

February 2019

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome all,

It's a new year, and a belated newsletter. If it's not too late to do so, I wish you a happy and healthier new year for 2019. It may seem like a while ago now, but I hope everyone had a good Christmas holiday season. How is the weather affecting you? For me the lack of daylight affects my mood and worsens my sleep problems. The body's flu-like ache has become so much worse, especially in the legs and lower back. I've used a sunbed and a sauna/steam which does seem to help a bit, but that in itself takes energy. If you have any tips for how you deal with it, please let us know.

It's been a busy time for ME and Fibromyalgia with campaigns resulting in parliamentary debates. MPs and MSPs, if not the ministers, can now be under no illusions about the disaster that is the PACE Trial and the current NICE Guidelines. We need to continue to campaign for these to be suspended, before the new guidelines are published late in 2020.

Craig Woods

Monthly Get-Togethers

First Thursday of every month 1pm – 3pm at Midsteeple, Dumfries



Feb 7th Making a 'Case for Change'. Julie Davidson from the Scottish Health Council will join us for discussion about what is going wrong in our care and showing that we are not getting the care that we should, from which she would help us draw up a 'Case for Change' to take to the Health Board and Localities.
March 7th Our guest from 1.30pm will be Frazer Donaldson, Specialist Podiatrist, to talk about the role of a Podiatrist in FM especially, and some practical advice.
April 4th With guest from 1.30pm, Jill Dobbie, a yoga teacher diagnosed with Fibro' and ME. Jill has used yoga for many years to help manage her symptoms. She will give a talk on the benefits of yoga along with some seated practice.

Refreshments will be provided at the Midsteeple meetings. Entry is through the blue Box Office door. We use the meeting room on the first floor. Press and hold the lift button to call it and press and hold the button until the door unlocks on the 1st floor.

Pop-Up Meetings

February 23rd Saturday From 1pm. Join us at **Mrs Howat's Vintage Pantry** in Dumfries for a lunchtime get-together. It is on Three Crowns Court, set back from Queensberry St.

March 10th Sunday From 1pm. Join us for a lunchtime get-together at **Castle Douglas Garden Centre Coffee Shop**. The Centre is on the edge of town heading out on the Dalbeattie road.

12th April Friday From 2:30pm. We hope to see you at **Just Be Lockerbie** for a blether and afternoon tea or coffee and cakes.

Look for our logo on the table to know where to find us.

Look out for other pop-up meetings on our Facebook page or website meetings page.

Contact us:

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email - admin@dgmefm.org.uk

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ME and Fibromyalgia in Parliament

2019 has so far proved busy for fibromyalgia and ME campaigners with 3 parliamentary debates within the first couple of weeks back.

Westminster Hall Debate

On 15th January there was a debate in Westminster Hall on the recognition of fibromyalgia as a disability. Many MPs talked about constituents and their plight. Andrea Jenkyns MP, herself a sufferer spoke movingly. *“The widespread pain is one of the worst things. I am talking about waking up in the morning and being bent over with pain. You feel like you are 80 because every muscle in your body is in pain, and that continues throughout the day. I have found that the medication provided really zonks me out. It causes me to have even more memory lapses, which in our profession is not good. You do not want to be feeling sleepy all the time.*

It is a good job that I have kept my sense of humour about this. I remember one occasion back in 2015, when I was newly elected and a guest on one of the political programmes. Even to this day—three years on from being elected—I get very nervous when I know that I have to speak in a debate or do a media appearance, because I never know when the fibro-fog is going to come on. I remember that during that political programme, I could not think of a word as basic as “economy”, and what other word is there for economy? I do not know whether anybody else can think of one. So I was there, with the cameras on me, and I just wanted the ground to open up and swallow me, but I just laughed it off and dealt with it.”

Scottish Parliament Public Petitions Debate

ME Action secured a debate in the Scottish Parliament, held on the 24th Jan. The petition stated:- Calling on the Scottish Parliament to urge the Scottish Government to review the level of support for people with Myalgic

- Investing in biomedical research and creating a centre of excellence for ME
- Ensuring healthcare professionals' training and education materials reflect the latest scientific evidence
- Providing specialist care for patients and discontinuing the harmful treatments graded exercise therapy (GET) and cognitive behavioural therapy (CBT).



Chief Medical Officer for Scotland, Catherine Calderwood offered her congratulations to the #MEAction Scotland petitioners for bringing forward their petition and highlighting the way in which ME has been, in her words, denied and ignored. She also acknowledged that, unlike other neurological conditions, there had been no provision of treatment or of funding for research. Dr Calderwood called for a co-ordinated approach across Scotland towards ME and explained that the Scottish Government is proposing the establishment of a working group that would look at provision of services, drawing on examples of good practice such as the specialist nurse post in NHS Fife.

House of Commons Debate

Carol Monaghan MP secured the highest profile of these debates, also held on the 24th of Jan. This took place in the main chamber of the House of Commons, which is a victory in itself. Carol Monaghan MP is a true ME hero, this being the third debate she's secured on ME in the UK parliament in 12 months. The debate was well attended, across political parties. After a well-



Carol Monaghan MP

informed debate with many MPs, seemingly with a good understanding of the condition and problems faced by sufferers speaking the Question was put and agreed to:- *“Resolved, That this House calls on the Government to provide increased funding for biomedical research for the diagnosis and treatment of ME; supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment; supports updated training of GPs and medical professionals to ensure that they are equipped with clear guidance on the diagnosis of ME and appropriate management advice to reflect international consensus on best practice; and is concerned about the current trends of subjecting ME families to unjustified child protection procedures.”*

The response from the government minister was not so hopeful however – backing NICE and the current treatment regime until guidelines are updated, and in defence of the lack of government funding on research complained that there was a lack of “good-enough research proposals” to fund. This is ironic considering the government very generously funded the highly-flawed, psychologically led PACE Trial which has done so much damage to ME treatment in this country.

Conclusion

Our facebook members helped bring about these debates by responding to petitions, signing them and sharing them. All of the debates have shown the respective parliaments in a good light, with MPs across parties, interested, engaged and informed and coming together in an attempt to right the injustice they see. There is hope to be taken from all debates, with cross-party groups being encouraged to be set up in the UK and Scottish parliaments. Please keep filling in the petitions we share, please keep writing to your MPs and MSPs and telling them of your problems related to ME and fibromyalgia.

Craig

Case For Change

During the December meeting the Network contributed to informing the new Neurological Standards for the NHS in Scotland. In future ME care will be shaped by these guidelines as it's been decided that ME will be treated as the neurological illness it is defined as by the WHO. Julie Davidson from the Scottish Health Council was shocked by our treatment (or lack of treatment) to date and suggested that she could help us make a 'Case For Change'. This will be evidence from our members of the problems we currently face accessing suitable health care along with the reasons we think things should change. This will be collated into a document to be used by the Network to pressure for improvements to our care. We envisage taking it to each of our four NHS localities and to NHS management in D&G and beyond and to use it as evidence when presenting our case to politicians and the council too.

Please come along and share your experience – however bad. When it's being used constructively it can be cathartic to share it. We need your ideas for how things can be improved. This will happen during our February Dumfries Midsteeple Meeting, from 1pm on Thursday 7th February

Research Round-up

There have been several interesting research studies being published recently in ME and fibromyalgia – two of them showing fibromyalgia to have strikingly similar problems to those found in recent discoveries made in ME.

In our last newsletter we reported on new findings showing widespread overheating in the brain of ME patients. That study has since been replicated elsewhere. Now very similar, widespread brain inflammation has been discovered in fibromyalgia by a joint study from Massachusetts General Hospital in the US and Karolinska Institutet in Sweden. *“We don't have good treatment options for fibromyalgia, so identifying a potential treatment target could lead to the development of innovative, more effective therapies, and finding objective neurochemical changes in the brains of patients with fibromyalgia should help reduce the persistent stigma that many patients face.”* Marco Loggia, PhD, co-senior author of the report.

Also, a reanalysis of previous studies done on female fibromyalgia sufferers by a collaborative team from Johns Hopkins University, National Institute of Nursing Research (USA) and University of Oviedo (Spain) has shown that they too, appear to be in a state of hibernation or ‘dauer’. The study’s intention was to find genes which would identify fibromyalgia sufferers from controls. They found 57 gene expressions differed to the healthy controls, many related to energy production and transport were down-rated. These results parallel an ME metabolomic study from last year.

A small New Zealand study has shown problems with 33 genes compared to healthy controls relating to inflammation, metabolic (the production of energy), mitochondria (the conversion and transport of energy), the circadian rhythm (the sleep/wake cycle) and inflammation and cellular stress responses.

Receiving widespread publicity in the UK was a study by King’s College, London, long time home of Simon Wessely and promoted by the Science Media Centre (neither friends to ME sufferers) – and all the more interesting for it. It didn’t directly relate to ME sufferers, but showed how a ‘CFS-like’ illness can develop when HepC sufferers were treated with a drug to generate an over-active immune system. It may offer the first blood-predictor of who will go on to develop ME.

Craig

Arts & Crafts open groups

Annan: The Art and Craft Club restarted in the United Reformed Church, Station Road, on Wednesday 9th January from 2-4pm. ‘This informal group is for adults who would like the opportunity to do arts and crafts, meet new people and enjoy a chat over a cup of tea or coffee. Art and craft materials are provided and each session will be led and focuses on a different activity. All welcome whether you are a beginner or an expert.’ £3 per session. The price includes art materials and tea/coffee. For further dates and activities contact: SHAP on 01461 207728

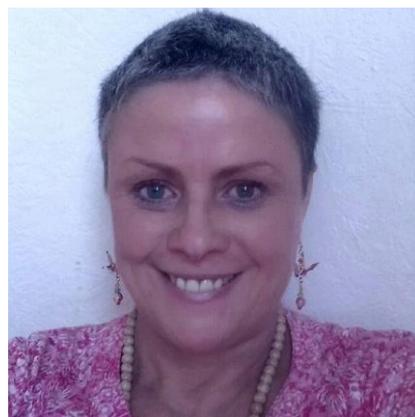
Stranraer: BHC West Wigtownshire have a self-help Arts Group, which meet every Thursday morning at the Coronation Day Centre, 10.30 am - 12.30 pm. Led by two BHC volunteers, there is a small cost of £1.50 which goes towards room hire and the scones and coffee that the centre provide. Contact: Building Healthy Communities (BHC) Wigtownshire Health & Wellbeing Team on 01776 700632.

Is there an open arts/crafts group in your area? – if so please let us know details and we’ll pass it on through the newsletter and our Facebook page.

Benefits of Yoga by Jill Dobbie

I'm looking forward to coming along to your meeting on the 4th April 2019. I will be sharing information about the benefits of yoga for people living with Fibro and ME and offer a gentle chair-based yoga practice for anyone who would like to join in.

I was recently diagnosed with Fibromyalgia and ME, after seeing Professor Stone at Edinburgh's Western General. I'm so grateful that there is a local group to offer support and information. It took a long time to get my diagnosis, with my illness starting 25 years ago after a terrible bout of Beijing flu, which I took years to recover from. I did manage to return to work again but sadly had to retire from my job in nursing 4 years ago due to ill health. After a very difficult period in my life, I re-trained as a yoga teacher at Mandala Yoga Ashram in South Wales, graduating in 2017. The training was challenging due to my ongoing symptoms of fatigue. However, I managed to complete the training and it's one of the best things I have done as I love teaching yoga.



When I started thinking about training as a yoga teacher I had it in mind that I wanted to help make yoga more accessible. I was thinking about those people who would not be able to join in a traditional yoga class, whether it was due to physical limitations or mental difficulties. I explored this issue in my final project and presentation at the Ashram which was about the benefits of Yoga for People with Dementia. I continue to share chair yoga classes with local Alzheimer Scotland groups. I still think there is a misconception that yoga is only suitable for fit, active people who can move their bodies into weird and wonderful postures! The truth is yoga can be adapted to suit anyone. I teach chair yoga to people in their 90's every week. Simple breathing, meditation and relaxation practices can be practiced by most people and they have been proven to reduce stress and anxiety, improve sleep, and to help to improve feelings of well-being. In yoga gentle physical movements are synchronised with breathing along with mindful awareness on the sensations within the body. Improving the mind and body connection. By gently stretching and releasing tension held within the muscles, connective tissue and joints there can be reduction in the pain and achy feelings within the body.

For me yoga has helped provide me with tools to lead a happier life despite the limitations that fibromyalgia and ME have brought. I would say the mental health benefits of yoga have been the most important to me as I suffered from depression for many years. The struggle of not getting physically better no matter how hard I tried took a heavy toll on me mentally over the years. Thankfully now my mental health is the best it has ever been. The relaxation, breathing, gentle movements and meditation can offer a place of calmness within, space to be yourself, not an illness or diagnosis.

The word Yoga means Unity.

Jill will attend our Dumfries, Midsteeples Meeting at 1pm on 4th April. Her gentle, beginner's yoga class is held on Thursdays at Lincluden Community Centre 10am-11:30am. £4 or £2 conc.

Chronic Medication Service

Recently one of our members has attended a relatively new service provided by pharmacies for the NHS called the Chronic Medication Service. She has found this very useful, having helpful medication reinstated, which had been removed when her G.P. changed.

The Chronic Medication Service aims to encourage joint working between GPs and community pharmacists to improve patient care by:

- Identifying and Prioritising risk from medicines
- Minimising adverse drug reactions
- Address existing and prevent potential problems with medicines
- Provide structured follow-up and interventions where necessary

It can be accessed by self-registration with a Community Pharmacy in Scotland if you get regular prescriptions to treat a long-term condition (fibromyalgia, ME are included) and are registered with a GP practice in Scotland. You can choose which pharmacy to register with. There are three parts to the service. The pharmacist will organise a medication review, a care plan and serial prescriptions. The service will help manage the medicine while the GP continues to give you medical care.

We hope to have someone from the service attend a future Midsteeples meeting to tell us of the benefits. In the meantime more information can be found on www.nhsinform.scot, on 0800 224488 or from your local pharmacy.

Mindfulness for Chronic Pain

Guest speaker at our December Midsteeples meeting was Dr Emily Kennedy, a member of the Dumfries & Galloway Health Board Prescribing Support Team, who gave us an introduction to ‘Mindfulness’ and how it may help us in coping with our symptoms.

‘Mindfulness involves paying attention to our thoughts and feelings so that we can become more aware of them, less enmeshed in them, and better able to manage them. It is an integrative mind-body based life skill that can help people become more aware of the ways they think and feel about their experiences, especially stressful experiences; and be better able to respond to these.’

‘Physical and psychological benefits from practicing Mindfulness can include: the ability to step back and see things more clearly; responding rather than reacting; coping better with negative thoughts; reduced symptoms of stress; reducing pain and the emotional response to it; more energy and enthusiasm for life; improved relationships; an improvement in memory and concentration; the ability to relax; improved sleep pattern; and greater self-confidence.’

Free short courses for people living with chronic pain, and unpaid carers, are being delivered by the NHS across the Region. For further information email sonya.pybus@nhs.net or post your details to Sonya Pybus, Oliphant Centre for Health Improvement, 12-28 Lochside Road Primary Care Centre, Dumfries, DG2 9BH

7 Things Mindful People Do Differently

1 Approach everyday things with curiosity—and savor them

2 Forgive their mistakes—big or small

3 Show gratitude for good moments—and grace for bad ones

4 Practice compassion and nurture connections

5 Make peace with imperfection—inside and out

6 Embrace vulnerability by trusting others—and themselves

7 Accept—and appreciate—that things come and go

List created by Elisha Goldstein, Ph.D., psychologist, author of *The Now Effect*

Hobbies and Pastimes

Towards the end of last year, Lesley asked members of our Facebook page to share for this newsletter their hobbies and pastimes, and how or why it helps cope with life in general.

'I like to do arts and crafts and up cycling. This helps as a distraction from pain as I enjoy it. It also helps my concentration as I get lost in my activity 😊' *Louise*



'I enjoy photography and find it takes my mind off a lot of things. Unfortunately, I don't get out very much with my camera



so am restricted to working in my shed. When I was at my lowest, my photography pulled me through. Many days, setting up my camera and shooting water droplets and still life pictures or the nature in my garden gives me a sense of purpose. I am an enthusiastic amateur (very on both counts). I just muddle along but seldom remember settings. Love playing with the water and experimenting. I am a member of Abbey camera club in Dumfries which is very supportive and not overly competitive.' *Duncan*



'My pets, affectionately called the Zoo, keep my brain busy and my legs moving on short dog walks, more often than most folk take to make up for the short distance. I have three dogs: Keisha is a bit bigger Jack Russel, Lucy is my beautiful Chihuahua, and Tyrian my Yorkshire Terrier who is a very lovable nuisance. My husband and son both help with the dogs or I would really struggle at times. I also have an African grey parrot called Oscar, two tortoises - Captain Jack Sparrow is Callum's (my son) and Herbie is my one. I bath them on a Tuesday or Wednesday, then it's cleaning out and putting grass in their pen. They have salad and kale everyday with either tomatoes, carrot, peas, and sweet corn is their favourite. Whatever veg is going really, they also like pineapple. I have a goldfish called Fishey - not very creative but nice fish just the same. So they keep me busy. I think I would get a bit more housework done without, but dust can't give me a cuddle or chatter away as Oscar does. Oh, I almost forgot Yazzi cat - his name came from a SciFi book and means beloved in Linyarrie alien language. He and Tyrian are at the moment sound asleep in front of the fire.' *Nancy*

'I like crafts and I do the garden and read and write how I feel. It helps forget the pain, takes my mind off everything that I try to forget. I've made all my Christmas cards as well.' *Mary*



'I love arts and crafts. Love cooking but it gets too sore now. I used to make tablet, fudge, toffee etc at Halloween and Christmas for people but don't have strength or energy to stir and stand for an hour at a time now then lift the pot.' *Sarah*

'My main hobby is reading fantasy novels. However I sometimes have to keep repeating chapters!' *Tara*

'My main hobby is sea fishing and keeping [local] cold water marine fish in aquarium tanks. If I'm well enough to get out in the boat, I'm sure the extra oxygen you get out at sea perks me up. When I'm not well enough to go out, I watch my fish at home. Oh - and though my balance is very poor, when I'm out at sea I don't have any problems; I think the constant motion makes my brain concentrate more than usual on staying upright. I do not kill any fish when sea fishing, other than a couple of haddock, pollock or cod for eating. When the fish in my aquarium grow to a certain size, I release them back into the sea unharmed. Several years ago, I was trained by an aquarist friend from Sydney aquarium over several months on how to handle fish without causing them any harm. Statistically, fish in aquariums [including large public aquariums] stand a very much higher likelihood of surviving than if they were in the open sea. With marine fish, it's case of eat other marine species, or be eaten by another species; the old mantra in nature of kill or be killed.' *Steve*



Tub gurnard



Octopus



A ling in my aquarium ...and a male cuckoo wrasse.



Female cuckoo wrasse



Tub gurnard



Streaked gurnard [very rare]

'Many thanks to all. It's difficult when you've had to give up something you love doing. I used to love going out with my dogs but I can't walk too far now. Like Steve, I find being near water helps to relax me, I love swimming, or should say bobbing about. Taking the pressure of my joint for a wee bit is great. I can imagine it's a great feeling being out at sea, it must help relax you watching your fish at home. I like a good book as well, I like thrillers. I've read a few of James Paterson's, great if you ever want to read a thriller.' *Lesley*

Tips for Newbies with Fibromyalgia and or ME/CFS (& reminders for the rest of us)

Taken from an article in Health Rising by Cort Johnson, Dec 2018

'If I knew then what I know now, I would have rested more/sooner before permanent damage was done.' *Person with ME/CFS*

One thing to know is that the worst is usually first, that while some people do decline, doctors say that most people improve and then plateau and some even recover. In short, there's hope! It's also very important, though, to get very real about what these diseases can do in order to avoid the worst they have to offer – which can be very bad indeed.

Get Real – 'The thing I would do differently is to do 3 years ago what I am trying to do now - stop trying to keep up with other people, discard all expectations, get rid of activities that don't sustain me, and distance myself from people who don't help. In other words, wake up to the fact that I have a serious disabling illness that needs a drastic change in lifestyle.' *John*

Take These Diseases Seriously – ME/CFS is one of the most functionally disabling diseases there is. Thinking ME/CFS or FM is something you can push aside or work through can be a recipe for disaster. You should know that studies indicate that chronic fatigue syndrome (ME/CFS) is more functionally disabling than heart disease, multiple sclerosis, kidney failure and other serious diseases. People with ME/CFS have a lower quality of life than people with cancer, stroke, renal failure and schizophrenia. Twenty-five percent are home or bedbound.



One study, found that only an astonishingly low 13% were employed full-time. Give the disease the respect it deserves.

'I would not have pushed myself so hard to keep going, now I know that it probably made me worse. The worse I felt, the more I pushed.' *Connie*

Pace, Pace, Pace – The hardest and most important tip is simply to pace, pace, pace. Rest. Don't overdo. Pace mentally as well as physically. Try and calm your body down and give it a chance to heal. Many people, in retrospect, rue their attempts to push through these illnesses, which led to worsened health.

Adjust – Yes, some people do recover, but don't expect a cure and don't be disappointed when you don't get one. Come to grips with the fact that your life is most likely changed for the foreseeable future. Try not to spend time focusing on what you don't have. Find new ways to enjoy yourself, to be engaged in life. Accept that for now – this is it – and get what you can from it.

Let go of unhelpful friends – people who don't believe in these illnesses or don't understand your new limitations are energy-sappers. Let them go. In fact, get good at letting things go in general. 'I would have listened to my body more and respected it when it needed to rest. I definitely would not have kept going when it was screaming at me to stop. I would have left my job far, far sooner. I would have worried less about trying to appear "normal" for friends and family.' *Curiosity*

Learn how to ask for help – self-reliance isn't the virtue it was. You might have been someone who enjoyed helping others. You can't do that much anymore but you can give that gift to others. You may very well have people around you who would love to help out with shopping, driving you to doctor's appointments, cleaning house. Remember that people are not mind readers. Don't be afraid to ask for help.

'I would have accepted my illness and found a way to reduce the stress in my life. It is easier said than done, but in my case, I believe it would have made a huge difference.' *Jayne*

Give Yourself a Break – having an illness does not mean something is wrong with you or that you are damaged or broken. It simply means something has gone wrong with your body. Instead of beating yourself and your body up for getting ill, try and accept it. People get ill all the time and everybody gets ill at some point.

Try to Relax a Bit – Neither ME/CFS nor FM is going to be solved in a day. Your fight/flight system is typically greatly activated in these diseases. Practice putting your body/mind into a relaxing state via meditation and mindfulness techniques and see if you can calm that system down and get some relief.

Understand that your family may not be able to meet your emotional needs – if you aren't getting the emotional support you need from your family first have compassion for them – they weren't ready for this either – and then look elsewhere to forums, Facebook groups and local groups and/or see a therapist to help you adjust.

Know that recovery is possible – Recovery is not common but it definitely does happen.

Find a good doctor – ME/CFS/FM experts are not common but they do exist. Get advice on forums and Facebook sites, see if you can find a good one. If that doesn't work, try and find a doctor who will listen and is open to trying new things.

'I wouldn't have wasted a second seeing doctor after doctor who were not specialists in ME/CFS, especially at the beginning when I was so desperately ill and every trip took so much out of me. I would have realized that the extra stress of having people refuse to help me or judge me or blame me just made things vastly worse. I would have found a sympathetic and supportive doctor right away.' *Curiosity*



Lower your expectations about the medical profession – Don't expect doctors to understand you! This is one of the hardest lessons these diseases bring. There **are** sympathetic doctors out there but there are also doctors who don't get ME/CFS/FM, aren't interested in getting it, just want to see you gone, and are not nice about it. You may very well encounter one at some point. Pay them as little mind as possible. Above all don't take them personally, and know you are not alone.

Ditch bad doctors – If you hit a bad doctor, don't get blue in the face and waste your energy on them – they're not worth the trouble. Instead move on as quickly as possible. Your job is, after all, to find a **good** doctor.

Get a thorough check-up – Make sure you have ME/CFS or FM. Lots of other diseases can mimic their symptoms. Other diseases occur along with it. Learn how to diagnose ME/CFS and/or fibromyalgia and the co-morbid diseases that often come with it or mimic it.

Maximize your doctor appointments – Doctor appointments can be particularly tough. You probably have a lot of symptoms, your mind is whirring, your short-term memory is pretty much shot and your health is at stake! In short, you need to get organized like you may never have before.

Learn how to tell the difference between depression and ME/CFS – Many doctors confuse ME/CFS with depression. Depression/anxiety is a natural outcome of having a chronic illness. If you are depressed, get treated for it, but run from doctors who think all you have is depression.

'When I first got ill with a virus ten years ago, I was left so weak that I could not stand for more than two minutes, my GP was adamant that I was suffering from depression and he put me on anti-depressants. I wish I had followed my instincts (knowing that this had nothing to do with depression) and not followed this ill advice.' *Gabby*

Be open to trying drugs – If you're not open to trying drugs, try to be open to that possibility. Many people have an aversion to drugs, but while drugs cannot cure ME/CFS/FM, they can be helpful. At the same time investigate each drug thoroughly and consider both short-term and possible long-term side effects and be sure to....

Start low and go slow – People with ME/CFS/FM often report that normal doses of drugs, particularly in the beginning, are too much. Always try to start with low doses and go slowly, giving your body a chance to adjust.

In general use opioid drugs sparingly, if possible, and watch for side effects – opioid pain-killers can be very effective for some but most people should probably use them sparingly, if possible. Watch for possible side effects such as tolerance (need to increase your dose), addiction and even increased pain sensitivity. Make sure that they are not being used as sedatives, as well.

Be open to alternative treatments – Some people, on the other hand, are skittish about alternative treatments including supplements and diets. While they, like drugs, are not cures, some find them quite helpful.

Try low dose naltrexone and medical marijuana – Instead of (or in addition to) opioid drugs, try alternative treatments such as low dose naltrexone, cannabis and CBD oil. Studies indicate that using cannabis products can reduce the need for opioid pain-killers.

Get your thyroid fully checked out – most doctors don't know how to diagnose thyroid conditions correctly and hypothyroidism is rampant in ME/CFS/FM.

Focus on getting better sleep – poor sleep has all sorts of negative biological effects including increasing one's pain sensitivity. If there's one symptom you should focus on first with these diseases, it might be getting better sleep. Learn as much as you can about sleep treatments and sleep hygiene.

Stay away from sites advertising cures – ME/CFS and FM are complex, heterogeneous diseases which are not amenable to single cures. It takes just a minute on a Forum site like Phoenix Rising to understand that people with these illnesses can respond dramatically differently to the same treatment; i.e. anyone who says they have a cure for these illnesses is lying.

Check for mould sensitivity – Most doctors don't know diddly about mould but it can have devastating effects on one's health. The turnaround stories from former mould patients are astonishing. Get out of the house with new stuff (clothes) and into a mould-free environment and see if that helps.

Do not exercise – at least in the way you know exercise. Do not engage in aggressive exercise which raises your heart rate substantially. Instead try a heart-rate based "exercise" program which keeps your heart rate in the safety zone or use a heart rate variability monitor for a more fine-tuned measure of your energy levels. 'I would not have listened to STUPID docs to exercise it away' *Mary Jane*

If possible avoid deconditioning – keep up some activity if you can to avoid the hits that come with deconditioning which include reduced blood volume, smaller heart, increased pain, poor sleep, etc. If you're bed-bound, try stretching to maintain some blood flow and prevent your muscles from locking up in painful positions.



Consider your finances when trying treatments – It's hard to hold off on possible treatments when you have the money. You never know, after all, when the right things will show up. On the other hand, some people have later rued the thousands of dollars spent on treatments, particularly alternative treatments, that had no effect.

Consider trying to keep working if you can – Several doctors (Clauw, Lapp, Cheney) reportedly recommend continuing to work if you can. For many the decision to stop working and seek disability is a no-brainer – you don't have any other choice. For the mild to moderately ill the decision is more difficult. Know that the idea that all you need to do is stop work and get complete rest generally doesn't pan out. Stopping working may help avoid crashes (and a further deterioration of health). On the other hand, work does provide money and often fulfilment.

News Round-Up

Remember you can keep up to date by visiting our website blog <http://dgmefm.org.uk/blog/> for a monthly round-up of topics of discussion and links to articles and news stories posted by members on our Facebook page. Thanks to Kim Jakobsen, committee member (web support) for putting this together.

It's Your Network...

Many thanks to the members who shared their experiences and thoughts in this newsletter. We are always very happy to receive contributions of articles, thoughts, personal stories, cartoons and more for the newsletter. If there's something you'd be happy to share, please feel free to get in touch.

If you'd like to organise a get-together in your area we can publicise it through the newsletter and the Facebook page.

Gift Day Thanks

Many thanks to all who contributed to our 'Gift Day'. It's a great help towards meeting the costs of the newsletter and other expenses incurred through our main activities. We would prefer not to have to rely on members' contributions but it has been a struggle for us to find the energy to make funding applications. If there is someone you know with background or expertise in this area who might offer to help us with funding applications, then please ask them to contact me, paul@dgmefm.org.uk – thanks.



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