

Student Records



Parental privacy notice

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 student personal data. You will have previously completed consent forms for a number of data uses and these remain in place (should you wish to review or change these please let your son/daughter's keyworker know and new forms will be sent to you for completion).

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.

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

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 student 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 Information Governance Manager 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 student 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 student 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 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/>

Privacy notice 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.

Student records

Information kept by Young Epilepsy.

Student information

Young Epilepsy may keep the following personal data and special categories of personal data relating to students:-

- ✓ Personal details
- ✓ Educational information
- ✓ Medical, therapy, psychology and health information
- ✓ Safeguarding information
- ✓ Social care information

This information may be held on computer, in our paper records or may take the form of video, photos or other electronic record, such as EEGs and telemetry. Data is always kept in an appropriately confidential manner with limited access.

The personal data we keep will either have been generated by our staff team or will have been obtained from relevant individuals and organisations either as part of the admissions process or during your son/daughter's time at Young Epilepsy. The records generated by our staff team will often be multidisciplinary and may involve staff from Education, Health, Wellbeing or Residential services.

Family information

Where it is pertinent to the treatment and care we provide to your son/daughter we will also keep some information on you and on other members of your family. For example, the family's medical history may be kept, where it relates to your son/daughter's health. This is extremely helpful to us but if you do not want this information kept please inform of us this immediately.

What this information is used for.

The information we keep on our students allows us to provide the most effective and efficient care and treatment for your son/ daughter. By reviewing any previous treatment or strategies used we are able to determine what care and treatment may work best for your son/daughter.

It is also important that we keep a record of the care and treatment the student has received. These records range from day journals which record a student's daily activities, to seizure charts and medication records. These allow us to monitor student progress and development. School and College also keep student work in order for students to obtain qualifications or other attainments.

Source of the personal data

In order to provide the most effective and efficient care and treatment for your son/ daughter it is essential that we have all pertinent information. This will involve obtaining information from the following sources:-

- The young person;
- Parents, family and friends of the young person;
- The funding authority/authorities;
- The referring authority;
- Former placement providers, such as previous residential placements or schools attended;
- Local service providers, such as your son/daughter's school, therapists and CAMHS team;
- Health providers including both primary and secondary care; and
- The individuals or organisations whose contact details you have provided us with, on our Application form.

Sharing information.

Routine sharing

Sharing information is beneficial for your son/daughter as it helps provide a comprehensive understanding of his/her needs and development and also allows for all those involved in their care and treatment to be aware of the young person's development whilst at Young Epilepsy.

Young Epilepsy will therefore routinely disclose correspondence, reports and information with the following people/ organisations:-

- All professionals involved in funding the placement, which may include Local Authorities, Social Care and Health Commissioners;
- Your son/daughter's Social Worker;

- Other Health professionals involved with your son/daughter's care including their GP, any local consultants and, if appropriate, the student's Child & Adolescent Mental Health Services team; and
- Individuals who have parental authority, such as parents, guardians or carers. (Both parents will be given information unless we have been informed that parental responsibility rests solely with one.)

For all other non-routine sharing of information consent will be sought on an individual basis.

Review of records

Your son/daughter's records may also be reviewed by regulators, such as when an Ofsted or CQC inspection is undertaken. They may also be accessed by independent reviewers, such as when a complaint or other issue is independently investigated.

Legal obligations

We are also legally obliged to share certain information and in such cases will not seek your consent to do so. For example, all safeguarding concerns must be disclosed to the relevant organisations and individuals, such as the Local Authority, your son/daughter's Social Worker and possibly the police.

When your son/daughter leaves Young Epilepsy a summary chronology of all safeguarding incidents will be provided to their new placement provider. If your son/daughter is a Looked After Child (LAC) then his/her Care Plan, Personal Education Plan and the minutes of LAC meetings will also be provided to their new placement provider.

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. Some data processors use anonymised personal data for their specific reasons, such as statistical, quality control, security, research or other purposes. Where this occurs, we can confirm the data is always anonymised and students cannot be identified from it.

An example of a data processor is Earwig Academic Reporting Ltd (EARL). EARL provides software that allows our Education staff to more effectively produce teaching evidence, assessments and reports and to track individual student progress. In order to utilise this software we have to upload and record student information.

The growth in cloud technology means that it is likely that the use of data processors will become more common. If you wish to know who are current data processors are please contact the Data Protection Officer.

Retention of student records

Young Epilepsy keeps records for different periods depending upon where the student has resided and the mental capacity of the student at time of leaving Young Epilepsy. The retention periods detailed below have been agreed by the organisation and accord with relevant legislation, guidance and legal opinion.

1. Students who have resided on a children's home

For a student, who has resided on a children's home all of the student's records will be kept for 75 years from date of birth. This accords with the Children's Homes (England) Regulations 2015.

2. Students who have not resided on a children's home, but lack capacity.

If a student lacks the capacity to understand the rights of action under the Limitations Act 1980 then all student records will be kept for 75 years from birth. This accords with legal opinion and the rights of action a student may have should capacity be attained at a later date.

3. Students who have not resided on a children's home and have capacity

For a student who has capacity at the time of leaving Young Epilepsy all student records will be kept for 30 years from the date of leaving Young Epilepsy. This accords with the NHS Code of Practice for Health & Social Care records and the minimum retention period of the Information Management Toolkit for Schools v5.

A detailed copy of Young Epilepsy's retention schedule is available upon request.

CCTV.

We have a small number of CCTV cameras on campus, for security purposes, such as by the Main Hall entrances and use CCTV in our Assessment & Rehabilitation Unit as an unobtrusive way to monitor students being assessed. Although it is not standard practice in a very limited number of instances live feed CCTV may be used in a student's bedroom, if this is the case with your son/daughter then you will be asked to consent to this.

All CCTV usage is approved by the Chief Executive, in accordance with the Code of Practice from the Information Commissioner's Office. Where there is CCTV there will be signage indicating its use. CCTV recordings are kept for seven days, unless an incident has been highlighted, in which case the CCTV will be kept until the incident is resolved.

Anonymised information.

We may also use anonymised information about the education/ care/treatment of our students for research (subject to Research Ethics approval) or for audit. It may also be used to provide training or for presentation outside of Young Epilepsy. Please be assured though that in these situations the information is fully anonymised so that it is not possible to personally identify your son/daughter.

Parental consent

If a Personal Welfare Deputy has been appointed please let us know, so that we may seek Deputy Consent where appropriate.

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 student records being kept, used and shared as detailed above.

No, I do not consent to my son/daughter's student 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 student:- _____

Relationship to student

If you should change your mind about this consent form then please contact the Data Protection Officer either through the main switchboard on 01342 832243 x 286 or by emailing dpo@youngepilepsy.org.uk.

Mental Capacity

Please note that once young people reach the age of 16 Young Epilepsy will apply the Mental Capacity Act 2005. This means we will either obtain student consent, (if the student has capacity), or a best interests decision will be made, which will involve consulting with parents and referring to this completed form. If your son/daughter has capacity it may also mean that he/she may decide that information should not be routinely shared with you, as parents.

Communications with parents

If you are interested in the activities we undertake and would like to receive our monthly newsletter or know more about our events and challenges, campaigns, training and conferences, the research we undertake or volunteering opportunities, please complete go to the following location and complete the form there :-

<http://www.youngepilepsy.org.uk/communication-preferences.html>