

**Multiple Sclerosis Centre, Mid Argyll SC020476**



**End of Project Final Report**



Project Start Date: 01/07/21

Project End Date: 31/12/23

Project Lead: Karen McCurry

Report Date: March 2023



## What we have done

We worked towards achieving our goal of offering a blended delivery service to extend our reach, connect our community and improve the health and wellbeing of people living with neurological and other long-term conditions.

We supported the person, as a whole rather than just focussing on individual symptoms and helped them to know that they are not alone living with their condition but have a supportive network around them. We do this by building relationships and connecting them with others who can support them on their life journey.

People just diagnosed are better educated on their own condition, better supported to self manage their own conditions and have access to a range of therapies and activities to improve their wellbeing.

For all activities, participants now have the option of coming into the Centre or joining via Zoom from their own homes. Anyone unable to attend in person or connect digitally, receive home visits and/or texts or phone calls.

Offering different ways to connect enabled some once unable to access activities due to location, limitations of own conditions, cost of travel, limitations of public transport – these factors are no longer barriers for those with access to digital devices.

Anyone connecting with us who were not used to working online were trained to use digital devices and we sourced tablets for those who never had access to one before.

This funding enabled us to build on our strong foundations, increase our capacity, develop our wellbeing services, increase the number and variety of activities offered weekly, develop and extend the reach of our ‘lifeline’ services to improve the mental and physical wellbeing for more people affected by various neurological conditions across the whole of Argyll and Bute including people living with the impact of long covid.

We also extended our Outreach project, which covered remote mainland and island areas to include a second fulltime member of staff to visit people in their own homes more locally who cannot make the journey to our Centre or connect digitally.

**Who we support** Currently we support over 300 people living in the remote rural areas of Mid Argyll. Kintyre, Islay and Jura a population of 20,586 widely dispersed over 1084 mainland and island square miles. Our members have a wide range of neurological conditions and other long term conditions and their symptoms can vary from mild to severe and complex.

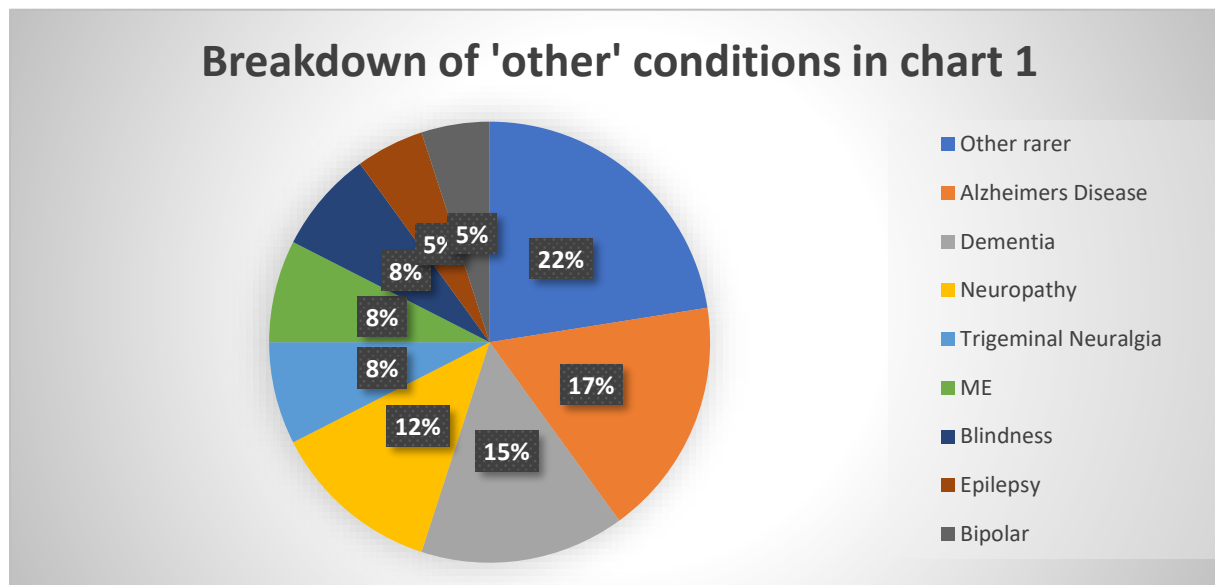
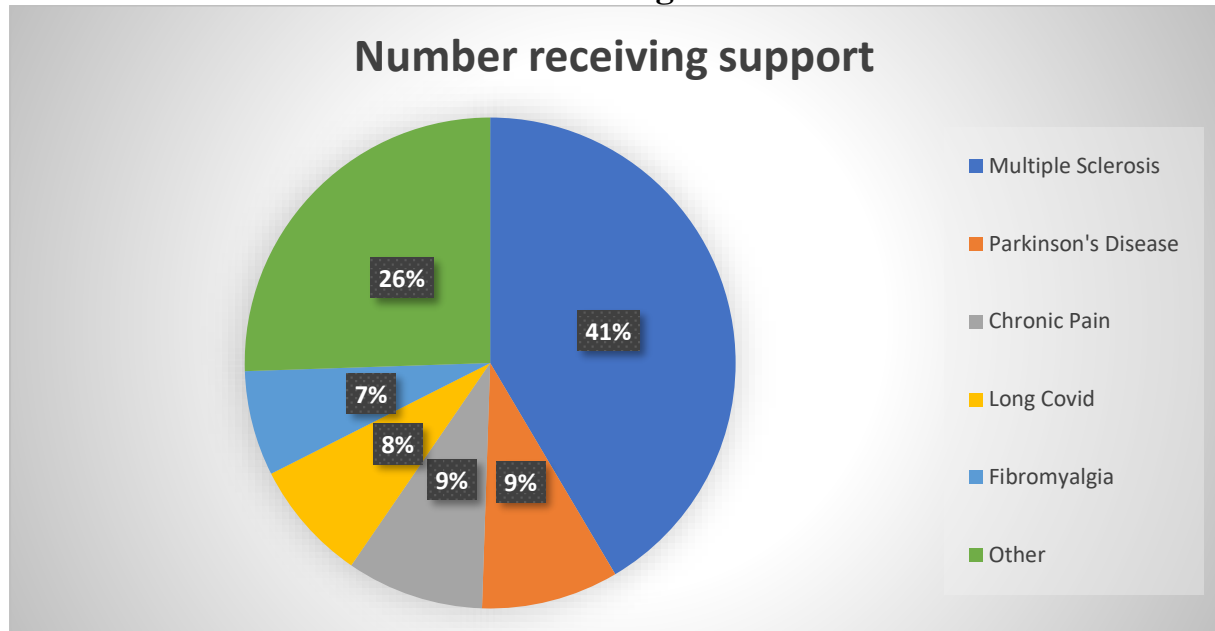
We can support them through the different stages of their journey and respond as needed to their changing requirements.

The work of the outreach team impacts the whole family not just the person with the neurological condition.

**88 families** now receive outreach support and strong, trusting relationships have formed. Post pandemic many of our members are still feeling isolated, especially those in the shielding categories - the world has opened up, but many still feel that they have been left behind still feeling clinically vulnerable - we have changed the delivery of our activities to include them.

The cost of living crisis is also having a detrimental impact on whole health, we run a warm space session and daily foodshare, many come now to talk about their mental health and fears for the future.

**Chart 1 Breakdown of Neurological Conditions**



**Breakdown of others receiving support:**  
**Carers:** 40 carers of people with neurological conditions receive outreach support.  
**Community:** Around 100 people with other long term conditions and people feeling isolated and lonely access the Centre for daily activities, for specialist information, to keep connected within their community and / or to access our food share.

## Our activities

As well as our a range of hands on therapies offered via a voucher scheme to give people choice. we also provide access to 4 oxygen machines for people to use in own homes if they can't come to us for oxygen therapy.

4 exercises classes – Cuppa Routine, Move it or Lose it, Giraffe healthcare, Movement and Memories (to allow for space between participants average is around 12 members in each class – additional 4 online )

4 craft sessions – Creating and Connecting, Crochet, Knitting and Quilting (average 12 members in each class)

2 wellbeing and self management sessions – Time to Talk, Pain Toolkit, 8 week menopause course, Participatory Photography (average 12 in each class – 6 online )  
since June 2021 we have:

- Re-established the Kintyre Parkinson's Peer Group - 9 participants
- Established a coffee and chat peer support group for people with neurological conditions in Tarbert facilitated by Outreach worker – 7 participants
- Ran 6 Digesting Science sessions for the community to educate on Multiple Sclerosis – 60 participants total
- Developed and run community sessions on using the Big Health Sleepio App, including running a weekly peer support group for people affected by poor sleep. 24 total participants
- Supported development of a peer led pain group to become established in Tarbert - 8
- Men's Wellbeing Group for men with long term conditions to improve mental - 12
- Offered ambient oxygen therapy for people with long term conditions including long covid in the Centre along with breathwork classes and access to therapists for massage for relaxation. 14
- Increased our outreach visits locally to community members affected by neurological conditions who are also lonely and isolated - 10
- We have improved wellbeing by organising outings to local beauty spots from picnics and walks around local loch to wildlife spot to an exhilarating men's trips out to the Corryvreckan Whirlpool for men affected by neurological and other long term conditions
- Re-introduced live music concerts for wellbeing – avg 20 people very 8 weeks
- Established a Participatory Photography group to encourage participants to have their voices heard. 12
- Establish a Movement and Memories group – with a different memories theme each week for people with cognition issues. 12

**Outcomes:**

- 1. I feel more hopeful and less fearful and anxious about my future** – to achieve this outcome- we use various communication resources – Talking Mats, Helen Sanderson Person Centred tools and Participatory Photography to carefully listen to what matters most to a person and create a personalised plan to help the person feel in better control and less fearful for the future. We keep them informed on own conditions, using our library of up to date condition specific resources, keeping our members connected and engaged with others, signposting to specialist agencies and accessing peer support helps reduce fear for the future and feelings on loneliness.

Example: T was feeling very lonely and hopeless after being diagnosed with ME and living in a remote rural area. She was fearful for her future and was worried she was no longer able to engage and get out on walks with her grandchildren. She was very concerned about her job having been off on long term sickness and did not know what she would be entitled to should she lose her job. After receiving home visits from our wellbeing worker who identify with T what mattered most to her we were able to support her in various ways from providing access to a mobility scooter when grandchildren visited, to arranging craniosacral therapy in own home, she was also given information on welfare advice and connected to organisations who could further help. This input and working with T has helped her feel more connected, less isolated, understood and less fearful for her future.

- 2. I receive support that increases my independence helping me feel in control and able to make my own decisions** – offering one to one person centred support, liaising with other agencies, keeping people informed to enable them to make own decision on the management of own conditions. We help people apply for the benefits they are entitled too, by being their scribe when form filling and keeping them up to date in welfare changes. We also support people who want to get outdoors for a while, offering a helping hand to do so. This may be encouraging them to have a walk in their garden with us as a companion, going for a drive in our wheelchair accessible vehicle to local beauty spot.

Example: John has MS, his wife is his carer. John found it difficult to communicate his feeling and express his needs to his health practioners. Working one to one with John in his own home using the communication resource, Talking Mats our outreach worker was able to help John express his feelings.

His wife sent this feedback:

*“Just wanted to say thank you so much for your visit last Friday. Asking John how the visit from the doctor had gone was interesting! It's also very helpful for me to hear John speak to someone else about a visit, and to get his idea of what it was all about.*

*I thought the Talking Mat session went really well-I couldn't believe how much it enabled John to speak about topics-mind you- you have an amazing way of asking pertinent questions to make John elaborate more upon his thoughts on the topic in question.”*

- 3. I feel physically stronger and have reduced my falls** – we have a staff member trained to deliver chairbased exercises and offer 3 different classes and physio to help people maintain and develop core strength to reduce falls. Those unable to attend the class can receive one to one support in own homes using our Sports Kits – that contain bands and balls to increase strength. The members of the Parkinson's Group also received these kit bags and enjoying

using them both at home and in their group. Our physio is online, however, we gather as a group weekly to exercise together with those at home joining virtually.

Example – Margaret had a stroke in her early 40s, she uses a wheelchair for most of her daily activities and would struggle to get in and out her car. She joined all our exercise classes online during the pandemic and when we could offer face to face activities her carer would drive the 80 mile round trip to enable Margaret to participate. Margaret recently proudly announced that she had managed to get out of the passenger seat of her car unaided, was standing more, taking more steps and is feeling more confident and less fearful of falling.

- 4. I sleep better at night using mindfulness techniques to reduce anxieties** – we run a weekly peer support group for those who were problem sleepers and helped them to sign up to and use the Big Health Sleepio App – we now have Sleep Peer Supporters who are sharing their learnings with others in our community.

Example: [DHCScot on Twitter: "Lived Experience Ep2 : Isobel - Improving Sleep with @Sleepio @msargyll https://t.co/WH9QhC3G3n" / Twitter](https://twitter.com/DHCScot) Isobel was not sleeping well as she suffers from chronic pain. We encouraged her to come along to our Sleep Session promoting the Big Health Sleepio App where using participatory photography resources we encourage an open conversation around sleep problems and solutions. Isobel signed up to and completed the 6 week course, which is very challenging and each week received peer support. Isobel is now delivering that course to other groups in our community. As well as sleeping better becoming a course facilitator has been a big boost in confidence and self esteem for Isobel.

- 5. I have access to community networks and support including peer support-** we run various peer support groups – Tine to Talk to look at mental wellbeing, Sleepio for those who have trouble sleeping, Participatory Photography for those who want to have their voice heard, Parkinson's Peer Group, Menopause peer support group and Island Self Management groups. We also facilitated community network days and invited local organisations and our members to come together to gain better understanding of all available support in our community.

**Example:** one lady with MS and poor mobility attended our 8 week menopause course – a self management course which looks at woman's health and focussing on what can be controlled by the individual. She gained confidence during the course to speak to her GP about HRT, as she had been taken off it. She was given a prescription again and within one week, reported that her 'MS legs' as she used to call her weak, wobbly legs were stronger. She was sleeping better as no longer suffering restless legs at night. These changes increased her self confidence, self esteem and low mood, and she signed up to our Stretch, Balance and Breathe class, before she didn't want to join groups.

- 6. I am in control of my condition and am now offering peer support to others.** – we encourage our experts to become peer supporters sharing their learnings and experience to help better the lives of others. Our experts are those with lived experience of a neurological condition and have participated in our self management courses and activities.

Example: Charlotte suffers chronic nerve pain and attends the Centre for self management support. She has completed our Change Can Happen self management course and attends our Cuppa Routine exercise class and physio class. Charlotte's confidence has been built up, she feels better connected and had a wider peer support group and is now offering peer support at a chronic pain support group in Tarbert.

- 7. I have gained digital skills and receive support from the MS Centre virtually** – we sourced devices and have trained many of our members in the use of digital programmes to keep them

engaged, connected and informed – most recently we have been offering community events to encourage the use of the Sleepio App – running community information days and helping people to sign up to and use the app. All our activities are offered in a hybrid way so people can connect both face to face and virtually. This has opened up our support to a wider audience.

- 8. My family understand the impact of my symptoms better, especially the invisible symptoms as they were invited to ‘Try on my Condition’** – we continue to raise awareness of the impact of long term conditions to individuals, their families and the wider community to increase understanding of the needs of people affected by neurological conditions.

Example: A young carer on the island of Islay was struggling to support her mum who has MS as her mum was refusing outside help, and did not want to talk about her MS, however, the daughter did want to talk and recognised she needed support. The girls teachers were concerned and asked our Outreach Worker to help. The Outreach Worker ran Digesting Science sessions for the girls whole class, so all gained an understanding and asked if anyone wanted time for a private chat afterwards. the girl came forward and now meets regularly with our Outreach Worker, who had a shared experience, having lived with a dad who had MS. The mum still refuses help from outside the family, but her daughter now has someone to speak to who understands, she has been given coping mechanisms and her mental wellbeing is better.

- 9. I learned new skills and the Centre supported me to become a volunteer** - we look at the gifts and skills our members have and encourage them to share their gifts with others as part of the own self management programmes - sharing their interest and skills helps improve their self esteem, self confidence and worth as well as keeping them connected and engaged with others.

Example – we have working in partnership with Live Argyll to encourage some of our members living with various long term conditions to gain new skills to improve their own wellbeing. We were proud when they received their first qualification. They are now working towards a Volunteers Qualification – and have formed a community Give Back group. Each week they come together to work on their assignments and to make and create items to benefit the wellbeing of our community.

## **Challenges**

Our work is an example of how the third sector can respond rapidly and successfully to challenging circumstances.

We can be very flexible, we’re used to adapting, we’re used to being resourceful.

We are small team, 3 fulltime and 1 part time but our reach is far and our impact positive.

We have never been more needed, which leaves staff always striving to do more, as we are always aware that we are not reaching all who need support. We are trusted in our communities and often the first port of call when someone is in need. The challenge here is preventing staff burn out especially at a time when Health and Social Care budget cuts and the rising cost of living place extra demands our organisation, as more people find themselves in a position of needing our support.

The results of the Neurological Alliance Survey were difficult reading, echoing the experiences of our members with neurological conditions who, without our support, say they

would feel alone as they are distressed at the lack of statutory support in Argyll, these feelings can lead to decline in mental wellbeing. We strive to prevent anyone feeling distressed, unheard, alone and fearful for their future.

Another challenge was developing a long Covid programme:- a self management course covering the various symptoms of long covid. The course was to be delivered in weekly sessions- each focussing on different controllables – sleep, hydration, nutrition, gentle exercise, breathing.

The tutors delivering the course with us, like all our tutors have lived experience of coping with post viral symptoms.

Our aim was to also work with local health teams to deliver specific areas of the course if needed by participants – for example speech and language – for anyone who may require additional support.

As the symptoms of long covid were similar to that of post viral syndrome and people suffering chronic fatigue we opened the sessions to include people with similar symptoms.

Feedback from those who had long covid changed the way we were initially working. On this occasion the peer support was not beneficial. Working in a group was causing those with long covid more worry and anxiety for the future as they were starting to feel that their diagnosis may be long term like others in the group with ME and CFS. We suggested a group for people specifically with long covid, however, the individuals affected said they would rather receive one to one support, or join activities not specifically designed for people with long covid.

We listened and re-evaluated and instead of running a long covid group the individuals received support in the ways that best suited them.

Most received oxygen therapy and some received either massage or craniosacral therapy. All were encouraged to join our various classes and benefit from the breathing techniques taught in these classes.



**Jay Helbert**

30 Aug 2022 · JustGiving · 

The MS (Snowdrop) Centre, Mid argyll supports people who suffer with all types of chronic illnesses and their families. They change lives.

Last winter I was floored by Long Covid. I had trouble breathing, focusing and even thinking straight. In addition to fabulous support from the NHS, the Snowdrop (MS) Centre provided space and therapy to support my recovery. It took 6 months but I got there and now am back, firing on all cylinders and ready to run 10k again. I'd like to dedicate this run to the folk who supported my recovery.



## Next Steps

We aim to continue to support our members on their life journey and improve their health and wellbeing by really listening to the voice of lived experience, those living with a neurological and or/other long term conditions living in rural isolation. This means not just getting people to engage but listening to what matters to them, and what they care about enough to act on. We try to clearly identify the unique needs people with long term physical and mental health conditions living in a rural area have.

We also aim to connect individuals with 3 others who do not have a medical role in their lives.

Post pandemic many of our members are still feeling isolated, especially those in the shielding categories - the world has opened up, but they are left behind still feeling clinically vulnerable.

The cost of living crisis is also having a detrimental impact on whole health, we run a warm space session and daily foodshare, many come now to talk about their mental health and fears for the future.

We are actively bringing local supportive organisations together to help us run a campaigning project, which we hope will help decision makers and service providers understand the needs of people living with neurological conditions in our rural area. This project will enable us to explore ways as a community we can best support others living with health conditions and feeling isolated and lonely to live their best lives.

We have offered a training opportunity to other organisations to equip us all with tools and resources to provide an accessible way to describe realities, communicate perspectives, and raise awareness of the health, social and community issues our members experience to different audiences to address their needs and help them to live their best lives – healthier and happier despite their life limiting or long term conditions.

Finance		
	Proposed	Actual
Proportion of 3 Staff salaries to offer blended services for 78 weeks	£53, 685	£60124
3 tutors with lived experience of neurological conditions for 3 of our classes	£5850	£1090
Online physio class with physiotherapist initial assessment support	£8190	£4672
	<b>£67,725</b>	<b>£67725</b>
Difference in proposed and actual – long covid group ceased and staff members worked on a one to one basis with individuals instead of tutors running the group.		
Physio class continues to run, led by member of staff, however, the physiotherapist doing initial assessments no longer runs her clinical work.		

## Some Stories

**Polly's story** Polly began attending the MS Centre, February 2022, after moving closer into the town following the death of her husband. Polly was feeling isolated and lonely and the move from her more rural location, was to help her engage with more people and make new friends. We knew that Polly had been an artist and thought that maybe she would enjoy some of our arts and crafts sessions, however, when receiving Wellbeing Check Ins to assess Polly's needs, skills, gifts and aspirations and identify with Polly what mattered most to her she said she wanted to exercise and improve her balance and strength. Polly was diagnosed 10 years ago with Parkinson's Disease and her balance was poor.

Polly initially came to our Cuppa Routine, a fun group we started post lockdown aimed at our older members. There are 3 exercises routines, some chair based, some standing depending on ability, that range from indoor walking to exercises of strength and balance using beach balls and stress balls. It's a fun lively class and afterwards everyone is rewarded with tea and cake. She then also joined our Giraffe Healthcare Physiotherapy class where physio exercises are completed in a group. It was at one of these sessions that Polly said 'Would you like to see my new trick' and got up on our feet and then her tip toes, with the biggest smile she announced she has not been able to stand on her tip toes since her Parkinson's Disease diagnosis. The class were delighted for Polly and she was awarded the weekly prize – a giraffe keyring. Her daughter messaged to say it was not just her mum's physical health that was improving but also her mental health and she could not thank us enough.

(Polly on her tiptoes!  
wellbeing sunflower)

Polly adding a Giraffe Healthcare petal to our community



Polly also tried our chair-based Zumba class and although she enjoyed the company she felt that was just a bit too quick for her. Although she has promised to do some of the movements from this and the other classes at home.

One of our community projects is to collect all the surplus fresh stock from our local Co-op and leave it on tables outside the Centre for the community to help themselves. Last week among the fruit and vegetables were lovely bunches of flowers. As it was Carers Week we offered a bunch to Polly to present to her daughter along with a Carers Week mug, which contained some Time Out bars. Polly's daughter is also carer to her own husband, as well as Polly's carer. The look on her daughter's face when Polly handed over her gifts and thanked her daughter for all she does and reminded her to take some time for herself was lovely. A

special mum and daughter moment for both. Sometimes the smallest gestures can have the biggest impact.

Polly has made lots of new friends and enjoys coming to the Centre twice a week.

### **Jack's story**

Jack is 26 and has autism. During lockdown Jack and his dad started coming to our food share to chat to the Centre staff. Jack has a special interest in learning about allergies and medical conditions so was keen to get to know the staff and members of the Centre.

While we were unable to offer face to face activities in the Centre we involved Jack with the smaller events we offered outside the Centre – for example, our Time to Talk day when we gave out free hot chocolate and cake and asked our community, were they okay? This was to check in on wellbeing and offer support where we could. Jack would help us give out the cakes and any information we had – our online timetable for example, to encourage connections.

When we were able to open our doors again, Jack was very keen to get involved in our various activities and after a Wellbeing Check In to identify his needs, as well as his skills, gifts, aspirations Jack joined our physio class, our Zumba Gold class, arts and crafts and our Wellbeing Check In Time to Talk sessions.

As Jack met more people his interest in long term conditions developed. He was fascinated with conditions such as Multiple Sclerosis and the different symptoms the people he met had, no one he met with MS had the same symptoms. We asked Jack if he would like to train as a Digesting Science ambassador. Digesting Science is a unique, science based educational resource to explain to children what MS is, the symptoms and treatments.



*(Above pics: Digesting Science Training)*

Jack loved training and learning with this resource and will help us the next time we run a Digesting Science event. Jack is an asset to the MS Centre, he is open about his autism and others feel comfortable talking to Jack about their own health conditions. By coming along to the Centre, Jack is learning new skills which he loves to do, is connecting with others of various ages and is staying physically and mentally active, which is helping him feel

healthier, happier and better connected in his community.



### **J's story**

This lady wishes to remain anonymous but is happy for her story to be shared.

J first approached us after speaking to the local Mental Health Team. She suffers from epilepsy, was recently widowed she was feeling very isolated and lonely. Her only close family was a son, who was struggling with his own mental health diagnosis.

During her Wellbeing Check our Wellbeing Development Worker used various Helen Sanderson resources to assess her needs, gifts, skills and aspirations. J initially told that she felt as though she doesn't exist, she felt left out from society, excluded and disconnected, she was no longer the person she strived to be. She was unhappy with her own company and although she wanted to improve her fitness and strength but was very wary since her epilepsy diagnosis of joining an exercise class, she was reassured our classes are chair based and everyone moves at own pace and ability and was encouraged to join our chair based classes and physio.

Our wellbeing worker could see the potential she did have, she is an articulate lady and had an interesting past. As well as listening to what was wrong our wellbeing worker encouraged her to focus on her strengths and gifts. She said she enjoyed crafts and photography so this became the starting point. She joined both our craft and Participatory Photography groups. It was during a Participatory Photography session that she first mentioned her money worries and the struggle she was having to heat her home. She admitted she was living in one room of her older, large house as very concerned about the cost of fuel.

We encouraged her to attend our weekly warm space sessions, and equipped her with warm goods supplies. We also invited Ali Energy and a Welfare Advisor into the Warm Space sessions to speak to all attending, as she didn't know who to approach for advice.

She also told us that the rooms in her house were very cluttered and she could not face the daunting, mammoth task of clearing them although for her own wellbeing she knew she had to.

We arranged and funded a local cleaner to visit once a week and start the process one stage at a time of decluttering. They are now working together to do this and she is starting to feel the benefit. She is also now aware of welfare money she should be receiving and has made connections with advocacy and the local carers centre.

Sleep was also a problem for her, we encouraged her to sign up to the Big Health Sleepio App and to meet weekly with the Sleep peer support group that we had established for individuals working through the app to come together and share experiences and advice.

It is early days and she has a long journey ahead, however, the small steps that she has taken with our support are beginning to help her feel less fearful for her future. She is engaging with others and building trusting relationships, helping reduce her feelings of loneliness and isolation.

**Neurological Care and Support  
in Scotland: A Framework  
for Action 2020 – 2025**

