Young Epilepsy

We’re here for you

Our strategy for 2025 to 2030

Why we are here

100K+

children and young people have epilepsy in the UK, 23 new cases are diagnosed every day

1 in 3

children and young people with epilepsy have seizures which cannot be controlled by medication

4X

more likely than their friends to struggle with their mental health

3 in 4

children and young people say living with epilepsy had a significant impact on their mental wellbeing

together we can change this...

The change we want to see

By 2030

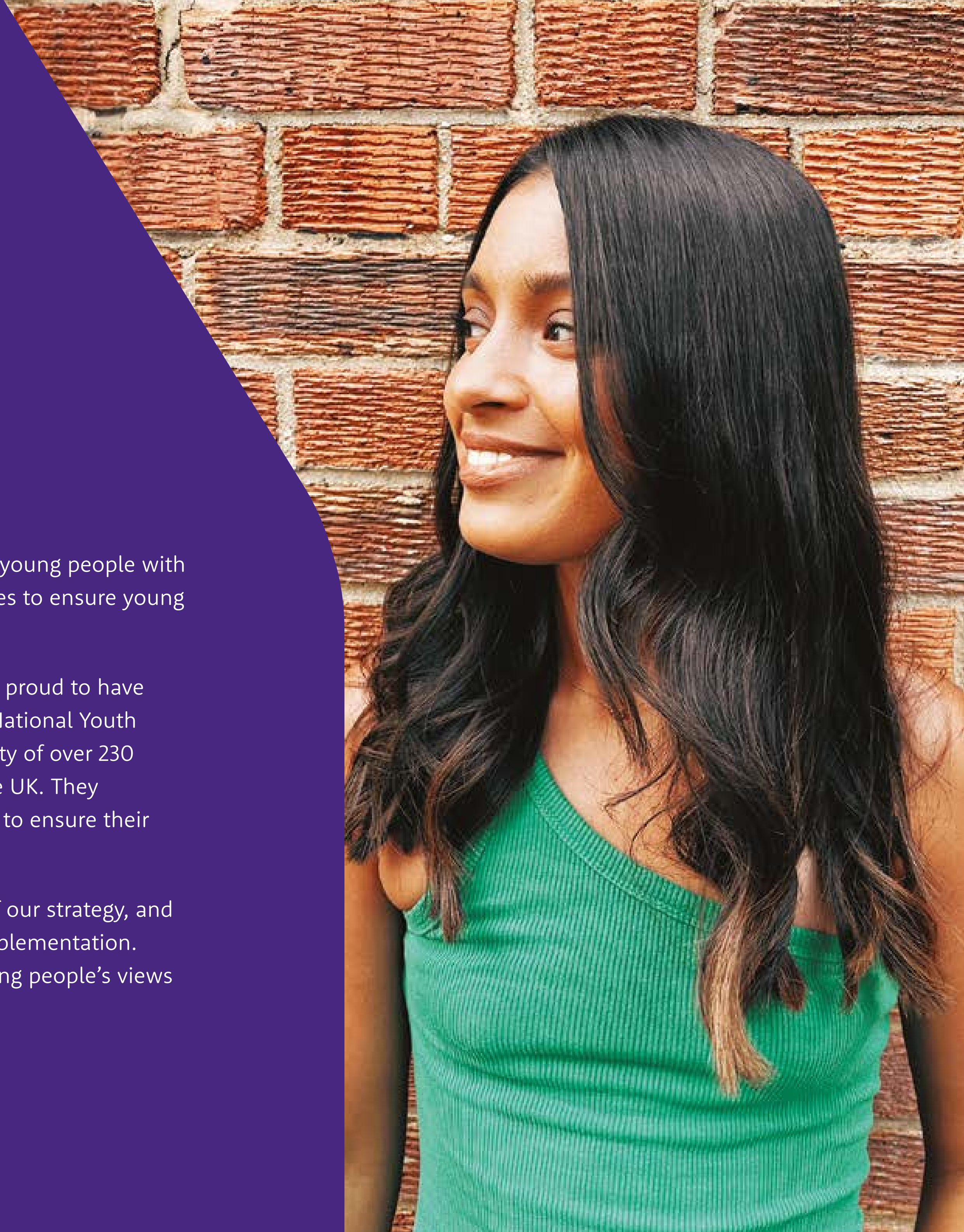
Every child and young person with epilepsy in the UK, or their care giver, can access the help they need.

We are led by young people with epilepsy

Listening to and understanding the lived experiences of children and young people with epilepsy is at the core of how we work. We are pushing the boundaries to ensure young people's voices are heard and their opinions respected.

Youth participation is fundamental to our work and Young Epilepsy is proud to have achieved Flagship status of the Hear By Right accreditation with the National Youth Agency. Young Epilepsy's Youth Voice Network is a growing community of over 230 children and young people with epilepsy, aged 13 - 25 from across the UK. They participate in projects across the organisation, and with our partners, to ensure their views and opinions influence our services and drive system change.

The Youth Voice Network played an active role in the development of our strategy, and we are in the process of developing a Youth Council to oversee its implementation. Young Trustees sit on Young Epilepsy's trust board, ensuring that young people's views influence the direction and management of the organisation.



Our Values

We work together to create a society where children and young people are not excluded because of their epilepsy.

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.

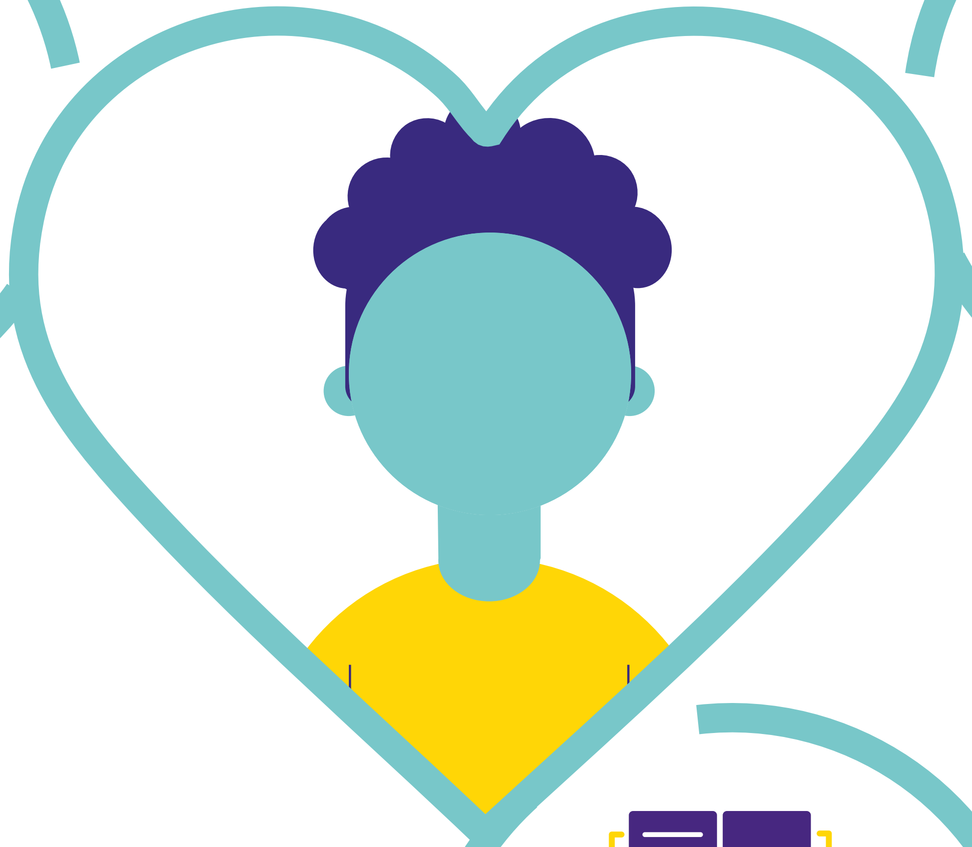
We believe a culture of partnership and collaboration is the best way to achieve positive lasting change for young people with epilepsy.

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.

Our Strategy

Me and my family gain confidence through information and support



My health and wellbeing needs are met

My education opportunities are inclusive

Programme One:
Me and my family gain confidence through information and support

For children and young people with epilepsy, and their families, access to the right information and support is essential. It builds confidence, reduces uncertainty, and helps them navigate life with epilepsy. Along with information and support, children and young people also need connection. They want to hear from others like them, see their experiences reflected, and be part of a supportive community.

This strategy will ensure that user led, high-quality, trusted information, support and community is accessible, engaging and inclusive. It will harness the power of digital connection to amplify the voices of children and young people. By improving resources and creating space for children and young people to share their own stories, it will enable them to thrive with epilepsy, not just manage it.

Our Vision for 2030

By 2030, all children young people with epilepsy across the UK will have access to information, support and community, delivered in a way that is relevant and meaningful to them. They will have a vibrant digital space where they can connect, share experiences and shape the conversation on epilepsy.

How We'll Achieve This

- We will research and then design a new, integrated model of support for children and young people aged 4 to 25.
- We will improve existing and develop new support products and services that meet the needs of children and young people throughout their epilepsy journey.
- We will develop co-created and user-led information that is trusted and relevant and accessible to all who need it.
- We will expand our digital reach, building a community for children and young people with epilepsy of all ages, where they can share their stories, build connections and find support.

Programme Two:

My health and wellbeing needs are met

Healthcare, research, and innovation must be shaped by the voices and lived experiences of children and young people. This strategy prioritises driving impactful research, influencing healthcare practices, and ensuring young people's needs are at the forefront of innovation.

Children and young people with epilepsy face significant challenges accessing mental health support. We have made good progress in this area and now there is an opportunity to stretch beyond campaigning, to ensure they receive the support, interventions, and advocacy they need.

Young Epilepsy played a pivotal role in the creation of the NHS England's Bundle of Care for children and young people with epilepsy. This set out standards for care in four key areas of focus in children's epilepsy care pathways. Now, led by young people's voices, we can influence lasting change in how epilepsy care is delivered across these priority areas.

Our Vision for 2030

By 2030, our research programme will have made meaningful progress in ensuring the best outcome for every child by optimising diagnosis, treatment, and support for all aspects of childhood epilepsy. Our partnerships will address the wider impact of epilepsy on their lives. Mental health support will be fully integrated into epilepsy care, and transition from paediatric to adult health services will become a well-planned and consistently supported process offered to all children with epilepsy as they approach adulthood.

How We'll Achieve This

- We will establish a programme of research that addresses the wider impact of epilepsy on children and young people living with the condition
- We will develop and expand our lived experience groups; to inform research and innovation ensuring young people and their families are involved at every stage of our research.
- We will increase the number of innovation partnerships and collaborations that align with our strategic objectives.
- We will strengthen and expand our programme of healthcare evaluations on the priority areas of the Bundle of Care, specifically Mental Health and Transition and use the findings to inform national policy and improve systems of care.
- We will grow the Youth Voice Network across the UK, so clinicians and decision makers can hear from young people in their area.
- We will review and improve our mental health and wellbeing support offer and define our role in this space.

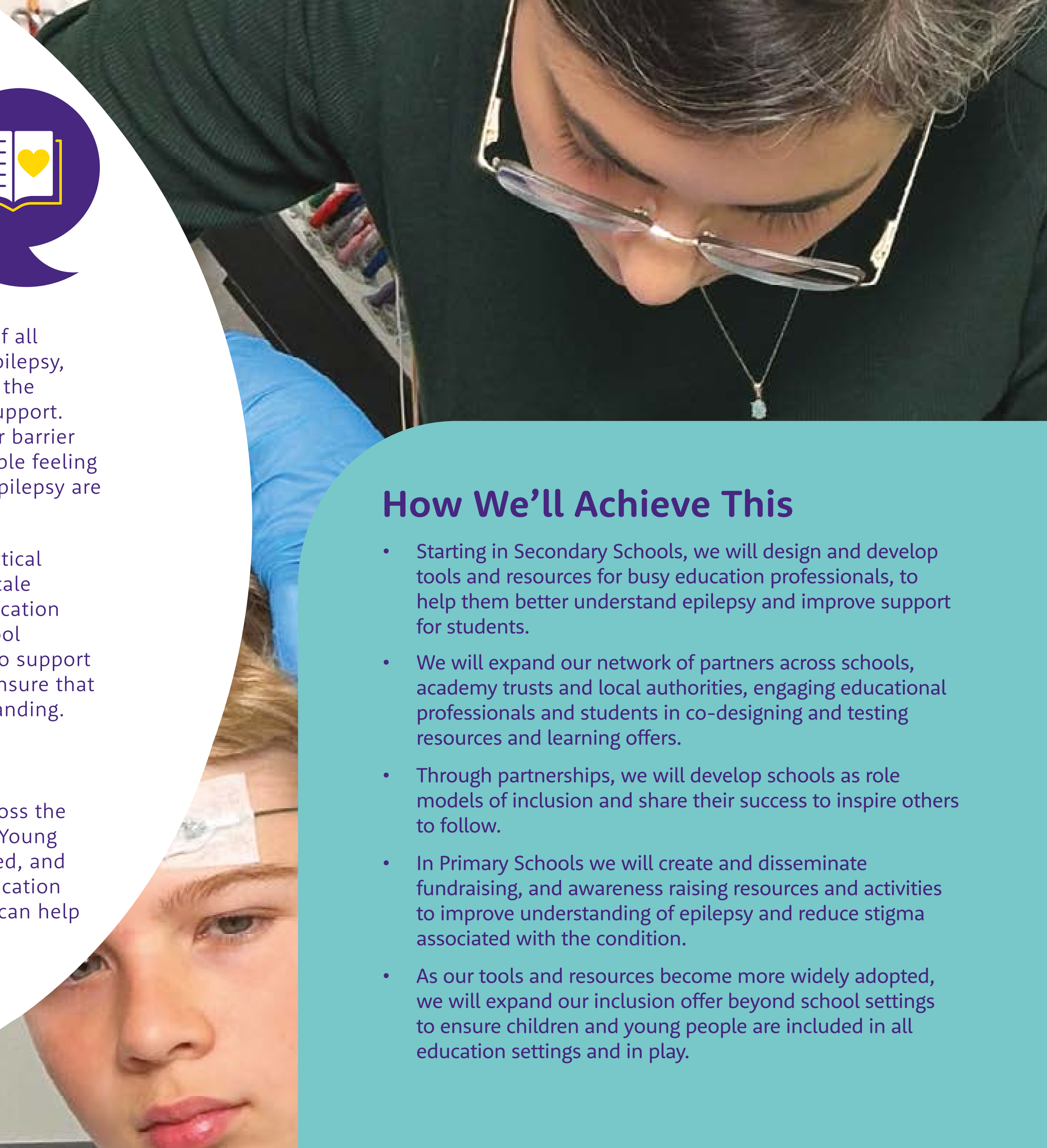
Programme Three: My education opportunities are inclusive

Education plays a critical role in shaping the lives of all children and young people, including those with epilepsy, yet many schools and education professionals lack the time, training, and resources to provide the right support. Misunderstanding of the condition remains a major barrier to inclusion, leaving many children and young people feeling isolated or unsupported. Too many children with epilepsy are missing out on childhood.

To create real change, we need to deliver both practical training and tools for educators and create large-scale awareness across schools and other youth and education settings. By equipping teachers, students, and school communities with the knowledge and confidence to support children and young people with epilepsy, we can ensure that no child's education is limited by a lack of understanding.

Our Vision for 2030

By 2030, epilepsy awareness will be embedded across the education system, and inclusion will be the norm. Young people with epilepsy will feel understood, supported, and empowered throughout their school and wider education journey and education professionals will know we can help them to better support their students.



How We'll Achieve This

- Starting in Secondary Schools, we will design and develop tools and resources for busy education professionals, to help them better understand epilepsy and improve support for students.
- We will expand our network of partners across schools, academy trusts and local authorities, engaging educational professionals and students in co-designing and testing resources and learning offers.
- Through partnerships, we will develop schools as role models of inclusion and share their success to inspire others to follow.
- In Primary Schools we will create and disseminate fundraising, and awareness raising resources and activities to improve understanding of epilepsy and reduce stigma associated with the condition.
- As our tools and resources become more widely adopted, we will expand our inclusion offer beyond school settings to ensure children and young people are included in all education settings and in play.

How we'll get there

Our strategic programmes clearly outline where we'll focus and why. In order to deliver our areas of focus, we will strictly follow a series of principles that direct how we work day-in and day-out, providing a strong foundational platform for our success over the next 5 years:

We always lead with the voices and experiences of young people

We will expand and strengthen the Youth Voice Network to ensure it truly represents the diverse experiences of young people with epilepsy, and amplify their voices to influence change.

We consciously collaborate and/or influence where we can't deliver impact directly

We know we're only one player in the epilepsy and broader healthcare and education ecosystems. As a result, we deliver impact at scale through our existing partnerships, while forging new partnerships in our strategic areas of focus. We convene and influence where possible so we're famous for and become the go to charity for those looking to incorporate the views and experiences of children and young people living with epilepsy. People with epilepsy, reaching marginalised communities, embedding co-production, and integrating peer support to foster deeper connections, empower young leaders, and amplify their voices for real advocacy and change.

Everything we do is based on evidence-based practice and research

Our work is driven by a commitment to evidence-based practice and the advancement of research. We will continue to conduct impactful studies that address the needs of children and young people, while strengthening collaborations with our research partners, including those led by the Prince Of Wales Chair of Childhood Epilepsy.

Vision

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

Purpose

To support children and young people with epilepsy to live ambitious and fulfilled lives

Where we’ll focus

Me and my family gain confidence through information and support

My health and wellbeing needs are met

My education opportunities are inclusive

What we’ll deliver

High quality, trusted and relevant information and support for children and young people and their families

Drive the healthcare, research and innovation agendas, putting the voices of children and young people front and centre

Best-in-class professional development and resources about epilepsy for education professionals

Increase digital reach to drive connection, peer support and awareness

Improve access to mental health support for children and young people with epilepsy

School-based awareness campaigns to improve understanding of epilepsy

How we’ll work

We always lead with the **voices and experience of children and young people**

We consciously **collaborate and/or influence where we can’t deliver impact directly**

Everything we do is based on **evidence-based practice and research**

We are Young Epilepsy

We stand up for children and young people with epilepsy. It is our job to listen to them and work with them so they can fulfil their potential.

www.youngepilepsy.org.uk

Young Epilepsy is the operating name of the National Centre for Young People with Epilepsy Registered Charity No. 311877 (England and Wales) @Young Epilepsy 2022