



The Neville Childhood Epilepsy Centre



Assessment and Rehabilitation Unit
Parent Guide



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Welcome to the Assessment and Rehabilitation Unit at Young Epilepsy. This guide aims to tell you all you need to know about your child's stay in the unit. We hope that it will help you to get the most out of your time with us.

If you have concerns or questions, do please ask, we're here to help and support you, as well as your child.



About us

Young Epilepsy is based on a beautiful 60 acre rural campus in the village of Lingfield, on the Surrey, Sussex and Kent borders. The charity provides medical, assessment, rehabilitation, care and education for children and young people whose lives have been adversely affected by epilepsy and other neurological conditions, including acquired brain injury resulting from accident and illness. Working with children and young people at an early stage using a range of therapy techniques – an ‘interdisciplinary approach’ – is key to reducing the long-term impact of these conditions.

Young Epilepsy works in partnership with Great Ormond Street Hospital NHS Trust (GOSH) and the Institute of Child Health (ICH). This means that we can draw on the unique expertise of professional staff from each organisation to provide high standard of services for young people with the benefit of the latest medical research. The Assessment and Rehabilitation Unit is located within the Neville Childhood Epilepsy Centre at Young Epilepsy and is registered with the Care Quality Commission.



The unit provides in-patient interdisciplinary assessments and rehabilitation packages for children and young people between 3 and 19 years of age. The service currently operates 39 weeks a year, in line with school terms.

Separate residential accommodation is provided for parents and families visiting their child.



Interdisciplinary assessments

The purpose of an interdisciplinary assessment is to provide detailed diagnostic information, in-depth evaluation of the impact of epilepsy or neurological problems and to make recommendations to address educational, medical and care support needs. The intention is to maximise the potential of every child and to improve the quality of life of the young person and their family.

Young Epilepsy aims to provide the highest standard of assessment and care, through a highly skilled multidisciplinary team.

The aims of the assessment and the length of stay are planned on an individual basis and usually last between 2 and 12 weeks.

We also offer tailor-made packages that combine a period of assessment with outreach and support by the multidisciplinary team at home or school. We liaise with your local team of doctors, social workers, teaching staff and therapists to support the implementation of recommendations once your child has left the unit.





Rehabilitation service

The purpose of the rehabilitation service is to provide a multidisciplinary goal-orientated service for children and young people who have sustained an acute brain injury (either through accident or illness) or who have undergone neurosurgery. It is also available to help individuals whose underlying medical condition has deteriorated and who require a period of intensive support to regain or improve skills.

We aim to provide the highest standard of care and treatment, working towards restoring lost skills, encouraging alternative skills and preventing other problems developing throughout the recovery. Supporting both your child



and your family through changed circumstances is central. The overall aim of the service is to re-integrate your child into the family and community. Liaison and, where required, outreach visits by the team are part of the programme.



Outreach service

An epilepsy nurse specialist (ENS) outreach practitioner supports all the services in the Assessment and Rehabilitation Unit. Children and young people referred to the service are visited at home and at school to gather additional information. This supports both the referral and families before, during and after their stay at Young Epilepsy. Occasionally, for practical reasons, this information may be obtained by telephone.

Each child attending the unit will have different needs. The referring paediatrician liaises with our team to decide which service is appropriate for your child. If you are unsure about your care package, please contact the unit administrator.





The team

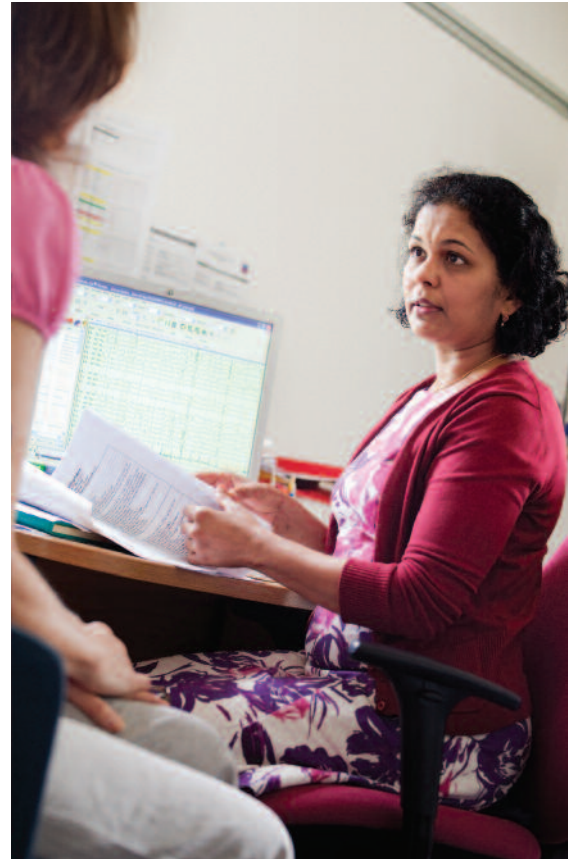
We have a highly skilled, dedicated team of professionals who support the children and young people admitted to the unit.

Under the direction of the Unit manager, assessment and rehabilitation support workers provide the day-to-day care for the children and young people. They have constant contact with the children and are vital in helping with the assessment and rehabilitation process, through supporting therapy programmes and recording observations.

The medical team comprises:

- Consultant paediatric neurologist
- Clinical fellows
- Specialist paediatric registrars
- Clinical physiologists
- Consultant child and adolescent psychiatrist
- Nursing team
- 24-hour medical/nursing care

The Neville Childhood Epilepsy Centre has a designated Manager registered with the Care Quality Commission (CQC) A file of biographies is available, in the unit, if you would like to know more about any of the team.



The Assessment and Rehabilitation Unit has its own dedicated clinical team led by the Consultant Paediatric Neurologist which comprises:

- Clinical psychologist
- Senior occupational therapist
- Senior physiotherapist
- Senior speech and language therapist
- Epilepsy nurse specialist outreach practitioner (ENS)
- Teacher
- Play specialist
- Care staff



The programme

All the children and young people staying in the unit have an individualised timetable that includes school and teaching, therapy, doctor's appointments and social activities.

Those who are in the assessment and rehabilitation programmes may access our on-campus St Piers School or College during their stay with us. Each child has their individual timetable and, wherever possible, they will help plan their own day and be involved in goal setting. They will have a nominated support worker, as their key worker, who will liaise with the team about their programme and be able to answer any questions they may have.

At some point during their stay, a period of video telemetry or ambulatory electroencephalogram (EEG) monitoring may be necessary. This may involve an overnight stay in a different room, supported by the nursing and care teams.

Both in the unit, and in school, we start the day with an orientation session where we discuss our plans and exchange news. Sometimes we have set themes depending on the time of year. School and therapy sessions may be for individual children, or a group, depending on our aims.



Where appropriate, helping your child develop skills needed to look after himself or herself is an essential part of their stay here. These activities will also be timetabled and your child will be helped by the support workers.

We have a comprehensive programme of on-campus after-school activities. In addition, we may arrange visits to the local cinema, bowling alley and the shops. All the children and young people are encouraged to participate in favourite hobbies and activities and try out new ones during the evenings. Bedtime routines are established as appropriate for each individual.



What can you expect from us?

On arrival

When you arrive, you will meet with the assessment unit manager to discuss the centre's induction agreement which will be in the admission pack sent to you prior to your visit. This agreement is a common starting point for all new admissions and their families to help us to work together.

When you leave your child

Before you leave for home we discuss times and frequency of telephone contacts so they can be mutually convenient.

During your child's stay

During the assessment or rehabilitation period you may receive calls from other team members, such as therapists, to update information. Early on during the assessment a date will be set for the final meeting. This is usually during the last week of your child's stay with us. As the assessment progresses different members of the team may invite you to observe specific therapy sessions that your son or daughter is having.

The last week of your child's stay

Our team will meet with you and your local team of professionals (who will receive a written invitation to attend) to discuss the findings of the assessment and make a plan of action for the future. If the child's key local professional cannot attend this meeting, a teleconference facility may be arranged to gain their input. In addition there will be an opportunity to meet with team members to discuss particular recommendations and therapy programmes. It is important to convey information to the local team before the full assessment report is available.

Discharge

A summary of findings and recommendations will be sent home with your child on the day of discharge, which will be between 12noon and 4pm.

Transport arrangements

Parents and carers will need to arrange their own transport on admission and discharge.

Eight weeks after your child leaves

Eight weeks after your child's discharge you will receive a copy of the final assessment report. If you have any queries or questions, our outreach practitioner will be happy to discuss them with you.



Hospital treatment



If your child needs hospital treatment

Should your child become unwell and require hospital treatment (including x-rays) during their stay in the unit, they will be transferred to Surrey and Sussex Healthcare NHS Trust. If this happens you will be contacted as quickly as possible and kept informed about your child's welfare. A member of the team will accompany your child and remain with them until you are able to get there. We would expect this to be within 24 hours of admission. If this is not possible the hospital staff will be provided with the appropriate information so they can take over the care.

If your child needs an urgent transfer to hospital, in consultation with a consultant or specialist paediatric registrar (SpR) and/or nurse, a decision will be made as to whether an



emergency ambulance should be called. If considered to be appropriate for children under the age of 16 years, the consultant/acute local hospital may discuss the transfer with the South Thames Paediatric Retrieval Service. Your child will be accompanied in the ambulance by a member of the care or nursing team, as appropriate.





Support

How can you support your child's stay?

In order to get the most out of the time your child spends with us, we aim to work in partnership with parents and families. You can support the assessment or rehabilitation programme in a number of ways.

Before you come to the unit

Please choose some of your child's favourite toys, CDs, DVDs or craft activities etc to bring with you, and any special belongings (maybe a pillow, duvet cover or beaker) and family photos to help your child settle in. It helps us if they are clearly labelled with





your child's name. It is also useful to provide your child with some pocket money for outings and treats which the care staff can look after – we suggest £10 initially and we will ask you for a bit more if it runs out! We have laundry facilities so you don't need to bring a huge amount of clothes. Remember to



pack toiletries, swimming kit, any medication that your child is currently on and any special equipment that your child needs. We provide towels for swimming and hydrotherapy.

When you arrive

Be prepared to spend several hours helping your child to settle in, longer if your child is very young, anxious or has specific or special needs arising from their disability (how long you stay will be discussed individually before you arrive). You will see a doctor who will go through your child's current health, seizures and medication. A member of the care team (probably your key worker) will go through your child's daily routine and write up a care plan.

We need to know as much as possible about your child's routine and his or her likes and dislikes. You may also meet with some members of the therapy/psychology team, to go through what they, and you, would like to achieve for your child while he or she is at the unit. It is helpful if you can show us how you look after your child. We will ask you to dress, or feed, or give medication and comfort him or her and manage his or her behaviour as you do at home. Your child's key worker (and other support workers) can be with you to learn how your child likes things to be done.





Supporting families

Once they have settled in, most children have a very happy time in the unit. We recognise however that this can be a stressful and anxious time for families and we are here to support you too. Senior members of the care team, the psychologists, doctors, senior nurses and the Young Epilepsy safeguarding officer are all experienced in supporting parents of children and teenagers with complex epilepsy and associated problems, and we will be happy to meet with you. We can also offer support for siblings.

What to do if you're not happy

If at any time during your child's stay with us, you are not happy about something, please talk to a member of the team straight away. We may not get things right all the time and need to know where we can make improvements. Your feedback helps us to learn. If you are not happy with the response you are given, please ask for an appointment with either the unit manager, consultant neurologist or the registered manager. We have a formal complaints procedure which is available in the unit – please ask to see it.

When it's time to leave

At the end of the assessment or rehabilitation period, usually on the final day, a meeting is held with the family and the team that has been working with your child during their stay. We also invite your child's local health and

educational professionals, and any other professionals who have a key role, to attend. This will include the local paediatrician who referred your child to the service, class teacher, social worker and any members of the local therapy team. You are welcome to bring a friend or advocate with you and it is important to tell us about anyone else you would like us to invite. The assessment or rehabilitation period is summarised and changes in medication and progress made during the programme are discussed. Recommendations for the future are also proposed. There is time for parents and other professionals to discuss these changes and/or progress and ask any questions. If appropriate the young person themselves may attend part of the meeting.

Next steps

Following the discharge summary, which is issued on the last day of your child's stay, a full and detailed assessment report is written by those involved with your child while they have been in the centre. This will include separate reports on what has been assessed, what has been achieved and also includes recommendations for the future. As it is very detailed and written by all of our team, the aim is to get this report out approximately eight weeks after the end of your child's stay. This will then be circulated to a previously agreed list of medical, education and other health care professionals as well as to parents.



Our outreach practitioner will organise any follow-up visits after the assessment or rehabilitation period. They will attend local meetings about school placements and will also be on hand for ongoing help and advice following your child's stay.

Ongoing support

Once your child has left the unit there are several ways in which continued support can be obtained, if needed. All the team are happy to discuss the assessment or rehabilitation programme and its outcome with parents or other relevant people, such

as teachers, therapists or other professionals supporting your child. We can be reached by calling the unit and asking for the required team member. Please note that as some of our team are part-time a message may need to be left for a return phone call. Your local services will take over from where the assessment and rehabilitation unit's team has left off, so they should be available to give help on a more local and day-to-day basis.



Life in the unit

All our staff are committed to the care of children and teenagers with complex needs. The care team have attended training courses at Young Epilepsy, and many have external training or qualifications.

All staff follow Young Epilepsy guidelines and policies, your child's care plan and individual medical and therapy programmes. We aim to provide clear and consistent care but different members of the team will, of course, look after your child during their stay.

An overview of the key policies that we follow relating to managing behaviour, promoting communication, emergency transfer procedures and safeguarding

the children and young people is available for parents/carers in the unit. Information on the Mental Capacity Act and its relevance to the work in the unit is also available.

We aim to provide a homely atmosphere but with up to three or four young people in the unit, and assessment and therapies to incorporate into the day, life here has to be more structured than at home.

Please be sensitive to the needs of other children and young people in the unit and their families. The details of each child need to be kept confidential.

We ask that you do not intervene in assessments, observations or treatments of other children. Occasionally you may be asked to leave the room or unit briefly if a child is having a difficult time. Please follow requests and directions from members of staff. If you are concerned about another child or young person, please discuss this privately with staff.





Visiting and access times

Please arrange with the team when you would like to visit your child, usually this will be at weekends and sometimes after school. Please limit parents/visitors to four at a time or check with the team before you arrive. Please do not arrange a visit if you are unwell. As the unit needs to be calm when settling the children for the night we ask parents to leave by 7.30pm, although there is flexibility depending on the ages and needs of children and young people who are staying. Of course, if your child is very young or acutely ill you will want to be with him or her as much as possible and we will discuss this with you individually.

Weekday access times

Mornings - 8:30am to 9:15am.
Afternoon - 4:00pm to 7:30pm.
The unit is not accessible to parents/carers/visitors between 9:15am and 4:00pm on weekdays.
Weekends - Please arrange with the unit team.

If you wish to take your child out of the unit when you visit, please ask a member of the team and say when you expect to return so we know where the children are at all times. When visiting your child please discuss with the support workers if you would like their help in caring for him or her.

Your child may not stay overnight in the on-campus family accommodation as it is not registered with the CQC.

The centre provides food for the children in the unit but we ask visitors to make their own arrangements. We cannot allow alcohol on the premises. If an adult visiting the unit appears intoxicated, or shows signs of any inappropriate behaviour he or she will be asked to leave. We also have a no-smoking policy in and around all of our buildings, including all accommodation, however covered smoking shelters are provided around the campus.

There is a computer with internet access in a quiet room within the unit. This can be used by parents and carers during access times with prior agreement from the team.



Facilities



At Young Epilepsy we have 'The Granary' providing a range of items including: morning snacks, a lunchtime hot meal option with a salad bar, a range of sandwiches and baguettes as well as afternoon tea, coffee and cake. It is open from 8.30am to 6pm during normal term-time. Please check for opening hours during school holidays. The kitchen in the unit is primarily for the use of the team and children, but may be used by parents to make drinks and snacks. Please check with a member of the team before using it.

There is accommodation available for parents on campus. If you are looking to use this please make a request in advance so we can let you know if there is a room available. For more information please contact the unit administrator. Other facilities are available in nearby Lingfield (see the information in the unit).

You are welcome to explore our large campus. We have a farm, small boating lake, sensory garden and a woodland area. Please use the safe pathways around campus to ensure your safety – they are clearly marked. There are lots of other residential homes around the campus for our school and college students, please respect the private areas around their homes and gardens. Do feel free to use the garden area of the unit at any time. If you'd like to take



your child out at the weekends, there is lots to do in the local area and further details are available from the unit.



Settling in

Assessment and Therapy

In the first few days we concentrate on helping your child to settle in and getting to know him or her. Much of our assessment is informal, happens through observations during the normal day and incorporates therapy into the child's daily activities wherever possible. The therapists may often work alongside the support workers in the unit and therapy exercises may be carried out by the team with guidance from the therapists. So during a fun visit to the farm, or a mealtime, your child may, for example, work on mobility, communication and behaviour goals – without being aware of this. We may need to try several therapy approaches or medications to see which works best for your child. Please do not expect instant results. Let us know how you think your child is responding. We will discuss any proposed changes to your child's medication or therapy programme with you. Please follow any medical/therapy guidelines if you take your child home for a weekend.



Communicating with your child

There are several ways for you to communicate with your child when they are here:


Internet – we have a computer for the children and young people to use in the unit under supervision and from this they can access their own email accounts. We also use Skype, a secure line where you can see your child as well as speak with them. It is free, all you need is a webcam and microphone on your home computer.

Telephone – you can phone your child at anytime during their stay or they can phone you. The telephone number for the unit is 01342 831224.


Letters/cards – if you wish to send your child a letter, card or present, just address it to them at *The Assessment and Rehabilitation Unit, Young Epilepsy, St Piers Lane, Lingfield, RH7 6PW*. All children love to get post, so please encourage friends and family to drop them a line too. We encourage contact with home, family, friends and school, and any contact will be set in agreement with you. We will try to be as flexible as possible with regards to providing contact.



Keeping in touch



Please feel free to contact any of the multidisciplinary team during your child's stay. You can leave a message at the unit and we will get back to you as soon as possible. Members of the team may also call you at home and liaise with professionals involved in your child's care locally.



If your child is staying in the unit for more than six weeks, we will schedule a meeting for you with key therapy and medical staff to review aims and progress towards the middle of the assessment or rehabilitation period. When your child is due to come home we may ask you to spend a day

(or sometimes several days) at the unit to practise strategies that the team have found helpful with your child. Therapists may also ask you to join in with assessment/therapy sessions at other times.

Please speak with a member of staff if you have any concerns. They will pass on your queries and comments to the relevant members of the team and offer to make you appointments if you would prefer this. Please bear in mind that the key worker is not medically trained, or a therapist, so may not be able to answer all of your questions.





About the Neville Childhood Epilepsy Centre

Opened in autumn 2009, the Neville Childhood Epilepsy Centre is the first purpose-built childhood epilepsy centre for assessment and research in the UK.

It comprises seven specially designed en-suite bedrooms and two family apartments, as well as all the state-of-the-art technology necessary for the assessment service. This is to ensure that children staying at the unit have the best possible visit resulting in the best possible outcome.

Training for doctors, nurses, teachers and other health and education professionals takes place in the centre. It is also the base for high quality day-to-day medical services for the 200 students attending St Piers School and St Piers College on campus.

Tailored to meet the needs of children and young people, the centre features:

- state-of-the-art electroencephalogram (EEG) equipment in specially designed, child-friendly suites
- on-site paediatric neurologists
- on-site speech and language therapist, physiotherapists, psychologists and occupational therapists
- video telemetry facilities to monitor and record seizures as they occur
- light, airy rooms with assisted toilets and bathrooms throughout
- family-friendly accommodation and a home-from-home feel for the young people staying there.

It has been built as a result of the generosity of donors and has been created as part of Young Epilepsy's purpose to provide better futures for young lives with epilepsy and associated conditions.





Contact Us

Please do not hesitate to ask if you have any further questions. We are here to support both you and your child and want you to get the most out of your time with us.

We look forward to welcoming you and your child to the unit.

For further information please contact:

The Administrator
Assessment and Rehabilitation Unit
The Neville Childhood Epilepsy Centre
St Piers Lane
Lingfield
Surrey RH7 6PW

Assessment and Rehabilitation Unit:

Email:

Unit administrator:

General manager:

Young Epilepsy switchboard (office hours):

01342 831224

assessment@youngepilepsy.org.uk

01342 831203

01342 831308

01342 832243

youngepilepsy.org.uk



We also have a National Services team which provides support for parents and young people themselves.

Epilepsy Helpline: 01342 831342
Monday-Friday 9am – 1pm.
Email: helpline@youngepilepsy.org.uk
Text us: 07860 023 789

An example of some of the resources available
See more in our online shop - youngepilepsy.org.uk






Young Epilepsy is a national charity providing education, medical and support services for children and young people with epilepsy and associated conditions. It works in partnership with Great Ormond Street Hospital for Children NHS Trust and University College London's Institute of Child Health.

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