

September 2022

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Flying visit from son and youngest daughter

Hello there! September already! It seems like time is flying but behind the scenes the trustees have been working to further our future projects and ideas. I am incredibly proud of the progress the board has made over this year. I could not do my job as Chair without such a dedicated team around me. As of 1st August, 2022 we are now a fully functioning Scottish Incorporated Charity (SCIO). The transition has been arduous at times, but very fulfilling to accomplish this feat. There is more in the body of the newsletter but they will be bringing support and networking to members in different ways.

For me, I've been enjoying family time and collecting spoons as much as possible in between. The weather has mostly been quite glorious and, although I don't do well in the heat, I am enjoying all the benefits of good weather. My garden has burst forth with greenery, blossoms and cherries. The greenhouse is producing salad veg and my spuds are just about ready for digging up. When I say 'digging' it's more gently forking to be honest. No sweat is broken in my garden; by me anyway!!

The dogs, Beryl and Bertie, are so easy to look after in the summer. The back door is kept open so they zoom in and out of the garden in a kind of figure of eight, then collapse for a snooze, before doing it all over again. My friend taught them not to chase her cats when they stayed over, so now the three Polish fancy chickens have free reign in our garden with no fear of being chased. They may get a bit startled by zooming pups though.

It always interests me to find out how members cope with their chronic issues. I know I play down my problems... I could complain but would folk listen? Also, I don't wish to become a Moaning Minnie. So, as a short poll on the Facebook group, I asked two specific questions on PAIN. There is no science behind this, just pure curiosity on my part. However, it does highlight how PAIN, as a word, is interpreted by people who have the lived experience as a chronic illness.

First question: 'Can you tell me the words you use on a regular basis with your family, friends and colleagues, and also to yourself to communicate your PAIN at any specific moment?'

The answers to this question in particular point out how different words can be easier to deal with. Whilst living with chronic pain it seems that the members who replied tend to play down the description of pain, almost making excuses:

"Sore"	"Uncomfortable"	"It is what it is"	"Really grumpy"
"Stiff"	"I'm done"	"Didn't sleep well"	"Not in the mood"
"Need rest"	"Feeling cranky"	"Exhausted"	

One comment I have reproduced here in full as it seems to embody what we all go through...

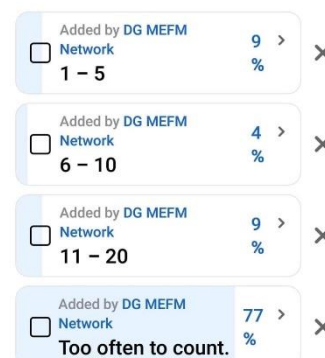
"My daughter can tell by my voice if I'm bad. On really bad days I actually fall asleep while talking to her on phone & start talking complete gibberish. On really, really bad days I can't even open my eyes or answer phone. My mum doesn't seem to understand at all. I do tend to put on a brave face & try not to let folk know how much pain I'm in unless it's seriously bad. My cousin, daughter & friends can tell by colour of my face, etc. Apparently, I tend to look grey on bad days. Apart from that no-one sees me when I'm suffering as I don't leave the house. I feel like I've written a book here. Sorry if it isn't clear xx" (Facebook Group member)

This is a perfect explanation, which links in with other comments. We do try to keep our families and friends cocooned somewhat from our full experience. Saying we are 'really really bad' is not a specific descriptor of pain. In my own case, despite trying to explain to friends what I am going through on a daily basis, they don't seem to be able to take it in. It is a case of 'Walk a mile in my shoes..'

Second question: How often do you actually USE or THINK the word PAIN in a day?

The results of this question are rather illuminating. When we think of our pain, we are only talking to ourselves. The 77% who replied 'too often to count' are likely the same members who commented on the first question. With ourselves, we use the actual word, PAIN; with others we tend to add some form of description, an aid to their understanding.

Living with chronic pain can only be understood by others who have similar lived experience.



At the end of this unscientific poll, I would say the best way to deal with life with pain is to be true to ourselves. Acceptance of the experience we are having and making sure that we do not put unreasonable expectations upon ourselves, goes a long way towards a happy life.

It's not easy, it takes quite a bit of getting used to, but life is doable with chronic pain.

Take care all, see you soon. Eileen



A Note of Thanks from Craig Woods

I'd like to thank the committee and members very much for the gift of the beautiful stained glass to mark me stepping down as chair. It is a beautiful piece and will be a reminder for years to come of my 21 years or so on the committee.

I am enjoying my retirement from the Network but I still don't have much in the way of free energy or low-pain days, as I am still catching up on everything that I'd neglected for so long.

I hope everyone is doing as well as they can be and the Network continues to facilitate support for as long as it's needed.

Social Meet-Up

Join us for a brew and a blether. Come 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, beginning 6th October. Hybrid meeting on zoom and face-to-face at Turning Point Scotland, Newall Terrace, Dumfries. Join any time between 2pm – 3:30pm.

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: 2022

Pop-Up Meet-Up

One of our Trustees, Paul, will be hosting a meet-up at Threave Garden Terrace Café for a pop-up on Sunday 30th October at 1.30pm. Please let Paul know if you are planning to attend.

Crafty Friday

One of our Trustee's, Corrie, will be hosting this winter's Crafty Friday zoom sessions on the third Friday of every month from 11.30-12.30. Starting October 15th 2022 and the last one before the summer on May 19th 2023.

During these sessions we can show and share our craft projects, discuss our patterns and techniques, and have a chitchat about crafts, crafting, the weather and the garden etc.

Any member can join this zoom meet. Login details/reminders will be posted a few days in advance of each session on our Facebook "get crafty with ME" Group page.

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

Annual General Meeting (AGM) 2022 Notification

Notice is hereby given that a Members Meeting of the Dumfries & Galloway ME and Fibromyalgia Network will be held on **Thursday 6th October 2022** at Turning Point Scotland, Wardens Flat Newall House, 22 Newall Terrace, Dumfries DG1 1LW. For a short video on how to access the meeting room at Turning Point Scotland go to <https://youtu.be/SLkPHF65EiM>.

The meeting will include the annual report from the chairperson, Eileen Longworth on the activities of the charity; consideration of the annual accounts for the charity from the treasurer, Paul Thompson; and election / re-election of charity trustees.

Attendance will also be available by audio-visual link i.e., **Zoom** as follows:

Meeting ID: 843 001 5846 Passcode: 2022

[If you would like a copy of the accounts, please get in touch beforehand.](#) Please note that only DGMEFM Network **members** can nominate board members / trustees and vote at the AGM, although non-members are welcome to attend.

Attendance

To assist us with registration, please contact us by 4th October 2022 to confirm if you wish to attend and if this will be in-person or via Zoom.

If you are unable to attend the meeting, you can nominate either another member or the chairperson to represent and vote on your behalf, by completing a 'Members Proxy Vote Form'. For this form, email us at admin@dgmefm.org.uk or telephone 07557 536110; forms to be returned to us by 4th October 2022.

The quorum for a members' meeting is **8 members**.



Trustee Recruitment

If you, or someone you know, may be interested in becoming a trustee, whether existing or new member, friend, partner, or family member, please contact: Eileen Longworth Tel: 07557 536110, or email admin@dgmefm.org.uk for an informal chat.

We are looking to secure four new trustees to the Board and would welcome applicants with the following skills: Charity accounting / Charity governance / Health and Safety / Human Resources / Business strategy and planning and management. A 'Members Board Nomination Form' is required, for return no later than 9am on Thursday 29th September 2022 for all new trustee nominations.

Member Story



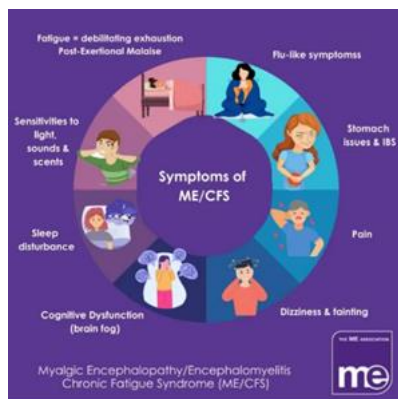
Hi everyone! My name is John Faircloth-Wood. I would like to share with you my ME journey, warts and all, as well as giving you a wee bit of information on "**What is ME**".

What is ME?

ME or Chronic fatigue syndrome is a complex multisystem illness that affects the brain and muscle function and, in some cases, other body systems as well. It often causes prolonged ill health and disability. ME stands for Myalgic Encephalomyelitis it is a neurological disease.

ME is usually triggered by an infection or virus. This can result in abnormalities involving the brain, muscle, immune and hormone-producing systems. The visible signs and restrictions that people normally associate

with being ill or disabled may not always be obvious in someone with ME. So, a person with ME/CFS may look perfectly well on the outside but are struggling inside, hence why it's called a hidden illness. The severity and range of ME/CFS symptoms varies from person to person. Symptoms and their severity can vary throughout the day, from day to day, from week to week and from month to month. For example, a 10-minute phone call may use up to 15% of your already depleted energy reserves one day but only use up 5% the next. These symptoms can lead to complete exhaustion. Even listening, reading a book or watching TV can be draining.



The symptoms

The main symptom is Post Exertional Malaise, basically this is doing too much either mentally or physically and the knock-on effect can be days, weeks or even months struggling to get out of bed or make a cup of tea.

Other symptoms include cognitive dysfunction – problems with short-term memory and concentration (brain fog), finding the right words, sleep problems, feeling faint or dizzy, ongoing flu-like symptoms, pain and sensitivity to light and noise. For me, living in a house with 3 teenagers would challenge anyone's noise sensitivity let alone having ME to make it worse!

The treatment

There is currently no medication to treat ME, so the way to manage it is pacing. Understanding your limits and listening to your body. You have to adopt a tight budget when it comes to energy. A good friend of mine told me about the spoons analogy, where a normal person would start the day with a 100 spoons of energy and somebody with ME only has ten. So spend wisely, as when the spoons have been used up there are no reserves to dip into.

My journey

In 2011, I became unwell and was given a diagnosis of Ulcerative Colitis, I then had an operation to remove my large bowel and have a stoma fitted. The large bowel was very badly diseased and to add to the complications I got sepsis after the operation. However, with great support from the medical staff, my family and my colleagues, I made a good recovery and got pretty much back to normal.

Towards the end of 2012, I was starting to feel unwell again and I had to go through another major operation and after my operation my body struggled to fight the infection. Things were not looking good and the recovery was slow and to be honest I have never really got back to normal after that. I was also diagnosed with Crohn's disease, quite a setback for me mentally, but again the support from my wonderful family and my employer got me through what was a difficult time both for my physical and my mental health.

ME can be a difficult illness to diagnose, especially when you have Crohn's and many of the symptoms are common to both illnesses.

From 2013 to 2019, I really struggled with Chronic fatigue, as well as periods of depression and anxiety. Unfortunately, my attendance at work was affected during this time. Those people that know me will know that I don't like taking time off work and have always put a lot of care and passion into my work. Each time I went to see a Doctor the diagnosis for my symptoms were Crohn's disease. But things just didn't stack up for as there are usually some obvious clues through blood tests and other inflammatory markers that would point to Crohn's. Eventually, in 2018 I was diagnosed with ME.

The problem with not being given the correct diagnosis was that when I would recover from a bout of chronic fatigue, I would then revert back to being "normal" again. As I mentioned earlier, with ME the only

way to manage the illness is to pace yourself, I only have 10 spoons each day to use up. I was trying to live a life as a person with 100 spoons when I only had ten and this would lead to a serious crash each time. It is not just physical exertion that triggers ME symptoms, but Mental exertion.

Coming to terms with having ME has been difficult for me and to be brutally honest has probably hindered my recovery at times. I didn't have the right information and felt like I was the only person in the world with this disease. I didn't have anyone to speak to that truly understood what I was going through. Trying to explain to friends, colleagues and relatives that I could only talk for 5 minutes on the phone as any longer was a mental exertion or that I was not able to visit people as often as I would like was all hard. I have always been an active outdoors person, lots of family camping holidays, walks and discovering new places. To be told that I had to reign all this back was hard and had an impact on my mental health.

In January this year, I contacted the ME association for advice and they were great, giving me advice and an understanding ear to listen. They were really helpful and put me in touch with The [Dumfries & Galloway ME Support Group](#) in my area. That was the real turning point for me, the group have been fantastic. The main reason I have put this together is to raise awareness of ME and other hidden illnesses and encourage people to talk about it. You can see a broken arm, but not a hidden illness.

However, there are signs we should look out for such as a change in mood, somebody just not being themselves looking drained and not eating properly. Many of these changes are very subtle and we tend to put a lot of energy into hiding the fact that we have a hidden illness. Please don't be afraid to ask for support.

Some people don't want the stigma often associated with the label of 'disability', or do not want to be defined by what might be regarded as a limiting health condition. This is particularly the case for disabilities which are often reported in negative terms in the media such as ME, depression and anxiety conditions.

We should never judge or assume what a disabled person can or cannot do. Many employees fear that their colleagues might treat them differently if they knew about their disability or long-term condition. Thank you all so much for reading, it is greatly appreciated.
John

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



New. Try MSE, the app! You've wanted us to do it for years, and we've spent six months building it, so now, at last MoneySavingExpert has an **Apple** and **Android** app. It has the whole site on it, plus some enhanced tools, and experimental first-try features. It's early days, but feel free to move to it, and give us **feedback & suggestions**.



Money Saving Expert App (recommended by one of our Trustees)

Updates from the Board

**NOT BEING
ABLE TO DO
AS MUCH AS
OTHERS DOES
NOT MAKE
YOU A
FAILURE.**

Privacy Policy

We have recently updated the Network's Privacy Policy to reflect the fact that we now send address details to the printers in order for them to post the newsletters on our behalf. The updated Privacy Policy can be found on our website.

Amazon Smile

For all who support us through Amazon Smile, we've now enrolled under our new charity number SC051578. The old one (SC030641) will become defunct. Existing funds will be transferred to the new charity number but this is the new link to use from now on <https://smile.amazon.co.uk/ch/SC051578>. Thanks again for your support.

Facebook Group

We've had reports of members not receiving notifications when content is added to the Facebook group. It's tough to beat the Facebook algorithms but one thing we know for sure is that the more you interact with the Group, the more notifications you will be shown. Please try to post, like and comment as much as you feel able.

ME Genetics Research Summit

Action for M.E. and the MRC Human Genetics Unit, University of Edinburgh are hosting the first M.E. Genetics Research Summit on 14 September 2022 in Edinburgh.

The summit will bring together researchers interested in ME, people with ME, carers and potential funders to drive collaboration in this field and develop a 10-year programme of ME/CFS genetics research. The summit is open to anyone who would like to join us and is available at no cost. Adjacent quiet rooms are available for use throughout the day.

The event will be hybrid and you are welcome to join in person or remotely. Please register your attendance:

<https://www.actionforme.org.uk/news/m.e.-genetics-research-symposium/>



Myalgic Encephalomyelitis: Northern Ireland Educational Webinar Series

Hope 4 ME & Fibro Northern Ireland Charity and the HSC Clinical Education Centre have developed a series of webinars to explore the radical changes taking place within the new proposed NICE Guidelines for ME/CFS and the important implications arising from the developing Long Covid crises. The webinar series brings together experts in the field of ME/CFS to share their knowledge and experience:

- The New NICE guidelines on ME/CFS (2021): How the paradigm has shifted
- Post-exertional symptom exacerbation: Activity and rest & Physiotherapy for ME
- ME: When the doctor becomes the patient
- Symptoms and diagnosis of ME in children & Adults with very severe ME
- Occupational therapy for ME: Patient self-management advice & ME/CFS patient support groups

All webinars can be viewed at the following link: <https://doctorswith.me/myalgic-encephalomyelitis-educational-webinar-series/>

DGMEFM



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

Impact Report 2021/22

"The Dumfries and Galloway ME and Fibromyalgia Network has recently become a SCIO. This is a fabulous move forward, after holding charity status for over twenty years. Over the past year we have been fortunate enough to secure funding for various projects, which make our future look very exciting indeed.

Our board of trustees are all volunteers, with varying life and work experience to bring to running the network. At the beginning of 2021 we contracted an Admin and Development Worker, Eppie, through funding from Awards for All.

Eppie has been instrumental in assisting the board with administrative duties, streamlining our process in many areas, and therefore making life much easier. She also instigated the public Facebook page. This spreads our reach to anyone on the Facebook platform and gives a direct link towards joining both the private Facebook group and the charity.

As we move towards face-to-face meetings on a regular basis, the zoom facility enable us to make our social meetings a hybrid of virtual and actual. This will then enable members to attend no matter what their situation.

The year to come is sure to be filled with even more growth for the Network, and I, for one, am excited to see where we end up this time next year!"

**Became a SCIO.
New charity number: SC051578**

Number of members: 395

**Members of our Facebook
Group: 427**

Funding Secured: £6,000



- Eileen Longworth, Chair



1. Raising awareness and promoting understanding

- Our stakeholders have better access to accurate information which improves awareness and understanding of ME/CFS and FM
- Public, third and private sector organisations across Dumfries and Galloway have more knowledge, skills and confidence to effectively support the needs of people with ME /CFS and FM

“Lovely group... whose encouragement was 100% positive.”



“I live on my own and have mobility issues so I’m grateful for these zoom sessions and not have to worry how I’m going to get transport to and from venues. They also allow me to interact with others who are not clinicians (dentist, doctors, etc) but with people with similar or related conditions.”



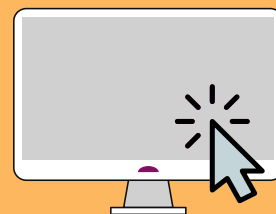
309 Facebook Page likes

427 Facebook Group Members

1688 Website Visits

24 Blogs Shared

4 Newsletters



6000 Leaflets & Contact Cards Distributed

3000 Flyers Distributed

55 Members Registered For Our Online Learning Events

3 External Speakers - Liz Forsyth, Sleeping Giants and Dr Shepherd



Our support base has expanded over the past 12 months with an increase in both members with lived experience and allies engaging with our work.

We now have a Facebook page, which allows us to share information directly with interested health and social care professionals.

Our online learning event (the culmination of the commission work carried out by Sleeping Giants to gather views on the development of our services), was an overwhelming success.

We were delighted with the number of delegates and the quality of the speakers was exceptional.



Impact Report 2021/22

2. Supporting access to services and support

- People with ME/CFS and FM have better access to a range of high quality clinical and peer-led services and support which enables more timely diagnosis and supports more effective self-management
- People with ME/CFS and FM and their carers / supporters have more opportunities to connect with their peers, which reduces isolation and increases wellbeing

The craft programme delivered in early 2021 has now developed into a craft and wellbeing project, for which we have secured funding for two years. We hope to deliver one workshop per month with topics ranging from mindfulness and yoga to soap making and calligraphy. Our meet ups are now gradually moving towards face-to-face again. With a series of pop-up face-to-face meetings over the summer months to assess interest, it is our hope that we will be able to establish a regular pattern going forward.



11 Craft & Wellbeing Workshops
3 Face-to-Face Meet Ups
Fortnightly Online Meet Ups

3. Building participation, skills and confidence

- People with ME/CFS and FM and their allies have access to high quality volunteering opportunities which build knowledge, skills and confidence and enable them to take leading roles in the delivery of services
- People with ME/CFS and FM have more opportunities to give their views, and are better able to influence decision-making and service design

Over the course of the year, Sleeping Giants (an external consultancy) have been conducting a piece of community engagement work to establish the appetite, amongst people with lived experience and health and social care professionals, for three projects:

- Befriending projects
- Peer (expert patient) mentoring project
- Clinical lead

The final report demonstrated support for all three of the projects. As a result, funding is being sourced to develop both a befriending project and a peer mentoring project. In addition, the team are in discussion with the Strategic Commissioners within the NHS to push for the eventual establishment of a clinical lead.

53 people responded to our online survey and 1 focus group took place





Impact Report 2021/22

4. Building our organisational capacity

- DGMEFM Network has the required resources, plans, policies, and systems to ensure that the charity is run safely, ethically, legally, efficiently, and effectively.
- DGMEFM Network has a confident, knowledgeable, skilled and effective Board and staff team.
- DGMEFM Network is accessible and inclusive, and better able to support individuals from protected characteristic groups and those with more complex needs.



Community Mental Health and Wellbeing Fund - £6,000

We have developed:

- Policies and procedures
- Trustee skills audit
- Risk matrix
- Communications strategy
- Strategic plan
- Delivery plan

**Eileen as new Chair
Eppie as Admin and Development Support**

"I felt cared for and calmer. I started out feeling very down... and ended the course feeling much happier"

As a result of the extra capacity the organisation has had over the last 12 months (in the form of our Admin and Development Support Officer, Eppie), we have managed to undertake a whole host of really important tasks relating to the management of our Network: we have changed to become a Scottish Charitable Incorporated Organisation (SCIO); we have developed a Strategic Plan and Delivery Plan; we have developed policies and procedures that will ensure our Board works as effectively as possible; and we have been successful in securing a range of funding to deliver our services.

"I have been off sick for months and feel very isolated and like I'm missing out on the fun bits of life. This really boosted my mood, self-esteem and I felt like going for a walk afterwards because I felt much better."





Impact Report 2021/22

The Network were awarded funding from the Communities Health and Wellbeing Fund for us to continue the craft workshops and implement wellbeing workshops to be presented via zoom on a one workshop per month basis for two years. The Lottery also funded our zoom license, which we use for the workshops and for all necessary meetings. During the pandemic this zoom facility was important in cutting down the feeling of isolation for many members across the region.

The NHS Endowment Trust paid for our quarterly newsletters. Some are sent out by post, others via email. We have also engaged a designer to update our flyer, leaflet, and contact cards. The funding for those came from the Lottery. These have all been sent out in hard copy to the Practice Managers of D&G, with a digital copy of the flyers for the waiting room noticeboard screens. As a direct result of this we have had referrals from GPs and other health professionals.

The Health and Social Care Alliance Scotland funding is having a great impact, building us into a more solid organisation. We would not have been able to go forward with fund-finding for the Befriending and Mentoring Schemes if we had not been able to carry out a thorough feasibility study. The Alliance project has improved our presence and started a positive journey for us within Health and Social Care, who totally believe in the validity and benefit we can engender through the Befriending and Mentoring Schemes.



In addition, our members took part in a recent Digital Inclusion survey, which raise funds for the Network. For each completed survey we got £30, so a total of £2,400 extra funds were made for the Network.

Gratefully acknowledging the support of:



**Foundation
Scotland**



‘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://dgmeffm.org.uk/donations>
For eligible donations there is a Gift Aid Declaration button on that page.
- You can post your donation with this form addressed to:
DGMEFFM Network Treasurer, Thistledew, Albert St, Dalbeattie. DG5 4JP.
Please make cheques or postal orders payable to ‘DGMEFFM Network’.
- If you feel able to make a regular (e.g. monthly) donation please contact admin@dgmeffm.org.uk for our bank details.

With many thanks in anticipation.

✂-----

To DGMEFFM Network:

I enclose my donation of £_____

Donor’s details

Title ----- First name or initial(s) -----

Surname -----

Full home address -----

Postcode -----

If you are a taxpayer, please consider signing this declaration. *From your donation we can claim an additional 25% from the Inland Revenue e.g. for a donation of £10.00 we get an extra £2.50.*



I want to Gift Aid my donation to the charity DGMEFFM Network.

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations, it is my responsibility to pay any difference.

Date -----

Signature -----

DGMEFFM



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

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