

Assessment & Rehabilitation Service



Parental privacy notice

Under the Data Protection Act 2018 and the General Data Protection Regulation Young Epilepsy is required by law to provide you with information about how we use personal data. The Regulation applies to both paper and electronic records. It also applies to written information and to other personal data, such as photographs and videos.

Data Protection Statement

Young Epilepsy tries 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 data & special categories of personal data¹ 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 Special categories of personal data are personal data that reveals: 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.

Young Epilepsy will not share patient information with any third parties unless consent has been obtained or there is a legal basis for doing so, such as a duty to report safeguarding concerns. Young Epilepsy will also not use patient information for automated decision making or profiling, nor undertake data portability.

Information will not ordinarily be processed overseas unless there is a specific request for us to do so, such as a need to send assessment 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 IT Services. 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 Z5611618.

Caldicott Principles statement

At Young Epilepsy we apply the Caldicott Principles, so that every flow of patient 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:

- 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.

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 ext. 286 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 website. You should occasionally check this page to ensure you are happy with the changes.

Consent

In the following pages you will find a number of consent forms for the specific use of personal data, which we would ask that you complete and return to us at your earliest opportunity. These cover the following uses of patient data:-

- ✓ Patient records
- ✓ Use of patient information by Young Epilepsy
- ✓ Disclosing patient information
- ✓ Sharing information with patients, parents and others
- ✓ Publicity and promotion

If you should change your mind about the consents you have either provided or not provided then please contact the Assessment Service team via main switchboard, so that we may record this change on our systems.

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

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 patient consent, (if the patient has capacity), or a best interests decision will be made, which will involve consulting with parents and referring to these completed forms. 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>

Patient Records



Assessment & Rehabilitation Service

The Assessment & Rehabilitation Service provides the following services:-

- Interdisciplinary and diagnostic assessments
- Rehabilitation
- Telemetry/EEG

The information provided below applies to all the patient records we hold for the above services.

Information kept by Young Epilepsy.

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

- ✓ Personal details
- ✓ Educational information
- ✓ Medical, therapy, psychology and health 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.

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 instance, the family's medical history may be kept, where it relates to your son/daughter's health. If you do not want this information kept please inform of us this immediately.

What this information is used for.

In order for Young Epilepsy to assess your son/daughter, information on his/her educational, medical, social and personal history is needed. This information will be used by our staff in order to make an assessment of your son/daughter.

The information we keep on our patients 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 patient has received. These records range from day journals which record a patient's daily activities, to seizure charts and medication records. These allow us to monitor patient progress and development. School and College also keep patient work in order for patients to obtain qualifications or other attainments.

Source of the personal data

The information we hold may be obtained from the following sources:-

- The young person;
- Parents, family and friends of the young person;
- The funding authority;
- 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; and
- Health providers including both primary and secondary care, such as your GP and local hospital; and
- The individuals or organisations whose contact details you have provided us with, on our Contact form.

Sharing information.

- Routine sharing

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

- The funding authority or authorities (if it is being jointly funded);
- The referring authority, for example Great Ormond Street Hospital;
- The individuals or organisations whose contact details you have provided us with, on our Contact form;
- Local service providers such as your son/daughter's school, GP Surgery, Hospital, therapists and CAMHS team; and
- Other Health professionals involved with your son/daughter's care including their GP, any local consultants and, if appropriate, the patient'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.)

This sharing is for the benefit of 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 and assessment whilst using the Assessment Service.

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 patient progress. In order to utilise this software we have to upload and record patient 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 records

Young Epilepsy keeps records for different periods depending upon the nature of the record and its value. The retention periods detailed below have been agreed by the organisation and accord with the Records Management Code of Practice for Health & Social Care Records.

1. Interdisciplinary and Diagnostic assessments

Records generated by Young Epilepsy staff will be retained for 30 years after the date the assessment is completed. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after six years.

2. Telemetry records

Records generated by Young Epilepsy staff will be retained for 30 years after the date the assessment is completed. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after six years.

3. Rehabilitation records

Records generated by Young Epilepsy staff will be retained for 30 years after the date when the rehabilitation has ceased. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after six years.

4. Preview assessments/visits

Records generated by Young Epilepsy staff will be retained for six years after the date the assessment is completed. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after one year.

5. Potential referrals for assessment

If we have received records on a young person, who does not end up attending a Preview visit or being assessed, then the records generated by Young Epilepsy staff will be retained for two years after a decision is made not to refer a young person or after contact ceases.

A full copy of the Assessment Service retention schedule is available upon request.

CCTV.

We have CCTV operational in the Assessment & Rehabilitation Service. Whilst we are mindful of the privacy and dignity of the young people CCTV enables us to monitor and assess patients without unnecessary intrusion.

We also have a small number of CCTV cameras on campus, for security purposes, such as by the Main Hall entrances.

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 patients 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

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

- Yes, I consent patient records containing information about my son/daughter being kept, used and shared as detailed above.
- No, I do not consent patient records containing information about my son/daughter 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 patient:- _____

Relationship to patient

Use of Patient Information by Young Epilepsy



There are three areas in which we seek your consent for patient information to be used by Young Epilepsy:-

1. Communication Books
2. Displays of photos and information on campus
3. Off campus sharing of information

Please read the information below and then complete the parental consent section. If you have any queries please do not hesitate to contact the Data Protection Officer via main switchboard.

Communication Books

Many of our patients have difficulty communicating. Consequently our Speech & Language team have devised Communication Books. These are booklets with symbols or pictures that patients can point to when they wish to communicate with someone else. The value of these Books to patients who have difficulty communicating is immense and really helps empower them. A few patients also communicate using iPads or other electronic Talkers, which speak the words we programme in.

If your son/daughter has a Communication Book, we would like to be able to include his/her photo in it. Similarly, we would like to be able to include photos of other patients, when relevant. For instance, if your son/daughter's friend uses a Book or a Talker, it would be helpful to include a photo of your son/daughter in it, so that the patient concerned may talk about his/her friends.

To help staff get to know youngsters who are not able to tell their own story, we also make 'All About Me' books. These are summaries of the important information about a patient's personality, likes/dislikes, medical needs, interests, friends, family and home etc. so that new staff can work with them in the best possible way. Photographs of the patient's friends are a helpful part of these 'All About Me' books too.

Should the situation arise where we would like to include a photo of your son/daughter, we will need your agreement, and would therefore ask that you sign the consent below.

You should be aware that Communication Books and Talkers travel with a patient, and will therefore be taken outside Young Epilepsy and people from outside Young Epilepsy will have access to them. However, only the photo and name of your son/daughter will be included, not any other information.

'All About Me' books generally stay onsite for new staff working with that young person to refer to. They can also travel to respite care and go with the patient when they leave.

If you have any queries please contact the Speech & Language Therapy Team.

Displays of photos and other information on campus

It is current practice at Young Epilepsy, on the Assessment & Rehabilitation Unit to display, where appropriate:-

- ✓ Medical, therapy and educational programmes
- ✓ Checklists
- ✓ Manual handling and other guidelines
- ✓ Photographs of the patients

Programmes, checklists and guidelines. These are placed in appropriate areas, for instance an eating programmes may be displayed in kitchen/dining areas. Having them on display is of great value as it means that they are easily accessible to all the staff working with your son/daughter and helps us to ensure that the correct procedures are being followed at all times

Photographs. Although having photos of the son/daughter on display does not have any direct bearing on their care, we believe that it does help to make the patients feel more at home. Photographs may also be displayed in other departments, such as the school or college, to show a particular achievement or activity that has been undertaken

Whilst we try at all times to be as discreet as possible, particularly when displaying programmes, you need to be aware that these items could be seen/read by other staff and patients or by other people visiting the relevant area.

Off campus sharing of information

Your son/daughter may go off campus, for example on an outing. An incident may arise where it is appropriate to share information with professionals in that location. For example, if the patient is in a nearby town and medical treatment is needed, doctors at the local hospital informed of the patient's medical conditions, so that the correct treatment can be given.

If there is an urgent need for treatment then it may not be possible to contact parents before the information is shared.

Use of patient information



Parental consents

If after reading this form you are happy to give your permission, please indicate this below.

1. Consent for communication books

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

- Yes, I consent to photos of my son/daughter being included in Communication Books, 'All About Me' Books and Talkers devised at Young Epilepsy

2. Consent for displays of photos and other information on campus

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

- Yes, I consent to photos and other information about my son/daughter being displayed on campus

3. Off campus sharing of information

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

- Yes, I consent to relevant information about my son/daughter being disclosed to local professionals whilst off campus

(Signature)

(Name)

(Date)

Name of patient:- _____

Relationship to patient

Disclosing patient information



There are four areas in which we seek your consent for patient information to be disclosed:-

1. ParentMail
2. Pharmacy provider
3. Training purposes
4. Work placements

Please read the information below and then complete the parental consent section. If you have any queries please do not hesitate to contact the Data Protection Officer on 01342 832243 ext. 286 or by emailing dpo@youngepilepsy.org.uk.

ParentMail

Communicating with parents is an important part of what we do, making sure you get the correct information about activities, events and things that really matter is something we care about. Traditionally we have always used printed letters but delivery of these can be unreliable; they are also expensive, take time to produce and are not environmentally friendly.

ParentMail benefits. We would like to use ParentMail to communicate with you electronically. The main benefits of ParentMail are that:-

- ✓ Messages will get to you reliably and quickly
- ✓ We can send messages directly to mums, dads and other carers at the same time
- ✓ Emergency or important information can be sent by text message
- ✓ It will provide you with just one account where you will receive all information from St Piers School and College
- ✓ You have your own personal account, so the information and any correspondence goes directly to you.

Please be assured that ParentMail is a proven service that is already used by over 5,000 schools, nurseries and children's clubs. It is also registered with the Information Commissioner's Office and guarantees that all information it holds will be kept private and not be passed onto to any other organisation. (For further details please go to their website <http://www.parentmail.co.uk/>).

Uploaded information. If you agree the following information will be uploaded ParentMail:-

Patient's first and surname	Class / Tutor / Year group
Date of birth	Parents First and surnames

(Please note that this does not include any confidential or sensitive information).

After this has been done we will then send you another letter with your unique user code and registration details.

Pharmacy provider

We do not have our own pharmacy on campus and this service is undertaken by our local pharmacy provider.

Disclosure of information. It would be beneficial if we could inform our pharmacy provider of:-

- ✓ Any allergies the patient may have
- ✓ Current medication being taken (this would be updated to take account of any changes made whilst at Young Epilepsy).
- ✓ Medical diagnoses

This would enable our pharmacy provider to provide us with an enhanced service. Pharmacists having access to this information are in a unique position to protect patients from adverse events. We would therefore, as an organisation, recommend that this information be shared. Our pharmacy provider will only use this information for the purposes of fulfilling prescriptions and will hold it in a confidential and secure manner.

If you require any further information on this please contact Sandra Bale, Pharmacy Advisor on ext. 226 or by email sbale@youngepilepsy.org.uk

Training

At Young Epilepsy we believe that training both our staff and other professionals can only enhance the treatment, understanding and future development of services for children and young people with epilepsy and special needs. We would therefore greatly appreciate it if you would grant us permission to use information about your son/daughter in our training sessions. .

Training Young Epilepsy staff. It is extremely valuable to use real-life patient examples when training. Photos, video and EEG, as well as case summaries are valuable training tools, which allow our staff to learn using actual scenarios. Whilst we would not identify a patient by their full name during a training session, any photos or video would usually show a patient's face, and case summaries may refer to a patient's first name (but not their surname).

Within Young Epilepsy this training is essential for staff development. It allows us to share knowledge from a specific discipline, such as the Health Services department, with staff from other disciplines, such as Care or Education. This enables us to ensure that all the staff involved with our patients have the skills necessary to effectively support our patients

Training other people. Young Epilepsy is a recognised authority on the treatment and support of children and young people with epilepsy and other conditions and we are often asked to share our knowledge with other professionals or interested parties. In these

circumstances it is very instructive to be able to use photos, video, EEG and case summaries.

Work Placements

Young Epilepsy is recognised as a centre for excellence for epilepsy care and treatment. Consequently we receive a number of requests from people to come onto our campus and learn from our staff and patients. Allowing placements at Young Epilepsy is not a decision we take lightly. We do so because we believe they have a benefit to both us and our patients. They raise the profile of Young Epilepsy and improve the understanding of the issues and needs our patients have.

We often have specialist work placements on campus. The activities they may undertake will vary depending on the nature of the placement. All placements sign a confidentiality agreement and understand that they cannot discuss any information about our patients outside Young Epilepsy and are vetted by our HR department. However, as information will be shared with people who are not Young Epilepsy staff we need your permission to be able to do so.

A specialist work placement is someone who attends Young Epilepsy as part of a specialist or professional course requirement or may be a trainee seeking to broaden his/her knowledge of epilepsy. The intention of such a person is to eventually work in or obtain a qualification in a speciality that Young Epilepsy provides to its patients. They could include trainee nurses, who spend time observing our own nurses in action or might be someone studying to become a therapist, doctor or a teacher.

There are two areas in which we seek your consent, to enable a specialist work placement to:-

- a. Take an observational and interactive role;
- b. Attend meetings at which your son/daughter will be discussed.

a. Observational and interactive role. It may be a purely observational role or it may involve closely supervised interaction with our patients. It is obviously of great benefit for someone on a specialist work placement if they can come onto our campus and observe both how our professionals work and the various needs and issues our patients have. It helps them to understand how the theory they have learnt should be implemented and develops their skills. It also helps to promote Young Epilepsy and the work we undertake here.

We would like to be able to share information, which may include medical and confidential information, about your son/daughter with someone on a specialist work placement at Young Epilepsy, to help them fully understand the issues. We can assure you that we would only share relevant information and the minimum amount necessary.

b. Attending meetings. It would also be beneficial to the specialist work placement if he/she could attend meetings at which your son/daughter may be discussed by a number of Young Epilepsy professionals. It is likely that sensitive and confidential information may be discussed.

Disclosing patient information

Parental consents



If after reading this form you are happy to give your permission, please indicate this below.

1. Consent for information to be shared with Pharmacy provider

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

- Yes, I consent to the information outlined above about my son/daughter being disclosed to Young Epilepsy's Pharmacy provider

2. Consent for information to be shared with ParentMail

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

- Yes, I consent to information about my son/daughter being disclosed to ParentMail

3. Consent for information to be used for training purposes

Please consider the following statements about your son/daughter, and **tick those you agree with.**

- Yes, I consent to information about my son/daughter being used to train Young Epilepsy staff
- Yes, I consent to information about my son/daughter being used to train external people not employed by Young Epilepsy

4. Consent for information to be shared with specialist work placements

Please consider the following statements about your son/daughter, and **tick those you agree with.**

- Yes, I consent to information about my son/daughter being shared with a specialist work placement who has an observational or interactive role
- Yes, I consent to a specialist work placement attending meetings at which my son/daughter will be discussed

(Signature)

(Name)

(Date)

Name of patient:- _____

Relationship to patient

Sharing with Patients, Parents & Others



Please read the information below and then complete the parental consent section. If you have any queries please do not hesitate to contact the Data Protection Officer on 01342 832243 ext. 286 or by emailing dpo@youngepilepsy.org.uk.

Sharing Photos, Video and information with other patients/parents

Often photographs are taken by Young Epilepsy staff, which patients and parents or guardians would like copies of. However, this is not always possible because they fall within the Data Protection Act and it is therefore necessary to obtain consent to share.

Sharing group images. Young Epilepsy staff may take photographs and/or video recordings of groups of patients. These will usually show patients with their classmates, peers and friends. Such photographs and/or video are often taken at special events organised by the care or education staff

E.g. Christmas parties, weekend outings, school drama productions etc.

At present such photographs are only displayed on campus (if this has been previously consented to). We know though that many patients and parents or guardians would also like to have copies of these group photos/video, particularly as they usually show our patients having fun with their friends. However, we cannot share images of one patient with another patient or with another patient's parents/guardians unless we obtain your permission to do so.

Departmental Newsletters/Updates. Many departments would like to produce newsletters or updates, to be shared with other patients and their parents or guardians. These updates or newsletters may include photographs or information about patient developments and achievements.

E.g. School or House newsletter – may include details on the work undertaken or the achievements obtained by a patient and could include a photograph to illustrate an article.

These documents would only be produced in hard copies and only shared with the other patients and their parents or guardians.

Young Epilepsy will not use public online services to support educational or social care activities, we will always aim to provide private cloud based services such as WordPress sites or our own web services to provide these spaces. This ensures we control the ownership, security and access to the information being posted about our patients and their activities. However, for those that provide permission for images and video to be used for marketing purposes, these images will be used on public social networking and web services.

Agreement not to copy or further distribute. We also, at the same time, need to obtain your agreement that, should you receive such photographs, video or newsletters, which include images and/or details of other patients, you will not duplicate these images or distribute them to anyone else.

Sharing with Patients, Parents & Others

Parental consents



If after reading this form you are happy to give your permission, please indicate this below.

1. Consent for sharing photos, video and information with other patients/parents

Please consider the following statements about your son/daughter, and **tick those you agree with.**

- Yes, I consent to group images that include my son/daughter being shared with the other patients (and their parents) who appear in that photo/video
- Yes, I consent information about and photos of my son/daughter being included in departmental newsletters and updates
- Yes, I agree not to further copy or distribute and of the above information, photos or video

(Signature)

(Name)

(Date)

Name of patient:- _____

Relationship to patient

Publicity & Promotion



Being able to publicise the work we undertake at Young Epilepsy is invaluable in raising the profile of epilepsy. It allows us to promote the achievements of our patients and the work we carry out.

At Young Epilepsy we produce a range of material to promote and publicise the work we undertake. The publicity may be for the organisation as a whole or it may be for the work of an individual department, such as, for example, St Piers School, St Piers College or our helpline service.

We may use photographs of our patients. These may be stand-alone photos or they may be accompanied by a few words identifying the patient by their first name. We may write a case study about the patient (again these would only refer to a patient by first name).

Our publicity material may take the form of a printed hard copy document or the material may be placed on Young Epilepsy's website, from where some documents may be downloaded. It may also be placed on Young Epilepsy's official Facebook page.

In some instances, we may wish to use photographs or case studies of your son/daughter to promote Young Epilepsy on Young Epilepsy's websites, radio, television and/or in the printed media (newspapers, magazines, newsletters etc.).

We may also wish to promote Young Epilepsy's work on social media outlets. This includes Facebook, Twitter, Flickr and so on.

When working with the media, information is often published on websites. When this happens it can be accessible to all web users. We will only use first names with case studies or with photographs sent by Young Epilepsy to the media. There may though be occasions, for instance at a photo-call where the press will request the full names of the patients being photographed and this will be provided; however no further personal/case study details will be provided in this instance.

We will never provide a photo, case study and surname together to the media without specific permission.

We may also want to film your son/daughter and produce a filmed case study about him/her to promote Young Epilepsy. These images may be used on DVDs for viewing by professional and wider public audiences and online via websites such as YouTube. We will never provide a photo, case study and surname together during such a film without your specific permission.

Please note that in all of the above we may continue to use your son/daughter's details for up to five years after they have left Young Epilepsy.

Publicity and promotion Parental consents



If after reading this form you are happy to give your permission, please indicate this below.

1. Publicity and promotion

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

- Yes, I consent to information about and images of my son/daughter being used for the purpose of publicising and promoting Young Epilepsy

(Signature)

(Name)

(Date)

Name of patient:- _____

Relationship to patient

Susan Turner
Data Protection Officer