

March 2022

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Well, here we are, well into the year. Spring on the doorstep and lots to look forward to.

It's been a busy time these last three months. Taking over as Chairperson for the Network was a bit sudden, after our previous chair, Craig, decided to resign. Luckily, I have a fabulous team of Trustees around me who are committed to the running and development of the DGMEFM Network, as am I. The Network is a solid foundation for the help and support of all its members, old and new, and this is in no small way due to Craig. We are, of course, indebted to him for his sterling work over the many years he has supported the Network and I am sure that he will continue to give his vast knowledge and advice in the years to come.

Here's a bit about me. I hail from Lancashire but have lived in Scotland for many years. My children, all three grown and flown, attended Eskdalemuir school and the schools in Langholm, which were a great platform to set them on their way in life. I'm about to be a first time Granny in a couple of months as well. Can't wait!! Please humour me at the time, I know I will be over excited and probably insufferable!

My life with chronic conditions started in my teens. I developed asthma at 21, after having suffered allergies for 7 years. During my pregnancies, I was told I had both iron deficient anaemia and B12 deficiency too. That's when the injections started; during the winter holidays of 1988. It seems like another lifetime. I trained as a psychiatric nurse. Yes, I do have a certificate that says I'm a registered mental nurse (I hope they have changed the wording since then) and I worked in hospitals, nursing homes and in the community. When I was 36, I was diagnosed with Sarcoidosis. During all the tests to discover what was causing all my lymph glands to swell so much, they also found that I had toxoplasmosis antibodies and hypothyroidism.

Over the years, my children remember me going to lie down on a regular basis. I had intermittent migraine so darkened rooms were my solace. It was only as I entered my 40s that the lack of energy and pain became more of a thing to bother my GP with. Previously, I'd assumed this is how life is with husband, children, foster children, pets etc... I was 50 when fibromyalgia was diagnosed. I've never been so pleased to have a label I can tell you. Feeling like a hypochondriac for a couple of years and wondering if I was turning into a neurotic old woman, was not the best time in my life. With menopause at the same time, oh I was a pure joy to be around! Not... 😊

Plantar fasciitis, costochondritis, allodynia, brain fog, all these are terms I have got to know and live with. Then along came covid. I never had a positive covid test, so spent a lot of last year trying to get my GP to recognise that something other than fibro was my problem. Maybe ME? But then I was diagnosed with Long Covid in October 2021. They call us long haulers but, to be honest, this hauler has been going for 62 years and I don't want any more labels thank you.

You are not weak because of
your illness .

You did not fail treatments.
The treatments failed you.

Your illness is not your fault,
you did not cause this .

You are not a failure.
You are a warrior.

Lupie Linda

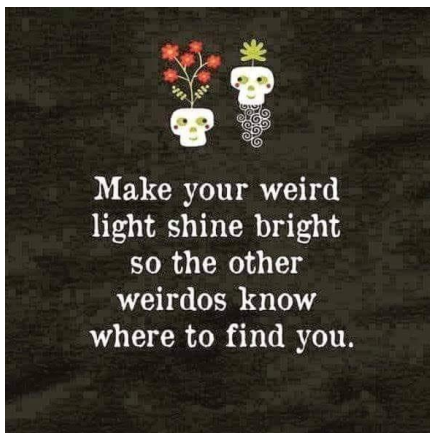
I only include all this to give you an overview of my life experience; to show that I have empathy for you all who are members here. Having lived through all these issues, I think I can understand how a diagnosis can affect the life you are living.

Now I live in Langholm, with my two Romanian rescue dogs, three silkies chickens, one budgie (her mate died recently, and boy has she found her voice!) and a continuing lust for life, art, craft and, of course, the brew and a blether.

Our next major transition is becoming a SCIO (an Incorporated charity). We have just heard from the charity regulator, OSCR, that we have been accepted. This will allow us to be bolder with our plans and future grant applications. We will give further details in the fullness of time and explain our plans and ideas for the extra help and support we hope to bring about.

So, here's towards more projects, fund finding and support for all the members of the network in Dumfries and Galloway and beyond.

Eileen x



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

Social Meet-Up

Next Social Meet-Up is Thursday 10th March.

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 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 4th March.

A little bit like a virtual knit and natter. Any craft is welcome.

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: 823 6353 7970, Passcode: 2022

**One minute you're
young and fun, the
next you're predicting
the weather with
your bad knee.**

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



Digital Inclusion Research

DGMEFM Network (in partnership with Third Sector Dumfries and Galloway) are taking part in a piece of research relating to the digital skills, access and motivation of individuals living in Dumfries and Galloway.

Some of our members have already benefitted from free iPads, as a result of being involved in this project, and we hope that the results of this research will enable us to help more of our members to access digital services.

In addition, for every survey that our members complete the Network is paid £30.

Therefore, if you are able to complete the survey, we would be very grateful as this additional income will help us to continue delivering our Facebook groups, craft sessions, meet ups and newsletters.

You will need a personal code to complete the survey. If you haven't yet received an e-mail from me, please e-mail me and I will send you your personal code and the link to the survey: eppie@dgmefm.org.uk

We expect the survey to take around 20 minutes to complete. If you need to take a break, leave it open on your screen. It won't time-out, so as long as you don't close the screen, you can take as long as you need to complete it.

The closing date for the survey is **31st March 2022**.

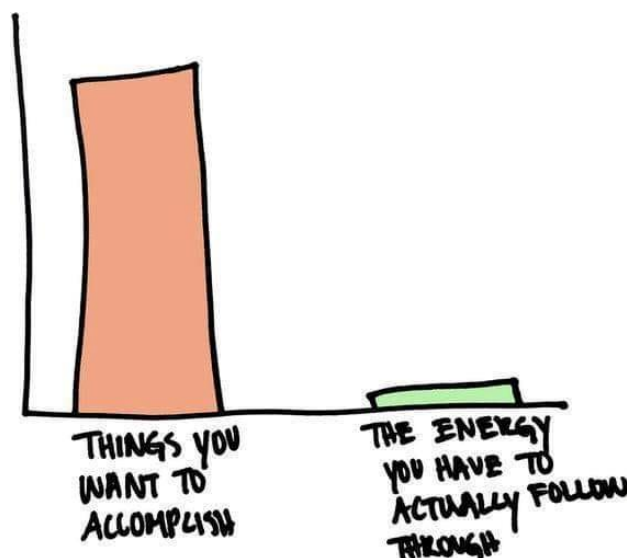
Thank you so much for your help!

Craft Workshops

After every craft workshop we have been asking participants for feedback. This feedback helps us to make improvements to the workshops whilst also helping us to justify a need for the workshops, when we're trying to access grant funding.

Workshop participants have told us the following things:

- 100% said the workshop left them feeling happier
- 100% said the workshop improved their skills
- 100% said the workshop improved their confidence
- 100% said the workshop helped them to feel less isolated
- 100% said they would participate in more workshops if they became available



Crafting for the energy challenged

Last winter, in deepest lockdown, the network launched the first of its crafting by zoom workshops, which paved the way for some great crafting experiences for network members; some already skilled crafters, and some really quite dubious and pessimistic would-be crafters like me. This first round of workshops were funded by the National Lottery Community Fund.

The first of the sessions I took part in was the wet wool felting. A very exciting box of goodies arrived beforehand, and off we went. The kits that arrive beforehand are always delightful little treasure troves of mysterious objects, put together by the crafter running that particular workshop.



The beauty of these workshops for network members is that it simply doesn't matter if energy runs out or brains give in. Because both things do happen, to at least some participants, in all of the workshops, I'm sure. Felting did prove to be a little too robust an activity for me but nonetheless I ended up with a picture I could be proud of.



I tried the crochet workshop next, and my brain just wouldn't work that morning. There was a lot of brain fog in the group, but again it didn't matter. The plan was to crochet squares to make a blanket, but on that day my brain could only go in circles, so circles I did! And I went on to spend many lovely hours making circular bowls, pots, baskets and bracelets with the wool that should have made up the blanket. And every so often I get the wool and needle out again and make a few more, for no good reason other than it's a lovely peaceful thing to do in the reclining chair.

Next up for me was rag rugging – something I'd been wanting to try for a long time but needed some direction and encouragement. And this is another activity that has stayed with me, can again be done in the reclining chair, and has resulted in assorted rugs for assorted cats belonging to assorted friends. The deal is, if you give me the old clothes, I'll make you the rug.



In the current round of winter crafting by zoom sessions, I've recently had a go at a stained glass sun catcher. Again, the wonderful parcel of goodies arrived, and the sun catcher is nearly done. Admittedly, not from the reclining chair this time, but it is a very peaceful and absorbing process.

The sessions are nearly over for this winter, but, funding allowing, will start up again next autumn. And I would encourage anyone who, like me, assumes they won't be able to manage it, to give it a go. You might just surprise yourself!

A Network Member

Communities Mental Health and Wellbeing Fund

We've been successful with an application for funding to provide more craft workshops and other 'wellbeing' activities by Zoom, once a month over the coming two years from this May to April 2024. Of course, not everyone can access Zoom, or would prefer 'in person' sessions but, unfortunately, we're not yet able to offer that option.

Our thanks again to Sleeping Giants, who wrote the application on our behalf; to Corrie for her huge amount of work producing a report of the first series of craft workshops last year; and to members who gave (anonymised) feedback for the report, to show the impact on their lives.

We'll be asking you for suggestions about the crafts and activities we might organise.

The craft workshops will run along the same lines as the current and previous series, with free kits for up to seven participants per workshop. 'Wellbeing' sessions could allow for larger groups in some activities e.g. mindfulness, seated yoga.

In the meantime, please get in touch with eppie@dgmefm.org.uk if you know someone who could offer to lead an activity.

Adult Disability Payment

Here are a few notes about the transfer of PIP and DLA over to Social Security Scotland. I have just picked out some of the more important things but have included the links in case you want to trawl through the website for more information. It is a bit of a minefield. There are lots of mentions of 'stakeholder events', which are actually for organisations such as CAB, who are there to inform and assist us as claimants: <https://www.socialsecurity.gov.scot/news-events/news/adult-disability-payment-legislation-unanimously-approved>

- Social Security Scotland will shortly introduce Adult Disability Payment. This will provide extra money to help with the costs of living with a disability and or long-term health condition.
- Adult Disability Payment will replace the Department for Work and Pensions (DWP) Personal Independence Payment (PIP) in Scotland.
- There will be a pilot scheme beginning 21st March 2022, ONLY in the areas of Perth and Kinross, Dundee City, and The Western Isles. This will be for new claimants only.
- Further council areas will be introduced in phases until Adult Disability Payment rolls out nationwide on 29 August.
- Individuals with ongoing awards of PIP or DLA do not need to apply for Adult Disability Payment. Their awards will be transferred automatically to the new Scottish system from August 2022, with no break in entitlement or payment.





It appears that for all existing claimants, who have been receiving PIP or DLA, the changeover should be seamless. Each person will be contacted by letter regarding when their changeover will happen. From what I can gather, there is no need to contact either the DWP or Social Security Scotland yourselves.

For new claimants, until August 2022, you should still contact DWP. They will be able to take all the details and advise regarding your own specific case.

In Dumfries and Galloway there is an excellent Citizens Advice Bureau who will assist anyone under the age of 60 years. They can advise on applications, appeals, tribunals and all situations in between.

They are contactable via telephone: 0300 303 4321 or via a contact form on their website: <https://www.dagcas.org/>

For anyone over the age of 60 years, there is the Financial Inclusion and Assessment Team who are based at the council offices in Annan. They are contactable via telephone: 030 33 33 3008
Email: fiatreferrals@dumgal.gov.uk or letter: FIWS, PO Box 9098, Dumfries, DG1 9EB.

There are also changes afoot in England via DWP. I would suggest that if any article in the media seems worrying, check to see if it is referring to the English system. The Social Security Scotland website should have updates on a regular basis as we move towards the transition.

Toxic Positivity

(<https://www.verywellmind.com/what-is-toxic-positivity-5093958>)

Toxic positivity is the belief that no matter how dire or difficult a situation is, people should maintain a positive mindset. It's a "good vibes only" approach to life. And while there are benefits to being an optimist and engaging in positive thinking, toxic positivity instead rejects difficult emotions in favour of a cheerful, often falsely positive, facade.

We all know that having a positive outlook on life is good for your mental well-being. The problem is that life isn't always positive. We all deal with painful emotions and experiences. Those emotions, while often unpleasant, are important and need to be felt and dealt with openly and honestly.

Toxic positivity takes positive thinking to an overgeneralized extreme. This attitude doesn't just stress the importance of optimism, it minimizes and denies any trace of human emotions that aren't strictly happy or positive.

Forms of Toxic Positivity

Toxic positivity can take a wide variety of forms. Some examples you may have encountered in your own life:

- When something bad happens, such as losing your job, people tell you to "just stay positive" or "look on the bright side." While such comments are often meant to be sympathetic, they can also be a way of shutting down anything you might want to say about what you are experiencing.
- After experiencing some type of loss, people tell you that "everything happens for a reason." While people often make such statements because they believe they are comforting, it is also a way of avoiding someone else's pain.

- When you express disappointment or sadness, someone tells you that “happiness is a choice.” This suggests that if you are feeling negative emotions, then it’s your own fault for not “choosing” to be happy.

Such statements are often well-intentioned people who just don't know what else to say and don't know how to be empathetic. Still, it is important to recognize that these responses can be harmful.

At their best, such statements come off as trite platitudes that let you off the hook so you don’t have to deal with other people’s feelings. At their worst, these comments end up shaming and blaming people who are often dealing with incredibly difficult situations.



Toxic positivity denies people the authentic support that they need to cope with what they are facing.

Why It's Harmful

Toxic positivity can actually harm people who are going through difficult times. Rather than being able to share genuine human emotions and gain unconditional support, people find their feelings dismissed, ignored, or outright invalidated.

toxic positivity	Genuine optimism
being negative won't help you	it's important to let it out. is there anything i can do to make this easier for you?
good vibes only	i love you through all your emotional states
you'll get over it	you are so resilient, and your strength will get you through it
other people have it a lot worse	you are not alone, and there is support to help you
smile, crying won't help	it's okay to cry, we all do. can i get you a tissue or a hug?
just stay positive	things are tough right now. do you wanna talk about it, or do something lighthearted?

- **It's shaming:** When someone is suffering, they need to know that their emotions are valid, but that they can find relief and love in their friends and family. Toxic positivity tells people that the emotions they are feeling are unacceptable.
- **It causes guilt:** It sends a message that if you aren't finding a way to feel positive, even in the face of tragedy, that you are doing something wrong.
- **It avoids authentic human emotion:** Toxic positivity functions as an avoidance mechanism. When other people engage in this type of behaviour, it allows them to sidestep emotional situations that might make them feel uncomfortable. But sometimes we turn these same ideas on ourselves, internalizing these toxic ideas. When we feel difficult emotions, we then discount, dismiss, and deny them.
- **It prevents growth:** It allows us to avoid feeling things that might be painful, but it also denies us the ability to face challenging feelings that can ultimately lead to growth and deeper insight.

The “positive vibes only” mantra can be particularly grating during times of intense personal distress. When people are coping with situations such as financial troubles, job loss, illness, or the loss of a loved one, being told that they need to look on the bright side can seem downright cruel.

It is possible to be optimistic in the face of difficult experiences and challenges. But people going through trauma don’t need to be told to stay positive or feel that they are being judged for not maintaining a sunny outlook.

Signs

Toxic positivity can often be subtle, but by learning to recognize the signs can help you better identify this type of behaviour. Some signs include:

- Brushing off problems rather than facing them
- Feeling guilty about being sad, angry, or disappointed
- Hiding your true feelings behind feel-good quotes that seem more socially acceptable
- Hiding or disguising how you really feel
- Minimizing other people's feelings because they make you uncomfortable
- Shaming other people when they don't have a positive attitude
- Trying to be stoic or "get over" painful emotions

How to Avoid Toxic Positivity

If you've been affected by toxic positivity - or if you recognize this kind of behaviour in yourself - there are things that you can do to develop a healthier, more supportive approach. Some ideas include:

- **Manage your negative emotions, but don't deny them.** Negative emotions can cause stress when unchecked, but they can also provide important information that can lead to beneficial changes in your life.
- **Be realistic about what you should feel.** When you are facing a stressful situation, it's normal to feel stressed, worried, or even fearful. Don't expect too much from yourself. Focus on self-care and taking steps that can help improve your situation.
- **It's okay to feel more than one thing.** If you are facing a challenge, it's possible to feel nervous about the future and also hopeful that you will succeed. Your emotions are as complex as the situation itself.
- **Focus on listening to others and showing support.** When someone expresses a difficult emotion, don't shut them down with toxic platitudes. Instead, let them know that what they are feeling is normal and that you are there to listen.
- **Notice how you feel.** Following "positive" social media accounts can sometimes serve as a source of inspiration, but pay attention to how you feel after you view and interact with such content. If you are left with a sense of shame or guilt after seeing "uplifting" posts, it might be due to toxic positivity. In such cases, consider limiting your social media consumption.

International ME Conference Week – 17 - 21 May 2022.



Dates have been set for the 2022 International ME Conference Week.

The 2022 week will see the biggest research Colloquium ever (BRMEC11) stretching over three days, and taking place over Tuesday 17th to Thursday 19th May 2022, with the public conference (IIMEC15) being held on Friday 20th May 2022. The European ME Alliance would then meet on Saturday 21st May 2022. (This is dependent, of course, on the status regarding the pandemic)

Warning from Fibromyalgia Action UK (FMA UK)

We have been contacted by FMA UK and asked to share the following warning with our members:

“We have been informed that there is a counterfeit Alpha-stim microcurrent device being marketed. We are sharing this information with all our support groups to make their members aware.

Please be warned there is a white device for sale on various websites claiming to be the ‘Original Alpha-Stim CES’. It has no research or safety certificates. The genuine Alpha-Stim devices are grey. FMA UK cannot endorse any product but have heard of people being misled. The safety and research of a product should always be checked before use. Please seek out the original manufacturer to verify any products you may be considering purchasing.”

Spoon Theory

Spoon Theory was devised by Christine Miserandino several years ago. I have included the link to her story, which you can read at your leisure:

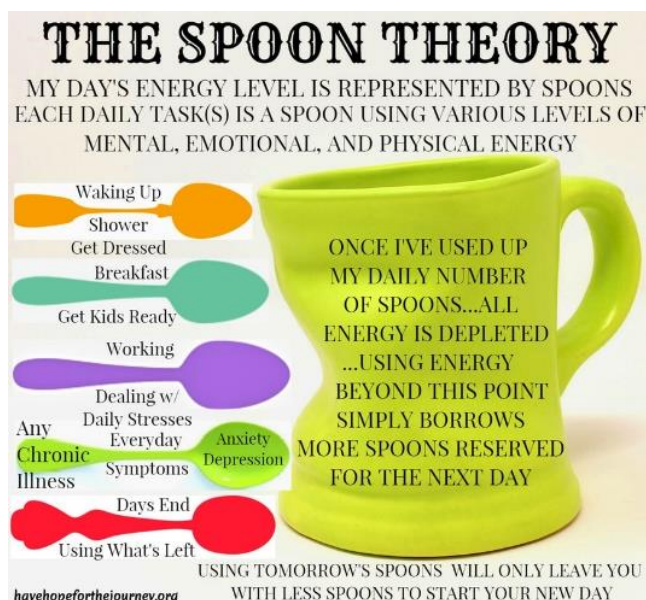
[But You Don't Look Sick? Support for those with invisible illness or chronic illness The Spoon Theory written by Christine Miserandino:](https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/)

<https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>



Christine has Lupus, but the theory has been adapted and used for many chronic illnesses, including ME, Fibromyalgia, CFS and no doubt Long Covid is on the list too.

The way it is explained is that a normal person, or you when you were well before chronic illness, would have innumerable spoons full of energy each day to do with as you please.



There have been those times, back in the day, when at the last minute someone has said, do you fancy going camping at the weekend? Or there's a band playing on Wednesday night, are you coming along? And almost without a thought your answer would be: try and stop me!

But now, after the advent of chronic illness, there has to be a lot of thought goes into making all the everyday decisions. Not just special one-off occasions but whether or not there is enough energy to shower or leave it until tomorrow.

The limit is 12 Spoons for a 'Spoonie', that's a person who uses this theory. I find it is a really good way of explaining to children, in order for them to understand what is

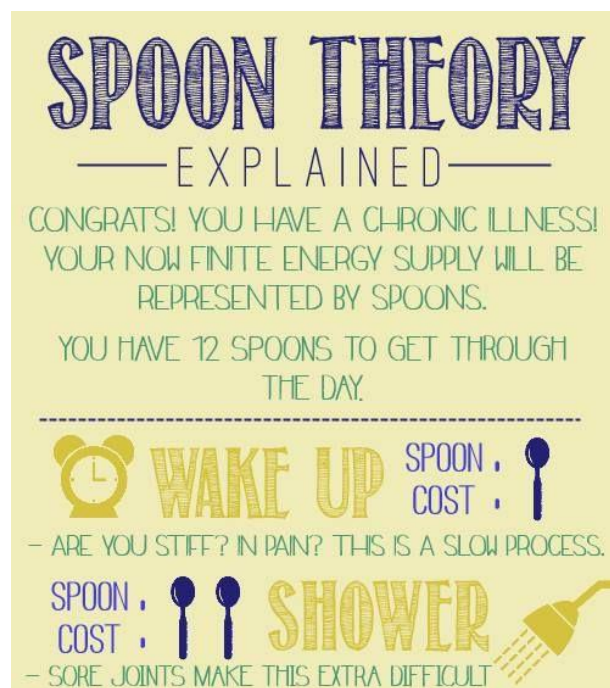
happening with the adult in their life who is living with chronic illness. To be honest, I'm in my 60s and I find it useful for explaining to those who have no concept of lack of energy. Those lovely people who suggest that you will be a lot better if you just have a bit of a rest, or do some exercise, or get out in the fresh air. It certainly focusses my mind and stops me from getting frustrated with them and their suggestions.

It's advised on the infographics here (and on the internet) that a shower would take 2 spoons. But, as you get to know your abilities and limitations, you will be able to work out whether you need those two or may require three or four spoons on any particular day. After all, pain and fatigue are unquantifiable, and rather indiscriminate at turning up the 'volume' at a moment's notice. Consider what are the important tasks you wish to complete on a daily basis and allow for these. After all, life is supposed to be fun, right? Not a constant slog from dawn till dusk!

When a day out beckons, or a visit from family or friends, it's always a good idea to 'save spoons' the day before, so that there is less chance of you fading part way through the day. It's a way of getting to grips with what life is now and living it. I spent a good two years of my life wanting my old life back, wasting that time after diagnosis instead of learning about my life now. I'm no different to lots of folk who cope with their conditions, but I hope that I can impart a bit of my experience to you, to help and support you along the way.

So, hopefully this will help some of you to understand pacing, which is a great strategy for living the ME/FM/CFS experience.

Eileen



Living in a woman's body: this body is a genetic mistake - but it is sex, laughter and beauty too

It is radical to love a body that the world says is wrong
- and I love mine completely.

This body is a genetic mistake, a pitiable stare, the scan on a mundane Tuesday lunchtime with a doctor speaking in hushed tones by the bed.

It is glorious too, thanks. It is deep-in-the-bones laughter at 2am with people who love you; only strangers care that it is sitting in a wheelchair while doing so ("Have you got a licence for that thing, sweetheart?"). It is straight-As, promotions and beating expectations as much as the odds. It is being buckled over from the pain, clutching a public toilet bowl, pills and dignity rattling at the bottom of a handbag. It is sex, fevered goosebumps and kisses to the skin like magic. It is warm summers with friends, sunshine on bare legs and 90s dance music ricocheting through the air. It is fucking knackered.

This body is more than twice as likely to be domestically abused, is paid on average £3.68 less an hour, is a third less likely to be able to access lifesaving breast cancer screenings, and is still told to be "grateful" for it. "Be grateful, love. You're lucky they hired you. He's a saint to be with you."

This body is a scrounger if it needs the state, a faker if it holds down a job. It is the reject of capitalist productivity, all the while working harder than any FTSE 100 CEO. This body is one in five, full of potential,

untapped and waiting. It is ready to burst, to make its mark, if only the trains were accessible, personal assistants funded and housing usable. It is just not trying hard enough.

This body is told to love something that hurts every day – #bodypositivity – or to loathe it, depending on the latest cultural winds. It is too ugly to be on the front cover of magazines, too pretty “to have to be in that chair, love”. It is a token, out front and centre when it suits, hidden in the back room when it all gets too much. It is more beautiful and powerful and astounding than words can muster.

This body is not “differently abled” or “handicapped”, and it is not your “inspiration” either. It is the herculean sum of all those who came before and those who will after; the young girl wearing her BiPap machine with pride on TikTok and the menopausal woman with a stoma choosing knickers in M&S. It is the changing of the seasons over centuries, from being hidden in institutions to regaling on the fourth plinth in Trafalgar Square, from begging in the workhouse to legislating in parliament. I believe they call that progress.

It is said that the greatest act of resistance is to live well, and I think there is truth in that. It is radical to love a body that the world says is wrong. This body, in all its joy and tears and moving edges, is loved completely – not despite its disability, but because of it.

Frances Ryan is a Guardian columnist and author of Crippled: Austerity and the Demonisation of Disabled People.

Reproduced from The Guardian:

(https://www.theguardian.com/lifeandstyle/2022/feb/09/living-in-a-womans-body-this-body-is-a-genetic-mistake-but-it-is-sex-laughter-and-beauty-too?utm_source=facebook&utm_medium=news_tab)

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 offers.

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.



Newsletter Feedback



We have mentioned that we will be transitioning to a SCIO, which is a Scottish Charitable Incorporated Organisation. As a result of this, the committee are working behind the scenes to be able to develop our projects further and therefore give help and support in more varied ways.

I would like to ask you all for your opinion on our newsletters.

Are you happy with the way that you receive them? There is the option for a hard copy posted out to you, or a digital copy sent via email. If you feel that you would like to change the way you get your copy let us know.

Is the frequency of the newsletters appropriate? At the moment we try to get the newsletters out quarterly and have been fortunate enough to have our funding applications granted for the printing and postage costs. However, there have been a few comments from members about the frequency, so could you let us know what your thoughts are please. For example, if it were to be monthly then it would be a much smaller publication, fewer pages, less to read. If we went for 6 weekly that would probably halve the size of the publication that you get now.

Also, do we cover all the topics you like to read about?

Are there any topics you would like to put forward for future newsletters?

My last question is, **would you like to write an article for the newsletter?**

I would appreciate it if you could email Eppie with your thoughts and ideas: eppie@dgmefm.org.uk

Eileen

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



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



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