

December 2024

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome from the Chair

As we head into the winter proper, I hope that members with worries about changes to their benefits or, in many cases, how to cope without the Winter Fuel Allowance, are making full use of the various services we have signposted throughout the year. These include the excellent advice given by [Citizens' Advice](#) and [FMA UK](#).

In the meantime, I am very pleased that we've been able to welcome several more trustees onto our Board since the October AGM, actually doubling the previous number after one resignation due to ill health. During December, we'll be meeting them at an induction event and hopefully introducing them to members at future events. You'll find their names and photos later on in this Newsletter and I trust you'll be hearing more from them in the coming months.



Behind the scenes, our fabulous Network Development Manager, Eppie, has been working hard in applying for grants (please, Santa!) while Christine has again weaved her magic spell to put together these newsletters and keep the back office running. Paul continues to run the accountancy side of the Network, which is no easy task and one that he has to keep on top of as we now report to the Scottish Charity Regulator, OSCR.

We've had a busy year with changes in the Board, new trustees, an extra summer activities programme and such a range of events on offer. I can't believe that I've been able to make chocolate, go carriage driving and throw pots - onto a wheel, I hasten to add, not around the kitchen. Our new trustee, Caroline, has demonstrated wreath-making just in time for Christmas, although I've noticed people putting these up at other times of year too now, like harvest time or to welcome in the spring. Once you know the technique, it's up to you how you want to decorate your wreath.

I do hope even more members will be able to join in with the 2025 programme and don't be shy, ask us if you'd like to attend an event, but just need a lift. We could try to match you up with a fellow driving member, if that's all that's stopping you from attending.

Thank you to each and every one of you for being a member and supporting the Board. It only remains for me to wish you the happiest possible festive season with very best wishes from the Board for 2025.



Bobbie

Who's who in the Network

We are delighted to have some more trustees to join our Board and are very grateful to them for agreeing to support the work of the Network. Here are the names and faces of our current trustees and staff.

Trustees

Bobbie Jeal - Chair



Paul Thompson – Treasurer



Lesley Grieve – Secretary



Corrie Schrijver



Julie Dawes



Sarah Chadfield



John Faircloth-Wood



Caroline Maybank



Staff

Eppie Sprung – Development Manager



Christine Aitchison – Admin Support



A huge thank you goes to Diane Bond for her service to the Network as a trustee, secretary and acting chair.

Competitions

We have not one but TWO competitions for you to have a go at!

The first is a **poetry competition** which will be independently judged by Pam Mellor, a local published poet. Your poem can be on any topic you wish and take any form or length – let your creativity flow! Entries should ideally be typed and emailed to christine@dgmeffm.org.uk. If you will have difficulty with this, send me an email and we can arrange an alternative option.

The second is a **recipe competition**. We would love to start including 'Quick Fix' recipes in our newsletters – easy to prepare and make meals which we can make on 'bad' days when energy or pain stops us from achieving much. They should be yummy and have some kind of nutritional value! The entered recipes will be included in the next few newsletters. A winner will be picked at random.

Prizes for both competitions will be a £20 gift voucher which can be used in local garden centres. Entries should be with Christine by **Wednesday 15th January 2025**.

Pop up Lunch Meet-Ups and Events

Thanks to funding from the Communities Mental Health and Wellbeing Fund, we are able to offer lunch free of charge at our meet-ups. Members will need to pay for their own drinks (at Castle Douglas meet up drinks are provided due to venue).

Annan – Friday 6th December at Westlands Country Park at 12.30pm

Book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/annan-meet-up-tickets-947906713497> or email christine@dgmeffm.org.uk

Dumfries – Tuesday 10th December at The Hitching Post, Eastfield Drive, Dumfries at 12.30pm.

Please book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/dumfries-meet-up-tickets-972084740627> or email christine@dgmeffm.org.uk

Castle Douglas – Monday 3rd February at Gordon Memorial Hall at 1.15pm

Please book your FREE place for lunch using the Eventbrite link <https://www.eventbrite.co.uk/e/castle-douglas-meet-up-tickets-1067530294849?aff=oddttdtcreator> or email paul@dgmeffm.org.uk

Stranraer – next lunch meeting to be confirmed.

Check out the website or Facebook page for more information on dates over the coming weeks.

Booking on Eventbrite confirms your space. No actual ticket is required. If you have any difficulty with booking or any queries, please contact christine@dgmeffm.org.uk.

emergence | ɪˈmɜːdʒ(ə)ns | noun [mass noun]
the process of becoming visible after being concealed

DGMEFFM Network is offering an exciting wellbeing activity for January 2025: **Emergence: Creating Mixed Media Self-portraits.**

Mixed media art is made using a variety of mark making media (pencils, oil pastel, paints, marker pens, ink stamps, etc.) and a variety of collage materials (paper, magazine or book pages, photographs, stickers, cards, etc.).

For this particular activity we have three goals in mind. First, we are offering it as an online wellbeing activity to boost our sense of self-confidence, belonging, as well as our right to be seen and to take up space in the world. Second, we want to raise awareness about hidden conditions and disabilities like the ones we cope with. Third, we want to raise awareness of DGMEFFM Network and attract new members.

Frank Hayes, who has led some of our previous art workshops, will be facilitating. He has offered to assist us in finding a venue to exhibit our self-portraits in early 2025. We think this could be an excellent way for our network to raise awareness and help new members find their way to us. We hope you'll consider showing your artwork, and we will keep you updated as more details become available.

The workshop will be online via zoom, part 1 on January 10th, 2:00pm – 3:30pm and part 2 on January 24th, 2:00pm – 3:30pm. You should be available for both sessions when booking. To book your place, email christine@dgmeffm.org.uk with your full name and address for posting out resources.

D Rhodes

Smart Phone, Smart Photography Workshop

The beautiful surroundings of Shambellie House, New Abbey, were the setting for a photography workshop attended by six members as one of the DGMEFM range of summer activities.

We were treated to an entertaining few hours under the guidance of tutor Keith Walker who knew how to deliver a course that was not only interesting and helpful, but done in a fun manner.

We were allowed to wander through the house to take test photos and would have been out in the lovely gardens too, had the rain not been lashing down.

We learned how to visualise a photo subject in “thirds”, how to use “lines” to best situate our subject and we downloaded an app that will help us process our images on the spot. We’re all ready now to snap our way around the region – better watch out!

We were also treated to a delicious lunch from the local Loch Arthur Shop, served by no less than John Stewart, Chair of the Shambellie Board of Trustees and a direct descendant of the family that originally built this stunning house.

Thanks go from us all to Keith, John and the DGMEFM Committee for making this possible.

Bobbie

Chocolate-making workshop at The Cocoa Bean Chocolate Factory

Another great outing was enjoyed by a dozen of us in August to the Cocoa Bean in Twynholm where we took part in a chocolate-making workshop.

Duly attired in our hair nets and purple aprons, we all stared goggle-eyed at the mixers containing the liquid chocolate, both milk and white, while before us on our tables was an array of pots containing a variety of sprinkles and sweetie toppings.

Our young tutors provided all the materials and explained clearly and patiently how we should use them. We decorated large chocolate slabs, filled truffles with tasty flavours like salted caramel or strawberries and champagne, and poured chocolate from a tub onto cellophane to make a lollipop.



Like they say, every picture tells a story, so here is a selection to prove how much we enjoyed ourselves.



Bobbie

Consultation Findings

In the spring / summer of 2024, we carried out some engagement activities to gather the views of both our members and health and social care practitioners on the Network's direction of travel.

Members:

66 people responded to an online survey that was distributed across social media and by email.

23 participants took part in engagement activities across three in-person social meet-up sessions.

4 additional people responded to the engagement activities across the Network's social media platforms (Facebook and WhatsApp).

Health and Social Care Practitioners:

19 took part in face-to-face interviews and group sessions.

10 responded to an online survey that was distributed by email. Questions related to the Network's current activities, the current programmes of work, gaps in our services and the prospect of a Network Wellbeing Officer in the future.

Conclusions / Recommendations

In general, people are finding the activities of the Network of benefit.

Recommendation 1 –

Retain the activities of the organisation to continue to provide benefit to people with the conditions.

Recommendation 2 –

Further raise awareness of the Network and its activities with health and social care professionals across the region.

The primary reasons behind the lack of uptake in the befriending and peer mentoring project include a failing in the marketing and promotion of the opportunities and the limitations faced by people as a result of living with the conditions.

Recommendation 3 –

Ensure that any future projects have a marketing budget within them and that any job description includes marketing and promotion – both to individuals with the conditions and to health and social care practitioners.

Recommendation 4 –

Should the befriending and peer mentoring activities continue, focus should be placed on ensuring that people understand that the opportunities are accessible as possible for people with the conditions. For example, making it clear that there are opportunities to connect in ways that require low levels of energy such as phone or text contact as opposed to meeting in person.

There was a clear appetite for both further activities with a wellbeing focus and the introduction of a Wellbeing Worker within the Network.

Recommendation 5 –

Source funding to continue the deliver wellbeing activities that focus on a reduction in social isolation.

Recommendation 6 –

Source funding for a Wellbeing Worker who would:

- Co-ordinate Network wellbeing activities
- Support members to take advantage of the wellbeing opportunities that the Network offer
- Support befrienders / peer mentors
- Provide signposting to other services
- Be a point of contact for the most vulnerable and newly diagnosed members
- Be a single point of contact for health and social care professionals
- Undertake marketing and promotional activities to raise awareness of the Network with both health and social care professionals and people with the conditions.

Eppie

Online Monthly Meet-Up: First Thursday of the month

We meet on the first Thursday of the month. Get to know us, chat, ask questions and make new friends. Sometimes we have talks or discussions from outside speakers. Meetings take place over zoom at 2pm – 3:30pm.

Join using this link :

<https://us02web.zoom.us/j/82063674933?pwd=VjJ3RjVDY3VnUGpkSGVUQWQzR1RGZz09>

Or enter this info into zoom: Meeting ID: 820 6367 4993, Passcode: 2024

5th December speaker – Jamie Crook from Social Security Scotland

Please note that meetings are recorded. Feel free to leave your camera off if you don't wish to be seen.

If you would like a link to the recording to watch at a time of your choosing, please contact Christine by emailing christine@dgmefm.org.uk or find it on a Facebook post.

There will not be a meeting in January due to it being the festive period.

6th February speaker – Mandy Cairnie from Capability Scotland (see below)



Mandy Cairnie
Self-Directed Support Link Practitioner
Dumfries & Upper Nithsdale

What is Self-Directed Support (SDS)

Self-directed support is the way Scotland delivers social care and support. It is for everyone who is eligible for social care in Scotland, and it is designed to enable people with support needs, of all ages, to live an independent life, and for unpaid carers to have a life outside of caring.

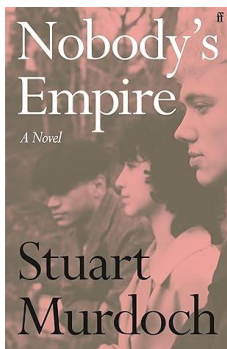
How can Capability Scotland help?

At Capability Scotland we strive to ensure that support services relate to the personal outcomes (that matter to the supported person), and the persons needs and wishes are communicated clearly and effectively. We ensure individuals are treated with dignity and respect, and their contribution is valued.

Fancy a good read?

Penny Lilley, a member, got in touch to tell us about a novel by Stuart Murdoch of Belle and Sebastian fame called 'Nobodies Empire' which is semi-autobiographical and recounts his experience of developing ME in his early twenties. It is also about spirituality and music. Below is a link to a Guardian interview with Stuart about his book.

<https://www.theguardian.com/books/2024/sep/28/stuart-murdoch-i-feel-like-this-book-will-be-the-trainspotting-of-me>



This book has a 4.8 out of 5 stars rating on Amazon and the following reviews were given.

'As memorable as it is moving.' *The Times*

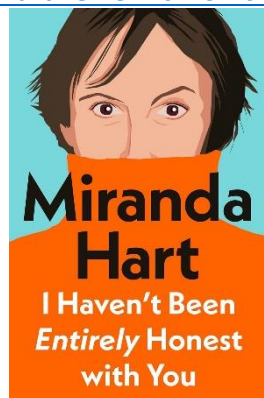
'A marvellous coming of age novel.' ROBERT FORSTER

'His most personal work to date . . . poignant but also darkly humorous.' *Irish Times*, Lauren Murphy

It is available to buy on Audiobook, Kindle, hardback or paperback book.

There has also been some discussion on our Facebook group regarding Miranda Hart's new book 'I haven't been entirely honest with you' which she has written since her diagnosis with ME. Below is a Guardian article reviewing her book.

<https://www.theguardian.com/books/2024/oct/10/i-havent-been-entirely-honest-with-you-by-miranda-hart-review-chronic-illness-and-love-at-last>



This book has been given a 4.2 out of 5 rating on Amazon and shares these reviews

'A bombshell, moving, inspirational. Hart passes on the tips that helped her emerge from psychological as much as physical doldrums. **No comedian, female or male, has been so taken to the nation's bosom since Victoria Wood'** *Independent*

'Irrepressible and joyous. Taking us affectionately by the hand, Miranda takes us through her ten-year journey to deep self-knowledge' *Daily Mail*

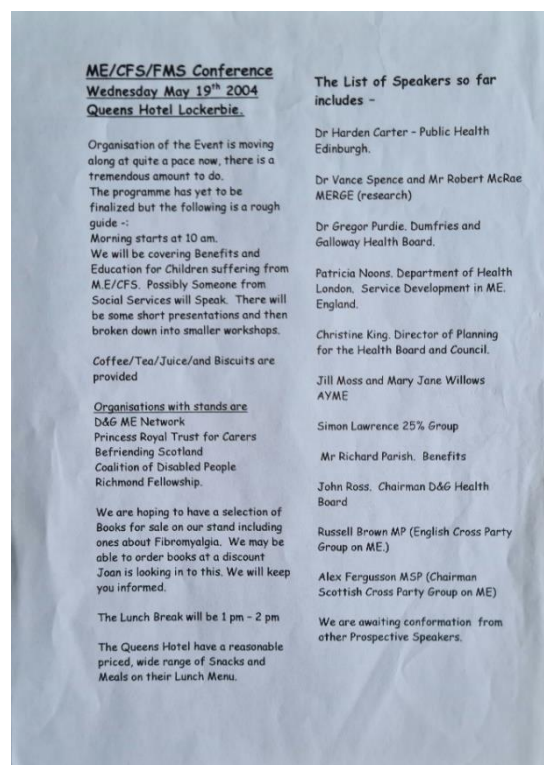
'A wonderful book, filled with treasure' *Julia Samuel*

It is available to buy on Audiobook, Kindle or hardback book.
Maybe these could be added to your list for Santa?

Christine

2004 ME/CFS/FMS Conference

DGMEFM Network has been working hard for its members for many years! Paul, our treasurer, has found this document showing an agenda for a conference 20 years ago which the Network attended. As you can see there were lots of influential people in attendance sharing their knowledge and work. I wonder if any of our members attended?



Powertex workshop

In September and October, we had zoom workshops delivered by Northstone Art on using Powertex – a liquid material which is a primer, paint, glue and varnish all in one. In the 2 sessions, our members made a piece from a CD or CD case and were encouraged to create another from things they had at home. It was a really enjoyable experience and these are some of the pieces members created.



By Irene Turner



By Irene Turner



By Lorna Bias

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@dgmeffm.org.uk



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