



2022 / 2023

Impact Report



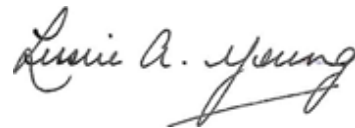
A MESSAGE FROM OUR CEO

As the national organisation for epilepsy, Epilepsy Scotland works with people living with epilepsy to ensure their voice is heard. Our team of dedicated staff support the emotional and financial wellbeing of the people of all ages who come through our doors, both physically and virtually. From our Purple Pandas support group for children as young as eight to our national helpline, we are there for the estimated 58,000 people with epilepsy across the country. We advocate for the best interests of people with epilepsy, raising awareness of the issues affecting people with the condition and campaigning to break down the many barriers faced by the community.

With the rising cost of living, the over-burdened National Health Service and a complex political environment, we are seeing more and more people come to us who are really struggling. Epilepsy Scotland strives to be there, to support these people, to listen and to represent. This sentiment is perfectly reflected in some recent feedback:

"I am so glad there are charities like Epilepsy Scotland that are passionate and powerful advocates for people with epilepsy." (Epilepsy Chat Session Participant)

Our 2022/23 Impact Report demonstrates the passion of each and every member of the Epilepsy Scotland team and the power this brings to the organisation. I hope you are inspired by the achievements of our past year.



Lesslie Young, CEO

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HELPLINE & INFORMATION

HELPLINE

We provide support and information to anyone who needs it. This year 1,870 people contacted our helpline. That is 1,870 people listened to, provided with support, information, signposting, help and reassurance.

"Thank you so very much for getting back to me so so quickly... I cannot begin to describe how grateful I am that you have taken the time to email me back... You have definitely restored my faith in humanity when nothing seemed to be going well. Thank you again from the bottom of my heart."

CHECK-IN SERVICE

Our check-in service helped 34 individuals with weekly calls to provide continuous support for often complex issues including uncontrolled seizures, mental health struggles and suicidal ideations.

"The service was a life saver to me. I was at my lowest point in my life and thanks to this service I am no longer stuck in the dark. I have improved tenfold both physically and mentally. Thank you Epilepsy Scotland, please don't ever stop this service."



EVENTS

We travelled more this year visiting Orkney, Inverurie, Aberdeen, Edinburgh and Helensburgh for 12 in-person events. We also hosted 18 online support groups, epilepsy chat sessions and information sessions.

"I thoroughly enjoyed joining the support group meeting. It is already helping me realise I am definitely not alone now..."

INFORMATION

Providing reliable information you can trust is a big part of what we do. We distributed 8,714 leaflets to individuals and healthcare professionals this year.

We produced a new student information leaflet and an Easy Read guide and reviewed and updated 10 leaflets on topics including new Scottish benefits and first aid.

8,714
leaflets
distributed

30
events

1,870
helpline
enquiries

34
check-in
clients

WELLBEING

Thanks to the generous financial support from the National Lottery Community Fund, the Henry Smith Charity, the Glasgow Community Mental Health and Wellbeing Fund, Scottish Government Neurological Care & Support Forum and our many supporters we have been able to support the emotional wellbeing of 88 people with epilepsy.

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

This year, we were delighted to start offering trauma-informed yoga classes and the Scottish weather even allowed us to offer social activities in the Epilepsy Scotland garden.

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

88

adults with
epilepsy
supported

1642

one-to-one
sessions

98

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."

NIK'S STORY



Nik shared it was "priceless to speak to someone neutral" and he valued having someone he could "vent to".

Wellbeing
and welfare
support

Nik is 38 and comes from Fife. He has co-existing conditions of epilepsy, psychogenic non-epileptic seizures, anxiety and depression. His epilepsy is currently uncontrolled, and stress is a known trigger for his seizure activity.

Nik is a single parent of a six year-old boy and enjoys helping him learn all about the world around him. He can't take his son swimming and is limited with other activities, but this has not stopped his son exploring the world in other ways and developing a passion for dinosaurs!

Nik was referred to the wellbeing team by his neurologist in October 2020. He was struggling with anxiety and depression, was having trouble sleeping and seizure activity was increasing. The fluctuating nature of these combined conditions worried Nik as he wanted to be the best father he could be.

During his one-to-one's with our Wellbeing team, Nik identified a goal of getting back into employment. We could see how frustrated Nik was and worked together on strategies to help take small steps towards his goal. This made a huge difference to his wellbeing and reduced his anxieties greatly.

As we got to know Nik we became aware that Nik's financial situation could be difficult and he was digitally excluded. We made a referral to our Welfare Rights team who supported him to get his full entitlement of benefits and he was awarded an iPad through Connecting Scotland. This means Nik has been able to support his son during his first years at primary school with video learning and it's also helped calm stress levels with the multi-tasking nature of parenthood. When Nik is focusing on making food and doing the dishes, his son is kept occupied learning more about dinosaurs.

DAVE'S STORY

We were delighted to present the first honorary lifetime membership award to our very deserving volunteer Dave. Dave is not shy of getting involved with everything and anything including collections, events, raising awareness about his experiences of living with epilepsy and as a moderator for the Epilepsy Scotland Facebook support group. Thank you for all your amazing support Dave!

"I initially decided to volunteer as a thank you for literally saving my life and I'm so pleased that I did. Volunteering gives me a purpose; it motivates me to keep fighting and makes me feel useful. The team at Epilepsy Scotland always makes me feel welcome and continues to show me support. Feeling like I belong and am valued is a huge boost to my mental health and my outlook on life."



The
power of
volunteering

COMMUNICATIONS



EPILEPSY ROADSHOWS

We visited Orkney and Grampian as part of our Roadshow events. We reached new audiences through in person events and local news outlets.

CHRISTMAS APPEAL

Our #BecauseOfEpilepsyScotland Christmas appeal saw the launch of our new videos showcasing the work of Epilepsy Scotland and highlighting some of the struggles faced by people with epilepsy. We raised over £3,000 and targeted support from sports teams including Football clubs Ayr United and the Glasgow Clan.

39 PEOPLE SHARED THEIR EPILEPSY STORY

"I have enjoyed the recent social media posts from people providing their own examples of their epilepsy journey..."

NATIONAL EPILEPSY WEEK

Our #ExcelWithEpilepsy campaign celebrated epilepsy as a condition you can excel with, that it is not always a barrier or a limitation. Our social media posts reached 44,861 people throughout the week and we gained PR coverage from platforms including BBC Radio Scotland and Third Force News.

PURPLE DAY

Over 40 buildings and landmarks lit up purple to celebrate international epilepsy day - including the The Pavilion Theatre and Perth Bridge. We shared the voices of people with epilepsy and sports teams including the Glasgow Clan helped promote the day. MSPs wore purple ribbons to mark the day and a motion was submitted to Scottish Government and an Early Day motion to the UK government.

270,654

Epilepsy Scotland website views

1,590,410

people reached on Facebook

46

press articles

1,384

#TalkEpilepsy podcast listeners

YOUTH SERVICE

168 young people supported

GROUPS

We run groups for young people with epilepsy aged over 12 in Glasgow and Edinburgh and online. We also hold online Purple Panda sessions for those who are aged 8-12 years.

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.

96 hours of online Youth Group
255 hours of in person Youth Groups
60 hours of Purple Pandas Groups
327 hours of 1:1 support

"It's the first time she's been happy to talk about her epilepsy and that's a massive positive step forward."

(Parent of group member)

RESIDENTIAL WEEKENDS

Our residential weekends returned in 2022. 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.



"Thanks for the session the class got today... She really enjoyed it and learned a lot. She was able to tell me about the different seizures and what she should do if she ever came across someone who was having one."

(Parent of school talk participant)

HAPPY MAIL

Each month, we posted out Happy Mail to over 90 children and young people affected by epilepsy. Happy Mail consists of a letter and fun activities.

SCHOOL TALKS

We hosted school epilepsy awareness talks in Orkney where we spoke to 153 pupils. The children were engaged and asked thoughtful questions.



"Epilepsy Scotland team are great at what they do from talking about epilepsy to helping people struggling with mental health. If Epilepsy Scotland did not come into my life then I don't know what I would be doing instead."

(Group participant)

FUNDRAISING

FAB FUNDERS

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.

Funding received from each grant made such a huge difference, and we'd like to send a heart-felt thanks to each and every decision maker. We truly value the time and sincere consideration you dedicated towards the epilepsy community.

And we would like to thank funders who continued their support and for supporting the work we do with multi-year funding. Thanks to The National Lottery Community Fund, Henry Smith, Northwood Charitable Trust, The Robertson Trust and the Gannochy Trust for their multi-year commitments.

In addition, we were delighted to be chosen by the Scottish Children's Lottery to feature on their TV advert!



65
Kiltwalkers
raised
£16,648

612 Limited
Edition Purple
Tunnocks
Teacakes
donated

Our biggest
ever Ladies
Lunch raised
£15,069

12 people
took on the
100-mile
challenge



CORPORATE CHAMPIONS

Corporate teams are fantastic to help raise awareness of epilepsy within the workplace. Aisling Bent, Health and Wellness Co-ordinator at Tigers Group reached out last year to do to the Kiltwalk in memory of their colleague. The team at Tigers have since signed up again for the 2023 Kiltwalk! Thank you for your support.

"As a team we came together and decided to raise awareness in memory of our colleague Richard who passed away unexpectedly 2 years ago, he was a great guy who would have done anything for anybody and remains a big presence within the company. To share a journey with your team is a great way to share and be accountable for the challenges ahead."

ROXANA'S STORY

Roxana lives with the constant fear and anxiety of never knowing when she will have her next seizure.

Roxana joined Epilepsy Scotland Youth Group in 2019 and has consistently attended our weekly groups, one-to-one support sessions and joined us on a residential trip.

Before joining the group, Roxana's Mum worried about her emotional wellbeing. Roxana didn't want to socialise with other young people and she knew this was due to experiences of bullying at school.

Since coming to Epilepsy Scotland, Roxana keeps in touch with several friends outside of the groups and refers to a couple as her 'best friends'.

Roxana has built the confidence to support other members and is very kind and caring. She has no problems sharing her experiences of epilepsy.

Her confidence and resilience has grown so much and she has even received an award in recognition of being hugely inspirational to her peers!

"She had lost her wee sparkle for months there and I couldn't figure out what caused her to lose that amount of confidence but over the past few weeks, I can see it, it's back. This group is making such a difference for her. I can see the sparkle in her again!" (Roxana's Mum)



"It has helped me so so much. They have helped me when I'm sad, they have helped me through when I'm stressed, they make me laugh. They are family. I call them family. They have helped me through so much and I really appreciate that. Loads and loads of times when I have been upset, they have helped me, and I love the way they treat me and the way I see them treat others like me." (Roxana)

PATRICK'S STORY



Recognising
the importance
of the carer
role

Patrick contacted us through our Facebook page. He had given up his job due to his child, Ann, being diagnosed with uncontrolled and unpredictable epilepsy which meant she needed to be home-schooled. The loss of income was causing financial hardship and adding pressure to family circumstances.

Patrick had previously applied for Disability Living Allowance (DLA) twice and had been refused on both occasions.

Our Welfare Rights team assisted Patrick to complete the DLA claim form and to obtain medical evidence. Within five weeks Ann was awarded Low rate mobility (£23.60 per week) and Middle rate care (£59.70 per week) for a period of two years which was backdated to the date of the claim. Patrick was able to claim Carers Allowance of £62.25 per week and was entitled to the Carers Allowance Supplement payments of £230.10 which are paid twice yearly by the Scottish Government. This equates to an annual benefit income of £8028.80.

This outcome has had a positive impact on the family unit. Patrick feels he is now contributing to the household finances and can focus on caring for Ann.



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.

1,407
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, their friends, family and carers the knowledge and confidence to manage their condition.

"The training was excellent. It has helped to build my self-confidence when supporting someone who has a seizure. It exceeded my expectations and I have learned more than expected. A real eye opener!"

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 have just completed today's training via Teams. Can I just say that this was excellent training and one of the most informative trainings I have had. It has greatly increased my skills and knowledge."

EPILEPSY FRIENDLY AWARD

Our Epilepsy Friendly Award (EFA) was successfully launched in 2019. We support companies who make adjustments to the workplace and have trained staff to ensure people with epilepsy are well supported. In 2022 we awarded the EFA to the Crown Office and Procurator Fiscal Service (Kilmarnock).



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 consultations ensuring we represent the needs of people living with epilepsy. This year we covered topics including the development a Disability Commissioner for Scotland and the new Scottish Carers Assistance benefit.

We hold the Chair of the Epilepsy Consortium Scotland and are an Executive Member of the Neurological Alliance of Scotland.

We hosted an event in the Scottish Parliament, bringing attention to our vital services, including our Welfare Rights Service. The event was attended by 14 MSPs.

We organised three Cross Party Group on Epilepsy meetings, with speakers including Dr Craig Heath who presented on the development of an Epilepsy Register and Alice Struthers from the Neurological Alliance of Scotland.

RESEARCH

We conducted research on clinical provision and waiting times across neurology in every health board in Scotland. The findings have influenced our policy priorities and sparked interesting discussions between Epilepsy Scotland and the Scottish Government. The report brings attention to the issues faced by people with epilepsy in Scotland when accessing specialist clinical care.

CAMPAIGNS

We launched our second #StudentSeptember campaign with the help of our Student Ambassador, Chloe. We worked to increase awareness of epilepsy within Scottish Universities and Colleges and amongst students, increasing the support available for students.

Our work is ongoing to increase the number of Epilepsy Specialist Nurses across Scotland, ensuring everyone with epilepsy has access to this vital support. We have campaigned for the provision of specialist support in the Western Isles in collaboration with Neuro Hebrides, MS Society Scotland and Parkinson's UK Scotland.

We launched a mental health survey which gained over 700 responses. We will campaign on the findings in the coming year.

WELFARE RIGHTS

INCREASING DEMAND

It's been an extremely busy year for the Welfare Rights service. Demand for the team's expertise in helping people with epilepsy maximise their household income has been higher than ever with the transition of many benefits from the Department of Work and Pensions to Social Security Scotland.

The ever-present challenge of the increased cost of living means this service which can be a lifeline ensuring families affected by epilepsy get their full entitlement has never been more needed. We are very grateful to The Robertson Trust Financial Security Fund and Bank of Scotland Reach fund who we have received recent financial support to allow us to continue this work.

"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."

THE VALUE OF THE SERVICE

This year, 100% of our clients reported a high satisfaction rate after working with us. 94% of our clients said that their anxiety or stress around the benefit claim process has been reduced as a result of their interaction.

From April 2022 to March 2023, we facilitated a financial gain in excess of £ 2,347,029 for our clients.

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

"The service does a fantastic job at supporting those who struggle through the grilling process. Eternally grateful."

4651

individual
contacts

176

clients

405

cases

£2,347,029

client financial gain

100%

high satisfaction rate

THE YEAR AHEAD

2022/23 was a busy year for Epilepsy Scotland. We continued to grow our reach, travelling as far as Orkney to ensure we are reaching people from all over Scotland. Following the challenges of COVID-19, we were thrilled to bring back more in-person events, while also continuing to grow our support online.

As we look towards 2023/24, we recognise that things will not be easy for many of the people we support. Extensive wait times for specialist epilepsy care and the rising cost of living will impact many people with epilepsy. We know there are challenges to come over the next year, but we will continue to be there for people with epilepsy, ensuring their voices are heard and needs met.

None of this would be possible without the support of our dedicated funders, corporate sponsors, legacy donators and fundraisers. For that we thank everyone who has helped make this happen.





Call our freephone helpline

0808 800 2200

Visit our website

www.epilepsyscotland.org.uk

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