

September 2020

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Welcome all,

I hope everyone is staying safe in this most-challenging of years. It feels like summer is long gone already and I'm not looking forward to this winter in the slightest with Covid-19 still threatening.

We continue to adapt however, and I must say that some aspects of it are not all bad. We're making good use of our Zoom subscription for the meetings and I'm really enjoying seeing members who I've not managed to meet in person due to distance or ill health. Having that face-to-face contact when the lockdown was most stringent was very welcome indeed. We have got quite a few guests in the works for upcoming meetings so please keep an eye on the Facebook page, the website and your inbox for details.

The news stories and reports around 'long-covid' continue to be extremely worrying. More and more it seems as if the unfortunate people who come down with this after the initial Covid-19 infection has gone are developing ME. They are not necessarily people who have been badly affected in the first place either, with many young people developing symptoms. It is already having an impact on the understanding of ME and ME research. Already I have read of a study into ME which has had extra money given to it to add on long-covid. With so many medical staff falling ill and not recovering, it is becoming very difficult for the usual deniers to ignore. This may be the silver lining to the very dark cloud of the pandemic.

It is the time of year where we ask for your help. We need people to attend the AGM so that we continue for another year. We also would love to have new members on the committee to help run the Network and potentially new projects. If you don't feel able perhaps a partner or carer would be interested in joining? While there is no obligation, we also would ask, if you feel able to, if you could make a donation towards the running of the Network. We operate with the lowest of expenses with the committee generously donating their time, but it does mount up, particularly the newsletter and postage cost.

Until next time, stay safe and hope to see you online.

Craig Woods

Online Get-Togethers Every Thursday 2pm – 3pm on Zoom.

Some guests and dates are still to be confirmed. We hope to have:-

Finlay Carson MSP – 24th Sep: A chance to share our ME and fibromyalgia health/welfare/housing etc problems with a member of the Scottish parliament.

Janet Sylvester from ME Action: 8th Oct: Janet will talk about ME Action's aims as they lobby government and aim for press coverage and greater understanding for ME

AGM - 15th Oct: This year we will also hold our AGM by Zoom.

Self-advocacy Training Session with Action for ME - 22nd Oct: this will be a 90-minute session empowering you to make yourself heard in your healthcare, welfare and family.

25% ME Group: TBA: We hope to hear from the 25% Group about the most severely impacted sufferers.

Look out for updates and Zoom meeting guests on our Facebook page or website.

Contact us:

Phone/WhatsApp - 07437 602610

email - admin@dgmefm.org.uk

Registered Charity No. SC030641



We are enjoying the benefit of Zoom for members to get together from across the Region as well as a few beyond Dumfries & Galloway, and the ability to invite guests from wider afield. For those of us missing our physical meetings, we'll start up again when it's safe enough to do so, although probably not until next year. Whenever we are able to resume our monthly get-togethers (and pop-up meetings) we'll hold our monthly Dumfries meetings at the new venue of Turning Point on Newall Terrace instead of Midsteeple. The facilities at Newall Terrace may allow us to continue to use Zoom at those meetings for anyone who wants to join in but can't physically attend, hopefully giving us the best of both worlds.



Our Online Meetings

The meetings happen every Thursday from 2pm. Using your browser go to www.zoom.us and click "JOIN A MEETING". If you don't have the app already it will download. Enter the meeting ID and passcode.

Meeting ID: 302-429-868

Passcode: Please Email, text or check Facebook for it

We won't change the Meeting ID or passcode unless we have to so it should work for every meeting. If we do change it, we will notify you via Facebook or email, so please check your contact details are up to date.

My Experience of the Online Meetings

I have been asked to write a few words on the Zoom meetings we have held each week during lockdown. For me personally it has been a real delight and a chance to get to know people in their own homes. For those of us who can't travel like me, it has given us a chance to meet and greet people we would never have met. Craig has done a great job setting it all up and it's quite simple to log on and 'zoom in'. I notice also that we have members from Edinburgh, Ayrshire and even down south, which otherwise would not be possible. I'm not saying way back in April the first meeting wasn't a bit dodgy as we tried to connect and the mute button would be on, but we got there and I think we have gone from strength to strength. We have covered all subjects under the sun and not just about our illness, and have learned such a lot with thanks going to Craig for getting us up and running.

We have with Craig's help again, had speakers like Phil Sizer from the Pain Clinic, Des Quinn FMAUK, Dr Shepherd, Emma Harper MSP and of course our very own Dr Purdie all giving their time generously to answer our many questions about our health problems. These meetings have been very well attended.

For more technical information I would refer you to John Bell's July Blog which tells you how to join Zoom and the best systems to use. I have used a Mac and iPad which have both been great so whether you are an IOS or an Android user why don't you come along any Thursday afternoon from 2pm and enjoy our get together. Looking forward to seeing you.

Jennifer Wood



Physical meetings - why I miss meeting people in person

Hello there my name is Nancy. Paul has kindly asked me to write a bit about why I am missing our old once-a-month physical meetings. I have been with the group for a long time. As a retired Midwife my natural instinct is to welcome people in to our meeting room and ask if they would like tea coffee ☕. To be fair, due to brain fog I often need help with this task, Craig helps, as does John, Carol and Lesley, I started putting milk and sugar on the table which helps a lot. How our meetings go depends if we have a speaker or not. When we do have a speaker our brains and ears have to work a little harder to keep up and the questions to be asked need to be remembered. We often start with hello I'm (insert name) and a little about ourselves. Taking part is optional and I remember how nervous I was for quite a long time. Don't worry if you can't remember names - it's a bit like a new quiz show as we try to fill in missing names or words, we all suffer from that. We bring biscuits and once a speaker from Tesco, Anne (their charities champion), brought lovely cupcakes. There is no charge for coffee, tea ☕ or biscuits. As usual I'm off topic. Why do I miss the meetings? I naturally want to look after people. We understand how painful, debilitating and unseen our illnesses are - we can see it in each other. There is no judgement or advice to take up exercise etc but you might need to suffer a Nancy hug - one poor guy looked so exhausted I wished I had something stronger to offer him. I miss seeing people but I still don't feel safe enough to be out and about. My immune system gives up in 10 seconds when I get a virus so for now I'm staying home 🏠. I want to be there to welcome those of you that are able to come to our meetings, familiar ones and new ones. We have helpful tips to share from pacing to alternative treatments and where to get support with benefits. We try to run awareness events; we send out leaflets and little business cards to GPs, chemists and supermarkets – places where we can let you know there is support for you. We also have our online Facebook page where medical articles are shared, and whatever the problem, someone in the group may be able to offer advice and support. There is, of course, our Newsletters which drops through the letter box or can be down-loaded from our website. I like the paper version - my son read the fibro article and I think he grumps a little less when I ask for help now. I still miss being in a room with patients - haha I mean people I can look after for two hours a month. I also usually washed the dishes but our new venue has a dishwasher! Knowing me the cups will be well rinsed as I do at home. I look forward to our meetings getting going again but I have no idea when that will be with Covid 19 so please all stay safe. xx 🌸👐👤👐🌸



Nancy Wilson

Dr Charles Shepherd, Zoom Meeting

We were honoured that Dr Shepherd agreed to give his time and energy to join us online for one of our meetings. Not surprisingly given his status it was our most well attended meeting to date with around 33 joining in. He talked for around 40 minutes on the current situation with ME, the NICE review – the next meeting of which he was preparing to attend, the Decode ME study and the worries around the 'long-Covid' post-viral element which is looking increasingly like ME that a significant minority of people are developing. He then stayed on for a further half hour or so to take our questions. The meeting was recorded. If you'd like a link to the video or to have the sound file emailed to you, please get in touch.



The 2020 Edition of the ‘Purple Book’



The latest edition of ‘ME/CFS/PVFS – An Exploration of the Clinical Issues’, (also known as the MEA Purple Book), is a comprehensive 150-page guide to research, diagnosis, symptoms, and all aspects of management. Written by Dr Charles Shepherd, Hon. Medical Adviser to the ME Association and Dr Abhijit Chaudhuri, Consultant Neurologist, from the Essex Centre for Neurosciences, it is available now from the MEA Association for £9.

Although aimed at health professionals, the book is written so that it can be easily understood by people with M.E. A Kindle version is also available from Amazon.

Free copies for health professionals:

The ME Association send out free hard copies to health professionals and medical students via their mailing list or on an individual basis. This can be done by direct request from a health professional or by people with M.E. sending the ME Association the name and address of a health professional who would like a copy.

<https://meassociation.org.uk/product/clinical-and-research-guide/>

Wound up, Overheated and Tweaked: A Look at the Fibromyalgia Brain and Nervous System. by [Cort Johnson](#) | Aug 18, 2020 www.healthrising.org

In “Key Milestones Contributing to the Understanding of the Mechanisms Underlying Fibromyalgia”, two Australian researchers give a fascinating overview of what they consider to be the breakthrough findings in FM. Tellingly, they quickly highlight neuroinflammation. In one of the first sections, “Neuroinflammation as a Peripheral Pain Mechanism”, they assert that neuroinflammation “likely contributes to many of fibromyalgia’s clinical features” ... and may even produce the small nerve fiber neuropathy and found in the skin and corneas of many FM patients. Not only that, but they lump FM’s allies (irritable bladder syndrome, migraine, restless legs syndrome (RLS), multiple chemical sensitivity (MCS)) in the same basket. (Why they didn’t include chronic fatigue syndrome (ME/CFS), I don’t know, but it would surely fit for them.)

In summary:

- Three nerves that transmit pain signals to the spinal cord have been found to be overactive in FM.
- Nerves should calm down and adjust to repeated stimulation, but in a process called windup the pain nerves that get activated in FM stay activated. They also respond more quickly to a stimulus and are apt to fire off spontaneously more.
- Twitchy nerves leading from deeply embedded mechanoreceptors around the spinal column could explain some of the upper body pain common in FM and the problems with bending, moving etc.
- Two neurotransmitters associated with pain, substance P and glutamate, have been found elevated in FM patients’ brains.
- The brain exerts enormous influence over the amount of pain we feel through a pain inhibition process which can reach all the way down the spinal cord to the spinal cord’s dorsal horns.

- When one part of the body is exposed to pain, our sensitivity to pain in other parts of the body actually reduces. This process – called controlled pain modulation – is due to a pain inhibition process which begins in the brain.
- This process has been shown many times not to be working well in many, but not all, people with FM. Interestingly, although it's not clear why, the low heart rate variability (HRV) found in FM is associated with reduced pain inhibition. Mestizon is one drug that has proved helpful for some people with ME/CFS.
- Pain signals are believed to need to pass through a series of checkpoints or gates in order to make it to the brain. Those gates are believed to be opened wider than usual in FM.
- Some researchers, though, think that the pain inhibition process in FM is working just fine. They believe its signals are being overridden by a constant stream of pain signals emanating from the body.
- Brain scans show more problems. Blood flows to various parts of the brain are altered. The pain processing areas of the brain are hyperactive. Even when the brain is resting, it still maintains its tight connection to those areas.
- The authors believe that widespread neuroinflammation could explain all the symptoms in FM.
- With so many validated issues in just the brain and nervous systems of FM patients, it seems incredible that any doctor worth his or her salt could dismiss this disease.

Some positive thoughts on Long Covid from Norwegian Prof. of Psychology Jonas Kunst: "Scientific understandings of diseases have never been static but always subject to change and revision. Often, big scientific leaps take place in times of crisis. My prediction is that the wave of [#LongCovid](#)-19 will fundamentally change how we view post-viral conditions. I believe that the "cognitive era" of post-viral conditions will find its end rather soon. That is not to say that CBT won't have its place in the treatment of patients. It can be crucial in helping them cope with their illness. But it cannot solve its physical causes.

Evidence for the biological basis of diseases such as [#MECFS](#) is mounting and promising early developments of diagnostic blood tests have been recently published in world-leading journals such as PNAS. <https://pnas.org/content/116/21/10250...>

As always, some, and especially those most invested in the old-fashioned approach, will resist these developments. But others will adapt. Indeed, for ambitious researchers, this is a scientifically exciting area where large discoveries still can be made.

So, why do I write this tweet today? I write it to give hope to all those suffering from chronic debilitating illnesses that have been ignored for too long. I believe that the coming years will bring unprecedented biomedical advances and hopefully effective treatment for many."

Jonas R. Kunst
Professor of Psychology @UniOslo, on twitter July 2020

How to conserve your energy

This is some of the practical advice given by the Royal College of Occupational Therapists aimed at people during and after having COVID-19, but relevant as a reminder for us.

When you are ill or recovering from an illness, you are likely to have less energy and feel tired. A simple task, such as putting on your shoes, can feel like hard work. This guide will help you to find ways to conserve your energy as you go about your daily tasks. By making these small changes you'll have more energy throughout the day.

The 3 Ps principle (Pace, Plan and Prioritise)

Learning to pace, plan and prioritise your daily activities will help you to save energy.

Pace

Pacing yourself will help you have enough energy to complete an activity. You'll recover faster if you work on a task until you are tired rather than exhausted. The alternative, doing something until you're exhausted, or going for the big push, means that you'll need longer to recover.

The pacing approach	The big push approach
Climb five steps, rest for 30 seconds and repeat. You won't need a long rest at the top and won't feel so tired the next day.	Climb all the stairs at once. You'll have to rest for 10 minutes at the top, and feel achy and tired the next day.

Top tips:

Break activities up into smaller tasks and spread them throughout the day.

- Build rests into your activities, it's key to recharging your energy.
- Plan 30–40 minutes of rest breaks between activities.
- Sit and rest wherever possible.

Plan

Look at the activities you normally do on a daily and weekly basis, and develop a plan for how you can spread these activities out. If certain activities make you breathless or fatigued, rather than do them in one go, plan ahead to do them throughout the day. Change the time of an activity: instead of having a bath or shower in the morning when you are busy, have one in the evening. Do weekly activities such as gardening, laundry and food shopping on different days, with rest days in between.

Top tips:

- Collect all the items you need before you start a task.
- Specially adapted equipment is likely to make tasks easier. If you have an occupational therapist, ask them for further advice and support.
- You may get more done when family or friends are visiting and can help you.

Prioritise

Some daily activities are necessary, but others aren't. Ask yourself the following questions to find out which of yours are necessary:

- What do I need to do today? What do I want to do today?
- What can be put off until another day?
- What can I ask someone else to do for me?

Self Advocacy Training

Action for ME have extended their self-advocacy training to Scotland and have offered us a session over Zoom on **Thursday 22nd October at 2pm.**



AfME writes:- People with M.E. have told us they can struggle to communicate their concerns and needs effectively: *“It is difficult to get social services, the NHS and the care agency to listen to or understand my needs. It feels like a constant struggle and it affects my health adversely.”* This training includes guidance to enable you to overcome such challenges and help yourself. To be a successful self-advocate you need to think about:

1. Your rights – including what support you might be eligible for
2. What is the issue – and what are your goals?
3. Effective communication – how to express yourself clearly.

The training will help you with these issues and point you towards further help if needed.

The training session will take up to 2 hours with a ‘comfort’ break in the middle. You can join using our usual Zoom link/meeting ID and passcode, but it will be led by AfME’s trainers. I hope that it will help give us the confidence to make our voices heard and listened to.

NICE Guidelines and Scottish Good Practice Guidelines

The dreadful NICE Guidelines on ME/CFS are being revised currently. Like so many other things the timeline has been set back because of the Covid-19 pandemic. New dates have been announced of November for the release of the draft guidelines and April 2021 for the final document.

What was fascinating was that NICE, in response to a question by felt the need to say that Graded Exercise Therapy (GET) should not be used for long-Covid yet the advice for it still stands, for now, for ME/CFS. This despite there being no research yet around long-Covid and the PACE Trial research on GET for ME being thoroughly debunked. I detected a note of caution towards GET for us in the statement NICE issued, along with restating that revised advice was being published soon – perhaps this is a hopeful sign that it will be withdrawn?

Graded Exercise Therapy – Have You Been Offered It?

Dr Purdie would like to gather an understanding of the number of people with ME & CFS being referred for Graded Exercise Therapy. Has it been suggested that you should do it? Have you been given information about GET and suggested that you do it – or in less formal terms that you ‘push through’ your pain and fatigue and increase your exercise day on day, week on week? Who was it that suggested that you do this?

Please let us know on the Facebook page or through the usual contact methods. No identifying details will be shared, of course.

NICE Chronic Pain Guidelines

As well as revising the guidelines on ME/CFS NICE have also produced a draft guideline for the treatment of chronic primary pain – this will include Fibromyalgia but should exclude ME. The draft guidelines call for people with chronic pain to not be given painkillers, for them to have 5 hours of acupuncture (what use is that over potentially decades of the illness?), to be prescribed anti-depressants (for all they may not be depressed) and for acceptance and group exercise therapy.

If these draft guidelines are confirmed it could have a large impact on our members with Fibromyalgia if it is implemented in Scotland.

As well as those Fibro sufferers who are misdiagnosed with ME it could well impact on those of us with ME or CFS diagnoses too. ME Research UK writes: "Concerns have been raised over the possible misapplication of provisions in a draft NICE pain guideline to those whose diagnosis of ME/CFS has yet to be completed. Of particular concern is the application of exercise and drug therapies which could have adverse effects on those whose pain is actually a symptom of ME/CFS rather than chronic primary pain".

This is going to be something that we will need to follow carefully and, sadly, I foresee arguments with our GPs in the near future.

Craig

Help To Get Online

Dumfries and Galloway Council, through their Lifelong Learning service, are offering one-on-one telephone support to help people get online during the Covid pandemic when so many are isolating. I spoke to a lovely lady called Shelagh Roberts who can talk you through joining online meetings and other things you might be struggling to do if it's all new to you. She works Monday to Thursdays from 9:30am to 4:30pm and will be delighted to hear from you. Her number is 07385 025725.



Emma Harper MSP

The Network had an excellent and constructive online meeting with Emma Harper MSP, dialling in from the Scottish Parliament recently. Emma has been a nurse at DGRI and seems to have a good understanding of ME and Fibro. We shared our problems, concerns and experiences – many of which led her to suggest that she sends a letter to various different organisations to gather the information we requested or to press our points. She also revealed that she's spoken with a local nurse, a sufferer themselves, about their own adaptations to cope with work, and to try to persuade them to consider putting a bid in to run a specialist service for us. The long-covid issue is particularly pressing. If their care is as poor as ours can be it will be troubling indeed. This is something we will continue to press on in the future. We hope to hear back with the responses to all the letter writing.

We sent out invites to our local MSPs across the parties. Next to join us will be Finlay Carson MSP on **Thursday, 24th September at 2pm** and we will make the same requests of him, and invite our members to join us on the Zoom meeting to share the more specific issues too. The MSPs' mailbags have been bulging with the pandemic so we're very grateful for their time and for them to be pressing our case.

Our discussions with all politicians to date have been kept non-political, as it should be. The best politicians are there to serve the needs of their constituents and it is heartening that we can find this support from at least some of our elected representatives locally.



Facebook Pages

The most up to date information regarding M.E and Fibromyalgia is always posted on our main Facebook page, and then many of the links are copied to the website blog at the end of each month.



As well as our recent Social Café page we now have a another new Facebook group 'Get Crafty With M.E.' which has been set up for our page members – this one to discuss their arts, crafts and hobbies. We have some remarkably talented members and it's wonderful to see all the contributions and areas of interest.

If there's interest this could potentially be developed further, perhaps with online crafting sessions or lessons. Let us know if that'd be of interest to you.

We would love your contributions. Please share your story, your crafts, poems, drawings, hobbies, or anything you think might be of interest.

Best wishes, stay safe and hope to see you online soon.

John Bell

Help to Run the Network – New Committee members needed in October

Through our June newsletter and survey we asked if you or someone you know have any contribution you could make in terms of skills, expertise or time towards helping run the Network.

We are approaching our AGM in October and we have been running with just five Committee members again this year. It's the minimum number we are allowed to operate with under our Constitution, and if for any reason one of us became unable to continue it would have implications for the future of the Network. At present, the five Committee members are willing to stand for re-election at the AGM, but we really need a few more members to join us to keep the Network viable, to ease the workload, and to help us to achieve more for the benefit of us all.

The current five members are Craig Woods (Chair), Paul Thompson (Treasurer), Lesley Grieve (Secretary), Nancy Wilson, and John Bell.

Most of our business and communication is done online through a combination of Office 365, and Facebook messenger. Committee members are each given an Office 365 licence and we use Yammer from that suite for all communication that needs to be secure, in line with our Privacy Policy. We have a Committee group on Messenger to keep in touch regularly, to share ideas and for mutual support and chat. We're currently using Zoom, instead of meeting physically, for our official Committee meetings which are held around four or five times a year. Travel expenses are met when we meet physically.



So please, let us know before our AGM on 15th October if you feel you could offer your help by joining our small friendly Committee team, or if you know of someone who might do.

Nothing Much

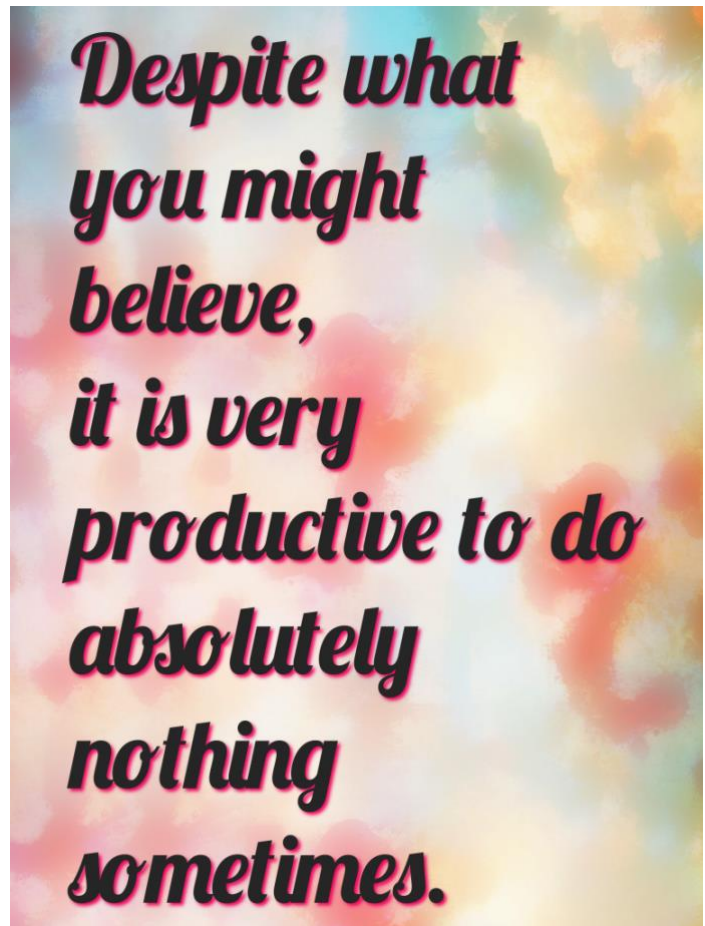
I'm doing nothing much
I'm thinking nothing much
I'm hoping nothing much
I'm wishing nothing much

I'm moving nothing much
I'm improving nothing much
I'll say nothing much
It'll come out double Dutch

So I'll explain nothing much
Or complain nothing much
Revealing nothing much
Or concealing nothing much

I'll peruse nothing much
And choose nothing much
I'll lose nothing much
And snooze nothing much

I'm planning nothing much
I'm scanning nothing much
Though I must write that letter
Nice to keep in touch



By Maria de la Mann in her book Verity Red Part 3, with the authors permission.
Thanks to *Jim Logan* for submitting it for the newsletter.

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 share by mid-November for our next issue. Member contributions are very valued.

DGMFM



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Please let us know if you no longer wish to receive the newsletter, or if you wish to cease being a member of the Network (all your details will be deleted from our files). In either case, contact admin@dgmefm.org.uk or text or phone 07437 602610.