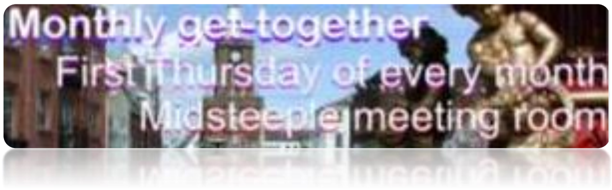
Dumfries and Galloway ME Network September 2015
Support for ME, CFS & Fibromyalgia



Welcome to the late summer edition of your Network's newsletter, and the summer is very late in arriving, indeed! August brings the annual report to OSCR, the charity regulator. It's a time to reflect on the year before. Although frustratingly little progress seems to have been made there are a few achievements.

Our meetings continue to be popular with members offering and taking advice from one another, as well as it being a chance for a laugh and a joke with like-minded friends. They continue to take place on the first Thursday of every month in the Midsteeple of Dumfries. 'Pop-up' meetings and gatherings have happened too – these are more sociable, taking place in cafes or even an afternoon at a home. Feel free to suggest and/or host a gathering yourself.

The Facebook page, and the strong community of over 100 on it, makes this type of thing possible. It also gives instant mutual support for anyone needing that understanding that only a fellow ME or fibro sufferer can offer. The funnies that are posted are always worth a giggle too. The group is 'closed' which means only members can see what is posted there. www.facebook.com/groups/dgmefm.

We have registered a domain name, but I'm afraid ill health has prevented the creation of a website for now. Hopefully there will be an information page coming soon to www.dgmefm.org.uk

There is also now a dedicated phone for the Network, the number is 07437 602610. This is for off-line members who need a one-to-one conversation.

Our funding situation is less worrying than it was at this time last year. We've received a donation in memory of a sufferer. Denis, our former chair, continues to play his piano in Garden Wise on the second Thursday of the month, raising a steady stream of income. Elaine Waugh has raised a remarkable total for us, us you can read about on page 3. The Gift Day is your way of giving a little back to help cover the costs of the Network (this year's form enclosed). Showing that we have the support of our members will help greatly in funding applications.

Various health boards, support charities and services as well as carers have made contact with the Network to seek advice on behalf of their patients/clients. Although it's great that we are getting more known about we aren't in a position to provide the support we'd like to, but we are able to advise and inform to a limited extent and welcome new people to our meetings and Network.

Craig Woods, Chair

Monthly Midsteeple Meetings - First Thursday of the month, 1-3pm in Dumfries.

September 3rd During this meeting Mandy Poole from Alzheimer Scotland will come along for some of it to talk to us a little about vascular dementia. This has many similarities to the temporary fibro fog and ME brain we experience. This is an incredibly frustrating and scary symptom, especially for new sufferers, so hopefully there will be some tips to help us cope and understand it.

October 1st This will be a social get-together with no speaker.

November 5th Remember, remember, our **AGM**! All members are welcome to join in the discussion and to vote in the new committee members. 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.

Benefits Advice Meeting - April 2015

We had a very informative talk and question session with Ian Sneddon of Inclusion Scotland and Rosie Hair of the council's Financial Inclusion and Assessment Team (FIAT). There weren't too many members of the network there but those that were there found it useful and we now have a little more knowledge to help other people in the Network.

I think it was fair to say that Ian was more downbeat and Rosie upbeat about prospects for the disabled and ill people claiming benefits.

I have heard good reports from people who have used the FIAT service for advice and help in form filling. Rosie and the FIAT team have brought many millions of pounds worth of help and support to people in the region, support which may otherwise have gone unclaimed. They can help you every stage of the way – except to represent you at an appeal.

The main message that both had was that it is important to seek advice before doing anything.

Craig Woods

Some comments from members on Facebook:

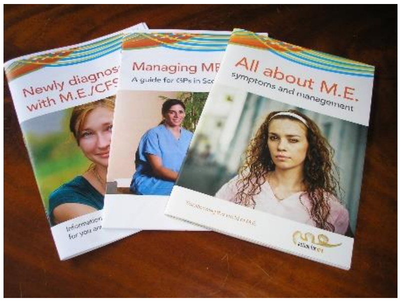
- *I had help from the FIAT team last year to fill out my PIP form, and glad I did as the advisor had a very good knowledge and understanding of my disabilities and was able to word things very well and mention things I may not have thought to include.*
- *Rosie was good so helpful and positive. It's nice to know there are nice people out there who want to help.*

Contact: FIAT ☏ 030 33 33 3008 E-mail: fiat@dumgal.gov.uk

ME Association guides

We have a few copies of the ME Association's guides to filling in forms for ESA - Limited Capability for Work Questionnaire (ESA 500), and for PIP. If you wish to borrow either of these then please contact Craig on the Network's dedicated phone line 07437 602610 or email Paul at paul.dgme@btinternet.com

Action for ME publications



We also have a small supply of Action for ME booklets entitled:

- All about M.E. - symptoms and management
- Managing ME-CFS – A guide for GPs in Scotland
- Newly diagnosed with M.E./CFS

These are available free of charge from Craig or Paul as above.

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

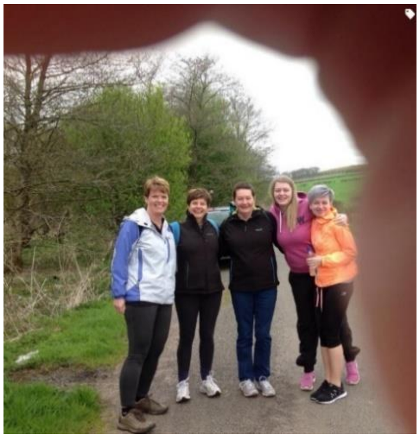
Action for ME
42 Temple Street
Keynsham
Bristol BS31 1EH
£21 to become a member
☏ 0117 927 9551
www.actionforme.org.uk
E-mail:
admin@actionforme.org.uk

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
Ingatestone CM4 9TE
☏ 0845 003 9002
www.tymestrust.org

Sponsored Walk - Raises £600

Sunday 3rd of May was an exceptionally lovely day for our sponsored walk. We set off from Torthorwald at 11.30am and walked to Tinwald and then back to Torthorwald. We just took our time and ambled along enjoying the views from up there. Although there was only 5 of us we managed to raise the phenomenal amount of £600. A big thank you to all the DGME members who kindly sponsored myself, also a huge thank you to my walkers and their sponsors.



I have also been raising money for the group through selling bits and pieces donated from DGME. Selling them online and Car Boot Sales, so if anyone out there has any bits and bobs that are in fairly good condition and are looking to get rid of. Please give me the chance of selling them to raise funds for our struggling group. It takes a lot of our funds just to publish and post this magazine. If anyone is able to donate I will attempt to collect if not too far away. You can contact me on 01387 264334 and ask for Elaine....

Elaine Waugh

Fibroduck Blackpool Event

On May 12th - International ME/CFS & FM Awareness Day - the Fibroduck Foundation charity were in Blackpool fundraising for fibromyalgia research. They managed to pull off a very successful event, raising £1380.82 through street collections, raffles and face painting. The day culminated in Blackpool tower being lit up with the charity's name to raise awareness of the condition! It was lit up in purple (the colour of fibromyalgia awareness), with the letters FIBRODUCK running through the heart. It was a spectacular way to raise awareness of fibromyalgia and I was honoured to have been a part of it (as official event photographer) - it meant so much to me to see fibromyalgia finally getting the recognition it should have, and making our invisible illness visible in such an amazing way! While taking photos of the tower in full darkness later at night I was stopped by several passers by who asked me what it what was all about and wanted to know more - which demonstrated the impact it had and the awareness raised!

If anybody would like to know more about the Fibroduck Foundation, their website is http://fibroduckfoundation.com and they can also be found on Facebook.

Emma Medd

Wanted – Secretary

The Network currently does not have a secretary. To be able to continue we need someone to fulfil this role. The main responsibilities will be database management and minute taking.

……..and 'Webmaster'

We would also like someone to help build and maintain our website. Basic training and support are available.

Integration of Health and Social Care

Dumfries and Galloway Partnership have issued a draft strategic plan entitled ‘Planning for our new health and social care strategy: 2016 -2019'. The plan was out for consultation until 28th August.

“This is the first version of our plan based on what we have learnt so far from listening to local people living across Dumfries and Galloway. The results from this consultation will shape and inform the second edition of the Strategic Plan. This will then be recirculated to all of those who have been consulted for final comment. The final version of the plan will help shape and inform strategic decision making that will change the way health and social care is developed in Dumfries and Galloway.”

You can see the document online at **www.dumgal.gov.uk/consultations** and click on the Strategic Plan for Health and Social Care Integration link. There is a link at the bottom of that web page to an Easy Read version of the plan.

Annandale & Eskdale Survey

The Annandale & Eskdale Survey results are still being processed and analysed, and it is hoped that a report will be completed in the next month or so. To date there were over 600 respondents, of whom a quarter were carers. The survey questionnaire did not include a category ME/CFs or Fibromyalgia as a condition or disability, however, because of our involvement SHAP have separated this out as a distinct group for their report, rather than us being grouped with ‘other’. Interim results suggest that loneliness and social isolation are a significant issue, and high on the list of what people would like to see are better communication and condition specific support. Around half respondents hoped to see less duplication and more joined up working as a result of integration. A large proportion of carers want more support, and significant numbers want respite and more opportunities for involvement.

Locality Plans

Stakeholder groups in each of the four localities are drawing up Draft Locality Plans. They outline the services from NHS and Council being joined together under health and social care integration and the links to other services and community resources in the area. “It looks at what is working well and what could be better. It looks at what we know about the changing needs of the local population and what we need to do to change the way we do things in the future. It sets out some key challenges and priorities for health and social care locally and how we might take these forward.”

It is expected that these plans will be out for consultation around October to December this year. The consultations are to be widely publicised and could take the form of presentations and focus groups. We will be advised directly by an Integration Programme Support Officer when and how these consultations will begin.

Paul Thompson

easyfundraising
.org.uk

Please help DGME Network by doing your online shopping via easyfundraising.org.uk .You will raise a free donation for the group with every purchase made. It is really easy and won’t cost you a penny extra. Register here, http://www.easyfundraising.org.uk/causes/dgmenetwork .

We currently have 16 supporters and as of the end of July we have raised £122.80 for the Network. Well done everybody!

Helen McCullough

New UK research could lead to a blood test to diagnose fibromyalgia

Fibromyalgia is common pain syndrome causing widespread muscle and bone pain, as well as fatigue and disturbed sleep. It has no obvious physical cause, is poorly understood and difficult to diagnose, treat and manage. For years there was doubt among the medical profession whether fibromyalgia actually existed – except in the minds of patients.

There is still no specific blood test, scan or x-ray that can confirm a diagnosis of the common pain syndrome, although blood tests are often carried out to rule out other conditions.

Now scientists at King's College London, funded by a three year grant of £171,000 from Arthritis Research UK, are hoping their latest research will lead to a reliable blood test to enable doctors to make a proper diagnosis.

The research team will examine samples and measurements taken from 400 twin volunteers from the 13,000 Twins UK Bioresource in which one twin has chronic widespread pain, to try to identify biomarkers in the DNA associated with the condition. It will be compared with the DNA of their healthy twin, to establish differences.

"Currently there is no blood test for fibromyalgia which makes diagnosis difficult," explained lead researcher Dr Frances Williams. "And treatment is limited, and in many cases unsatisfactory.

"Our research will help patients in two ways. First it will contribute to our understanding of how fibromyalgia – and other chronic pain syndromes such as irritable bowel syndrome – develop – and point to pain pathways, which we may not have suspected.

"Secondly, we hope it will lead to identification of a biomarker which we could work into a blood test. As well as enabling the condition to be diagnosed more effectively, it could help to 'stratify' patients into groups depending on disease severity, which will help in clinical trials of potential new treatments. It might even help us predict how the condition will progress."

Nancy Wilson - from 'Medical Xpress', May 2015, by Jane Tadman

Chronic Fatigue Syndrome found worse than Diabetes, Multiple Sclerosis, Cancer, etc.

A Danish research group put the impact of chronic fatigue syndrome to the test recently. They compared the quality of life scores of people with ME/CFS with people who had serious medical disorders.

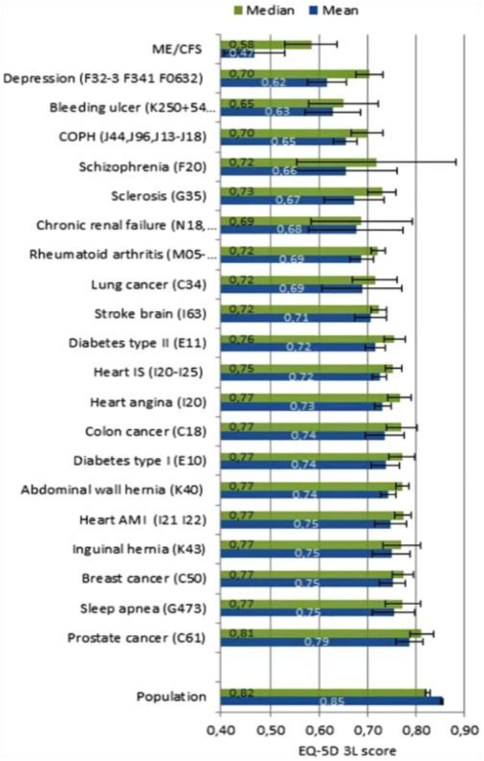
The authors looked at median and mean quality of life scores. How did the quality of the lives of people with ME/CFS stack up next to those of people with cancer, multiple sclerosis, heart attack or stroke? They were worse – significantly worse.

People with the big, scary diseases (the ones people think – "Please, Lord not me!") all had consistently **higher** quality of life scores than people with ME/CFS.

People with ME/CFS had the lowest median quality of life (QOL) scores of any disease tested. If the median scores were disturbing, the mean scores were frightening. A significant drop in the mean ME/CFS QOL score surely reflected a significant subset of ME/CFS patients, with very, very low quality of life scores.

Chronic fatigue syndrome is widely regarded as a rather minor disease and its funding reflects that. This study, though, suggests ME/CFS places a greater burden on those afflicted with it than do many of the most serious diseases of our time.

From 'Health Rising', August 2015, by Cort Johnson



M.E. and Me

Me, get M.E.?
No way, not me.
Doesn’t exist anyway, does it?
Just an up market flu for the delicate few, isn’t it?

OK, so maybe this ‘post viral fatigue’ could become
M.E., Doc,
But not with me.
Just need a rest, a few weeks off.
Positive attitude, that’s all it takes.

Um.
This is dragging on a bit now.
So if this isn’t fixed after six months, then it’s
M.E., you say?
But there’s medication, right? Rehabilitation.
Exercises, physiotherapy,
Specialists, clinics, consultants………
No? None?
Nowhere?

Diet!
Macro, micro, organic, superfoods.
Not exactly mainstream, but it’ll fix it, so worth it.
Bit of reiki, bit of homeopathy,
Bit of meditation, bit of reflexology.
And a lot of money.
It’s a plan.
Action!

But it didn’t. Fix it.
Mind said, ‘GO’ and Body said, ‘no.’
And I’m not one of the delicate few with flu.
This thing is real.
And here.
A whole new gear
I didn’t know existed.

Sloooowww……
Fuzzzzeee……

Time to smell the roses, watch the world go by, put my
feet up, stick the kettle on, relax, take the weight off my
feet, take stock, re group, evaluate, figure, ponder,
wonder,
Retire.
‘Tired, but not re-tired’ isn’t going to work for me.

ESA/DLA/PIP/
Greenock/Wolverhampton/Belfast/
Deductions/enhancements/assessments/
It’s more like work than work was.

But, hey, it’s okay.
I’m still smiling –
most days.
It’s just different.
That’s what.
Just
Different.

Sarah Chadfield

Apache Blessing

May the sun bring you
New energy by day
May the moon restore you
Softly by night
May the rain wash away your worries
May the breeze blow
new strength into your being
May you walk gently through the world
And know its beauty
All the days of your life.

Activity Management and Pacing

Many people with ME, CFS, and FM tend to follow the 'boom and bust' pattern of activity. This means on better days you do as much as you can then you relapse for days, weeks or even months after. We all do it and sometimes if the activity is a special event, then it's worth it. If you really overdo it though then this can send you to a really bad place – physically, mentally and emotionally. If we want to change this pattern of activity to one which is more sustainable, then we need to look at pacing. The aim of pacing being to find a baseline level of activity that you can sustain from day to day, week to week etc. In many cases this baseline will be less than what you currently achieve.

Where do you start?

Firstly you need to look at your activities and see where all your energy is going. You should bear in mind that activity is not just doing physical things but also includes mental and emotional activities. These can be just as draining, if not more-so.

Make a list of all the activities you undertake each day. These can include reading, getting washed and dressed, watching TV, preparing meals, shopping, housework, cooking, meeting friends, phone calls etc. Beside each activity write down whether this is a High (H), Medium (M) or Low (L) level activity for you. That last bit is important as each of us has different capabilities. For instance, taking a shower for me is a high energy activity, for others, getting out of bed, or going to work might be what can be achieved.

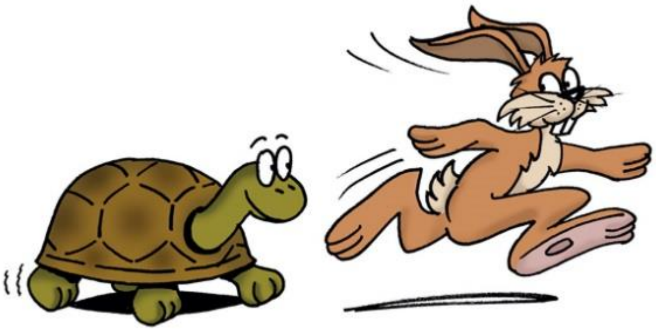
Now you need to use coloured pens (five pack highlighter pens are good) to fill in your activity diary overleaf. This can be photocopied, or if you want a printable version please e-mail Paul at paul.dgme@btinternet.com. The activity diary is in one hour blocks so if your activity lasts less than this then just colour in part of the block. If you want to makes some notes of your actual activities, or keep a pain diary then do so using a pocket diary to go with the sheet. Just jot down some main features.

Remember in the daily sheet that rest is where you are quiet both physically and mentally. This would include meditation time, bed rest etc. Reading and TV is not classified as rest but as activity.

You should complete this activity diary for as long as you are able, until you see a pattern developing. Are you working on 'boom and bust', or do you actually manage your activities well? We will look more closely at this in the next newsletter.

A good booklet on Pacing is available from Action for ME. It is free to AfME members and free to download, otherwise costs £4. We have a number of these booklets available so if you would like one for free, please e-mail Paul at the address given above. The ME Association also have leaflets on pacing that can be downloaded from their site.

June Randell



Activity, Rest and Sleep Diary

Week 1	*Morning – a.m.*												*Afternoon/ evening – p.m.*											
__/__/____	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Week 2	*Morning – a.m.*												*Afternoon/ evening – p.m.*											
__/__/____	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Key:	🟥	High Energy Activity	🟧	Medium Energy Activity	🟨	Low Energy Activity	🟩	Rest	🟦	Sleep