

Summer 2018

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome all,

This year there's no mistaking it is summer. What a year of contrasting weather – from the snowiest winter I remember in a long time, to the driest, hottest summer I think I've ever experienced. How is it affecting your conditions? I find the contrasts difficult to deal with. For me the cold increases my pain and makes my extremities very sore. I hate the darkness and the damp. I love the long days of the summer but the heat this year is too extreme for me, sapping my energy, increasing the overall aches in the body and worsening the headache. I think I'm best in the Spring and Autumn – or a typical Scottish summer! Let us know how you are doing.

It's been a busy time with our own awareness events and those of other organisations. Read about them over the next few pages. Meeting new sufferers and professionals and lay people without experience of the illness really brought home to me the importance of raising awareness. I was shocked at the uninformed and haphazard treatment and the misconceptions. Every day should be awareness day. Please keep on informing your family, friends and medical staff of the ME and fibromyalgia basics and tell them about the latest biomedical research. We shouldn't need a date in May to do it.

Craig Woods

Monthly Get-Togethers

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



August 2nd Topic: Holidays and short breaks - are they at all do-able, and if so what makes them easier and more enjoyable?

September 6th Topic: Hobbies. What do we do to pass the time? Have you found enjoyable or creative things you are able to do? Bring examples and show us!

October 4th This will include our **AGM**. Please come and join in discussion about the way ahead for the Network in the coming year.

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

August 14th Tuesday 2pm-3:30pm **Just Be, Lockerbie** on the High Street. A chance for the members a little East of Dumfries to meet up. Come along for a tea and scone and blether. Look out for the table with our dragonfly logo.

August 15th Wednesday 12pm – 2pm **Custom House, Stranraer**. Another chance to meet up with fellow members in the Stranraer area for a blether over a coffee or brunch. Family, friends and carers very welcome, of course. Look out for the table with our dragonfly logo.

September 16th Sunday 1pm - 3pm social at **Castle Douglas Garden Centre Coffee Shop**. There will be the usual menu of meals and snacks. Join us for lunch or just for a cuppa.

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

Registered Charity No. SC030641



Awareness Week Events

For Awareness Week the Network organised two events centred around Unrest, the critically acclaimed film by Jen Brea, at the Robert Burns Centre Film Theatre in Dumfries. The first, held on Friday the 11th of May was aimed at lobbying and educating those we need to influence in the NHS, council, third sector organisations and politicians. The second, on Tuesday 15th May was a full public showing of Unrest to be followed by a discussion, hosted by us, with Dr Shepherd of the ME Association.

The Friday professionals' event was designed to follow, but on a local level, an event I attended in the Edinburgh Parliament in March. We had a showing of the first 25 minutes or so of Unrest, which was to be followed by a discussion via Skype to the cinema, with Jen Brea, and then a discussion around our local situation, experiences and needs.

Just the organising of the event helped massively with awareness. The MSPs in particular impressed me by being engaged, interested and willing to help. Finlay Carson, Joan McAlpine, Emma Harper and Colin Smyth all responded well. It's reassuring that through the four of them they cover the 3 main parties in Scotland, as non-partisan, cross party support is always a good thing to have. The NHS were a bit more reluctant. Time constraints obviously are a struggle, but they had representation there and it has helped move us up the agenda. There was talk of us taking a similar event to NHS management so perhaps something will come of that in the near future. Disappointingly the only GP to request to attend didn't show, and neither did the leader of the council. The event was rounded out by some third sector charities and agencies who support ME and fibromyalgia clients.

It seemed that everyone was very moved by what they saw of Unrest. Many had no idea that ME could be so severe. Jen Brea was supposed to join for a skype discussion from her home in California, but she was too unwell to do so. Instead at the last minute I asked Nancy, Paul, Lesley, Connor, and Sarah. We made up a panel and briefly told our histories and took questions from the room. It was quite an imposition on them so late in the day but they all



spoke very well and did us proud. It probably was more effective, and certainly was more relevant to our region than a discussion with Jen would have been. Finlay Carson MSP told us that, although he wasn't comparing what he went through to our experience, he had some understanding from a summer when he was struck down by a virus and just couldn't recover. He tried to force his way through the exhaustion but was knocked back and back. It lasted a couple of months for him, but it

gave him a fright, and made him realise just how real and cruel this illness can be. The discussion then moved on naturally to the care (or lack) locally. It seemed everyone agreed that it wasn't acceptable and ideas were floated for how it can be improved. Some advice which the Network was given was that we should be concentrating on the individual localities within the D&G region. This is something we will explore in the future to see if our vision for improved care can be taken forward.

It seemed to be a successful event, helping move us up the agenda and making the invisible sufferers more visible.

The Tuesday Unrest showing was arranged with the RBCFT, who were very helpful, and it was advertised as part of the RBCFT's programme open for all. We felt this was important to reach out beyond our Network. Around 28 people bought tickets for the showing, and there was the Network representation on top of that too. The compact cinema looked respectably full.

We laid on refreshments after the film and were due to speak to Dr Charles Shepherd, Medical Director of the ME Association, but unfortunately, and after we'd done the publicity for the event, he realised he had a schedule clash and couldn't make the discussion. We hope to make use of him in the future – maybe through a teleconference with NHS management or doctors. I tried to replace him with Jen, but she had not recovered enough by then, and another top ME doctor, but no one could join us. He was very apologetic and I was most embarrassed. Instead about half the audience remained for a discussion among ourselves.

A couple of those remaining were people who were in the early stages of ME. Unrest is not an easy watch for those of us well aware of the length and severity of the illness so I can only imagine how difficult and worrying it is for those still struggling to get a diagnosis. What really struck me was the way they were questioning themselves and whether they were really ill – this coming from their experiences with doctors (and lack of abnormal test results). It underlined to me just how important awareness raising and educating the care-givers is – the diagnostic process seems to be very haphazard and has moved backwards, it seems. We need to keep on fighting.

Craig

Jen Brea

Shortly after Awareness Week Jen announced that she has thyroid cancer. She's had an operation to remove her thyroid and is expected to make a full recovery. She is a remarkable woman who has done so much despite her own very poor health to raise awareness – she is 'star' and director behind the Unrest film and the driving force behind the Millions Missing and ME Action campaigns. We wish her well.

Unrest is available to buy and stream now. It is available as part of the Netflix streaming subscription. Trial memberships are available.



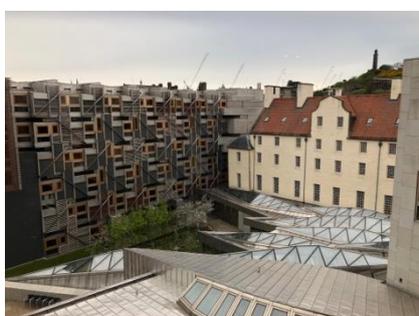
This is M.E. in the Scottish Parliament

In the lead up to Awareness Day I represented the Network at This Is M.E., an event hosted by Gail Ross MSP, in conjunction with Action For ME, at the Scottish Parliament. It was well attended with a good few MSPs there along with patient groups and patients themselves. Gail Ross spoke movingly about how a friend had been badly affected by ME. Theresa Burns, from Action for ME then spoke and introduced sufferers who told their tales of how the illness affects them and how the NHS, education and welfare systems in this country is letting them down. Keith Anderson, Scotland's sole ME specialist, who is a nurse in Fife, spoke of his experiences with patients. MSPs and sufferers alike lamented that he can barely scratch the surface of the needs in Fife, let alone his role not being replicated in the rest of Scotland.

I took the opportunity to speak to some of our local MSPs, having good conversations with Colin Smyth, Emma Harper and Finlay Carson from our region. They know that our needs go unfulfilled here and have offered their help and representation in pressing for better care.

I spoke to Keith Anderson too. When I pointed out that things seem to be going backwards and therapeutic treatments that were available in the past are no longer prescribed he said that he'd be willing to help advise GPs across Scotland as to treatments for patients with ME within reason.

The evening event was a success, it was well attended and the politicians were enlightened and engaged. There is little doubt that more is required to be done. This event, along with the hugely successful Millions Missing campaign for Awareness Day, helped to get a hearing for a motion in the Scottish Parliament. Politicians are aware of the problems of the UK National NICE Guidance that the Scottish Good Practice Guidelines and benefit awards are based on, but they still need pressuring to speed up its replacement, removing the influence of the flawed PACE Report from Scotland.



AfME/CSO to fund PHD Student

Action for ME and the Scottish Government's Chief Scientist's Office announced the funding of a 3-year PHD studentship to study T-cell differences under Prof Chris Ponting at the University of Glasgow. This is exciting as they are looking to replicate Stanford's Dr Mark Davis study showing immune activation in people with ME. This showed that T-cell activation is on a par with cancer, MS and infection.

Prof Chris Ponting says: "We are thrilled with this award because it will allow us to pursue research into this devastating condition. The technology that we wish to use would be an extension to what others have done previously and, importantly, it would be cheaper. We hope – once the technology is established – to generate new hypotheses that may eventually reveal causes and affordable diagnostic tests for some across the M.E. spectrum."

Committee news

We are pleased to welcome Lesley Grieve to our committee. Lesley was co-opted when Kim Dams and Alex Thelwell stepped down for personal reasons. Our thanks go to Kim and Alex for their work while on the committee. We are now just 5 committee members which is the minimum number allowed by our constitution, so we hope that a few more members will come forward at the AGM (see back page) to join the new committee.

CBT

Cognitive Behavioural Therapy (CBT) has received a lot of bad press through association with the NICE guidelines for ME/CFS in conjunction with Graded Exercise Therapy (GET), and further so with inclusion in the PACE trials. Nevertheless, some of our members have spoken about it being helpful for coping with their illness. We invited Dr Alison Wren, D&G Clinical Health Psychologist, to our April meeting at Midsteeples to share our views and hear about the approach taken by NHS in our region. This is what she had prepared for our meeting:

“What is CBT?”

Cognitive Behavioural Therapy (CBT) is a type of talking treatment which focuses on how your thoughts, beliefs and attitudes affect your feelings and behaviour, and teaches you coping skills for dealing with different problems. It combines cognitive therapy (examining the things you think) and behaviour therapy (examining the things you do).

Some CBT therapists and Clinical Psychologists integrate ideas from other psychological therapies such as Mindfulness and ACT (Acceptance and Commitment Therapy).

CBT is a short term therapy. It is skill based so hopefully improvement can continue after therapy has finished. It involves some things to try at home - "homework". It requires people to feel comfortable talking about thoughts and feelings, and a commitment to regular sessions.

CBT in D&G is based on assessment of individual needs (i.e. it is formulation driven not protocol driven) so not everyone will get the same thing!



CBT for ME/CFS

Therapists in D&G believe ME/CFS is a physical problem not a psychological problem.

CBT won't eliminate symptoms but may help come to terms with the illness, alleviate associated distress and help the development of practical coping skills.

We aim for manageable, meaningful and realistic goals. It's an individualised approach.

Although it looks at unhelpful thinking, we do not believe that personal thoughts & beliefs are responsible for causing or maintaining illness. We don't believe that you can think yourself out of ME/CFS. Pacing is a large part of the therapy.

It may help relieve depression and anxiety secondary to ME/CFS.

There is no GET!

CBT is not for everyone.”

Dr Alison Wren, Clinical Health Psychologist, NHS D&G,

Referral to Clinical Health Psychology can be through your GP or any other health professional. Waiting times are 8 to 16 weeks. It could entail between 3 to 12 therapy sessions.

Social Prescribing

Healthy Connections (known in some areas as Community Link) is delivered by NHS Dumfries & Galloway Health and Wellbeing Teams across the region. The initiative aims to increase levels of social interaction and improve lifestyle choices to help individuals support their own health and wellbeing.

The work is aimed at adults experiencing:

- Low mood
- Reduced motivation
- Lack of direction / purpose
- Social isolation
- Long term conditions

Healthy Connections / Community link can help you to identify what *really matters to you*, and will work with you to find solutions and ways to improve your own health and well-being. It puts you at the centre and focuses on allowing you to take the time to explore your current situation and make plans for your future. Staff can also help you to identify and access appropriate services or sources of support in your local community.

Referrals are through a variety of organisations and professionals including GPs, Social Workers and Occupational Therapists. To find out more, you can contact your local Health and Wellbeing Team:

Annandale & Eskdale: 01461 204741 / dumf-uhb.AandE-Community-Link@nhs.net

Nithdale: 01387 244401 / dumf-uhb.nithsdalehit@nhs.net

Stewartry: 01556 505724 / dumf-uhb.HCS@nhs.net

Wigtownshire: 01671 402015

Patient Participant Groups

A suggestion of a way to influence GPs and our care came from Julie Davidson of The Scottish Health Council after the Awareness event. She suggested that our members join the Patient Participation Group (PPG) of their local GP Practice. It's a way for GPs and practice staff to hear the views of their patients. Only a few GP practices in our region have these. These are at Greencroft Medical Practice in Annan, Greyfriars in Dumfries, Lochinch in Stranraer and both Galloway Hills Medical Group and Cairnsmore Medical Practice in Creebridge, Newton Stewart.

If you attend any of these surgeries please consider joining their PPG and making representation on behalf of your fellow fibro and ME patients.



Appointment Frustrations

I attend Lockerbie Medical Practice. I've been finding it increasingly difficult to get an appointment to see a GP. They removed the option for book-ahead appointments, which is what I generally want, with only on-the-day appointments released. To get one of those you need to phone at precisely 8am (any earlier and you are put through to the out-of-hours service). There follows 15 minutes of redialling on the engaged signal only to get through to be told that all appointments have been taken for the day.

After so long with ME little is so pressing as to warrant an emergency appointment. Occasionally the Nurse Practitioner will phone back and can be helpful.

All this happens at 8am. Not normally a time that I'm waken. It takes a lot of effort for me at that time in the morning. Forcing myself to do anything early on has dire consequences for the rest of the day.

Finally, they've opened up book-ahead appointments again – but like the last time they did that they didn't tell anyone. If you're attend the Lockerbie doctors be aware that you can ask for your preferred doctor ahead of time again. If you're struggling to get an appointment at your surgery ask if the system has been changed without informing the patients.

Craig

The Carers (Scotland) Act 2016

This took effect on April 1, 2018. It has been designed to ensure better and more consistent support for carers so that they can continue to care, if they so wish, in better health and to have a life alongside caring.

From April 1, 2018 there is:

- A new right for carers to be offered or request an Adult Carer Support Plan (ACSP) or Young Carer Statement (YCS), setting out their personal outcomes and identified needs.
- A duty for local authorities to provide support to carers, based on the carer's needs which meet the local eligibility criteria. They also have a power to provide support to meet carers' needs which don't meet these criteria.
- a requirement for local authorities to establish and maintain an information and advice service for carers. They must also publish and review a short breaks services statement.
- a duty for local authorities and health boards to 'take such steps as they consider appropriate' to involve carers and carer representatives in the planning and evaluation of services that support carers, including the preparation of the local carer strategy.
- a requirement for the responsible local authority to consider support in the form of a break from caring, and the desirability of breaks from caring provided on a planned basis.
- a duty on health boards to inform the carer and to invite their views before a cared-for person is discharged from hospital. These must be taken into account before the discharge of the cared-for person.
- the publication of a Carers' charter to accompany the Act, which sets out the rights of carers in or under the Act.



The One Bucket Rule

There is no doubt that pacing is one of the most important tools that we have for managing our ME. What this pacing actually looks like in our daily lives will be different for each of us, as we all have our own particular circumstances and priorities, so I thought I'd share one aspect of my pacing with you.

It's that time of the year when the gardens go mad. And not just with stuff you want! I have a fairly big garden, with fairly big weeds. After many years of dreading this sudden growth, and doing the classic boom and bust in frenzied bursts of digging and pulling, I have finally got the situation under control with my One Bucket rule. I have a small bucket, and that is all I allow myself to fill, with one session of weeding, once a day. I generally do it at the same time of day, just after breakfast, when energy levels are good. It does mean that the weeding process is a bit like the painting of the Forth Road Bridge – no sooner have I got to the end of the last border, I have to start again at the first. But that's OK. And instead of dreading and hating those borders, I now enjoy being in them. The pressure is off, the situation is under control.



I'm now working on introducing other, food related rules....the One Biscuit rule, the One Square of Chocolate rule, the One Slice of Cake rule....but that's not going so well!

Contributed by a Network member



Not Every Disability Is Visible

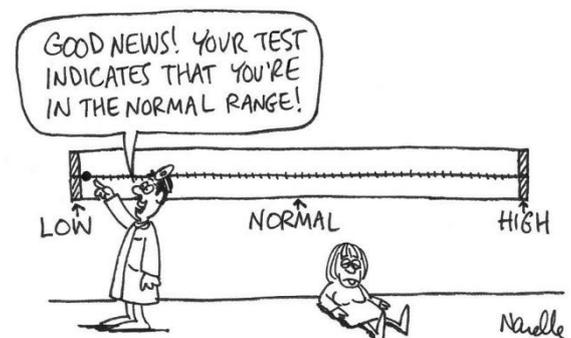
It's nice to see things are changing, it may be a slow process but it's going in the right direction. A recent trip to Tesco in Dumfries and the little girls room I noticed the sign on the disabled toilet door. No longer a "Disabled Toilet" but now it's an "Accessible Toilet". It's good to see these signs changing, hopefully it won't be too long before people's attitude towards disability change, although this may take a little longer. I have since noticed the same sign in another supermarket, let's hope all public toilets follow suit.

Lesley Grieve

B12 Supplementation

A topic which regularly crops up on our Facebook page is the discussion around B12 and its benefits. B12 injections are a fundamental part of Dr Myhill's protocol but is something GPs around here are very reluctant to prescribe - yet it's cheap, has little in the way of side-effects and often has good effects on muscle pain, fatigue and cognitive function. For me it stops the muscle cramps and spasms too. From other forums I read good things about B12 skin patches which are available without a prescription. It may be an alternative for those who find their GP isn't willing to give them a course of injections.

Craig



Specialist healthcare support to help people remain at work or make a healthy return to work. With free physiotherapy and counselling for employees of small businesses and the self employed in Dumfries and Galloway.



Working Health Services Scotland

Working Health Services is a free and confidential service. It's designed to help people who work for a small business with less than 250 employees who are attending work or are absent from work. Also we help the self employed.



We provide rapid access to assessment, advice and access to interventions including physiotherapy and counselling. Confidential support can be valuable for anyone experiencing work related stress and can help prevent it turn into something more serious.

People can self refer to the service by calling 0800 019 2211 and asking for option 3. Fast access to four free treatments of physiotherapy or counselling can be quickly organised following a telephone assessment. Case management services include support with employer liaison, work station risk assessments, free employment legal advice, advice on funding for workplace adaptations, signposting for debt problems and a host of other free support systems.

Contact Working Health Services Dumfries and Galloway:

Freephone: 0800 019 2211 option 3

Local contact – Ailsa Black Tel: 01387 244626

Email: ailsa.black@nhs.net

NHS Working Health Services

I have had a number of people over the years use Working Health Services who have chronic fatigue or ME. We have been able to support them in a number of ways. Some people have benefitted from a work station assessment. Too much office based work can contribute to joint pain if the work station is not properly set up. Often I am able to refer people on to access funding for new chairs, desks, ergonomic mice and so on.

Some people, have also benefitted from support with acupuncture through referral to our physiotherapist and this has helped with joint pain and fatigue.

If people are struggling with anxiety or depression due to their health problems they may benefit from a referral to counselling to help them develop skills they need to keep their mental health positive.

As a case manager I am also able to help people who may need some support speaking to their employer about their problems and helping their employer to have a better insight in to why they may be struggling. This can include return to work planning if the person is off sick. Carrying out a stress risk assessment and general work planning to look at any areas of their job they may be struggling with specifically.

Ailsa Black, Case Manager, NHS WHS

Notice of Annual General Meeting (AGM)

Thursday 4th October 2018, Midsteeples, Dumfries 1pm to 3pm

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 will need to fill the Secretary vacancy. Committee meetings are held 3 – 4 times a year, with communication between meetings on-line using Office 365, with each Committee member being allocated a license for that purpose.

Notice of
AGM
Thursday 4th October
Midsteeples, Dumfries
1 – 3pm

If you may be interested in becoming either a Committee Member or an Office Bearer, please let us know in advance of the AGM either by speaking with a current Committee Member or by email to admin@dgmefm.org.uk

We will be happy to talk with you about what it can entail and how we don't pressure ourselves to do more than we can within our limitations.

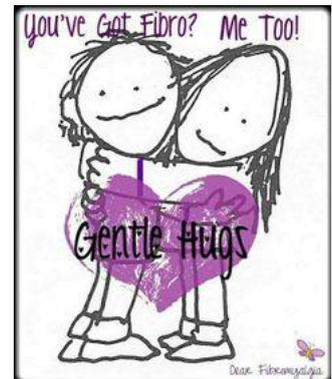
News Round-Up

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...

If you'd like a meeting in your area or if there's an article you think should be in the newsletter please feel free to get in contact. We are always very happy to receive contributions of articles, thoughts, personal stories, cartoons and more for the newsletter. We envisage the Autumn newsletter coming out in late September.

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



DGMEFM



Dumfries & Galloway
ME and Fibromyalgia Network
SC030641 | www.dgmefm.org.uk

Phone or WhatsApp: 07437 602610
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paul@dgmefm.org.uk (Treasurer)

OSCR

Scottish Charity Regulator

www.oscr.org.uk

Registered Charity

SC030641

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.