

A photograph of two hands shaking, symbolizing agreement or partnership, set against a teal background. The hands are positioned in the center of the page, with the fingers interlocked.

# STRATEGIC PLAN 2022 - 2026

**WORKING TO ACHIEVE A SOCIETY WHERE NO  
PERSON'S LIFE IS LIMITED BY EPILEPSY**



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Developed with the support of the RTE Does Comic Relief Fund:  
- The Community Foundation for Ireland  
- RTE Does Comic Relief  
- The Government of Ireland



# INTRODUCTION

June 2022

**Cathy Grieve**  
Chairperson



**Peter Murphy**  
CEO



Thank you for taking the time to read Epilepsy Ireland's 2022 - 2026 strategic plan.

This plan is the culmination of a comprehensive 12-month process in which all those involved in our organisation and the wider epilepsy community took the time to reflect on the changing needs of people with epilepsy and how the organisation could best meet those needs.

We were also able to reflect on the ups and downs of the previous five years. In that time, we have responded to increased demand for our support, education and training services; taken major strides in improving public understanding of epilepsy; significantly expanded our advocacy activities and invested in world-leading Irish epilepsy research; all while maintaining both our financial wellbeing and the highest standards of governance.

Recent years have also been a period of unprecedented challenges. The last two years of our 2017-2021 Strategic plan were dominated by the impact of the Covid-19 pandemic, which sparked a period of great innovation in the work we do, how we do it and how we fund it.

Beginning our new planning process in mid-2021 against the Covid-19 backdrop, we were able to build on a year in which change became the norm and in which great confidence was found from tackling the array of challenges that presented.

It has been a rewarding and empowering process, exemplified by the enthusiasm and passion of everyone we engaged with. As you will read, our new strategic plan is centred on people with epilepsy and their families, reflective of the views of our stakeholders, and underpinned by our core values of **R-E-S-P-E-C-T** and by a new organisational mission.

Our plan is ambitious and unrelenting in its desire **to empower all those affected by epilepsy to achieve their full potential** and to achieve our ultimate vision of **a society where no person's life is limited by epilepsy**. The board, management and staff of the organisation are motivated daily by this great responsibility entrusted to us by the 40,000 people with epilepsy in Ireland.

While we can look forward with renewed clarity and ambition to the next five years, we also remain cognisant that Covid-19 is not yet fully behind us and there are new economic challenges emerging in the form of rising inflation, both of which mean that we also need to be measured and creative in how we invest in the tools needed to meet our five-year goals.

Resourcing our plan will be the biggest challenge and so we invite everyone with an interest in epilepsy to join us on our five-year journey. Meeting our goals will be a team effort and there are many ways to contribute. Reach out to us today to find out how YOU can help advance towards a society where no person's life is limited by epilepsy.

## THANK YOU

We are very grateful to the Community Foundation/ RTÉ Does Comic Relief: Adapt and Respond fund for supporting the development of this strategic plan.

We want to thank 2into3, who brought great expertise and experience in co-ordinating the process along with Paul Fahey (Board member) and Tara Smith (Director of Services) who joined us on the Strategic Planning working group to shape the many contributions into a robust strategy.

Most importantly, we would like to thank all those who participated in our stakeholder consultation process, in particular all the volunteers, members, staff, healthcare professionals, researchers and umbrella organisations whose contributions we hope are reflected throughout the final plan.

# WHAT IS EPILEPSY?

The word 'epilepsy' describes a group of disorders, all of which are characterised by recurrent unprovoked seizures involving abnormal electrical activity in the brain.

It is one of the most common neurological conditions, affecting an estimated 50 million people worldwide. With recent population growth, there are more than 40,000 people living with epilepsy in Ireland and there are an estimated 1,300 - 2,100 new diagnoses each year. It affects people of all ages, including an estimated 10,000 - 15,000 children under the age of 16. It is also more common in the elderly and in people with an intellectual disability.

In about 60% of cases, no specific cause can be identified. In the remaining 40% of people, common acquired causes include head injury, stroke, brain infections and birth defects. Genetics also plays an important role. Hundreds of genes have now been implicated in epilepsy. Some types are associated with a single gene but more commonly, it is associated with complex interactions between multiple genes and environmental factors.

Epilepsy is very much a treatable condition for the majority of people. Thanks to advances in medications and surgical techniques, up to 70% of people can become seizure-free. However, there are still up to

15,000 people living with uncontrolled seizures in Ireland today. For this group in particular, epilepsy can be a source of long-lasting, yet often hidden, disability. The condition can affect all aspects of a person's life including education, employment, social & family life, psychological & cognitive functioning, and independent living. People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications and for many, the social stigma and economic impact that can be associated with it. It can also have a direct and significant impact on the wider family unit.

There is also an increased risk of mortality associated with epilepsy with an estimated 130 epilepsy-related deaths in Ireland each year. Deaths may result from the underlying cause of the seizures, injury/ trauma, prolonged seizures or Sudden Unexpected Death in Epilepsy (SUDEP).

The financial cost of epilepsy is also significant. In Europe, more than €15 billion is spent annually on the treatment of epilepsy, a figure comparable to that of lung and breast cancer combined. Based on recent (2022) international data, Epilepsy Ireland estimates that the total cost (direct and indirect) of epilepsy in Ireland is c. €584m per annum, equating to almost €15,000 per person.



## WHAT IS epilepsy?

A NEUROLOGICAL CONDITION characterized by *recurrent seizures*

Seizures are due to *brief disturbances* in the *electrical functions* of the brain



## What is the IMPACT of epilepsy?

50 000 000

More than 50 million people are living with epilepsy globally

3-6 TIMES  
GREATER RISK  
OF PREMATURE DEATH

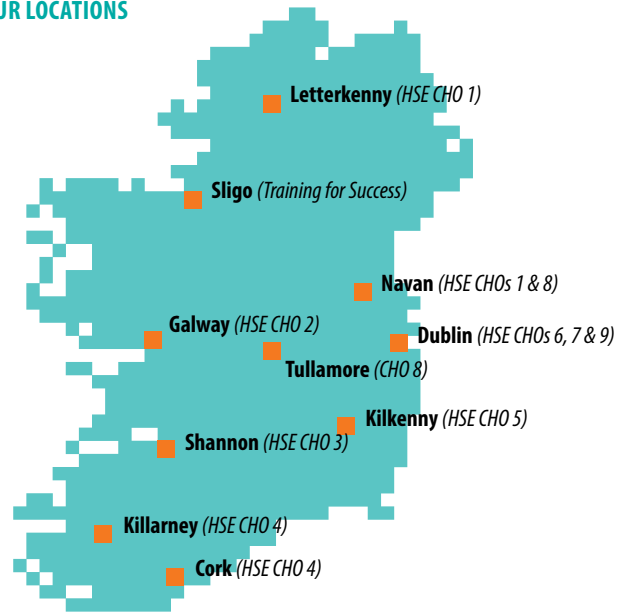
# ABOUT EPILEPSY IRELAND

Established in 1966, Epilepsy Ireland is the national organisation for those impacted by epilepsy, a neurological condition that affects over 40,000 people in Ireland.

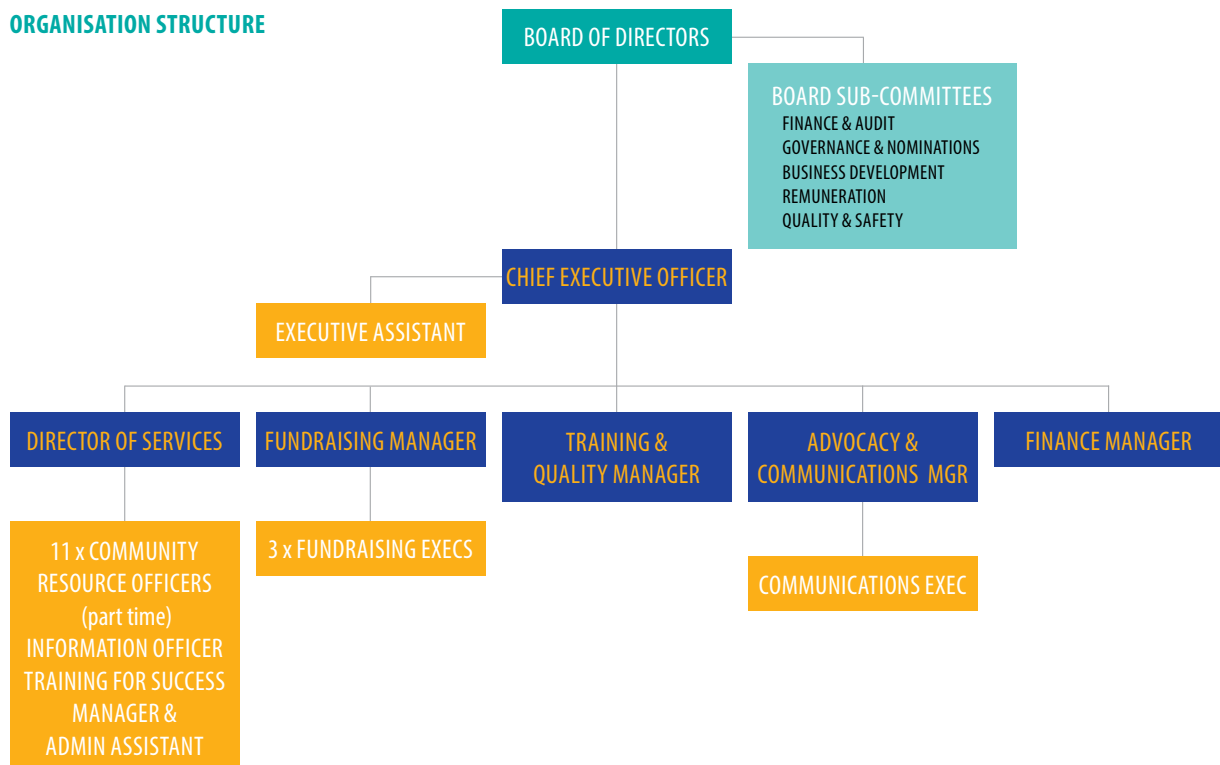
From our head office in Dublin and nine regional locations, we work to meet the needs of people living with epilepsy, their families and their carers through the provision of support & information services and educational & training programmes. We also work to improve public understanding of epilepsy, to advocate on behalf of the epilepsy community and to support and fund epilepsy research.

We are a registered charity, governed by a voluntary board of directors. Our work is funded through fundraised and earned income, as well as through state funding, the most important of which is HSE Section 39 funding which enables us to provide our community-based services.

## OUR LOCATIONS



## ORGANISATION STRUCTURE



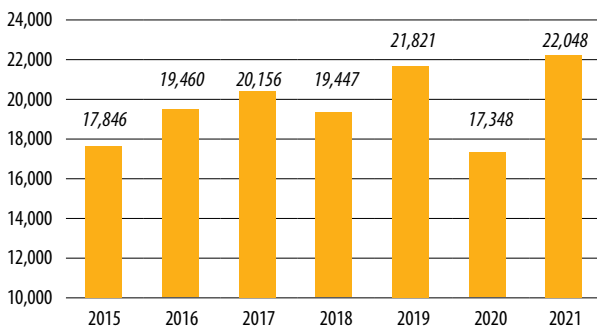
# EPILEPSY IRELAND IN 2022

## SUPPORT SERVICES

Our support services are primarily delivered by our regionally based team of Community Resource Officers. Over the period of the last strategic plan, the team have provided information, advice and support to people with epilepsy and parents/ carers of children with epilepsy through one-to-one and small group work. We also support service users in the self-management of their condition through our Living Well with Epilepsy Programme and self-management courses such as STEPS.

Other services include subject-specific talks, workshops and seminars; our annual conference, family activities and events for children & teens and personal advocacy support. As a result of Covid-19, many of these services were adapted for an online setting. A focus of recent years has been to work collaboratively with HSE epilepsy services on joint education programmes, in particular to assist patients with a new diagnosis of epilepsy.

**SERVICE USER CONTACTS 2015 - 2021**



## TRAINING & EDUCATION

Reducing and removing barriers for people living with epilepsy through our epilepsy awareness training in education and work settings has been an important element of our work over the last five years. We have also significantly grown our training programme in epilepsy awareness & the administration of emergency medication and developed guidelines on best practice for health care workers, teachers, disability professionals and others whose work brings them into contact with people with epilepsy. Our long-running Training for Success one-year QQI level 5 course for people with epilepsy continues to be an important pillar of our service, meeting education needs of up to 12 participants a year. The course is based at Atlantic Technological University, Sligo and funded by Mayo Sligo & Leitrim Education and Training Board.

## RAISING EPILEPSY AWARENESS

Significant developments in care for people with epilepsy, and increased public awareness and understanding about the condition, enable many with the condition to live full lives. However, stigma and misunderstanding are still common issues affecting individuals and their life experiences. We organise or participate in numerous awareness-raising campaigns throughout the year, addressing different epilepsy-related issues and targeting a range of audiences. In recent years, International Epilepsy Day, held in February has become the flagship event for Epilepsy Ireland with campaigns addressing epilepsy stigma, myths & misunderstandings and seizure first-aid to the fore. Other annual campaigns take place for National Epilepsy Week, Brain Awareness Week, Purple Day® and SUDEP Action Day. We also work to actively highlight epilepsy through the media, by expanding our social media presence and by promoting epilepsy awareness through our community-based team and training programmes.

**ADVOCACY**

Over the past five years in particular, championing the rights and needs of people with epilepsy has become an even bigger part of our work than in the past. By investing in new staff resources, we have led important campaigns on access to care & treatments, medication safety and risk reduction, education needs, online safety, and social protection entitlements.

**SUPPORTING EPILEPSY RESEARCH**

Epilepsy Ireland is committed to supporting high quality Irish epilepsy research that has the potential to add significantly to existing knowledge into the causes, cures, care, treatment, impact and effect of any type of epilepsy, including SUDEP. Over the past decade, we have invested over €1,000,000 in a wide range of projects (basic, clinical, psychosocial and health services research), many in conjunction with the Health Research Board and Irish Research Council.

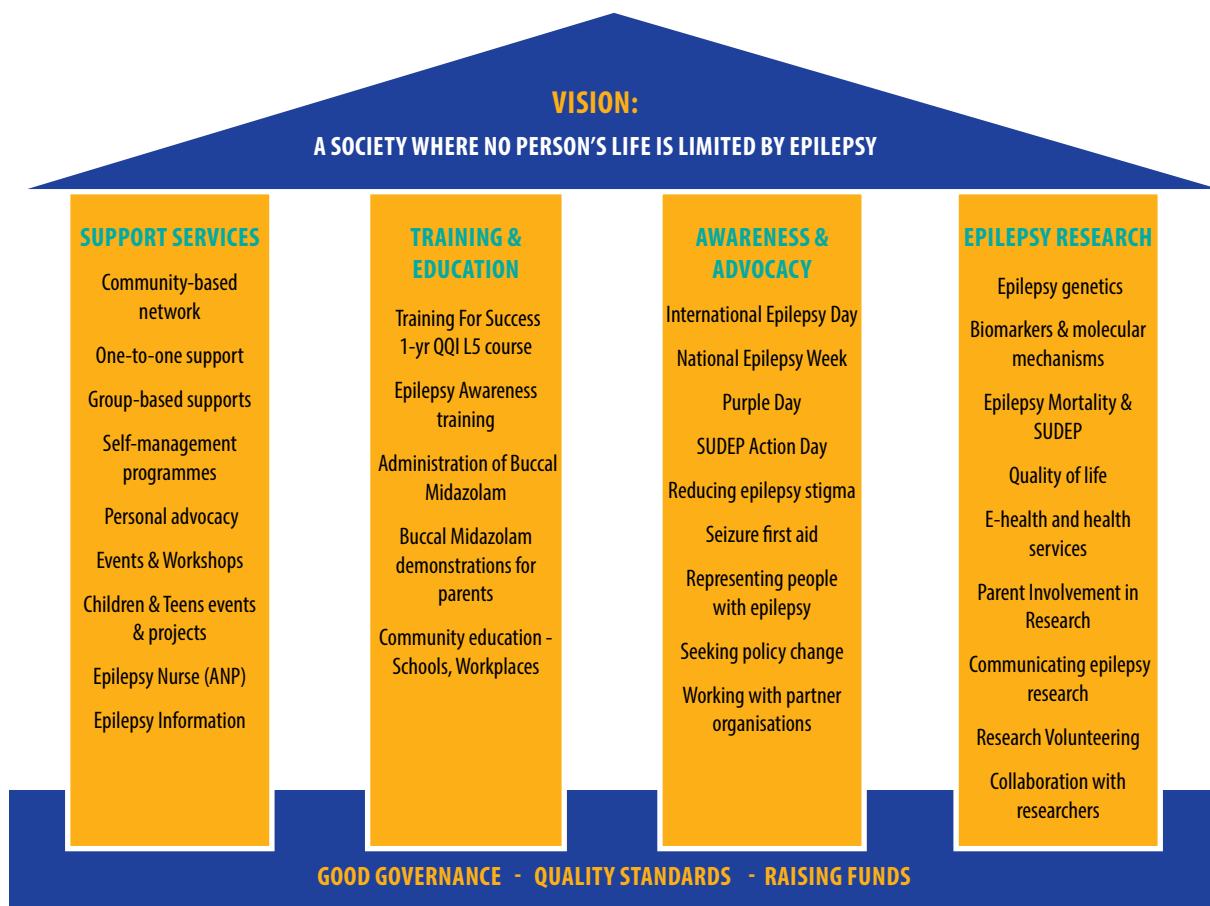
**RAISING FUNDS**

Prior to the Covid-19 pandemic, income had steadily increased in recent years to c. €1.75m per annum. Traditionally, fundraising has accounted for

approx. 40% of our income, raised mainly through traditional, community-based and volunteer-led efforts. The Covid-19 pandemic has led to a 50% drop in fundraising since early 2020 and increased our reliance on state funding sources, especially HSE Section 39 grants. In 2020, state funding accounted for almost two-thirds of all income. Since 2020, we have worked to introduce new fundraising technologies and strategies to offset the impact of Covid-19 on traditional fundraising.

**GOVERNANCE & QUALITY**

We take our commitments to good governance and quality seriously, not only to reassure our members, service-users and stakeholders, but to ensure that the right structures are in place to maximise our impact in everything that we do. We are fully compliant with the Charities Regulator Governance Code, have fully implemented Charities SORP and hold Triple Lock status from Charities Institute Ireland. In addition, we have held an accredited quality standard since 2015, most recently attaining the Improving Quality (IQ) Foundation standard in 2021.





# CONTEXT TO PLAN

## FINANCIAL CONTEXT

In recent years, our financial performance has seen modest though non-linear growth (see above). Reserves have been used to fund special strategic projects such as awareness campaigns, a transition nurse post and research projects. At the end of 2021, we maintained total reserves (restricted, designated and general) to cover 9-10 months of operations.

An important focus of the Board is to ensure the long-term financial sustainability of the organisation, mainly due to stagnant HSE funding, rising costs and a changed fundraising environment.

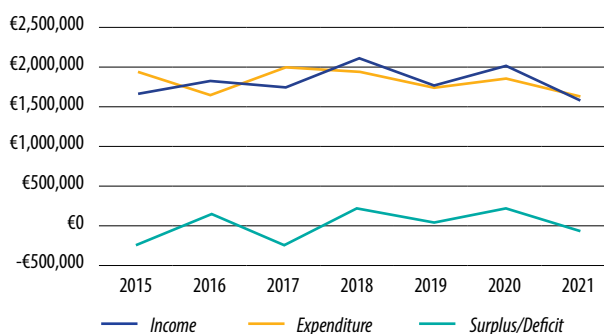
## SOCIAL & ECONOMIC CONTEXT

The development of this Strategic Plan took place during the Covid-19 pandemic and the unique opportunities and threats were ever-present during the process. Particularly at its height, the Covid-19 pandemic created barriers to many caring and community activities for people with epilepsy. It has also accelerated a period of innovation and adaptation with many social, medical and community supports moving online – a development that is experienced differently across different groups.

The Irish non-profit sector has so far remained more resilient than expected during the pandemic, though organisations with a high dependence on community-based fundraising such as Epilepsy Ireland were particularly hit. Trends in fundraising visible before the pandemic accelerated, including moves towards relationship-based giving, and the increasing use of digital, mobile or social media methods.

Looking more broadly at the Irish economy, while unemployment rates increased during the pandemic, the easing of restrictions precipitated a strong recovery in late 2021 and in mid-2022, unemployment rates are comparable to those of the 2000's. The nature of work is also changing with remote or hybrid working models becoming the norm. At the time of writing, Ireland is experiencing multiple overlapping economic pressures including record levels of inflation and increases in cost of living. These issues, if unchecked, will affect non-profit organisations, their workers and their service users in multi-faceted and complex ways. Meanwhile, new 2022 CSO data suggests that the Irish population now exceeds 5.1 million people, a 7.6% increase from 2016. Not only will this add pressure to health and other public services, it will also see an increase in the total number of people with epilepsy and in turn, greater demand for Epilepsy Ireland's services.

## EPILEPSY IRELAND FINANCIAL PERFORMANCE



## RELEVANT POLICY CONTEXT

The Irish healthcare landscape is complex and there are several trends which are impacting the care of people with epilepsy and their families. For example, while Sláintecare holds great promise for equalising access to quality, integrated and localised healthcare for everyone, implementation has been slow and sporadic. While Covid-19 exposed a lack of resilience around overall healthcare infrastructure and systems, it was also a time when hospital-based epilepsy services exhibited great innovation in adapting to new models of care including e-health and tele-health technologies. E-health will be a cornerstone of how HSE epilepsy services develop in the coming years, building on the many service improvements that were made during the 2010s such as the Electronic Patient Portal and the EI-supported Epilepsy e-Portal. Some of the many other factors include national policy on access to new medications, moves towards greater use of genomic medicine and the need for additional neurology services and personnel to improve access to care.

# DEVELOPING OUR STRATEGIC PLAN

Having an active plan for strategic development is crucial to ensure the ongoing relevance, sustainability, and continued growth of an organisation. In mid-2021, with our 2017-2021 strategic plan reaching its conclusion, the Epilepsy Ireland board decided to undertake a new five-year planning process.

With the support of the Community Foundation for Ireland through the RTE Does Comic Relief: Adapt and Respond fund, the agency 2into3 were chosen to facilitate the development of the plan following a competitive process. A strategic planning working group was set up to lead the work, which began in July 2021. This involved analysing and understanding the evolving policy and funding environments within which the organisation operates; as well as recognising the opportunities and threats posed by the ongoing pandemic and the changing economic environment.

Central to the process was the need to fully involve key stakeholders. We undertook a highly participative process consisting of several online workshops

(figure 2) that strove to recognise the commitment and mission-driven nature of our activities, as well as the core reasons for Epilepsy Ireland's existence. Our process ensured representation from internal and external stakeholders, including those who avail of our services, staff, volunteers and representatives from the medical & scientific community. These consultations have shaped a plan which we believe captures the needs of people with epilepsy, their families and the wider epilepsy community.

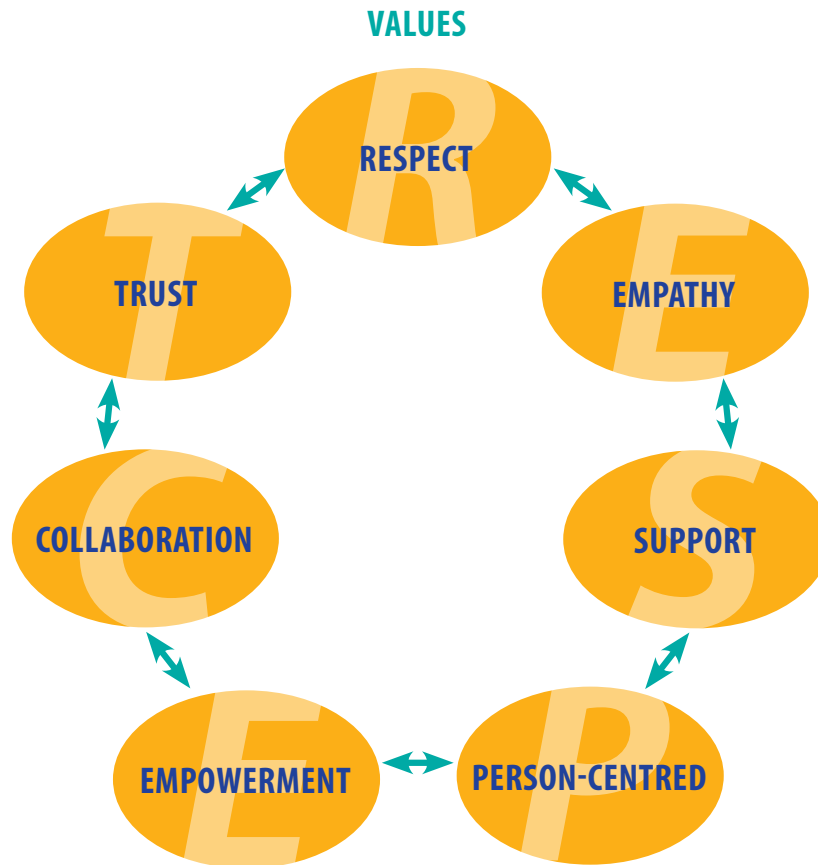
Encompassing stakeholder feedback, the working group began writing and costing our strategic plan in late 2021 and this plan was approved by the Board in April 2022. The result is a positive and ambitious, yet challenging roadmap for the next five years. By working to achieve the detailed annual plans which will result from the strategic plan, we will ensure that Epilepsy Ireland continues to improve the lives of all those living with epilepsy in Ireland.

## STRATEGIC DEVELOPMENT PROCESS UNDERTAKEN BY EPILEPSY IRELAND



# OUR VISION, MISSION AND VALUES

From our consultations with stakeholders, we agreed the following Vision, Mission and Values to guide our work and decisions over the next five years.



## VISION

To achieve a society where  
no person's life is limited by epilepsy.

## MISSION

To empower all those affected by epilepsy  
to achieve their full potential by providing  
high-quality community-based support and education,  
raising public awareness, conducting effective advocacy  
and supporting research.

# STRATEGIC PLAN 2022-2026

## OVERVIEW

### STRATEGIC THEMES

### STRATEGIC AIM

### OBJECTIVES

## 1 Support and Education

Empower people with epilepsy through support and education

1.1 Provide the highest quality support and education services.

1.2 Identify and fill gaps in epilepsy service needs.

## 2 Membership and Engagement

Centre people with epilepsy and their families in the work of Epilepsy Ireland

2.1 Develop a new volunteering and engagement approach that is centred on lived experience.

## 3 Collaboration, Care and Knowledge

Work collaboratively to improve the care of people with epilepsy and knowledge of the condition

3.1 Advance a community-based, patient-centred and collaborative model of care with HSE and others.

3.2 Provide training and education for those involved in epilepsy care.

3.3. Commission and fund epilepsy research.

3.4 Advance strategies to reduce the risk and incidence of epilepsy deaths.

## 4 Advocacy, Campaigns & Communications

Transform perceptions of epilepsy and public policy relevant to the condition

4.1 Use campaigns and advocacy to create positive change for people with epilepsy.

4.2 Increase the visibility of epilepsy and the work of Epilepsy Ireland.

## 5 Fundraising

Increase and diversify income

5.1 Raise the funds needed to implement strategic objectives through existing streams and by embracing new techniques and technologies.

## 6 Capacity and Governance

Demonstrate highest standards of governance and ensure structures are in place to meet objectives

6.1 Demonstrate the highest standards of governance, financial management and quality.

6.2 Strengthen our organisational structure and capacity.

6.3 Invest in our technology needs.

## **1. SUPPORT & EDUCATION**

We will continue to provide information, advice and support to people living with epilepsy, their families and carers. We will work to empower people in the self-management of their condition through one-to-one and group-based work, while also further developing our online service delivery. We will work to reduce or remove potential barriers for people with epilepsy in education and employment by working with and upskilling schools and employers. We will develop information resources appropriate to the needs of those living with epilepsy and professionals. We will seek to identify gaps in service delivery, including for those with specific or complex needs and work to develop supports to meet identified needs. We will also expand the provision of epilepsy aids & appliances and put new links and referral pathways in place with the medical community.

## **2. MEMBERSHIP & ENGAGEMENT**

We recognise that the success of the organisation is dependent on an active and engaged base of members and volunteers who have traditionally been the driving force behind many aspects of our work including grassroots advocacy, raising awareness and fundraising. We will increase the number of volunteers engaged with us and harness the expertise of those living with epilepsy to support the delivery of work across the organisation. We will increase opportunities for people with lived experience to contribute to our work and we will develop mechanisms to consult with and seek feedback from our membership about our services and wider activities. We will also review our membership model; assess if and how greater value can be added and ultimately increase our membership base.

## **3. COLLABORATION, CARE & KNOWLEDGE**

Collaboration with other stakeholders invested in ensuring the wellbeing of people with epilepsy is a vital part of our strategic plan. We will work with the HSE to improve access to care and develop collaborative models of service that promote community-based care. We will work with the medical community to provide epilepsy training opportunities for health professionals and continue to deliver and grow our own training programmes. We will develop a research strategy to guide our investments in epilepsy research over the next five years, expand our ability to collaborate as research partners and promote the increased involvement of people with epilepsy

in epilepsy research. Finally, we will work with the medical community to promote improved knowledge and understanding of SUDEP and advance strategies to reduce the risk and incidence of epilepsy deaths.

## **4. ADVOCACY, CAMPAIGNS & COMMUNICATIONS**

Stakeholder feedback indicated that while gains had been made in recent years, improving public understanding, knowledge and visibility of epilepsy remains a key priority. We will continue to use targeted awareness campaigns such as International Epilepsy Day, Brain Awareness Week and others to reduce stigma and discrimination and improve awareness of and attitudes to epilepsy. We will design and implement advocacy campaigns on issues that reflect the needs of people with epilepsy to create positive change. We will also expand our social media reach and engagement, raise the profile of the organisation and ensure that all our communications are centred on a diverse range of personal experiences of epilepsy.

## **5. FUNDRAISING**

Implementing our strategic objectives requires successful income generation strategies. We will increase and diversify our fundraising streams including through corporate partnerships, regular and digital giving, and by embracing new techniques and technologies. We will review and where possible grow existing fundraising activities and aim to develop Purple Day<sup>®</sup> into a flagship annual fundraising event. We will also expand earned income activities e.g. our training services, and work with state funders, particularly the HSE, to secure increases in grant funding for services which has remained static for over a decade.

## **6. CAPACITY & GOVERNANCE**

Demonstrating the highest standards of governance, financial management and quality is vital to preserving our reputation and the confidence of our service-users, donors and all stakeholders. We will maintain compliance with the Charities Governance Code and preserve our Triple Lock Standard, as well as expanding our quality assurance framework. We will ensure we are governed by a diverse, skilled Board and we will work to secure funding for additional staff posts needed to deliver on our strategic objectives. It is also vital that we invest in the technology needed to effectively and efficiently deliver on our goals in service delivery, training, communications, fundraising and administration.

## IMPLEMENTING THE STRATEGIC PLAN

The 2022-2026 Strategic Plan encompasses Epilepsy Ireland's ambitions for the medium-term future of the organisation and exists to provide direction for sustainable development, to respond to the growing needs of the community, and to deliver services that positively impact our service-users.

The Epilepsy Ireland Board approved the Strategic Plan in April 2022. Management is tasked with developing and implementing annual plans and budgets to achieve the objectives outlined in the plan. Reports will be given to the Board at each of its meetings, progress will be monitored, and periodic evaluations will take place. Where necessary, updates will be made to the plan at these evaluations to account for changing circumstances.





The Board recognises that the plan is ambitious and that there are several challenges to implementation. Primarily, investing in the plan with the appropriate level of resources will be a hurdle, while external challenges include the ongoing Covid-19 pandemic, the increased cost of operating due to inflation and funding shortfalls. Equally, we believe that the plan is robust, measurable, achievable, and representative of the needs of the epilepsy community. With clear targets to aim for, we look forward to continuing working towards of vision of a society where no person's life is limited by epilepsy.



RESEARCH



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