

June 2024

# DGMEFM Network

Support for ME, CFS, Fibromyalgia

## Welcome from the Chair



I feel honoured to have recently been elected as Chair of the DGMEFM Network and would like to introduce myself to the many members I haven't yet met or spoken to through our active Facebook group.

On a personal level, I have just celebrated my 70<sup>th</sup> birthday, I'm happily married to Peter and we live in Dalbeattie. I have a son in Stranraer with his family and a daughter in Lochaber with her family. They have given me three wonderful grandchildren and I want to be as pain-free as possible to enjoy them growing up. I'm originally from West Lothian and moved to Dumfries and Galloway in 1999 after many years in France, then Edinburgh. I love this part of Scotland and hope my health allows me to enjoy it for many years to come.

The Network is now increasing its activity level with funding which will allow us to continue the soup-and-sandwich gatherings around the region, provide a programme of summer activities, our Befriending scheme, and with other offerings in the pipeline.

We have wonderful "back office" staff undertaking admin and seeking funding and we are going out and about to hold information days to promote our services to potential new members.

We are also working with other agencies to offer free online art classes, mindfulness workshops and other helpful activities that we hope are providing mental health and wellbeing opportunities.

I personally have been diagnosed with fibromyalgia which explains the many years suffering from strange pains, IBS, chronic sleep apnoea, dry eye syndrome and all the associated gut issues that are common with fibro. I also have osteoarthritis and polymyalgia rheumatica, so I appreciate the discussions members are sharing with each other about medication, new research, relaxation techniques and so on.

It is through the DGMEFM Network that I discovered Tai Chi and now attend a weekly class, and an acupuncturist who has helped me with numerous niggles. Thank you, members and Network!

My current attitude is to stop crying over what I used to be able to do and instead, congratulate myself on everything I do manage to achieve, even if it's something as simple as being able to do a washing, hang it out and bring it back in all in the one day! Just don't ask when the ironing gets done!

Thank you for being a member of the DGMEFM Network and I look forward to meeting as many of you as possible.

Bobbie

## Drawing workshop art

From January to April, a group of our members have been participating in a series of 4 drawing workshops facilitated by Frank from Outpost Arts and organised by DGMEFM Network. Throughout this newsletter you will see some of the fantastic work created by our members. They are a talented bunch!

## Taking Art Home Art Workshops

If you fancy having a go at creating some art, you may want to join these online art sessions run by 'Taking Art Home'. Jeni Alison has shared the following information and invited our members to participate.

*Taking Art Home is a project run by Art in Healthcare for people living in Scotland who find it difficult to get out and about due to long term health conditions.*

*We have 2 online groups running weekly, and materials are sent out in advance.*

*During a series of free relaxed weekly art sessions, artist Jeni Allison will introduce you to a range of techniques chosen to promote fun and relaxing creative making. Don't worry if you can't make every week, we will have pre-recorded versions available via Youtube. No previous art experience is required.*

*We're going to have two groups - an art group where we'll try out lots of different techniques, and a more meditative sketching group. Both groups will start W/C April 22nd and will run for 10 weeks. The last week of this block will be W/C June 24th. You can join one or both groups:*

### 1. **Taking Art Home art group – Wednesdays 2pm**

*Relaxed weekly art class exploring different materials and techniques. Activities will be suitable for doing from home, and can be adapted to suit any access requirements.*

### 2. **Taking Art Home online sketching group – Thursdays 10am**

*Sketching group travelling around Scotland and internationally from your living room. You'll receive a sketchbook and some art materials in advance.*

*We hope that these classes will be chance to take time out of your week to do something creative and will let you meet likeminded people facing similar circumstances. We'd love you to join us, to register your interest please contact Jeni - [jeni@artinhealthcare.org.uk](mailto:jeni@artinhealthcare.org.uk)*



By Lorna Bias

## Dumfries and Galloway College Information Day

ME Action Scotland estimates that around 58,000 adults have been diagnosed with ME while over 270,000 adults are affected by Fibromyalgia. As it is often difficult or a lengthy process to obtain a diagnosis, these figures may not represent the true magnitude of the situation.

The mission of the DGMEFM Network is therefore to spread information and offer support to people with these conditions throughout our region.

In April, the Network was fortunate to have been given an information stand at Dumfries and Galloway College at the Dumfries Campus where two of us met with numerous students and staff too.



Although we don't work with minors under 18, the spread of ages amongst the over-18 students made sure that we were able to speak with people, mainly female, in a broad age range.

We distributed information leaflets about Fibromyalgia and ME along with our own and signed up more than half a dozen new members. As they came from around what we used to call Dumfriesshire, we were able to invite them to events such as our Annan soup-and-sandwich lunches. As you know, the DGMEFM Network is not a Dumfries-centric organisation.

We also hope to organise an information stand at the Stranraer Campus in the new academic year and have been invited to return to Dumfries.

Please feel free to pass on our details to anyone you may know who has recently been diagnosed with either condition or has been too shy or wary to contact us in the past.

Bobbie

## Relaxation Techniques

We have put together a set of relaxation techniques which are free to download from our website.  
<https://dgmefm.org.uk/resources/>

Just in case you have a preference, one set is read in a male voice, the other in a female voice. Both are the same length, just over 37 minutes.

If you'd rather borrow one of the original CDs that were produced by NHS Fife and gifted to us by EDMESH (Edinburgh ME Self-help Group), we have four copies in our Library. Please contact [diane@dgmefm.org.uk](mailto:diane@dgmefm.org.uk).

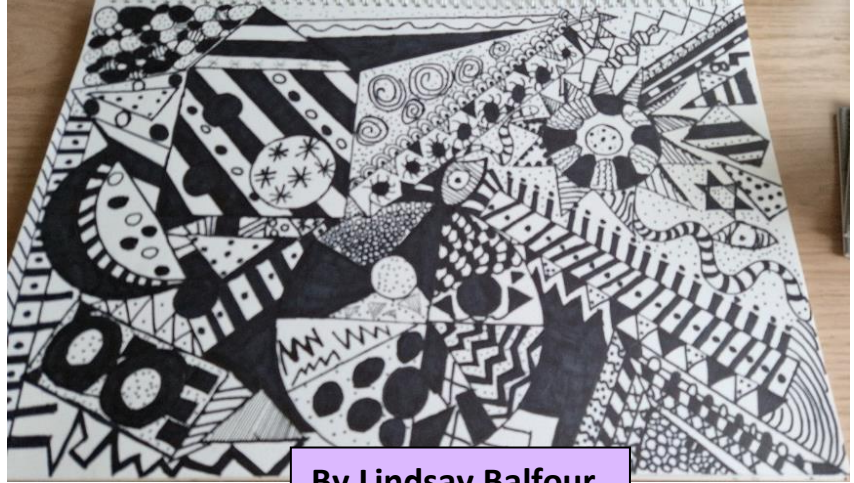
We do hope you find these helpful and please don't hesitate to send us your feedback.

Bobbie

## Pop-Up Meet-Ups

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 (at Castle Douglas meet up drinks are provided due to venue).

Check out the website and Facebook page for more information 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.



By Lindsay Balfour

**Castle Douglas** - Monday 10<sup>th</sup> June at Gordon Memorial Hall at 1.15pm

Please book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/castle-douglas-meet-up-tickets-828615440087>

Next date for your diary at Castle Douglas is Monday 9<sup>th</sup> September – same time and place.

**Annan** – Friday 14<sup>th</sup> June at Queensberry Arms Hotel, High Street at 12 noon.

Book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/annan-meet-up-tickets-893635627217>

**Dumfries** – Tuesday 23<sup>rd</sup> July at SnaQ (Queen of the South Arena) at 11.30am

Please book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/dumfries-meet-up-tickets-901341254957>

**Stranraer** – Thursday 1<sup>st</sup> August at Rustique Cafe, Commerce Rd at 12.30pm.

Book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/stranraer-meet-up-tickets-901335427527>

Booking on Eventbrite confirms your space. No actual ticket is required. If you have any difficulty with booking or any queries, please contact [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk).

### Still not sure about coming? Here is some recent positive feedback from members.

- It was lovely to see everyone yesterday. The group are very friendly and welcoming. See you in June.
- It is a great way to feel connected to others in the same situation as yourself.
- We really enjoyed our time together with you all, it was lovely so here's to the next time.
- Thank you Paul and all concerned for making our lovely meet up with each other. (Husband) and I thoroughly appreciate and enjoyed our time together with all who attended, and for the information that we shared.
- Just done the survey with (daughter). She is still talking about yesterday, it definitely left an impression 😊
- Also thanks for such a good lunch at St Ninian's church its nice for a catch up, some new faces as well.

## Befriending and Peer Mentoring Project

We now have a group of befrienders and peer mentors who are trained and ready to find someone to be paired with. Two of our volunteers have created a bio so that you get to know them a little bit better.

If you would like to have the support of a Befriender or a Peer Mentor who can support you with navigating a new diagnosis, learning tips and techniques to deal with symptoms or have someone you can chat with who understands, please email [kalpana@dgme\\_fm.org.uk](mailto:kalpana@dgme_fm.org.uk) who can discuss your needs and pair you with someone suited to you.

### Corrie - Befriender and Peer Mentor



Hi all, my name is Cornelia Lee-Schrijver. "Corrie" for short. Born in the Netherlands, I moved to Britain in 1977, and lived for 18 years in Garnkirk, just east of Glasgow. Now I live just below the Scottish border. I have a husband, Frank, 3 grown up children, 2 grandchildren. Pre ME my hobbies were; I was a dancer and musician, a potholer and hill walker. I was diagnosed with ME (Lyme, fybro etc.) after I fell seriously ill in 2018. After 6 weeks spent crying on the floor, I slowly managed to get some useful movement back, only to crash very severely again after following doctor's advice. I never recovered from that second major crash and have had to re-invent myself to stay positive. After 6 years I can occasionally go out socially and can also walk or drive short distances. I work a little on crafts and do little bits of gardening. I know from lived experience that in the early (acute) stages of ME, it is almost impossible to get good information about how to best deal with the situation. Also, the friends I used to do things with gradually fall away as they carry on with their own lives. Then we exist in a kind of time warp where nothing is the same anymore, and 'normality' has become a word without meaning. Having had much needed good input from some DGMEFM members in my early days, I now hope to be able to help other sufferers along the journey to regain some of their life.

### Rhian - Peer Mentor

I'm Rhian, rhymes with Ian ☺, and I am one of the newly trained peer mentors. Brought up in Staffordshire in the English Midlands, I moved to Dumfries in 2012. My work and hobbies were all very active, with jobs in wildlife conservation and helping people walk and cycle more. In 2018 I was diagnosed with Chronic Fatigue Syndrome (CFS), after several months suffering with post-viral fatigue. The members of Dumfries and Galloway ME and Fibromyalgia Network were invaluable, helping me understand my illness, even before my diagnosis. With their support, I came to terms with my new boundaries, learnt about pacing and felt enabled to make decisions in my life to help avoid relapses of fatigue. After 6 years, I am still very much living with CFS, but feel capable of around 80% of activities I did before I became unwell. A fantastic improvement on the times I was at around 10%. I am keen to help people through the peer mentor scheme, who may be going through a similar experience.



# Hidden Disabilities Sunflower Scheme

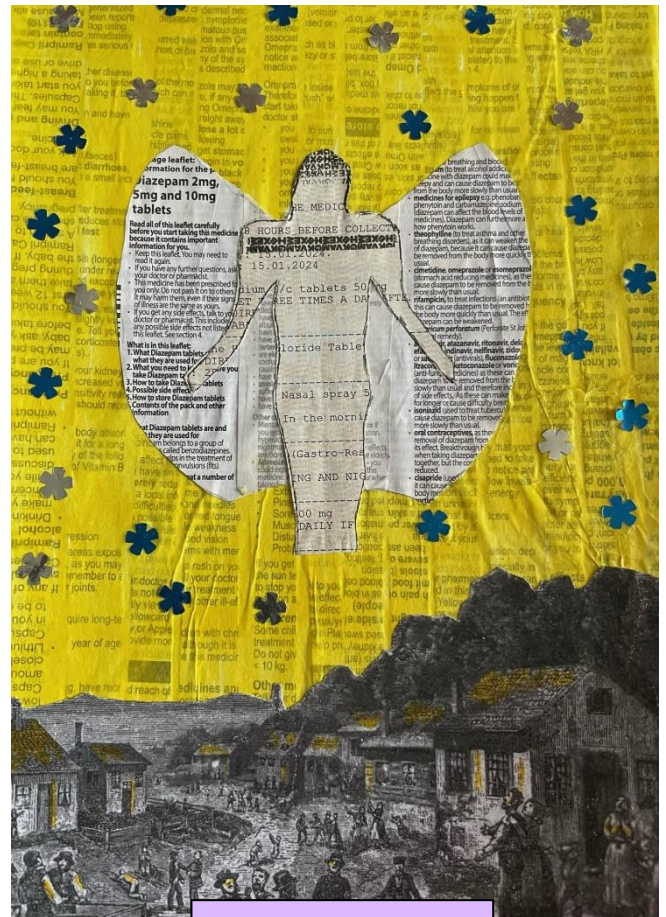
To quote the official website, *“Some disabilities, conditions or chronic illnesses are not immediately obvious to others. For some people, this can make it hard to understand and believe that someone with a “non-visible” condition genuinely needs support. Some people question whether you have a disability because you don’t look ‘like you have a disability’.*

*That is why we created the Hidden Disabilities Sunflower - to encourage inclusivity, acceptance and understanding.*

*It is a simple tool for you to share that you have a hidden disability voluntarily. Simply by wearing the Sunflower lanyard, you’re just letting everyone know that you might need extra help, understanding, or just more time.”*

For me personally, it has been an absolute boon when travelling, not being able to rush, or stand in queues for too long, or suffering an IBS episode, for example. So many more businesses around the world are now recognising the Sunflower and everywhere I go, I speak to staff in businesses to suggest they ask management to sign up if they haven’t already done so.

Bobbie



By Dawn Rhodes



Read more on the Hidden Disabilities Sunflower website: <https://hdsunflower.com/uk/insights/post/for-people-with-non-visible-disabilities>.

## Disability Rating Scale

The ME Association have produced a Disability Rating Scale that expands on the illness severity definitions recommended in the NICE guideline on ME/CFS. It is more detailed and relevant, can be used to explain your current situation to others, in medical or benefit discussions, and as an aid to monitoring progress. The scale is in % where 100% is the most severe and 0% is deemed as recovered. It also includes a helpful link to PIP descriptors, and how points are awarded. This document can be downloaded from The ME Association website or through this link <https://meassociation.org.uk/literature/items/disability-rating-scale/>



### MEA Disability Rating Scale on ME/CFS

*How symptoms and ill health impact all aspects of everyday living*

## Online Social Meet-Up: First Thursday of the month

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.

We meet on the first Thursday of every month. Meetings take place over zoom only for the time being. Join any time between 2pm – 3:30pm.

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to [www.zoom.us](http://www.zoom.us) on your computer. Enter this info: Meeting ID: 820 6367 4993, Passcode: 2024

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



By Jennifer Smith

## Acupuncture taster sessions

In April, the Network offered acupuncture taster sessions in both Annan and Castle Douglas, stemming from a suggestion from a member.

Eldene attended the Castle Douglas session and has written this piece about how it went.



*Matthew (the practitioner) was refreshingly very knowledgeable about fibromyalgia which immediately set me at ease. He asked pertinent questions (my life, traumas, how/when I was diagnosed etc) and I did not feel ridiculous when my speech went weird. My amazing husband waited patiently whilst I had my session.*

*I can't say that I felt any different upon leaving. Matthew did stick 4 x the minutest ballbearing-like pressure attachments to my outer ear and 1 larger one to my forehead. The last one was to help with my sleeping struggles. I truly can't say that it made falling asleep nor staying asleep any better bar one good nights sleep - but I'll take that thanks! The treatment to my lower legs and feet certainly had a marked difference. I've experienced much less spasms & twitches in my lower limbs.*

*I will definitely recommend anyone to try acupuncture. It honestly is not painful and if any area does feel a tad uncomfortable, you just have to say so to the practitioner as all of us have different thresholds. Thank you for an interesting event I probably wouldn't have considered or tried on my own steam.*

Eldene

## Quiz Night

DGMEFM network will be hosting a pub (without the pub) quiz which you can participate in without moving from your home! It's a night out – but in!

Gather together your family, friends – even the dog! – and create your own team. Teams can be 1 – 6 players. If you have more people – just have 2 teams!

Put Wednesday 19<sup>th</sup> June at 6.30pm in your diary and start getting your team together. It will be a fun night so we want to see as many of you as possible! Here is the link but I'll also send it out by email nearer the time.

<https://us02web.zoom.us/j/82240570644?pwd=NnZ3ZkpxWVBXV1dsWGhCVU9ZZlI3UT09>

Meeting ID: 822 4057 0644

Passcode: 550367

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](mailto:admin@dgmefm.org.uk)

## Take a Moment

Be still.

And in that stillness  
A moment, a moment,  
a moment of quiet.

And in that quietness  
A moment, a moment,  
the blink of an eye.

And a vision of peace,  
in that moment.



Paul

**DGMEFM**



Dumfries & Galloway  
ME and Fibromyalgia Network  
SC051578 | [www.dgmefm.org.uk](http://www.dgmefm.org.uk)

Phone or WhatsApp: 07557 536110

Website: [www.dgmefm.org.uk](http://www.dgmefm.org.uk)

Facebook: [facebook.com/groups/dgmefm](https://facebook.com/groups/dgmefm)

Email: [bobbie@dgmefm.org.uk](mailto:bobbie@dgmefm.org.uk) (Chair)

[paul@dgmefm.org.uk](mailto:paul@dgmefm.org.uk) (Treasurer)

**OSCR**

Scottish Charity Regulator  
[www.oscr.org.uk](http://www.oscr.org.uk)

Registered SCIO  
SC051578

*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](mailto:admin@dgmefm.org.uk) or text or phone 07557 536110.*