

December 2021

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Welcome all,

As 2021 draws to its conclusion, it's a good time to reflect back on another remarkable and momentous year. The world is still experiencing the pandemic and plans are once again in flux with the new Omicron variant. As many as there are with acute covid catching the headlines, with daily numbers on the news, there is, sadly, a growing number of those who are chronically affected. The sheer scale of people falling ill with the same viral trigger makes it difficult to ignore. I've said it before, but it's worth saying again; I think the research funding and interest aimed at post-viral Long Covid will result in treatment for people with ME. This will be the silver lining to this very dark cloud.

Talking of recognition and understanding, the new NICE Guidelines for ME/CFS have finally been published and the harmful version from 2007 thrown out. Please make sure your health practitioner knows this and encourage them to read it. The headlines from it are: that they (finally) recognise ME/CFS as being a physical condition rather than psychological; graded exercise therapy (GET), which has terribly harmed many of our members, is advised against; cognitive behavioural therapy (CBT) is now only advised as a coping mechanism rather than a treatment; and patients should have an individual treatment plan drawn up in conjunction with their GP. There is little in the way of treatments suggested, but at least what is there will no longer risk severely harming us, and that is a big step.

These are the big news stories nationally, but on a personal level the big story is that I've met someone after being on my own for 11 years or so. While it is wonderful, it has led me to make the incredibly difficult decision to stand down as Chair and from the board of Trustees of the DGMEFM Network. I simply don't have the energy and pain levels for it now with the existing and new commitment. The Network feels to be in a good position now, with a strong committee and with outside funding paying some of our biggest ongoing bills and for the part-time work of Eppie – who continues to be a great asset to the charity. I've been a committee member for around 22 years and Chair for around 8, the Network has been a large part of my life and I really regret being forced into this decision – but I'm pleased I'm going for a happy reason. I want to thank the committee and all who've helped out over the years, and wish Eileen, your new Chair, the best of luck as I hand over the reins.

Wishing you all a very merry Christmas and a happy, healthier, New Year 2022.

Craig Woods

Online Zoom Meetings: Every second Thursday 2pm – 3pm

30th December: Join your fellow Network members for a Festive Quiz and New Year's resolutions discussion.

13th January: Reaction to the Omicron variant and the restrictions over Christmas, how folk have got on and what we think this will mean for the future.

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 5695 7034, Passcode: 2021

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

NICE Guidelines on ME/CFS

Finally, on the 29th October, NICE published the much-delayed, and much-needed, new ME/CFS Guidelines. The importance of the new guidelines should not be understated.

The previous version, which was utterly terrible, has shaped our care, treatment, benefits, insurance claims and public attitude since 2007. It forced many sufferers into graded exercise therapy, usually to their severe detriment, and suggested that the illness was simply tiredness caused by deconditioning and unhelpful thought processes. The massive uphill battle to get the medical care we deserve and benefits we need was massively hampered by this previous document.

While in Scotland we have the SIGN 'Good-Practice Statement on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis' and, in theory, they should take precedence here, the NICE Guidelines have shaped our care here too (the SIGN Scottish guidelines will be updated now that NICE have published). The old NICE Guidelines have also been exported around the world, seen, wrongfully, of course, as the 'gold standard'.

I'm very pleased to report that the new document is a vast improvement. There's a clue in the name before anything is read – it's gone from being CFS/ME to ME/CFS. Before I get your hopes up there's no big breakthrough in medication or, indeed even treatment suggestions, BUT there are big breakthroughs in the understanding that it is a biological, multi-systemic illness (and not psychological as previously suggested); in attitude to patients; and in the removal of the harmful graded exercise therapy instruction and in the removal of cognitive behavioural therapy as curative (but retaining the option of it as a coping mechanism).

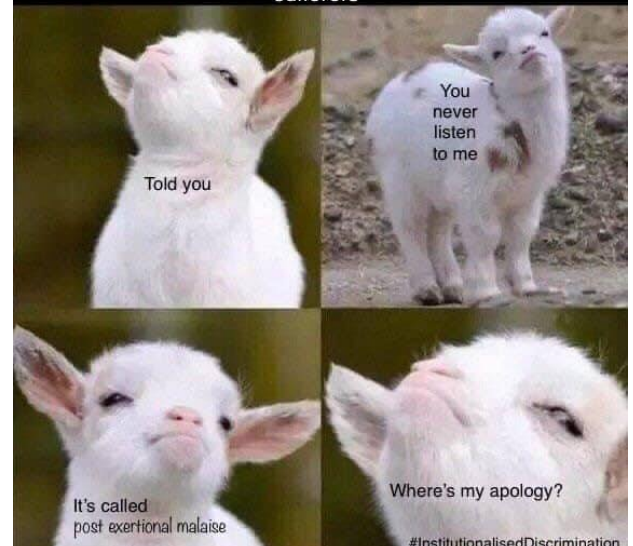
A huge advance is the recognition that much of the bio-psycho-social trials are of 'poor quality' or 'very poor quality' and should no longer be used to influence our care. This includes the fiddled (and I use the word advisedly as it was possible to worsen on the trial and be marked as 'recovered') PACE Trial. The PACE Trial cost a huge amount of public money and was, and I believe still is, the only medical trial the DWP has ever part-funded. The authors of PACE and similar trials have been largely responsible for the dreadful treatment we've received over the last 30 years or so. They have huge vested interest in maintaining the status quo and they placed huge pressure on NICE to halt publication. For it to have gone ahead, only mildly watered down from the draft, and for these authors to have their work publicly humiliated is very pleasantly surprising and gratifying to me and to many long-standing ME sufferers.

In NICE's own words:

"The guideline identifies the symptoms of ME/CFS as debilitating fatigue that is worsened by activity, post-exertional malaise, unrefreshing sleep or sleep disturbance, and cognitive difficulties ('brain fog'). It says that people with all 4 symptoms that have lasted 3 months or more should be directed to a ME/CFS specialist team (in the case of children this should be a paediatric specialist team) experienced and trained in the management of ME/CFS to confirm their diagnosis and develop a holistic personalised management plan in line with this guideline."

"People with ME/CFS should receive individually tailored support focused on personal agreed goals and a range of approaches should be used depending on the patient's preferences and priorities."

When the Dr didn't believe that too much exertion harmed you but then the PACE trial was discredited and NICE followed the Mayo clinic and the CDC by removing GET from their treatment guidelines as it's proven to be harmful to ME/CFS sufferers



“And the guideline makes it clear that any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET), should not be offered for the treatment of ME/CFS. Discussions with stakeholders highlighted that the term ‘GET’ is understood in different ways and the guideline sets out clearly what is meant by the term.”

“The importance of ensuring that people remain within their energy limits when undertaking activity of any kind is also highlighted. The guideline recommends that any physical activity or exercise programmes should only be considered for people with ME/CFS in specific circumstances and should begin by establishing the person’s physical activity capability at a level that does not worsen their symptoms. It also says a physical activity or exercise programme should only be offered on the basis that it is delivered or overseen by a physiotherapist in an ME/CFS specialist team and is regularly reviewed.”

“Although cognitive behavioural therapy (CBT) has sometimes been assumed to be a cure for ME/CFS, the guideline recommends it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.”

I would urge you to ask your GP to read the new NICE Guidelines. If they would like to know and understand more, Dr Nina Muirhead’s CPD Module, which earns your healthcare worker the Continuing Professional Development points that they need to remain in practise, is an excellent follow on. They can find it at www.studyprn.com/p/chronic-fatigue-syndrome.

Please let us know if this Guideline update or the CPD modules alters or improves your GP’s opinion or care. Let us know if you’ve been offered the individually tailored care program.

Craig

Online Support

2021 has passed without us being able to resume our regular Dumfries or regional ‘pop-up’ meetings. This has been very frustrating for us and, I know, some of you as well. Just as people were getting vaccinated and levels dropping, we had a surge again and it’s remained high ever since. Knowing how damaging a covid infection could be on top of ME or Fibro we just didn’t want to risk it.

Meetings have continued online however, with our Thursday Zoom meetings still proving popular. These continue to take place fortnightly and, as well as bringing us guest speakers and consultations, they provide us a chance to see our Network friends and to meet new ones. New members have been welcomed and, I think, they’ve found the mutual support and advice very helpful and reassuring.

If you haven’t already joined us, please pop in – details on the front page.



Digital Inclusion

We are very aware that not all of those we support have access to digital technology, or the understanding of it, to enable them to join our Zoom support meetings or craft sessions. We would like to help with that, if possible.

There is a big, albeit uncoordinated, push across Scotland to bridge the digital divide and get everyone connected. There are various 'digital inclusion' schemes, which pop up in the region from time to time. If you aren't online already, and would like to be, please get in touch. The Network may be able to help those we support by tapping into one of these schemes to get you a device and a 24-month internet connection.



To register your interest contact us:

phone: 07437 602610

write a letter: Paul Thompson, DGMEFM Network Treasurer, Thistledew, Albert Street, Dalbeattie, DG5 4JP

or email: admin@dgmeffm.org.uk

You should state your name, postcode, age and any issues you have with getting online currently. If/when an opportunity arises, we will be in touch.

We can't promise anything, as it very much depends on the funding available - and funding opportunities open and close very quickly indeed. There may also be geographic or age limitations imposed too – for example if the funding comes from a specific windfarm or is targeted at the elderly. The device needs to be for the use of someone we support, but other devices may be available through other local charities for other people who are digitally excluded.

Third Sector Dumfries and Galloway are also launching a study into the reasons people may not be online or only partially connected and will be trying to gauge the numbers who are digitally excluded in the region. If you are interested in feeding back this info to Third Sector, please also get in touch using the contact details above.



My Time with DGMEFM Network

The Network has come a long way since I attended my first meeting in Castle Douglas Church Hall in 1999. Since then, we've formed as a charity in our own right. Communications technology has advanced massively and makes it so much easier to connect and helps us to find one another. I built the first website for the Network, but it was Facebook which really advanced the mutual support. Penny, and Denis and Norma before me, did fantastic jobs heading the Network, and while I wasn't keen to be Chair over 8 years ago, I couldn't let the charity fold, as it had helped me, and many others, so much.

Since then, we've included Fibromyalgia fully in the name and our activities, we've continued the Newsletter, expanded our online presence and meetings, run awareness events, attended the Scottish Parliament, hosted many dozens of speakers, promoted awareness of the illnesses, run craft projects and so much more. Recently we've applied for and won outside funding, which has allowed us to buy-in the expertise and help of Sleeping Giants and Eppie. Now we are investigating providing a 'Befriending' and/or 'Expert Patient Mentoring' project for new sufferers.

The need for better support, awareness and NHS liaison is so large that, at times, it felt like we were only scratching the surface. There's so much more I'd like to have done had I been able to, which led to a feeling of constantly having a never-ending list of priorities.

The Network now has more potential to provide these services and to continue making an impact, and with the new understanding coming from the pandemic and the new, much-improved NICE Guidelines, I think. Challenges remain with Fibromyalgia, which doesn't seem to be benefitting from biological research yet. And there is now a large cohort of people who are newly chronically ill and experiencing post exertional malaise and similar symptoms to us, through Long Covid, who will need support and hopefully will find us over the coming months and years.

Stepping down and handing over the Chair's reins feels a bit like handing over Fraoch's puppies (I kept one!) to their new owners earlier in the year. There is so much invested time, energy and emotion – as well as a strong feeling of protection and responsibility – that it makes it a difficult thing, necessary though it is, for me to do.

I'm really sorry that energy and commitments mean I can't be there to guide us forward – but I will still be here as a member wishing the Network, Eileen as Chair, and all its members, all the best for the future.

Craig

I THINK IT'S BRAVE

i think it's brave that you get up
in the morning even if your soul is weary
and your bones ache for a rest

i think it's brave that you keep on
living even if you don't know how to
anymore.

i think it's brave that you push
away the waves rolling in every day
and you decide to fight

i know there are days when you
feel like giving up but i think it's brave
that you never do

—Lana Rafaela

Confronting Our Next National Health Disaster – Long Haul Covid

"Unfortunately, current numbers and trends indicate that "long-haul Covid" (or "long Covid") is our next public health disaster in the making." shares Steven Phillips, M.D., M.P.H., and Michelle A. Williams, Sc.D. in the New England Journal of Medicine. <https://www.nejm.org/doi/full/10.1056/NEJMp2109285>

"What form will this disaster take, and what can we do about it? To understand the landscape, we can start by charting the scale and scope of the problem and then apply the lessons of past failures in approaching postinfection chronic disease syndromes."

"To understand why long Covid represents a looming catastrophe, we need look no further than the historical antecedents: similar postinfection syndromes. Experience with conditions such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia, post-treatment Lyme disease syndrome, chronic Epstein–Barr virus, and even the 19th-century diagnosis of neurasthenia could foreshadow the suffering of patients with long Covid in the months and years after infection."

"The health care community, the media, and most people with long Covid have treated this syndrome as an unexpected new phenomenon. But given the long arc and enigmatic history of "new" postinfection syndromes, the emergence of long Covid should not be surprising."

"Some of the disregard can be attributed to the fact that long Covid has disproportionately affected women. Our medical system has a long history of minimizing women's symptoms and dismissing or misdiagnosing their conditions as psychological. Women of color with long Covid, in particular, have been disbelieved and denied tests that their White counterparts have received."

Up To Half of All Long Covid Patients have ME

“Researchers at Icahn School of Medicine at Mount Sinai in New York took 41 Long COVID patients and tested them against ME/CFS criteria and found 46 per cent had four or more symptoms of ME/CFS and had experienced a substantial impact to their lives as a result of fatigue. A further 13 long COVID patients met the criteria but were excluded on account of having a large BMI or a cardiac disease.”

This small study seems to have been the first to have tested long COVID sufferers against the ME/CFS criteria. It was very small scale and it had some problems – like not measuring post exertional malaise with a 2-day CPET test, but it still caught the attention of the press and, along with articles like the previous one, begins to bring to public attention that long COVID and ME might be the same condition.

They also begin to show the scale of the problem with an estimated 10% plus of all those who’ve suffered COVID-19 going on to develop long COVID and, if these data can be believed, 50% plus being able to be diagnosed with ME. With 10.5 million people having tested positive for COVID-19 in the UK to date, that’s around half a million new ME sufferers in the UK alone, and more than 13.3m in the world.

It is too big a problem to be ignored any longer.

Craig



‘Toxic Positivity’

I had the very unpleasant duty of blocking someone from our Facebook Group recently for a truly terrible attack on some of our group members. This person stated that we should get on a bike, move to Spain or Greece, take Pregabalin and ‘push through’. When it was gently pointed out that the pushing through could be harmful, they went on a hideous attack on us. It was the most horrible, nasty and hurtful attack we’ve had within the Network in my 22 years+, and it was ironically incredibly hypocritical from someone accusing the rest of us of being negative. Although, admittedly, the idea of uprooting us and moving us all to warmer climes has some appeal...

Admitting that we are ill, that we can struggle at times and seeking support is not a weakness. It is not even being negative. It is a necessary part of our coping mechanism for many of us. Pretending that everything is fine by putting a cheery face on and pretending these illnesses are easy, and forcing ourselves through the pain and fatigue barriers, can be very damaging physically and mentally too. These are horrid and cruel illnesses and need to be acknowledged as such. We do remarkably well considering and we can have banter with one another and have a positive and realistic attitude without denying or denigrating what we face.

We are a SUPPORT network. It is perfectly fine to share your experiences and seek advice. Don’t ever be afraid to do that! Remember to share the good as well as the bad, the triumphs as well as the setbacks, but never be afraid to reach out during the bad times. We are all different and we have a great deal of experience that we can share. The vast majority of us can empathise and it is reassuring to know we are not alone.

To help avoid upset, please try to give your experience rather than telling people what to do and make suggestions rather than statements. What works for one of us might not work for the rest, particularly as we have different illnesses and the full array of severities among our members.

We are one of the nicest, friendliest and most supportive online groups about. When the illnesses are horrible enough to deal with, keeping that camaraderie and mutual support is very important.

Read about toxic positivity and the harms of it at: <https://tinyurl.com/4pju2k3e>

Craig

Thank You To Gift Day Donors

Many thanks to all of you who were able to contribute to our 'Gift Day' and for other donations over the year. It's a great help towards meeting our running costs, such as the newsletter and other expenses, including fees for funding applications for new projects.

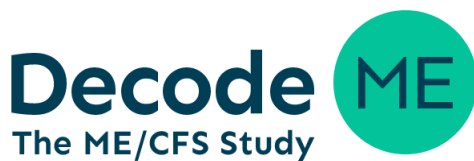
Online Fundraising

If you shop on Amazon, please consider signing up with AmazonSmile at smile.amazon.co.uk and choosing Dumfries & Galloway ME and Fibromyalgia Network (must be our full name) as your charity. AmazonSmile will donate 0.5% of the net purchase price (excluding VAT, returns and shipping fees) at no cost to you. We've received £230 from them so far.

Through Easyfundraising, there are many shops and merchants who will give a % donation at no cost to you. If you sign up with them at <https://www.easyfundraising.org.uk/> we're known as DGMEFM Network.

So far we've received £500 through Easyfundraising. Thank you!

Update: DecodeME to launch in January 2022 – taken from www.decode.me



Decode ME is a very large University of Edinburgh-led trial which is looking to see if there's a genetic predisposition to ME. It will be the world's largest biomedical study of ME. They're looking to collect a DNA sample from 20,000 participants - and it's still not too late to register.

Quick summary:

DecodeME will launch in January 2022. Recruitment will happen in two phases. If you are in the UK and have registered your interest in taking part, we will email your invite when you can take part and send reminders, so you don't miss it.

More detail:

First, a test phase with randomly chosen participants allowing us to check everything is working well and get feedback. We will then open full recruitment to everyone soon after.

This is a few months later than we hoped. We know this wait feels like a long time when people with ME/CFS have waited so long for a study like this to happen. Thank you so much for bearing with us.

We are committed to ensuring this study delivers to the highest standard possible, with maximum impact for people with ME/CFS. This means that some tasks have taken longer than expected, while other unexpected issues contributed to the delays.

We know openness is important to the ME/CFS community, so we have detailed some of the key reasons for the delays below:

* Impact of the pandemic: this impacted supply chains, making it difficult to find key items like cardboard boxes for the spit kits, and made contracting times take longer.

- * Avoiding launching over the busy Christmas period: this is to avoid spit kits being lost in the post and managing holidays/office closures over this period.
- * People with ME/CFS are at the heart of this study, involved in every aspect of the design and development. We have adapted what we're doing and sometimes slowed things down to be as inclusive as possible.
- * Sickness and impact of loss of loved ones: we have had a number of people from our small team off at times during the project.
- * Needing to work through more data protection issues than we anticipated to ensure your health information is protected to the highest level possible.
- * Hiring more staff for the project, ensuring they are fully inducted while working from home.

The good news is we're making excellent progress, like getting ethics approval, designing the survey and spit kit that are as easy to use as possible for people with ME/CFS. We are also working with the 25% ME Group to organise support for people with very severe symptoms.

You will receive your invite by email as soon as you can take part. We will send reminders if you miss this.

You may see some people posting about their spit kit online who are part of the first phase before the full launch. If you are not part of this randomly selected small group, you will receive your invite as soon as full recruitment launches.

However, we remain confident of completing the study on time thanks to the fantastic level of support from the community. We're excited about launching in the new year.

It's not too late to sign up. More information and the sign-up link is on the website above.



Norwegian Study Shows Fibromyalgia can be a Post-Infectious Illness

Cort Johnson of www.healthrising.org reports:

While some people report that their fibromyalgia (FM) occurred after an infection, the idea that FM can be triggered by a pathogen and, in some cases, may be considered a post-infectious disorder, really hasn't made its way down to the FM research community at large.

- Long COVID presents a once-in-a-generation opportunity to learn about how infections can cause long-term health problems years after the infection has apparently been resolved.
- Another infectious event – an outbreak of giardiasis infection (after contamination of the water supply) in Norway about 15 years ago – presented a similar opportunity. Studies since then have identified increased incidences of chronic fatigue syndrome (ME/CFS) and irritable bowel syndrome (IBS) in those infected.

- This study found an almost 3-fold increase in people with fibromyalgia after a *Giardia lamblia* infection. People who came down with fibromyalgia (FM) often also came down with irritable bowel syndrome and/or chronic fatigue but the same was not true for people who came down with IBS – as many people with IBS patients did not experience FM. This suggests that infectious events can produce a wide variety of outcomes – something the long COVID studies have the opportunity to pick up in spades.
- The study also suggested that post-infectious fibromyalgia may be worse than fibromyalgia which was triggered in other ways.
- This is the first study to show that infections can trigger a dramatic increase in the incidence of fibromyalgia – putting FM solidly in the post-infectious disease category for the first time.
- The huge long COVID studies underway should tell us much about how infections can trigger chronic illnesses of all types.

Craig comments: *More so than even ME, Fibromyalgia is rarely studied biologically. This is a fascinating and potentially important study.*



Dr Shaun Qureshi's experience of Long COVID/ME

Shaun is a palliative care doctor, and a good friend of mine. I'd known him for several years, when, in March 2020, in the very early days of the pandemic, through the course of his work, he fell ill with Covid-19. Over the following months, through his messages, I recognised so many warning signs of post-viral chronic illness in him. A year ago, he pretty much collapsed and has been unable to work and has been very badly disabled since. It was something that has been very difficult for me to see - although I have many friends with ME, this is the first time I've known someone before they were ill and watched them come down with ME or something very similar.

Since then, he's become a brilliant advocate for people with ME, joining Doctors With ME and Doctors With Long Covid advocacy and awareness organisations. This is from one of his awareness raising Twitter threads and shows what an ally he has become:

Long Covid has had a devastating effect. I've lost my independence and quality of life. So many of us long-haulers are sadly still waiting for medical treatment. Those from early 2020 like me have been waiting for >1.5 years.

When we say treat Long Covid, we don't just mean patient 'self management'. People with ME/CFS wrote the book on that (stop, rest, pace) and we have learned so much from them. But we need more than 'self management'. That's all we've had for months-years. We need medical treatment.

When we say treat Long Covid we don't just mean rehabilitation. Of course rehab is important, but it's



inappropriate to expect someone with a multi-system inflammatory disorder to heal through rehab when there has been no assessment and treatment first. We've gone from high functioning to incapacitated due to a physical pathology. For many of us, after acute Covid-19 we got sicker and sicker despite trying to carry on with our normal physical and mental activities. Our illness is not caused by deconditioning / lack of fitness.

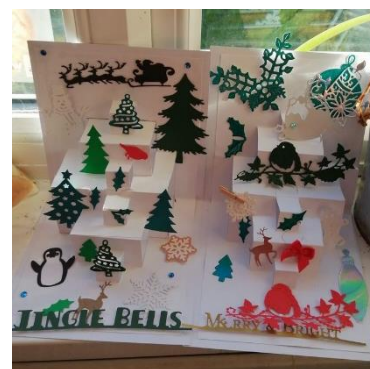
In fact many people with Long Covid experience Post Exertional Malaise / Post Exertional Symptom Exacerbation, i.e. exertion beyond a narrow, safe, individual level of energy expenditure worsens our condition. It is vital to screen for this!

When we say treat Long Covid we mean:

- we need medical treatment (same as any other chronic immune-mediated illness)
- we need comprehensive assessment. Don't write us off as 'just Long Covid' when we present with physical symptoms
- invest in services to assess & treat us
- check for common and often treatable complications of Long Covid e.g. POTS, myocarditis, blood clots
- stop the word association between 'chronic fatigue' and 'graded exercise'/CBT
- invest in research into post viral chronic illness
- support the translation of research findings to clinical practice to help people with Long Covid - and ME/CFS
- acknowledge the scope and severity of Long Covid
- believe us

Winter Craft Workshops

Our craft workshops for this winter kicked off with a bang with the pop-up Christmas Card workshops. Participants had a chance to make some very intricate and impressive Christmas Cards (see photos) thanks to the expert, yet very patient, instruction of Anne McLauchlan from Card Cabin in Dumfries.



The second craft that was offered was Christmas wreath making and our new Chair, Eileen Longworth, took on the role of delivering these workshops with some very festive wreaths being created!



Both the card and wreath making workshops were so oversubscribed that the Committee made the decision to put on two workshops for each craft, meaning that everyone who had wanted to take part, was able to have a place.



Feedback tells us that all people felt happier, more confident, more skilful and less isolated as a result of taking part in the workshops.

Our next workshop will be glass painting on 14th January (already full but do contact me if you should want to have your name added to the waiting list). We will then have workshops covering rock painting, glass window hanging creation, bath bomb making and quilting in the early part of 2022.

Eppie – eppie@dgmeffm.org.uk



ME.RRY CHRISTMAS!

ON THE FIRST DAY OF ILLNESS
MY ME GAVE TO ME
A SHRUG FROM MY LOCAL GP

ON THE SECOND DAY OF ILLNESS
MY ME GAVE TO ME
A SHED LOAD OF PAIN
A BOG FOR A BRAIN
AND A SHRUG FROM MY LOCAL GP

ON THE THIRD DAY OF ILLNESS
MY ME GAVE TO ME
LEGS THAT WON'T GO
BODY ON GO SLOW
AND ANOTHER SHRUG FROM LOCAL GP

ON THE FOURTH DAY OF ILLNESS
MY ME GAVE TO ME
A BODY SET TO WILT
A BIG DOSE OF GUILT
AND DRUGS FROM MY LOCAL GP

ON THE FIFTH DAY OF ILLNESS
MY ME GAVE TO ME
HIT BY A TRAIN
HUGE ENERGY DRAIN
ROLLED EYES FROM MY LOCAL GP

ON THE SIXTH DAY OF ILLNESS
MY ME GAVE TO ME
BEATEN UP AND BRUISED
JUST SO CONFUSED
NO CONCENTRATION
ILLNESS MY CREATION
WERE THE THOUGHTS OF MY LOCAL GP

ON THE SEVENTH DAY OF ILLNESS
MY ME GAVE TO ME
NEW FACEBOOK FRIENDS
WHO REALLY COMPREHEND
NO MORE CONDESCENDS
FROM MY NOW EX-LOCAL GP

By Bill Clayton ©2017

Poster Distribution

Have you seen our flyer out and about? We distributed it with the newsletter last time around and asked you to ask your local shop, supermarket, chemist, library, etc, etc to display it. It's not too late to do this!

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 offer.

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



Single Access Point

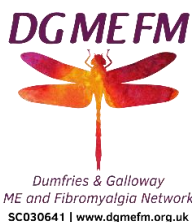
One of our recent Zoom guest speakers was Amanda Stevenson, Team Manager of the NHS and Social Care's Single Access Point who came along to tell us about the roll-out of this project, launched using lessons learned from the COVID-19 Shielding Partnership. This will bring together many NHS and the Council's social care programs in one 'access point' telephone call. It will mean that more self-referral is available for services such as needs assessment, Long Covid self-management, physiotherapy, podiatry, children's services, speech and language and many more. The telephones are manned by trained council employees who will be able to refer on to existing services which are most suitable. In theory you should only need to give the background to your situation once, with Single Access Point passing this information to the appropriate services. They have been building up the number of telephone operatives over the year and aim for a full complement of 21 call advisors in the new year. If you've previously not managed to get through, or been met by an answer phone, try again. We were reassured that this should not happen now.

Please let us know your experience of this new way of accessing health and social care services.

The telephone number is: 030 33 33 3001, lines are open 8am to 5pm.

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@dgmeffm.org.uk



Phone or WhatsApp: 07437 602610
Website: www.dgmeffm.org.uk
Facebook: facebook.com/groups/dgmeffm
Email: eml@dgmeffm.org.uk (Chair)
paul@dgmeffm.org.uk (Treasurer)
kim@dgmeffm.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@dgmeffm.org.uk or text or phone 07437 602610.