June 2026

DGMEFM Network
Support for ME, CFS, Fibromyalgia

Welcome from the Chair

It's May Day as I write this, when we should all be out gathering in the lily of the valley and washing our faces in the May dew. Well, like many of you, I wouldn't be able to bend down as far as the dew these days, nor crouch, nor sit, so I'll leave that to some fitter folk.

But as it's a glorious spring day with the temperatures due to positively soar to 16 to 18 degrees, I could just be tempted to sit outside and let the sun work its magic on my old bones.

I know many of us feel one disappointment after another when we speak about medication and pathways and medics in general and I felt like that after a recent consultation. All was going well - I didn't have to wait long for a doctor's appointment regarding the excruciating pain in my knees, I soon had an X-ray done and was so looking forward to the results.

Perhaps stupidly, I was actually hoping that a knee replacement would be required because of osteoarthritis, but no such luck. The pain that means I have to be helped to stand up, have great difficulty managing stairs and is affecting both knees turned out to be diagnosed as fibromyalgia, not arthritis. So there is basically nothing that can be done about it except that I was prescribed amitriptyline. It seemed to help a bit during the first two week, but now, the pain levels are back to where they were before. So, it's a case of grin and bear it, I suppose.

Speaking of pathways, though, reminds me that we're forging ahead in our participation in the new NHS Steering Group that has been set up to work with various D&G agencies to improve diagnosis and treatment pathways for a range of conditions such as ours – ME/CFS, Long Covid and Fibromyalgia.

Two Board members sit on the Steering Group while Kalpana, our Wellbeing Officer, is in the Operations Group. So we are making sure that your voices are heard and will no doubt be approaching you in the near future to help provide solid facts and figures for the Steering Group to work with. And, of course, we'll update you regularly on any progress.

Well, it's time for me to decide between lunch and sunshine. Or maybe I should opt for lunch in the sun and have the best of both worlds. Best wishes to one and all until next time.

Bobbie

Upcoming events and activities

Thanks to funding from The National Lottery Community Fund and Corra Foundation Henry Duncan Grants, we are able to offer a range of activities across the region and online. Keep an eye on the website https://dgmefm.org.uk or Facebook group www.facebook.com/groups/dgmefm for up-to-date information on activities over the coming weeks.

Friday 5th June – Stranraer lunch meet up, The Swan @ 1pm
Join our Stranraer members for lunch and a blether. This is not a funded activity so lunch will have to be paid for by the individual. To book your place, message the Stranraer WhatsApp group or email kalpana@dgmefm.co.uk

Wednesday 17th June – Fused glass workshop, Annan @ 1.45pm
Learn about different types of glass, the skill of glass cutting, designing and creating a piece of fused glass art. The class will be led by Mary Palmer of Fiery Fusions. This activity is partially funded. A contribution of £10 per person is required and is non-refundable. To book email christine@dgmefm.org.uk

Friday 26th June – Cyanotype printing workshop, Dumfries @1pm-3pm
Join us in Dumfries for a hands-on in-person experience exploring the amazing world of cyanotypes! Discover this cool, old-school photographic technique that uses sunlight to create stunning, blue prints. Perfect for anyone looking to get creative and learn something new in a chill, fun atmosphere. This workshop is fully funded. To attend this workshop please use this link **https://www.eventbrite.co.uk/.../cyanotypes-dumfries...** or email kalpana@dgmefm.co.uk

We have so many talented members in our group and would love to give you the opportunity to share your skills with others. Other members would love to learn from you and share your talents.

If you feel you could lead a workshop (online or in person), please get in touch and we can get something organised. You would be fully supported by staff and funding is available for any resources you would need. Other members who have done this already have really enjoyed it and participants have really appreciated it.

Go on, give it a go!

Poem

This poem was an entry in last year's poetry competition written by Rhian Davies.

Lutra lutra

River tumbling
weir high
pebbles glistening
water jewelled
white island
bone dry
dark form
fur thick
strong rudder
toes webbed
whiskered snout
needle toothed
streamlined body
water carved.

Rhian Davies

Sound Baths

A wonderfully relaxing time was had by all on February 21st this year at Lochvale House in Dumfries when we were treated to a sound bath by June Meagher.

She set up an array of bowls and other equipment on a table, we turned down the lights while June turned on some semi-psychedelic lights and invited us to either lie on the floor on a yoga mat or sit comfortably on a chair for those of us who couldn't get down to the floor.

June spoke to us in a very soothing voice, all the while making ringing sounds from the bowls and inviting us to relax. Which, I must admit, I found very easy to do, even though I was sitting up on a hard chair. The whole session was extremely relaxing, great fun and I'd be ready to do it again in an instant, even though I was slightly sceptical of what I thought was a bit of "hippy dippy nonsense" going in!

Just goes to show you should never judge a book by its cover. So do come along and join us for some of the activities we have on offer, even if, like me, you're occasionally sceptical about things.

Bobbie

A brighter future for energy limiting conditions in D&G

In line with the Scottish Government's requirement for regions to provide support for those of us with energy limiting conditions, including ME, Fibro and Long Covid, D&G has recently established a group of health professionals and third sector representatives to develop and roll out a pathway through the services for anyone with a relevant diagnosis. Representatives from the Network are included in this group.

This pathway, once created, will be a great improvement for anyone seeking support. It will direct diagnosed sufferers to one or more of Occupational Therapy, Physiotherapy and Psychology, and utilise the rehabilitation clinic at Mountainhall, along with community-based services and community link workers. In the last few months, relevant staff have undergone training in fatigue and energy limiting conditions and are able to support with pacing and energy management for individuals in their own particular life situations in a very person-centred way.

The Network already has members who are benefiting from these new developments, even though the pathway is not yet formalised and launched. This is great news! Referral into these services is still problematic though, as not all GPs are yet aware that this specialised help is available. Work will go on to address this. However, self-referral is also possible. Simply phone the services Single Access Point on 03303333001 and ask for an Occupational Therapy assessment. Home visits will, hopefully, be available if necessary.

It is early days, but this can only be good news. Any updates will be shared in future newsletters.

Sarah

Severity of ME/CFS

A recent email asking about those with severe ME/CFS brought forward the very valid question as to what is defined as 'severe' or 'very severe'. This image has been taken from the ME association website detailing what each level of severity presents like.

Definitions of severity are not clear cut because individual symptoms vary widely in severity and people may have some symptoms more severely than others. The definitions below provide a guide to the level of impact of symptoms on everyday functioning.

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MILD

People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.

MODERATE

People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

SEVERE

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

VERY SEVERE

People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

BPS guidelines for ME

The British Psychological Society (BPS) expects to publish their final **ME/CFS Good Practice Guidelines** in **summer 2026**.
Those of us living with ME/CFS are understandably wary of the involvement of psychologists in our care and management of symptoms. However, we should hopefully get some reassurance from the good practice guidelines being developed.
The project is a collaboration between the BPS, Action for ME, and the ME Association to ensure the voices of those with "lived experience" shape the final advice. The last update, in October 2025, introduced the people working on the guidelines and their expected progress.

BPS-ME-guidelines-October-2025-update.pdf

While a final date isn't set, the project was estimated to take roughly 14 months from its major update in late 2024, placing potential completion in late 2025 or early 2026. However, the timeline has been subject to change because many members of the working group, including psychologists and "Experts by Experience," have ME/CFS themselves and must manage their own health throughout the drafting process.

💡 Key Objectives of the New Guidelines

The BPS aims to shift the role of psychology in ME/CFS care from attempting to "cure" the condition to supporting patients with its physical reality.

- **Acknowledge ME/CFS as a physical illness:** The guidelines explicitly state that ME/CFS is a debilitating physical condition, not a psychosomatic one.
- **Support, not cure:** Focus is on helping patients navigate the emotional toll, grief, and life transitions caused by the illness rather than treating the underlying physical symptoms as psychological.
- **Rebuild Trust:** The society is following the 2021 NICE guidelines to repair the relationship between the psychological profession and the ME/CFS community.
- **Competence and Confidence:** The guidance will provide clear standards for psychologists in primary care, hospitals, and private practice to provide high-quality, validated care.

💡 **Key Takeaway:** The upcoming BPS guidelines will formalise that psychologists are there to help you cope with the impact of a physical disease, not to treat the disease itself as a psychological issue.

Shift from Previous Approaches

The development of these guidelines marks a significant departure from older "biopsychosocial" models that were often criticised by patients.

- **No CBT as a cure:** Following NICE NG206, the BPS aligns with the recommendation that Cognitive Behavioural Therapy (CBT) should only be offered to support symptom management, not as a recovery-focused treatment.
- **Opposition to GET:** The BPS supports the removal of Graded Exercise Therapy (GET) and fixed incremental activity programs from treatment plans.
- **Validation:** Psychologists are encouraged to provide validation and "belief" to patients who have historically faced medical gaslighting.

A Note on the "BPS Model"

In the ME community, the acronym **BPS** often refers to the Biopsychosocial Model, which historically suggested that psychological factors played a role in maintaining the illness.

- Many of us and charities like the ME Association view the older "BPS model" as harmful because it was used to justify exercise-based treatments that caused relapses.
- The British Psychological Society is explicitly trying to move away from these old interpretations in its new official guidelines.

Paul

It costs the Network a considerable amount of money to post out newsletters every quarter. If you would be happy to only receive an emailed copy of the newsletter and not have one posted out to you, please let us know so that we can amend your details and use the money elsewhere.

One Year On

By the time you're reading this I will have been in post for just over a year. For those who don't know who I am, my name is Kalpana and I am the Wellbeing Worker here at the Network. You may have seen posts and polls on Facebook, emails and other articles in past newsletters. My role involves meeting with professionals at network meetings and events. These meetings are mainly to raise awareness of the Network, what it does and what our members want from services. To date I have been involved in job and health fairs for Job Centres in Dumfries and Annan. I have been in contact with every GP practice in Dumfries & Galloway as well as Community Link Workers and Public Health Practitioners across the region. I will continue to raise awareness at every opportunity possible. If you know of any events going on near you that you think it would be good for me to be at, please let me know and I will try my best to be there.
Now to the part that I really enjoy! Organising all the lovely fun activities that members ask me to run. To date we have had over 60 activities across D&G from the Isle of Whithorn to Sanquhar. I hope to be able to have even more next year! Please let me know if there is anything you would like me to organise. We have had activities such as online Expressive writing, online chair yoga, Easter Wreaths, Iris folding, Gelli plate printing and hair appointments at D&G colleges. We have worked with several local facilitators, but I am always looking for any members who would like to share any of their interests and skills. Do you have a talent or interest you would like to share with us? All materials and organisation will be provided, just get in touch with me: kalpana@dgmefm.org.uk.
I have really enjoyed getting out and about and meeting lots of members, old and new and will definitely be doing more of that in the years to come. If you would like to meet with me or chat with me about any Network things, please don't hesitate to get in touch.
We have seen our WhatsApp and Messenger groups grow this past year, which has been great as these groups are your support groups so please feel free to chat and reach out to other members there. If you are not in a group and would like to be, please let me know.
The Befriending and Peer mentoring service is still running, and I will be offering some training in the Autumn. If you would like to volunteer or know about the projects, please reach out to me.

Kalpana

Useful weblinks

Free mobility scooter rental in Dumfries town centre:

https://www.dumfriesandgalloway.gov.uk/roads-transport-parking/public-transport/free-use-mobility-scooter

ID and discount card for paid and unpaid carers.

https://blueskycard.uk/nominate-a-carer/

Charity worker discounts. For anyone who works for a charity, volunteers for a charity or fundraises for a charity, joining up gives you lots of discounts.

https://www.charityworkerdiscounts.com/

Disabled user testers

https://abilitynet.org.uk/jobs/disabled-user-tester

Daffodil art

Spring is a beautiful time of year where we see so many flowers bloom in all of their glory. Janey Miller, a member of the Network, has captured some daffodils in this piece of watercolour art. What a talented lady. Thank you for sharing your work with us Janey.

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 contribute something for us, please do so and send to: christine@dgmefm.org.uk

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