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 theUK,with23newcases diagnosed every day

1 in 3

children and young people with epilepsy haveseizures theycan't control with medication

3 in 4

children and young people say living with epilepsy greatly affects their mentalhealth

1 in 3

children and young people

with epilepsy don't getthe support they need totake part fully in life at school

Together, we can change this...

We work together with children and young people with epilepsy, their parents and carers, education and healthcare professionals, our partners and the wider public.

together, we create possible

The change we plan to see

By 2030

All children and young people with epilepsy in the UK will be a part of a community that gives them the support they need, when they need it. Their voices will be heard and respected. Healthcare services will meet their physical and mental health needs. They'll take part fully in all aspects of school life and be able to thrive.

Every child and young person with epilepsy in the UK, and their care givers, will know we're here to help.

Who we are?

We are Young Epilepsy

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

Young people with epilepsy will lead the strategy for change

Every child and young person with epilepsy has a unique story. AtYoungEpilepsy,

they tell us what they've experienced, and we listen. We make suretheirvoices are heard and respected, and their opinions taken seriously.

The Youth Voice Network is a growing community of young people with epilepsy from across the UK, aged 13–25.
Members of the Youth Voice Network get involved with the charity at all levels.

They help shape our policies, campaigns, products and services in support of the rights of children and young people with epilepsy.

They've played a lead role in developing our strategy for change in wider society.

As well as the work of the Youth Voice Network, two Young Trustees sit on Young Epilepsy's Board of Trustees. They directly influence the organisation's direction and how it's managed.

At Young Epilepsy, we're proud that the National Youth Agency has awarded us Hear by Right Flagship status. The award recognises that we listen to what young people with epilepsy have to say – and act on it.

But we aren't finished. As part of this strategy for change, we're introducing a youth advisory council, for children and young people ages 8–25. They'll help lead this strategy along with staff and trustees.

Our Values

Young people are at the centre of everything we do

Our work is drivenby theexperience and voices of young people. We support young people to be advocates for change.

We work together to make a greater difference

We believeaculture 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 for change

Vision

“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

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**

How we’ll get there

Ourstrategicprogrammes clearly outlinewhere we’llfocus and why. In ordertodeliverour areasoffocus,wewill followcoreprinciples thatdirect how we work day-inandday-out, providing a strong foundation for success over the next 5 years:

We’ll always lead with the voices and experiences of young people

We’llexpand andstrengthenthe YouthVoice Networktoensureittrulyrepresentsthediverseexperiencesof young people with epilepsy, and amplify their voices to influence change.

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

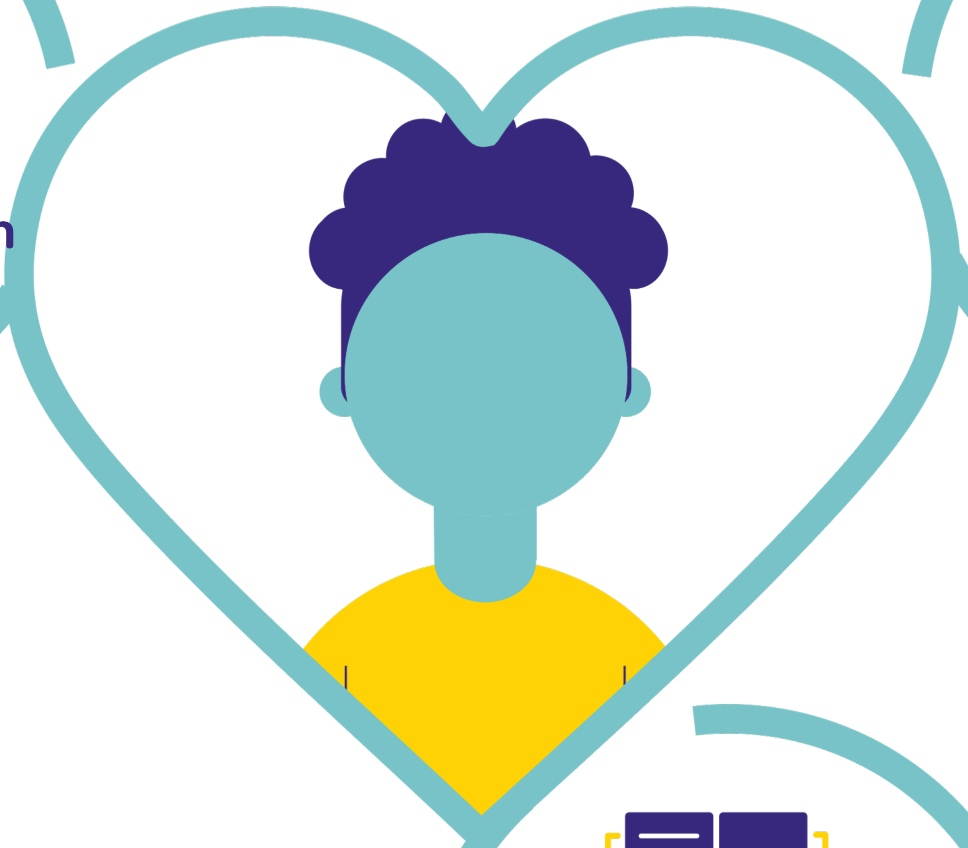
We know we’re only one player in theepilepsyandbroader healthcareand educationecosystems. Asa result, we’ll deliver impact

at scale through our existing partnerships, while forging new partnerships in our strategic areas of focus. We’ll convene and influence where possible so that we become the ‘go-to’ charity for those looking to incorporate the views and experiences of children and young people living with epilepsy.

Everything we do is guided by research and evidence-based practice

Ourwork isdriven by a commitment to evidence-based practice andthe advancementofresearch.We’llwill 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.

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

By 2030,children and young peoplewithepilepsy, their families and carers will be getting the right information and support.

The information will be easy to access and understand, for people of all ages, backgrounds and learning levels. It will be available to people with limited online access.

The information will be good quality and trustworthy, and developed in partnership with children, young people, their families and the professionals who support them.

Through group and one-to-one support, they'll understand more about epilepsy and how to live with its challenges. Through digital channels, they'll make their voices heard, share their stories and connect with others with the same experiences. They can be part of a community that supports them. Then, they can thrive with their epilepsy, not just manage it.

Our goals for 2030

1. Every child or young person who needs help and support can find us quickly and easily.
2. Every child or young person we support feels more confident about living life with epilepsy.
3. Every child or young person will know they're not alone. They'll be able to connect with others who live with epilepsy.

How we'll achieve this

To achieve our 2030 goals, we'll:

- research and design a model of support for children and young people aged 4–25, bringing together health information and group, one-to-one and community support – because for a child or young person with epilepsy, connecting with others who get it, is an impactful experience
- improve existing support products and services and develop new ones that meet the needs of children and young people throughout their epilepsy journey
- develop relevant, trustworthy information, shaped by users and easy to access by everyone who needs it
- expand our digital reach, building a community for children and young people with epilepsy of all ages, to share their stories, build connections and find support.

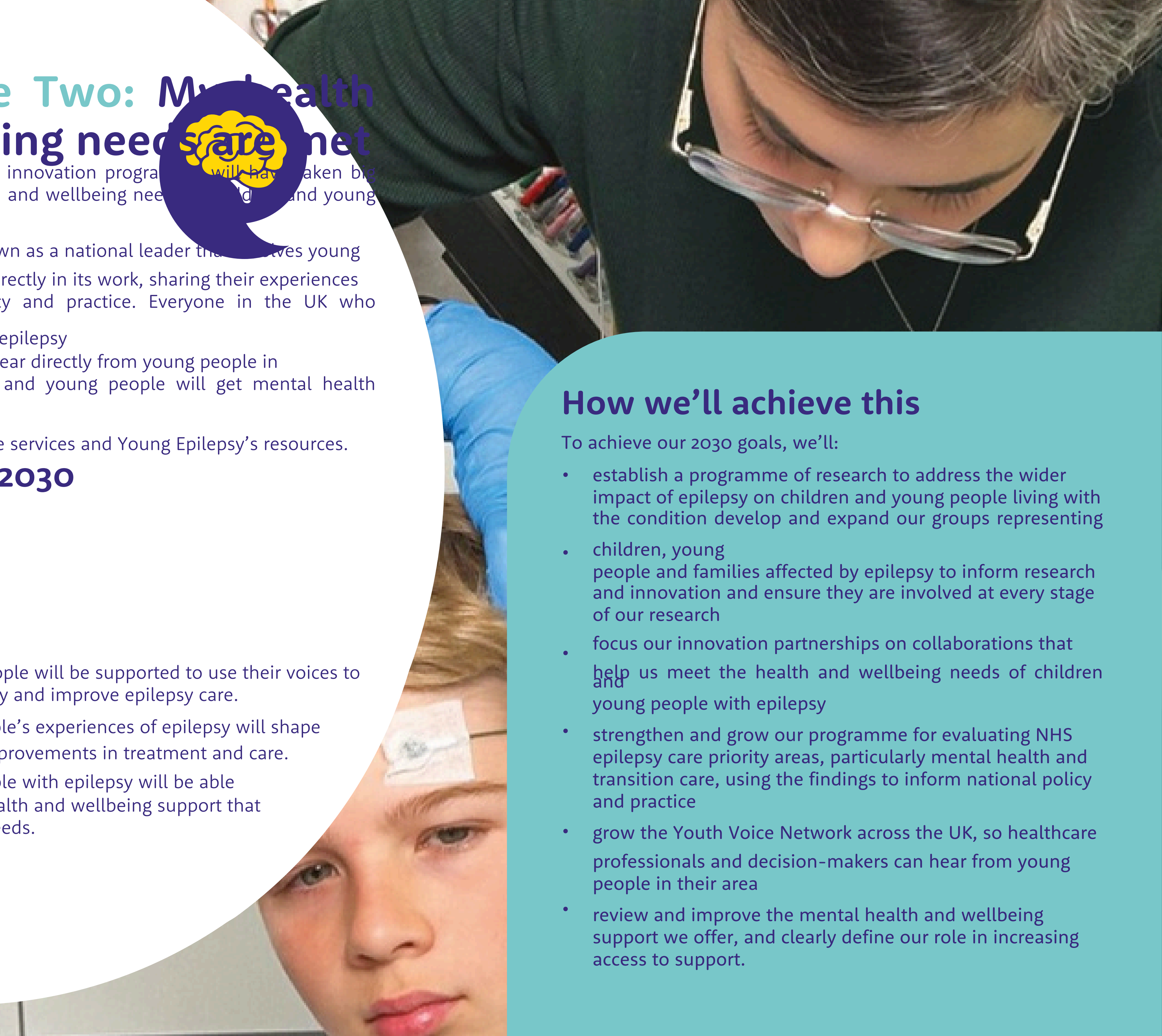
Programme Two: My health and wellbeing needs are met

By 2030, our research and innovation programme will have taken big steps to address the health and wellbeing needs of children and young people with epilepsy.

Young Epilepsy will be known as a national leader that involves young people and their families directly in its work, sharing their experiences to shape healthcare policy and practice. Everyone in the UK who influences decisions about epilepsy healthcare will be able to hear directly from young people in their area. More children and young people will get mental health support through epilepsy healthcare services and Young Epilepsy's resources.

Our vision for 2030

1. Children and young people will be supported to use their voices to influence national policy and improve epilepsy care.
2. Children and young people's experiences of epilepsy will shape research that leads to improvements in treatment and care.
3. Children and young people with epilepsy will be able to get better mental health and wellbeing support that meets their personal needs.



How we'll achieve this

To achieve our 2030 goals, we'll:

- establish a programme of research to address the wider impact of epilepsy on children and young people living with the condition develop and expand our groups representing
- children, young people and families affected by epilepsy to inform research and innovation and ensure they are involved at every stage of our research
- focus our innovation partnerships on collaborations that help us meet the health and wellbeing needs of children and young people with epilepsy
- strengthen and grow our programme for evaluating NHS epilepsy care priority areas, particularly mental health and transition care, using the findings to inform national policy and practice
- grow the Youth Voice Network across the UK, so healthcare professionals and decision-makers can hear from young people in their area
- review and improve the mental health and wellbeing support we offer, and clearly define our role in increasing access to support.

Programme Three: My education opportunities are inclusive

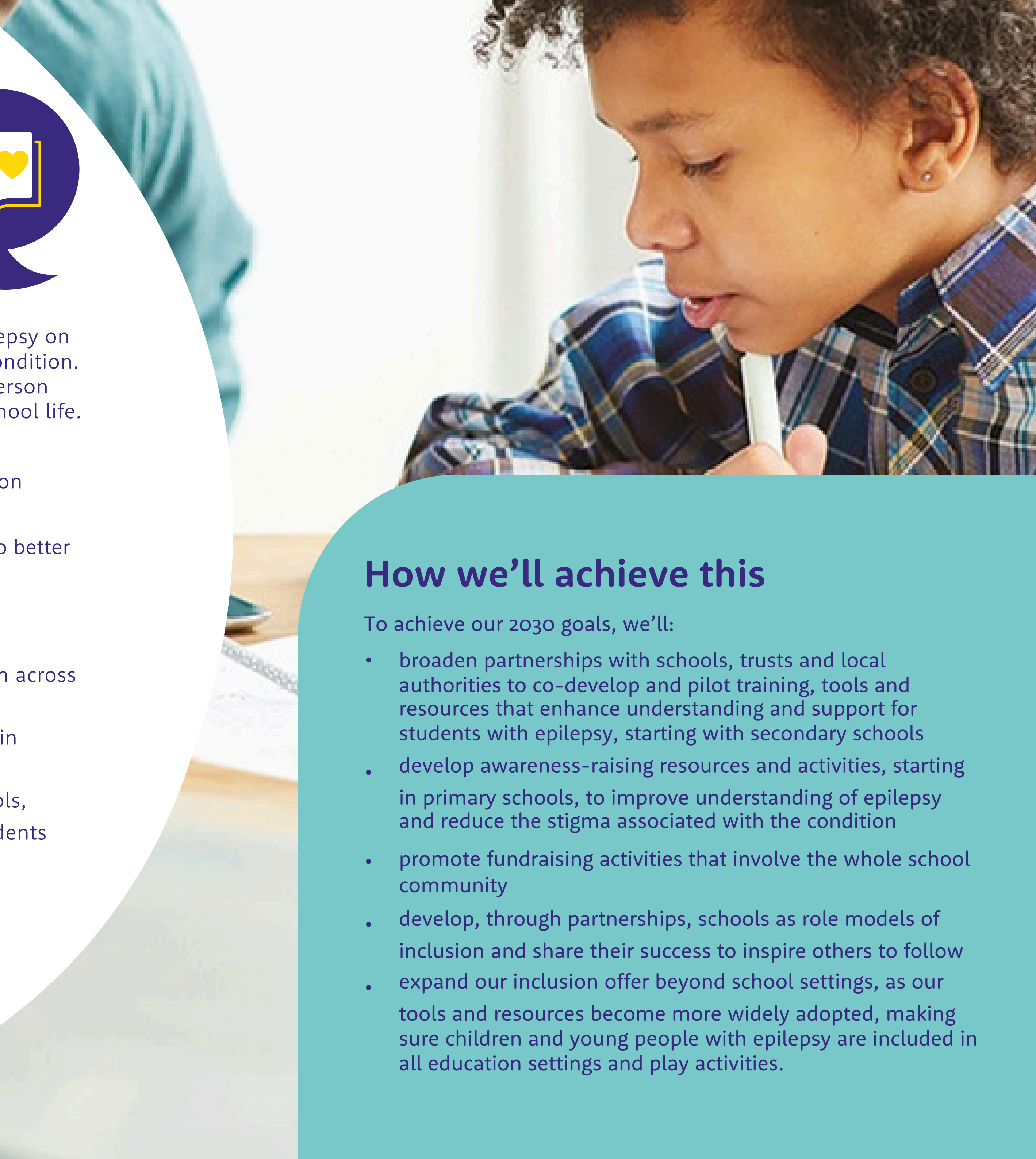
By2030, educators will understand the impact of epilepsy on students and will have improved knowledge of the condition. Inclusion will be the norm – every child and young person with epilepsy will take part fully in every aspect of school life.

Young people with epilepsy will feel understood and supported throughout their school and wider education journey.

Education professionals will know we can help them to better support their students.

Our vision for 2030

1. Epilepsy awareness and inclusion will be the norm across the education system.
2. Every student with epilepsy will be fully included in school life.
3. Education professionals will have the training, tools, resources and understanding to support their students with epilepsy.



How we’ll achieve this

To achieve our 2030 goals, we’ll:

- broaden partnerships with schools, trusts and local authorities to co-develop and pilot training, tools and resources that enhance understanding and support for students with epilepsy, starting with secondary schools
- develop awareness-raising resources and activities, starting in primary schools, to improve understanding of epilepsy and reduce the stigma associated with the condition
- promote fundraising activities that involve the whole school community
- develop, through partnerships, schools as role models of inclusion and share their success to inspire others to follow
- expand our inclusion offer beyond school settings, as our tools and resources become more widely adopted, making sure children and young people with epilepsy are included in all education settings and play activities.

No child should have to face epilepsy alone

When a child starts having seizures, their world can become full of fear. Once they get their epilepsy diagnosis, their world can fall part - knowing they have a long-term health condition for which there may not be a cure.

Epilepsy can be cruel - causing emotional turmoil that no child should have to face alone.

Often, families cannot access the support they need at this crucial time. Nearly every hour in the UK another young life is thrown into crisis. They need help. They need information. They need hope.

You can help them get the support they need.

Scan here to get involved

Email us **supportercare@youngepilepsy.org.uk** or call **01342 831245**

together, we create possible

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We are Young Epilepsy

www.youngepilepsy.org.uk

YoungEpilepsyisthe operating name of the NationalCentrefor YoungPeople with Epilepsy Registered Charity No. 311877 (England and Wales).

Young Epilepsy