March 2020

DGMEFM Network
Support for ME, CFS, Fibromyalgia

Welcome all,

For this newsletter I'm very pleased to say that we have been asked to facilitate two consultations around our illnesses and care. It is very exciting that we are actually being noticed and that our opinions are being sought with a view to improving our lot. That we are moving up the agenda is in no small part down to the campaigning of ME Action and their clever publicity campaigns and targeting of the media and politicians in Holyrood and Westminster. With Awareness Day approaching on the 12th of May look out for this year's campaign from them. If it is even half as poignant and moving as the unused shoes, labelled with the stories of their now-ill owners from last year, it will catch attention and further our cause.

There will be a change of our regular Dumfries venue soon from Midsteeple in March to Turning Point on Newall Terrace from April onwards. Details are on page 5. This is a pleasant, accessible room, and it will give us access to remote conferencing facilities. The meetings continue to be popular, particularly, it seems, the meetings where we are being consulted and where we have expert speakers. Your suggestions, as ever, for future topics, speakers and how best to use the remote conferencing facility are very welcome. It is good to see you there, but if you don't feel up to coming along, or if meeting is just not for you, please do still keep in touch.

Craig Woods

Monthly Get-Togethers

First Thursday of every month 1pm – 3pm

March 5th Our final meeting at **Midsteeple**. Our guest will be Julie Davidson of the Scottish Health Council consulting on behalf of the Scottish Government about our 'lived experience' with ME/CFS. Entry is through the Box Office door. We use the meeting room on the 1st floor. Press and hold the lift button to call it and press and hold the button until the door unlocks on the 1st floor.

Apr 2nd Our guest at this first meeting in the new monthly venue **Turning Point** Scotland will be Ruth Griffith, Strategic Planning and Commissioning Manager for D&G NHS, for discussion on long term conditions - what works well and not so well here in D&G, and what is needed locally to support people with managing their long term conditions.

May 7th At **Turning Point**. There will be a themed discussion around diet and how it affects ME and fibromyalgia as well as the chance for a social chat and catch-up.

Refreshments will be provided at the meetings.

Pop-Up Meetings

Mar 22nd Sunday From 1pm. 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.

Apr 17th Friday From 2:30pm. Afternoon coffee meet-up in **Just Be,** on **Lockerbie** High Street.

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

Contact us:
Phone/WhatsApp - 07437 602610
email - admin@dgmefm.org.uk

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Consultations

We are pleased to have been approached to contribute to two different consultations over the coming months. The Scottish Government is undertaking a large study into our "lived experiences" of ME/CFS. Please, please try to find the energy to contribute to this. Shout about our needs, and where improvements can be made while they are actually listening to us!

There are many ways to contribute to this consultation, as the Scottish Health Council's leaflet explains. If you are coming along to our March Midsteeple meeting or contributing your views by telephone it may be useful to consider these questions before attending or picking up the phone:-

3. What health care and support (for ME) has made a difference to the quality of your life?

4. What health care and support (for ME) is making a difference to the quality of your life?

5. What health care and support (for ME) would make a difference to the quality of your life?

6. What social care and support (for ME) has made a difference to your quality of life?

7. What social care and support (for ME) is making a difference to your quality of life?

8. What social care and support (for ME) would make a difference to your quality of life?

9. What healthcare professionals have been involved previously in your care and support for ME?

10. What healthcare professionals are currently involved in your care and support for ME?

11. What healthcare professionals should be involved in your care and support for ME?

12. What social care professionals have been involved previously in your care and support for ME?

13. What social care professionals are currently involved in your care and support for ME?

14. What social care professionals should be involved in your care and support for ME?

15. How can healthcare and support provided to you for other reasons (another condition or ailment unrelated to ME) be more responsive to your needs and wishes around ME?

16. How can social care and support provided to you for other reasons (another condition or ailment unrelated to ME) be more responsive to your needs and wishes around ME?

You can also request a paper copy to fill in at home at your own pace.

For our April meeting the consultation will be more local. It is for NHS D&G, undertaken by Ruth Griffith, Strategic Planning and Commissioning Manager and it will be open to fibromyalgia sufferers as well as ME/CFS. This will be about what works and what does not work locally. Have a think about how you can be better supported here, what health care you'd like and what discipline you'd like it from. Should it be delivered by a nurse, in a group setting, by a GP or someone with specialist knowledge? Could you benefit from being taught about pacing, diet, being introduced to 'expert patients', gaining access to specialists to help manage symptoms and pain? What could work well here to support our specific needs and also that of others with long-term conditions?

Invisible Disabilities Sticker

You’ll have noticed by now a window sticker falling out of your newsletter that we have produced for our members. This is designed to help deal with the stigma we feel which society can sometimes direct towards people like us with invisible, long term and fluctuating conditions. I’ve felt it myself, even when people don’t say anything. I look relatively fit, one day I can do something and I can’t the next. I’m very slow in the mornings, and am often embarrassed to answer my door to deliveries in my dressing gown as late as midday. This sticker should, at a glance, help explain our problems to people we encounter. We certainly shouldn’t feel any need to explain ourselves, but sometimes it is easier, and less unpleasant all round.

Stick it on a car for when you feel you may be judged for using your disabled parking badge; stick it on your front door to instantly explain why you may be slow to answer it and why you may look dishevelled and tired into the day.

We are able to create this and send it to you thanks to the funding we have received from The Robertson Trust.

Please display it in time for ME and Fibromyalgia Awareness Day on May 12th. Blue and purple ribbons can also be worn when you are out and about. You might still have one from previous year’s newsletter, otherwise pop along to a meeting before May to collect one from us.

Extra stickers are available on request from meetings, or drop us a message. *Craig*

Sunflower Lanyards

Our stickers were inspired partly by the signs on the disabled toilets in Tesco which we have been impressed with.

There is also a nationwide sunflower lanyard scheme where big retailers and organisations have trained staff to offer extra help to people wearing this lanyard in store. Tesco, Sainsbury’s, M&S, many airports, airlines and more organisations are part of the scheme. It is aimed at people with hidden conditions and difficulties and it subtly signals to staff that you have a hidden condition and may need extra time or help. In our region you can ask for one for free at the customer service desk in Tesco or Sainsbury’s and it should be recognised in store. If you try it please let us know how you get on.

It is heartening to see big retailers and organisations becoming more aware that disability is so much more than being confined to wheelchair users only.

DAGCAS

For our February Midsteeple meeting Emma Munro from the D&G Citizens' Advice Service came along to talk about their work and the current situation with the welfare state in the region and the help and advice they can give around it, and for other problems you may encounter around employment, housing, debt issues and more.

Emma told us about a service they offer called Support 4 Life which aims to help you identify and claim social security benefits you might be entitled to and to help with other issues which you may encounter in relation to long-term illness and disability. It is a free service which people who are affected by long-term conditions, carers, single people, families, seniors and people not claiming their full social security allowance can self-refer to. Of benefit to us is that this is a service which can be accessed by requesting an appointment at a bureau, or at home if unable to attend a bureau, without needing to sit and wait for potentially hours, which requesting their help can sometimes entail.

She also strongly recommended that anyone making a new claim for benefits, facing an appeal, or renewing contact DAGCAS for help in filling in their forms. The Scottish government's devolving of benefits is still continuing, but she didn't have clear dates or information on this as it is progressing very slowly. Where the benefits are being devolved the changes being made sound like they are for the better.

Support 4 Life is available in Annan, Dumfries and Stranraer, or with a home visit if you can't attend a bureau. Telephone 0300 303 4321 to make an appointment.

Carina MacLeod's Fibro My Arth' Comedy Show

As you'll have seen in the last newsletter a comedian who suffers from fibromyalgia came to the Theatre Royal in Dumfries to deliver her show. Around 40 Network members were there, making up around half the audience. Most of the audience would be sufferers, or close friends/relatives/carers of sufferers. Some looked poorly, giving away the effort required to be out, and quite a few who were there are rarely able to go out any longer.

There was some excited anticipation as no one of us really knew quite what to expect. I think live stand-up comedy was new to quite a few of us too. Much, but not all, of the show was based on her symptoms, observations and experiences. A joke that I found funniest was a one-liner about fibro fog: "it takes 45 minutes for three friends with fibromyalgia to have a 15 minute conversation". There was plenty of swearing, some sexual stuff to make me blush (as I'd brought my Mum), plenty of digs at the Tories – she really doesn't like them - and plenty of toilet humour around the gastro issues with fibro and IBS.

Yes, there's a lot of base humour (belly laughs – pun intended) in it, but it also helped to broach a topic that can be embarrassing – and that's a very good thing.

In contrast with other comedians, Catrina referred back to her 'cheat sheet' to keep herself on topic. You could see her tiring during the act, then she perked up a bit for the second half. For the finale she bounced about the stage and danced along to 80's hits, but it was obvious to see the toll it was taking on her and her thought process.

Everyone seemed to really enjoy the show and we all had a good laugh – sufferers and friends/family alike. It was entertaining, light, silly, crude and rude, yet it also helped to give an insight into the condition. *Craig*

New Venue

Because of the council cutbacks and uncertainty around the future of the Midsteeple we have had to search for a new, regular venue for our monthly, first-Thursday, meetings. After exploring various options, we settled on the meeting room at Turning Point's building at 22 Newall Terrace, Dumfries, DG1 1LW. It covers our needs of being central; being accessible; having a kitchen that we can use for teas and coffees; having internet access; and being affordable. We will be able to use their conferencing facilities which gives us the option in the future of having video meetings with people in the ME and fibromyalgia worlds. There is also a capsule coffee maker for those wanting something rather posher than the instant coffee and tea that we provide (for a 50p charge). It's close to the town centre and the bus stops on Great King Street and some parking is available on street, in the council HQ and Loreburn car parks, and in Turning Point's own car park accessed off Catherine Street.

To gain entry to the building you need to use the buzzer at the front door and say that you are there for the DGMEFM meeting, then sign in (and out again when leaving). *We will be updating our website with a video showing how to access the building and meeting room.*

Our first meeting there will be at 1pm on Thursday April 2nd, and it will be a consultation with NHS D&G around our experience of healthcare for long-term conditions (details on the front page).

My Remission Story

This should be an easy thing to write about, but it isn't and I've kept putting it off. However, when I read John Bell's post last autumn about having to give up work, it bore many similarities to my own circumstances and I thought I must put pen to paper, to let others see there can be some light at the end of the tunnel and cause for hope. But I would immediately point out that what I am writing about here is remission, not recovery.

Some of you will know that I've had ME for a very long time, in fact my 53rd 'anniversary' was on the

28th October last year. Not all sufferers can pin down so accurately the date ME got its claws into them, but I can, because that day I had a ruptured appendix, with major complications and never fully recovered. It took 24 years to get a correct diagnosis, during which time I'd been repeatedly misdiagnosed with other conditions I never had and had developed other health problems which were completely missed; I had also, like John, been forced to give up work. If I was asked for my personal definition of recovery, it would be being able to just about hang on to a full time job, but having very little energy left for anything else, using the time when not at work to rest and recharge the batteries.

However, I am one of those sufferers whose symptoms fluctuate considerably and though I did get progressively worse, I also had four periods of remission which I would categorise as getting some of my former life back and feeling a great deal better, but by no means fully recovered. I could list these remissions chronologically - and the relapses that followed – but suffice it to say that the length of the periods of remission got shorter and the relapses longer, with poorer health each time I relapsed. I had one relapse of seventeen years when my symptoms would have been classed as more or less severe and I spent a lot of time during the day in bed or on the sofa. However, around 9 years ago, my symptoms [still fluctuating on a daily basis] started to ease gradually from severe/moderate to moderate/mild. I noticed a slow improvement in health with fewer bad days, then in the spring of last year, the really bad days became further and further apart until at the end of June, they stopped. This is why I have been reluctant to tell people that I am currently going into remission, because I'm pretty sure it won't last [but it could, I suppose]. Also, infuriatingly, I don't know either what has caused remissions or relapses – if only, so I could spread the word.

Now during the previous periods of remission, most of what I would think of as my ME symptoms have cleared up or lessened. This time, the brain fog has lifted to a great extent and I have more stamina, but that's about it; I still have all the pain, the IBS, the poor memory, sleep disturbance and other symptoms I have in common with most sufferers. It's brilliant to be able to think more clearly again and I suspect some other health issues I still have might be down to advancing years rather than ME [like an increasing inability to learn/retain anything new, particularly technology]. But even thinking clearly has a downside, because I'm more aware of what I've missed out on and in my 53 years plus of ME there are gaps in my memory when I can remember absolutely nothing for periods of months – even a couple of years. I'm talking complete loss of what happened in those periods, unless I have someone to prompt me or something inconsequential triggers recall [for Father Ted fans, think Father Dougall and his blue jumper].

Overall, though, I'm delighted to be where I am now and would say that spontaneous remission could happen at any time for others even if it has never happened before. It also demonstrates to my way of thinking that many of the symptoms of ME and the damage it has wrought can be reversed, if only the right trigger is found. I also think that my own experience of remission and relapse reinforces the need for ME to be diagnosed as early as possible, even if currently prolonged rest and careful pacing are all that has been proven to work. I have three close relatives with ME.

One, my mother, has had ME for around the same time as me, but was diagnosed within a few weeks of going down with the wretched illness. She has by no means fully recovered, but now has significantly fewer 'bad days' and has made it to 98 years, which I consider to be remarkable. The other two regard themselves as 'recovered', but I know both have made significant changes to their lifestyles and frequently look over their shoulders to see if ME is still 'stalking' them. I have yet to meet anyone who has completely recovered from ME [although I'm sure some people do] but when I read tabloid stories of miraculous recovery because of this, that and the other amazing 'cure', I'm afraid that mostly when you delve deeper into what these individuals were still capable of when their illness was at its worst and in some cases they were only ill for a matter of months, the conclusion is that although they may have been very ill, ME was not the culprit. For example, if the 'lightning process' cured you, then you had a very different health issue altogether!

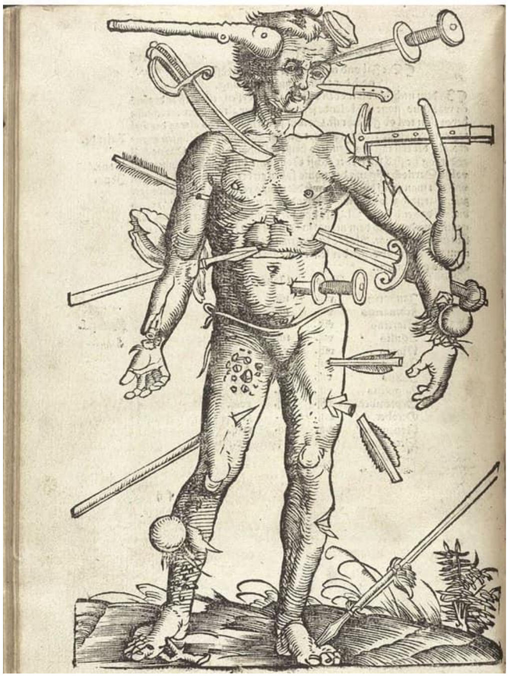
Steve Boyle

Fibro/ME Group by Pam Walker

I've met a group of like-minded people.
Once a month we gather at the steeple.
It's a friendly wee group I must admit.
Some they talk others just sit.
Those who sit will take it all in.
Our, problems, are similar, not all the same.
Some debilitating others more tame.
For each of us it's changed our lives.
Discomfort, pain, struggles and strives.
Fibro/Me, can be misunderstood.
Meeting up is all for the good.
I'm glad I've joined this group of people.
Who monthly meet at the Mid Steeple.

Thanks to Pam, a new member, and now becoming a regular face for this wee poem. We're pleased you're finding benefit from the mutual support of the Network. See you at the next meeting!

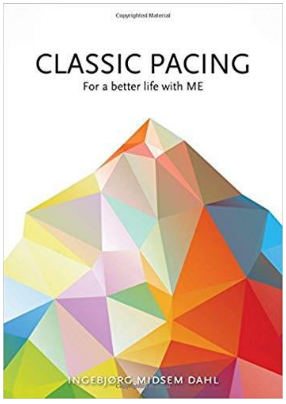
Doctor: Tell me where it hurts
Me:



Lending Library

In our May newsletter last year, we listed books which were donated for lending to members. You can now view the list on our website: https://dgmefm.org.uk/resources
We have recently added a copy of 'Classic Pacing - For a better life with ME', by Ingebjorg Dahl. Although aimed at people with ME most of it is said to be relevant to people who have other illnesses which also cause low energy levels. It contains advice for all degrees of severity and most ages. Easy to read, and written in a way that makes it possible to read in little bits at a time.

If you wish to borrow books please email admin@dgmefm.org.uk or phone us on 07437 602610 giving your details and request. The books can be delivered and returned by post, or by hand at one of our meetings. For postal returns, an address label will be issued but you will be responsible for the return postage.



What to Eat When You Have Chronic Fatigue Syndrome

By Adrienne Dellwo, updated January 2020 - website https://www.verywellhealth.com

Following a chronic fatigue syndrome diet can be an important part of managing the condition, which is also known as myalgic encephalomyelitis (ME/CFS). While diet won't cure chronic fatigue syndrome, eating to boost your energy and address possible nutrient deficiencies can help you experience less muscle pain, minimize extreme and ongoing fatigue, and feel better overall.

A chronic fatigue syndrome diet is focused on eating more balanced and nutrient-rich meals and snacks and avoiding certain foods and drinks that could be worsening your symptoms. It will take some trial and error to find what works best for you, and that starts with learning what you can about how food may be impacting your symptoms.

Benefits

There isn't much good quality research on diet and nutrition for chronic fatigue syndrome, and the research that is available isn't conclusive. ME/CFS is believed to involve chronic inflammation. So far, an anti-inflammatory diet hasn't been studied for this disease. However, because it's a healthy diet overall, many doctors recommend it for people with this condition.

A 2017 review on nutritional treatments for chronic fatigue syndrome published in *Biomedicine & Pharmacotherapy* found that many people with ME/CFS have vitamin, mineral, and essential fatty acid deficiencies.

Eating a healthy and balanced chronic fatigue syndrome diet may help to correct underlying nutrient deficiencies that could be contributing to ME/CFS symptoms. Supplements, if needed, may also help.

A review of studies on diet and nutritional supplements published in 2017 in the *Journal of Nutrition and Human Dietetics* found some evidence that certain components in foods improved fatigue and other symptoms. They included:

- Nicotinamide adenine dinucleotide hydride (NADH)
- Probiotics
- CoQ10
- Polyphenols (especially from chocolate with a high cocoa content)

The polyphenols in chocolate are a type of antioxidant that may be especially important in chronic fatigue syndrome. One study specifically looked at the benefits of polyphenols in dark chocolate and found that they minimized symptoms associated with ME/CFS.

Foods like green tea, berries, and legumes also contain polyphenols. They may also help reduce symptoms, but they haven't been studied specifically.

Polyphenols and other types of antioxidants are believed to reverse damage to molecules that may cause illness. One theory about the underlying mechanisms of chronic fatigue syndrome is that oxidative stress plays a part, and antioxidants combat the free radicals that overwhelm the body as a result of this process.

There is also some evidence from a review of 22 studies that supplementing with either D-ribose or omega-3 fatty acids reduces some of the symptoms of ME/CFS.

Most of these studies focus on supplementing the diet because low levels of many nutrients were found in people with chronic fatigue syndrome. However, it makes sense to turn to food in order to boost your nutrient intake before you add supplements.

How It Works

The goal of the chronic fatigue syndrome diet is to use nutrition to reduce fatigue, prevent nutrient deficiencies, and keep inflammation in check. There aren't any rules here. Simply aim for foods that provide a steady supply of long-lasting energy and a healthier balance of fats and antioxidants to reduce inflammation-promoting chemicals in your body.

Duration

The chronic fatigue syndrome diet is meant to be a long-term healthy eating plan that you can and should follow for the rest of your life if you have this condition. Although you might find that it helps your ME/CFS symptoms, it's also a diet that promotes good health overall.

What to Eat

There is no one-size-fits-all chronic fatigue syndrome diet, and you'll find it easier to stick with this healthy eating pattern if you make it your own. It's a flexible way of eating that's based on a balanced diet that includes a wide variety of whole foods with each meal and snack.

Best Choices

- **Fruits:** Berries, cherries, and apples are among the highest sources of polyphenols. Given the research on the polyphenols in dark chocolate, they're worth adding to your diet.
- **Vegetables:** Try to include as many brightly-coloured leafy greens and red or orange vegetables (think carrots, sweet peppers, tomatoes, and sweet potatoes) for their rich antioxidant content. Aim for a good mix of cooked and raw; cooking enhances some nutrients while eating them raw preserves fibre and other nutrients.
- **Fish and Seafood:** They're all good sources of lean protein, but fatty fish like salmon, mackerel, and sardines are especially good sources of omega-3 fats, which can reduce inflammation.
- **Nuts and Seeds:** Walnuts win in the nut category, along with flax seeds (or flax meal, which is easier to digest), chia seeds, and hemp seed—all great plant sources of omega-3 fats.
- **Fermented Dairy:** Unsweetened kefir and Greek yogurt are good sources of beneficial bacteria. They support a healthy gut, but also provide a food source of probiotics, which research suggests might be helpful for reducing your symptoms.
- **Healthy Fats**: Olive oil, olives, avocados, and all nuts and seeds provide healthy, unsaturated fats, which can help to reduce inflammation.
- **Chocolate:** It's a good source of polyphenols, but stick to a little bit of dark chocolate rather than milk chocolate bars or chocolate desserts.

Foods to Limit

Snack Foods and Packaged Meals: They're usually highly processed and made with pro-inflammatory omega-6 fats like corn, soybean, or other vegetable oils.

Sweets, Desserts, and White Bread: These are made with added sugar and white flour, which can trigger the production of pro-inflammatory compounds called cytokines.

Caffeine and Alcohol: These may increase inflammation, but they're also known to increase cortisol—a stress hormone that might overload your already exhausted body. However, there's little research on their effects on ME/CFS, so use them in moderation and be aware that they may trigger symptoms.

Recommended Timing

There are no firm guidelines about when to eat, but you might have more energy if you don't skip meals and you spread them out throughout the day. At a minimum, aim for three meals a day, starting with a breakfast shortly after waking up.

If you feel hungry in between meals, add some balanced snacks, like berries with Greek yogurt and a handful of nuts. Balanced meals and snacks should include a variety of food groups, like fruits, vegetables, and especially some protein and/or healthy fat to help keep you full and energized until your next meal.

Cooking Tips

When preparing your food, cook with olive oil instead of corn or vegetable oil, and use healthy cooking methods like sautéing, grilling, roasting, braising, or air-frying instead of deep-fat frying.To retain more nutrients in your vegetables, lightly steam instead of boiling them. Also, herbs and spices are concentrated sources of antioxidants, so use them liberally.

Considerations

Until there's more research on the chronic fatigue syndrome diet, the best recommendation is to test foods out for yourself and see what helps (or doesn't). Make dietary changes one at a time so you can gauge their effect on your health. Sudden or extreme changes — even beneficial ones — could temporarily make your symptoms worse.

If you want to try some of the supplements mentioned, be sure to work with your doctor. Not all supplements are appropriate for everyone, and some can interact with other medications or have unwanted side effects.

Diet changes help your body to work better and heal itself, and that often takes time. Try to be patient and dedicate yourself to this process. Even if your diet doesn't seem to make a difference in your symptoms, remember that many aspects of the chronic fatigue syndrome diet are beneficial for your overall health.

Mutual support network

Members are now using our Facebook page to arrange coffee meets and to get companions for crafting…. It's what I always envisaged this Network becoming when the technology allowed, but it's only now that it's beginning to happen. Feel free to post on our facebook page and share coffee meet-ups, swimming trips, cinema outings and more if you'd like the company of your fellow Network members.

If you're not on Facebook but would willing to host a 'pop-up' get-together at a café or venue in your area then let us know the details and we'll add it to the upcoming events on our website and in the newsletters.

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