

June 2022

# DGMEFM Network

Support for ME, CFS, Fibromyalgia



So how on earth is it June already?

It seems to me that the years 2020 and 2021 were directed by Quentin Tarantino, with a soundtrack of improv jazz. Now 2022 seems to me like it's on fast-forward. I don't know about you, but life seems to be going by much quicker as I'm getting older.

Since the last newsletter there have been some developments in the Network. The research by Sleeping Giants has been completed and we had an online learning event on the 12th of May (ME/FM Awareness Day). We have a lot to look forward to with regards to this research and seem to be on the same track with NHS Dumfries and Galloway. The next area that I want to be part of is helping people become their own advocate. I feel that being fully conversant with the signs, symptoms and treatment of the conditions that we are living with is the way to go. Being proactive in our treatment and not afraid

to challenge or discuss any aspect with our health professionals. So that's why the Facebook group is important, where members can share their lived experiences and understand more fully any coping strategies that may be useful.

The Thursday social zooms have been popular with some new members joining, as have the crafty Friday zooms. Spreading our reach within the region is an important part of what we do. We have some new workshops organised and advertised and can look forward to one workshop per month at least for the next two years, as we have the relevant funding.

Finally, I'm excited to announce that we're now ready to have face-to-face meet ups again. These summer Pop-Ups will be an experiment to firstly, see how many members are happy to meet face-to-face and secondly, to decide if the venues are adequate for further Pop-Ups going forward.

**Sunday 26<sup>th</sup> June, Dalbeattie Garden Centre Cafe, 1:30pm. Host, Paul – paul@dgmefm.org.uk**

**Saturday 9<sup>th</sup> July, King's Arms Hotel, Lockerbie, 12.30pm. Host, Eileen – eml@dgmefm.org.uk**

**Sunday 24<sup>th</sup> July, Castle Douglas Garden Centre Cafe, 1:30pm. Host, Paul – paul@dgmefm.org.uk**

If you are planning to attend, please e-mail the host to let them know.

The monthly face-to-face meet ups will be discussed after we have some idea from the Pop-Ups. For the time being the Zooms will continue, and they will not be combined with the Pop-Up meets.

Until next time... I will just sit back and revel in the joyous feeling of being a first time Granny.

Regards Eileen



Make your weird  
light shine bright  
so the other  
weirdos know  
where to find you.

## Online Zoom Meetings:

### Social Meet-Up

Next Social Meet-Ups are Thursday 2<sup>nd</sup> and 16<sup>th</sup> June.

Social meetings are fortnightly, 2pm until 3.30pm.

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 but at the moment there are no definite dates for visiting speakers.

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to [www.zoom.us](http://www.zoom.us) on your computer.

Enter this info: - Meeting ID: 843 001 5846, Passcode: 2022

### Crafty Friday

Craft Friday is also fortnightly, 11:30 until 1pm.

The next one is Friday 10<sup>th</sup> June.

A little bit like a virtual knit and natter. Any craft is welcome. Enter this info into zoom: - Meeting ID: 823 6353 7970, Passcode: 2022

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

## Meet Some of The Board

### Kim Jakobsen



I'm Kim, Network Secretary since October 2021. This is my second time as a Trustee for the Network. I found the Network in 2015, after meeting a member at one of the monthly pain association meetings in Dumfries. For me, being a Trustee is both rewarding and hard work as I want to give 100% when I might only have 10%.

Thankfully, we have a super Board of Trustees who have collective responsibility for the Network, which means making informed decisions about the direction to take the Network as a whole. Having something to motivate me remain as active as able is really important but I find the line between too little and too much, very fluid.

Moving to Dumfries when I was in Primary 2, I have been married to a Doonhamer for over 30 years. We have 2 adult children who, like my husband, make me proud every single day. I have 30 years lived experience of my illnesses, which led to ill health retirement in 2019. My background is management and accountancy, working with the Forestry Commission, Dumfries & Galloway Council and finally with NHS Dumfries & Galloway.

Gentle hugs to you all ☺

### Paul Thompson



I'm Paul, the Network's Treasurer. My background is in Health and Social Care but I had to give up work 18 years ago through post-viral fatigue, later diagnosed as ME. I live with June, who also has ME, and our two cats here in Dalbeattie. We moved back in 2014 after a few years away in Cumbria, but during that time we each benefitted from an ME clinic in Keswick and learned some helpful coping strategies. It wasn't a cure but it was better than nothing! Let's hope that the work by our Network's Trustees, and by any members who can influence the powers-that-be, will help towards getting better support here in D&G for all of us soon.

June and I have been very cautious, keeping ourselves away from people during the pandemic, but I'm looking forward to catching up with folk as our local café meetings start again.

### Diane Bond

Hello, I'm Diane, a Trustee since October 2020. I came across the Network after moving back to D&G, having been working away for some years and having lost my career to ill-health, now retired. I've had lived experience of ME & Fibromyalgia (since 2010, eventually diagnosed in 2015) along with these conditions I have other conditions related to these two, a list which seems to grow with time.

I first became aware that I was unwell at the beginning of 2010 after feeling I'd hit a brick wall. Things didn't improve, thinking back. I regularly got colds, ear infections, basic stuff, nothing really to worry about. I had spent the best part of 25 years then caring for children and in the children's sector health and social care. Then came pneumonia in 2015, a week of antibiotics and I got better over two weeks. Then it came back with a vengeance and I couldn't get out of bed... I could not manage without my darling, caring, lovely hubby. Brings a whole new meaning to in sickness and in health. Not the retirement we'd planned for but we work it out. I'm an ambler now not a rambler, no more scaling great hills and forests.

It was lockdown that made me look for something and others to connect to, whilst safe and shielding at home. I've never looked back, what a great wee team of lovely folk we have. It's fun, tiring, sometimes very tiring but oh so rewarding! I feel I've been able to resurrect my confidence and motivation during lockdown by being part of the committee. I've learned new skills and also made new friends. What I feel is really important though to me is giving back, being party to developing a new website and also improving the Network so that we can inform and support anyone with or suspecting they have this lived experience.

I remember only too well trawling the internet hoping for the same support after diagnosis. I'd never heard of M.E. I was extremely fortunate to be in England at the time and attended group sessions to learn all about my illness and a new ME. I hope our team efforts are helping members, families and carers. Here's hoping for a brighter future where we can feel safe to meet again. We will meet again.



## New Scottish Charitable Incorporated Organisation

In her introduction to the last Newsletter in March, Eileen mentioned that the Network was given approval by the charity regulator to change our structure and become incorporated. We are now registered as a Scottish Charitable Incorporated Organisation (SCIO) with consent for us to wind up the old charity and transfer assets to the new one.

- The new charity has a new constitution and the formal name Dumfries & Galloway ME and Fibromyalgia Network [SCIO], aka DGMEFM Network. Registered number SC051578.
- The old charity, number SC030641, will wind up on 31<sup>st</sup> July 2022 and all assets transfer to the new charity and its new bank account.



What does this mean for members?

- Your membership will automatically transfer. You don't need to do anything unless you want to cancel your membership, in which case you'll need to write to us to say so. You shouldn't notice much difference in practice, but if you have any questions please get in touch.
- The current seven Committee members will become the new Board of Trustees, until any step down or are newly elected at the AGM which will be held as usual in October.

Without getting too technical, incorporation means that DGMEFM Network becomes a legal entity and can enter into contracts in its own right, where previously the trustees had to do that on behalf of the charity and could be personally liable if something went wrong.

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

As an incorporated charity we can employ staff (if we get the funding). Eppie, our admin and development support, is self-employed. We've applied for 2 to 3 years of funding to employ two part-time staff (in addition to keeping Eppie). The new staff would set up and run befriending and mentoring services offering support to our members and others in the region living with ME/CFS and Fibromyalgia, including people newly diagnosed. These ideas were broadly welcomed by professionals and those with lived experience who took part in the feasibility study we asked Sleeping Giants to carry out for us.

The study found that there may be many GPs and others in health and social care who haven't yet heard of us. If we're successful with the funding bids and can take our plans forward, the mentoring project should hopefully build closer links with health and social care practitioners across the region.

## Communities Mental Health and Wellbeing Fund

In the spring, we received funding from the Communities Mental Health and Wellbeing Fund to enable us to deliver a series of craft and wellbeing sessions, covering one topic per month over the next 2 years.

We have just had our first workshop – interactive card making – which was a hit for all! It was delivered by Anne McLauchlan of Card Cabin in Dumfries and her workshops are always very well received by our members.

Coming up in June we have Chair Yoga, in July we hope to have an introduction to Mindfulness and then in August we will be dipping our toes into Storytelling.

Workshops are promoted in our Facebook Group and are e-mailed to members who aren't on Facebook.

Other topics that we are looking to offer include:





- Pain management
- Journaling
- Glass cutting / stained glass
- Acrylic painting
- Calligraphy
- Flower arranging
- Decoupage
- Basket weaving
- Macrame
- Alcohol ink painting
- Soap making

I am always on the hunt for workshop instructors, so should you know of anyone who could deliver a workshop on the above topics, or if you would like more information, please contact me at [eppie@dgmefm.org.uk](mailto:eppie@dgmefm.org.uk)

## Online Learning Event

Our learning event took place on 12<sup>th</sup> May. The event was a platform for us to share the findings of the extensive piece of consultation work that Sleeping Giants have been carrying out on our behalf. Most notably, sharing the appetite, of both health and social care professionals and people with lived experiences, for the three project ideas:

- Expert Patient Peer Mentoring Scheme
- Befriending Scheme
- Clinical Lead

Dumfries and Galloway ME and  
Fibromyalgia Network:

Consultation Key Findings  
Final Report

April 2022

The event brought together health and social care professionals and those with lived experience of ME, chronic fatigue syndrome, fibromyalgia and long covid. It included talks from Dr Charles Shepherd (Medical Advisor, ME Association) on the updated NICE Guidelines and Liz Forsyth (Strategic Commissioning, NHS Dumfries and Galloway) on the way in which the work of our network fits within the aims of the NHS Strategic Commissioning Plan.

sleeping  
GIANTS



The final report and the event itself (which was recorded) can be found on our website and on our Facebook page. Should you wish to have the links e-mailed to you, please contact [eppie@dgmefm.org.uk](mailto:eppie@dgmefm.org.uk).

## Self-Management Tool from Pain Concern

<https://painconcern.org.uk/the-navigator-tool/>

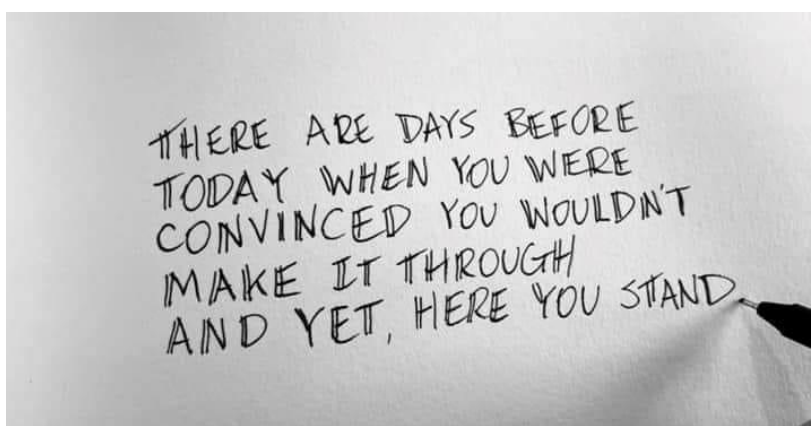
Chronic pain impacts more than just the body. We know that for people living with pain, raising concerns about wider aspects of health in appointments with their health-care professional is not always easy and their concerns and worries do not always feel relevant. Doctors can also find it difficult to introduce wider issues around pain during routine appointments. Exploring wider aspects of pain can benefit people's ability to self-manage their pain.

Pain Concern has now developed a paper-based tool for patients to prepare themselves to bring up their concerns and worries in appointments. Designed to help patients navigate their concerns and bring the most important questions up in primary care appointments.

If you are the person with pain, download **My pain concerns form** to your tablet, computer or print a paper copy. The form **Questions to ask your health-care professional** has some suggested questions that you might want to ask. You might also have your own questions based on the concerns you have identified.

HINTS:

- How you feel about the statements may change from day-to-day; choose **agree** or **disagree** according to what you feel right now.
- **My pain concerns form** and **Questions to ask your health-care professional** are colour-coded to make them easier to use together.





# My pain concerns form

Read each statement and tick either 'agree' or 'disagree' as to whether this is something you would like to talk to your health-care professional about. Then choose the three most important (by underlining or making a note of them).

Diagnosis and cure	Agree	Disagree
I don't think enough has been done to find out what is wrong.		
I don't know the cause of this condition.		
I don't understand my diagnosis.		
My pain is not getting any better.		
My pain is getting worse.		
Other (please write below).		

The way I'm feeling	Agree	Disagree
I feel frustrated or embarrassed that I can't do the things I used to.		
I feel in a low mood.		
I feel stressed.		
I feel that people are judging me.		
I feel lonely and isolated.		
Other (please write below).		

Changes to my life	Agree	Disagree
I don't see my family and friends.		
I can't continue in or return to work.		
I can't do my usual day-to-day tasks at home.		
I can't get a good night's sleep.		
I can't do leisure activities that I used to enjoy.		
I have money worries.		
Other (please write below).		

My medications	Agree	Disagree
I am concerned about the amount of medication I'm taking.		
I am concerned about the combination of medications I'm taking.		
I am concerned about the side effects of the medication I am on.		
I am concerned that my medication does not help my pain.		
Other (please write below).		



# Questions to ask your health-care professional

These are some suggestions for questions that you could ask your health-care professional based on the three concerns you have identified in Part 1.

Diagnosis and cure <input checked="" type="checkbox"/>	
I don't think enough has been done to find out what is wrong.	<p>Is there anything more that could be done to find out what is wrong?</p> <p>Have all reasonable tests been carried out?</p> <p>Should I see a pain specialist about my condition?</p>
I don't know the cause of this condition.	<p>What is causing my pain?</p> <p>Why did nothing show up on my scan?</p>
I don't understand my diagnosis.	<p>Can you explain my diagnosis again?</p> <p>Do you have any written information on this?</p> <p>The feedback from my scan was 'wear and tear'. What does this mean?</p>
My pain is not getting any better.	<p>Are there other treatment options that we haven't tried yet?</p>
My pain is getting worse.	<p>How can I tell whether or not my symptoms mean I should get immediate medical help?</p> <p>Should I see a pain specialist about my condition?</p> <p>Is my pain going to keep on getting worse?</p>
Changes to my life <input checked="" type="checkbox"/>	
I don't see my family and friends.	<p>What strategies can I use to make sure I can still enjoy time with family and friends?</p> <p>How can I explain my pain to family and friends?</p>
I can't continue in or return to work.	<p>Are there any restrictions on me going back to work?</p> <p>What help is available to me for getting back to work?</p> <p>How am I going to be able to cope with work after being off because of my pain?</p> <p>Is there anything I should stop or avoid doing?</p>
I can't do my usual day-to-day tasks at home.	<p>What strategies can I use to make sure I can do everything I need to?</p> <p>Is there anything I should stop or avoid doing?</p>
I can't get a good night's sleep.	<p>What can I do to help get a good night's sleep?</p>
I can't do leisure activities that I used to enjoy.	<p>Am I still able to.... (ride a bike, go hillwalking, and so on)?</p>
I have money worries.	<p>Where can I get advice on financial support?</p>





# Questions to ask your health-care professional

The way I'm feeling ✓	
I feel embarrassed that I can't do the things I used to.	<p>How can I get back to doing the same things that I used to?</p> <p>What is available to help me deal with these negative feelings?</p> <p>How can I explain to people about the effect my pain has on me?</p>
I feel in a low mood.	<p>What can I do to stop feeling so low?</p> <p>What help is available to me for these negative feelings?</p>
I feel stressed.	<p>What can I do to stop feeling so stressed?</p> <p>What is available to help me deal with these negative feelings?</p>
I feel that people are judging me.	<p>What is available to help me deal with these negative feelings?</p>
I feel lonely and isolated.	<p>How can I connect with other people who are going through the same thing?</p> <p>How can I explain to people about the effect my pain has on me?</p>
My medication ✓	
I am concerned about the amount of medication I'm taking.	<p>Can you tell me what all my medications do?</p> <p>Will I become addicted to the medications I am taking?</p> <p>Are there other ways to treat this condition that does not involve medication?</p>
I am concerned about the combination of medicine I'm taking.	<p>How do these medicines affect one another?</p>
I am concerned about the side effects of the medication I am on.	<p>What are the side effects of all the medication I am taking?</p> <p>Will any of these medicines harm me?</p> <p>Can you explain to me the difference between side effects and harm caused by medications?</p>
I am concerned that my medication does not help my pain.	<p>Should I stop medications that do not help?</p>

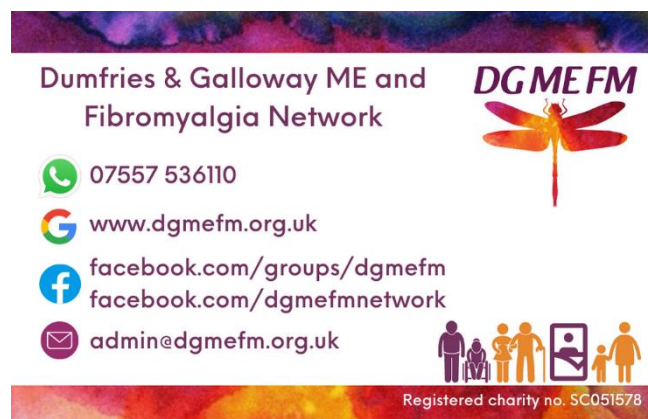
## Leaflet and Contact Card Distribution

We have new leaflets and contact cards that we've included with this newsletter. These include our new charity number. If you are able to distribute them in your local community (notice boards, waiting rooms etc), you would be really helping the Network!

We know that there are many people out there with ME-like symptoms following Covid-19, as well as those with Fibromyalgia and ME who still don't know of us, and it would be good for them to find the mutual support this Network offers.

Our new leaflets and contact cards have been sent out to GP clinics. If you're in contact, please ask if they have them; ask staff and practitioners to be aware of them, and ideally to put some in patient areas. We can always send more if they're running short.

We still have leaflets and contact cards available. If you can distribute them, please get in touch and we'll be happy to pop more in the post to you.



**Dumfries & Galloway ME and Fibromyalgia Network** **DGMEFM**

07557 536110

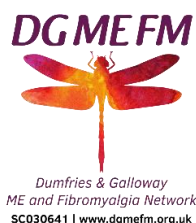
[www.dgmefm.org.uk](http://www.dgmefm.org.uk)

[facebook.com/groups/dgmefm](https://facebook.com/groups/dgmefm)  
[facebook.com/dgmefmnetwork](https://facebook.com/dgmefmnetwork)

[admin@dgmefm.org.uk](mailto:admin@dgmefm.org.uk)

Registered charity no. SC051578

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](mailto:admin@dgmefm.org.uk)



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Website: [www.dgmefm.org.uk](http://www.dgmefm.org.uk)  
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[paul@dgmefm.org.uk](mailto:paul@dgmefm.org.uk) (Treasurer)  
[kim@dgmefm.org.uk](mailto:kim@dgmefm.org.uk) (Secretary)



*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](mailto:admin@dgmefm.org.uk) or text or phone 07557 536110.*