

Welcome all,

By now you'll have noticed the leaflets dropping out of this edition. These have been put together using Network funds, in an attempt to spread word of our existence and to point those newly diagnosed towards the help and support which is available. This is something GPs struggle to do, so we'll be hoping to distribute the leaflet through the region's practices. In the meantime please share your spare leaflets with anyone who may benefit from learning of our group, or perhaps you could take it to your GP's surgery, or ask to leave it somewhere such as your local library or shop.

Christmas and the new year are rapidly approaching. A busy and tiring, but hopefully, fun time for all. There's still just time to book your place at our Christmas meal if you're quick. This year it'll be held at the popular inn, The Swan, at Kingholm Quay. Search online for their Christmas menu and pricing. *If you'd like to go you need to please call, text or message us with names and an indication of what you'd like to order.*

We, at the Network, wish you a wonderful Christmas, and a happy, healthier new year, when it comes.

Craig Woods

Monthly Get-Togethers

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

December 1st Our guest will be Hazel Borland, Fibromyalgia Action UK administrator.

January 5th Our usual social get-together.

February 2nd and March 2nd Our usual social get-together.



As with all the Midsteeple get-togethers refreshments will be available. There's no charge to attend. Feel free to bring along a snack. It is fully accessible with a lift to the first floor meeting room (press and hold the button to call it and then again until the door unlocks on the first floor). Entry is through the blue Box Office door - see our website for a video guide. Stay for as much or as little as you'd like. Use the Facebook page to request or offer transport.

Pop-Up Meetings

Look out for other pop-up meetings on our Facebook page or the website

December 11th Sunday 12.30 for 1pm Christmas Lunch at The Swan, Kingholm Quay, Dumfries.

January 22nd Sunday 1 – 3pm 'pop-up' social at Castle Douglas Garden Centre Coffee Shop. There will be the usual menu of snacks and also the option of their weekend 2/3 course lunch. The Centre is on the edge of Castle Douglas heading out on the Dalbeattie road.

Contact us:

phone - 07437 60261

email - admin@dgmefm.org.uk

Registered Charity No. SC030641



Research News round-up

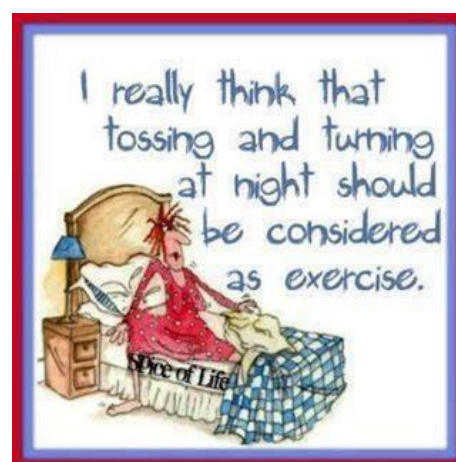
ME Research has been in the news a lot since our last newsletter – but also strangely absent.

Several major developments have broken recently. The University of California believe they have developed a blood bio-marker, which can be developed into a blood test for ME. This in itself is a huge advance as once that happens, and your GP can see in black and white that you actually have a biological reason for your pain and fatigue, attitudes will change and therapeutic treatment options should become easier to access.

What was more surprising from the study however was the particular bio-marker they discovered – it showed that their ME patients were in a state of 'dauer', a state akin to hibernation! This is a state found in nematode worms, where the worms adjust to difficult environments by slowing down to survive.

This raises many questions but it could lead to possible treatment pathways. The ME Association have launched a Christmas Appeal 'Make Me Better' to raise £50,000 to fund further research on this by scientists from the Universities of Oxford and Newcastle looking at metabolomics, the study of the unique chemical fingerprints that specific cellular processes leave behind. The research will analyse blood samples, many of which will come from the ME/CFS Biobank – its first significant use by external researchers – in comparison to those from a control group.

Meanwhile, the figures behind the PACE Trial were released after Queen Mary University London (QMUL) spent £200,000 trying to keep them hidden. The PACE authors grossly exaggerated the effectiveness of CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) by up to fourfold, but an independent reanalysis, based on the original protocol, brought the 'recovery' statistics down to 7% for CBT and 4% for GET, at which level they would be regarded in scientific study terms as 'not statistically significant' - a null result.

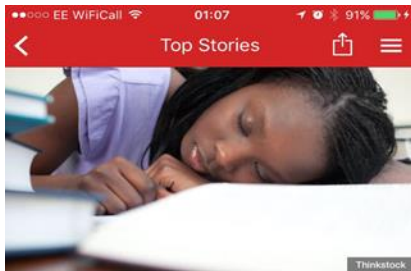


As you may remember from previous updates on this scandal the trial was very flawed and heavily skewed to show beneficial results in many other factors too.

Strangely, and scandalously in the case of the PACE Trial given its potential harm to patients and the large cost to the taxpayer, neither of these stories hit the mainstream press, going unnoticed by most outside the ME community.

However what was headline news, and top story on the BBC News, was the report that a new 'FITNET' intervention could cure (later amended to 'treat') two-thirds of teenagers. This was strange as the trial had not even begun and will be based on delivering CBT by Skype to ill teenagers. CBT has its place in helping people cope with illness, but was shown as ineffective as a 'treatment' for ME/CFS under the original terms of the PACE trial in adults.

The FITNET-NHS trial on 734 children, will use 'intensive online therapy sessions to adjust sleeping habits and activity levels'.



Landmark chronic fatigue trial could cure two-thirds



James Gallagher
Health and science reporter, BBC News website

23 mins ago | Health

A therapy that successfully treats two-thirds of children with chronic fatigue syndrome is being trialled for NHS use.

The disease affects one in 50 children, leading to mental health problems and missing school.

"If anyone has done a cross-country [run] or a marathon... that is how it feels all the..."

However, the reporting was inaccurate because it grossly exaggerated and mis-represented the findings of a small Dutch study in young people upon which the FITNET trial relies as evidence of efficacy: whilst there was a significant difference in school attendance at six months in those who received internet CBT versus those who received "usual care" (75% vs 16%), the ultimate findings of the Dutch study showed no difference between the groups at 2-year follow-up.

Based on the extensive biomedical evidence, the FITNET trial cannot offer hope or promise of recovery.

It is of concern that these youngsters who take part in the FITNET-NHS trial, and their parents, will have their hopes raised and perhaps feel under greater pressure to 'get better', yet with the possible repercussion from taking part in the trial of worsening symptoms and further emotional let-down.

More favourably from the BBC, the Kaye Adams programme on BBC Radio Scotland discussed ME on 7th November with ME Association medical adviser, Dr Shepherd, and a number of callers. Participants spoke about harmful or unhelpful consequences from following the NICE guidelines on ME/CFS, which recommend GET and CBT, and of the poor level of support to patients, who are left to find their own way to manage the condition. Dr Shepherd explained that while the NICE guidelines on ME/CFS came out before the PACE trial, NICE then used the supposed findings to justify their guideline. The programme is available on BBCi player until 6th December <http://www.bbc.co.uk/programmes/b081myv0> - the bulk of discussion on ME is in the final hour of the 3 hour programme.

**BBC
RADIO**



Scotland

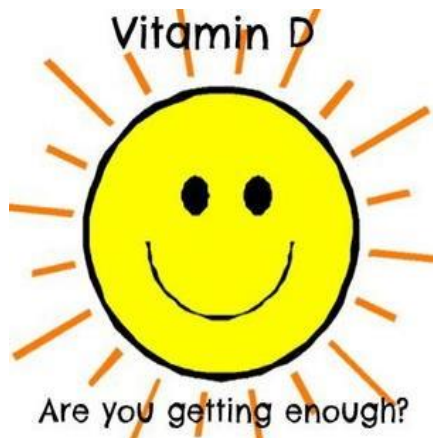
In our recent meeting with Dr Bell, the region's Associate Medical Director, Primary Care, she expected that GPs in our region would follow the Scottish Good Practice guidelines rather than the NICE guidelines. It would be helpful to see if that is the case and to know whether any of you have been recommended GET and CBT as a treatment regime.

Committee News

Many thanks to Margaret Blake and Elaine Waugh for all their help over the years as Committee members, who both stood down at the AGM in October. Craig Woods (Chair), Kim Jakobsen (Secretary), Paul Thompson (Treasurer) and Nancy Wilson continue to serve, and we are pleased to welcome Louise Marie Adair and Kim Dams to the new Committee.

Whilst the Committee meet formally just 3 to 4 times a year, we are in regular contact and discussion through a dedicated Committee page on Facebook.

If there are any matters you would like to raise with the Committee please let us know by phone ☎ 07437 602610, or email admin@dgmefm.org.uk



Vitamin D3 (cholecalciferol)

At this time of year the sun is too weak in our part of the world for our skin to create any vitamin D. Practically everyone in Scotland is deficient. Scientists think this may explain the higher incidence of MS here and it could have some implication in ME and FM too. Taking a daily supplement is a sensible precaution and may also help lift our moods over the dark winter months. The Department of Health advise that people who have very little exposure to sunshine should take a daily supplement containing 10mcg of Vitamin D.

The Ever Shrinking and Expanding World

This year, more than most, I have had more extremes to my ME than usual. There have been many reasons for that: from Gabapentin masking the warning signs to slow down which has led to too many crashes and two full-blown relapses; to a new pill pulling me out of one of the relapses, but the effects of which were limited to a boost lasting about 5 weeks or so, followed by the effects of a seasonal cold/flu bug.

It has shown me, in stark contrast, how my world, and how all our worlds expand and contract with our health.

At my worst this year I was limited to my cottage and immediate surroundings by the extreme fatigue and pain. Nothing existed before midday, and the day ended again around 5pm when I'd flake out, before I'd get another couple of hours of reasonable time in the evening as I should have been getting sleepy. My car barely turned a wheel and even Dumfries or Lockerbie (both 7 miles from me) were a struggle to get to – and even more difficult to get home from. My world didn't even reach into Galloway or to the border.

During reasonable, and more average periods of health, my range is not much greater than Lockerbie or Dumfries, but it's accessible more often and more regularly. Carlisle could be got to, at a push, so long as I took it easy when there, and rested for a few days afterwards. Glasgow again is possible, but only by train, and with the help of taxis and lots of stops for a sit-down when there.

However during the 5 weeks or so good spell the world opened up to me. My car clocked up many more miles as I started catching up on commitments which had long been postponed. Friends who I'd not seen in ages saw me again, I went out for meals and to shops and didn't collapse back into my little, exhausted world of the cottage at the end of the day. Possibilities opened up. I dared to plan.



Sadly that spell has come to an end. The fatigue, pain, malaise, non-refreshing sleep are all back. Energy is more limited and my horizons are drawing in again.

It is almost a process of mourning as the extent of my world shrinks around me and travel plans, life possibilities and dreams again become more unlikely to happen, or at the very least more difficult to accomplish.

Craig Woods

Would you like to share your experience of living with ME, CFS or Fibromyalgia?

What has made it worse and what has helped?

If you are happy to write a bit for a future newsletter please send it to admin@dgmefm.org.uk

A letter to the healthy world from the land of Fibromyalgia

My pain - My pain is not your pain. It is not caused by inflammation. Taking your arthritis medication will not help me. I cannot work my pain out or shake it off. It is not even a pain that stays put. Today it is in my shoulder, but tomorrow it may be in my foot or gone. My pain is believed to be caused by improper signals sent to the brain, possibly due to sleep disorders. It is not well understood, but it is real.

My fatigue - I am not merely tired. I am often in a severe state of exhaustion. I may want to participate in physical activities, but I can't. Please do not take this personally. If you saw me shopping yesterday, but I can't help you with work today, it isn't because I don't want to. I am, most likely, paying the price for stressing my muscles beyond their capability.

My forgetfulness - Those of us who suffer from it call it fibrofog. I may not remember your name, but I do remember you. I may not remember what I promised to do for you, even though you told me just seconds ago. My problem has nothing to do with my age but may be related to sleep deprivation. I do not have a selective memory. On some days, I just don't have any short-term memory at all.

My clumsiness - If I step on your toes or run into you five times in a crowd, I am not purposely targeting you. I do not have the muscle control for that. If you are behind me on the stairs, please be patient. These days, I take life and stairways one step at a time.

My sensitivities - I just can't stand it! "It" could be any number of things: bright sunlight, loud or high-pitched noises, odour. FMS has been called the "aggravating everything disorder." So don't make me open the curtains or listen to your child scream. I really can't stand it.

My intolerance - I can't stand heat, either. Or humidity. If I am a man, I sweat...profusely. If I am a lady, I perspire. Both are equally embarrassing. And don't be surprised if I shake uncontrollably when it's cold. I don't tolerate cold, either. My internal thermostat is broken, and nobody knows how to fix it.

My depression - Yes, there are days when I would rather stay in bed or in the house or die. Severe,

unrelenting pain can cause depression. Your sincere concern and understanding can pull me back from the brink. Your snide remarks can tip me over the edge.

My stress - My body does not handle stress well. If I have to give up my job, work part time, or handle my responsibilities from home, I'm not lazy. Everyday stresses make my symptoms worse and can incapacitate me completely.

My weight - I may be fat or I may be skinny. Either way, it is not by choice. My body is not your body. My 'appetate' is broken, and nobody can tell me how to fix it.

My good days - If you see me smiling and functioning normally, don't assume I am well. I suffer from a chronic pain and fatigue illness with no cure. I can have my good days or weeks or even months. In fact, the good days are what keep me going.

Anon

Fibromyalgia Action UK

Our guest at the Midsteeple 'get-together' on December 1st will be Hazel Borland, FMA UK administrator. Fibromyalgia Association UK merged with FibroAction in July 2015 to form Fibromyalgia Action UK (FMA UK). Since both charities had the same mission and aims and provided similar services benefiting the same group of people nationally, they agreed to combine their expertise, experience and resources to better serve people affected by fibromyalgia.

FMA UK operate a general fibromyalgia helpline ☎ 0300 999 3333 (week days 10am – 4pm) and a benefits helpline ☎ 0300 999 0055 (Mon, Wed, Fri 10am – 12pm)

For more information about the support and resources available from FMA UK, visit their website fmauk.org or phone ☎ 0844 826 9022

Dumfries & Galloway LGBT Plus

There is a support service within the D&G Lesbian, Gay, Bisexual and Trans group aimed at those suffering with, or caring for someone with long term conditions. They offer support services and also training throughout the region. Upcoming courses include Understanding Health and Social Care; Assertiveness Training; Know Your Care Rights; and Self-manage Long Term Care Conditions. The courses are held in Stranraer, Castle Douglas, Dumfries and Lockerbie. They are well funded and can tap into many more resources than we can. If you, or someone you support, fall under the LGBT+ banner check out how they may be able to help you. Their number is: 0800 020 9653 or email: support@lgbtplus.org.uk.

The poster is for Dumfries & Galloway LGBT Plus LTC support. It features a purple cross logo with 'DUMFRIES & GALLOWAY LGBT PLUS' and 'LTC support' written on it. The text describes the Long Term Conditions (LTC) support service, which is available to LGBT Plus adults, their carers, and families. It lists various support services: 1:2:1 Support, Online Support, Telephone Support, Group Support, Advocacy, Monthly Newsletter, Befriending, Bespoke Courses, and Factual Information. It also mentions that the LTC advocacy and support service is available Tuesday, Wednesday, and Thursday for LGBT Plus people with LTCs, their carers, and families. For enquiries, it provides the email support@lgbtplus.org.uk or the phone number 0800 020 9653. The poster is signed off by the Alliance for LGBT+ People and includes the text 'Dumfries & Galloway LGBT Plus is a Scottish registered charity No SC045377'.

Our Long Term Conditions (LTC) support service is available to LGBT Plus adults, their carers and families. Through our self-management service we aim to put you back in the driving seat, to live your life better on your terms.

DUMFRIES & GALLOWAY LGBT PLUS
LTC support

1:2:1 Support
Online Support
Telephone Support
Group Support
Advocacy
Monthly Newsletter
Befriending
Bespoke Courses
Factual Information

Our LTC advocacy and support service is available Tuesday, Wednesday and Thursday for LGBT Plus people with LTCs, their carers and families. For enquiries, please email: support@lgbtplus.org.uk or call: 0800 020 9653

Dumfries & Galloway LGBT Plus is a Scottish registered charity No SC045377

D&G Wellness & Recovery College

We may have the opportunity to develop and run a short course through DGWRC on living with ME/CFS and Fibromyalgia. However, this would require the involvement of a professional in the field, i.e. Medical, OT, Social Work or similar. If you know of anyone qualified who might be interested to help with this, please ask them to contact us admin@dgmefm.org.uk to arrange initial discussion.

Starting your own business whilst having Fibromyalgia

Claire Shaw brought us the piece entitled 'Living with Fibromyalgia' in our June 2016 Newsletter, and we are now pleased to share her follow up story on how she set up her new business.

After being medically retired from the Scottish Prison Service at the age of 40, I really did not know what to do as regards to the rest of my working years! I had two options, get a job or start my own business, I had a lot to think about!

I didn't know what type of job I wanted, what I did know was that I had to get a job that paid well as I was used to a good annual income with working for the Scottish Prison Service and I had bills to pay! But I kept telling myself, who is going to employ a 40 year old with no qualifications other than what I achieved when I was at secondary school and has a medical condition that could mean I potentially could have more days off sick than the average person. So, my mind was made up, it has to be self-employed as this would allow me to work when I wanted and be my own boss, and if I was my own boss I knew I couldn't lose my job because of my disability, but most importantly I had to do something that I would love to do and would make me happy. I know within myself that when I am happy my Fibromyalgia symptoms are not as bad and I can cope with them better.

The next decision I had to make was, what do I do? I had always loved dogs, and looked at careers within the dog industry, I knew I didn't have the time to choose a career that required a lot of training. I chose dog grooming, as the training was a 25 day course which consisted of lots of practical work but also theory work, my only concern I had was the theory work! I hadn't done anything like this since I left school at the age of 17 and I didn't have 'Fibro Fog', severe fatigue or severe pain throughout my body when I was at school!

But before I committed myself to anything, I had to gain some work experience in the dog grooming industry. I was very fortunate that one of my bosses at the prison knew a couple that had their own dog grooming business at Livingston, so my boss set it up with them that I could go and visit to see if I could do the job and to see if I liked it. I knew that I would love it, but being quite an impulsive person I thought I really need to be sensible about this, so I took my oldest sister with me, as she had had experience working for Business Gateway and I needed to have someone with me that knew about businesses. The couple I visited could not have been any more helpful, they advised me where to do my training, they talked about the bad points of dog grooming and being self-employed, they talked about their annual income and how much they loved what they do, so after two days of working with them, my mind was made up. I want to be a dog groomer.

Setting up the business was easy, I worked with Business Gateway who were great and I did several of their workshops and took all their advice. I did my training at a dog grooming college in

Somerset, this was the hardest part of setting up my business. I had to do 5 weeks training. Each week started with a 334 mile drive to Somerset followed by 5 days of practical work and in the evening was theory work, then on day 5 after a day of practical work I had another 334 mile drive to get home! I found the 5 weeks very hard, not because it was difficult, but because my body and mind struggled to cope with all I had to do and this was solely down to having Fibromyalgia! My body was so sore due to the physical side of it, standing all day, lifting heavy dogs and using the same muscles over and over again! My mind could not take in all the hours of studying or learning a new trade, my brain just could not retain all what I was studying/learning and no matter how many hours I studied it still didn't sink in!

What kept me going was my end goal, my dream, this was having my own business doing something I was going to love! I passed all my practical and theory exams and qualified on the 2nd October 2015. When I finished my training I had to get my shop ready which took just over four weeks and my business started the 7th/8th November. I was excited and a little scared about it all. Excited because it was a new adventure and scared it wasn't going to be a successful business.

I am now fully booked with clients 3 months in advance, even though I have Fibromyalgia my business and my life is great. The strange thing is, if I didn't have Fibromyalgia I wouldn't have started my own business doing something that I love. Even though I wake up every day with my body feeling like I had gone 15 rounds with Mike Tyson the day before, feeling like the energy fairy has come through the night whilst I was sleeping and stole all my energy I'm still very thankful I wake up every day!

Claire Shaw

Website Monthly Blog

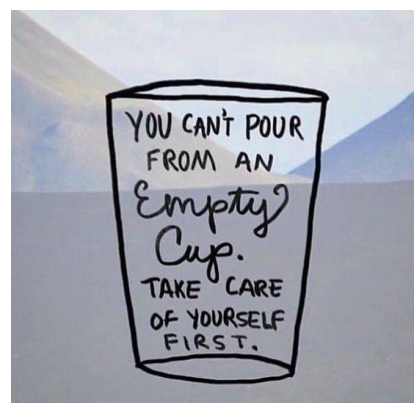
Michelle Mungin and network secretary, Kim, have kept up a monthly 'blog' on our website to capture key elements from our Facebook community posts. This includes links to the wide ranging articles and news stories posted by members, and an anonymised summary of members' discussions. If you haven't joined our Facebook group you can keep up to date by visiting our website <http://dgmefm.org.uk/>

Gift Day thanks



Many thanks to all who contributed to this year's 'Gift Day'. We have received £695 in donations and claimed £132 in Gift Aid from HMRC on eligible donations, totalling £827 which will nearly cover the cost of our quarterly newsletters.

It's never too late if you meant to donate but forgot - please visit our website <http://dgmefm.org.uk/donations/>



DGMEFM



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

Phone: 07437 602610

Website: www.dgmefm.org.uk

Facebook: facebook.com/groups/dgmefm

Email: craig@dgmefm.org.uk (Chair)

kim@dgmefm.org.uk (Secretary)

paul@dgmefm.org.uk (Treasurer)