

Project Title: Improving mental health outcomes for people with epilepsy (PWE).

Project funded by: Neurological care and support: framework for action 2020-2025
Final report: 31 July 2023

Overall Aim:

The overall aim of the Epilepsy Scotland Lothian Wellbeing Service was to improve the wellbeing for people with epilepsy and their families. By widening the geographical area that this established wellbeing service can serve and increasing the number of people the service can support, the service works toward the overall neurological framework vision that ‘Everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms.’

Additional project outcomes aligned with commitment 9 of the Neurological care and support: framework for action 2020-2025:

- A project to integrate the NHS and third sector (Epilepsy Scotland [ES]) in one clearly defined pathway.
- To evaluate the electronic, community-based screening tool for depression, anxiety, and suicidality in PWE (people with epilepsy) used by NHS Lothian.

What your project has done

We delivered an effective and innovative method of health and social care for PWE through a tailored 6–12-week programme run by the Epilepsy Scotland Wellbeing Service.

The Epilepsy Scotland Wellbeing Service offered a six-week digital programme to NHS Lothian referred clients comprising of:

- 1:1 support sessions (telephone or zoom)
- breathing and relaxation and support group (zoom)
- professional counselling for those who identify subjects the wish to explore further in 1 to 1 support (telephone or zoom)
- free ‘Newly Diagnosed’ training to service participants, their families, and carers.

Patients are referred directly from NHS Lothian following a mental health screening by the NHS Lothian Psychologist at their specialist epilepsy clinic appointment. Those flagging “amber – moderately to severely emotionally distressed” are asked if they would like their details to be passed onto The Epilepsy Scotland Wellbeing team or be given some NHS self-help resources.

The Epilepsy Scotland Wellbeing Service is person centred and the programme was designed to be modular rather than a linear model of activities that people with epilepsy can access how it suits them. Flexible support is there to mirror the fluctuating needs of our participants so they are not alone and isolated when struggling with the physical and emotional disruptions that seizures can cause.

30 people were referred to Epilepsy Scotland and 22 of these became wellbeing group participants and completed at least the initial 6-week programme, 15 of them went opted complete a further six one-to-one sessions or attend the breathing and relaxation support groups. 7 participants opted to explore issues with a professional counsellor and 6 were referred to our Welfare Rights Service. There was one re-admission as a participant contacted us for a refresher of.

9 family members or carers have increased knowledge and skills to care for someone with epilepsy including an increased understanding and awareness of the wider implications of a diagnosis of epilepsy.

What has changed as a result of its activities?

82% of those who have already completed the programme reported improved wellbeing on completion. Participants learned mindfulness, breathing and relaxation skills and other stress management techniques, which they will be able to use to self-manage their going forward via long term stress management.

NHS referred patients engaged better with this type of ‘active referral’ rather than a passive referral e.g. ‘handing out a leaflet about the service’. NHS Lothian reported PWE are actively referred to Epilepsy Scotland with their details passed on, their feedback is significantly more positive. Click here for the full report:

[ES-Adult-Wellbeing-Service-2017-2022.pdf \(epilepsyscotland.org.uk\)](#) - See pages 32-34. Testimonial from the Assistant Psychologist NHS Lothian on page 62.

Evaluation Methods

We recorded:

- individuals’ goals set in week 1
- The number of participants: in total, completing the programme, working positively toward their goal, and achieving their goal
- Session notes for each participant including any ‘break through moments’, progress in group works and case studies and, photos, videos and quotes where appropriate.
- We conduct regular feedback surveys to keep track of overall feedback and feedback on individual parts of the service, for example breathing workshops.

Participants completed NHS questionnaires after six months to ascertain if further support is needed and whether in person or online interventions are preferred and why. At this point any re-admissions would be recorded.

Impact data

82% of people with epilepsy showed improved wellbeing as part of the Epilepsy Scotland Lothian Wellbeing Service 6-12 week programme.

90% of people with epilepsy showed positive steps toward achieving their goals set in week 1 as part of the Epilepsy Scotland Lothian Wellbeing Service 6-12 week programme.

80% of people with epilepsy referred by NHS Lothian to Epilepsy Scotland achieved their goals set in week 1 as part of the Epilepsy Scotland Lothian Wellbeing Service 6-12 week programme.

9 family members or carers reported increased understanding, knowledge, and skills to care for someone with epilepsy.

Participants scored 8.93* for both levels of self-rated engagement and perceived effectiveness of pathway interventions.

*For engagement: 0 – ‘I did not engage’ to 10 – ‘I engaged fully’.

For usefulness: 0 – ‘not useful at all’ to 10 – ‘extremely useful’)

Case Study – “Olivia”

Olivia was referred to the team following an amber screening at her specialist epilepsy clinic appointment. Olivia is 38, lives alone and was diagnosed with epilepsy in her early 30’s. Olivia works full-time but at time of referral was on sick leave as she was going through a medication change and her doctor wanted to observe how the medication change would affect her and ensure it stabilised the increased and changed seizures she had been experiencing.

In her first meeting with the Wellbeing Worker, Olivia discussed her low mood and anxiety, she described that she sometimes felt overwhelmed in her job which could have very stressful periods. She described not sleeping well and attributed her recent increase and change in seizures to the stress at work. Olivia acknowledged the vicious circle she seemed to be in; stress causing seizures, the increased seizures causing her stress and so-on. Olivia also described that the impact on her physical appearance that had been a side effect of her previous medication had dented her confidence and was causing her further stress.

Over her six sessions Olivia with the Wellbeing Worker, Olivia explored why we get stressed and recognising when it can be useful and when less so. They explored the stress triggers she could control and tools and techniques to deal with those she couldn’t. They also looked at boundary setting at work, sleep hygiene and techniques for getting good quality sleep. At the end of the six sessions, Olivia said she would be keen to learn more and also meet with other people with lived experience of epilepsy. Shortly after, she began to attend the six-week Breathing & Relaxation Support Group. Here she learned more techniques to help develop her awareness of when she felt overwhelmed and how she could deal with it.

Olivia has now been able to return to work, firstly on a staggered basis. Olivia has negotiated with her employer that they give her “personal development time” for one and a half hours per week to allow her to become a buddy volunteer in future Breathing & Relaxation Groups. A buddy volunteer is a former participant who attends the group and supports new members.

In Olivia's own words;

"The service helped me to keep perspective and to not fall back into gloomy thoughts. I feel like I've got my equilibrium back, and attending the groups helps me to keep it. Even when times are hard it's brilliant to have a safe place to go to get support, and it's the kind of support that gives you the tools to keep yourself in good mental health. Thank you."

Quotes from other participants

"I found the wellbeing program very supportive"

"They have been great, and I would recommend it to anyone"

"It was a brilliant experience"

"Just to say thank you, this service is invaluable and I don't know what I'd do without it."

"Your staff are amazing, so knowledgeable, kind and approachable."

Difficulties and learnings

We were fortunate enough to be able to start the project quickly as Epilepsy Scotland and NHS Lothian had already been delivering a pilot model in partnership via other funding sources up until March 2022. It would have been impossible to get the project off the ground and completed in the funding period otherwise. Not least because we had originally arranged with NHS Lothian to distribute our number to people who expressed an interest. We quickly realised that an active referral where NHS Lothian asked permission to pass on the number was far more effective. This can be seen in the evaluation report referenced above.

We also learned, that although we had planned for a 6–12-week programme, that using our tried and tested person-centred approach was far more effective in retaining engagement. This meant being sensitive to missed appointments, reassuring participants it was ok to pause the programme and return later and changing the direction of topics if there were themes the participant wanted to focus on. Rather than a 6–12-week programme where if a session was missed, the participant would not complete this session, we delivered a 6-12 session programme, sometimes over a period of months. This, however, did mean that we worked with less participants than we had originally envisaged as individual participant's journeys were often slower. If we had not taken the more flexible approach, it is unlikely that as many as 22 participants would have completed the programme as it would have been very off-putting for them.

Next Steps

The project was completed in March 2023 coinciding with the cessation of funding from the Neurological care and support: framework for action 2020-2025.

We have NHS Forth Valley, NHS Tayside as well as NHS Lothian prepared as potential future partners subject to funding. Currently the Epilepsy Scotland Wellbeing Service is operating at capacity and experiencing a funding deficit.

The assessment tool used by NHS Lothian can be replicated across health boards as a simple way of ensuring people with epilepsy are referred for additional wellbeing support when it is most needed. It could be adapted as a formal social prescription tool for other neurological conditions and even other lifelong conditions such as diabetes. Quick access to third sector support takes pressure off NHS waiting lists and can prevent hospital re-admissions as PWE learn to self-manage their condition.

We believe replication of this project in other health boards or even with other long-term health conditions presents an opportunity for the charitable sector to help relieve the burden on the NHS by helping improve the patient's whole wellbeing. We know those with long-term physical conditions experience poor mental health. By screening those as they attend their specialist clinic appointments, we can offer timely and effective interventions. The other health boards we discussed this project with were excited by the prospect. However, they agreed staffing resources were necessary to carry out the screenings as current pressures meant they could not commit to disseminating and collating the screening tools.

Further reading

Questionnaire-based screening for mental distress in epilepsy: Outline and feasibility of an outpatient screening and intervention pathway- Gillespie et al

<https://pubmed.ncbi.nlm.nih.gov/36801165/>