DGMEFM Network

Support for ME, CFS, Fibromyalgia

December 2022

Hello everyone.

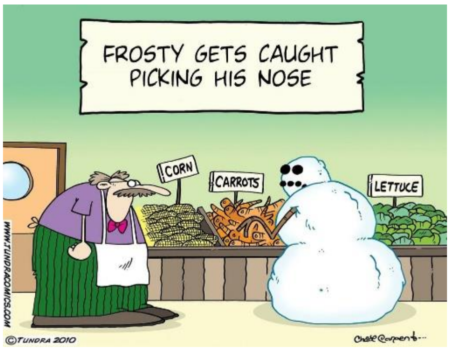
The festive season is upon us where all things shiny, twinkly and bright decorate our high streets and windows. I do love December and the darker months, probably because it's the time of my birthday so has nostalgic hints of joy and happiness, but this year, more than ever, we are all very aware of the cost of living, heating and eating. Not wishing to be political in any way, the powers that be in the UK leave a lot to be desired relating to our economy. Luckily the Network is here to help, advise, and point the way for further help and assistance. So please reach out if you feel in need of support. This can be via our Facebook groups which are private, so all are a safe place for any discussion. The trustees are always available too via admin@dgmefm.org.uk and we will reply to any emails as soon as possible. There is also the phone number, which gets through to me between 11am and 4pm daily: 07557536110. There is a facility for leaving a message if you ring outwith these times or if I am busy on another issue. We do not want any of our members to feel lost or worried in any way.

There have been a few adverts regarding free or cheaper meals at some of the larger supermarkets. This is a fabulous initiative if indeed you do live near to one of their shops. There is also a Warm Hub initiative, where there are places anyone can go to be warm during the day, thus saving on heating at home. I know that all museums and some galleries throughout Scotland are free admission and have joined in the Warm Hub initiative to encourage anyone to go in to be warm during these colder months. Of course, there are libraries too.

There are local food banks across the region where help is available for anyone on a low income. This is not necessarily involving benefits as many working people are having financial issues at the moment. So don't hesitate to get in touch with your local food bank, there is no judgement or stigma attached to using these facilities. I have dealings with Kate's Kitchen, which is based in Annan but does a pop up in Lockerbie and Langholm every fortnight. There are many other advantages to contacting them, in particular they have a gardening group, craft groups and a walking group. Also, there is a Reduce Food Waste Initiative across the region, well its countrywide to be honest. In Langholm, where I live, there is free food available most weeks at a local butcher's shop. This food comes from Tesco at the moment, but in other areas other supermarkets are involved. It is atrocious that there is so much food waste in this day and age. The yellow/orange ticketed produce, which is reduced in supermarkets - if it is not sold on the sell by date then it has been going into the bin. Basically landfill. The Reduce Food Waste initiative intervenes before this produce is thrown away. Please enquire in your area because these initiatives are there to stop food going into landfill. We must use what is available in order to reduce waste in general.

https://www.dumgal.gov.uk/cost-living-support
https://www.dumgal.gov.uk/article/25586/Food-Banks

I'm sure you have all noticed that the weather has been unseasonably mild in temperature, although we have had more than enough rain. For myself this has meant that I have not had my heating on as much as I would normally in November. But when I look out at my garden there are buds forming on some of my trees and one of my clematis looks like its thinking of flowering again. Yet during the summer I only got two apples



from a normally fully laden tree. This is all so topsy turvey, not at all what we are used to living in Scotland. I leave my garden as natural as possible, partly for the wee animals and insects, but also partly because of my energy levels. At this time of year, I love seeing all the wee birds foraging for insects in the drying flower heads of the hydrangea, collecting seeds from the teasels and ragwort, and enjoying the fat balls that I put out for them too. There are a family of sparrows who live in the mass of clematis that has grown over my shed and a family of blackbirds living in a Leylandii at the bottom of the garden.

I have been trying to get a dog-flap installed in my kitchen door because my two terriers, as you know, are little terrors, and Beryl especially loves to play the 'I want to go out' game. Then five minutes later she wants to come back in.....and so on throughout the day. Especially if the local cat is crossing our garden. I swear she can smell him through the draught from the keyhole! Getting up and down all the time uses too much energy when there's not that much in the tank!

Anyway, with encouragement from my children I asked my ex to fit the thing for me. Well, it's a good job I am a patient person. First of all, the reason for not coming to do it was that it was raining, almost every day. To be honest I didn't really think too much on this one, until it went on for a few weeks and I remembered that the door opens inwards. So, he wouldn't be getting wet! It was a lightbulb moment for me and a realisation that my fibro fog had probably been in full flow. Now he has got other jobs on the go, and my request has slipped down the ladder of preferment. Thankfully the weather has been kinder, so I have left the door open for ease of access most of the time. Does Beryl want to go outside much now? Of course she doesn't! She just sits cuddled up in her bed quite happy in the knowledge that I have left the door open just for her. Well, the time of the dog flap will arrive, and she will certainly be taught well how to use it!!

The Network has quite a lot of new and interesting projects coming up. Our monthly hybrid meetings will go ahead into the coming year, with the December one being our Christmas get together. It was decided by the trustees that this year we would not have a Christmas meal get together, mainly because of the extra cost. This has been advertised on the Facebook groups and on the website, as will all future meetings. We have had a few pop-up face to face meetings during the summer months, which have been successful in some areas. Looking into next year we are lucky enough to have sourced funding to help face to face meetings be more accessible for our members. There is more about this in the body of the newsletter.

We are overjoyed to welcome Kalpana Ratnam-Roarty as our new member of staff. The Befriending and Mentoring Project for which she is the volunteer coordinator will get off the ground in the new year. You will hear more from Kalpana in this newsletter but also via social media and the website.

I'll finish now and wish you all a Happy and hopeful Festive season. Whatever you are celebrating, and whoever you are with, I send you all good wishes from myself and my fellow trustees of the network.

Eileen

Social Meet-Up – First Thursday of the month – in person and online

Join us for a brew and a blether. Come get to know us, chat, ask questions and make new friends. Sometimes we have talks or discussions from outside speakers.

First Thursday of the month. Hybrid meeting on zoom and face-to-face at Turning Point Scotland, Newall Terrace, Dumfries. Join any time between 2pm – 3:30pm.

Sometimes there's even cake!!

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to www.zoom.us on your computer. Enter this info: - Meeting ID: 843 001 5846, Passcode: 2022

Pop-Up Meet-Up

One of our Trustees, Paul, will be hosting a meet-up at Threave Garden Terrace Café, Castle Douglas, Sunday 11th December from 1.30pm. Please let Paul know if you are planning to attend.

Crafty Friday

One of our Trustees, Corrie, will be hosting this winter's Crafty Friday zoom sessions on the third Friday of every month from 11.30-12.30. The last one before the summer on May 19th, 2023.
During these sessions we can show and share our craft projects, discuss our patterns and techniques, and have a chitchat about crafts, crafting, the weather and the garden etc.
Any member can join this zoom meet. Login details/reminders will be posted a few days in advance of each session on our Facebook "get crafty with ME" Group page.

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

Cost of Living Crisis

We have all felt the impact of the cost-of-living crisis. Third Sector Dumfries and Galloway have recently published a piece of research into the impact of energy prices on third sector organisation in Dumfries and Galloway. Following the release of their research, the BBC asked local organisations to share the ways in which their members / service users have been impacted on. Our Treasurer, Paul, provided the following quote:

> *"Dumfries & Galloway ME and Fibromyalgia Network organise social meet-ups for their members, many of whom are physically and socially isolated, unable to work, and struggle emotionally and financially to get by. The cost-of-living crisis has made it even more difficult for them to get out and enjoy the mutual support these meet-ups offer. The Network are grateful for a grant from The Communities Mental Health and Wellbeing fund that will meet the cost of 'soup, a sandwich and a drink' at meet-ups. This should remove the financial barrier for those who would have felt unable to attend due to a lack of money, and allow them to take advantage of the mental health and wellbeing benefits our meet-ups provide."*

Thanks to a grant from the Communities Mental Health and Wellbeing Fund, we're able to offer free meals for our members at Pop-Up meetings, starting next year until May 2024.

We know how important it can be to get out and socialise with fellow members, and that's why we're back to organising face to face meetings. We've always provided some refreshments at the monthly get-together in Dumfries (drink, biscuits/cake), but now with us all facing the huge rise in cost of living, it could mean some of us being unable to afford to go to the café meetings held around the Region.

We applied for the grant to allow us to provide soup, a sandwich and a drink at Pop-Ups, so that any of us who want to can enjoy the friendly mutual support at these meetings, without the cost of paying for a meal.

Cost of Living DG – a new one-stop shop detailing help with money and benefits, household bills, finding work, health and wellbeing, as well as support for families, young people, the elderly and disabled.

https://costofliving.dumgal.gov.uk

Millions of people should pay less for broadband, says watchdog

(reproduced from BBC new online, 18th October 2022)

“Millions of people on benefits are missing out on cheaper broadband tariffs because firms are failing to promote them properly, the media watchdog Ofcom has said.

Only around 3.5% of those eligible for the deals are currently on one.

Social tariffs are low-cost broadband deals offered to customers on benefits and cost about £15 a month.

The average customer could save £140 a year by switching to one of these deals, consumer group Which? says.

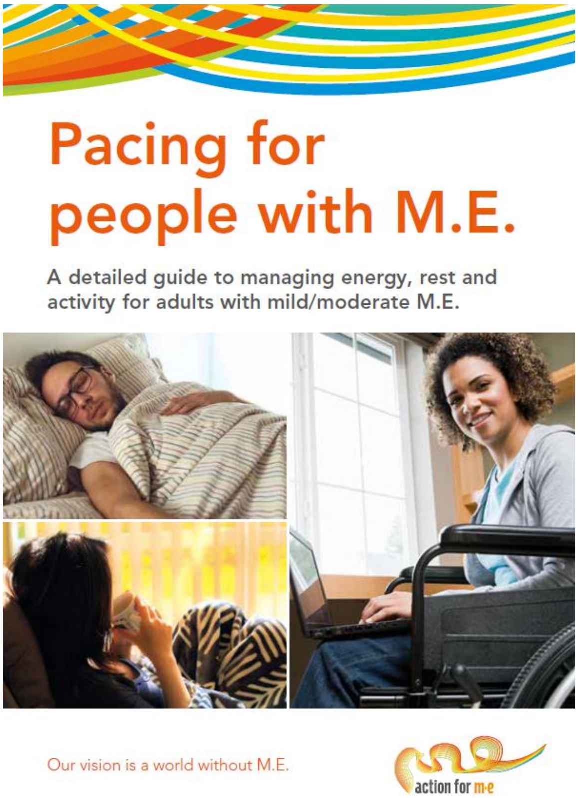
Broadband providers are not obliged to offer social tariffs, but have been encouraged to by the government and Ofcom.

Around four million UK households could be getting cheaper broadband, but only around 150,000 people are currently on one, according to Ofcom.

All of those in receipt of Universal Credit are eligible, although some providers extend eligibility to those in receipt of other benefits, such as Pension Credit, Employment and Support Allowance, Jobseeker's Allowance and Income Support.”

Full article can be accessed here: https://www.bbc.co.uk/news/business-63287452?xtor=ES-208&fbclid=IwAR3bxEazODVeIID2-5TrM9X06XueRBcWYUFYgEuJ8wcw9aMx6zRrjNf-96w

Pacing for People with ME



Pacing for people with M.E.

A detailed guide to managing energy, rest and activity for adults with mild/moderate M.E.

Our vision is a world without M.E.

Action for ME have produced a detailed guide to managing energy, rest and activity for adults with mild/moderate ME.

“This booklet is aimed at adults with M.E. who are new to pacing, perhaps because they are newly diagnosed, and at those who are familiar with the concept but would like a refresher.

You might find it helpful to also share it with the health professionals, carers or family/friends supporting you.

Because everyone’s manageable level of activity is different, it’s essential that they understand the limitations imposed by M.E., and specifically how these impact you.

This booklet is, by necessity, long and detailed. Pacing isn’t easy, and most people tell us they have found one or more aspects of it challenging. The knowledge, skills and strategies take time to learn and develop, which can be difficult with M.E., especially for someone more severely affected.

Bearing this in mind, this guide can be read in short sections – please don’t try to take it in all at once! – and the skills can be practised one at a time until you build up your own approach to pacing. Like so many things in life, it takes time to learn how to put theory into practice in real life.

The essentials of pacing are covered on 14 pages in the “Your step-by-step pacing guide” (pages 14 to 27).

Other things you may find useful in your self-management toolkit come under the “Pacing as part of self-management” section (pages 28 to 52).

Deciding to try pacing, or any other management approach, is your decision. You should fully understand what a particular approach involves before you decide to go ahead with trying it.

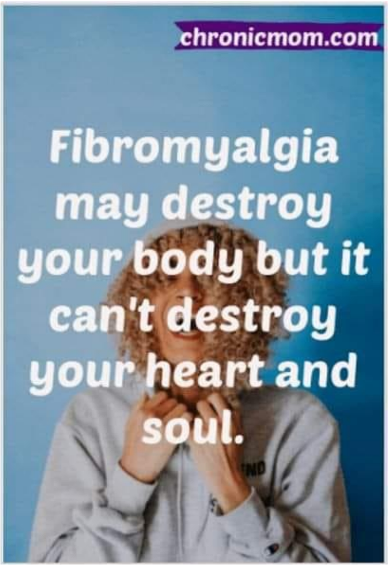
Other people may share a particular approach that has helped them; throughout the booklet, we have included some experiences of pacing (the quotes in orange), shared in our 2019 Big Survey of more than 4,000 people with M.E.

While this can be helpful in considering how to move forward, please remember that this booklet is not a substitute for medical advice from an appropriately qualified healthcare professional, who has experience of M.E. and understands how it affects you."
The booklet can be accessed here: https://www.actionforme.org.uk/uploads/pdfs/Pacing-for-people-with-me-booklet-Feb-2020.pdf

Self-Management Course (provided by Public Health Improvement)

The course is weekly over 12 weeks, anyone can self-refer via the Single Access Point (SAP) ON 03033333001 OR you can ask at your GP surgery for an appointment with the Community Link Worker. There are 4 areas across Dumfries & Galloway, East to West: - Annandale & Eskdale, Nithsdale, Stewartry and Wigtownshire.
As someone with M.E. and Fibro I signed up for this course before covid 2019 but they only restarted this Sept 2022 in Newton Stewart. I'm finding it hugely informative and fun.
The course has been really helpful thus far and I'm finding week on week, as is everyone else I attend with (lovely fun bunch of folks), "gosh we didn't know this was even available", "I didn't know you could refer yourself", "I didn't know there was help out there, you don't hear about it". I'm sure many of us have felt the same. You don't have to attend every week, (here they keep leaflets from speakers to pass on later for folk who weren't able to attend). The speakers often offer time to ask questions openly for discussion or personally with the speaker at the end for a short time.
Each session we have a good blether (free tea/coffee& biscuits). Then they get you to work it off with standing or sitting exercise (gentle stretches, the nurse reiterates each session - only to your own ability, or not at all, it is to meet YOUR needs).
So far, we covered really helpful topics (different speaker each week, sometimes two) such as Citizens Advice (benefits, form filling, advice etc for folk UNDER 65 years). Stroke Services (come to your home/GP and advise). FoodTrain (not just shopping) Can shop for you once/ regularly etc (for a small fee). They will go into homes and put shopping away, not drop it off on doorstep like with online shopping. They have odd job staff who can help if mobility energy is an issue. They are also doing some befriending support. Dietitian- mainly if you struggle to maintain weight, get the right nutrition, need support after an operation perhaps. Carers Center is for family and carers not just the person needing support. Even if you don't need help/ care now, they can advise for the future. It was stated that "the more folk they have on record in the county, obviously helps planning and funding for the future, so don't feel afraid to ask". Versus Arthritis (some medicines available these days). Podietry (can help with supports in shoes, specially made shoes where necessary, advice on foot care) Pharmacy, not just your local chemist- there's a team in hospitals who can advise – your GP use them often, but if something's not suiting you as far as medication goes you can also ask for a referral (phone call) they are only too happy to help.
Attendance Allowance (for OVER 65 years), many people believe they need looking after to apply. You can live on your own and still be entitled to help. The speaker was lovely and easy to speak to. They talk over the phone to gather your information) and then fill the forms in for you. I would highly recommend this (forms are 40 pages and a minefield – they do it all the time, no bother). They do a home visit where extra support may be needed - speech/language /understanding.
There's also to come talks on: - Power of Attorney (advice & wills). Care Call. Capability Scotland. Anxiety & Depression.
The only downside to this course is having to travel to a venue for each week. I must say though, I found it really worthwhile and tiring, but found out about what's in my area. Nothing worse than finding out it's on your doorstep and not knowing about it. We need to use this service to get the help we need and are entitled to. It's the old adage, use it or lose it when it comes to services / funding.
I hope this has given enough insight to be of worth to many of DGMEFM NETWORK members. Take care all.

Diane Bond



What You Should Know About Me and My Life

(reproduced from Facebook, original author unknown)

1. My pain - My pain is not your pain. It is not caused by inflammation. Taking your arthritis medication will not help me. I can not work my pain out or shake it off. It is not even a pain that stays put. Today it is in my shoulder, but tomorrow it may be in my foot or gone. My pain is believed to be caused by improper signals sent to the brain, possibly due to sleep disorders. It is not well understood, but it is real.

2. My fatigue - I am not merely tired. I am often in a severe state of exhaustion. I may want to participate in physical activities, but I can't. Please do not take this personally. If you saw me shopping in the mall yesterday, but I can't help you with yard work today, it isn't because I don't want to. I am, most likely, paying the price for stressing my muscles beyond their capability.

3. My forgetfulness - Those of us who suffer from it call it fibrofog. I may not remember your name, but I do remember you. I may not remember what I promised to do for you, even though you told me just seconds ago. My problem has nothing to do with my age but may be related to sleep deprivation. I do not have a selective memory. On some days, I just don't have any short-term memory at all.

4. My clumsiness - If I step on your toes or run into you five times in a crowd, I am not purposely targeting you. I do not have the muscle control for that. If you are behind me on the stairs, please be patient. These days, I take life and stairwells one step at a time.

5. My sensitivities - I just can't stand it! "It" could be any number of things: bright sunlight, loud or high-pitched noises, odours. FMS has been called the "aggravating everything disorder." So don't make me open the drapes or listen to your child scream. I really can't stand it.

6. My intolerance - I can't stand heat, either. Or humidity. If I am a man, I sweat...profusely. If I am a lady, I perspire. Both are equally embarrassing, so please don't feel compelled to point this shortcoming out to me. I know. And don't be surprised if I shake uncontrollably when it's cold. I don't tolerate cold, either. My internal thermostat is broken, and nobody knows how to fix it.

7. My depression - Yes, there are days when I would rather stay in bed or in the house or die. I have lost count of how many patients suffer from FMS as well as other related illnesses. Severe, unrelenting pain can cause depression. Your sincere concern and understanding can pull me back from the brink. Your snide remarks can tip me over the edge.

8. My stress - My body does not handle stress well. If I have to give up my job, work part time, or handle my responsibilities from home, I'm not lazy. Everyday stresses make my symptoms worse and can incapacitate me completely.

9. My weight - I may be fat or I may be skinny. Either way, it is not by choice. My body is not your body. My appestat is broken, and nobody can tell me how to fix it.

10. My need for therapy - If I get a massage every week, don't envy me. My massage is not your massage. Consider how a massage would feel if that charley horse you had in your leg last week was all over your body. Massaging it out was very painful, but it had to be done. My body is knot-filled. If I can stand the pain, regular massage can help, at least temporarily.

11. My good days - If you see me smiling and functioning normally, don't assume I am well. I suffer from a chronic pain and fatigue illness with no cure. I can have my good days or weeks or even months. In fact, the good days are what keep me going.

12. My uniqueness - Even those who suffer from FMS are not alike. That means I may not have all of the problems mentioned above. I do have pain above and below the waist and on both sides of my body which has lasted for a very long time. I may have migraines or hip pain or shoulder pain or knee pain, but I do not have exactly the same pain as anyone else.

I hope that this helps you understand me, but if you still doubt my pain, your local bookstore, library and the internet have many good books and articles on fibromyalgia.

Author's note: This letter is based on communications with people throughout the world, males and females, who suffer from fibromyalgia. It does not represent any one of the over 10,000,000 people with FMS, but it can help the healthy person understand how devastating this illness can be. Please do not take these people and their pain lightly. You wouldn't want to spend even a day in their shoes...or their bodies.

What Primary Care Practitioners Need to Know about the New NICE Guideline on ME/CFS in Adults

A pre-print is available of a review of the NICE guideline on ME/CFS that Dr Shepherd (Hon. Medical Adviser to the ME Association) has co-authored with 3 other members of the NICE guideline committee: Adam Lowe, Caroline Kingdon and Dr Luis Nacul.

Abstract:
“The new NICE guideline for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), published in October 2021, makes significant changes in treatment recommendations.
It acknowledges the complexity of this chronic medical condition, which always impacts quality of life and can be profoundly disabling, recognising the prejudice and stigma that people with ME/CFS often experience in the absence of any specific diagnostic test.
The guideline outlines steps for accurate diagnosis, recognising post-exertional malaise as a core symptom; importantly, ME/CFS can now be diagnosed after just 3 months in a bid to improve long-term health outcomes. It recommends the need for individual, tailored management by a multi-disciplinary team, ensuring that the wellbeing of the individual is paramount.

The guideline makes clear that any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET), should not be offered as a treatment for ME/CFS and emphasises that cognitive behavioural therapy (CBT) should only be offered as a supportive intervention.
Because of the rigorous methodology required by NICE Committee review and the inclusion of the testimony of people with lived experience as committee members, this guideline will influence the future diagnosis and management of ME/CFS in the UK and beyond.
As this is a pre-print we welcome comments – which can be added to the pre-print website.”
The full pre-print can be accessed here:
https://www.preprints.org/manuscript/202211.0016/v1

Hi, my name is Kalpana and I am the new part-time volunteer coordinator.
A little bit about myself. I love reading, music and arts & crafts. I have a couple of cats and a young daughter that keeps me on my toes. I enjoy meeting new people and look forward to meeting and getting to know people in the network. If anyone is interested in finding out more about me, the new post or is interested in becoming a volunteer please get in touch with me at kalpana@dgmefm.org.uk.

The project

The new volunteer service will help reduce loneliness and isolation and increase confidence amongst people with lived experience. Volunteers will either be

- befrienders: supporting people by interacting with them on a social level
- peer mentors: supporting people to navigate health and social care systems (including diagnosis, treatment pathways and social care support), by sharing their own lived experience

The project will be a safe space without judgement or stigma, something that can be hard to find for sufferers of these conditions. For instance, there will be no need to explain fatigue, brain fog, pain and other symptoms and there will be flexibility to rearrange sessions if need be.
I will be responsible for recruiting, training and supporting volunteers on an ongoing basis. I will also match volunteers with people with lived experiences to make sure that it is a positive experience for everyone.
Volunteering can take place via phone, video (e.g. zoom) or in person, depending on people's needs. The volunteer and the person/people they are matched with will decide how often they connect.
Volunteers will also benefit from being part of the project with their own loneliness and isolation being reduced. In a rural area, such as Dumfries and Galloway, it can be difficult for volunteers to find flexible opportunities without a lot of travel.
There will also be opportunities to support DGMEFM Network in other ways, such as newsletter production, website updates or joining the board.
The whole project will raise awareness of DGMEFM Network and the conditions it supports.

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

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