A WORLD WITHOUT LIMITS

2024-2030 STRATEGY EPILEPSY ACTION

Contents

Setting the scene

Epilepsy Action has been fighting to improve the lives of people with epilepsy for over 70 years, and we've delivered some life-changing support in that time. But the recent feedback gathered from over 5,000 people impacted by epilepsy, and the evidence we have gathered across the years, demonstrates that we are not making the progress that is needed to improve the lives of everyone affected by epilepsy.

As we create a strategy post-pandemic, we know there are even bigger challenges within healthcare, and in society more generally, and that we have to be bolder and more ambitious in what we do.

Our central goals as a charity have not significantly changed, but the scale needed to achieve them, the focus we need to maintain on identified areas of work, and the ways we demonstrate the impact we are having, have changed, and this is at the heart of our 2024-2030 strategy.

By extending our reach, we will be able to support new communities and audiences and become a more inclusive organisation. We know that epilepsy has no boundaries, whether demographically or by location, and we also know that we need to be more effective in reaching into new communities and into areas of social disadvantage, and that will involve thinking big: ensuring epilepsy is as much in the public consciousness as other major health conditions.

let's talk about epilepsy

Creating a new strategy

Post-pandemic, we know there are things we can never predict that will impact on the development of the charity. This strategy is about setting out the ambitions we can deliver and demonstrating the impact we are having. Every year we will mark progress by analysing our performance through measures described in the section **How we will measure success (page 28)**, and make the changes needed to our strategy to achieve that success.

We have been through the review process of looking at:

- **where we are now**
- **our current strategy**
- **what people want us to do**
- **and how our teams will prioritise it**

The survey and feedback from over 5,000 people, representative of the groups we support, demonstrates we need to do more to reach people unaffected by epilepsy and to expand the services we offer to people with epilepsy.

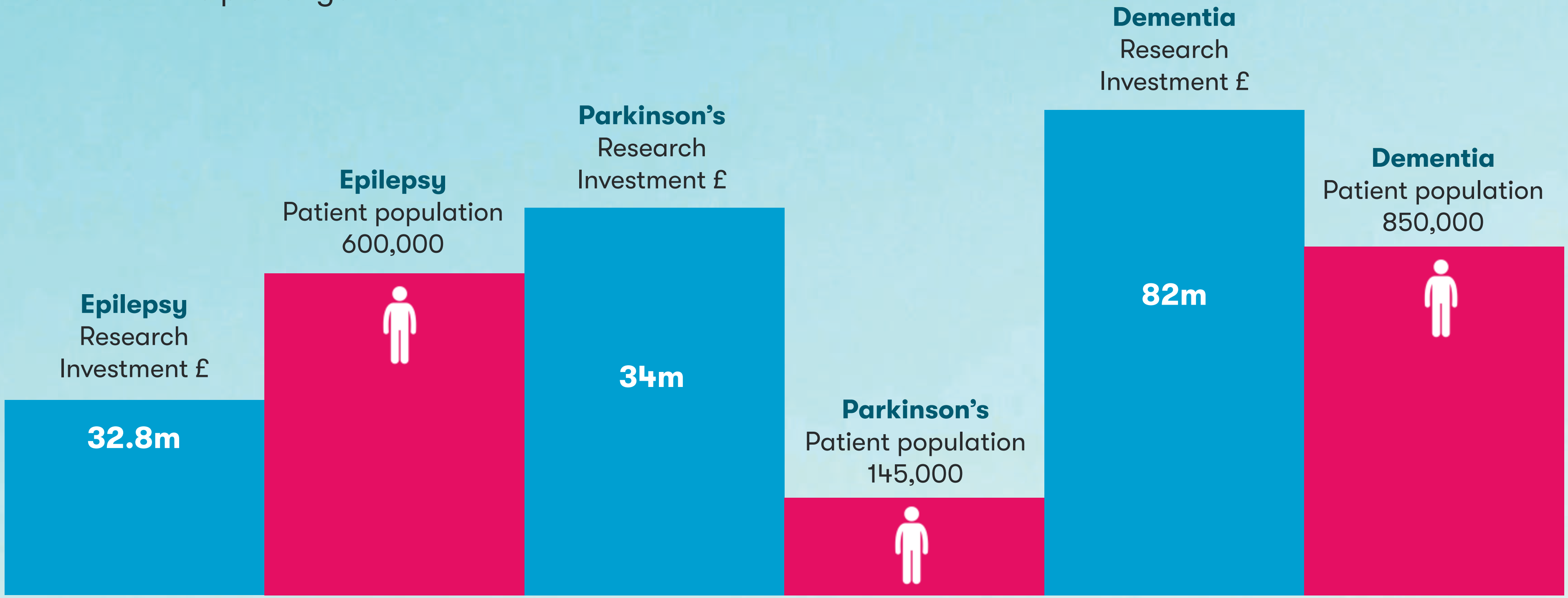
Quarterly, YouGov ask a representative sample of the UK population to name their favourite charities. With over 160 different entries, it demonstrates the variety of charities that we have in the UK – from animals to health, political extremes to religious focus. But there is no mention of an epilepsy charity in that list.

Creating a new strategy

The challenges of being a charity supporting epilepsy

We know around 1 in 100 people live with epilepsy – that‘s four times more than live with Parkinson’s and half the number of stroke survivors in the UK.

We know there is a chronic underinvestment in research and we are hopeful that the establishment of an Institute will help change that.



Amount of investment in research in 2022 v number of people with the condition.

Creating a new strategy

We know not everyone's epilepsy can be controlled by treatment but 7 in 10 people are able to control the condition through medication. We also know that there are side effects from medication and restrictions on day to day life that go unsupported and unrecognised.

We know that epilepsy can be a killer and around 500 people die every year from SUDEP (sudden unexpected death in epilepsy).

We know that in disadvantaged communities prevalence and incidence rates are at least 40% higher than in the least deprived areas.

We know that epilepsy effects all demographics, but that as the population ages we are seeing a growing number of older people developing co morbidities, including epilepsy.

We know that the unpredictability and social stigma around epilepsy can mean it is hidden. You rarely hear someone high profile talk about it in the same way as motor neurone disease or cancer.

We know that there are a number of medium sized charities supporting people with epilepsy, rather than one large one, which can fragment the message and the services on offer, and that to stop duplication we have to define our space clearly.

But we also know what other charities have achieved over the last decade or so grappling with similar dilemmas, for example MIND, Parkinson's, Versus Arthritis, MND. So we know there is real potential to raise the issue of epilepsy and to grow if we learn from these successful charities.

Our vision

Our previous vision:

We want all people affected by epilepsy to receive the healthcare and support they need and the public respect, fairness and understanding they deserve.

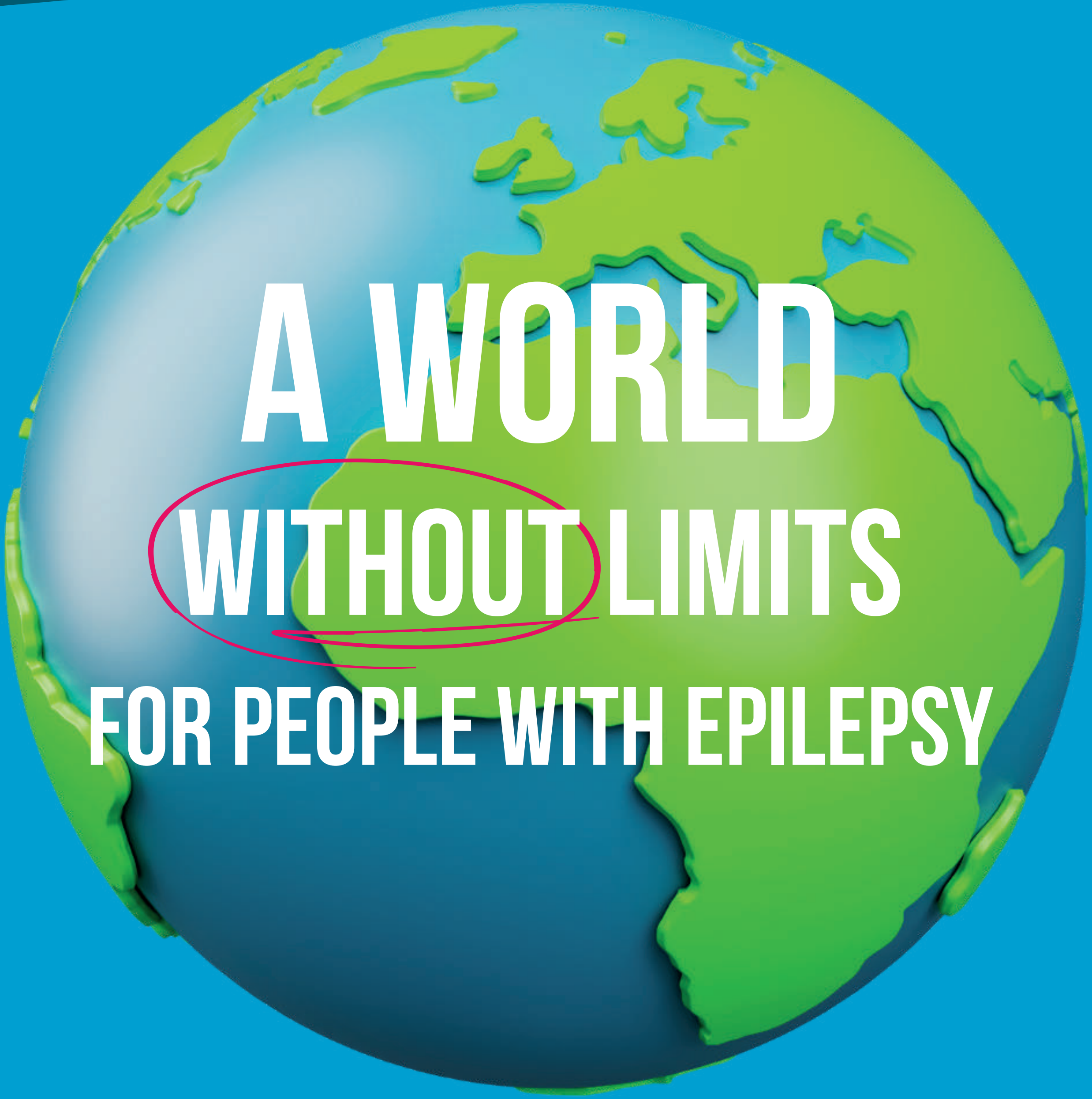
Our previous mission:

To strive to improve the lives of everyone affected by epilepsy.

There is an overwhelming view from our community that central to supporting people with epilepsy is making sure everyone understands it. This increased public awareness will be a contributing factor to their lives improving. Our previous vision and mission do say these things, but we felt that the mission sounds more like a vision and that there needs to be something bolder about the way we present it.

With that in mind we have found a vision that is more ambitious, aspirational and inclusive. It also positions us as the charity that supports people who are living with epilepsy.

Our vision



A WORLD WITHOUT LIMITS FOR PEOPLE WITH EPILEPSY

Our values

Our values need to reflect the strategic aims of being inclusive and ambitious, and to capture our dual role of offering support, but more importantly, moving to a role of empowering others. Being more ambitious and bolder was the clear message that came from people responding to our survey.

VALUES WE WILL MAKE A DIFFERENCE BY BEING:

AMBITIOUS

We will do whatever is needed to create a world without limits for people with epilepsy.

INCLUSIVE

We will be here for everyone affected by epilepsy.

EMPOWERING

We will put people with epilepsy in control of creating the world, community and life they want.

SUPPORTIVE

We will be by your side every step of the way.

Our values

Being ambitious

We will do whatever is needed to create a world without limits for people with epilepsy.

Epilepsy Action isn't just about making small changes; we're not afraid to think big to change the world for everyone affected by epilepsy. Our bold ambitions drive us to set courageous goals and constantly innovate to create sustainable positive change.

We will do this by collaborating with partners and developing successful services and initiatives to create lasting impact.

Being inclusive

We will be here for **everyone** affected by epilepsy. We will work with individuals from all backgrounds and communities, fostering a sense of belonging and equality in all we do.

In our community, all individuals, regardless of their backgrounds, identities, abilities, or circumstances, feel valued and respected to participate fully.

We know that inclusivity isn't about numbers; it's about embracing diversity and ensuring that everyone's voice is heard, needs are met, and contributions are acknowledged.

Being empowering

We will put people with epilepsy in control of creating the world, community and life they want. We will enable this by providing the platforms, tools, resources, and opportunities needed for them to achieve their full potential and create positive change in their lives and communities.

We empower our community to lead our work, whether it's our dedicated staff, volunteers, or the people we support.

Our values

Our culture is built on open communication and giving everyone a chance to make a difference.

We're here to enable people to take ownership of their individual journey and embrace opportunities.

Being supportive

Everyone's epilepsy journey is unique, and we will be there every step of the way, ready to support you when you need us.

While people with epilepsy will be in control of their journeys, they will not be alone. The Epilepsy Action team are here to listen, understand, and provide guidance when needed. Our goal is to create an environment where everyone feels valued and cared for.

OUR VISION:

A WORLD WITHOUT LIMITS FOR PEOPLE WITH EPILEPSY

OUR BIG 3 AMBITIONS

1. By 2030 everyone in the UK who has epilepsy will be able to say that life has improved because of the things we are achieving together.

2. By 2030 everyone in the UK will understand what epilepsy is and how they can support people who live with epilepsy.

3. By 2030 we will be fully inclusive in who we are and who we support.

Ambition 1: By 2030 everyone in the UK who has epilepsy will be able to say that life has improved because of the things we are achieving together.

People with epilepsy tell us they feel isolated, stigmatized, and discriminated against. These feelings are a combination of a general lack of understanding and the impact of the condition, the life changes it brings and the side effects caused by medication.

Anxiety, depression and memory loss are regular symptoms, and put alongside life changing restrictions, such as not being able to drive, employer discrimination and struggles in the education system, it is no wonder people with epilepsy feel the way they do.

But we know that life with epilepsy can be a positive one, and that your contribution to society needs to be celebrated. So we promise that we will help you by understanding the journey you are on and how we can support and empower you at all the different stages.

Ambition 1

Social Prescribing, also known as community referral, is when GPs, nurses and other primary-care professionals refer people who are experiencing issues that can't be fixed by medicine alone to local community groups and activities.

Goal 1:

We will address the issues of isolation for everyone who reaches out to us for support, by creating a route map to living your best life with epilepsy with recommendations that are tailored to you. This will take a holistic approach, looking at interests and characteristics, and be provided at whatever point you access our services, whether it is the helpline, support group or through the information on our website.

Measures of success:

- We will capture data that provides greater insight into providing the right support at the right time and helps us demonstrate the impact we have had. For example, postcode data will help us understand the increasing impact we are having on supporting people in areas of social deprivation.
- Every person who comes to Epilepsy Action for help will be able to say how the charity has helped them and the positive impact it has had on their life.

Goal 2:

We will support all healthcare professionals to understand the wide-ranging impact of epilepsy on people's lives and how to engage in Social Prescribing as part of a treatment programme. Our initial focus will be on developing relationships with GPs as well continuing to work with nurses and consultants. We will review the key areas of influence of our work, to take account of commissioning, new NHS structures, and changes in social care.

Measures of success:

- Every person with epilepsy who engages with a healthcare provider will be able to state that they have been dealt with in an informed and positive way.
- People who work with epilepsy will have an increased understanding of the impact medication and its side effects has on the lives of people with epilepsy (baseline currently tracking 15% lower than for people with epilepsy).

Ambition 1

Goal 3:

We will develop all our services with strategies for co-production, maximising reach and demonstrating a measurable positive impact. We will look for ways to innovate traditional services and empower people to take control of living their best life. Our "living well" services will improve understanding of the condition and provide access to a range of support measures needed to manage the practical and psychosocial complexities of life with epilepsy.

Measures of success:

- All people engaging with Epilepsy Action services will agree that Epilepsy Action offers the services needed to support them at all stages of their epilepsy journey or can signpost them to the right place.

Goal 4:

Collaboration with others is key. We will grow our impact by working with major charities where epilepsy is a comorbidity, for example Dementia, Alzheimer's, Stroke, Brain Injury, Parkinson's to ensure their staff are trained in epilepsy and can signpost people to our information and support. We will collaborate with major charities who can offer services that support the symptoms resulting from epilepsy and the side effects of medication. We will signpost to their support networks when we think the support they offer is more relevant and develop joint support networks, such as Neuro Cafes, that reduce isolation as well as pool resources and expand reach. We will also partner with organisations that work in underserved communities and who address health inequalities.

Measures of success:

- There will be a network of collaborative services across the UK that offer support for isolation, depression, memory loss and other identified issues that people with epilepsy want support with.

Ambition 1

Goal 5:

We know that most contact with Epilepsy Action is through our information pages, and we will make sure that we are the number one provider of up to date, evidence based and accredited information on epilepsy. We will create interactive tools that empower people to use our information and templates with health professionals, employees, public services and in any other space that they need it, to understand and challenge the support they receive.

Measures of success:

- We will find new ways of capturing data that demonstrates that our information is relevant and supports people in every aspect of their life with epilepsy. This will include a way of monitoring if people have been signposted to us by nurses and other healthcare professionals.
- We will regularly ask people to tell us what impact our information has had on living with epilepsy and cross-reference this with the communities we are trying to reach.
- By 2030, less than 5% of people surveyed will state that a priority of Epilepsy Action needs to be more information provided on medication and its side effects (baseline of 22%).

Ambition 1

Goal 6:

We understand that epilepsy is first and foremost a health condition, and while we can take action to support the impact of the condition, we need to recognise that everyone needs to receive optimum care and treatment for their epilepsy. We will therefore create a centre to improve the quality of the lived experience, and this quality improvement hub will work with the relevant partners to have one voice on policy relating to epilepsy in the political, social and health sectors. It will support the work of the new Epilepsy Research Institute UK in increasing research funding and getting epilepsy recognised as a major health condition.

Measures of success:

- A new joint policy and campaigning strategy for epilepsy rather than for individual charities.
- A new quality improvement centre for Epilepsy Action that is the voice of the lived experience and provides input into the new Institute, helping to turn research into services.

Goal 7:

We will create a digital space for people to share their experiences of companies, public services, technologies and medical experiences so that they can share the good and bad experiences with others and provide us with a listening space to help our focus on changing attitudes and reducing stigma. This will be a space for you to talk and for us to understand what needs to be challenged and changed.

Measure of success:

- Every year, this listening project will have a target set for the number of actions we take as a result of what we hear are the needs for training, campaigning or challenging medical practices.

Ambition 2: By 2030 everyone in the UK will have a positive attitude to epilepsy and understand how they can support people who live with epilepsy.

This ambition is about improving public understanding and attitudes to epilepsy: it is about the people who don't have contact with epilepsy in their lives. We have been told by people with epilepsy that this is the number one thing we can deliver because it has such an impact on their wellbeing and sense of isolation. By reaching beyond those experiencing epilepsy, we will help make day to day life better for people with epilepsy.

We know that stigma thrives where there is silence and we want epilepsy to be part of the public consciousness in the same way other major health conditions are. This will be achieved through a staged approach to reach our targets by 2030.

Ambition 2

400,000 people signed CALM's petition for government action on suicide. It resulted in the government appointing the world's first ever Minister for Suicide Prevention.

Goal 1:

We will focus on one major national campaign every year in National Epilepsy Week. This will be themed around understanding epilepsy and will bring together all the elements of our offer, including our fundraising. We will use bold messaging, challenging statistics and stories to engage the media and reach as wide an audience as possible.

Measures of success:

- Epilepsy Action will become a recognised brand that appears in external charity awareness surveys, for example YouGov and the Third Sector.
- An annual survey will gauge increased awareness about the key things we want everyone to know about epilepsy: the different types of epilepsy, the different causes of epilepsy, the impact it can have and the first aid basics.
- Target set of increased data captured of people who "have no connection to epilepsy".

Goal 2:

We will find new ways to embed epilepsy into our national media and culture, for example in high profile dramas, films, books and articles. We will work with major commercial partners to extend our reach into new communities and form campaigning partnerships with keys areas of the public sector, including public transport, police and prisons

Measures of success:

- Epilepsy will be highlighted through channels such as drama or fiction with a focus on storylines on the soaps and popular TV series. We want to see at least two characters across the main UK soaps living with long term epilepsy, representing the 1 in 100 that live with the condition.
- A major national commercial partner will work with us to raise awareness of epilepsy.

One example of a commercial partner extending the reach of a charity is the partnership Dove have with the World Association of Girl Guides on self-esteem and being body positive.

Ambition 2

Goal 3:

We will use a growing public consciousness to call out for people in the public eye to come forward and speak about their experiences of epilepsy, so that by 2030 there are a group of high profile celebrities and influencers leading this conversation. We will normalise the conversation by capturing the openness of the younger generation to talk, meet them in their digital spaces and target influencers as advocates.

Measures of success:

- There will be a number of high profile names spearheading our national campaigns.
- We will use fundraising events, such as the London Marathon and Doodle Day, as well as campaigning and media campaigns, to target celebrities and high profile individuals to support us.
- A target will be set for extending our reach in digital spaces via the communities of influencers.

Goal 4:

We want to see a reduction in discrimination in the workplace through a wider understanding of the value of training and support for staff. We will invest new resources in both face to face and eLearning training, with a primary focus on training programmes for employers and their employees that will increase awareness and reduce stigma. Our primary targets will be based on maximum impact and include major transport companies and public services. As part of this we will acknowledge they are “epilepsy friendly” and partner with existing disability and mental health schemes to incorporate epilepsy learning into their assessments

Measures of success:

- 20% of all UK private sector businesses with 250+ employees and 50% of public sector organisations will have completed epilepsy awareness training.
- Epilepsy will feature in all the national training programmes for disabilities.

The Disability Confident Scheme has over 18,000 businesses and organisations signed up. There is currently no mention of epilepsy.

Ambition 2

Goal 5:

We will proactively target local online community networks to reach out to new people to explain the impact of epilepsy, rather than wait for people to come to our digital channels. We will use national platforms, such as Healthwatch, to increase our reach into diverse communities.

Measures of success:

- There will be a network of volunteers and supporters across the UK accessing their local digital spaces to highlight key messages about epilepsy and look for non-digital community spaces to reach older people.
- Annual surveys will highlight a more diverse and larger group of respondents to questions.

Ambition 3: By 2030 we will be completely inclusive in who we are and who we support.

There is no point delivering our first two ambitions if we are only reaching certain communities. We understand that communities come in many shapes and sizes and that some are more definable than others. But we also know that there are some key communities that we have evidence we are not currently reaching, and they are often the most at risk in terms of isolation, discrimination and social barriers.

We also understand that we need to demonstrate that everything about our organisation, culture and ways of working defines us as an inclusive charity: if we are unable to do that we will never achieve inclusivity in our strategy.

Ambition 3

Being inclusive in the communities we support

We will continue developing our relationships with…	We will build stronger relationships with…	We will achieve this by…
Our traditional demographics - primarily white, female, middle aged	Older people, men, and people from ethnically diverse communities	Using interests, online and physical spaces to target the demographics we are currently not reaching
Our own social media communities	Local online community groups and influencers	More proactive work in accessing other networks rather than relying on our own
Healthcare professionals, in particular Epilepsy Specialist Nurses, Consultants and Care professionals	GPs with special interest in epilepsy and comorbidities, and pilot new approaches to embed epilepsy into curriculum and training for healthcare professionals	Highlighting to healthcare professionals the need for a more holistic approach to treatment. Providing support information around the delivery and prescribing of medication and support services
Communities in Wales, Northern Ireland and England where deprivation, healthcare, politics and culture create differences in experience of epilepsy	Areas of deprivation in England, such as the North East, and areas with diverse populations such as London	Extending existing and new services in these areas through grant funding and partnership work

Ambition 3

Being inclusive in who we are

We aspire to be a diverse workforce, but appreciate this is a narrow view of what being an inclusive charity means. We know that to be a truly inclusive organisation we need to be able to demonstrate that we are open, transparent and maximise every opportunity for people to feel part of our community. This needs to be demonstrated through the way we are governed and in our organisational ways of working.

Our governance

Our organisation is governed through a membership model where people currently pay a set amount each year to be a formal member of the charity, giving them access to certain communications and the right to vote for the leadership of the charity: the Council of Management.

The number of members has remained static over the last decade at 7,000 - 8,000 and in 2023 just 3% (237 people) of the membership voted for who they want to lead the charity. We know this is unacceptable when thousands of people engage with us every week, seeking online information, volunteering, fundraising or using our services, and to become a truly inclusive organisation we need more of those people to have a stake in the charity.

There are a range of ways to govern a charity.

MIND's constitution requires over 50% of the Board to have lived experience.

MS Society have the same criteria plus 50% are appointed to the Board.

Both have changed their membership model to ensure as many people as possible are defined as members and can vote.

Ambition 3

Many charities have changed their membership models, making membership more flexible and recognising that volunteers and regular donors have as much of a stake in the future of the charity as those paying for membership. We will look at creating a flexible membership model that moves membership from something transactional to an ongoing relationship with the charity and encourages more interaction with decision making.

The unique perspective that trustees who are experts by experience bring keeps us focused and prevents mission drift. We know that we need to combine this with identified skillsets that will move the charity forward in a challenging and technologically complex landscape. We will therefore explore what governance structure will be fit for purpose for the ambitions of the strategy and create a timetable for a comprehensive governance and constitutional review.

Our ways of working

Every step of the working journey will be tested for how **equality, diversity and inclusion** are put at the centre of our policies and processes. Our values will hold us to account in the behaviours we demonstrate, the people we recruit, the way we work with volunteers and the day to day culture of the organisation. A new organisational development plan will be developed so that by 2030 we can demonstrate that every aspect of who we are has created an inclusive community.

Transparency and honesty will be built into all our systems and communications. We will share up to date progress on what is working and what isn't in our public digital spaces; we will evidence the locations we are working in and the numbers of people we are working with; and we will be honest about the costs of the services we are delivering, acknowledging when it is better that someone else delivers a service, information or support. Our targets and measures will always include specific references to the communities we have identified that we need to do more to reach. For example, our social media content calendar will represent a broad range of interests and beliefs.

Ambition 3

Quality Improvement will be at the heart of everything we do: we will create change when we see it has a positive impact for people with epilepsy and the ways we empower them. We will ensure this happens by having a core team that review all elements of our work and it will involve co-production with our volunteers, professionals and other experts by experience.

Shared responsibility will be key to how our staff work: we will acknowledge that we are all fundraisers, all communicators and all here to support people with epilepsy. By doing so, “that’s nothing to do with me” will not be part of the way we work.

We will constantly look for ways to **empower** people, whether that is staff or people we work with and support. We will provide the tools that give everyone the ability to maximise their potential and extend their impact.

In April 2023 the Charity Commission released the report: Charities and their relationship with the Public.

It highlighted the growing trend for the public to be more trusting of local charities with a focus on volunteer led activities. It recognises that this makes it more of a challenge for larger charities, but recommends the way to deal with this is to be as honest and transparent as possible:

“A charity whose work is more readily understood and supported is also one which is more likely to be trusted.”

How we will measure success

There are four key things that we need to measure to know that we are achieving our goals:

1. **That we are increasing public understanding of epilepsy**
2. **That we are improving the lives of people with epilepsy**
3. **That we are reaching more diverse and underrepresented communities**
4. **That people want to engage with Epilepsy Action and help deliver these ambitions**

These measures will remain the consistent part of the strategy. What will not remain consistent is the objectives we focus on to achieve them. We see this strategy as providing a framework, but if the work we are doing does not impact on engagement growth, income growth, impact of services or an increase in public perception, we will stop doing them and reframe the strategy. We will do this through an annual review that these measures will support.

Let's Talk About Epilepsy ongoing survey

This will be a survey monitoring progress in how people feel about living with epilepsy and the impact we are having on that.

It will help us understand if the work we are doing on increasing public understanding is working through monitoring how people with epilepsy feel about the world around them and if they change the priorities they want us to focus on.

It will be a continuous survey, offered at every touchpoint with Epilepsy Action, and collated twice a year for review. The survey responses from the 5,000 people that inform this strategy will be used as a baseline along with the data we collect.

It will help us understand the gaps in who we are representing and where we need to refocus priorities.

How we will measure success

We will create a dashboard of the results that will be available on our website for all to view. As well as this marking our progress, and generating information for us to respond to, it will be available for others to use and it will provide transparency to our work.

Every year we will set any new objectives needed to achieve our vision.

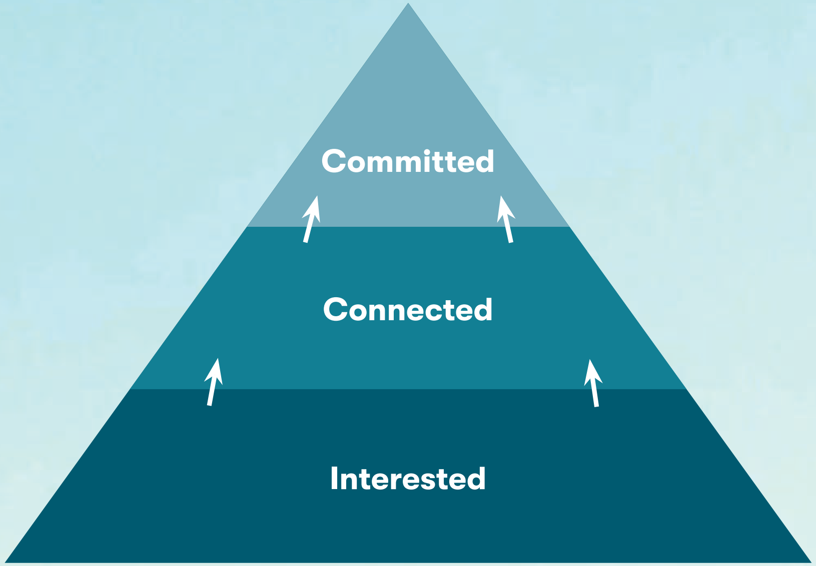
Let's Talk About Epilepsy longitudinal survey

This will involve the people who completed the original survey and have agreed we can keep in touch with them. We will use this group as a barometer for how things have changed by going back to them each year from 2024-30 to understand if our work has had any impact on their original responses.

The engagement journey with Epilepsy Action

We want people to engage with us as much as possible and we will measure this through the data we collect in our customer relationship management system (CRM).

Our target will be to move people up the engagement journey: from being actively interested, to being connected and finally being committed to our work. This will be an organisation-wide measure that will form part of everyone's performance reviews, and annual targets will be set for the data we collect, how many people we can to engage and at what level.



How we will measure success

Evidencing our impact

We will create one monitoring tool linked to the CRM and other sources of feedback, such as social media spaces, that provides a channel for all the feedback coming from our services and communications. This will help us understand in real time the key issues we need to react to and what is having a positive impact.

Additional measures

- From year two of the strategy we use external benchmarking to assess external brand awareness of the charity and measure awareness in diverse communities.
- We will measure engagement in our digital activities through key analytics and monitor the way our website is accessed and used.
- We will measure media activity through established reach metrics.
- We will measure the impact of specific services by value/improved quality of wellbeing.
- We will measure the effectiveness of our fundraising through return on investment.

What we need to deliver this strategy

We cannot achieve this strategy unless we can find ways to grow our income and get others to help us achieve the targets. There are therefore four key factors to delivering this work.

1. **Income generation strategy**

2. **Aligning our organisational culture**

3. **Growing our volunteers and advocates**

4. **Partnership development**

What we need to deliver this strategy

1. Income generation strategy 2024-30

Goal one

To maximise all fundraising income with a focus on growth in three core areas where there are new income generation opportunities with high growth potential.

Goal two

To develop an eLearning and training programme with a focus on employer engagement that generates income and creates major opportunities to develop partnerships for joint communications campaigns, sponsorship, advertising and charity of the year.

Goal three

To develop new strategies for data capture, and use digital and AI analytic tools in order to increase the conversion rate of people interested in the charity to people who are committed supporters.

While we recognise it is hard to budget for large increases in income, we know that it only takes the right fundraising activity or endorsement to change everything.

In 2016 the TearFund raised an additional £7.6m from a toilet twinning idea, and Movember has now raised over £600m in 17 years.

What we need to deliver this strategy

Goal one

To maximise all fundraising income with a focus on growth in three core areas where there are new income generation opportunities with high growth potential.

To ensure Epilepsy Action's future financial stability, the fundraising strategy will develop income streams with a particular focus on the acquisition and retention of regular giving.

Years 1-3 - we will realign our resources in line with the new strategy, with the goal of putting the building blocks in place to secure income growth that is consistent and reliable for the future.

Years 4-7 - we will learn from our successes in year 1-3 and will use these to accelerate income, while maximising the impact of increased public awareness as a result of the new strategic direction.

What we need to deliver this strategy

Where we want to be

Our new strategic goals mean we will have a wider audience of potential supporters, and we need to maximise the opportunities this brings through effective data capture and new income streams that focus on building a regular and reliable pipeline for the future. By doing this we are reducing the impact of external factors outside our control. Our primary targets are therefore:

Target 1 - Increase donor retention and giving

We will develop a strong donor engagement and stewardship plan which focuses on:

- Developing a donor-centric approach that builds strong relationships and personalised communications. We will utilise the CRM and AI software to understand the giving potential of our supporters and the best ways to communicate with them.
- Increasing the number of members who add an additional donation to their membership subscription.
- Implementing a new marketing strategy for building the legacy pipeline.
- We will run an annual cash to committed telephone campaign, and an upgrade campaign, every other year.

Target 2 - The acquisition of new supporters

- We will work with external fundraising agencies to recruit new regular donors using private site settings.
- We will target those most likely to give using data insight harvested from the CRM.

Target 3 - Developing corporate partnerships

- We will establish mutually beneficial corporate partnerships that offer a series of benefits to attract corporate support. Campaigns will not only raise funds but also enhance our brand reputation.
- We will recruit a new business lead fundraiser and set them ambitious targets for developing growth in this area.

What we need to deliver this strategy

Other areas for future investment/development

1. **Community fundraising** - alongside the new organisational volunteer strategy, we are also exploring the potential income generation from community fundraisers through fundraising volunteers.
2. **Sponsorship and advertising** - with a greater reach we will be able to deliver better sponsorship and advertising opportunities to corporate sponsors. Areas for development include website and eLearning advertising and fundraising event sponsorship.
3. **Trusts and Foundations** - In the last 3 years we have generated £750,000 in income from trusts for restricted projects. These have included projects such as the Befriending services, and Counselling in Wales and Northern Ireland.

We will work across the organisation to ensure any new or expanded service is assessed for the potential to gain trust funding before work begins and we will identify the potential for more fundable roles beyond those related to new services, for example in volunteer support and training.

What we need to deliver this strategy

Goal two

To develop an eLearning and training programme with a focus on employer engagement that generates income and creates major opportunities to develop partnerships for joint communications campaigns, sponsorship, advertising and charity of the year.

Where we are now

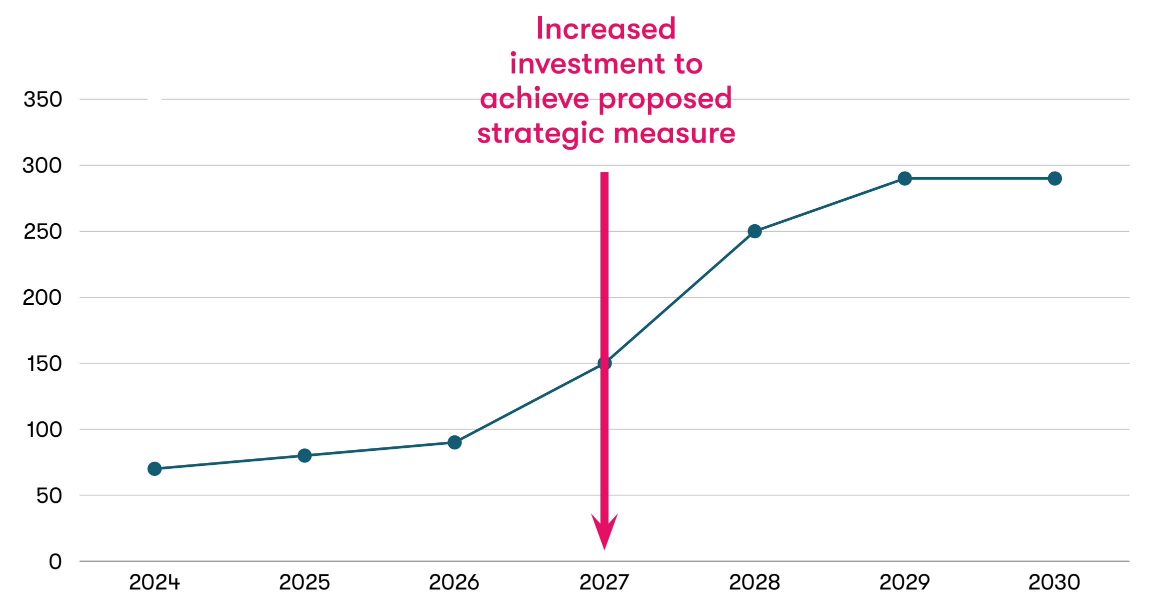
During 2023, we have been testing the market to understand the demand for training targeted at employers and employees. Our strategy has been to approach large scale organisations to maximise our reach, and we have already confirmed programmes with the English Football League that not only involves reaching the 72 professional football teams, but also the community teams that they support.

A new eLearning collaboration with a leading business software company means we not only reach their employees, but also have the potential of reaching the 47,000 organisations they provide management software for.

What we need to deliver this strategy

Where we want to be

To achieve our target of 20% of all UK private sector businesses with 250+ employees, and 50% of public sector organisations having completed epilepsy awareness training, we would need to train over 1,500 private sector companies, and over 750 public sector organisations by 2030. We will achieve this through two phases, the first being incremental growth and the second increasing our resources for significant growth:



Goal three

To develop new strategies for data capture, and use digital and AI analytic tools to increase the conversion rate of people interested in the charity and people who are committed supporters.

Where we are now

The last seven years have seen major investments in the development of systems and technology in a CRM and website. The last 3 years we have seen the biggest impact of that investment, with the launch of the new CRM system and new website in October 2022.

Both of these long-term investments have not reached a stage where they are demonstrating a return on investment.

But we will ensure that we are moving the CRM and website from systems that store data and information to systems that can drive new income.

Everything we do from this stage in terms of investment in systems will be decided on four criteria:

1. Does it deliver, in a measurable way, our new strategic objectives?
2. Does it generate income and a return on investment to support the charity?
3. Does it reduce expenditure?
4. Does it reduce our environmental impact and support more sustainable delivery?

What we need to deliver this strategy

The first stage of being an organisation that puts data at the heart of everything we do and ensures that staff understand its importance, is the organisational engagement measure in our strategic plan.

Where we want to be

We are proposing an acceleration of our data gathering strategy. As with the other parts of this strategy, we are predicting steady growth from 2024 to 2026 and faster growth from 2027 to 2030. From 2027 to 2030, we are projecting that our data gathering will increase 25% year on year. By 2030 this would mean we have a database of hundreds of thousands of engaged contacts who can both gain support from us and give us support.

What we need to deliver this strategy

2. Aligning our organisational culture

We need to put our "ways of working" into practice by creating and living the values that will make us successful. Collaboration will be at the heart of everything we do so that we make every contact count, whether that is financially or to increase reach. We need to develop sustainable relationships with those we work with rather than one-off interactions, and demonstrate our responsibility to a wider sustainability agenda by minimising our environmental impact and acknowledging our wider societal responsibilities.

We have created a more flexible workforce through hybrid working and new performance review systems to make sure people are clear about what is expected of them. We are already moving away from a rigid experience criteria to create a more diverse staff group that are employed because they share our values as well as having the skills we need.

We now need to make sure we are using our new systems to put collaboration at the heart of everything we do, both in the organisation and with the people we support. We want to be able to evidence how every relationship is being thought through as being sustainable rather than as one-off transactions and make sure this is a measure of performance. We also need to change the balance of our relationship with people with lived experiences and volunteers, demonstrating how we are embracing co-production and feedback in the way we respond to their input and stop doing things that are not working.

We now have the tools through a new CRM and website to really focus on data driven decision making. This means we need people to analyse and respond to data led information and this will become a key skill for our staff. We also recognise we will not always be able to recruit the level of skills we need to deliver new ways of working and we will look to external support to help us move forward.

What we need to deliver this strategy

We understand that as well as our commitments to our charitable purpose we also have a commitment to wider societal issues and this includes our environmental impact. We will therefore have a new policy that sets our clear targets for how we are going to achieve net zero emissions by 2050 and deliver the UK businesses target emission reductions by 2030.

What we need to deliver this strategy

3. Growing our volunteers and advocates

We cannot rely on staff alone to deliver this strategy. Grassroots delivery can only happen through volunteers and we need to make it as simple as possible for them to engage with communities, and that will mean looking at more informal delivery models. We will empower people with epilepsy to spread the word with family and friends, schools, workplaces or the places they visit every day, and understand that we cannot create widespread change without them.

Working in partnership with volunteers

If we are to have a real societal impact, we need to harness volunteers to help us deliver at the scale that will make a difference. We have spent time on systems and processes and creating capability amongst our volunteers, but now we need to focus on capacity, innovation and new ideas.

We need to design capacity into our current working to embed volunteers and therefore need to redeploy resources in the short term and look for funding to support expansion in the longer term.

We know that there is a need for face to face support but we will only be able to provide it on a national scale with the support of volunteers. With this in mind we need to simplify all processes and look at how successful grassroots organisations deliver with minimum resources. We also need to link into community networks rather than deliver ourselves. A new Volunteer Strategy has been developed alongside this strategy to meet the needs of expanding our network.

Working in partnership with advocates

As well as volunteers, we need people with epilepsy and their networks to understand that we cannot increase public awareness without their active support. We will develop tools for them to use that will help change attitudes, whether that is their GP, employer or school. As part of our annual monitoring, we will be asking people with epilepsy how they have helped spread the word, while understanding that not all people will want to do this.

What we need to deliver this strategy

4. Partnership development

We will do everything we can not to duplicate work and will focus on our areas of strength. We need to get much better at networking with our peers and recognising how much we need other charities and organisations to spread the word if we are to reach as many people as possible.

We will work with other charities to ensure we do not duplicate, remain focused on our priorities and extend our reach. Our key partnerships will include: **Epilepsy Research Institute UK:** as a founding partner and member of the board we will provide resources to ensure the voice of people with epilepsy is represented at every level of the research discussion.

Epilepsy Nurses Association (ESNA): a new joint membership scheme with ESNA will mean we are providing the information and training needed by nurses who are supporting people with epilepsy. We will also develop new tools to support nurses and provide joint bursaries to support relevant areas of work. We will look for ways to link into other nurse groups, in particular, paediatrics, maternity and learning disabilities.

Young Epilepsy: we will work together to create a journey that ensures there are no gaps in support for children, young people and parents.

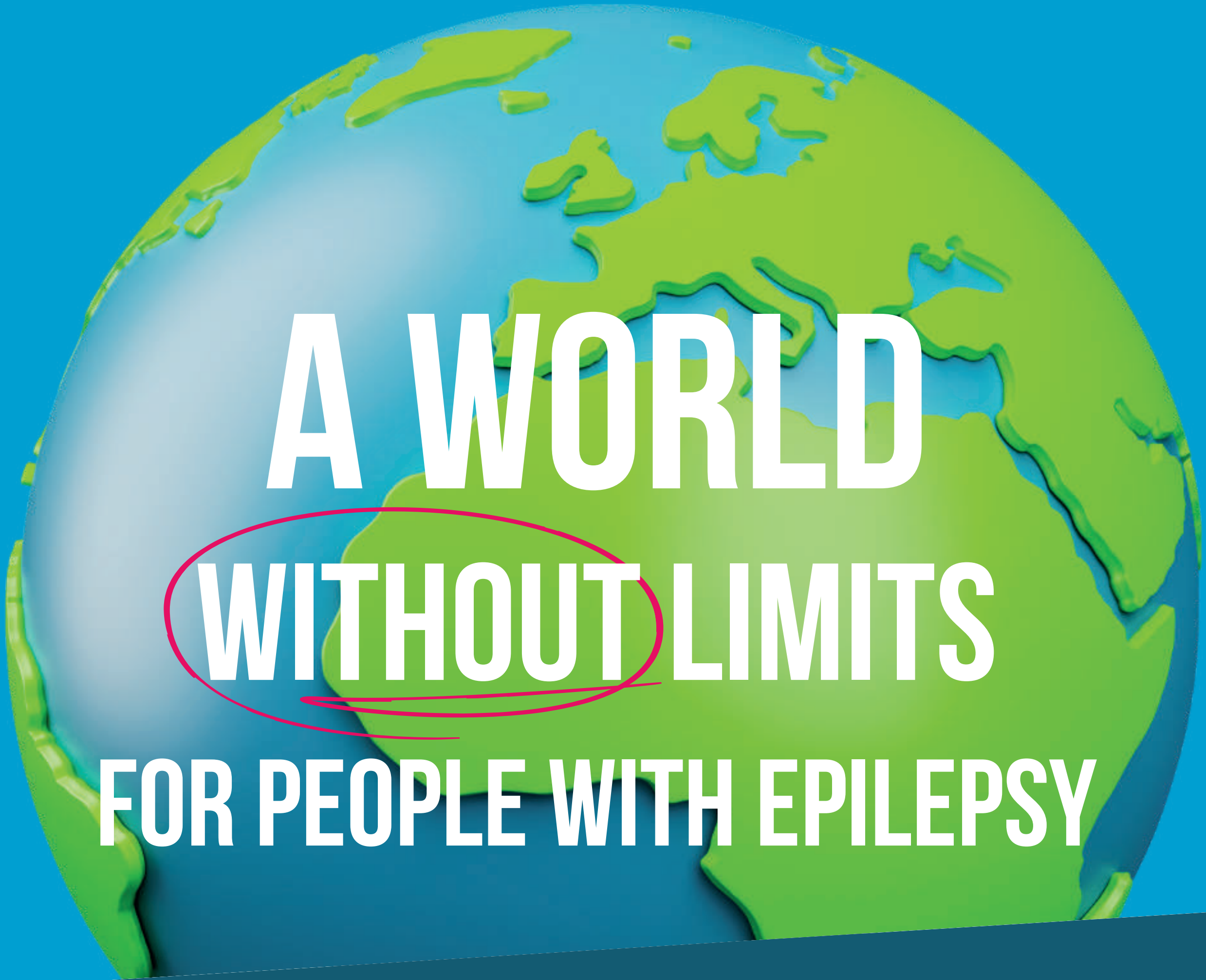
What we need to deliver this strategy

Neurological Alliance and all epilepsy charities: we will work to create one voice on epilepsy. We will identify opportunities to work with niche interest and lobbying groups when we think the partnership will be mutually beneficial.

Other charities: We will establish new collaborations with major national charities where comorbidities mean joint working is a positive experience. Each one will be established with the goal of getting epilepsy understood and supported by both staff and the people they support.

We will also work through targeted charities and public sector bodies to support the wider impact of epilepsy on everyday life, challenging barriers and fighting for change that will improve day to day living.

If we can realise the ambitions in this strategy, we will have achieved our vision of



A WORLD WITHOUT LIMITS FOR PEOPLE WITH EPILEPSY

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