

ME and Fibromyalgia Network

SC051578 | www.dgmefm.org.uk

Impact Report

August 2022 - July 2023

In the 2021/22 Impact Report, I wrote that I was excited to see where we would be 12 months down the line, well, here we are, and what an exciting 12 months it's been! We have been successful in securing funding for both projects and our core activities. We've launched our Befriending project and are about to launch our Peer Mentoring project; we are hosting social meet-ups across the region where we're able to provide food to attendees free of charge; we continue to offer craft and wellbeing sessions with a different taster each month and we've sustained our engagement activities, including newsletters, contact with health and social care practitioners and, of course, the very active Facebook Groups.

Our new Volunteer Co-ordinator, Kalpana, has brought a whole host of skills and knowledge to the Network and we

are about to welcome an Admin Support Officer, who will bring our staff team up to three people.

We have been very lucky to have received the assets of Edinburgh ME Self Help Group as they wind up their charity. We are saddened that the support in Edinburgh will inevitably reduce as a result of their closure but we are very grateful to them for selecting us as their recipients. The money will help to secure the sustainability of the Network for years to come.

As we move into the year ahead, I'm particularly looking forward to seeing the impact our Befriending and Peer Mentoring projects will have for some our most vulnerable members. After all, helping one another is why we do what we do.

Number of members: 402

Members of our Facebook Group: 444

Funding Secured: £35,433



- Eileen Longworth, Chair



1. Raising awareness and promoting understanding

- 92% of survey respondents said the Network is raising awareness and promoting understanding of ME/CFS, Fibromyalgia and Long-Covid
- Our stakeholders have better access to accurate information which improves awareness and understanding of ME / CFS and FM
 - Public, third and private sector organisations across Dumfries and Galloway have more knowledge, skills and confidence to effectively support the needs of people with ME /CFS and FM

"It's very existence lets me know my illness is real, not imagined by me, and that I am not alone with it."



349 Facebook Page likes (^ 40 from last year)

444 Facebook Group Members (^ 17 from last year)



"The Network was like an early intervention for me. The advice and guidance I received from people in it early on helped me recognise my condition (CFS) and gave me the knowledge and practical tips to manage my CFS, and am now much less affected by it. I feel like the network saved my life as I knew it and without it I wouldn't have recovered to the point I have."

"I feel less isolated. I know I can ask for help and advice on the Facebook group. I'm so pleased to see leaflets produced by the Network in my Drs practice and many other places. If people are recently diagnosed they now have access to help and support from other ME/ Fibro sufferers. The leaflets also help the general public understand about ME/ Fibro. I feel proud to be part of such a brilliant group"

1888 Website Visits (^ 200 from last year) 20 Blogs Shared 4 Newsletters



We have been working hard this year to develop and maintain partnerships, particularly with the local Council and NHS. These partnerships have helped us to secure additional funding to be able to deliver our services more widely. They have also meant that we are being approached by statutory services as an avenue to engaging with our members.



2. Supporting access to services and support

- 92% said the Network is providing appropriate services and support.
- People with ME/CFS and FM have better access to a range of high quality clinical and peer-led services and support which enables more timely diagnosis and supports more effective self-management
 - People with ME/CFS and FM and their carers / supporters have more opportunities to connect with their peers, which reduces isolation and increases wellbeing

We have launched our Befriending Service, to provide support to the most isolated of our members. We are also in the planning stages of our Peer Mentoring service, which will provide a hand to hold through the journey from diagnosis to living with your condition day in day out.

Our hybrid sessions have been ensuring that our monthly sessions are accessible to all members, whilst our face-to-face meet ups have been allowing members to enjoy in person connection.

Our Soup and Sandwich meet-ups have allowed people to return to face-to-face gatherings, without the concern of financial strain that is facing so many of our members during the cost-of-living crisis.

The craft and wellbeing taster sessions have enabled our members to enjoy a whole host of new activities, in the company of their peers; reducing isolation and improving both skills and confidence.

"Somewhere where everyone understands"

11 Craft & Wellbeing Workshops36 Met Up Face-to-Face55 Met Up Hybrid11 Member WhatsApp Group

- 3. Building participation, skills and confidence
- 92% said the Network is building participation, skills and confidence.
- People with ME/CFS and FM and their allies have access to high quality volunteering opportunities which build knowledge, skills and confidence and enable them to take leading roles in the delivery of services
- People with ME/CFS and FM have more opportunities to give their views, and are better able to influence decision-making and service design

We have recruited 5 volunteer befrienders to our new Befriending service. These volunteers are undergoing a period of extensive training prior to being matched with "friends".

Our monthly hybrid meetings provide our members with the opportunity to influence the views of decision makers. Each speaker who attends our sessions leaves with a clearer understanding of the needs and experiences of our members.

5 Befriender Volunteer Roles Deployed





Impact Report August 2022 - July 2023

4. Building our organisational capacity

- 97% said the Network is running smoothly
- DGMEFM Network has the required resources, plans, policies, and systems to ensure that the charity is run safely, ethically, legally, efficiently, and effectively.
- DGMEFM Network has a confident, knowledgeable, skilled and effective **Board and staff team.**
- DGMEFM Network is accessible and inclusive, and better able to support individuals from protected characteristic groups and those with more complex needs.



"The network has been a lifeline to me, when I was first diagnosed with fibromyalgia I didn't know anything about it and was quite scared of what might be in front of me. Having the support of the network helped me come to terms with it and I have also made some true friends who. I don't know where I would be if I hadn't found the group"

- £22,734 from The Lottery **Community Fund**
- £9,999 from The Dumfries and Galloway NHS **Endowment Fund**
- £2,700 from The **Communities Mental Health and Wellbeing Fund,** Round 2

Kalpana Ratnam-Roarty joined us a Volunteer Co-ordinator and **Eppie Sprung began providing us** with line management support.

Thanks to the contribution of our staff team, the Board have been able to take a step back from operational matters this year, and, instead, focus on the strategic direction of the Network.

Our Audit and Risk committee is scrutinising the Network's finances and risk on a quarterly basis and the Communications Working Group has been focusing on extending the reach of the Network, across our platforms.

We are also incredibly grateful to the Edinburgh ME Self-Help Group (SC001024) for the transfer of their assets upon their closure. They were kind enough to select us as the beneficiary organisation for £7,417.

"The network has helped me understand and come to terms with my condition. It is good to talk to people who feel the same and know you are not alone."



In this last 12 months, the Network have received funding from the National Lottery Community Fund to pilot a Befriending project and a Peer Mentoring project. The Befriending project will support members who are socially isolated, whereas the Peer Mentoring project will have a particular focus on supporting members through key transitions, such as diagnosis, learning to live with a chronic condition and adjusting to life following retirement through ill-health. The funding will last for two years and we are approaching the end of the first year (end of October).

Dumfries and Galloway NHS Endowment Fund have provided us with funding to support the delivery of our strategic plan, including membership engagement, Network promotion to health and social care practitioners, hybrid meet ups and governance support for Board members.

Finally, we received funding from the Communities Mental Health and Wellbeing Fund (Round 2) to combat the cost of living crisis by providing a free soup and sandwich meal to each attendee at our social meet ups. These meet ups promote social connections between members and reduce isolation. This funding means that no one is left out as a result of financial barriers.



"Sharing with others who understand the conditions, mutual support, caring and learning from one another. A voice on our behalf with health and care services."

Gratefully acknowledging the support of:







Foundation Scotland







Resignation of the Chair of the Board of Trustees

Chair of the Board of Trustees from November 2021 to November 2023, Eileen Longworth, has made the decision to step down from her role as Chair. Eileen's contribution to the Network has been immense and her passion and drive have helped to move the Network forward in leaps and bounds. Our sincerest thanks go to her for all of her efforts.

Diane Bond, the Secretary of the Board, has agreed to step in as Acting Chair until a permanent replacement can be decided upon.

If you are interested in volunteering as a Trustee for the Network, please reach out to us on the email: admin@dgmefm.org.uk.



AGM

Our AGM, which was initially planned to take place on 5th October, did not have enough members in attendance to be quorate. It was therefore rearranged for 2nd November 2023, both in person and online.

We're pleased to say that the meeting was quorate on 2nd November and so the AGM was able to go ahead.

The Chair and Treasurer both provided reports on the charity's progress.

The full minutes are available on request.

Faces of Fibromyalgia

In September, Fibromyalgia Action UK launched Faces of Fibromyalgia! This initiative is aimed at sharing the faces of the real people who have the condition.

Fibromyalgia affects everyone differently with some able to work full time and others confined to their house or bed. Please see the Faces of Fibromyalgia website (https://faces.fmauk.org/) and follow the #fibrofaces campaign on Facebook to see the different faces and stories.

Online Social:

First Thursday of the month on Zoom

Join us for a brew and a blether. Come and get to know us, chat, ask questions and make new friends. Sometimes we have talks or discussions from outside speakers.

First Thursday of the month. Join any time between 2pm – 3:30pm.

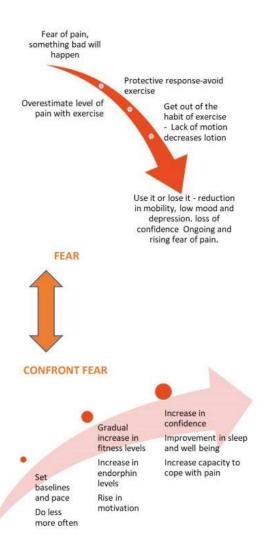
You can even bring your own cake!!

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to www.zoom.us on your computer.

Enter this info for the December meeting: Meeting ID: 843 001 5846, Passcode: 2023

Enter this info for all meetings in 2024: Meeting ID: 820 6367 4933, Passcode: 2024

Look out for updates on Zoom meeting topics and guests on our Facebook page, website or in your email inbox.



Pop-Up Meet-Ups

We have social meet ups arranged for Castle Douglas on:

- Monday 4th December
- Monday 5th February
- Monday 15th April

Please contact: paul@dgmefm.org.uk to book.

We have social meet ups arranged for Dumfries on:

- Tuesday, 16th January 2024
- Tuesday, 12th March 2024

Please contact: admin@dgmefm.org.uk for the booking link.

We are hoping to have meet ups in Annan and Lockerbie in the Spring.

Thanks to funding from the Communities Mental Health and Wellbeing Fund, we are able to offer a soup and sandwich meal free of charge at our pop-up meet-ups. Members will need to pay for their own drinks.

Check out the website and Facebook page for more info on dates / locations over the coming weeks. Alternatively, give us a call on: 07557 536 110 to find out where we'll be meeting and when.

Befriending / Peer Mentoring Project

It's Kalpana here As I'm writing this little piece for the newsletter, it's national befriending week and I thought it would be a good time to let you all know how the project is going.

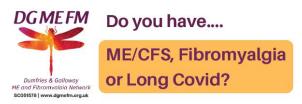
I'm excited to say that we have the first cohort of befrienders now trained and eagerly waiting to be matched. We will be running more training in the New Year.

If you would like to either volunteer as a befriender or think that you or someone you know would benefit from a befriender, please do contact me.

I am also super excited to let you all know that we have now started the Peer Mentoring part of the project.

Sadly, we didn't have a great response in our call out for peer mentors. I know there are some members who have a lot of experience and expertise in their conditions and treatment pathways and who could make such a positive difference to someone in the early stages of either being dialogised or newly diagnosed. If this sounds like you, please consider volunteering your time.

Please rest assured that I understand the potential restrictions on your energy levels and peer mentoring can be done in a variety of ways and not just face-to-face.



Are you feeling isolated or alone?

Would you like some company (online, on the phone or face-to-face), from someone who understands what it's like to live with a chronic condition?



If you would like to find out more, please do not hesitate to contact me.

Member contributions are very valued. Thank you to everyone who has contributed to this edition. If there's something you'd like to see in the next newsletter, or you feel able to write something for us, please do so and send to: admin@dgmefm.org.uk



Phone or WhatsApp: 07557 536110 Website: www.dgmefm.org.uk

Facebook: facebook.com/groups/dgmefm Email: diane@dgmefm.org.uk (Acting Chair)

paul@dgmefm.org.uk (Treasurer)



Please let us know if you no longer wish to receive the newsletter or if you want to change how you receive it. Also, if your contact details have changed or if you wish to cease being a member of the Network, please contact us on admin@dgmefm.org.uk or text or phone 07557 536110.