

Dumfries and Galloway ME Network Support for ME, CFS & Fibromyalgia

December 2015

Welcome to the winter edition of your Network's newsletter. As winter bites, the hours of darkness are at their longest and as the end of the year approaches, it is a time for reflection.



It has been another challenging one for the Network and for many of us. For me personally I had a very big relapse after pushing myself too hard (I'm better at giving advice on pacing than following it myself). The Network has carried on however. Modern technology, Facebook in particular, has helped us maintain contact and mutual support even when unable to attend meetings. It's a pleasure to see the increasing numbers of new faces at the monthly Midsteeple meetings. We are being contacted increasingly often by other charities and health groups to provide support to sufferers and carers and have been having meetings to push for our priorities with the integration of NHS services and social care. Looking forward, the new year should be exciting with a potential name change to better reflect the many fibro members we have and hopefully some funding to allow us to better support one another.

Craig Woods



Christmas lunch at Three Crowns Court Bistro, Dumfries 1.30 for 2pm on Saturday 19th December.

We have reserved an area of the Bistro for a Christmas lunch get-together. It is a set menu with traditional choices and vegetarian options. Cost £12.95 pp. You are welcome to bring family members and friends. Please book ahead by text or phone to Craig on our dedicated phone line 07437 602610 or email craig.dgme@yahoo.co.uk

The Bistro would find it helpful to know choices in advance. You can see the menu on our website – follow the link in the event calendar. Alternatively, phone Craig for the detail, or contact Niki at the Bistro on 01387 279540. They are willing to try and cater for any special requests if known in advance.

Monthly Meetings

Check our website for updates: dgme fm.org.uk or facebook.com/groups/dgme fm

December 3rd 1 – 3pm at Midsteeple, Dumfries. This will be a consultation on Health and Social Care Integration with Nithsdale and Regional representatives. Come and make your views known.

January 10th Sunday 1 – 3pm at the **Granite Kitchen, Dalbeattie**. We have reserved the area at the back of the café. Join us for a cuppa or more from the Granite Kitchen's menu.

February 4th 1 – 3pm at Midsteeple, Dumfries. This will be a 'General Meeting' to decide about the name of the Network and revision of our Constitution. There will be time for the usual chat too.

As with all the Midsteeple get-togethers refreshments will be available. Feel free to bring along a snack. It is fully accessible with a lift to the first floor meeting room. 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.

I have written about it here before but the PACE Trial has been causing controversy again. An American academic and freelance writer called David Tuller published an in-depth investigation of the UK government-funded trial and completely (and deservedly) tore it to shreds on almost every level. Professor Michael Sharpe, one of the trial's lead authors took to the newspapers with a re-stating of the data 2.5 years on from publication leading to such dreadfully misleading headlines such as ***Exercise and positivity 'can overcome ME'*** which appeared on the front page of the Daily Telegraph. Needless to say they didn't report the findings of the investigative piece which led to such a defence. Since then six prominent research scientists and doctors have put their name to a letter calling on the Lancet to accept an independent investigation of the PACE Trial data. Attitudes and understanding may be slow in changing here, but the tide appears to have changed in the understanding of ME-CFS in the US. Actual biological science is now providing proofs which are difficult to ignore and quality journalists are taking note. This article is by Michael Brooks, PhD in Quantum Physics.

Craig Woods

Time to swot up on chronic fatigue **NewStatesman**

Future general practitioners need to be made aware that “psychosomatic” should not be the default suspicion.

Around 250,000 people in the UK suffer from chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME). The symptoms include debilitating tiredness, pains, dizziness, insomnia and depression. The standard recommended treatment has three strands: cognitive behavioural therapy, an exercise programme (“graded exercise therapy”) and medication that counters some of the pain, nausea, sleeping problems and other symptoms.

That prescription has been reinforced by a review published in the journal *Lancet Psychiatry*, which followed a group of sufferers and concluded that cognitive behavioural therapy and graded exercise therapy are better than “specialised medical care”.

The ME Association, however, responded with a detailed criticism of the study. It complains that cognitive behavioural therapy treatment attaches a label that marks CFS as a psychological disease while doing little good. Moreover, graded exercise therapy makes a significant proportion of people worse, it argued, and the hypothesis that those with CFS respond to the therapy because they are inactive and deconditioned “is no longer tenable”. The association pointed to research showing that sufferers have “significant abnormalities in the muscle, brain and immune system”, which are likely to contribute to CFS symptoms and induce fatigue in those compelled, against their inclination, to exercise as part of their treatment.

There is something to these objections. In 2011, researchers in Norway announced an accidental discovery: an anti-cancer drug called Rituximab had eased a cancer patient's CFS symptoms.

A larger follow-up study published in July this year found that the initial discovery had been no fluke. Of the 29 people in the trial, 18 experienced significant relief from CFS symptoms, with 11 of them still feeling good after three years and some still in remission, with no symptoms, after five. Now, 150 people are taking part in a new study on the effects of Rituximab on CFS. The drug destroys the immune system's white blood cells; these cells may have been playing a role in creating CFS symptoms.

Things may be about to improve for sufferers. The US National Institutes of Health announced that it has been spending too little on the disease and is planning a study on the possible role of infection in triggering CFS. Oversight of CFS studies has been moved from the Office of Research on Women's Health to the National Institute of Neurological Disorders and Stroke. In other words, it is being taken seriously.

Educating future doctors about CFS would also help. According to a study into medical students' attitudes to the syndrome, published by researchers at the University of Manchester, UK students acquire their knowledge “largely from informal sources” and they “expressed difficulty understanding chronic fatigue syndrome within a traditional biomedical framework”. Many didn't see how it was a medical problem – and some considered sufferers as malingerers or time-wasters.

Future general practitioners need to be made aware that “psychosomatic” should not be the default suspicion. A compromised immune system now looks like a reasonable diagnosis. Although treatments are not yet ready, at least sufferers will not be cajoled on to therapies that might prove problematic. Remember: “First, do no harm.”



How time banking can work with fluctuating conditions like M.E. and fibromyalgia



No doubt many of you have had to, like me, stop working because of your illness. And no doubt you also, like me, feel pretty rubbish about that.

But for the last two years I have had my earning power given back to me by the Annandale and Eskdale time bank. I 'earn' hours doing stuff I can easily manage for other members of the time bank, and then I 'spend' these hours when other members do stuff for me. Simple!

It really is that simple, and so much more do-able than a job. I can opt in or out, depending on energy levels, and just offer to do things that I can manage, doing them at my own pace and at a time to suit me.

Members offer skills to other members, and make requests for things they need help with. It can all happen via e-mail if you want, or by phone and post if preferred. E-mail really works for me, and most weeks I get bulletins from the time broker, with new requests from members. If I'm not feeling great, I don't respond to any of them, but if there is a request for something I feel I can cope with at that time, and think I could do, and want to do, I reply to the e-mail, saying I would like to help out with that specific request. I am then either put in touch with the requesting member direct, or it is all organized by the broker – whichever work best for both members.

Similarly, if I have a request for something I need help with, I e-mail the time broker and my request goes out in a bulletin, or sometimes the broker knows of a member who has the necessary skills, so contacts them direct.

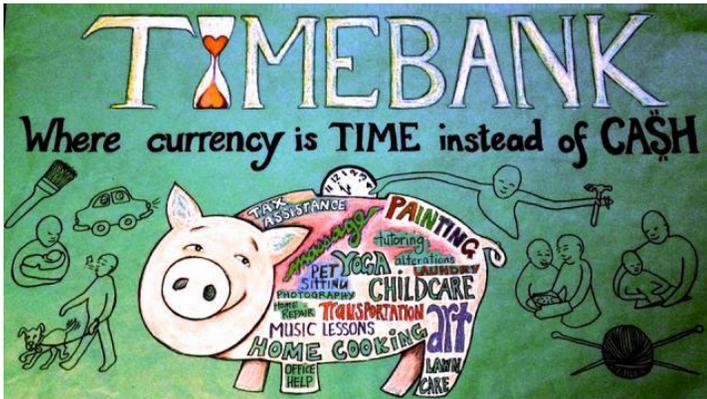
Everyone's skills are worth the same - an hour is an hour, regardless of what is done in that hour. We are all just as valued as each other. Furthermore, any member who is, for whatever reason, not able to 'earn' at that time, but who is in need of help, can access hours to spend from the community 'pot'; these being hours that other members have donated at times when they have spare hours in their personal accounts that they would like to see made use of. It is a lovely community scheme.

The reality of all this for me is that I have 'earned' hours doing low energy things like giving people lifts (in their car), computer work like poster and leaflet design, writing articles for the time bank, and attending or helping out with time bank meetings and get-togethers. I have 'spent' hours on clothes and curtain alterations, knitting bed socks, making a small blanket out of wool squares, a pedicure, and I currently have a request in for a bit of furniture restoration. With the time bank now two years old, and membership constantly rising, it is amazing just what skills are on offer.

Other offers and requests I know of happening through the bank include gardening, wall paper stripping, shopping errands, proof reading, French lessons, website design, ironing, computer lessons, dog walking, companionship, baking.....you name it, they'll be a member either needing it or offering it!

The time bank also organizes regular activities and get-togethers. Although these don't work for me as they soak up too much energy generally, you could get involved in art and craft groups, singing, walking, and coffee mornings, earning hours every time you attend.

The broker of my bank, the Annandale and Eskdale bank, is Mia Glendinning - 07956 056 859 or mia.glendinning@lifecaretrust.org.uk. Information on region wide time banking is on the website www.timebankdg.org.uk. Or you could get in touch with Mia and she will signpost you to time banking in your area.



Give it a go! There's absolutely nothing to lose, and a whole lot to gain.

Sarah Chadfield

There are time banks in Dumfries, Dalbeattie, Glenkens, Kelloholm, Lockerbie, Annan, and Langholm. The time bank broker for Nithsdale & Stewartry is Cat Walker. She can be contacted at Third Sector in Dumfries – 0300 303 8558 or cat@thirdsectordumgal.org.uk

As yet there are no time banks in Wigtownshire but if you would be interested in this please contact Cat.

Gift Day

Many thanks to all who contributed to this year's 'Gift Day'. We have received £610 in donations and just short of £120 in Gift Aid from HMRC – a total of nearly £730. This will hopefully cover the costs of the next three newsletters.

It's never too late if you meant to donate but forgot – please make cheques payable to DGME Network and post to DGME Network Treasurer, Thistledew, Albert Street, Dalbeattie. DG5 4JP. Thank you.

ME Alert Cards

These cards are available from the ME Association for £2 including p&p, or free to their members. I have found the cards very useful when I have been away from home and been ill as some doctors haven't heard of ME or been educated on this illness or all the other outlying symptoms that go along with the illness. I personally think it is a good idea to carry a card with you at all times, it would help doctors to understand what they were dealing with. I only know it helped me on several occasions.



Mary Murdoch

Activity Management and Pacing continued.....

I hope some of you found the activity sheet, in the last newsletter, useful. Don't worry if it was too much to complete, just focussing on your activities can be helpful.

Pacing is a useful tool, especially if you overdo things on good days and then relapse. Learning not to push yourself is a huge lesson in itself. Listen to your own body and not to 'helpful' people who think they know what's best for you. They don't – only you do.

If your tendency is to overdo things then look at your areas of high activity. Can you cut these down into manageable chunks and rest in between? Can you 'switch' between activities so that you spend less time on each activity? Be truthful with yourself - are these activities appropriate at all now that you have an illness to cope with as well? Many of us still look to how we were and forget the limitations these illnesses have placed on us. Better to look instead at what we can achieve, albeit in a limited way.

Most of us need to cut back on our activity during good days and leave something in the bank for tomorrow. This may mean prioritising things a bit more, delegating or getting help. In some cases it will mean saying 'no' to activities or people that completely drain you. This may sound selfish, but it isn't- in caring for yourself you are more able to care about others.

Finding a baseline of activity that is sustainable for you is the ultimate aim of pacing. This can take some time so don't get disheartened. Even small changes can take time to implement, so be gentle with yourself. Once you have this baseline then you can start to increase your activity in small degrees- doing 5-10% more is enough. Again, run with this for quite a while until this is also sustainable. Remember – small steps at every stage.



For those of you like me, who used to enjoy sports and a certain amount of exercise before becoming ill, then consider investing in a Wii console – the package that includes the balance board, 'sports' and 'fit plus' programmes is good. This is a fun and gentle way to get yourself moving a bit. Beware though, you can get carried away with yourself!

June Randell

There has been a lot in the news recently about 'PACE Trials' and GET – Graded Exercise Therapy. Please don't confuse Activity Management and Pacing with GET. In Graded Exercise Therapy you are encouraged to push yourself more and more – this is why so many have relapsed badly when they have been persuaded to try it.

Alzheimer Scotland

We had an interesting talk at our September get-together from Mandy Pool, Dementia Advisor for Dumfries & Galloway. She made comparisons between our symptoms and those of dementia sufferers. The word dementia describes a set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language. While we may have similar symptoms to those of vascular dementia, we are aware of them, whereas Alzheimer sufferers are not.

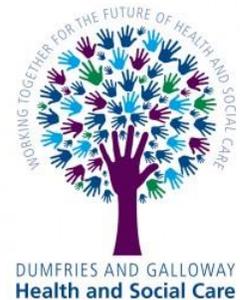


Mandy gave us handouts on tips they have for dementia sufferers and their carers: to support daily living; to aid good sleep; and to support memory. Many of the tips were helpful to us too, as aids for managing our symptoms. If you would like copies of these contact Mandy at the Dementia Resource Centre, Dumfries. Tel 01387 261303 or email mpool@alzscot.org

Is there anyone you would like to come and give a talk at one of our get-togethers? Let Craig know if you have any suggestions.

Integration of Health and Social Care Consultations

Five of us from the Stewartry attended a consultation event in Castle Douglas hosted by Third Sector on behalf of the NHS and Council. It was aimed at people with long term health conditions but we were the only group there. We were asked to share our experiences and ideas set against the nine 'National Health and Wellbeing Outcomes' which are a framework for the integration of health and social care.



This took all afternoon which was very tiring for us, but we felt it was well run and drew out all the important issues that we would like addressed. We spoke about how difficult it is for anyone outside of our immediate circle to know just what life is like for people suffering from ME and Fibromyalgia, and how vulnerable we feel at a lack of understanding from doctors and health care workers, the trials and tribulations with social security, and misconceptions in the wider public. We suggested that personal advocates or 'champions' could help speak up for us, but what we really need is to be respected and believed, for training in health and social care to bring better understanding of our needs, and for ME and Fibromyalgia specialists to be appointed within local health and social care teams.

Another of our members gave her views at one of the public consultation events. It was held in the foyer at Lochthorn library which wasn't an ideal setting, however, the staff presenting it were attentive and interested to hear of our concerns.

We're taking whatever opportunities we can to feed in to the consultation process and have invited representatives from the Nithsdale Locality and the Regional Strategic Planning teams to attend our meeting on 3rd December. This will be another important opportunity to have our views heard.

The consultation period ends on 11th December.

Paul Thompson

Pain Association

The Pain Association run a free rolling programme with monthly meetings in Dumfries and in Stranraer. There are 11 sessions (they have a summer break) covering subjects such as relaxation, pacing, flare up management, improving sleep, stress management – see their programme for the full list.

They say: 'This is a professionally led training group for people with all forms of chronic pain. Sessions focus on building skills that help you to regain control and cope more effectively. You are welcome to attend at any point during the programme. You do not need to be referred by your Doctor.'

The sessions in Dumfries are held at the Mitchell Room, Holiday Inn, Bankend Road and run from 10.30 am to 12.30pm. In Stranraer they are held at the Conference Room, Wigtown Locality Office, Victoria Place and run from 10 am to noon.



The next sessions have as their topic 'Thoughts and feelings' and are scheduled for Monday 14th December in Dumfries and Wednesday 2nd December in Stranraer. The programme continues in 2016.

To find out more phone their Freephone enquiry number on 0800 783 6059.

Website - <http://www.painassociation.com/1-2/dumfries-and-stranraer-group/>

New Committee

There are now six members of the Committee, elected at the AGM. Craig was re-elected as Chair, and Paul as Treasurer. We are pleased to welcome Kim Jakobsen as our new Secretary. Margaret Blake, Elaine Waugh and Nancy Wilson are the three other members re-elected.

Craig Woods (Chair) – craig.dgme@yahoo.co.uk

Kim Jakobsen (Secretary) – kim.dgme@btinternet.com

Paul Thompson (Treasurer) – paul.dgme@btinternet.com

Dedicated phone line: 07437 602610

General Information

ME Association

7 Apollo Office Court

Radclive Road

Gawcott MK18 4DF

£18 to become a member

☎ 01280 818964

www.meassociation.org.uk

E-mail:

admin@meassociation.org.uk

Action for ME

42 Temple Street

Keynsham

Bristol BS31 1EH

£21 to become a member

☎ 0117 927 9551

www.actionforme.org.uk

E-mail:

admin@actionforme.org.uk

FMAUK (Fibromyalgia)

Studio 3007

Mile End Mill

12 Seedhill Road

Paisley PA1 1JS

☎ 0844 826 9022

www.fmauk.org

E-mail: charity@fmauk.org

Tymes Trust (For younger

people with ME)

P.O. Box 4347

Stock

Ingatstone CM4 9TE

☎ 0845 003 9002

www.tymestrust.org

Should we change our name to include Fibromyalgia – what do you think?

We are called the Dumfries & Galloway ME Network and yet we have many members who have Fibromyalgia. We've incorporated FM into our Facebook and Website addresses, but not into the name of the Charity. Is it now time to change this? Members at the AGM in November thought that we should, but what do you think? Our monthly get-together in February will also be a General Meeting where we can discuss and decide on this.....

Notice of General Meeting: 1pm on Thursday 4th February at Midsteeples meeting room, Dumfries.

Motion 1

To change the legal name of the Network to Dumfries & Galloway ME and Fibromyalgia Network, also known as DGMEFM Network, and to amend the Constitution accordingly.

Motion 2

To make further amendments to our Constitution, including some changes in wording but not in substance, and the following substantive changes:

- 2.1 In the furtherance of our objectives to add: 'facilitate a mutual support network'.
- 2.2 To amend the criteria for membership to include sufferers, their carers and family members living in Dumfries & Galloway (without any limit to the number of such members). Any other individuals will remain subject to their number not exceeding 25% of total membership.
- 2.3 To add that membership will be automatic on giving contact details and status to an Office Bearer.
- 2.4 To add that membership will cease automatically by request of the member or when the contact details held are no longer current, or if found to be acting in contravention of our objectives.
- 2.5 To include members who are carers or family within the criteria for sufferers, in the numbers for quorum of GMs and eligibility for Committee.
- 2.6 To allow for telephone/ remote conferencing in the numbers for quorum and for voting at GMs and Committee meetings.
- 2.7 To open GMs to non-members as observers.
- 2.8 To amend that Office Bearers will be elected either at the AGM or the following Committee meeting, and comprise Chairperson, Treasurer, and Secretary.

If you can't attend the meeting on 4th February but would like to cast your vote on each or all of the proposed changes then you can vote by proxy if there will be someone attending on your behalf. A person acting in proxy must make this known at the start of the meeting.

Alternatively, please text or call Craig on 07437 602610, or email to craig.dgme@yahoo.co.uk

Issued: 27th November 2015