deal with a request within one month. We may exceptionally need to extend this when a request is particularly complex.

### **10. Security and safe storage of your personal information**

Once we've received your information, we'll use appropriate procedures and security features to try to prevent unauthorised access.

Unfortunately, the transmission of information via the internet isn't completely secure. We take your personal data very seriously and endeavour to protect your personal data. We can't guarantee the security of data transmitted over the internet however and transmission of data is at your own risk.

We aim to keep any information supplied by you, to us, within the European Economic Area to select third-party processors, who also keep data within the European Economic Area. This also goes for any data that we collect about you, or that may be transferred, and stored by us. Exceptionally, in order to provide a service to you, we will select a third-party processor outside the European Economic Area, and where this occurs we use the model clauses as issued by the [European Commission](#) or other appropriate safeguards where applicable and will ask for your consent.

We may monitor the use and content of emails, calls and secure messages sent from and received by us, so that we can identify and take legal action against the unlawful or improper use of our systems. The main examples of unlawful or improper use are

attempting to impersonate SUDEP Action, the transmission of computer viruses and attempts to prevent this website or its services from working.

### **11. People who contact us through social media**

We use third-party providers Facebook, Twitter, LinkedIn, Pinterest and Hootsuite to manage our social media interactions.

Private or direct messages will be stored in line with our data retention policy and will not be shared with any other organisations.

### **12. Children's data**

If a child under 16 years old contacts the charity, their information will only be used to deal with their enquiry.

We recognise the need to protect the privacy and safety of children under 16. We use photographs of models.

Parents may give permission to use images of children under 16 who have died.

### **13. How long we keep your data**

We will retain and process your personal information for as long as necessary to comply with our legal obligations.

### **14. Third-party websites**

Our website may, from time to time, contain links to and from third-party websites, including those of our partner networks and affiliates. If you follow a link to any of these websites, please note that these websites have their own privacy policies. We don't accept any responsibility or liability for these policies. Please check these policies before you submit any personal data to these websites.

## 15. Cookies

Cookies are small pieces of information sent by a web server to a web browser, which enables the server to collect information from the browser. Essentially, it takes the form of a small text file deposited on your computer's hard drive.

None of our website cookies collect personal data about our website visitors.

SUDEP Action uses cookies so that you can interact with our websites successfully, to identify when you visit our website and track your browsing patterns. This is used to improve your experience and to determine ways to improve the effectiveness of our website and marketing campaigns.

The use of cookies does not give us access to the rest of your computer.

We use a small number of cookies. These are the ones we use:

- **CMS cookies** – our SUDEP Action website is created in a CMS (Content Management System) called Drupal, which places a small number of standard cookies on your computer as you use it. Other SUDEP Action websites (for example, SUDEP Action Day, Epilepsy Deaths Register) are created in different CMS systems and they can create cookies too. Additional cookies will be placed on your computer if you are an editor on one or more of these CMS systems (for example if you are a SUDEP Action staff member or an IT contractor)
- **Analytics** – Google Analytics. Google Analytics will only collect data such as IP address, physical location (using the IP address) and such things as the Operating System, Web browser and if the browser is Mobile, Tablet or desktop based. These cookies don't collect information that identifies you. All information these cookies collect is aggregated and therefore anonymous. These cookies allow us to see how visitors use our website and help us to continually improve its usability
- **Consent cookies** - the Cookie Consent dialogue box that appears when you are a new user on the site. When the "Okay" is clicked on the cookie consent dialogue, this

creates a cookie to tell the browser that they have accepted the cookie consent and will not show the popup box again

- **Paid advertising (Google, Facebook)** – we use standard cookies from third parties to measure the effectiveness of paid advertising to ensure the money we spend is used effectively. They also enable us to either service advertisements to or exclude people who have visited our websites. Cookies from Google and Facebook allow us to track traffic to our website to tell us if our marketing campaigns are successful, and ensure we are spending our advertising budgets as efficiently as possible, but we do not use them to collect personally identifiable information about you.

### **How to manage your cookie settings**

Many web browsers such as Internet Explorer, Google Chrome or Safari, will allow some control over cookies through their settings. To manage your cookie settings, please refer to your browser software. For more information about cookies and how to delete them, visit [www.aboutcookies.org](http://www.aboutcookies.org) or [www.allaboutcookies.org](http://www.allaboutcookies.org) and [www.youronlinechoices.eu](http://www.youronlinechoices.eu)

### **Acceptance of cookie use**

By using our website, you agree to our use of cookies. This is subject to any preferences or browser setting you may have.

## **16. Reporting your concerns or complaints**

If you have concerns about the way we handle your personal data, you can contact the [ICO](http://ico.org.uk) or raise a complaint via the SUDEP Action Data Secretariat at [info@sudep.org](mailto:info@sudep.org).

## **17. Changes to the Privacy Policy**

We may change our Privacy policy from time to time. If or when changes are made, we'll include them here, so be sure to check back occasionally.

**March 2018**

**Contact: SUDEP Action Data Secretariat**

**[info@sudep.org](mailto:info@sudep.org) or phone: 01235 772852**

**SUDEP Action, 12a Mill Street, Wantage, Oxfordshire, OX12 9AQ.**