

## Living Well with Epilepsy: A Supported Self-Management Service Funded by the Scottish Government – Framework for Neurological Care 2020 - 2025

**Self-management** is a concept defined in ‘Gaun Yersel’ (2008) the self-management strategy for long term conditions in Scotland as: **‘a person-centred approach in which the individual is empowered and has ownership over the management of their life and conditions’** (p.12)

Thanks to the Scottish Governments Framework for Neurological Care 2020–2025 Funding, Quarriers have successfully developed and piloted an innovative model of Supported Self-Management and embedded this approach within the William Quarriers Scottish Epilepsy Centre (WQSEC). 75 people with complex epilepsy and 40 staff received personalised support to improve their understanding and confidence to make use of self-management principles. The project has:

- Supported staff to learn and utilise the practice of self-management.
- Enabled people with epilepsy to explore their own situation, gain insight, skills, and motivation to make changes in their own lives.
- Changed the clinical practice and approach within the WQSEC.
- **“..self-management wasn’t ever a tactic I used...Now I have more structure and lower stress levels.”** Patient
- **“I think there has definitely been a change in staff approach to patient care”** WQSEC Staff

Embracing a person-centred, collaborative and whole system change approach “Living Well with Epilepsy” has evidenced the following outcomes for those who took part:

People living with complex epilepsy -

- *Can make informed decisions relating to their own care.*
- *Have improved their capacity for self-management and have an improved quality of life.*
- *Have increased their resilience, improved their confidence and feel less isolated.*
- *Have improved their understanding of the wider impact of their medical condition.*
- *Feel supported to develop the belief and ability to control and effect change in their lives.*
- *Have improved their knowledge of wider services available to them and increase their engagement with these services.*

WQSEC Nursing and healthcare staff -

- *Have enhanced their knowledge of self-management.*
- *Feel more able to embed a self-management ethos within the centre.*

The project was led by a new Wellbeing Worker and delivered with partners, Thistle Foundation (Appendix 6). The Project direction was informed by a Steering Group comprising of people we support, WQSEC staff (including our in-house psychologist) and wider health and care stakeholders, who guided the co-design process, and who continue to meet on a regular basis.

Our key project milestones included:

1. Recruitment and establishment of Steering Group
2. Consultation and Initial Project Planning
3. Staff Capacity Building
4. Development of Project Design
5. Pilot Delivery – Lifestyle Management Course
6. Reflection and Review of 1<sup>st</sup> Pilot
7. Pilot Delivery - Second Lifestyle Management Course
8. Reflection and Review of 2nd pilot

## 9. Post Pilot Evaluation

### **Project Delivery**

Informed by early consultations with patients and staff, the steering group and Wellbeing Worker developed the main areas of focus - the arms of the project (see diagram). For the condition of epilepsy, we concentrated on elements of self-management which reduced stress, improved routine and sleep, increased levels of fitness and developed relationships and social cohesion.

**Solution-focused staff training** was delivered throughout and reached all 40 staff members. It began with an initial stakeholder engagement presentation during a WQSEC Staff Development Day and was followed by:

- Staff Training sessions hosted by Thistle Foundation.
- Regular bite-sized training and information emails to staff.

Two key changes to clinical practice were subsequently implemented:

- Formation of the Supported Self-Management Staff Development Group.
- “What Matters to You” question included in patient admission paperwork.

What Matters to You? - this simple question was added to the nurse admission paperwork. Nursing and healthcare staff have said what an impact there has been taking a complex patient admission system and adding one simple question:

*“It really helped the nurses to understand the person’s story and personal circumstance, what had brought them to where they are today, and helped to shed light on any issues they are battling through alongside their epilepsy.”*

*“The paperwork having that little box for ‘what matters to you’, because I think we generally do speak about that with patients, but it just draws importance to it and makes sure it’s embedded and we touch on it with everyone.”*

Staff feedback confirms that the team have enhanced their knowledge of self-management and feel more able to embed the self-management ethos within their clinical approach:

*“I try to consider Supported Self-Management in all my communications/interactions with patients...I always keep in mind that the patient is in charge of their care/assessment, and we are supporting that.”*

*“...when you pick away at it and think about all the aspects of self-management, like wellbeing and looking after yourself generally, there’s a wider circle that I never would have connected with it so it definitely has increased my perspective of self management as well.”*

*“I think there has definitely been a change in staff approach to patient care.”*

The additional delivery arms of the project included:

**Pre-admission information** - Patients were provided with information that is clear and inviting so they feel prepared to undertake positive changes during their admission.

**1:1 Solution-focussed Support** - carried out by the Wellbeing Worker. Participants had the opportunity to be constructively listened to and supported to make the health and wellbeing changes they envisage for themselves.



**Lifestyle Management Courses** - Two 10-week Lifestyle Management Courses (one physical and one online) provided the space, facilitation, and opportunity for people with epilepsy to engage in the Lifestyle Management process and were delivered by Thistle Foundation and our Wellbeing Worker.

**In-centre Self-Development Program** - We provided a targeted program of physical, educational and creative activities in response to areas of interest identified by people with epilepsy.

**Evaluation**

A robust evaluation of the project was undertaken, and the evidence gathered supports positive outcomes for people living with epilepsy and the successful embedding of self-management learning and principles within the WQSEC.

This process included Outcome Mapping, plotting our project plan onto a colour-coded heat map which shows a process of change in relation to the impact of the support that was provided throughout this project. The colour shows the level of progress towards any given outcome or aspect of the map, level of confidence denotes the robustness/reliability of the data that has been collected to evidence progress. (Appendix 1 and 2).

Embedded Data Sources included:

- **Stakeholder Review Meeting Transcriptions (with Staff, people we support and Steering Group)** (Appendix 3).
- **Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS)** – WEMWBS were implemented as part of the admission and discharge process as well as before and after the Lifestyle Management courses.
- **Case studies and notes** – 1:1 sessions were facilitated. Documentation was based on the Thistle Foundation model which captures participant progress (Appendix 4).
- **Sparkle box** – An informal method for collecting and storing qualitative data throughout.

**Impact**

Below are highlights/feedback from both staff and participants evidencing the impact of the project against stated outcomes (Additional Case Studies included at Appendix 5):

Engagement levels -

Lifestyle Mgt. Course	1:1 Support Sessions	Signposting	Lifestyle Management Workshop	Total
23	26	8	24	75

***“I’m using belly breathing to help my sleeping and it’s working!”***

***“I’ve been more dedicated to stick to a routine and a bit of exercise. I feel better organised and am getting up at the same time, healthy routine. I feel more motivated, less scatter-brained, I know the direction I’m going during the day.”***

***“Now I have more structure and lower stress levels. I’m not over thinking, worrying about stuff as much. I’m more chilled out now, more motivated...”***

People with epilepsy feel more resilient

People with epilepsy feel more confident

People with epilepsy feel less isolated

With significant number of people have shown through data that a positive impact has been made through engagement with the service, therefore these outcomes are solid green.

Below are the WEMWBS scores for 11 people who engaged with 1:1 support:

	Pre Wellbeing Score	Post Wellbeing Score	% Improvement
Average	32.6	45.1	38%
Minimum	22	31	41%
Maximum	52	69	33%

The average increase of wellbeing score is 38%, while minimum scores rose by 41% and maximum increased by 33%. All scores saw a significant rise from before to after the support, and the biggest improvement is experienced by people with the lowest initial scores.

WEMWBS from the first Lifestyle Management course shows a 23% average increase in individual score. The average improvement of individual score is 9.1 out of a total of 70. The range of improvement goes from 1-23. This is reinforced by feedback from patients:

***"The course put day-to-day self-management at the fore of my mind, self-management wasn't ever a tactic I used...Now I have more structure and lower stress levels."***

***"It changes the way you look at the world."***

***"The 1:1 consultation has given me the motivation to pursue the goals I've set for myself."***

***"(it has given me) the building blocks of something new."***

***"My overall quality life has improved and it's up to myself to improve a lot or a little from the suggestions of the course."***

***"I've been feeling I've been getting the old me back."***

People with epilepsy have an improved quality of life

People with epilepsy increase their confidence and ability to control and effect change in their lives

People with epilepsy are more empowered to make informed decisions relating to their own care

People with epilepsy improve skills for peer delivery with people we support

As the above are longer term aims, we have had more limited capacity to capture evidence, however the following statements from participants indicate that the project has empowered them to progress towards these outcomes:

***"I have been getting so much from hearing other people's stories. I've been getting out the house more and meeting up with old work friends, even taking long bus journeys to visit people in the borders."***

***"The course gives a lot of different ways of dealing with things that you might not have thought of. My overall quality life improved and it's up to myself to improve a lot or a little from the suggestions from the course."***

***"I have better control of my health, sleeping better, eating properly, meditating."***

A participant of the first Lifestyle Management course was retained as a peer facilitator and contributed his experience of epilepsy to the second lifestyle management course. He will continue to be involved in a facilitation role going forward.

## Learning/ Challenges

Our planned delivery model was adapted to accommodate the on-going impact of Covid-19 which placed additional demands on staff capacity and reduced the numbers of patients visiting the centre. In response, staff training was modified to share learning in bite-size chunks and was disseminated with support from staff champions. We also introduced an on-line lifestyle management course in addition to our “in-person” delivery within the centre, which expanded our reach. This approach proved successful and is a model we are exploring further.

## Celebration event

We were delighted to deliver an “in-person” celebration event at the end of our funded project hosted within the WQSEC. This event welcomed participants from our Lifestyle Management Course who attended from across the country and generously shared their personal experiences which included highlighting impacts:

***“I have a new job now, I’m a happier person.”***

***“I take things at my own pace. I’m relaxing and sleeping better – that’s what helped. My seizures have reduced.”***

A Quarriers Friends group chat has been set up since the Lifestyle Management Course:

***“There’s always someone to chat to. Not just parents and friends, people with the same condition, people who know how we feel.”***

Representatives from NHS, Health (GP), Lanarkshire Epilepsy, C-Change, The Alliance, Quarriers Executive and Scottish Government were also in attendance for what was an interactive, learning experience for all involved. Feedback from a Clinical Nurse Specialist and Neurologist on the day included:

***“I realise today that a lot of these comments come up within our clinics, but our staff don’t always have the capacity or remit to help and support”*** (Nurse Specialist)

***“It would be interesting to look at those who are regularly admitting to hospital and whether this might be an early intervention for them.”*** (Neurologist)

## Future steps

Thanks to the generous support and flexibility shown by the Scottish Government, our learning and experience gained from this project enabled us to successfully apply for a further two years funding from the Health and Social Care Alliance Scotland to continue developing the approach in partnership with Thistle Foundation. This will include a focus on increasing the reach of self-management provisions for people with epilepsy through digital means.

We are continuing to deliver our Lifestyle Management Courses both in person and, as detailed above, have embedded a supported self-management culture within the centre that is sustainable for the long term. We will also continue to develop our relationship with the wider neurological community identified by the Framework for Neurological care 2020 -2025 and build on the connections that have been formed through this Government led programme.

Financial Breakdown:

ITEM	£
Salaries – Wellbeing worker and other staff	£27,583
Celebration Event and IT Equipment	£1455
Thistle Foundation	£27720
Insurance	£221
Quarriers Internal Training	£552
Quarriers Overhead Charge and insurance	£2141
<b>TOTAL</b>	<b>£59672</b>