



STRATEGY 2020 – 2025



Welcome to Young Epilepsy – the children and young people’s epilepsy charity.

We are excited to share our five-year strategy, which builds on our strong heritage of national expertise and innovation in the education, health and care of children and young people living with epilepsy.

The Young Epilepsy strategy is directly shaped by the voices and views of the children and young people with whom we work and is enhanced by a world-leading clinical research partnership with Great Ormond Street Hospital and UCL GOS – Institute of Child Health.



Why we exist

Introduction from our Chief Executive

We exist to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.

Epilepsy affects 112,700 young people in the UK and is one of the most common serious long term conditions in childhood. Two thirds of young people will be able to control their seizures over time with antiepileptic drugs or experience spontaneous remission. However, one third will continue to have seizures.

Epilepsy is symptomatic of a complex spectrum of conditions and no two experiences will be exactly the same. The common feature of these conditions is being prone to seizures – which are universally called ‘epilepsy’ or ‘the epilepsies’. The epilepsies, and seizures themselves, are varied in type, severity, frequency and cause.

Through clinical research, real advances are being made in our understanding of the underlying causes of epilepsy, as well as how they affect all aspects of a child’s life. Research presents a real opportunity to improve outcomes. However, health services can still be inconsistent in terms of access to specialist services, speed of diagnosis and adequate face-to-face support.

Beyond the seizures, there are higher rates of cognitive, developmental and behaviour disorders among young people with epilepsy, who are also four times more likely than their peers to experience mental health problems.

Many of these problems remain unrecognised or unsupported and result in academic underachievement or school exclusion. There sadly remains significant social stigma about the condition and many young people feel isolated and anxious.

Even though schools have a legal duty to support students with medical conditions, one in three children with epilepsy still don’t have an individual healthcare plan to ensure they are safe and included in all areas of school life. Young people with epilepsy face further challenges when moving away from home and developing their careers. They are faced with the fact that people with epilepsy are more than twice as likely to be out of work than their friends. So there is a huge need for information to improve public understanding, professional care and access to support for children and young people.

Young Epilepsy is at the forefront of advocating with young people for positive change in attitudes, across society, and towards greater understanding of the condition. We campaign for improved specialist support for children, young people and their families in our national health, education and social care systems.

Mark Devlin, Chief Executive



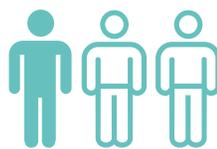
Forest school, St Piers

The challenges faced by children and young people

Epilepsy affects almost **6** in every 1000 children and young people.




Two-thirds of education professionals have received no training in how to support children with epilepsy in their care.



1 in 3

children with epilepsy don't have an individual healthcare plan at school.



Young people with epilepsy are **four times** more likely than their peers to have mental health problems.



Only 52% of people with epilepsy in the UK are seizure free. With the right treatment around 70% could be seizure free.



In 2018/19, **30%** of 16 to 24 year olds with epilepsy had their Personal Independence Payment (PIP) applications 'disallowed'.



Young people with epilepsy have told us that the lack of available information and support is a key barrier to becoming independent.

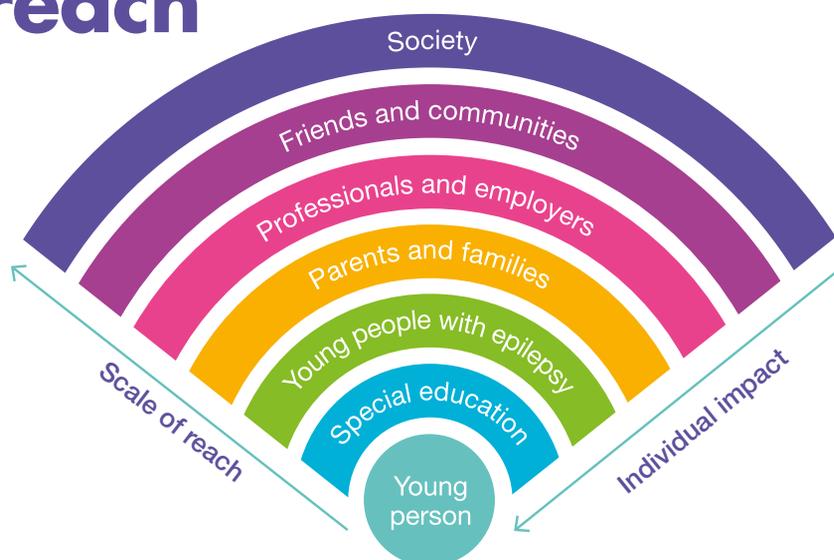


Children and young people with epilepsy say that the most important issues for them are support at school, support for worries and anxieties, and face to face support.

Young Epilepsy's impact and scale of reach

Young Epilepsy supports young people with epilepsy and their families, as well as the professionals who work with them.

We raise awareness of the issues facing young people with epilepsy to break down barriers and stigma in society.



How we work

Our five year strategy to 2025

Our new values



Young people are at the centre of everything we do

- Our work is driven by the experience and voices of young people.
- We support young people to be advocates for change.

We work together to make a greater difference

- We believe a culture of partnership and collaboration is the best way to achieve positive lasting change for young people with epilepsy.

We are courageous and ambitious for change

- We promote and uphold the rights of children and young people with epilepsy.
- We campaign for their voices and best interests to be respected.

What we do

Our offers



Information



Health



Learning



Research

Our offers



Information

We equip young people with knowledge and promote public awareness

- Our digital information service will enable young people with epilepsy to access information, advice and support, wherever they are.
- Our app will help young people to improve self-management of their condition and record the data clinicians need to accelerate diagnosis and improve treatment.
- Our parent and sibling events will connect families affected by epilepsy, equip parents with the knowledge to advocate for their children's health and education, and give them an insight into what it's like for a young person living with epilepsy.



Just days before his 18th birthday, Renell collapsed. He was diagnosed with epilepsy.

“Through Young Epilepsy I found the courage to face up to epilepsy. I now don't see it as a burden - it's part of me, and it's made me a better version of myself.”



“I remember hearing myself bang on the floor. Next thing I know there were two paramedics standing over me. It was scary, not knowing what just happened. Everything was normal up until that point.

“It was hard to accept the epilepsy. I had no control over it. It made me sad. I didn't know where life was going. There was this uncertainty about the future.

“Everything that I had taken for granted was being taken away from me: my football, my career, driving, hanging out with my mates. I lay in my hospital bed and the realisation about what was happening struck me hard. I hadn't taken into account how my epilepsy was affecting those around me: my parents, my brother and sister, my friends, my club. They were as scared as I was. But I wanted to be treated in the same way they had always treated me, even though things were challenging.”

With the help of Alex, a Specialised Case Worker at Young Epilepsy, Renell was able to talk about his fears and frustrations with someone who really understood him. By allowing Renell to express his feelings through therapy, practical support and everyday conversation, Alex enabled Renell to face up to the changes he needed to make to get his life back on track. Alex also worked with Renell's family and football club to help them with practical and emotional strategies needed to support Renell.



Health

We drive improvements in healthcare and advocate for young people's right to the highest standards of health

- We will campaign with young people and families for mental health support to be a priority.
- We will deliver training to support healthcare professionals working with young people with epilepsy.
- We will deliver innovative clinical services, including home-based telemetry and a magnetoencephalography (MEG) brain scanner.
- We will campaign with young people and families for more epilepsy specialist nurses.

Axel is a devoted musician living with epilepsy. At the age of 16 he was diagnosed with juvenile myoclonic epilepsy, Axel has managed to control his epilepsy through medication.

The music industry demands very late nights and Axel's main trigger is sleep deprivation. He risks his health on a daily basis to do what he loves.

"This is my career choice and I forge forward with it... my family are concerned for my future. My friends are supportive and stand by me but I think they find it difficult to relate to the condition. Unless you suffer with it or are involved with someone who does, it's difficult to understand... I can struggle with feelings of depression."

“I won't stop doing what I love for a living or let epilepsy define me.”





We deliver innovative education services and advocate for young people with epilepsy's right to an education

- We will campaign with young people and families for young people with epilepsy to be safe and included in all education settings.
- We will expand our Epilepsy Friendly accreditation to more schools, nurseries, colleges and universities.
- We will provide epilepsy awareness training and resources for education professionals.
- We will pioneer improvements in the education of young people with epilepsy and special educational needs through our St Piers School and College and beyond.



Olivia, a 22-year-old university student, first experienced the significant impact of absence seizures from the age of 11.

"When I was younger my teachers thought I was naughty and not listening to them but I was having absence seizures. It's not like daydreaming – it's like having a bad nightmare that leaves you feeling drained and needing to sleep. I have other types of seizures too but absence seizures are the worst for me because they are not obvious, can be embarrassing and many people don't know how to respond when I black out."

“Once we worked out the problem, my teachers and friends at school and uni have been so supportive and have helped me catch up when I miss parts of lessons.”



William is 20 years old and is a college student.

"My mum researched and found St Piers and showed me the college and asked me what I thought. I came for a visit twice and thought it was amazing as it was tranquil and peaceful.

"I would really like to be a plumber when I leave here and live independently in my own flat. The skills that I am being taught here will help with my aspirations. I am completing my Maths and English at Level 1 which will help me work towards my Level 2 which is the level I will need for plumbing. I am also learning about transition and what this means for me. Currently I am learning about first aid in the home. I go to an off site college to do cooking, which will help me when I move into my own home."

“Young Epilepsy has given me the opportunity to aspire to my dreams, which would not have been achievable if I had stayed at home.”





Research

We coordinate and fund research into the causes, treatments and impact of childhood epilepsy

- We will use this research to champion earlier, more accurate diagnosis; earlier, better treatment; and holistic, effective epilepsy services.
- We will raise the profile of our research to increase its impact.
- We will share our research with clinical experts, young people and the public, both nationally and internationally.
- We will use research evidence in every area of our work.



Our research programme is a collaborative initiative between Young Epilepsy, Great Ormond Street Hospital and UCL GOS – Institute of Child Health. The programme, currently in its 15th year, is led by Professor Helen Cross OBE, The Prince of Wales’s Chair of Childhood Epilepsy, and coordinated by Young Epilepsy.

“Young Epilepsy’s vision is to build a society where children and young people with epilepsy are enabled to thrive and fulfil their potential.

Our research programme exists to establish successively better outcomes by driving early diagnosis and intervention in every aspect of childhood epilepsy.”

Professor Helen Cross
OBE, The Prince of
Wales’s Chair of
Childhood Epilepsy



Key strategic enablers to deliver the strategy



Investing in our people

- **Creating the best workforce** in the sector through investment in our teams to positively change the lives of children and young people with epilepsy.
- **Leading and inspiring** an engaged and diverse team committed to delivering our purpose through a clearly defined organisational strategy.

Effective communications

- **Using expertise in digital channels** to optimise our impact for children and young people.
- **Driving the news agenda** for issues facing children and young people with epilepsy, through authoritative content and continuous dialogue with our stakeholders, supporters and new audiences.

Financial viability

- **Building solid income** streams to ensure we have a strong and sustainable future.
- **Delivering efficiencies** that provide real value for money, investing in what genuinely matters to children and young people.
- **Developing our estate** to meet our students' needs.

St Piers School and College

Expertise in special educational needs

St Piers School and College support children and young people with epilepsy and associated conditions, as day and residential students.

St Piers School is a caring, supportive, learning environment for children and young people aged 5 to 19.

The students are at the centre of everything we do. Our dedicated, enthusiastic and experienced staff provide first class support. The education, health, care and therapy teams work in partnership and we pride ourselves on having strong relationships in place with parents, carers and funders. This tried and tested approach ensures every St Piers student reaches their optimum level of achievement. The school is an incredible place for children with neurological conditions and behavioural difficulties to thrive, learn new skills, grow in confidence and make new friends.

St Piers College provides a warm, friendly and unique environment for students aged 19 to 25.

Many of the young adults we support have learning and behavioural difficulties as well as specific medical or physical requirements. At St Piers College they are able to thrive, thanks to a calm, structured, safe environment and the support of a team of highly experienced professionals. We don't believe college should only be about academic achievement. Instead, we place a huge emphasis on life skills and independent living, with the aim of making sure each of our students is happy and confident in meeting life's challenges.

#FacingEpilepsy

We place young people at the centre of everything we do, championing their voices.

In 2019 Young Epilepsy launched a new campaign called **#FacingEpilepsy** to ignite a conversation around living with epilepsy.

We hope this campaign will build a stronger community and a shared voice for young people with epilepsy across the UK and globally. The key message is that no-one should feel ashamed of their condition, and no-one should live in silence and fear. We are glad to be starting this collaborative movement with young people to share their lived experience, reduce stigma and increase understanding.



Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy (NCYPE). Registered Charity number 311877 (England and Wales)

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