March 2026

DGMEFM Network

Support for ME, CFS, Fibromyalgia

As I write in early February, I hear that a friend near Annan has snowdrops peeking through the ground, although it's still quite cold in Dumfries and Galloway as a whole. And yet, there's a severe weather warning out for the north-east of Scotland again along with some other parts of the country. We're lucky here to dodge the worst of the bad weather but I actually enjoyed living through snow showers, giant icicles and a biting cold wind over Christmas and New Year when my husband and I stayed with family in Aberdeenshire.

It was easy to "enjoy" the weather from inside while watching the snow ploughs trying to clear the railway line opposite. It's so long since I've seen proper snow and it was drifting three or four feet deep in places. Some residents were stuck in their houses because of snowdrifts and delivery lorries couldn't get through to the local shops, which ran out of staples like bread and milk.

But the situation highlighted the wonderful community spirit, with people helping their elderly or disabled neighbours with supplies or clearing away the snow around their homes. And one outstanding aspect was seeing the local farmers clear both roads and pavements with their tractors, every single day, for the benefit of the community.

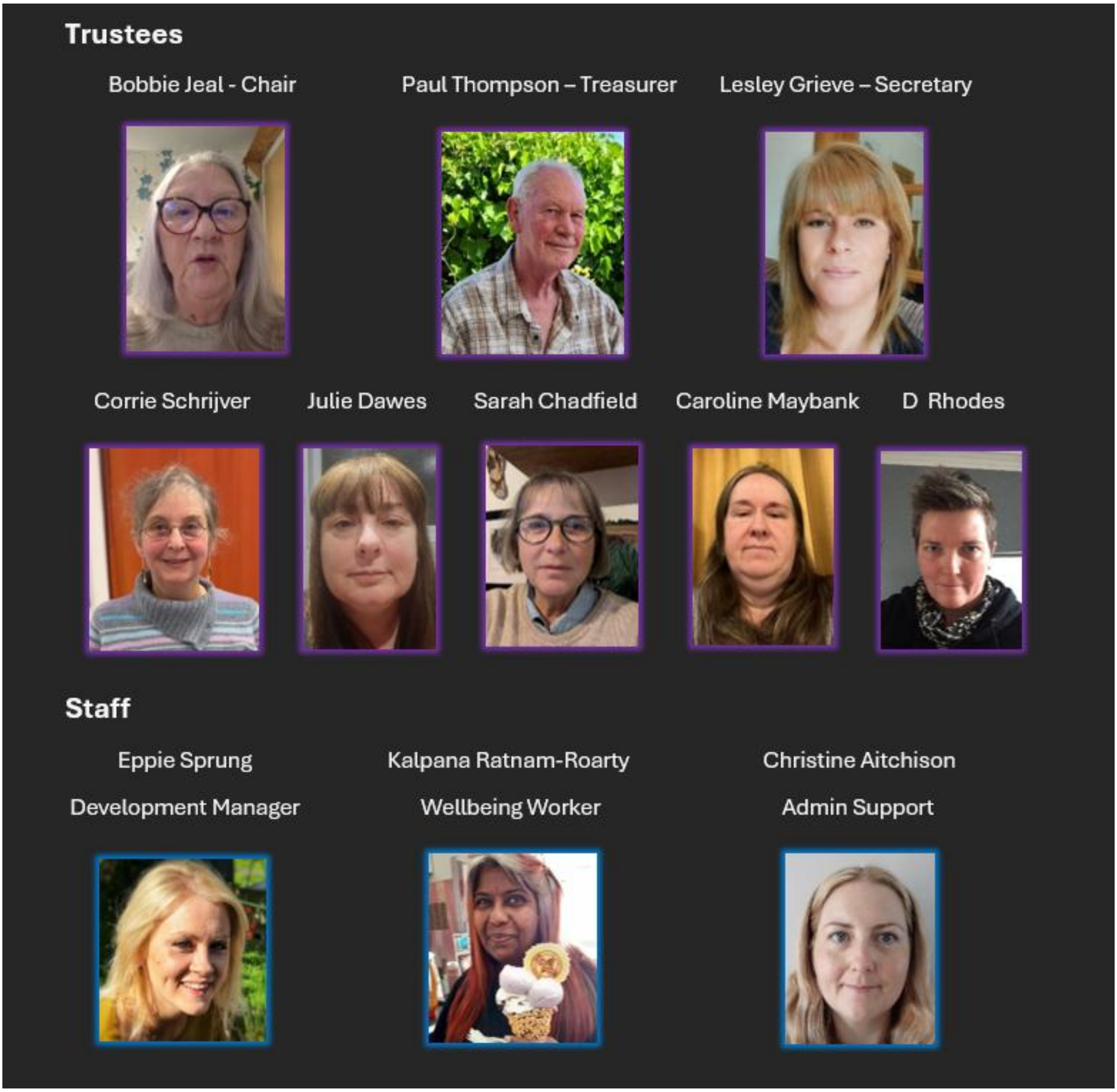
And that's what I admire about the DGMEFM Network - its community spirit that brings together many people living with similar health conditions and how they help each other with suggestions or comparisons with their own situation or simply getting together at one of our meet-ups and offering each other friendship and companionship.

As we begin a new year, we trust that you are keeping in touch, through the Newsletter, emails and Facebook posts, with the exciting range of events and activities we are offering. Our Wellbeing Worker, Kalpana, is working hard behind the scenes too on fostering links with the medical community throughout D&G to raise awareness of our conditions and collaborate with them for our mutual benefit.

I hope it's not too late to wish you all a very happy and healthier new year fae a cauld and dreich Dalbeattie!! Bobbie

Who's who of the Network

We have had some changes to our Trustees and Staff this year so here is an at-a-glance view of who we all are.



Trustees

Bobbie Jeal - Chair
Paul Thompson – Treasurer
Lesley Grieve – Secretary

Corrie Schrijver
Julie Dawes
Sarah Chadfield
Caroline Maybank
D Rhodes

Staff

Eppie Sprung
Development Manager

Kalpana Ratnam-Roarty
Wellbeing Worker

Christine Aitchison
Admin Support

Have you seen our Facebook pages?

Lots of information is shared on our Facebook groups and we don't want you to miss out! Search for DGMEFM Network (support for ME, CFS, Fibro, Long Covid) on Facebook or click this link and ask to join the group.

You will find lots of discussions, links to articles, up to date information on our planned events and loads of support from those who 'get it'.

We also have another group for the crafters among you – or those who like to look at others' crafts! Search for Get crafty with M.E. and Fibro on Facebook or click this link and join this crafty community.

New trustee – D Rhodes

I was born and raised in the Pacific Northwest of the United States. After graduating from high school, I moved to Seattle and lived in that area for twenty plus years. I took on interesting jobs while I went to Uni part time. I did everything from driving a forklift in a recycling plant to making batches of fried chicken at a place called The Yankee Deli…which was also a petrol station. Don't ask. I have no idea. I have a Bachelor's degree in poetry and urban studies. I know…I know. It was the late 80s and early 90s. What can I say? After Uni, my first career was in data management, mostly for fundraising and development in not-for-profit organisations. I was a member of a poetry ensemble, an avid hiker and bird watcher, and worked backstage in community theatre on occasion.

Just before moving to the U.K. in 2009, I started cooking in restaurants part time. Once I settled in Scotland, I became a qualified chef. I moved over here because my partner is Scottish and although she would happily have moved to the States, there was not marriage equality for same sex couples at that time in the States. It was much more feasible for me to make the transatlantic move. I love it here for many reasons and I am so very grateful to be in a place as beautiful as Dumfries & Galloway. I became a British citizen in 2015. I live in Dalbeattie with my beloved better half and two adorable cats.

Like so many people who fell ill during the pandemic, I found myself unable to work and really struggling with fatigue and an array of unsettling symptoms. I'm fortunate to have a GP who listens and who believes me. At some point after my diagnosis of Fibromyalgia and suspected Long Covid, I came across information about the Network and got in touch. It has been a lifesaver for me. The arts wellbeing offerings in particular are very important to me and have had a very positive impact on my mood, engagement, and self-confidence. I developed, with Christine Aitchison's help, a self-portraiture workshop for members of the Network. We showed our finished pieces at the Gracefield Arts Centre café and, I hope, raised some awareness about hidden conditions.

When Paul approached me about becoming a trustee, I thought it sounded like a great opportunity to give a little back to an organisation that has helped so many of us feel connected and less alone in the world.

Could you contribute to the next newsletter?

Things we would love to include are:

Yummy, simple to make recipes

'Top tips' – non-medicinal things that have helped with pain, pacing, fatigue, social isolation etc.

Short stories

Outside agencies who have been a big help

Tell us about one of our events that you have attended.

Send your contributions to christine@dgmefm.org.uk

Poem

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

Reflections

Right back at you
Trading insults
Venom drips from a clueless,
poisoned mind
all at once envious and unkind.
This time, I sought eyes that glisten,
sparkle and shine bright.

You'll be my mirror as the velvet voices might have promised.
A soft stroke in the dark of night,
caressing not critical.
The past
reflected back at me in painful
arrows and sore spots
melts away.
Nothing really matters.

No thoughts of cycling
and sleep no longer like a beautiful stranger
comes like a release.

By Emma Davies

Easyfundraising

Did you know that DGMEFM Network is registered with easyfundraising? Easyfundraising is an online site that has over 7,000 different brands registered with them. When you buy something, going through easyfundraising, you pay the same amount as you normally would but the company donate part of that amount to us! It is a very easy method for you to help us fundraise! Our link is: https://www.easyfundraising.org.uk/causes/dgmefmnetwork

All you have to do is register with them on a computer or laptop and download their browser extension (all of this is super easy to do – just follow website instructions). Then it will automatically pop up if you are shopping at a brand that uses easyfundraising! Look out for this logo:

easyfundraising

Alternatively, you can download their app onto your phone or tablet which looks like this.

Please consider supporting us at no cost when purchasing online.

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 6th March – Stranraer lunch meet up, The Swan, Stranraer @1pm.
Eat lunch and enjoy good company. This is not a funded event.
To book email kalpana@dgmefm.org.uk or via the Stranraer WhatsApp group.

Friday 13th March – Mandala dot painting at Castle Douglas @ 1pm
Relax with the mindful activity of making a mandala using dots. Enjoy chatting and a cuppa as you work. Workshop will be held at Gordon Memorial Hall. This is a fully funded activity. To book email kalpana@dgmefm.org.uk on Facebook or via the Castle Douglas messenger group.

Friday 20th March – Lino Printing workshop, Annan @ 2.20pm
Using a v-shaped tool to gouge spaces into a lino sheet and using rollers to apply ink, you can create your own printed design. This workshop will be led by Julie Stephen of The Artful Corner. This is a fully funded activity. Parking is available directly outside the venue.
Book your place on Eventbrite **https://www.eventbrite.co.uk/.../lino-printing-workshop...** or by emailing: christine@dgmefm.org.uk

Friday 27th March – Coffee, cake and Spring art activity, Lockards Farm, Dumfries @2pm
Come along for a chat with some cake and coffee with fellow members.
There will also be an opportunity to make a Spring bookmark to take away with you. Food and drinks ordered need to be paid for by each individual. To book your place, email kalpana@dgmefm.org.uk

Friday 17th April – Meet up and Spring activity, Castle Douglas @1pm
Come along for a lovely afternoon of chatting with friends over coffee and cake. We will also have a small Spring activity. This activity is fully funded. To book your place, email kalpana@dgmefm.org.uk

Friday 17th April – Sound Bath, Annan @ 2.45pm – 4.30pm
Enjoy being enveloped by resonant sounds from instruments like singing bowls, gongs, chimes, and drums. This is a fully funded activity. Parking is available directly outside the venue. Book using the Eventbrite link:
https://www.eventbrite.co.uk/.../sound-bath-annan-tickets...
or by emailing christine@dgmefm.org.uk

Tuesday 5th May – Swimming session – Annan @11am-12 noon
Come for a splash or a swim at this privately booked swimming pool. Please note the pool is accessible by steps and a handrail and while the changing rooms are accessible, individual cubicles are not. This is a fully funded activity. Maximum of 10 people per session so book quickly to avoid disappointment. Book using the Eventbrite link:
https://www.eventbrite.co.uk/e/swimming-session-tickets-1983252956982?aff=oddtdtcreator
or by emailing christine@dgmefm.org.uk

There have been times where an event has been organised and booked but then no participants attended. This wastes precious funding and takes up time of staff and tutors. It is completely understandable if you feel too unwell to attend or something comes up, we just ask that you please let us know if you can’t attend.

Pacing – my journey

I think it’s something most of us have to do – find out how best to manage our symptoms and energy levels, each with our unique circumstances, and maybe again as those circumstances change. Pacing is one of the methods that many find helpful, and for any of you new to this concept, it’s not to be confused with Graded Exercise Therapy (GET). The latter was misguidedly recommended for ME/CFS until discredited as harmful. Don’t go there! Pacing isn’t just for people living with ME/CFS but can be helpful for any energy limiting condition.

For me, pacing is about learning to live within the limits of activity that I can endure, be it physical, mental or emotional, and in combination, without running out of steam or making my symptoms much worse, or falling into the ‘boom and bust’ cycle. It’s about what I can manage repeatedly, day by day and week by week, and how to approach events or circumstances that will be more demanding than I’m usually faced with. It’s also about being able to say “No”.

Of course, for most of us life isn’t linear – there’s always an unexpected curve ball to knock us sideways, or extra demands that weren’t anticipated. I wrote in the last newsletter about how I was unexpectedly floored in the summer, and took months to get back to ‘normal’ – but I knew what I had to do (or rather, not do) to slowly recover. There’s a context to that crash which I didn’t explain, and that’s the change of circumstances this last two years, in which I was testing myself to find what my new limits might be.

‘Stop trying to push your limits’… Yes, but it’s important to know my baseline and when circumstances changed I wanted to find out what that is now, and whether my limits had changed. Most of my energies had been taken up in caring for my wife, June, who had severe ME and in later years terminal cancer.
So, after June passed a couple of years ago, when I went out for walks in areas of the countryside we’d enjoyed together, I’d gradually extend the distance to see what I could manage with reasonable comfort. Similarly, I tested how far I could drive, engage in activities, and spend time socially. I was careful to build up gradually and so recognise quickly whenever it had been too much. I admit I’m not good at resting between activities – I rely on ‘switching’ between different types of activity, but I do tend to stick to a window of between 5 to 7 hours as my higher ‘energy envelope’, outside of which are low intensity activities and rest/sleep.

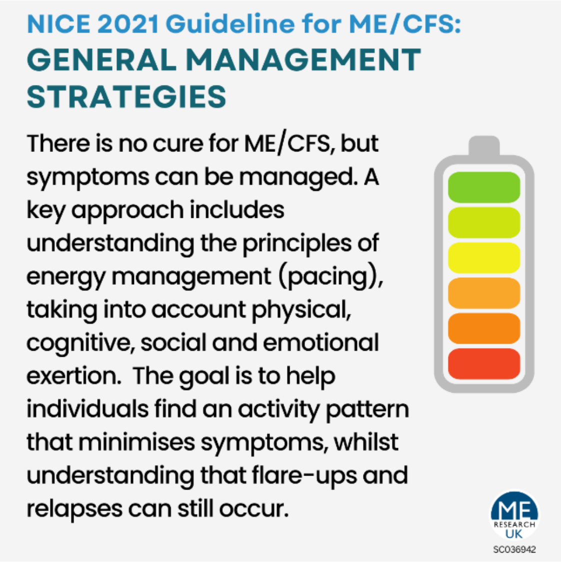
STOP trying to push your limits. Overexertion may be detrimental to your recovery.

REST is your most important management strategy. Do not wait until you feel symptoms to rest.

PACE your daily physical and cognitive activities. This is a safe approach to navigate triggers of symptoms.

The crash last summer took me by surprise, but in retrospect I wasn’t listening closely enough to the signs that I was pushing too hard. For example, it had been suggested by both my son and the physio to try Nordic walking to build strength. Off I set into the woods with poles a-swinging as if I were a fit young person. Twenty-five minutes later – jiggered! Not surprising as I was getting upper body work-out as well as a brisk walk. The poles went back in the cupboard, and my leisurely strolling and pottering along looking at the plants and insects came back to the fore.

I know I could have carried on with the poles though more gently, but to be honest I’d rather take the time to just enjoy being out in nature. Instead, I joined a weekly Tai Chi class for the health/strengthening benefit.



NICE 2021 Guideline for ME/CFS:
GENERAL MANAGEMENT STRATEGIES

There is no cure for ME/CFS, but symptoms can be managed. A key approach includes understanding the principles of energy management (pacing), taking into account physical, cognitive, social and emotional exertion. The goal is to help individuals find an activity pattern that minimises symptoms, whilst understanding that flare-ups and relapses can still occur.

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One of the biggest difficulties I've experienced with ME, right from the start over 20 years ago, is socialising for any extended length of time or with too many people. My close friends and family know this and are quick to recognise when I'm getting tired – but I think it must be difficult for some of them to truly understand. I'd been invited to join them for a holiday last September in a shared house, and had thought to maybe try that, but the summer crash put paid to it. It also made me stop and think – could I really manage to spend a few days and nights in a shared house with eight other people? No.

Managing others' expectations is important for me in managing my symptoms, energy and overall wellbeing. I decided that as the group of family and friends wanted to get together similarly each year that I'd need to rule out any commitment to join them. So, this January when the email went round with suggestions for a holiday this September, I made it clear that although I would like to join them, even if only for a short while, it will be nearer the time that I'll decide about it, and not to hold any expectations. It's not quite a 'No' but close enough for me to choose that later, and maybe see if there's another way to meet up with them for short spells, which feels more realistic.

The subject of Pacing has come up frequently within the Network and there are lots of good resources that can be helpful, such as PACING-V2-1.pdf from the ME Association; a summary by Action For M.E. What is pacing? ; and a comprehensive book well worth the mention is 'Classic Pacing - For a better life with ME' by Ingebjorg Dahl.

But most of all, my advice is – listen to your body.

Paul

Festive Food

There were a few Christmas lunch meet ups across the region. We enjoyed some delicious food and enjoyed each other's company.

Sound baths

I didn't know what to expect from a Sound Bath experience but it turned out to be a very interesting experience. First of all, the Gordon Memorial Hall had been prepared with closed curtains and some soft armchairs. On one side of the hall there was an array of instruments ranging from a variety of small instruments through various sized crystal bowls to one big gong. We sat with our eyes closed and the sounds started slowly and quietly ... I felt myself beginning to relax almost at once with the gentle sounds. At this point you should know that I don't relax easily and have suffered from anxiety and panic attacks (PTSD) for a very long time. The sounds came flowingly and smoothly without ever falling into silence. The variety of sounds ranged from shaken delicate shells to bells to crystal bowls through to the big gong which wasn't ever too loud but which reverberated vibrationally through my body and made me feel safe and connected in a new and welcome way. None of the sounds were jarring ... they all flowed seamlessly from one to another and had the effect of making me forget my problems and stresses. Eventually (maybe 20 minutes in) I had the very rare feeling of almost floating above my body (I'm not saying it was an out of body experience!) but it somehow left the constant chronic pain behind. It wasn't that the pain stopped ... it was still there ... but I was somehow 'distanced' from it. It felt so good. I was totally content to 'float above the pain' and let every cell in my body relax with the varying vibrations from all the different instruments all playing and weaving from gentle to strong and back again. I have to say the instruments were in the hands of a very experienced practitioner of over 40 years which meant the whole experience was of high quality and professionalism. It lasted around an hour and when it was over I felt so much more relaxed than I have for a very long time ... I also felt refreshed ... and very eager to have another Sound Bath as soon as possible. If you have the opportunity to experience a Sound Bath I genuinely recommend it to you. The sounds and vibrations are not in the least bit harmful ... exactly the opposite if my experience is anything to go by. So I hope to see as many of you as can make it on the day at the next Sound Bath. My thanks to Kalpana for organizing the event. Kalpana will have the details of the next one. I can't wait. Love to everyone ... hoping you're all as well as we can ever be.

Jay 🙂 x

We LOVE it when members contribute to our newsletters!
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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