

December 2025

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Best wishes for Christmas and New Year from the Chair



As I write this, the Christmas adverts have already been showing for the past few weeks on TV and I must admit that the supermarkets and big stores are each outdoing the other this year and I'm actually enjoying watching them. And Christmas wouldn't be Christmas without the Coca-Cola trucks, all brightly lit up, on our screens. Or would it? Because I'm a wee bit fed up with the Americanisation of Christmas in this country – apologies to any American members reading this.

"Holidays are comin', holidays are comin'" goes the Coke jingle. But for me, "the holidays" were that wonderful six- or even seven-week period in the middle of the year when we didn't have to go to school and included the Edinburgh Fortnight and the famous Glasgow Fair. Of course, the Scottish weather wasn't always conducive to lying on a beach or tramping through The Highlands, but it was still "the holidays".

I see this American term being used more and more often in this country and it must be even more galling for the religious amongst us. What's wrong with Christmas and New Year? Or the festive season?

Of course, Coca-Cola is also responsible for the creation of the rosy-cheeked, rotund Santa Claus dressed in a red costume who delivers presents to good children. But this Santa was a marketing ploy created by Coca-Cola and, in the spirit of Americanising things, we've practically forgotten that he was based on the original Sankt Nikolaus (Germany), le Saint Nicolas (France) or Sinterklaas, a term which Dutch settlers took to the United States and which developed into Santa Claus. St Nicholas' Day is still celebrated on December 6th in many parts of the world.

But let's not be grumpy about Americanisation, let's be full of good cheer instead. A very merry Christmas to you all and a healthy, guid New Year.

Bobbie, Chair

Wellbeing Worker Update

Hello everyone,
Thought you might like a wee update on what I've been up to these past 6 months. I can't believe it's been half a year already! I've been a busy bee organising activities and meeting lots of people. Some of the activities we have taken part in are:

- Iris folding with our very own Paul
- Zen Tangles, which I had the pleasure of doing in CD and Dumfries
- Swimming at a private pool in Annan
- Japanese head massages in Stranraer
- Expressive Writing Workshops, online
- Mandala Dot Painting in Annan, Dumfries and Stranraer with me



- Marbling with me at our AGM, which resulted in some lovely cards
- Geli Printing in Whithorn
- We have, of course, had the regular lunches/meet ups across the region too

We are all looking forward to Christmas lunches as well. These are like the workshops, open to any members to attend. You don't need to only go to your 'local' one.

Things to look forward to in the New Year

- Sound Baths across D&G
- Online Music groups
- More Geli printing
- Chair yoga
- Lino cutting
- Cyanotype printing
- Cupcake making and decorating
- Planetarium
- Gin Distillery
- Pottery painting
- Escape Room
- Tullie house
- Kelvingrove museum



Please do keep giving me your requests and I will try and sort as many of them possible 😊



Other things I have been up to are a number of health and wellbeing fayres across D&G, promoting the Network. We will be having another round of Befriending and Peer Mentoring training, so please think about whether this is something you would like to volunteer for or something you would like to access. I have also been meeting potential new members in some of our outlier areas such as Whithorn, Upper Nithsdale and Canonbie. If you live somewhere you would like the Network to have more of a presence, please let me know. I have also been busy visiting GPs and other health care providers. I have been popping into huddle meetings with Home Teams and generally inviting myself along to things. I am now a member of the Third Sector Wellbeing Forum and the Health and Social Care Forum, where I represent the Network and our members to ensure our voices are heard by other services and decision makers.

As always, I can be reached at kalpana@dgmefm.org.uk or 07761 048514. I am in the WhatsApp groups and messenger group so can be contacted there too.

Wishing you all a wonderful, relaxing Christmas and a peaceful New Year. See you in 2026!!

Kalpana, Wellbeing Worker

Post-Exertional Malaise

You'd think I'd know better! Over 20 years of living with ME, navigating its twists and turns to find what works best for me to keep on an even keel. Learning to recognise the early signals that I've been overdoing it and need to ease off for a while. Balancing physical, mental and emotional energy – not always feasible, but managed as best as possible. Until this summer, in late July, with a sudden and harsh reminder of how fragile that balance is, taking until mid-October to get back to my 'normal'.

I'd been given some exercises by the physio to help support an arthritic knee and found they were being beneficial. I was then given some new exercises but one of them triggered an old whiplash injury, which in turn triggered an onslaught of ME symptoms. I wondered at first if it was Covid, but tested negative. Straw and camel's back comes to mind. Just one small extra exercise bringing all that on. I'll spare you the details but let's just say it was scary, and I really don't want to go there again.

My body screamed STOP. I was back at square one, as bad as when I first got floored with PVFS, so I knew I had to cancel everything for months ahead – it would not be for just a few days. I was due to take a short break with family in September – not going to happen. It's hard dealing with their disappointment and trying to explain that I know I won't be able to go, and my need to take the pressure off expectations. There has to be space for me to gradually manage a recovery. The worst of the symptoms passed in a couple of weeks, but it took very little exertion to set them off again.

So, after taking slow, slow, steps to find my baseline again over the past few months, I'd say I'm back to my normal now.....but cautiously.

Paul

£4.5 Million Funding for Long COVID, ME/CFS and Other Similar Conditions

In late September 2025, Neil Gray, the Scottish Government's Cabinet Secretary for Health and Social Care, announced to Parliament that annual funding of £4.5 million would be allocated to Health Boards for new specialist support for Long COVID / Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS) and other similar conditions. After listening to Health Boards' concerns, Mr Gray also announced that this would be recurrent annual funding over a three-year period.

For NHS D&G, the annual sum to be awarded amounts to £133,076, a move which has been welcomed by the NHS D&G Long Covid / ME / CFS working group.

The group currently comprises of the NHS Lead AHP, the NHS Deputy Medical Director, and a Clinical Psychologist.

An invitation has also been sent to Third Sector D&G while either the local Lead O/T or a representative from the Community Rehab Team will also participate, along with a part time Project Manager yet to be identified from within the workforce.

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‘When asked what could alleviate PEM symptoms, virtually every participant agreed that while in an episode of PEM, complete rest was absolutely necessary to reduce symptoms. Many participants emphasized that this was not a strategy so much as an outcome. For these participants, complete rest was a “demand from the body.”’

Stussman, B. et al. (2020) ‘Characterization of post-exertional malaise in patients with myalgic encephalomyelitis/chronic fatigue syndrome’,
Frontiers in Neurology



It is also foreseen that a GP 'champion' could be added to the group while we at DGMEFM were delighted to be invited to join too and our Wellbeing Worker, Kalpana, will take on this role.

One of the points discussed was training and it came to light that the NHS lead person was not aware of the CPD module, podcasts and webinars available from Action for ME, but was very interested to hear about them. The Action for ME resources were warmly welcomed and will be shared with the team. Action for ME, meanwhile, has been awarded a further £33,000 to support its Learn about ME programme and will be producing further podcasts, webinars and resources.

For interest, you can access a summary of the NICE guidelines by searching on the internet for: NICE GUIDELINE ON ME/CFS AND ME ASSOCIATION SUMMARY V2

I THINK IT'S BRAVE

i think it's brave that you get up
in the morning even if your soul is weary
and your bones ache for a rest

i think it's brave that you keep on
living even if you don't know how to
anymore.

i think it's brave that you push
away the waves rolling in every day
and you decide to fight

i know there are days when you
feel like giving up but i think it's brave
that you never do

—*Lana Rafaela*

Thoughts and reflections on the Expressive Writing Course from the course facilitator Carolyn

Each session was formatted as follows:

The 90-minute session started with an inspirational quote (usually from a writer) to set the scene, followed by a reading of a poem The Emergency Poet. Kalpana – this was a great suggestion to have a course book and was clearly popular with the participants.

Participants would then work through a series of prompts, loosely based around a writing technique.

This was followed by a longer writing session (10-15 minutes) to music, to give everyone a chance to develop ideas from the prompts and write a longer piece.

At the end of the 90 minutes there would be 15-20 minutes to share work and reflections on the session.

There were an additional 15 mins at the beginning and at the end of the session for socialising which was a nice way to put everyone at ease before starting the workshop and create as close as possible the feeling of being in a real room together.

We had a core group of 6 regular attendees.

Some members of the group were more forthcoming than others when reading, sharing or contributing, but that is to be expected in a Zoom workshop. This was slightly complicated by the fact that several members did not want to be seen in the recording, so we got round this by stopping the recording when we went into the longer write at the end of each session, and by the end of the 5 weeks, all those in attendance were comfortably sharing work with their cameras on.

Work produced in the workshops could often be quite reflective and personal, sometimes sad and painful, and it is testament to the safe space we created in the session that allowed for the participants to have both the confidence and the security to share some of their more personal writings.

For me personally, this is one of the most powerful and meaningful elements of a creative writing course like this. Firstly because all of the members are living with chronic disease there is shared understanding that underpins the group. And secondly because the prompts are open to interpretation and come from a creative place this allows for an outlet or a space for past experiences, emotions, thoughts to unfold and come forth unbidden, unforced, and in their own time. There was space for the participants to reflect on past events and through their creative writing find a new perspective. There were some very heartwarming and meaningful moments in the sessions for all participants.

There was room for participants to write at whatever level they wanted, to interpret the prompts in any way they wanted to. A desire to write, or to be a writer was not a requirement for this course but it did seem to be that those who were regular attendees had done some writing in the past. One member said she had been suffering from writer's block for years and these sessions had helped her write for the first time since Covid.

I was very grateful to have Kalpana in the Zoom with me to help with any technical issues and to ensure all participants could access the materials without anything getting in the way. I also appreciated the patience of the group as I got to grips with finding ways to make the materials easier to access and read for all the group.

Events and Activities

Thanks to funding from The National Lottery Community Fund and Henry Duncan Grants, we are able to offer a range of activities across the region and online. Keep an eye on the website or Facebook group for up-to-date information on activities.



December 5th – Mandala Dot painting, Stranraer

December 12th – Sound bath, Castle Douglas

December 14th – Christmas lunch, Stranraer

December 17th – Christmas lunch, Dumfries

We'll announce the date of an Annan Christmas date ASAP.

Blood test 'can detect ME/CFS', UEA Researchers Claim

A research paper entitled 'Development and validation of blood-based diagnostic biomarkers for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) using EpiSwitch® 3-dimensional genomic regulatory immuno-genetic profiling' was published in the Journal of Translational Medicine.

Abstract

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating, multifactorial disorder characterised by profound fatigue, post-exertional malaise, cognitive impairments, and autonomic dysfunction. Despite its significant impact on quality of life, ME/CFS lacks definitive diagnostic biomarkers, complicating diagnosis and management. Recent evidence highlights potential blood tests for ME/CFS biomarkers in immunological, genetic, metabolic, and bioenergetic domains.

Chromosome conformations (CCs) are potent epigenetic regulators of gene expression and cross-tissue exosome signalling. We have previously developed an epigenetic assay, EpiSwitch®, that employs an algorithm-based CCs analysis. Using EpiSwitch® technology, we have shown the presence of disease-specific CCs in peripheral blood mononuclear cells (PBMCs) of patients with amyotrophic lateral sclerosis (ALS), rheumatoid arthritis (RA), prostate and colorectal cancers, diffuse Large B-cell lymphoma and severe COVID-19. In a recent paper, we have identified a profile of systemic chromosome conformations in cancer patients reflective of the predisposition to respond to immune checkpoint inhibitors, PD-1/PD-L1 antagonists, with 85% accuracy. In this Retrospective case/control study (EPI-ME, Epigenetic Profiling Investigation in Myalgic Encephalomyelitis), we used whole blood samples retrospectively collected from n = 47 patients with severe ME/CFS and n = 61 age-matched healthy control patients to perform whole-genome 3D DNA screening for CCs correlating to ME/CFS diagnosis.

We identified a 200-marker model for ME/CFS diagnosis (Episwitch®CFS test). First testing on the retrospective independent validation cohort demonstrated a strong systemic ME/CFS signal with a sensitivity of 92% and a specificity of 98%. Pathways analysis revealed several likely contributors to the pathology of ME/CFS, including interleukins, TNF α , neuroinflammatory pathways, toll-like receptor signalling and JAK/STAT. Comparison with pathways involved in the action of Rituximab and glatiramer acetate (Copaxone) (therapies with potential in ME/CFS treatment) identified IL2 as a shared pathway with clear patient clustering, indicating a possibility of a potential responder group for targeted treatment.

Question in the Scottish Parliament

Question

To ask the Scottish Government whether it will provide an update on how the £4.5 million fund that it announced for NHS boards as part of the budget for 2025-26 will deliver specialist support for long COVID, myalgic encephalomyelitis (ME)/chronic fatigue syndrome and other similar conditions.

Answer

Further to Parliament's approval of the 2025-26 Scottish Budget on 25 February 2025, the Scottish Government has been engaging closely with NHS boards to support the allocation of resource for new specialist support for Long COVID, Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) and other similar conditions.

Boards told us that having funding only for a single financial year would be a barrier to their ability to develop new support. Therefore, following further assessment in line with Scottish Government spending controls, we wrote to NHS Board Chief Executives on 18 September to confirm that this funding will now be made available on a recurring basis. This commitment provides the longer term assurance necessary to enable boards to plan on a sustainable basis, and support the recruitment and retention of the skilled members of staff required for the delivery of services.

NHS Boards' shares of the available 2025-26 funding will be allocated in full on an recurring basis. From the financial year 2026-27 onwards NHS Boards will receive the £4.5 million resource annually.

In 2025-26 the £4.5 million funding is being provided in addition to remaining resource of approximately £3 million from the £10 million long COVID Support Fund (established 2022). The £10 million fund will be fully disbursed by the end of the 2025-26 financial year.

A breakdown is as follows:

NHS Ayrshire and Arran	£327,482	NHS Highland	£300,399
NHS Borders	£99,208	NHS Lanarkshire	£561,378
NHS Dumfries and Galloway	£133,076	NHS Lothian	£676,576
NHS Fife	£307,495	NHS Orkney	£21,985
NHS Forth Valley	£246,390	NHS Shetland	£21,466
NHS Grampian	£437,038	NHS Tayside	£346,825
NHS Greater Glasgow & Clyde	£957,544	NHS Western Isles	£29,138

Total £4,466,000

We will also provide funding of £33,366 to Action for ME to support their Learn about ME online CPD module for health & social care professionals.

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: christine@dgmefm.org.uk



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