

Connect Project:



Privacy Notice for Young People/Parents

This Privacy Notice has been drafted to meet the requirement of the Data Protection Act 2018 and the General Data Protection Regulation to provide you with detailed information about how we use personal data.

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 General Data Protection Regulation (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 GDPR.

Young Epilepsy holds personal data¹ & special categories of personal data² on both computerised, digital and hard copy filing systems. The information is held in a confidential manner with limited access, in accordance with the Data Protection Act 2018 and the 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 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

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

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.

Caldicott Principles statement

At Young Epilepsy we apply the Caldicott Principles, so that every flow of person identifiable information is regularly justified and routinely tested against the principles developed in the Caldicott Report.

Principle 1	Justify the purpose(s) for using confidential information
Principle 2	Only use it when absolutely necessary
Principle 3	Use the minimum that is required
Principle 4	Access should be on a strict need-to-know basis
Principle 5	Everyone must understand his or her responsibilities
Principle 6	Understand and comply with the law
Principle 7	The duty to share information can be as important as the duty to protect patient confidentiality

Individual Rights

Under the Data Protection Act 2018 and the 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 information for automated decision making or profiling and will not undertake data portability.

Should you wish to exercise any of these rights or wish to discuss any concerns or queries please contact our Data Protection Officer either through the main switchboard on 01342 832243 ext. 286 or by emailing dpo@youngpilepsy.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 website. You should occasionally check this page to ensure you are happy with the changes.

Connect Project records



To be completed by:

- Young person if over 16
- Young person and a parent if 13-16
- Parent if under 13

Information we keep

We keep the following information about you:-

- ✓ 'Referral forms' usually written by a nurse or teacher (if you want a copy of this just ask)
- ✓ Any information you tell us about your health, education, or personal life.
- ✓ Notes of any meetings you have with your project worker.
- ✓ Any forms or surveys you may complete whilst part of the project.

This information is kept on computer and in paper records

Information about others

Should you provide us with information about other people, such as family members or others who work with you, please ensure you have their agreement to do this.

What this information is used for.

In order for us to give you the best possible support, we need to keep information about you. This is so we can remind ourselves before each meeting with you to save you repeating your story.

We are also required to keep information by our funders, Big Lottery, so that we can prove we are spending the money they give us properly.

Source of the personal data

Some of the information may have been provided by you and we may obtain some information from family, friends or other professionals who work with you

Sharing Information

We will routinely share information with:-

- ✓ Your parents (if you are under 16 or with your consent if you are over 16);
- ✓ Other professionals (whose contact details you have provided), who can provide help in different ways

Also, our funders, may ask to see information to prove we are spending the money they give us properly. Usually funders will only be provided with anonymised data, but if they wish to audit the project they may view all the records.

If we have any safety concerns we are also legally obliged to report these to the appropriate authorities.

Keeping records

We will keep information on you for six years after contact with you ceases. Your records will then be anonymised and the anonymised records kept until six years after the project ceases, which is a requirement of our funding.

Young person's consent

Please consider the following statement and tick the box if you agree with it:-

- Yes, I do consent to my information being kept, used and shared as detailed above.
- No, I do not consent to my information being kept, used and shared as detailed above.
If this is the case, then please detail below your concerns or any restrictions or modifications that you would like put in place. Our staff team will then contact you to discuss these.

 (Signature)

 (Name)

 (Date)

Parental consent

Please consider the following statement about your son/daughter and tick the box if you agree with it:-

- Yes, I do consent to my son/daughter's Connect Project records being kept, used and shared as detailed above.
- No, I do not consent to my son/daughter's Connect Project records being kept, used and shared as detailed above.
If this is the case, then please detail below your concerns or any restrictions or modifications that you would like put in place. Our staff team will then contact you to discuss these.

 (Signature)

 (Name)

 (Date)

Name of young person- _____

 Relationship

If you should change your mind about this consent form then please contact National Services either through the main switchboard on 01342 832243 or by emailing your project worker.