

Fundraising and Communications Directorate



Privacy Notice

Young Epilepsy is committed to safeguarding your privacy, and to letting you know how we use any personal information that you provide to us.

Developing a better understanding of our supporters allows us to fundraise more effectively and efficiently. We have made improvements to this policy so that we are more transparent in how we use your personal information in accordance with the law.

Please read the following privacy notice to understand how your personal information will be treated. By visiting www.youngepilepsy.org.uk you are accepting the practices described here. This policy may change from time to time so please visit our website periodically.

If you have any queries about this policy please contact the Data Protection Officer; Post: Young Epilepsy, St Piers Lane, Lingfield, Surrey, RH7 6PW. Email: dpo@youngepilepsy.org.uk Telephone: 01342 832243

Privacy Notice

Data Protection Statement

Young Epilepsy endeavours to meet the highest standards when collecting and using personal information. We are committed to upholding the standards and regulations embodied in the Data Protection Act 2018 (DPA 2018) and the UK General Data Protection Regulation (UK GDPR). Personal data will therefore at all times be:-

- ✓ Processed lawfully, fairly and in a transparent manner;
- ✓ Collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes;
- ✓ Adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed;
- ✓ Accurate and, where necessary, kept up to date;
- ✓ Kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; and
- ✓ Processed in a manner that ensures appropriate security.

Young Epilepsy will furthermore:-

- ✓ Be responsible for and be able to demonstrate compliance with the DPA 2018 and the UK GDPR.

Young Epilepsy holds personal data¹ & special categories of personal data² on both computerised, digital and hard copy filing systems, such as the Fundraising database system and the paper records maintained by the Fundraising team. The information is held in a confidential manner with limited access, in accordance with the Data Protection Act 2018 and the UK General Data Protection Regulation.

We are committed to ensuring that personal data is secure. In order to prevent unauthorised access or disclosure, we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information we collect.

Information will not ordinarily be processed overseas unless there is a specific request for us to do so, such as a need to send staff information to an individual or organisation in another country. If information is to be sent overseas then this will be done in accordance with the Data Protection Act 2018 and the General Data Protection Regulation and under the guidance of the Data Protection Officer and the IT department. The manner in which this will occur will be discussed with you prior to information being sent overseas.

Young Epilepsy is registered with the Information Commissioner's Office under our legal name of the National Centre for Young People with Epilepsy. Our registration number is Z5611618.

Individual Rights

Under the Data Protection Act 2018 and the UK General Data Protection Regulation you have the right to:

- Be informed (the purpose of this Privacy Notice);
- Access your information;
- Rectify inaccurate or incomplete data;
- Request the erasure of your information;
- Restrict how your data is processed; and
- To object to the use of your information.

There are two additional rights with regard to automated decision making and data portability. With regard to these Young Epilepsy will not use staff information for automated decision making or profiling and will not undertake data portability.

¹ Personal data is any information relating to an identified or identifiable natural person ('data subject')

² Special categories of personal data are personal data that reveal an individual's: racial or ethnic origin; political opinions; religious or philosophical beliefs; trade union membership; It is also: the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person; data concerning health; or data concerning a natural person's sex life or sexual orientation

Should you wish to exercise any of these rights or wish to discuss any concerns or queries please contact the Data Protection Officer either through the main switchboard on 01342 832243 or by emailing dpo@youngepilepsy.org.uk.

Please note that should you be unhappy about the way we implement data protection you have the right to lodge a complaint with the Information Commissioner's Office <https://ico.org.uk/>

Amendments

We may update this privacy notice from time-to-time by posting a new version on our intranet or website. You should occasionally check these pages to ensure you are happy with the changes. For more information about how the privacy notice is changed please contact us at fundraising@youngepilepsy.org.uk

This privacy notice explains:

1. Information kept by Young Epilepsy
2. How we use this information
3. Sharing information
4. Lawful basis for processing your information
5. Your marketing communication preferences
6. How long we hold your information for

1. Information kept by Young Epilepsy

Young Epilepsy may keep the following information about you that includes but is not limited to:

- Your name
- Contact details (address, email, phone number)
- Your date of birth
- Records of any contact you may have had with our fundraising team
- Survey response (if you complete a survey and provide your contact details)
- Other details that you provide to us

We may also ask for, or collect, some additional information about you (i.e. your interests or your relationship to epilepsy)

This information will be kept on our fundraising database. We are committed to ensuring that your information is secure. In order to prevent unauthorised access or disclosure, we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information we collect.

If you no longer want us to keep in touch, you can unsubscribe or update your details and/or preferences at any time. Please call 01342 831 245 or email fundraising@youngepilepsy.org.uk. **Please note** this may take 30 days to have effect.

2. How we use this information

Your personal information will only be used by us to:

- process your donations, to fulfil online orders, bookings or requests;
- respond to your questions or comments;
- provide or administer services, such as e-newsletters, or training materials;
- provide you with information relating to Young Epilepsy, or that we feel may be of interest to you;
- maintain our organisational records;
- ensure you are on the correct and most age-appropriate mailing list(s) and that we have parental consent where required by law.

3. Sharing information

Young Epilepsy will not share your personal details with third parties.

Young Epilepsy is subject to a number of regulatory standards and may therefore allow its records to be inspected as part of that process, to ensure that Young Epilepsy is meeting the necessary standards. Inspectors will be given access to records but only provided with copies in exceptional circumstances, for example if a safeguarding concern is identified.

Please note that we use data processors. A data processor is an organisation responsible for processing personal data on behalf of Young Epilepsy. It does so under instruction from us and our contract ensures that Young Epilepsy's, the DPA 2018's and the GDPR's standards are upheld at all times.

An example of a data processor is the company that provides the software that allows us to manage our relationships with donors and supporters and the company that manages our financial merchandise sales and donations. In order to utilise this software we have to upload and record donor and supporter information, but would do so via our own password protected secured account. If you wish to know who our current data processors are, please contact us using the details below.

If you need any further fundraising information, please use the 'Contact us' form on our website - <http://www.youngpilepsy.org.uk/about-us/contact-us.html>

4. Lawful basis

The lawful basis for the processing of this personal data includes: -

- ✓ Consent
You have consented to us processing your data – for example, all digital communications will only be sent to you, if you have consented to this method of contact;
- ✓ Contract

There is a contractual relationship with you – for example, the records we keep on any financial support you may have given us;

- ✓ Legal obligation
We are legally obliged to process your data – for example, HMRC requires us to keep Gift Aid records;
- ✓ Legitimate Interests
We believe it is in the legitimate interest of either you as the data subject, or us as the charity, to process your data – for example, we may send you details of a fundraising campaign through the post as it is in Young Epilepsy’s legitimate interests to circulate this as widely as possible. If you do not want to receive such communication on this basis please let us know.

Please remember if you do not want to receive information from us, contact us by email at fundraising@youngepilepsy.org.uk with the word “unsubscribe” in the subject field.

Your consent to receive our marketing communications will apply for approximately three years after your last contact or action with us e.g. you make a donation unless you contact us to change your communication preferences. After approximately three years we'll contact you to ask if your consent to receive our marketing communications remains. If we do not receive a response, we shall assume you do not wish to hear from Young Epilepsy by email or SMS and will not contact you again, by these means, until you inform us otherwise.

Please note that Young Epilepsy also complies with the Privacy and Electronic Communications Regulations.

5. Your communication preferences

We use communications to keep you up to date with what we’re doing, how you can get involved, and news and features about the charity which we feel will be of interest to you. This may include newsletters, surveys, financial appeals, raffle appeals, notices about our online shop, fundraising opportunities or updates about Young Epilepsy services.

We use a variety of methods to send marketing to you including electronic channels, telephone, social media and post.

Electronic communications

These include emails and text messages.

Telephone

We may contact you by phone to discuss your involvement with Young Epilepsy or as part of a specific fundraising campaign.

Social Media

Young Epilepsy uses social media to communicate with you and share information about campaigns or events. Currently we use Facebook, LinkedIn, Twitter and

Instagram, but this may be expanded upon. We do this through advertising on your social media or through posting messages and information on our own social media pages which you may choose to “like”, “follow” or interact with.

Post

This is where you receive information about Young Epilepsy through your mailbox. Postal marketing enables us to contact a wide range of individuals and is an easy way to keep you updated. It allows you to donate and get involved in your own time and in a way which is not intrusive for you.

Changing your marketing preferences

You can always tell if you change your mind. You can stop receiving marketing communications altogether or change your preferences at any time either by following the instructions in the communication you have received or by contacting us at fundraising@youngepilepsy.org.uk with the word “unsubscribe” in the subject field.

6. How long we hold your information for

Young Epilepsy will keep your personal information only for as long as we need to use it for the purposes set out in this policy.

The criteria we use for determining retention periods is based on various legal requirements:

- The purpose for which we hold your personal information, and whether there is legitimate reason for continuing to store it (such as in order to deal with any future legal disputes or legacy bequests);
- Financial records in accordance with government HMRC requirements;
- Guidance issued by relevant regulatory authorities including, but not limited to, the Information Commissioner’s Office (ICO).

In exceptional circumstances some records may be retained for longer than the usual retention period where these form part of Young Epilepsy’s historic archive. .

If you have asked use not to use your information for marketing purposes we will not do so, but we may retain your details (for example, as on a suppression list) to help ensure we don’t continue to contact you.

Personal information that we no longer need is securely disposed of, suppressed, and/or anonymised so that you can no longer be identified from it, as applicable.

We never store payment card details after a transaction has been completed.

Contacting us

If you would like us to correct or update any information about you, then please email us at fundraising@youngepilepsy.org.uk .

You can also ask us to stop using your information – the simplest way to do this is to withdraw your consent, which you can do at any time, either by clicking the unsubscribe link at the end of any newsletter, or by emailing us at fundraising@youngepilepsy.org.uk .

If you need any further Fundraising information please use the 'Contact us' form on our website - <http://www.youngepilepsy.org.uk/about-us/contact-us.html>