DGMEFM Network

Support for ME, CFS, Fibromyalgia

Autumn 2018

Welcome all,
The summer is well and truly behind us now. The days are shortening, the leaves are turning and we feel the chill in the air. It also brings the time of year that we ask for your help on two counts. Could you attend our AGM which will be a brief part of our October Midsteeple meeting? And, if you feel able, would you consider contributing towards the running costs of the Network?

We were very pleased to be asked to help inform Nithsdale PDT of the effects of fibromyalgia. A panel of volunteers did a brilliant job in conveying the challenges that the illness brings – helped by the recent publicity from Lady Gaga and Kirsty Young. We are now in some fine company! We’ve had an MSP request a meeting with us and we have also been asked to share information from D&G’s Home Energy Assistance Scheme. It seems that our effort at promoting ME and fibromyalgia during the May Awareness week is getting us noticed and moving us up the agenda.

It’s with great sadness that we share the news of the passing of Sir Alex Fergusson, our former patron, and a man who has done a lot for our Network and for the cause of ME in Scotland.

Craig Woods

Monthly Get-Togethers

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

October 4th This will include our **AGM.** Please come and join in discussion about the way ahead for the Network in the coming year.
November 1st Our usual social get-together.
December 6th This month our guest speaker is Dr Emily Kennedy. Emily is a member of the Dumfries & Galloway Health Board Prescribing Support Team, and runs occasional free courses on Mindfulness for Pain. Come along and hear about how Mindfulness may help you cope with your symptoms.
January 3rd A relaxed get-together to unwind after the Christmas holidays.

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

November 27th Tuesday 2:30pm – 4pm. Get inside and out of the cold and have an afternoon cuppa with us at **Just Be**, on **Lockerbie** High Street.
December 9th Sunday 1pm - 3pm. Join us for lunch from the Xmas menu at **Castle Douglas Garden Centre Coffee Shop**. The Centre is on the edge of town heading out on the Dalbeattie road. We will have tables in the corner area far left from the servery (looking towards the garden area).
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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A Tribute to Sir Alex Fergusson

Denis and I were shocked and saddened when Craig contacted us to say that Sir Alex Fergusson had passed away. He had been such a good friend to the Network and sufferers of ME. Our sympathy goes out to his wife Merryn and his three sons.

A new Scottish parliament was formed in 1999. While the permanent building at Holyrood was being constructed, a temporary home for the Parliament was found in Edinburgh. The General Assembly Hall of the Church of Scotland on the Royal Mile was to host the parliament. It was here that the X-Party group on ME was formed, and meetings were held monthly. Denis first met Alex in 2000 at one of these meetings.

On Wednesday 23rd January 2002 Alex secured a slot for his motion 'Research into M.E' to be debated in the Scottish Parliament. He spoke extremely well in support of ME sufferers which included his son Christopher who was only 11 years old at the time. He had first-hand knowledge of the illness.

At one point during his speech, the public gallery erupted with applause whereupon everyone had 'their hands slapped' because the public are not allowed to be heard in any way whatsoever.

After that a security officer was placed in the public gallery to stop any further outbreaks.

In 2004 when the Lockerbie ME Conference was held, Alex was of great support and one of our prominent speakers.

During ME Awareness weeks at the Scottish parliament, events for ME would be staged, Alex was always there to lend his support

In 2006 he became patron of our Support Group he wrote this letter to the D & G ME Network,

"I can only start by thanking the group for doing me the signal honour of appointing me as your Patron. Although I was assured that this position would not cause any increase in my workload, I trust that members of the group will not hesitate to contact me if they feel I can do something – anything – different to highlight the issues which so affect…..

*………these diseases are not going to go away just because 'the system' ignores them. They are on the increase, as we all know, and the day is surely dawning when that **has** to be recognised within the mainstream NHS and by the Medical Research Council. Then we will have achieved the significant step forward that we continue to work towards. Keep up the good work."*

He would often take time out of his busy schedule to visit some of our local meetings. Sharing a cuppa, talking to members and being generally supportive.

Alex would often be asked to do an interview especially with MORI - he would only do it if they would pay a donation to the group, so we would often get cheques in the post from them, this was greatly appreciated.

Sir Alex announced his retirement from politics in 2016. He was then knighted in the 2016 Birthday Honours list for services to politics, the Scottish parliamentary process and public life in Scotland.

He was a hardworking true gentleman, kind and thoughtful, fair in his assessments and enjoyed a little banter with his opponents. He will be sorely missed by all that knew him.

Norma Turner

Mindfulness and chronic pain

Our guest at the monthly Midsteeple get-together on December 6th will be Prescribing Support Pharmacist Dr Emily Kennedy. Together with Nithsdale Public Health Practitioner Tina Gibson, she ran a free Mindfulness Course last Spring using the book 'Mindfulness for health' by Vidyamala Burch and Danny Penman (for which there was a small charge).
The mindfulness course had a special focus on chronic pain and offered approaches aimed at helping people manage this pain, and get the most out of their lives.

Dr Kennedy says: “Part of mindfulness is meditating, to really help people to understand their own thought patterns and feelings – becoming more aware of them but not occupied by them, and better able to manage them. The majority of people who take part in the mindfulness course report lasting physical and psychological benefits.”

Work

I gave up. I’ve never not worked so when I suffered a fibro flare up I was off work for about four months. Always had intended to go back to work but after trying a phased return it was clear I couldn’t manage it. So I took the decision to leave and rest up for a bit without the stress of being on the sick and trying to get back to work. You would think great I can relax and start to get back on my feet, not that easy. I changed the stress of getting back to work to feeling guilty for not earning. I constantly thought I should be doing something, hubby is out working all day and I’m not doing anything. Note to self: You have an illness. You’re not working for a reason. If you could you would. It’s ok to rest when you need to. You’re not a bad person. Be kind to yourself.

Lesley

Bras

One of the recent discussions on the DGMEFM Facebook page was about bras and the trouble our female fibromyalgia members have finding something which isn’t painful. Underwired bras were found by everyone who commented to make it feel as if the ribs were bruised. Sports bras, without the wire, were found to compress too much and could be even more painful because of it. Properly sized and fitted, Marks and Spencer’s Sumptuously Soft T-shirt bra was found by a couple of our members to be the best option.

This was a great example of Network members helping one another - quite literally a support group.

To do or not to do...that is the question

There is, quite rightly, much concern over graded exercise as a ‘treatment’ for ME. Hopefully it is being consigned to the medical bin imminently. However, I recently met a situation that called for me to really evaluate just what I could and should be doing in the way of gentle exercise, and I am really happy to report that more has proved to be possible than I at first thought.

I have on going neck and shoulder pain and mobility issues. Not an ME thing.....more to do with being slam dunked off a less than cooperative horse many years ago. I ended up at my local physiotherapy department a few months ago and they ‘prescribed’ daily yoga, via a free app called Down Dog.

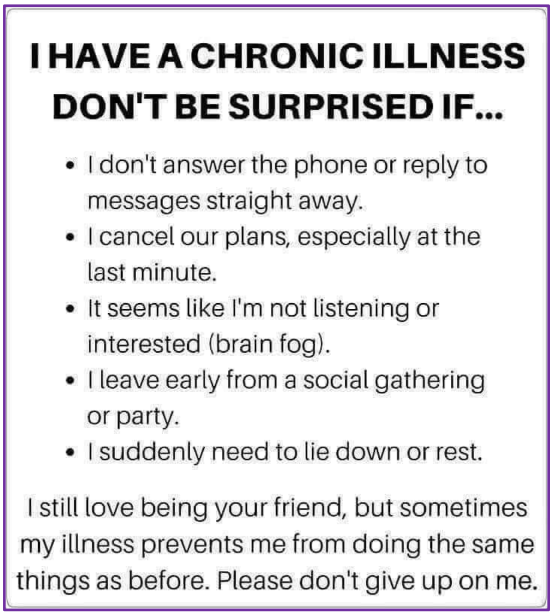
My immediate thought was, I can't, and it would be unwise to even try. The physio assured me it was very gentle etc, etc, but I was secretly thinking, ah, but you don’t have ME you don’t understand.

However, I thought about it for a couple of days and decided I would give it a very careful and cautious go, with my eyes wide open to any negative effects. The app has two 12 minute introduction routines then onto the first 20 minute session, which you should be onto by day 3. Well! That wasn’t going to work for a start. I’m now 3 months in, and still on day 3, and only do the first 12 minutes of the 20! It took me a couple of weeks to get to the end of day 1. My day 1 made me feel dizzy, sick and done in, and I only did half of the 12 minutes. I panicked, but kept going the next day, and the next. A week later, I was beginning to feel less sick and dizzy, and was actually beginning to enjoy the process, still just doing 6 minutes.

I’m now on day 3, as I said. Cheating throughout, making up my own easier versions of some of the positions, but really enjoying doing it badly! My neck and shoulders have definitely benefited, and I am really enjoying getting back a fraction of that feeling I used to get from fittening my body. And I now have pink lycra leggings and a neon green mat. What’s not to love?!So, this process has taught me something about my ME. Caution and pacing are crucial, but don’t be afraid to sometimes give it a go. Maybe you are capable of a tiny bit more than you thought.

Contributed by a Network Member

For ME and CFS, especially, it is very important to avoid exertion which puts your body into aerobic or anaerobic states. It’s this state which seems to cause the worst of the post exertional malaise (PEM) and can cause damaging relapses. Using a Fitbit type fitness tracker to monitor your heart rate to ensure it doesn’t go too high can help you pace and reduce the risk that exertion could cause a relapse. *Craig*



I HAVE A CHRONIC ILLNESS DON'T BE SURPRISED IF...

- I don't answer the phone or reply to messages straight away.
- I cancel our plans, especially at the last minute.
- It seems like I'm not listening or interested (brain fog).
- I leave early from a social gathering or party.
- I suddenly need to lie down or rest.

I still love being your friend, but sometimes my illness prevents me from doing the same things as before. Please don't give up on me.

My Journey

This morning I went to the doctor. He had a medical student in who is an ENP (Emergency Nurse Practitioner) and he was giving him a brief outline of my conditions and telling him how well I'm dealing with them. We got onto the subject of how I have attended a pain management course and asked how useful I had found it. He seemed genuinely interested and my doctor had commented on how I would make a great counsellor for people who suffer with chronic pain conditions.

So that set me thinking what I have learned from my journey so far… Living with pain is hard. It doesn't just affect our bodies but it affects how we think as well. People think that going to a Pain Management course is a complete waste of time because "How can talking help the pain!!"

Sometimes helping cope with our conditions isn't just about how many drugs we can get the doctors to give us. It's about learning to look at it from a different way of thinking and changing our mindset. In the first few years we are diagnosed we go through what I call "The Mourning Stages". We are initially shocked and upset, then we get angry. Then we move on to the why me phase and from there we start comparing this new life we are going to lead to our old life. We start hating the world because we can no longer do what we once did and there's nothing wrong with that but we fail to see what's in front of us. Yes, our lives have changed and not necessarily for the better but we fail to see what's around us.

I have learned to start appreciating who and what I have in my life. E.g. I have an amazing husband who has stood by my side through the good and the ugly, the best little boy anyone could ever ask for, family who for the most part are supportive and I have a small handful of wonderful friends who are there for me no matter what.

They have all come to understand that I have limits and can't always do things that they want me to do and that I also have days where we have made plans but they have had to change because I'm in a flare up or simply can't get out of the house but the important thing is they understand. The friends who I thought were there for me have long since gone and it has really opened my eyes as to what a friend really is.

I celebrate the days I can do things and take the days where I can't as they come, which are more often than not these days. I've learned to pace myself as much as I can and not to overdo things on the good days. I'm getting to spend much more time with my family rather than killing myself trying to get out to provide a wage for my family but that also doesn't mean I don't want to go back to work one day. It just means that right now I can't and I'm appreciating watching my boy grow and being able to provide him with life skills and appreciate what my husband does for us even though he is struggling to work as well. Living with a condition isn't all about being miserable and self-loathing. It's about finding who the new you is with a pinch of the old you. We will always have our bad days but learn from them and don't beat yourself up. We are going through enough without having to be so harsh on ourselves as well. There's no reason to stop living our lives to the fullest but just in a new way and within the limits of our body. The only person that is stopping you from doing that is you.

I hope that this will help some of you think about things in a different way and help you live a better life alongside what we battle on a daily basis.

Kristy Wilson, Network member, founder of UK Fibro Fighters group.

Report on Nithsdale Development Day

The Network was asked to give a presentation on fibromyalgia for health development in Nithsdale. While being asked to do it I was told that they are seeing a lot more people going through the services with fibromyalgia these days and they don't have any training and really don't know how to handle us.
As chance would have it, the weekend before we were due to give the presentation Kirsty Young announced a sabbatical from Desert Island Discs due to her fibromyalgia. This probably led to the release by the BBC of a very useful 8 minute long video which cover how fibromyalgia affects several people. It was very well done and perfect for opening the presentation. You can find it by searching for 'fibromyalgia' on BBC.com.

Thereafter I gave a brief overview of the Network, what we do, and some results from our survey. The main part of our hour however was taken up by 3 brave fibro-suffering members of ours who I'd asked along to tell their story and to answer questions from the many disciplines there. The four of us sat in front of a large, u-shaped table at which was sat around 18 representatives from physiotherapy, psychological support services, Care Scotland, Community Nursing and more.

Nancy, Carol and Samantha, who is new to the Network and we rather threw in at the deep end, did a great job of explaining how fibro affects them – showing just how different it can be for each of them. They spoke movingly and informatively of their lives before fibro, how it came on, their symptoms, their treatment by the NHS, what they do to help themselves and the adjustments they've had to make. They gave a very useful insight with some suggestions for how care can be improved. The questions asked of us were informed. The most interesting was from one of the attendees whose mother suffers from fibro. She asked if any of our members had benefitted from Sativex, which is a prescription cannabis medication. We pointed out that for the most part it's difficult to get doctors to try anything different. Most of all Nancy, Carol and Samantha gave a new understanding of the illness to the people attending and I'm sure the next time the attendees care for a fibromyalgia sufferer in Nithsdale there will be an improvement.

Famous people with fibro and how it raises awareness

A new awareness and, perhaps a new respect too, were given to people with fibromyalgia with the coverage surrounding the news that Kirsty Young, a well-respected news reader and presenter announced that fibromyalgia was the reason she was taking a break from Radio 4's Desert Island Discs. The coverage was very sympathetic towards her and it was informative, giving an overview of the illness and its symptoms.

Also this year we got the news that Lady Gaga was halting her tour and getting hospital treatment due to the pain caused by her fibromyalgia. She revealed around this time last year the cause of her chronic pain in a documentary which you can see on Netflix, entitled Gaga: Five Foot Two. The news of her fibromyalgia reached a very different audience from the coverage of Kirsty Young's fibro.

The coverage these two high-profile, and widely admired women bring should help awareness, understanding and are already helping to raise the news agenda for an illness which is too often difficult to understand and invisible to the general public.

Newton Stewart Hospital Community-Based Course

From a news item by Dumfries and Galloway What's Going On, July 2018:
A successful, innovative approach to addressing long-term and chronic health problems and how we can better self-manage these is being driven forward in Wigtownshire. The Community Link Unit which has been established at Newton Stewart Hospital is focused on those people who have a chronic, long-term condition and is aimed at helping to maintain or even improve their health. Community Link Unit Co-ordinator Michelle McAuley said: "We're really pleased with how this work has been going, and we're definitely seeing results. What is being offered through the unit is a 12-week course, open to anyone with chronic, long-term conditions including stroke, chronic obstructive airways disease, Parkinson's disease, fibromyalgia and many other long-term or chronic conditions. The course takes a 'head-to-toe' approach, looking at everything from psychology to podiatry services which can help to reduce the impact of a chronic condition on physical and mental health – as well as social health and wellbeing."

Explaining what features as part of the course, Michelle added: "We run a staff-led exercise class which includes fall-prevention exercise as well as Tai Chi and also chair-based exercise. In addition to this we also provide information sessions which feature guest presenters from the fields of health, social care, private companies, community groups and charity organisations. This not only allows those people on the course to find out about what sort of additional support is available – it also provides a means for them to help shape what is being offered. Referrals to the service can come from any health and social care team, the third sector, and patients can also self-refer. We offer this service to all adults in our region."

This course was news to us and we'd be pleased to share feedback about it. Has anyone in Wigtownshire been referred to it by their GP, specialist or other practitioner? If so, what did you think of it, and does it address the physical symptoms and pain in fibromyalgia and ME or is it more psychological in its approach? Please let us know on facebook, by email or by whatsapp/mobile.

D&G Home Energy Assistance Scheme

Colin Holden, Project Officer with Dumfries & Galloway Home Energy Assistance Scheme has asked us to share details of a new service with you. A home visit is open to anyone who spends more than 10% of their income after rent/mortgage costs on heating their home. The officer can identify energy-saving home improvements with funding available for insulation and draught proofing, LED lighting and heating upgrades. They can give information on other funded schemes, general energy advice and help with filling out forms and switching supplier. The advice is not determined by whether you are in receipt of benefits, so could be of help to those who haven't managed to succeed in a disability claim.

For more info contact Colin Holden on 01387 269161 ext 214 or colinholden@energyagency.org.uk

As we go to press

As we go to press the awful news has come to us of the discovery of the body of Dr George Porteous (known as Alex) in woodland near Beeswing. The police say there aren't suspicious circumstances. He had been missing for over a week, not arriving home to his family in the evening after his day's work at Lockerbie Medical Practice. He is a doctor I've attended many times over the years. He was hard-working, caring and he is well liked in Lockerbie. Everyone who knew him is very shocked and upset to hear of his passing.

While it is wrong to speculate as to the cause of his death it may have been influenced by the pressure a doctor is undeniably under. Like many practices locally Lockerbie practice is short-staffed and it has become increasingly difficult to get an appointment. It must put a great strain on the GPs who are struggling to cope with demand and feel pressure to work ever longer hours.

ME and Fibromyalgia is something that the doctors who try to treat it get frustrated with. They know there's no easy fix, and a doctor can feel helpless. I feel sympathy for those doctors who eschew their limited teachings (basically CBT, GET and anti-depressants) and are kind, caring and keen to help in an illness that science is still struggling to fathom out. They are limited by what the NHS allows them to do.

Being in a respected profession and being someone that people turn to for help Doctors may feel less able to share their troubles, their stresses, strains and worries with other people.

With ME and fibromyalgia too, we may find it difficult to share – perhaps because we feel that family and friends do not understand what we go through with these illnesses on a daily basis. One of the reasons this Network is here is to make speaking to people in similar circumstances a lot easier. When things are getting too much for you then please feel able to contact us. That could be on the Facebook page where whatever you write will only be visible to other page members. It could be in a private message to one of our committee members, or you could leave a message on the Network's mobile/whatsapp number and someone will get back to you. No one is going to judge you for it. We all have our bad spells and darker times. With our health problems and the compromises the illness forces upon us it is only natural.

Please don't bottle things up. Reach out.

Our thoughts go out to the family, friends and colleagues of Dr Porteous.

Brain On Fire: Widespread Neuroinflammation found in ME/CFS

From An article on Health Rising by Cort Johnson, September 2018:

It's only recently that the technology has been able to pick up the lower levels of neuro-inflammation believed present in diseases like ME/CFS and fibromyalgia. Researchers have long believed that inflammation produces central fatigue (fatigue emanating from the brain), which plays a major role in ME/CFS. A big breakthrough came in 2014 when a Japanese startled just about everyone with a PET scan study which found widespread neuroinflammation in the brains of ME/CFS patients.

The neuroinflammation was widespread but was highest in the areas of the brain (thalamus, amygdala, midbrain, hippocampus) that had shown up in ME/CFS before. Plus, the Japanese were able to link specific regions of inflammation to specific symptoms. Inflammation in the thalamus was associated with cognitive impairment, fatigue and pain; inflammation in the amygdala was associated with cognitive issues; and inflammation of the hippocampus was associated with depression.

Jarred Younger – who runs the Neuroinflammation, Pain and Fatigue Lab at the University of Alabama at Birmingham has also long believed that neuroinflammation plays a major role in chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM).
The microglia immune cells are sensitive to so many factors and can be triggered in so many ways that virtually any stressor, from an infection to toxins to psychological stress, can potentially trigger a state of microglial sensitization in the right individual. With their ability to produce dozens of different inflammatory mediators, Younger believes that the difference between ME/CFS and FM could simply come down to small differences in how the microglia are tweaked.

The cingulate cortex – which Younger called the "seat of suffering" was particularly inflamed.

Younger found lactate – a product of anaerobic metabolism – widely distributed across the brains of people with ME/CFS. The fact that the temperature increases overlapped with the lactate increases provided further confidence that Younger had identified some key areas.
The interior cingulate cortex, in particular, which Younger called "the seat of suffering" in the brain, showed up in spades. It's associated with a lot of nasty symptoms (malaise, fatigue and pain) and it's shown up in both ME/CFS and fibromyalgia studies in the past. The high choline signal in that region of the brain suggested that inflammation there was producing a pattern of destruction and replacement; i.e. quite a bit of damage – even possibly neuronal damage – was happening there. Overall, the lactate levels weren't as high as in other diseases – they were just consistently present. Younger didn't expect to see really high levels; really high lactate levels would have meant irretrievably damaged neurons – the kind of neuronal damage seen in M.S., Parkinson's and Alzheimer's – the kind of neuronal damage that is really hard to reverse. The fact that Younger saw inflammation in ME/CFS but not neuron-destroying inflammation is good news indeed for people with ME/CFS.

Younger's new approach looked at the entire brain and found signs of inflammation almost everywhere. When asked what could cause that, Younger said that any neurodegenerative/ neuroinflammatory disorder like MS or a severe brain injury that tweaks the microglia (immune cells in the brain) enough to produce a sustained period of inflammation, burns up the oxygen in the system. Once that happens, the cells resort to anaerobic metabolism and lactate builds up just as it does in the muscles during exercise.

Documenting that neuroinflammation is present and is affecting functioning in ME/CFS could have dramatic treatment implications. It could lead the scientific and medical communities to focus less on drugs that target the nervous system and more on ways to reduce inflammation. For example, attempts could be made to modify current anti-inflammatories so that they pass through the blood brain barrier (most do not).

Reminder of Annual General Meeting (AGM)
Thursday 4th October 2018, Midsteeple, Dumfries 1pm to 3pm

Please come and join in discussion about the way ahead for the Network in the coming year. Annual reports from Chair and Treasurer, and election of a new Committee. Craig and Paul are willing to stand again as Chair and Treasurer, but we are looking for a new Secretary.

AGM
Thursday 4th October
Midsteeple, Dumfries
1 – 3pm

If you may be interested in joining the Committee, please let us know in advance of the AGM if you can, either by speaking with a current Committee Member or by email to admin@dgmefm.org.uk
We'll be happy to talk with you about what it can entail and how we don't put ourselves under pressure to do any more than we can within our limitations.

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

We are grateful to all who are able to make a donation towards our costs. A Gift Day form and return envelope are enclosed with this newsletter. The form describes the various ways you can donate and even if it's just a small amount……….'many a mickle makes a muckle'. Please remember to affix a postage stamp if you use the return envelope. 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.