

Expertise in specialised diagnostic assessments,  
health assessments and rehabilitation service



 **Young  
Epilepsy**

## Young Epilepsy

The range of health services are operated by Young Epilepsy, a national charity with over 100 years expertise in neurological conditions. By choosing Young Epilepsy, you can have the confidence the young person will be cared for by an award winning organisation with a reputation for providing excellent health services.



## Welcome to Young Epilepsy Health Services

The Neville Childhood Epilepsy Centre is based on our beautiful 60 acre campus in Lingfield, rural Surrey. The campus houses our specialist health centre, research facilities, school, college and residential homes. This means we can offer an all-encompassing service to children and young people with epilepsy and other neurological conditions.

Understanding the impact that epilepsy and related conditions can have on a young person and their family is at the centre of all our work. Not only can seizures be difficult to treat, but epilepsy may cause behavioural and emotional issues, communication challenges, physical disability and have an impact on the young person's education.

We are the only assessment and rehabilitation unit in the UK that specialises in young people with epilepsy.



“ I left feeling relieved that there was a diagnosis after three years. I could not thank everybody enough for their help advice and most importantly their time. ”

## The work carried out by the Assessment Service

There are several pathways that can be taken, which will allow a young person to receive a holistic service from our experts, in the field of epilepsy and psychiatry. These include a pre-visit assessment, diagnostic assessment and an intense assessment of the young person's needs relating to epilepsy and behaviour.

Young people with epilepsy, behavioural difficulties and social challenges require specialist support which considers all factors that could be affecting the young person's life. Our interdisciplinary team of health and education specialists offer a holistic approach. This ensures that future programmes of treatment and educational choices are made on the basis of detailed evaluation and an understanding of the individual's needs. The young person is at the centre of all the work undertaken by the team.

### What is the impact of our multi-disciplinary approach?

Our highly skilled and experienced team of professionals are dedicated to supporting the children and young people who are admitted to our centre. Under the direction of the unit manager, assessment and rehabilitation support workers provide the day-to-day care, support therapy programmes and record observations. This means the young person has someone they can relate to, building their confidence in the team around them and

encouraging the young person to express their concerns and anxieties.

The unit's dedicated clinical team includes a consultant paediatric neurologist, consultant psychiatrist, clinical psychologist, physiotherapist, occupational therapist, speech and language therapist, teacher, play specialist and epilepsy nurse specialist. The team work very closely with the young person to understand the effect that the condition is having on their development and implement different strategies for the young person's future.



## How do we set goals and review success?

On receipt of a referral to our unit the young person could be offered a home visit, outpatient appointment or a two day pre-visit assessment. This allows our team to fully understand the nature of the young person's needs, and to set detailed short-term goals and long-term aims. These will form the basis of each young person's individual programme.

Review meetings are held weekly to monitor and measure the young person's progress against the aims. Parents are encouraged to participate in meetings to allow them to understand the progress made and what could be required in the young person's local home community.

All relevant professionals, including those from the young person's local community, health, social services and education, are invited to the final review meeting. The meeting will give all involved a chance to understand what services need to be put in place around the young person on their discharge from the unit.

A comprehensive report is compiled by each member of our interdisciplinary team outlining their specialist input during the young person's stay.

## How are our outcomes developed

Our outcomes are developed in conjunction with the young person, their family and the referring team. The outcomes are tailored to the individual and may include seizure reduction, ratifying medication, reducing in behaviour episodes, increasing independence, developing social interaction and activities, and expanding their communication.



What was really good was the support information given, what they said they would do was done quickly. Both myself and daughter received information which has changed both of our lives.





I was very impressed by how well we were looked after. Everyone we met was not just professional and efficient but also very helpful and friendly. ”

## What do our flexible packages offer?

- Outpatient appointment
- Preview assessment
- EEG/video telemetry and ambulatory EEG
- Diagnostic assessment
- Epilepsy assessment and management
- Behaviour management
- Outreach
- Training
- Research

To ensure the young person's needs are completely understood, following a referral we will offer an outreach visit and a preview assessment. This allows us to plan their admission and goals of the assessment and its strategic outcomes.

Our **Diagnostic Assessment Service** provides a three to five day diagnostic assessment performed in the telemetry suite of the Neville Childhood Epilepsy Centre. The main objective is a

medical diagnosis and usually includes a minimum of 48 hours of video telemetry, which can be extended to five days. This assessment is done in collaboration with the paediatric neurologist, neurophysiologist, clinical psychologist and specialised nursing staff.

Prior to the assessment taking place each young person is visited by the epilepsy nurse specialist outreach practitioner. Detailed medical and seizure history is obtained from the parents and the young person is observed in their current provision.

We also provide an EEG, ambulatory, video telemetry service. An outreach ambulatory EEG service is also available for young people who are unable to visit our facilities.

We will respond to the referrer within an agreed timeframe with a full report. Where appropriate, an immediate telephone response can be given to the referring consultant.

Our **Epilepsy Assessment and Behaviour Management Services**

provide detailed diagnostic information and an in-depth evaluation on the impact of epilepsy, neurological conditions or behaviour on the young person. The assessment makes recommendations that address medical, educational, social and care support needs. These inpatient assessments are carried out within an agreed timeframe which could be from 2 to 12 weeks in duration.

Following on from the assessment our epilepsy nurse specialist can offer an outreach service. This means the service continues to support the local professionals and family with the young person's discharge and transition back into their local community.

Our **Rehabilitation Service** provides a multi-disciplinary, goal-orientated service for children and young people who have sustained a brain injury (either through accident or illness) or who have undergone neurosurgery. It also helps individuals whose underlying medical condition has deteriorated and who require a period of intensive support to regain or improve skills.



We provide the highest standard of care and treatment. Our multi-disciplinary team work towards restoring lost skills, encouraging alternative skills and preventing other problems developing throughout the recovery. We understand that supporting both the young person and the family through these changed circumstances is central to their recovery.

The overall aim of the service is to re-integrate the young person into their everyday life, family and community. The team strengthen the inpatient stay with outreach visits and liaison with local medical, education and care professionals.

Our outpatient clinics allow us to review the young person prior to admission and offer follow up appointments after discharge. This means that we continue to appraise the young person and their progress once they have transitioned back home for an agreed period of time. We continue to feed back our findings to the young person's local team.

We offer an outreach service as part of our pre and post assessment or as an individual provision, delivered to support local community services or schools and colleges nationwide.

## Our therapy team

Occupational therapists aim to assist young people to develop skills in education and in everyday life. The occupational therapists identify the young person's strengths and work to minimise or compensate for their functional limitations.

Physiotherapists are responsible for the overall physiotherapy management of individual young people. Regular timetabled exercise sessions will be devised for young people and these, where relevant, will include structured relaxation sessions.

The physiotherapists will be involved in the training of staff and delivering specific guidelines regarding the implementation of physiotherapy programmes.

Speech and language therapists establish how effective a young person's communication skills are, rather than just their speech or language skills. This involves looking at all the ways the young person interacts and how they are functionally able to communicate with those around them. They also support young people with oral difficulties affecting their eating and drinking.

Play therapists work with children to help them explore their feelings. Using toys they allow the young person to deal with their anxieties without the need to verbalise their feelings. The outcome sought is a reduction in their anxiety, raised self esteem, behaviour changes and improving relationships.



The psychology service we offer is unique. The team has a multi-disciplinary approach with input from clinical psychologists, educational psychologists, neuropsychologists, assistant psychologists and play specialists. The psychology service aims to make a difference to the lives of young people by embedding psychological principles in the work carried out. This is achieved by working in collaboration, with other professionals and the parents and young people. We follow a systemic and social interactionist model.





## How do we meet expectations?

- Young people receive an understanding and non-judgemental approach from the professional team. Having the young person's voice heard is at the core to everything we do.
- Parents are consulted and listened to. Parental outcomes are central to the process and parents are provided with follow up support.
- Professionals have access to our highly qualified team who will work collaboratively to ensure aims for assessment are met. Updates and comprehensive reports will be delivered in a concise and timely way.
- Referral pathway.
- Outreach visit to home and school by epilepsy nurse specialist outreach practitioner, if appropriate.
- Overnight pre-admission visit to set outcomes.
- Obtain funding agreement from local team.
- Admission.
- Comprehensive report.
- Outreach follow-up support.

## How do we support families?

We are committed to supporting families; we fully recognise the importance of the family in relation to the young person's development and progress. We offer training, emotional support, outreach prior to admission and following discharge, and on-site accommodation during assessment.

“

They understood our concerns and were very patient with our daughter.”



## Training

We deliver training to parents, carers and professionals both on and off site and cover a vast array of subjects linked to epilepsy and other neurological conditions. Our training includes:

- Administering emergency epilepsy medication
- Living with a child who has epilepsy
- Epilepsy awareness
- Epilepsy and young adults
- Study days
- Conferences



## Research

Paediatric epilepsy research is carried out through a joint unit which works across Young Epilepsy, UCL-Institute of Child Health and Great Ormond Street Hospital.

The research is undertaken by The Prince of Wales's Chair of Childhood Epilepsy and other leading professionals in the field of epilepsy. The programme focuses on all aspects of childhood epilepsy, looking toward optimising outcomes in children with epilepsy and exploring the health, psychosocial and educational impacts and interventions

The unit is in a unique position of reviewing children with a range of severity from newly diagnosed to complex epilepsy. Further collaboration across UCL allows continuation of work into adulthood, allowing study across the whole age range. The educational and behavioural expertise within Young Epilepsy allows interventional study beyond medical treatment.

## Superb facilities

Our medical, health, research and assessment facilities are situated in the state-of-the-art Neville Childhood Epilepsy Centre and the additional facilities based on our 60 acre campus.

- A three and a four bedded unit
- One individualised unit consisting ensuite bedroom, living room and kitchen facilities
- Nursing unit – 4 beds
- Preview room
- Therapy suite
- Multi-sensory room
- Ceiling tracking
- Full internet access
- Outside play area
- Classroom
- EEG suite
- Hydro pool
- Gym
- Low ropes course
- Soft play area
- Sports hall
- Boating lake
- Working farm
- Parental accommodation suites





## How to make a referral?

Referrals are welcomed from the child's or young person's GP, Paediatrician or Consultant.

For further information please contact:

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


Email: [assessment@youngepilepsy.org.uk](mailto:assessment@youngepilepsy.org.uk)  
Tel: 01342 831203

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

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