



Welcome all,

This time of year brings our annual return to OSCR, the regulator of charities in Scotland. It asks for details of progress over the year, and as such it's a time of reflection for the committee. It has been a struggle again with all of us involved in running the Network suffering ill health but never-the-less important changes have taken place, chiefly the inclusion of fibromyalgia in the Network's title, recognising the many of our members who suffer it, along with the growing diagnosis of it from doctors who may have diagnosed ME or CFS before now.

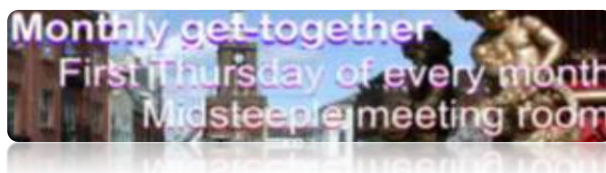
The Network requires funds to continue to operate. If you enjoy and appreciate this newsletter or the meetings please consider making a small donation towards it. None of the committee members take any payment so all the money goes towards the newsletter and running costs.

Our meetings continue to grow and we've been delighted to see many new faces visiting throughout the past year. They are informal gatherings and everyone is very friendly, having a laugh and joke with each other as well as sharing our experiences, frustrations and knowledge of the condition. Please remember that it's the DGMEFM *Network*. If you'd like to hold a meeting near you we can share it on our facebook page and email as well as the Newsletter, if there's time.

Craig Woods

Monthly Get-Together

First Thursday 1 – 3pm at Midsteeple, Dumfries



October 1st Saturday from 2pm 'pop up' social at the **Devil's Porridge Museum Café, Eastriggs.**

October 6th We have brought forward our **AGM** to October. All members are welcome and encouraged to join the discussion, vote in new committee members, with time for our usual chat.

October 23rd Sunday 1 – 3pm 'pop up' social at the **Granite Kitchen, Dalbeattie**. We have reserved an area at the back of the café. Join us for a cuppa or more from the Granite Kitchen's menu.

November 3rd Our usual social get-together with no speaker.

December 1st Our guest will be Hazel Borland, Fibromyalgia Association UK administrator.

Our Xmas meal get-together will be later in December (to be arranged).

As with all the Midsteeple get-togethers refreshments will be available. There's no charge to attend. Feel free to bring along a snack. It is fully accessible with a lift to the first floor meeting room (press and hold the button to call it and then again until the door unlocks on the first floor). Entry is through the blue Box Office door. Stay for as much or as little as you'd like. Use the Facebook page to request or offer transport.

Indicator of ME/CFS found in gut bacteria

Cornell Chronicle | 24 June 2016

Researchers have identified biological markers in both gut bacteria and blood that can be used to diagnose ME/CFS - in more than 80 percent of patients tested.

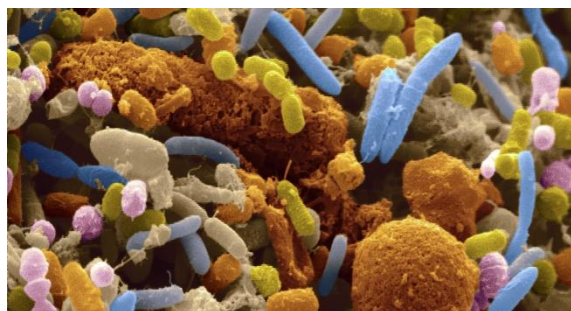
In the new study, researchers at Cornell University used biological markers for diversity in gut bacteria, as well as blood-based inflammatory markers - such as lipopolysaccharides and C-reactive protein - to diagnose the presence or absence of ME/CFS in 87 patients.

Out of the group, 48 had ME/CFS, and 39 were healthy controls - and simply by looking at their biological markers, the team could predict which was which with an 83 percent accuracy rate.

Not only is that exciting in terms of future diagnostic tests, but it also suggests a link between gut bacteria health and ME/CFS.

"Our work demonstrates that the gut bacterial microbiome in chronic fatigue syndrome patients isn't normal, perhaps leading to gastrointestinal and inflammatory symptoms in victims of the disease," said Maureen Hanson, the paper's senior author.

"Furthermore, our detection of a biological abnormality provides further evidence against the ridiculous concept that the disease is psychological in origin."



The researchers found that ME/CFS patients had less diversity in their gut bacteria than the control group - specifically, fewer bacterial species that were anti-inflammatory and more which were pro-inflammatory.

They could also identify changes and specific markers of inflammation in the blood, which the researchers think could be due to intestinal problems leaking bacteria into the blood - which triggers an immune response, and might worsen symptoms in patients.

"In the future, we could see this technique as a complement to other non-invasive diagnoses, but if we have a better idea of what is going on with these gut microbes and patients, maybe clinicians could consider changing diets, using prebiotics such as dietary fibres or probiotics to help treat the disease," said Ludovic Giloteaux, first author for the new research.

To be clear, the researchers still aren't sure if this change in gut bacteria is one of the causes of ME/CFS, or whether it's a symptom. The study has been published in [Microbiome](#).

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Norwich | 8 July 2016

Researchers on the Norwich Research Park have published a detailed review of evidence for a role of the gut microbiota and virome in ME/CFS. The review, published in *The Journal of Clinical Medicine*, examines mounting evidence pointing towards an infectious and autoimmune basis for ME/CFS, with emphasis placed on the impact of the bacterial and viral communities resident within our gut.

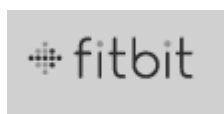
Spiritual Healing Experience

Myself and two other group members spent a wonderful evening with Elaine Waugh, who practises spiritual healing. Elaine was not only a fantastic hostess, but a very dedicated healer. She made everyone welcome, explained how she worked, and generally made us feel comfortable and relaxed.

The healing experience resulted in each one of us feeling very pleased with the outcome! Louise said she particularly enjoyed a great sense of calm and wellbeing, and that the overall experience was extremely powerful. Lesley enjoyed the feeling of being so relaxed, and the next day felt very calm both in body and mind. She says she would love to go back for another session and would recommend it to everyone. Personally, I felt my mind was at peace and my body had been swaddled in warmth and comfort. I was also very surprised to learn, that she had even been able to identify a medical problem which is totally unrelated to my fibro. I would definitely recommend an evening with Elaine!

Christine Russell

You can contact Elaine through private message on Facebook, or e-mail admin@dgmefm.org.uk with your contact information, which we will be pass on to Elaine.



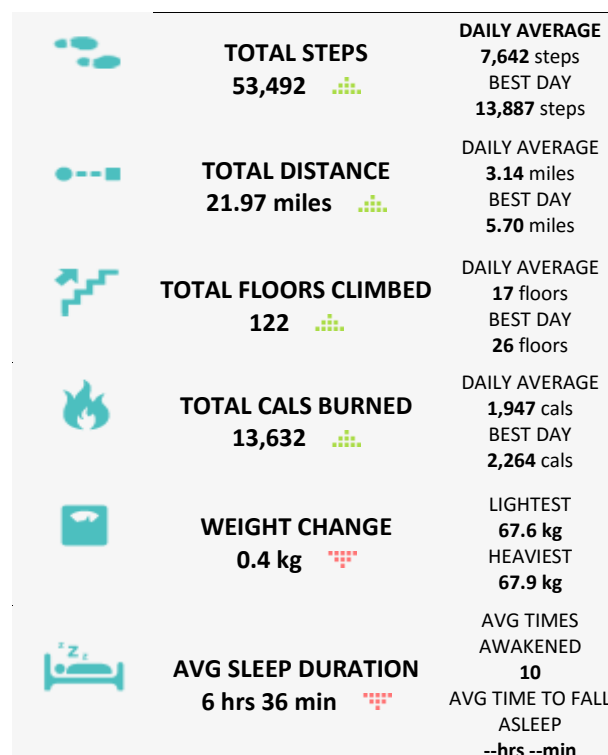
Fitbit Charge HR

After a friend told me about her Fitbit I wondered if getting one myself might help with pacing a bit better, so off I went and did some research. There are a number of different models on the market but I went for the Fitbit Charge HR.

It's got a lot of useful functions from how many steps to how well you've slept. It can also read your heart rate so it helps me manage panic and anxiety attacks.

The HR Charge is also a watch with the option to set alarms so it can help with reminders, for example when to take medication. This chart is taken from a weekly summary of my activity, emailed to me from fitbit.

Lesley



Whilst fitbit is aimed at encouraging people to exercise more, it can also be used in the way Lesley does, to monitor and manage activity levels.



Free memberships available for audiobook library service

Listening Books is a national charity that provides a postal and online audiobook library service to children and adults who struggle to read or hold a book due to an illness, disability, mental health issue or learning difficulty, and they have recently received funding to offer a number of free memberships to people living in Scotland who would find the usual membership fees (£20 - £45 per year) a barrier to joining the service.

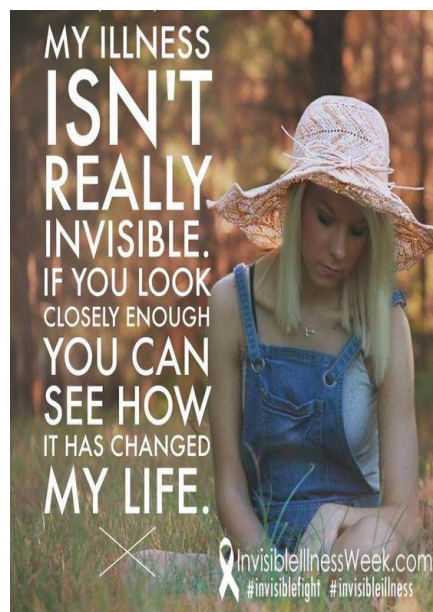
The library has a huge range of brilliant fiction, non-fiction and educational audiobooks from bestselling authors such as Philippa Gregory, James Patterson, Agatha Christie, JK Rowling, David Walliams, Jacqueline Wilson, MC Beaton, Terry Pratchett and many more, including study guides supporting the National Curriculum. Titles are available across three easily accessible formats: **MP3 CDs** sent through the post (all postage is included in the membership), **downloads** from the website which can be transferred to a portable device such as a tablet or smart phone, and **online streaming** through a Windows PC, Mac or compatible device.

To apply for a free membership, please contact Jo Cord on 020 7407 9417 or jcord@listening-books.org.uk You can also apply online by visiting <https://www.listening-books.org.uk/join-us.aspx> and ticking the box to apply for a free place.

'Gift Day'



Can you help us with a 'Gift Day' donation towards our costs? There is a separate Gift Day form enclosed with this newsletter, but now you can also donate (and Gift Aid it) on-line through our website - <http://dgmeffm.org.uk/donations> We appreciate any donation however small, as we need this support to carry on some of our main activities. Thank you.



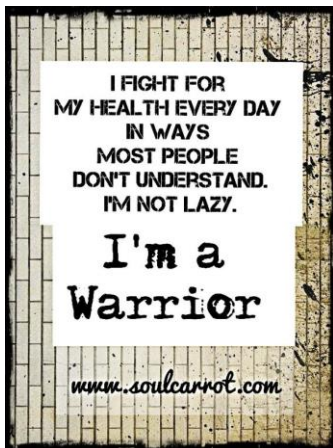
Would you like a 'pop-up' meeting with other DGMEFM Network members at a café or venue near you? If so, do you want help to arrange it? Phone: 07437 602610 or email: admin@dgmeffm.org.uk

Website Monthly Blog

In July Network member, Michelle Mungin, kindly offered to capture key elements from our Facebook community posts into blogs for our website: <http://dgmeffm.org.uk/>

If you have not joined our Facebook group, please feel free to get some updates, which Michelle will be blogging about monthly, by visiting our website. For peace of mind to members, Michelle will be making her blogs anonymous. Michelle's first blog is about her own journey

..... Fibromyalgia, a day in the life of a Warrior – A little about my past



I went to college to start my brilliant life in care when I was 16. Never once did I think my life would have fibro or any disability. After a year studying I joined a company that looked after severe mental health issues. At first I was a student then continued to become a support worker to senior support worker to deputy manager back to senior support worker. Through my working life and home life I suffered with depression. But I managed to work through. At the age of 24 I started to get a lot of pain, I ignored it and tried to carry on. 2001 was the year I got married. Between working and planning my wedding, I was under a lot of pressure. I put my back pain to the back of my mind (well tried).

Well 3 years passed and the pain in my back spread. I had got to the stage where I had to sit down after every little task. Walking was getting harder. In 2004 I was putting a mirror up at home. I stood on a foot stool, I wobbled a bit, and when I got off the foot stool I had a massive amount of pain all over. I went to the GP the next day, as I had an accident when I was a child (I fractured a vertebrae) he decided to send me for an X-ray. It turns out I have Scheuermann's disease (a disease where the bones in your spine soften and when they firm up they are misshaped leading to a curvature of the spine). I was told that I was born with it and the only time something could have been done was when I was between the ages of 10 and 14. Well at the age of 27 it was too late and I would have to live with the symptoms. Now fast forward to the age of 33, I was constantly off sick and finding it hard to do anything. When I did manage work I would cry in the bathroom as I was so tired and sore. But when I went to the GP, I was told there was nothing wrong. So I tried to continue working. It got to the stage where I needed to leave my job as I felt pressured too much, such as life.

At the age of 35, I was unemployed but a little happier. It was 2 days before Christmas and I had been at my sisters helping her sort out things for the big day. After saying goodbye to everyone, myself and my husband wondered into the dark winter's night. We had a taxi waiting, so we slowly wondered to the taxi chatting. My husband got into the taxi as I made my way around the taxi. As it was dark, I didn't see the massive pot hole and before I knew it, I had fallen to the ground. At first it was my pride that was hurt, then a massive amount of pain surged throughout my body. My hubby helped me get up and got me into the taxi. We got home and I was crying because of the pain. My husband then decided to take me to accident and emergency. I had 2 sprained ankles and wrists and bruising. As I tried to recover the pain seemed worse. I had many GP appointments to be told there was nothing wrong but they could try upping my painkillers. I became very depressed and even suicidal. I would refuse to open the curtains and sit in the dark constantly. I refused to go out with my animals, I bowed out of life. I had wide spread pain, migraines, numbness in my hands and joint pain. The one GP I did trust was off on maternity leave so with seeing other GPs they all said there was nothing wrong.

In February 2014 I had enough of avoiding GPs, so I called at 8am and got an appointment with a doctor that had retired but was doing cover. I went through my symptoms especially the numbness in my hands. At this point I couldn't hold a cup long enough to get a drink. He said "Well at this point I'm not sure what is wrong but we will do some blood tests".

Imagine my joy at hearing these words. All the tests came back normal so the GP decided I should see a neurologist, my appointment came through rather quick. It was 25th March 2014, I remember this date because I was going to my sister's last scan on her little boy. I went to my appointment and the doctor did some test, then asked me to go to X-ray. I cheekily asked if I could go to my sister's scan which I was able to attend. After my X-ray I went back to the bay to wait to be seen again and when called was told by the doctor that I had Fibromyalgia, I stopped listening at this point. After the doctor stopped talking I left and met up with my husband. I thrust a piece of paper into his hands that I assume the doctor gave me. It was a little about fibromyalgia. My husband asked "well what's happening next, have you to see the doctor again?" my answer was "nothing happens next". I went to many GPs but nothing helped. Then on my last GP appointment I was told to take 2 paracetamol and lose weight, I never went back to the GP again for 6 months.

I was in a right mess. Pain was ruling everything. My husband then found out my GP was back from maternity leave and made an appointment. At the appointment the GP was understanding and started a few different medications, some things worked, some didn't. But it didn't matter to me as for the first time in a while a GP believed in me and was willing to work with me to help me feel a little better. A few months on, one of my brother-in-laws asked if there was a support group for fibromyalgia (my brother in law has Parkinson's and thinks support groups are a big help). As I didn't think there was, he went off to google it and the next I heard was him texting with the name of this group on Facebook. I quickly made a request to join. I went to the first meeting and it was like a light had been turned on. I didn't attend any other meetings that year through one reason and another but I received support and information from the Facebook page.

Well a year on I am in a better place mentally and have found ways to get me through the bad days and I enjoy the good days. I'm on a cocktail of meds that are helping me. I'm even on a weight loss journey, the weight coming off has helped the pain as well.

Well I will close for now. I hope my story will help another warrior. Much love <3<3

Michelle Mungin



Food Train Update

The Food Train is a grocery shopping, befriending and household support service for older people in Dumfries & Galloway.

www.thefoodtrain.co.uk

Referrals can now be made for Food Train services for people aged 50 to 65 either by social work or through any NHS professional.

My take on 'The Five stages of Grief' when you have a chronic condition

I was reminded that we go through these stages, dipping in and out of them, when I met someone this week who was clearly in the 'Anger' stage.

DENIAL

Surprisingly, denial is not a stage we may get stuck on as generally people with a chronic condition have been searching for an answer to why they feel they way they do. Just knowing that it's not all in your head is actually such an important part of moving on to final acceptance.

I was a bit shocked when diagnosed, only for the fact that someone had suggested I had the condition about 15 years before. At that initial time I went and bought a book on the condition and thought, that sounds just like me. For some reason, however, I got it in my head that I didn't meet the conditions for it to be real so I put it out of my head.

ANGER

They say you should be willing to feel your anger, even though it may seem endless. Underneath anger is pain and since pain can be such a fundamental part of our life it can be understandable we have a lot of anger. When things go wrong, unexpected things happen or we don't like what we hear, having something or someone to blame gives you focus for your anger. Anger can make us act irrationally not to mention what it does for your energy levels as it zaps all your strength.

I think the only time I was really angry was when a consultant told me I didn't have a particular condition. Looking back, they were a specialist in a particular field which unfortunately meant they were not in a position to consider the 'bigger picture' which I think is personally important for us. I wasn't really angry at the consultant, I was angry because I didn't know what to do next.

BARGAINING

Wouldn't you just give anything not to feel like this? "What if", "Can I try"?"

Why do many of us cling to the belief that there is a quick fix available for our condition when if this were true don't you think our GPs would offer it? I am sorry but I don't believe GPs knowingly keep treatments from us. I appreciate there are costs and testing that's needs to be completed. I know in our desperation being a guinea pig sounds like a plan. But let's think about this, when the 'miracle' cure doesn't work what do we do? We go straight back to 'Angry' mode blaming everyone and anyone for not having a cure or not spending enough money or time to find one.

DEPRESSION

Grief comes from loss. For us this is the loss of the life we no longer have. We long to have our old life back which in turn can lead to depression. Many treatments for chronic pain include low dosage antidepressants, taking them does not mean you have a mental illness.

At some point after diagnosis, in our cycle of grief, we stop looking for a cure and begin to advocate being "as well as possible" - for as long as possible. It stops being about delaying life until we are cured, but enjoying the moment.

Lisa Copen

RestMinistries.com

If grief is a process of healing, then depression is one of the many necessary steps along the way. For me I tend to slip into depression when something I try to improve my condition doesn't work. It's not a state you can just snap out of.

ACCEPTANCE

Acceptance could for us be confused with the notion of being "all right" or "OK" with our condition. I don't think this is the case. I do think it is about accepting that your old life is gone and that something different is ok.

Alexander Graham Bell made the famous quote; "When one door closes another opens". This quote may seem overly optimistic; but, there are many scientists and entrepreneurs that originally failed in their endeavors only to learn from their mistakes and move forward.

For me, I have not come to acceptance as a reason to quit, rather the cross roads to look for new opportunities either to do things differently or to try something new.

About me:

Believe it or not I am quite a private person when it comes to my illness, but I did decide to start a blog in February to record my journey; both treatments tried and my progress currently. Let's be realistic, there's no quick fix, but if you are interested, feel free to read some of my other blogs;

<https://fibromyalgiajourneyblog.wordpress.com/2016/02/>

By: Network member

Would you like to join our Committee?

We would welcome more help. If you would like to put your name forward to join the new Committee, please get in touch with Craig or Kim before our AGM.

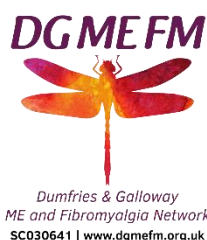
Would you like to write and tell other members about your experience of living with ME, CFS or Fibromyalgia?

What has made it worse and what has helped?

If you are willing to contribute to a future newsletter please contact admin@dgmeffm.org.uk

It helps us all to know that we are not alone.

Notice of
AGM
Thursday 6th October
Midsteep, Dumfries
1 – 3pm



Dumfries & Galloway ME and Fibromyalgia Network (DGMEFM Network)

Phone: 07437 602610

Website: www.dgmeffm.org.uk

Facebook: facebook.com/groups/dgmeffm

Email: craig@dgmeffm.org.uk (Chair)

kim@dgmeffm.org.uk (Secretary)

paul@dgmeffm.org.uk (Treasurer)