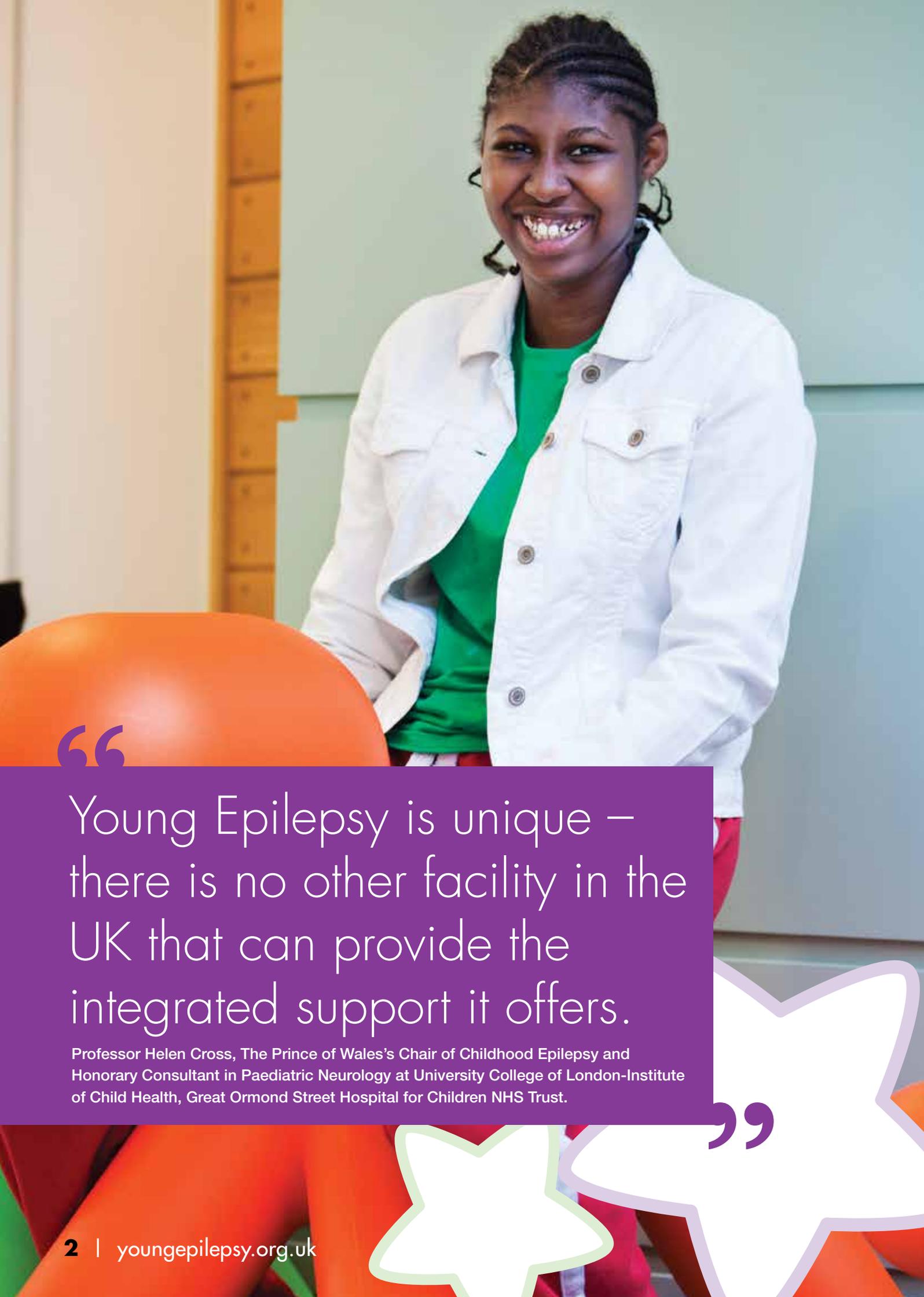




**Young
Epilepsy**

Better futures for young lives with epilepsy



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Young Epilepsy is unique – there is no other facility in the UK that can provide the integrated support it offers.

Professor Helen Cross, The Prince of Wales's Chair of Childhood Epilepsy and Honorary Consultant in Paediatric Neurology at University College of London-Institute of Child Health, Great Ormond Street Hospital for Children NHS Trust.

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Young Epilepsy is the national charity working exclusively on behalf of 112,000 children and young people with epilepsy. With over 100 years expertise it provides world class research, diagnostic, assessment and rehabilitation for children and young people with epilepsy.

Young Epilepsy has a specialist school and college. It provides day, residential and short break services, education and healthcare, for around 200 children and young people, up to the age of 25, most severely affected by epilepsy, autism and other neurological conditions.

As the voice for these children and young people, Young Epilepsy campaigns for better access to, and quality of, health and education services.

The charity provides a range of national support services and free information for parents, children and young people, such as handbooks, diaries, parent support groups, and training for professionals.

The Young Epilepsy Helpline offers people the chance to speak, or email, confidentially with trained staff.

For personal help and information, call 01342 831342

Monday-Friday or email helpline@youngepilepsy.org.uk

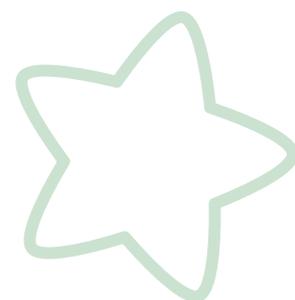
For more information visit youngepilepsy.org.uk





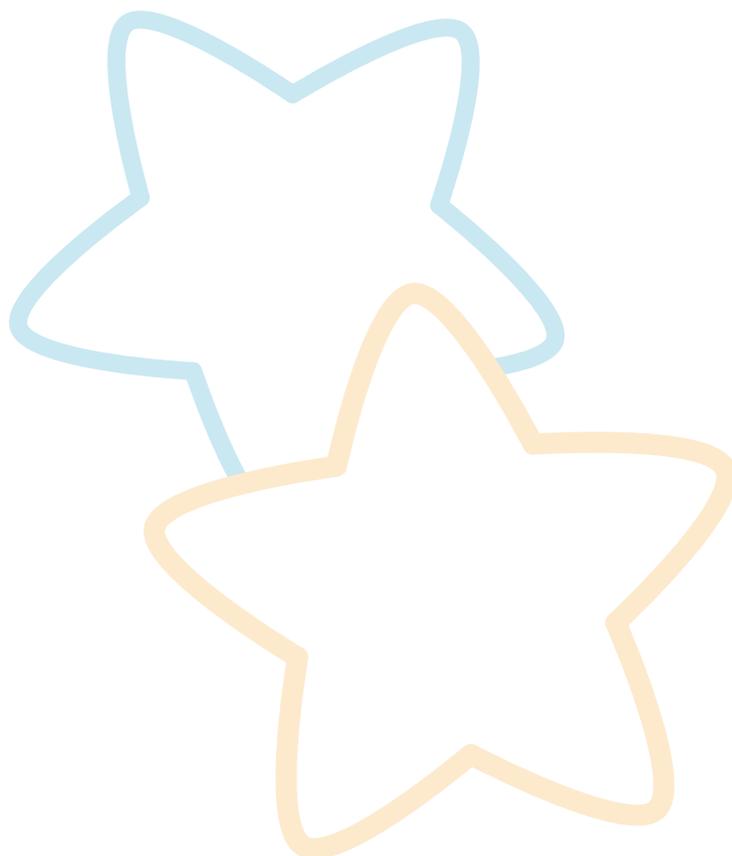
What is Epilepsy?

Epilepsy means someone is having recurrent seizures (sometimes called 'fits') where excess electrical activity in the brain sends confused messages to the rest of the body. This can lead to twitching of the limbs, stiffness, loss of consciousness or brief 'absences' where the brain switches off, but the person appears normal.



There are more than 40 different types of epilepsy and several different forms of seizure. Someone may:

- fall to the ground unconscious with a sudden loss of muscle tone
- experience jerks in one or more parts of the body and /or
- have short absences when the brain seems to 'switch off'
- display odd behaviours, mannerisms or repetitive movements.



About Epilepsy

- Epilepsy is the most common serious neurological condition worldwide. Epilepsy can happen to anyone at any age. For most there is, as yet, no cure but with effective treatment up to 70% of adults can control seizures with medication.
- Epilepsy is a complex condition with no simple diagnostic test. It relies on history, eyewitness accounts and the expertise of a clinician, to develop an accurate diagnosis which allows for the optimal treatment.
- Living with epilepsy has a profound affect on the individual, as well as their families, friends and other networks.
- For some young people, seizures can cause learning problems and antiepileptic drugs can lead to unwanted side effects. Epilepsy can seriously affect learning, memory and behaviour. More than one in five people with epilepsy have learning or intellectual difficulties.
- Academic underachievement is common in children with epilepsy, with evidence suggesting that up to 50% of children with epilepsy underachieve at school.
- One of the biggest threats to young people with epilepsy is misunderstanding. A widespread lack of awareness leaves many young people feeling stigmatised and isolated, battling low self-esteem, bullying and a lack of understanding from both peers and adults. Young Epilepsy is striving to remedy the stigma attached to this condition.



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The epilepsy misdiagnosis rate can be up to 40% amongst children and young people.

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Epilepsy – the facts

Approximately 600,000 people in the UK have a diagnosis of epilepsy. Young Epilepsy is committed to creating better futures for the 112,000 children and young people, aged 25 and under who are living with epilepsy in the UK.

Misdiagnosis rates in the UK, where a diagnosis of epilepsy is incorrectly made, are 20-31%. The misdiagnosis rate can be up to 40% amongst children and young people.

The estimated total cost of misdiagnosis in the UK is £268 million per year.

Access to epilepsy services for children and young people is variable across the UK. Currently only around 43% of children with epilepsy get access to a specialist epilepsy nurse, against recommendations that all eligible children should have access to one.

Surgery stops seizures in 70% of carefully selected cases. Recognising children who are suitable could save £280 million and improve the lives of hundreds of children and young people.

Over 1,000 people die every year from epilepsy in the UK – and in England and Wales alone over 100 of these deaths are of children and young people under 25.

Research has shown that two out of three of the deaths of those under 18 are possibly or potentially avoidable.





What is Young Epilepsy doing to make a difference?

From our campus

Pioneering research

Research is a vital part of our work. Our research programme, co-ordinated by Professor Helen Cross, The Prince of Wales's Chair of Childhood Epilepsy, Honorary Consultant in Paediatric Neurology at UCL-ICH and GOSH*, is internationally renowned. We are focused on gaining valuable insights into childhood epilepsy, and ultimately, enabling better long-term outcomes for children, and reducing the impact of epilepsy on their lives.

Just some of our current research projects include:

- Research into the genetic basis of complex epilepsy.
- A study into the effect of a child's epilepsy on siblings.
- A study of how sleep abnormalities may impact on learning in epilepsy.
- A study of the educational impact of epilepsy in early childhood.
- Research into techniques for optimising learning in children with epilepsy.

A very special education

From our Surrey headquarters, Young Epilepsy operates a school and college for 200 of the UK's most special children and young people, aged 5 to 25, who are most severely affected by their epilepsy.

“As parents of a child with severe epilepsy, we're on constant high alert. When Hannah is having a bad day of up to 40 seizures, we are always waiting for the next seizure. We are just so relieved that she is in the best place to manage them now.”

Home-from-home environment

Around 150 children and young people live on our beautiful 60-acre campus, in Surrey, either on a term-time, 'boarding' basis, or all year round. We provide a home-from-home environment suited to different ages and levels of need, complete with our on-site farm. We also provide short-term breaks which children, young people and their parents/carers find invaluable.

World class health, assessment and rehabilitation services

The Neville Childhood Epilepsy Centre, based at our Surrey headquarters, is the first purpose-built specialist childhood epilepsy facility in the UK. At the centre we support children and families effectively throughout diagnostic, assessment and rehabilitation processes. We also provide nursing care and a broad range of therapy services to children and young people, both attending our school and college, and from across the UK.

“I am in absolute awe of all of you for the hours and hours of dedication, energy, compassion, warmth, laughter, fun and love you put into every day.”

Jenny, whose child Keegan spent time in the Neville Childhood Epilepsy Centre.

* University College of London-Institute of Child Health, Great Ormond Street Hospital for Children NHS Trust.



Support across the UK

Awareness in schools

So far we have worked with almost 14,000 pupils, 5,000 education staff and 240 schools through our Epilepsy Education 4 Schools programme. **“We are working with schools to bring up a generation of young people who are talking openly about epilepsy, so they know how to support those affected.”** Emma Tingley, Young Epilepsy Education Officer.

Training

We have provided information and training to almost 1,000 professionals in the health, education and care sectors through our national training programme. **“Now I would put myself forward to help if I saw someone having a seizure.”** Receptionist, Dormers Wells High School, Ealing.

Helpline

The Young Epilepsy Helpline team provides support with our confidential information and signposting service for families, health, education and social care professionals. **“A mother whose four-year old son had recently been diagnosed with epilepsy called us because she had been given very little information. She was tearful during the 40-minute call. We suggested our free resources – A Parent’s Handbook, information for siblings, picture books and our Children’s Seizure Diary. The caller said she felt reassured and more able to cope.”** Specialist Epilepsy Nurse, Young Epilepsy Helpline.

Campaigning

We are delighted that following years of campaigning for greater provision of epilepsy surgery, it has recently been announced that the National Health Service is to increase its capacity for epilepsy surgery at four hospitals in England. We recently contributed to the Epilepsy12 report, which has revealed more still needs to be done to ensure epilepsy services are consistent across the UK. We will continue to strive to push epilepsy further up the health agenda to ensure young people have access to the best possible help and support.

Free resources

We have developed a range of highly successful resources including:

- Online teen seizure diary.
- Young Epilepsy smart phone app.
- Seizure diary and handbook for teens.
- Magazines for school children.
- Parent handbooks for newly diagnosed epilepsy and complex epilepsy.

Parent support groups

Ten parent support groups are now up and running. Each group can develop according to the needs of its members. We bring people together to share their experiences and help them to obtain practical information and emotional support.

“It’s always nice to talk to people who understand what you are going through as you can feel alone unless you talk about issues.”



Better futures for young lives with epilepsy

In our Education Resource Centre

Once built, our groundbreaking new Education Resource Centre in Surrey will have a dual purpose:

- To continue to deliver exceptional education and care for children with severe epilepsy and other neurological conditions and disabilities, including autism.
- To provide a cornerstone for research into educational attainment for all young people with epilepsy throughout the UK, providing solutions that will transform lives forever.

In schools

We have ambitious plans to build on our existing successes in schools to ensure:

- Better epilepsy training for teachers and education professionals.
- More epilepsy education resources for teachers and students.
- Improved support for students with epilepsy.
- All students with epilepsy to achieve their full academic potential.

In the home

A diagnosis of epilepsy can have a huge impact not only on the individual, but also on family and friends. We want everyone touched by epilepsy to have the support they need, including:

- Availability of short-term breaks.
- More resources to help manage the condition.
- More UK-wide support groups.

112,000
and young
aged 25 and
are living
epilepsy in

We cannot create better futures for young

– Looking to the future

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In health services

Healthcare for children and young people with epilepsy simply isn't good enough – yet. We want to see:

- Improved care pathways for children and young people living with the condition, as well as better transitions from paediatric into adult services.
- Better access to epilepsy specialist nurses.
 - All epilepsy services delivering care as recommended by NICE/ SIGN standards.
- More consultant paediatricians to acquire expertise in epilepsy.
- All children who are eligible for epilepsy surgery to receive it.

In society

We need the support of our leaders to ensure that the voices of children and young people with epilepsy are heard. We need:

- Epilepsy to be pushed higher up the health agenda.
- Greater awareness of the economic implications of the mismanagement of epilepsy.
- Better understanding of the condition through improved media coverage of people living with epilepsy and the issues they face.

lives with epilepsy without your help.

Our key people

Directors

Mrs Anna Walker CB

Chairman

Mrs Kathryn Cearns

(Chairman, Audit and Risk Committee)

Mrs June Davies

(Lead Trustee – Education, Chair of Education Governing Body)

Mr Michael Plant

Prof. J. Helen Cross

Mr Michael Sydney

(Lead Trustee – Trust Board Performance)

Mr Tony Chalkley

(Lead Trustee – Estate)

Mr Philip Hughes

(Lead Trustee – Finance, Strategy)

Mr Benjamin Osborn

Mr Angelo Rombo

(Lead Trustee – Better Futures for the 112,000, Equality and Diversity)

Mr Nigel Kennedy

Mr Michael Kirilloff

Dr Anita Devlin

President

Sir Gerald Acher CBE, LVO

Life Vice Presidents

Sir Bryan Nicholson GBE

The Rt. Hon. the Lord Howe of Aberavon

Chief Executive

Mr David Ford



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Download our FREE app: youngpilepsy.org.uk/app

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