epilepsy scotland

2023 / 2024

Impact Report

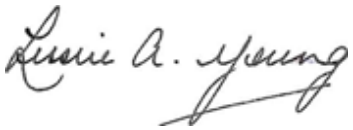
A MESSAGE FROM OUR CEO

This report is full of information about what Epilepsy Scotland does, how we do it and who benefits from every service we provide. It also contains incredibly powerful personal stories from those who have used our services, and I want to thank them for sharing them. All this in an increasingly challenging time for all; service providers, service users, their families and the wider community.

None of this has been easy. In fact, like so many other charities, it has been an incredibly challenging year. The list of challenges is long and well known to everyone but to highlight a few; rising costs not being met by an equivalent rise in funding, disposable income being squeezed making fundraising and donations more difficult to secure, overstretched statutory bodies like the NHS and social services referring people to Epilepsy Scotland but not contributing monetarily to the service and all this with a significant increase in demand across the board. Our helpline alone has seen a 125% increase in calls since before the pandemic and our Welfare Rights team have had to pause accepting new clients on 3 separate occasions this year due to demand. That huge increase in demand combined with the increase in costs and the fundraising challenges, the charity was faced with difficult decisions including not filling some roles that became vacant and albeit temporarily, reducing all staff working hours by 10% to save on costs.

It is testament to the commitment of all staff, facing the same challenges with the cost-of-living crisis etc., that they continued to provide the vital, person-centred support we deliver across Scotland from Shetland to The Borders. This includes our Scotland-wide Helpline, Adult Wellbeing Service, Welfare Rights Service and Youth Groups. This year we directly supported over 2,000 people with epilepsy and indirectly we have supported over 17,000 people across Scotland. Additionally, we published an influential report on mental health called Epilepsy On The Mind, which was discussed in the Scottish Parliament. We also continued our role in influencing government for positive policy change by responding to 3 separate government consultations and leading the Cross-Party Group on Epilepsy in the Scottish Parliament. I want to take this opportunity to thank the staff for their unwavering commitment and for achieving so much during such a challenging period.

In 2024 we celebrate 70 years of support and service provision to those living with epilepsy. We have made so much progress but there remains so much to do. Whilst we know challenges remain, we are in a much better position, and are looking forward to investing in our services. We know how important our services are to the 80,000 people living with epilepsy in Scotland. So we will continue to provide the person-centred support we can and continue to ensure decision makers in government, in the NHS, in local authorities are provided with all the information they should have to make properly informed decisions to improve the lives of those living with hugely under-represented, underfunded and misunderstood condition.



Lesslie Young OBE, CEO

HELPLINE & INFORMATION

HELPLINE

The helpline provides much needed emotional support, reliable information and guidance to anyone living with or affected by epilepsy. This year, we supported 1924 people reaching out to our helpline service via phone, email or social media.

"It's really nice to know that if needed the helpline is there, and at the other end of the phone is someone who understands and genuinely cares."

"Forever grateful to the helpline officer for being a calm voice in the madness when I was first diagnosed."

CHECK-IN SERVICE

Our check in service is a person-centred listening service providing a safe and non-judgmental space for anyone struggling with their epilepsy and often their mental health. Weekly calls over a period of time provide a platform to talk, ask questions, and reflect, empowering the client to better manage their epilepsy. During the last year, we supported 58 clients with our weekly continuing telephone support.

"I can't stress enough how much the helpline officer helped me through the difficult moments. If it wasn't for them, I don't know where I would be now. Thank you for doing what you're doing. It makes a massive difference."

EVENTS

We engaged with Job Centre staff, students, health professionals and the general public about epilepsy. All in all, we attended 13 in-person and online events, reaching around 280 people directly.

INFORMATION

Our information booklets remain as popular as ever, particularly with epilepsy specialist nurses. We distributed a total of 8,795 publications helping to raise awareness in general and keeping NHS patients informed.

We produced a new factsheet on Treatment, helping those diagnosed make informed decisions.

Our new epilepsy resources in Easy Read, aimed at those living with a learning disability, continue to be popular making our information more accessible and inclusive.

8,795 leaflets distributed

13 events

1,924 helpline enquiries

58 check-in clients

WELLBEING

Thanks to generous financial support from the National Lottery Community Fund Improving Lives programme, the Henry Smith Charity, the Glasgow Wellbeing Fund, the James Weir Foundation and our many supporters, we have been able to support the emotional wellbeing of 62 adults with epilepsy.

We offer a bespoke programme of one-to-one and/or group support using counselling, relaxation techniques and peer support. These activities empower participants to deal with the challenges of their diagnosis and its impact on their emotional wellbeing.

We continued to hold trauma-informed yoga classes, and the Scottish weather even allowed us to hold a pizza day in the Epilepsy Scotland garden!

We offer our services through a hybrid model of telephone, digital and face-to-face appointments.

62
adults with epilepsy supported

1091
one-to-one sessions

40
group activities

MORE THAN NUMBERS

These numbers only tell part of the story. We encourage everyone to view Philip's Story to understand the impact of the condition and how our service has helped our participants. Philip's openness, honesty and ability to tell his story so powerfully led to the film winning bronze in the UK wide Smiley Charity Film Awards.

You can view the video here:
https://www.youtube.com/watch?v=PqxMnSbXPtk

"Being involved in the wellbeing service has helped me gain the confidence and belief in myself to go back to college and now also get a part time job which a few years ago I had given up hope in achieving."

"I can't thank Epilepsy Scotland enough, they have changed my life. I've confidence in myself now and I'm able to do so many things on my own. Thank you so much I appreciate it."

Check-In Service

JACQUI'S STORY

This is Jacqui's powerful account of how Epilepsy Scotland's Check-In Service has helped her come to terms with her diagnosis.

"We all have some experience of ill health or loss, but there are few illnesses like epilepsy, which are so common yet so misunderstood, even by health care professionals. This is why I want to share my story.

"I was an extremely fit, healthy 46-year-old, making plans to return to my chosen career in medicine as my only child started school. My husband and I had worked hard to realise our dream of a rural lifestyle, surrounded by nature, and were setting down roots for our son. Then BOOM! One day is all it took to change my small family's life irrevocably.

"I became acutely unwell and spent months in hospital recovering from Encephalitis and a Traumatic Brain Injury, and was then given the devastating diagnosis of generalised tonic-clonic seizures and mild cognitive impairment. My seizures were poorly controlled despite medication, and coping with this illness left me barely able to care for myself, let alone anyone else.

"My driving licence, proudly strived for at age 17, was revoked. Work was no longer an option. The education I had received and my qualifications, so paramount to my sense of identity, no longer useful. Our rural retreat, once so cherished, became a huge barrier as it heightened my isolation. Rather than care for my son and I, my husband was left with little option but to work longer hours to support us, leaving us incredibly vulnerable. Every aspect of life was changed, and a struggling NHS left us poorly supported and ill-equipped to adapt. Years of injuries, hospitalisations, and little to no help of any kind, straight into a global pandemic, left me traumatised, unmoored, and questioning the point of my existence. In retrospect, I was in crisis.

"My overworked but incredibly dedicated Epilepsy Specialist Nurse recognised this but had very little resources within his remit. However, he still had one ace up his sleeve – a referral to Epilepsy Scotland's Check-In Service.

"To the untrained eye, this may not seem like the answer to such complex issues, but believe me, this seemingly minor intervention CAN, over time, become a lifeline. It became mine. Until that first call, yes, I was sceptical. However, I soon learned due to the experience, compassion, understanding and patience of "my Uschi" as she is known to us Kilties, I was able to be open and vulnerable.

"Through Uschi's wisdom and investment of all of the staff of Epilepsy Scotland, I was helped into a place where I am no longer in 'crisis mode' and feel better equipped to deal with the challenges posed by my illness. That first call was two years ago, and this organisation, who help so many, have never failed to support me. They remain firmly by my side to celebrate my triumphs, enjoy my news and are a constant source of strength to me.

"So when my family were asked to be involved with a fundraiser within our community, there was no debate as to which charity would benefit from our efforts. I feel so privileged to be able to give back to an organisation that not only helps people LIVE with epilepsy, but in my case helped to save a life."

COMMUNICATIONS

EPILEPSY ON THE MIND

Our mental health and epilepsy report revealed the findings of our mental health and epilepsy survey, showing that one in three respondents said they had depression, and 46% said they had anxiety.

The report included five recommendations for the Scottish Government, local authorities, health boards and stakeholders to implement to help people living with epilepsy and struggling with their mental health. Our campaign had cross-party support from MSPs, with the findings of our #EpilepsyOnTheMind report debated in the Scottish Parliament and covered widely by the media.

CHRISTMAS APPEAL

We launched a CrowdFunder appeal to raise money for an adventure weekend for young people living with epilepsy. Sports clubs Ayr United, Queen's Park and Glasgow Clan supported our appeal. We also had shares on social media from Clyde 1's Callum Gallagher, TV presenter David Tanner, former footballer Leon Legge and Star Wars actor Gregg Grunberg. The appeal raised £5,286, exceeding its target of £4,500.

HELPLINE TURNS 20

Our freephone Helpline service celebrated its 20th anniversary in May 2023. Queen's Park Football Club helped celebrate this milestone with us by recreating a photo of when we launched the Helpline. We gained PR coverage in the Glasgow Times highlighting this milestone.

PURPLE DAY

On 26 March, 49 buildings and landmarks lit up purple to celebrate Purple Day, including the OVO Hydro, RRS Discovery, Camera Obscura, Abertay University and McCaigs Tower in Oban. We shared stories on Purple Day from people living with epilepsy, gaining significant media coverage. Queen's Park Football Club and former Star Wars actor Greg Grunberg shared videos on their social media channels to help promote the day.

174,670
Epilepsy Scotland website views

1,420,000
people reached on Facebook

58
press articles

2,224
#TalkEpilepsy podcast listeners

YOUTH SERVICE

183 young people supported

GROUPS

Our online and in-person youth groups for those aged 12+ meet weekly in Glasgow and Edinburgh. We also have the Purple Panda group for those aged eight to 12.

1:1 SUPPORT

We deliver one-to-one meetings with young people all over Scotland. We support them to understand and live with their condition. Common themes in these sessions are often anxiety, issues with friendships/peers and attendance at school or education placements. We are determined to provide young people with the time and a safe space to talk about issues, so they feel listened to and have agency.

88 hours of online Youth Group
225 hours of in person Youth Groups
54 hours of Purple Pandas Groups
360 hours of 1:1 support

"Thank you for providing a happy, safe place for my granddaughter to make friends and enjoy fun and laughter every week and especially on all the outings."

RESIDENTIAL WEEKENDS

In the summer of 2023, 20 young people participated over two weekends, taking part in outdoor group activities. An atmosphere of peer support helped push comfort zones, building motivation and confidence. Friendships were made, connections were strengthened, and confidence was boosted whilst parents and carers had a weekend of respite.

HAPPY MAIL

Each month, over 90 young people received Happy Mail, which included information about epilepsy and wellbeing, and games and fun activities to do at home.

SCHOOL TALKS

Primary schools across Scotland received workshops and assembly talks about epilepsy in which 278 pupils took part. These explain what epilepsy and seizures are, how to help someone during a seizure and to raise understanding and empathy for someone living with epilepsy.

"I was 11 when I was diagnosed with epilepsy, it was a bit of a struggle to cope with the new diagnosis, medication etc, but it felt like a relief when I discovered there were other people my age going through the same thing too. Here I am today, proud and taking it one day at a time."

FUNDRAISING

Donations from trusts and foundations make up a large part of Epilepsy Scotland's income. The kindness and support we received from a range of funders across Scotland and around the UK has made an enormous difference to thousands of people with epilepsy and their families throughout another challenging period for everyone.

A particular thank you to funders who supported the work we do with multi-year funding - The National Lottery Community Fund, Henry Smith Charity, Northwood Charitable Trust, The Robertson Trust, Gannochy Trust and the Scottish Government CYPFAL Fund.

And of course our wonderful community of individual supporters put the fun into fundraising - from Kiltwalkers to firewalkers, 10k runners to ultrarunners, mountain climbers to zipsliders, your support and dedication is hugely appreciated. Thank you!

172 Kilkwalkers raised £39,720

Christmas Crowfunder raised £5,660

Our annual Ladies Lunch raised £13,699

Supporter Kim hit £20,000 fundraised since 2018!

MARATHON DE SABLE

Martin and Monica took part in the iconic Marathon des Sables in Morocco. Running and walking through desert sandstorms and intense heat over seven days, the race is regarded as the toughest footrace on earth. This was Martin and Monica's second attempt after 50% of racers did not finish in 2021 due to norovirus. This time around they made the finish line and raised both awareness and funds for Epilepsy Scotland, a charity which means a lot to them after Martin's brother Kenneth passed away in 2018.

RUTH'S STORY

Ruth's son has absence and tonic-clonic seizures. She explained the challenges her son has faced and how being part of Epilepsy Scotland's Youth Group has helped her son:

"It was a challenging, confusing, and emotionally draining time when my son was diagnosed with epilepsy. I was very concerned about what this meant for him and for us as a family and also what could have triggered it. He has social and learning difficulties because of the seizures. He also feels stressed by the requirement to take medication daily.

"Epilepsy Scotland's Youth Group has giving him a sense of belonging and acceptance. He enjoys the activities organised by the group. The consistency of the groups and activities gives my son something to look forward to and the fact that I get support with getting him there by way of taxi. This greatly reduces the feeling of yet another thing to accomplish that is very specific to one member of my family.

"The support from staff giving one-to-one visits during a difficult time in the family was very beneficial. It means that my son has a place where he is not defined by his disabilities. He is accepted for who he is and not treated as 'weird'. He is around people who have patience and understanding about his limitations as well as an appreciation for his many capabilities."

ABBIE'S STORY

Abbie was diagnosed with epilepsy when she was 19 years old. She shared the challenges she has faced and how Epilepsy Scotland's check-in service has helped her.

"I felt like my full world had flipped upside down. My auntie passed from epilepsy due to a seizure when she was younger, and I feared my life had permanently changed. I felt I'd lost myself, lost my confidence, and isolated myself from everyone. I have faced challenges with my mental health being affected by my medication and understanding my diagnosis and what that means for me individually.

"I have had an amazing experience with Epilepsy Scotland's check-in service with Stuart. He helped me understand that it's important to celebrate all achievements, big or small, and encouraged me to get back to doing the things I love, in particular the gym which I'm slowly getting back to regularly. Stuart also helped me with my college course in children's mental health and as of last week, I have completed and passed the course.

I feel with the 1:1 support through Epilepsy Scotland, I have gained confidence in my diagnosis. I have a clearer understanding of what epilepsy means for me and that I am not alone.

"Without the check-in service, I believe I would be in a really bad place mentally, I have found Epilepsy Scotland's check-in service more effective than any other support I have previously had. You are not alone! The support you will receive is not only about epilepsy it's about you, your personal circumstances, and concerns. I don't think I would be where I am today without Stuart and his support."

TRAINING

Epilepsy Scotland continues to be one of the leading providers of epilepsy training in Scotland.

OUR TRAINEES

We work extensively within the care sector, schools, colleges and employers to raise awareness of epilepsy and reducing stigma many people experience. This is key to a safer society for the 58,000 people affected by epilepsy in Scotland.

1,421
trainees this year

OUR TRAINING

Our training includes a detailed description of different seizure types, treatments and first aid. We also offer comprehensive training on the best practice techniques for administration of rescue medication. This provides people who live with epilepsy, there friends, family and carers the knowledge and confidence to manage there condition.

"I thoroughly enjoyed this training. It was clear, concise, and the trainer made epilepsy so much easier to understand. I was really nervous about giving Midazolam, but now I feel confident. And now if I need to, I will be able to give it properly without panicking."

IN PERSON & ONLINE

As well as our in-person training, we also provide online courses that are flexible and easy to access. This has given us the opportunity to reach out to organisations and individuals where attending courses in person is impractical geographically or due to work schedules.

"I feel like I learned new things in this training even though I've completed it a few times before. Great insight, and stopping to ask questions was really helpful. Great trainer."

EPILEPSY FRIENDLY AWARD

We support companies to make adjustments to the workplace and have trained staff to ensure people with epilepsy are well supported. This year we awarded our Epilepsy Friendly Award (EFA) to West Lothian College and West End Adventure After School Care in Glasgow.

Epilepsy Friendly
www.epilepsyscotland.org.uk

POLICY & CAMPAIGNS

Our policy team works to improve the lives of people with epilepsy by influencing policy and decision makers. The team works closely with the Scottish Government, engaging with MSPs and MPs where possible to ensure the voices of people with epilepsy are heard.

INFLUENCE

We contribute to Government and Parliamentary consultations ensuring we represent the voice of people living with epilepsy in policy development. This year we contributed to consultations covering Work Capability Assessment, Learning Disabilities, Autism and Neurodivergence Bill and Disability Commissioner (Scotland) Bill. We hold the Chair of the Epilepsy Consortium Scotland and sit on the Board of the Neurological Alliance of Scotland, where we are also a Member of the Policy Group and Member of the Mental Health Subgroup. We continue to meet MSPs, government ministers and civil servants throughout the year to update them on our work and influence positive policy changes. We also continue to be the secretariat of the Cross-Party Group on Epilepsy at the Scottish Parliament, where we organised meetings that involved topics such as Men's Health and Epilepsy and Client Contributions for Non-Residential Care.

RESEARCH

We conducted research on mental health and epilepsy, resulting in the powerful Epilepsy On The Mind report, in which we called for better mental health support for those living with epilepsy. We are currently principal contributors to two influential reports being authored by IRISS and the Neurological Alliance of Scotland. Both reports will be published next year.

CAMPAIGNS

We launched our third #StudentSeptember campaign with the help of our Student Ambassadors. We worked to increase awareness of epilepsy within Scottish Universities and Colleges and amongst students, increasing the support available for students. We launched our #EpilepsyOnTheMind campaign, which highlighted the call to action noted in our Epilepsy On The Mind report and put a spotlight on the fact that so many people living with epilepsy – whether their seizures are controlled or not – are suffering mentally and need specific targeted mental health support. During National Epilepsy Week, we launched our #EpilepsyMatters campaign, which aimed to highlight the impact of epilepsy on people's lives and the lack of awareness of one of the most common neurological conditions.

WELFARE RIGHTS

It was a busy year supporting clients who had been transferred from the UK government benefits of Child Disability Living Allowance and Personal Independence Payment to Social Security Scotland's equivalent payments of Child Disability Payment and Adult Disability Payment.

Additionally, the Department for Work & Pensions' Universal Credit managed migration transfer from legacy benefits such as Employment & Support Allowance, Housing Benefit and Tax Credits meant an increase in clients who required our support with the transfer to Universal Credit.

Claiming benefits or challenging benefit decisions can be anxiety provoking for many people. The opportunity to have support when doing this can alleviate stress, improve confidence and allow people to pursue their rights to social entitlement. The Welfare Rights Officers ensure they are familiar with legislation, guidance and the social security decision-making framework so they can provide the best possible support to their clients, achieving excellent outcomes and improving the quality of life for people with epilepsy and their families.

4352 individual contacts

165 clients

375 cases

£1,836,772 client financial gain

POLICY WORK

We submitted responses to the UK Government consultation on Work Capability Assessment. We also attended the Scottish Parliament to provide input to the Social Security (Amendment) (Scotland) Bill Roundtable hosted by Jeremy Balfour MSP.

100% satisfaction rate

"Without the service I would not have been able to secure the funding that allows me to live an independent life with epilepsy. I would have given up because of the many hurdles put in place to seemingly deter applicants from furthering their claim."

"Keep doing what you are doing. I think I would have been dead if it was not for you helping me out so much."

SPECIAL THANKS

We are very grateful to the following funders for their support of our services:

A M Pilkington Charitable Trust
Agnes Hunter SCIO
AMW Charitable Trust
Ann Jane Green Trust
Bank of Scotland Foundation - Reach
Blackford Trust
Cecil Rosen Foundation
Commonweal Fund
Cruden Foundation
Gannochy Trust
Garfield Weston Foundation
Glasgow Community Mental Health & Wellbeing Fund
Glasgow Nursing & Medical Relief Association
Henry Smith Charity
Hospital Saturday Fund
Hugh Fraser Foundation
James Weir Foundation
John Watson's Trust
Ludlow Trust
MEB Charitable Trust

Merchants House of Glasgow
Mrs MA Black Charitable Trust
New Park Education Trust
Northwood Charitable Trust
Patricia Routledge Foundation
Ponton House Trust
Robertson Trust
Scottish Government:
- Advice in Accessible Settings
- Neurological Care & Support Framework
- The CYPFAL Third Sector Fund
Templeton Goodwill Trust
The National Lottery Community Fund:
- Awards for All
- Improving Lives
- Young Start
UCB Pharma
W M Mann Foundation
WCH Trust for Children

epilepsy scotland

Call our freephone helpline

0808 800 2200

Visit our website

www.epilepsyscotland.org.uk

Email: contact@epilepsyscotland.org.uk

Epilepsy Scotland, 48 Govan Road, Glasgow G51 1JL

Tel: 0141 427 4911

/epilepsyscotland

/epilepsy_scot

@epilepsy_Scotland

/company/epilepsy-scotland

@epilepsy_scotland