

May 2019

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome all,

Another Awareness Day is almost upon us. The need for it is as great as ever, sadly. Shockingly this was brought home to me at one of our own meetings when one of the guest speakers that had been invited, looked up our illnesses and told us what he'd read, rather than talking about his own subject. It was straight from the Wesseley school of thought and included a slide "sofa to 5km in 5 weeks". I wasn't the only one who was angered and we tried our best to alter his ideas, but while the flawed PACE Trial is allowed to stand it is an uphill battle – and for fibromyalgia there is even less research to refer to.

We have many heroes such as Carol Monaghan MP, the volunteers with Millions Missing, David Tuller (the health journalist), Dr Charles Shepherd of the ME Association all fighting hard to increase knowledge and fight bad science and misconceptions. But we need to do our bit too. Please use May 12th to tell your friends and family how the illness affects you, distribute our leaflets, share the memes and links we'll be posting to facebook and wear your blue (for ME) or purple ribbons (for fibromyalgia) with pride – you can pick some up from our May meeting

Craig Woods

Monthly Get-Togethers

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



May 2nd The Midsteeple isn't available on this date so we will hold our usual social get-together upstairs at The Stove, 100 High St, Dumfries DG1 2BJ

June 6th Our guest from 1.30pm will be NHS Dumfries & Galloway Service Development Pharmacist, Catherine Smith.

July 4th With guest Claire Irving, Reflexology Practitioner, and a particular focus on patients with Fibromyalgia.

August 1st A social get-together themed around how you are able to enjoy yourself whilst coping with ME/Fibromyalgia. E.g. hobbies, pastimes, crafts etc – feel free to bring along a 'show and tell'.

Refreshments will be provided at the Midsteeple meetings. 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.

Due to uncertainty around the future availability of the Midsteeple room, please check our website for any future change of venue.

Pop-Up Meetings

June 23rd 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.

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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Chronic Medication Pharmacy Service

6th June 2019 Monthly Meeting with Community Pharmacy.

Our guest at the June meeting is NHS Dumfries & Galloway Service Development Pharmacist, Catherine Smith. Find out about community pharmacy services available to help support you. Although this monthly meeting will start as usual at 1pm, the talk with Catherine, who will be accompanied by a Community Pharmacy Champion will start at 1.30pm. If you are unable to attend, please feel free to e-mail any questions you have in advance to admin@dgmegm.org.uk

Members' cautionary tales:

After many years (over 8) of unexplained symptoms I was finally diagnosed with fibromyalgia in 2014. While I was already at the door ready to leave, the Rheumatologist asked me to wait as he had decided to listen to my chest. This was a first in many years as no doctor ever had given me a full physical. He asked me how long I have had the heart murmur.... I was unaware of any heart murmur and didn't think anything of it. To be safe he referred me to a Cardiologist. Little did I know that this last-minute Stethoscope exam would save my life years later. After a consultation months later with the Cardiologist I was diagnosed with heart Valve disease, possibly due to Rheumatic fever in the past. Again, I was unaware of ever having had Rheumatic fever. He assured me that surgery would be about 20 years off. I was 38 years old at the time and wasn't overly worried. Months went by and my Fibromyalgia got worse and worse. I found myself bed bound for 6 months, weak, breathless, I couldn't sleep on my back, pain....

The next Echocardiogram 15 months later showed a slight deterioration which meant I would probably need surgery in about 10 years. Having my own dog walking business (Doonhamer Dogs) meant that slowing down wasn't really an option and work became unmanageable at times. Several visits to the doctor about my breathing problems got dismissed even though they confirmed that I didn't have asthma after all and just assumed it was one of my Fibro Symptoms without any physical examination! Time passed and the fatigue, brain fog, pain, muscle weakness and other symptoms were getting worse. I eventually gave up going to the doctors as I kept getting fobbed off even after I changed surgery. Having an existing condition seems to be the answer to all further complaints. At the next Echo another year later my heart valves had deteriorated further and only then did I wonder if some of my symptoms were connected. When I mentioned a whole catalogue of FIBRO SYMPTOMS I was told that I was now symptomatic and surgery was the next step! 5 months later I found myself in Glasgow undergoing a double heart valve replacement via open heart surgery. As my body was so weakened from being ill for years, my recovery was and is slow and was marked by step backs. If I had waited another 6 months I would have died at the age of 42!!! This week marks my first anniversary and only now can I see how sick I was and how many symptoms were in fact my heart.



Fibromyalgia is still a big part, but I feel stronger, have more energy, can breathe and even the pain has improved greatly. Thanks to my wonderful husband, my friends and customers, I have been able to increase my working hours slowly. The days I had to stop every few meters and could only walk with another person present, the love of the dogs gave me comfort and a much needed boost.



Being able to sit in the sunshine while the dogs were happily playing and enjoying life showed me how lucky I was to be alive. The mental impact of having had open heart surgery, having my heart stopped for 7 hours and everything that came with it only hit me months later and I ended up with severe depression, anger and anxiety. It has been a rough ride, but while the surgery has left me with several new issues, I am alive thanks to pushing to see a Rheumatologist and being lucky enough that this doctor took me seriously. I have since joined a charity to raise awareness of heart valve disease. 80% of patients under 65 never get a Stethoscope exam at the doctors and undetected heart valve disease is one of the biggest killers in the UK.

I have now started pushing for further tests in regards to other Fibro Symptoms and have been diagnosed with other conditions which can be managed to a certain degree. Most of us just accept what we get told by the doctors and suffer in silence. DON'T! Listening to your body, asking questions, pushing for answers and questioning worsening or new symptoms can save your life! It did mine.

Tina Duncan

Beware Dental Anaesthetic! (or any anaesthetic for that matter.)

This may be something everyone but me knew about, but I found out the hard way! DONT LET YOUR DENTIST USE ANAESTHETIC WITH ADRENALINE IN IT. i.e. the normal stuff.

I went for the first of a series of appointments for root canal treatment a while ago, and had a vague memory of something about anaesthetic and M.E., but thought I'd just 'wing it,' and all would be well. All wasn't well! About 10 minutes in, my legs started to shake, and I began to feel very other worldly.....a feeling that lasted over a week.



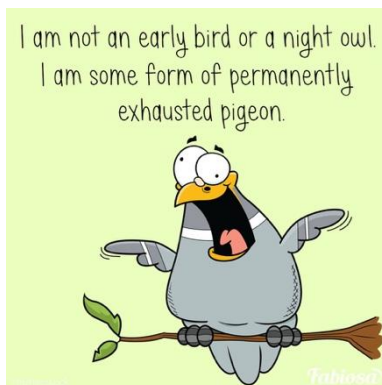
Thanks to the network's brilliant Facebook group, I discovered winging it was the wrong thing to do. I was to request adrenaline-free anaesthetic next time....which was in two weeks time. I assumed this request would cause all sorts of raised eyebrows and disbelief in the dental surgery, but far from it. Absolutely no problem, they had loads of the stuff, all you have to do is ask etc, etc. (This was Annan Dental Practice.)

So all subsequent work has been done using adrenalin free injections. And I can confirm a.) The stuff works just as well as the stuff with adrenaline, and b.) It doesn't mess with your M.E.

This all applies to hospital surgery and anaesthesia too, of course. And the moral of the story is, tell them you have M.E., and BEFORE they anaesthetise you.

A Network member

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



Unrefreshing sleep and permanent exhaustion is one of the most frustrating symptoms of ME and fibromyalgia. Some of us sleep a lot, some struggle to get any length of sleep at all. Some are awake and better in the mornings, whereas a majority, like myself seem to get the best of their sleep around then. If anyone comments on my late rising in the mornings I will say “the early worm gets caught by the bird”. It may cover it with a joke, but it is something I feel embarrassed about – I’ve learned over the years however to use my abilities when I can, and that forcing myself into regular hours only makes the fatigue worse.

Craig

Information and Programme provided by Pain Association Scotland

An Introduction to the Monthly Groups

For over 30 years, the Association has been providing self-management groups for people living with chronic pain.

Over that time, people participating in the groups have confirmed that living with persistent pain impacts on their lives. It affects both their health and well-being as well as relationships with family, friends and work colleagues.

People report experiencing isolation, stress, depression, poor mobility, lowered self-esteem, fatigue and an increased use of medication.

The groups provide support and an opportunity to develop the skills in self- management that can help you address some of these problems.

Why Self-Management?

Self-management is an important approach to health that explores the things that you can do to improve the quality of your life despite living with a painful condition.

It is not a replacement for medicine and it does not necessarily provide direct pain relief. What it does do for many people, however, is to help them cope better with their pain.

How do Groups Help?

The groups are professionally led and focus on helping you to improve the quality of your life. The groups do not provide a cure for your pain, but they can offer a positive way forward for people who are ready and willing to engage with the monthly topics.

The ‘open door’ style means that you only attend the groups when it is convenient or where the topic of the month appears relevant to you. You are free to attend as many or as few groups across the year as you wish.

Most people find participating in the groups on a regular basis a great source of support, regardless of the topic being explored.

Who are the Groups Designed for?

The groups are designed for anyone who has chronic pain, whether or not they have a diagnosis. They are particularly helpful for those who are ready to consider non-medical approaches to improving their quality of life. Carers and partners are also welcome.

It is understood that people living with pain find it difficult to sit for long periods. Participants are encouraged to get up and move about when they need to. Also there is a coffee break half way through each session. A cushion may help you to feel more comfortable.

Useful Links

This short video was made for professionals referring patients to Pain Association Scotland in Dumfries & Galloway. It gives a good introduction to the Association from the perspective of Susan, who lives with chronic pain and has benefited from attending the courses and groups. Phil, the Lead Trainer, explains what to expect from the groups and courses. The video is available on YouTube at: https://youtu.be/sr_PkT5Y00A

A fast-moving film from Australia but it gets across a lot of important points, including the difference between acute and chronic pain; the impact chronic pain can have on your life and some ways to understand and manage your experience of pain. The video is available on YouTube at: <https://youtu.be/RWMKucuejls>

This is the website of the British Pain Society: <https://www.britishpainsociety.org/people-with-pain/> It lists links to a lot of useful information about pain including available support, publications relevant to people living with pain, a reading list, useful addresses and “Patients Voices Video Resources”.

Frequently Asked Questions

Can I speak to the medical team again?

Attending a group should complement any medical help you are receiving. However, participating in a group has resulted in many people doing a lot more for themselves and being less reliant on medical services. They also feedback that having a better understanding of pain makes it easier for them when speaking with healthcare professionals.

What benefit will I get from attending a group?

Self-management is not a cure. However, it can make a big difference. Benefits vary from person to person. They also vary according to the extent to which people engage with the group.

Over the years, the benefits reported include:

- Being able to cope better.
- A growing sense of being in control rather than having pain influencing what they can and can't do.
- Better able to adjust the pace of their work and activities to avoid over doing things (having flare-ups).
- Reducing stress levels and better able to relax.
- Getting back to work / staying at work.
- Improved relationships with friends and family.
- Improved self-esteem and confidence.
- Fewer flare-ups that pass quicker.

The team

The groups are led by a Training Officer who has training and experience in teaching self-management for chronic pain. They ensure that there is a safe, supportive and friendly environment. Although everyone is encouraged to participate, there is no pressure to say or do anything if you prefer not to. You will not be asked about your medical condition.

What do I do now?

Just come along to the next group meeting. There is no need to make an appointment and there is no cost involved. You can bring a family member or friend with you for support.

Upcoming meetings are as follows:

Mitchell Room, Holiday Inn, Bankend Road, Dumfries, DG1 4ZF			Stranraer Library, 2-10 North Strand Street, Stranraer, DG9 7LD		
Date	Topic	Time	Date	Topic	Time
Friday 12/7	Improving Sleep	10.30 - 12.30pm	Wednesday 10/7	Improving Sleep	11.00 - 1pm
Friday 16/8	Emotional Intelligence	10.30 - 12.30pm	Wednesday 14/8	Emotional Intelligence	11.00 - 1pm
Friday 20/9	Anxiety & Racing Minds	10.30 - 12.30pm	Wednesday 11/9	Anxiety & Racing Minds	11.00 - 1pm
Friday 11/10	Communications	10.30 - 12.30pm	Wednesday 16/10	Communications	11.15 - 12.45pm
Friday 15/11	Acceptance	10.30 - 12.30pm	Wednesday 13/11	Acceptance	11.00 - 1pm
Friday 20/12	Flare Ups	10.30 - 12.30pm	Tuesday 17/12	Flare Ups	11.00 - 1pm

If you have any questions or concerns, please do not hesitate to get in touch by...

- Telephone on 0800 783 6059 (Freephone)
- Email: info@painassociation.com
- Twitter: [@painassocscot](https://twitter.com/painassocscot)
- www.chronicpaininfo.org

A member of the Pain Association team will be guest speaker at our monthly get-together on 5th September.

ME and Fibromyalgia Awareness Day

Most of us are familiar with Florence Nightingale as an English social reformer and the founder of modern nursing. However, it is perhaps less well known that May the 12th was chosen as International ME Awareness Day because it was her birthday.

Tom Hennessy, the founder of RESCIND (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases) chose May the 12th as the International Awareness Day for the spectrum of illnesses he called Chronic Immunological and Neurological Diseases (CIND) because it coincided with the birth date of Florence Nightingale. Nightingale became chronically ill in her mid-thirties with a ME/CFS-like illness (probably a particularly extreme form of brucellosis) and was often bedridden for the last 50 years of her life.

Hennessy included ME/CFS, Fibromyalgia, Multiple Chemical Sensitivity and Gulf War Syndrome under the CIND umbrella. These illnesses share characteristics including cognitive problems, chronic muscle and joint pain and extremely poor stamina and afflict people around the world in alarming numbers.



Early support came from a UK group called BRAME (Blue Ribbon Awareness for Myalgic Encephalomyelitis), which highlighted the May 12th International Awareness Day at a World Medical Conference on ME/CFS in 1995, resulting in the date being adopted internationally for ME/CFS.

by Millions Missing/ME Action

We have included a few of our leaflets with your newsletter mailing. Please share these to help raise awareness around the time of Awareness Day. You could ask your doctors, chemist, library, post office, supermarket, etc, to display them.

Lending Library

After donations of books The Network is launching a lending library service for our members. Below are the titles we have in stock. You can request to borrow them for up to 6 weeks at a time. With warning we can hand them over at one of our meetings or your choice can be posted out to you. Further donations of books will be gladly accepted too. Note that these titles are shared for your information and the views expressed in them are not necessarily those of the Network.

Please contact our secretary, Lesley Grieve to arrange by email on lesley@dgme fm.org.uk or call the Network's number.

Tietelbaum, Jacob	Beat Sugar Addiction Now!
Comber, Anne Marie	Believe in ME Patients' Experiences of Accessing and Using Services in Lothian to Treat ME, CFS, PVFS
Association Invisible Disabilities	But You Look Good! A Guide to Understanding and Encouraging People Living With Chronic Illness and Pain
Crowhurst, Greg	Care For Someone With Severe Myalgic Encephalomyelitis
Goldberg, Burton	Chronic Fatigue, Fibromyalgia and Lyme Disease, An Alternative Medicine Definitive Guide
Matallana, Lynne	The Complete Idiot's Guide to Fibromyalgia, 2 nd Edition
Stott, Robin	The Ecology of Health (Schumacher Briefings)
Starlanyl, Devin	The Fibromyalgia Advocate: Getting the Support You Need to cope with Fibromyalgia and Myofascial Pain Syndrome
Salt, William Bradley	Fibromyalgia and the MindBodySpirit Connection: 7 Steps for Living a Healthy Life with Widespread Muscular Pain and Fatigue
Wright, Pam	The Fibromyalgia Coach: Strategies and Support for Your Personal Journey
Smith, Shelley Ann	The Fibromyalgia Cookbook: More Than 120 Easy and Delicious Recipes
Craggs-Hinton, Christine	Fibromyalgia Healing Diet (Overcoming Common Problems)
Do, Leon Chaitow ND	Fibromyalgia Syndrome: A Practitioner's Guide to Treatment
Goldenberg, Don L	Fibromyalgia: Understanding and Getting Relief From Pain That Won't Go Away
Edgson, Vicki	The Food Doctor – Healing Food for Mind and Body
Trock, David H	Healing Fibromyalgia
Simon, Lilly Sue	Healing With Crystals and Chakra Energies
Howe, Russell	Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia
Hurrell, Janet	The Journey Through ME-Chronic Fatigue Syndrome

George, Mike	Learn to Relax: Easing Tension Through Strategies for Living with ME/CFs and Multiple Chemical Sensitivity
Stein, Eleanor	Let Your Light Shine Through: Strategies for Living With ME/CFS, Fibromyalgia and Multiple Chemical Sensitivities
Kubler-Ross, Elizabeth	Life Lessons: How Our Mortality Can Teach Us About Life and Living
Shepherd, Dr Charles	Living With ME
Shepherd, Dr Charles	ME/CFS/PVFS
Boulton, N	Lost Voices From a Hidden Illness
Hyde MD, Byron	Missed Diagnoses: ME & CFS
Simester, Lisha	The Natural Health Bible: Stay Well, Live Longer
Nathan, Neil	On Hope and Healing: For Those Who Have Fallen Through the Cracks
Johnson, Hillary	Osler's Web: Inside the Labyrinth of the CFS Epidemic
Selby, Anna	Pilates: Creating the Body You Want
Heckenlively, Kent	Plague: One Scientist's Intrepid Search for the Truth about Human Retroviruses and ME/CFS, Autism and Other Diseases
Williams, Margaret	Quotable Quotes about ME/CFS
Marriott, Hugh	The Selfish Pig's Guide to Caring
Bailey	The Sound of a Wild Snail Eating
Shomon, Mary J	The Thyroid Diet, Manage Your Metabolism for Lasting Weight Loss
De Vries, Jan	Treating Body, Mind and Soul, Alternative Solutions for Modern Living
Ediger, Beth	Treating Fibromyalgia
Bassett, Jodi	What is ME?
Amand, R. Paul St	What Your Doctor May Not Tell You About Fibromyalgia: The Revolutionary Treatment That Can Reverse the Disease
Parsa Stay, Flora, DDS	The Fibromyalgia Dental Handbook, A Practical Guide to Maintaining Peak Dental Health
Macintyre, Dr Anne	ME Chronic Fatigue Syndrome: A Practical Guide
Mitchell, Lynn	Shattered : Life With ME



Phone or WhatsApp: 07437 602610
 Website: www.dgmefm.org.uk
 Facebook: facebook.com/groups/dgmefm
 Email: craig@dgmefm.org.uk (Chair)
paul@dgmefm.org.uk (Treasurer)
lesley@dgmefm.org.uk (Secretary)



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.