

September 2023

DGMEFM Network

Support for ME, CFS, Fibromyalgia



My daughter and I at the beach

Well, I don't know about you but I feel we've been hard done by over the summer. We had four warm weeks, seems like about four years ago now. That was nice weather and since then it's been raining, raining and raining with a bit of wind thrown in, occasionally hailstones and then a bit of blue sky, about enough to make a pirates bloomers and then back to raining again. I think that next year we should see the terms and conditions before we agree to 2024 being installed.

My two wee dogs, Beryl and Bertie, absolutely despise the rain. They've spent most of the last couple of months avoiding every drop and frantically drying paws as soon as they come in from a walk.

We haven't had a holiday as yet, but we have had some lovely days out. One in particular to North Berwick left the grey skies of Langholm behind to find a beautiful sunny day, if not somewhat blustery. There's nothing quite like spending a little bit of time on a beach, that's one of my happy places.

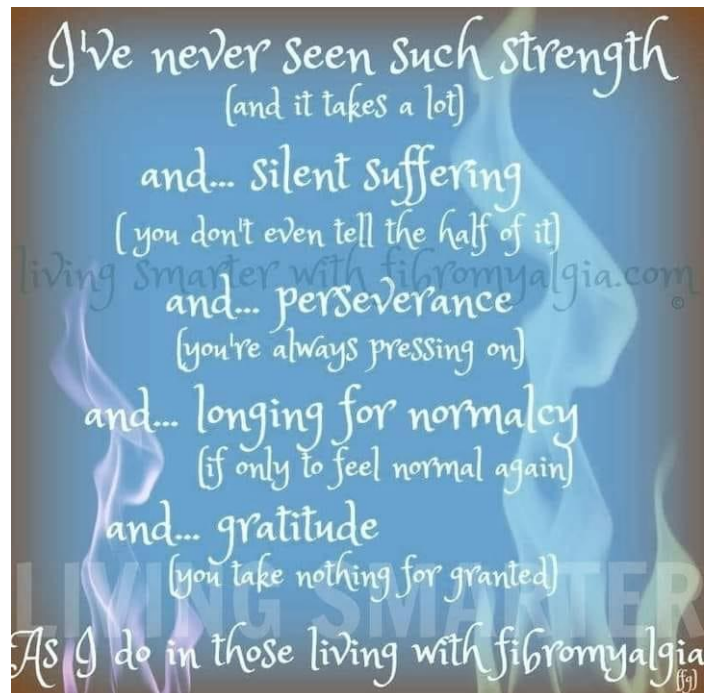
Seriously though, the weather does play a huge part in how we can cope or not with the chronic conditions that we live with. I have been horrendously creaky in my joints and extremely stiff in my walking. It would be interesting to know how people cope with this kind of uncontrollable effect; what do you do to feel better when the weather isn't being kind to our sensitivities? I probably should put answers on a postage stamp but to be absolutely honest the answers would probably fill a book about as big as War and Peace. So we are definitely turning towards autumn, I've noticed the leaves are turning on some of the trees already.

Despite the weather, we've had quite a good summer in the Network. We've continued with our monthly meetings at Turning Point and we've had some successful pop-up meetings in various places across the region. The Befriending Project is continuing apace, with training of the first cohort of Befrienders now underway. We have also taken on an admin assistant to help Eppie, who will now be focusing on management and development of the Network. Over the last couple of years, the network has really grown. We are able to provide help and assistance to many more members than before.

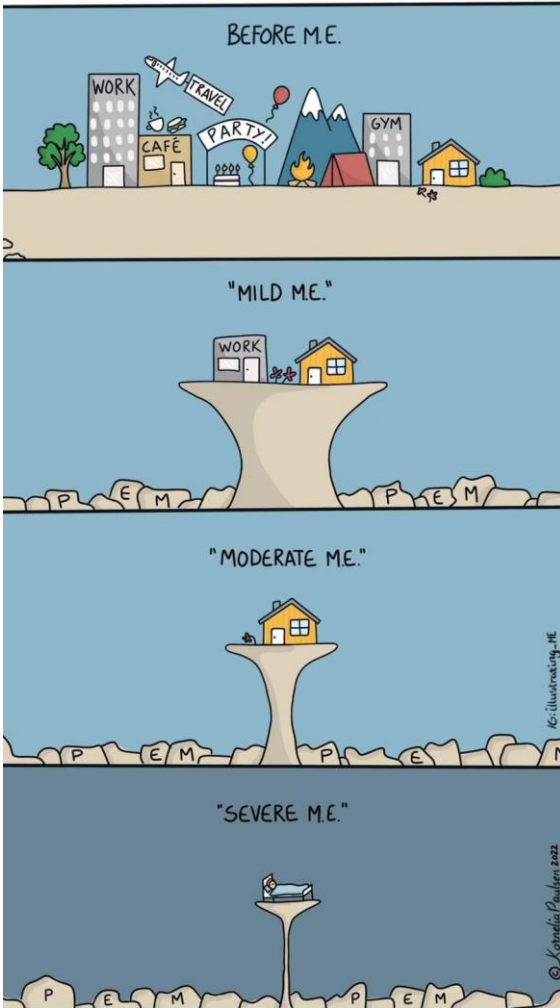
As always, we are only a message or a phone call away.

Kind regards,

Eileen x



M.E. HOW IT CAN SHRINK ONE'S WORLD BITS BY BITS



Social Meet-Up: First Thursday of the month In person and online

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.

First Thursday of the month. Hybrid meeting on zoom and face-to-face at Turning Point Scotland, Newall Terrace, Dumfries. Join any time between 2pm – 3:30pm.

Sometimes there's even cake!!

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to www.zoom.us on your computer.

Enter this info: Meeting ID: 843 001 5846, Passcode: 2023

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

Pop-Up Meet-Ups

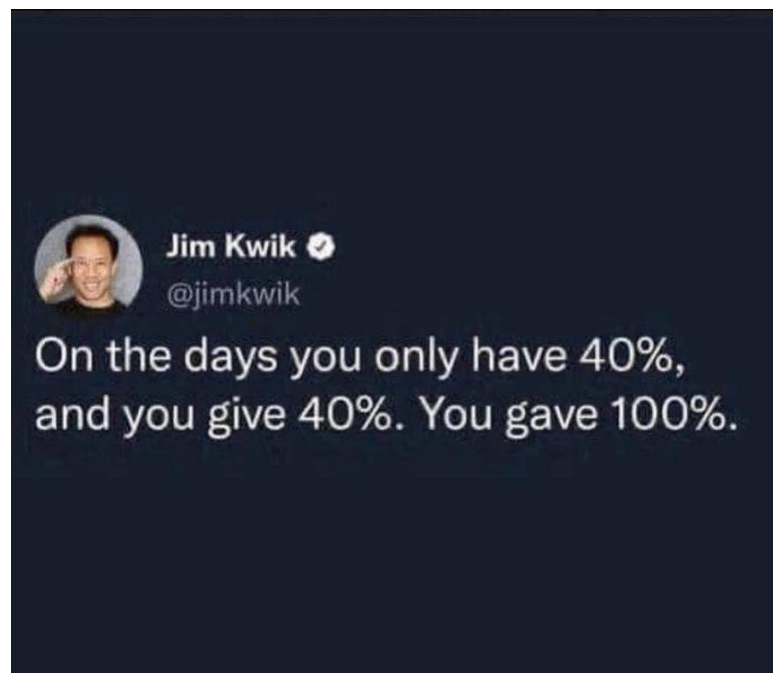
We have social meet ups arranged for Castle Douglas on Monday 25th September and Monday 4th December. Please contact: paul@dgmefm.org.uk to book.

Unfortunately, due to staff ill-health, we have had to postpone our meet ups in Lockerbie and Annan. However, we'll be getting dates in the diary ASAP.

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.

Check out the website and Facebook page for more info 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.



M.E. Is Like A Burglar Who Steals From You

M.E. is like a burglar who steals from you every minute of every day. Its booty is your energy, half a sackful of cognitive functions, and whatever else it can find. Out goes your profession, your social life; your mobility, vision, memory; your ability to look after yourself without help; your idiosyncratic vitality in short: the way you were in the world. Hardest though: your intelligence curls up in a ball and rolls out of reach, and you lie in wait for those rare instants when you can seize it by the scruff of its scrawny neck and pull it from under bed, for a wee while.

By Marion Michell (reproduced from M.E. Association's blog 'Severe ME Week 2023: Poems')

Goodbye to the career I trained so hard to get

Goodbye to the career I trained so hard to get
Hello to days filled with pain and regret
Goodbye to dinners out in the crowd
Hello to my bed where even a whisper is loud
Goodbye to make up and feeling a queen
Hello to a face that I am unable to clean
I am too young for this, it's not fair it's insane.
I have too much to do, so I pick up a cane.
The pain hits my body like a ball hits a bat.
I fall on the bed like it's a big comfy mat
I close my eyes and hope for the best.
That maybe just maybe all I need is rest.

– By Joanna (reproduced from M.E. Association's blog 'Severe ME Week 2023: Poems')

Research Recruitment: What happens when people with ME keep symptom diaries?

(Reproduced from ME Association blog)

Hannah would like to hear from anyone with ME/CFS who uses (or has used) a diary to help keep track of symptoms. The study will comprise a series of focus groups that will help her understand the effects that diary keeping and symptom tracking can have and will lead to publication as part of her thesis.

Hannah Field, PhD Researcher at LICA, University of Lancaster

About Me

When I first got sick, back in 2011, it wasn't clear why I wasn't recovering. I spent the whole summer after my A-Levels sleeping, then gradually, rebuilding my strength so that I could go to university. While I was there, my health was, in short, a disaster. I missed a lot of seminars and lectures but was still met with a shrug whenever I told the doctor. It wasn't until 2018, after years of struggling, that I finally got an answer: it's ME.

But getting diagnosed was only the first hurdle. As empathetic and understanding as my consultant was, he was open in saying that he didn't believe there was enough quality research out there to suggest a treatment. He was already critical of GET (which has now been thoroughly debunked) and didn't want to risk suggesting anything that could make me feel worse. What he did suggest was that I keep a diary and learn about myself.

Lots of ME patients are advised to keep a diary. Some clinics rely on symptom tracking diaries as a way to encourage patients to stay within their energy envelope. Some patients go it alone and figure out their own tracking methods and goals. And yet, there is still so little research available into what happens when people keep symptom diaries and how they may or may not affect us.

So, in 2019, when an opportunity came up to do a PhD looking at this question, I jumped at it. And, a couple of years later, I was pleased to see that in their recommendations for research, the NICE Guidelines for ME/CFS 2021 called for further research into self-monitoring management strategies, noting that "there was a lack of effectiveness evidence on strategies and tools to support people to self-monitor activity management." I hope I can start filling that gap in knowledge with my research.

My Research

My research has so far examined the range of apps and methods for tracking available to people with ME. I have also researched the quantified self and the cultural significances and impacts of diary-keeping. But the main goal of my research is to answer the question, *what happens when people with ME keep symptom diaries?* To answer this question, I need help from the wider ME/CFS community.

Can I help?

If you have a diagnosis of ME, ME/CFS or CFS, and you keep a diary or track your symptoms you may participate in this research. You may also join if you used to keep a diary or track symptoms but stopped.

I am now running focus groups to ask people with ME/CFS about their experiences of keeping a diary and/or symptom tracking. In the focus group, you will join up to 3 other participants on Zoom to discuss your experience. I will lead the conversation through a series of questions over an hour.

I will start running focus groups as soon as possible.

What will I be doing?

We will have a conversation via zoom about your experience of keeping a diary. We will use a Miro board to track the conversation and record responses. The focus group will take 1 hour but as it is online, you can be anywhere you find comfortable, whether that's at your kitchen table or your bed. And, yes, you can keep your camera off if you prefer.

There are no right or wrong answers, and no particular expected outcomes for the focus groups. The intention is to gather a variety of different opinions, so, no matter what your experience is, it is valid.

What will joining in achieve?

If you choose to join the study, you will be contributing to our understanding of diary-keeping and symptom tracking. You may also benefit from insights from other participants. I will be writing up the results of the study as part of my PhD thesis and hope to publish a paper recording the study too.

Do I have to take part?

No. It's completely up to you to decide whether or not you would like to take part. Your participation is voluntary and you are free to withdraw up to 2 weeks after the focus group, without giving any reason.

Is there a deadline?

There is no particular deadline for this study though it should end before Christmas. I will organize focus groups according to your availability and at your convenience.

Is there a limit to how many people can get involved?

There is no limit to the number of participants; I will run as many focus groups as it takes to ensure everyone who would like to contribute may be heard. It is important to hear as many members of the community as possible to gain as broad an understanding of the experiences of diary-keeping as possible.

Who has reviewed this project?

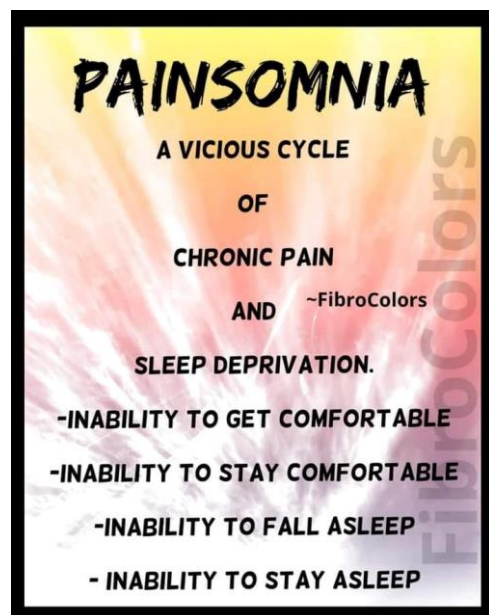
This study has been submitted for review by the Faculty of Arts and Social Sciences (FASS) Research Ethics Committee.

I have questions, can I get more information?

Yes! Please email me, h.field1@lancaster.ac.uk and I will send you the participant information sheet and consent form for review. You can also ask any further questions you may have before you decide whether to join the study or not.

Thank you

As I live with ME myself, I understand that asking you to join a study is a big ask. So, if this one isn't for you, then thank you for reading this blog post anyway and I wish you all the best. If you do think you are able to contribute and would like more information, please email me, h.field1@lancaster.ac.uk.



Ten Tips for Pacing with Fibromyalgia

Reproduced from Fibromyalgia Action UK newsletter

1. Make Lists

This reduces anxiety around forgetting what needs doing and, conversely, how much we have still to do. This can also help us to feel more in control which also alleviates stress.

2. Prioritise

Once the list is visible (rather than spinning out of control in our head) it is easier to see what are the things that must be done, the things it would be good to get done and the things that we would like to do but could be put off if necessary.

3. Split Jobs Up

It may make our to do list look longer but splitting a job into several tasks makes it more manageable (with more satisfying ticks as we complete them!)

4. Ask For help

This is probably the most difficult thing for many of us but when people offer help, they generally mean it. We need to be the best person we can and exhausting ourselves isn't going to facilitate this.

5. Set A Timer During Tasks

Some tasks are self limiting within your energy ability but others can go overtime without you noticing. Limit yourself to only doing something for a set period of time and stick to it. This will be individual (some will be able to do more than others) and task-dependent. Using a timer stops us from getting carried away and is an auditory reminder to take a break. If we simply use a clock or watch, it is easy for time to run on without us realising.

6. Set Time To Rest

We all start the day with good intentions but if something takes longer than we expected, the temptation is to crack on through our list whereas if the rest breaks are on our list, it is easier to incorporate them. Use the timer for our rest breaks too, they are important.

7. Make Sure Your List Includes Physical, Mental, Emotional and Spiritual

This will help us to have a well-rounded balanced life. We all need to pay more attention to each aspect, there is not point in building up our physical capabilities if we are then depressed, upset and feeling cut-off!

8. Listen To Your body And Stop When You Need To

You know yourself better than anyone else and you know when you should stop. I am the worst at this as I always want to "finish this bit" but deep down we know that if we leave it at the right time, we are more likely to be able to carry on later without the physical and/or cognitive barriers carrying on will cause.

9. Build Up Slowly

Although Pacing Can be tough, it is largely a case of determination and once we get it right, we feel so much better. The important thing is to resist the temptation to do too much. We need to have discipline and continue with it, even when we have a good day. Once we start to have more good days than bad, then we can increase either the intensity or the time.

10. Appreciate Your Achievements

We need to be looking at positives, managing our expectations and definitely not putting ourselves down because we have set ourselves unmanageably high standards. Rather than focusing on what we still have to do, celebrate what we have already achieved, be it during a day, through a long-term project or since we were diagnosed.

Befriending Project

Our first cohort of Befrienders began their training in August. We are therefore getting closer to beginning the process of matching Befrienders with their Friends.

Our Befrienders are an incredibly friendly bunch and will do a wonderful job of putting their new Friends at ease and finding topics to connect over.



If you feel isolated or lonely and would enjoy connecting with a Befriender (online, by phone or face-to-face), please contact Kalpana on 07761 048 514 or kalpana@dgmefm.org.uk.

Self Management Week

The ALLIANCE hosts a Self Management celebration annually, celebrating self management across Scotland with a range of events, ALLIANCE Live activity and the Self Management Awards.

In 2023, Self Management Week will run from 18-21 September with online, in person and hybrid events.

The aim of the week is to bring people together and share learning across the Self Management Network Scotland, the Self Management Fund projects and the wider ALLIANCE membership.

Check out the Alliance Website for more information: <https://www.alliance-scotland.org.uk>



'Gift Day' September 2022

It's that time of year again when we ask if you can make a donation towards our costs.

We don't have a subscription fee for membership of the Network but we appreciate any donation, however small, as we need this support to carry on our main activities.

- You can donate by PayPal through our website - <http://dgmefm.org.uk/donations>
For eligible donations there is a Gift Aid Declaration button on that page.
- You can post your donation, addressed to:

DGMEFM Network Treasurer, Thistledeew, Albert St, Dalbeattie. DG5 4JP.

Please make cheques or postal orders payable to:
Dumfries and Galloway ME and Fibromyalgia Network

- If you feel able to make a regular (e.g. monthly) donation please contact admin@dgmefm.org.uk for our bank details.

With many thanks in anticipation.



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

DGMEFM



Dumfries & Galloway
 ME and Fibromyalgia Network
 SC051578 | www.dgmefm.org.uk

Phone or WhatsApp: 07557 536110
 Website: www.dgmefm.org.uk
 Facebook: facebook.com/groups/dgmefm
 Email: eml@dgmefm.org.uk (Chair)
paul@dgmefm.org.uk (Treasurer)
diane@dgmefm.org.uk (Secretary)

OSCR

Scottish Charity Regulator
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 or text or phone 07557 536110.