

*Welcome all,*

First of all, please allow me to apologise for the later than usual arrival of your newsletter. As you will see we have been busy preparing the new data protection policy, attending meetings and arranging a couple of Awareness events for May - which we wanted to give you details of in this edition. It follows a bad spell for me up until January which of course itself led to a large backlog of work for me to get through. The Network is run entirely by sufferers of ME and fibro, so I'm afraid it has to fit around our energies and our fluctuating abilities. Again, apologies.

It is an interesting time in the history of ME and also fibromyalgia. I am sensing a shift in understanding away from the purely psychological back towards a biological cause. This is partly an own-goal by the people behind the discredited PACE Trial and partly as a result of advances in science, particularly in America. This is something we have to promote at the highest level we can within the region and beyond. The current misconceptions affect us every time we use the NHS, apply for benefits, and it causes social stigma. Hopefully our Awareness events can go a little way towards enlightening the general public and those who direct our care. We will campaign to change this – and you can do your bit too by learning about, and explaining your illness, to friends, family and health professionals, every day and especially in Awareness Week.

*Craig Woods*

## Monthly Get-Togethers

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



**April 5<sup>th</sup>** On the controversial theme 'Cognitive behavioural therapy (CBT) – could it help me cope better with my illness?' This is not a CBT workshop but discussion around what it is/isn't, how it might help, and any negative views. Our guest from 1.30pm is Dr Alison Wren, D&G Clinical Health Psychologist.

**May 3<sup>rd</sup>** Q&A – sharing with each other our understanding and experience of ME & FM; and discussion about 'Expert Patient' mentoring.

**June 7<sup>th</sup>** Discussing ideas for hobbies and pastimes with ME/FM.

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 1<sup>st</sup> floor.

## Pop-Up Meetings

**April 19<sup>th</sup> Thursday** 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. We usually have the table area at the corner with the sofa.

**April 22<sup>nd</sup> Sunday** 11am – 1pm social at **Brambles Tea Room**, 1 Commerce Road, **Stranraer**. Come along and meet other members in the Stranraer area over a cuppa or a snack.

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

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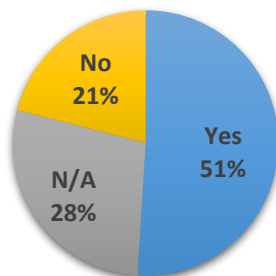
To comply with the General Data Protection Regulation (GDPR), we enclose a new Privacy Policy Notice with this newsletter. As part of our commitment to privacy and transparency, we want to give you information about how we collect and use personal information. This Policy clarifies your rights under the new regulation and provides more information about how we administer and manage your personal data.

You don't need to take any action. Our Privacy Policy went into effect in March 2018, and by continuing to use our services (i.e. remain as a member) you'll be consenting to the Privacy Policy.

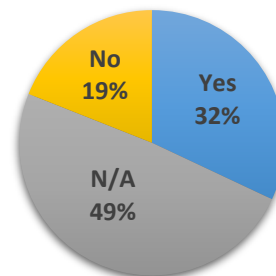
## Feedback questionnaire

In the last newsletter we summarised some of the findings from the questionnaire sent out to members in the summer. Our December issue described respondent's views about our Newsletter and about Meetings. Other key findings were about the support that members receive.....or not.

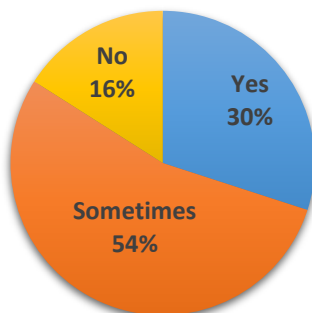
Do you get the welfare support/benefits you need?



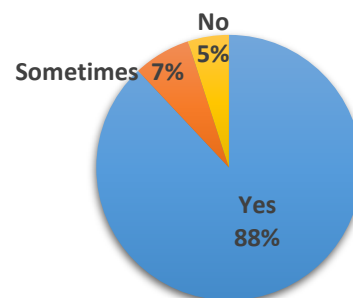
Do you get the personal care required that you need?



Do you feel isolated?



Does your illness impact on your social life?



While there were a few respondents at each end of the 'severity of illness' scale, the majority ranged within levels 5 to 8, on a scale of 10 being most severe.

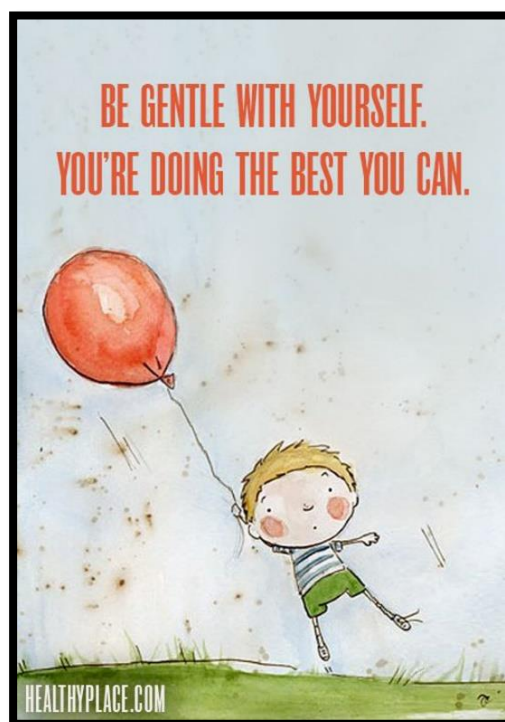
The charts highlight that a significant proportion of respondents are not getting the financial or personal support they need, and that most feel isolated at least some of the time, with their illness impacting significantly on their social lives.

While we may not be surprised at this feedback, it will be helpful anonymised information to support our lobbying on members' behalf. *The Scottish Government are currently consulting on a National Strategy to tackle social isolation and loneliness. We gave our views at a meeting in March with one of the co-ordinators contributing to a regional response.*

## Helpful Tips

One of our members sent in their suggestions, tips and reminders for coping with ME/CFS and Fibromyalgia.

- ☐ Lower your expectations of what you can achieve.
- ☐ Don't think you are lazy.
- ☐ Don't push yourself.
- ☐ Be gentle and kind to yourself.
- ☐ Learn how to say 'no'.
- ☐ Delegate.
- ☐ Make time for things that you enjoy.
- ☐ There's no quick cure.
- ☐ Find a doctor who you can build up a rapport with.
- ☐ Be your own friend.
- ☐ Use meditation tapes/CDs for resting.
- ☐ Don't listen to the 'shoulds'.
- ☐ Accept things as they are - another day is a different day.
- ☐ Be really truthful with yourself and others about how you are feeling.
- ☐ See the blessing in small things.



## Workwell Foundation – Stevens protocol

I recently had to undergo a cardio stress test and it reminded me of my permanently low oxygen uptake and also of the 'Stevens Protocol' test developed by the Workwell Foundation. I won't comment on the full technical details of the test [which can be found easily on Workwell's website, 'workwellfoundation.org'], I will just comment on its relevance to ME sufferers. From memory, the Workwell Foundation's predecessor was the Pacific Fatigue Laboratory and part of its original purpose was to test athletic performance.

The test is basically a measure of an individual's physical capabilities, involving standard equipment, viz an exercise bike hooked up to CPET [Cardiopulmonary Exercise Test] scanner – in essence, more or less what I was hooked up to for my cardio stress test, but far more data is gathered. Those being tested by Workwell are urged to push themselves to the limit. However, the difference with the Stevens Protocol is that the patient undergoes two tests, 24 hours apart; I'm sure some of you will already have an inkling of where this is going! The results of the two tests are then compared, giving the difference in capability between the two days and thus demonstrating that not only does post-exertional malaise [PEM] exist – it can be measured and correlates to the severity of the patient's symptoms.

Nowadays, the Workwell Foundation focuses mainly on ME [their term is CFS/ME, which I hate], but also does work on Fibro and other fatiguing conditions. The test has been used to overturn decisions where insurers and welfare agencies have turned down claims for payouts/benefits. Moreover, Workwell claim that the test cannot be faked, that it not only proves the presence of PEM and the severity thereof, but it also supports the physical nature of ME and can be used as a diagnostic biomarker for ME, with a 95.1% accuracy. Also, the test is now long-established and endorsed by many organisations in the USA, such as the American College of Sports Testing.

I'm sure you will now be asking yourself why this test isn't already in use in the UK; well, I've been asking myself the same question since I first stumbled across Workwell's activities, probably 15 years ago now. I wrote in a couple of times to 'Perspectives', the ME Association's magazine that preceded their current inhouse magazine, ME Essential, and I also wrote directly to Dr Charles Shepherd; there was little interest. I contacted a few researchers direct to ask if anyone other than Workwell was using two day testing for ME, but only one scientist, Dr Errina Bowman [of the London School of Hygiene and Tropical Medicine] bothered to reply. I have to say that her response was so courteous and thorough that she made up for the others. At that time, only two other scientists were conducting studies which involved testing individuals on two days, but here the emphasis was on the difference between 'good' and 'bad' days – something else I tried to promote to the MEA with no success. From memory, although the two good day/bad day studies were far more complex in that they were analysing many more aspects of PEM, the conclusions were similar – a significant difference in metabolic function. I have to say that sometimes I get frustrated because it seems some scientists are so close to their own specialities that they get blinkered and can't see the wood for the trees. Nearly everyone I have met with ME has good days and bad days, or boom and bust, or pushing too far with the inevitable flare-up. The exceptions have been the severely afflicted – the 25% - and these sufferers present unique challenges to researchers for obvious reasons, which would also preclude them from the Workwell test, but then again, they shouldn't need to have to demonstrate just how ill they are to anybody.

I read very recently some correspondence from one sufferer to the Department of Work and Pensions asking, via a Freedom of Information [FOI] request, why the Workwell test wasn't already in use here; that sufferer is still getting little more than obfuscation and delaying tactics – PACE FOI all over again. Then they wonder why we become 'activists' !

Steve Boyle

*Having recently purchased a fitness tracker I can very easily see my activity levels, heart rate, sleep quality, oxygen levels and blood pressure. Following a busy day I am already noticing that 2 days later my steps taken are half the number – and much more difficult and painful with it. It is going to prove a very useful tool in helping me to pace. Post Exertional Malaise needs to be taken into account in testing and benefits applications.*

Craig

## Brain Fog Strikes

It wasn't a great Christmas and New Year for me. I'd been in a big relapse in the months leading up to it. Pain and energy levels were very high, as was the cognitive dysfunction; the brain fog. On the 1<sup>st</sup> January it was particularly bad. I had had a coffee, earlier in the day, which is incredibly rare for me as it eases my stomach up. I went in to the fridge for the lactulose and had a gulp of it. It tasted odd however. Looking at the bottle I realised I'd downed my wee dog's anti-biotic. I forgot all about it and rested up to visit my brother's house party later. I arrived late, feeling awful, but had a glass of rum to try to get into the spirit of the new year. There must have been a reaction with the antibiotic as I became very drunk, made a bit of a scene and had to be sent off home! The hangover was dreadful. Brain fog 1, Craig 0.

We used to ask people to send in their own brain fog stories to add a bit of humour to the newsletter. There were some funny ones published, but someone complained that we were making a mockery of the illness - which I don't think we were at all. I think it's healthy to be able to have a laugh at the sillier things we can do when the fibro and brain fog strikes because there's

precious little else to laugh about. In no way are we belittling or diminishing the illness or the effects of it – and the cognitive dysfunction is one of the hardest symptoms to deal with, merely having a chuckle at some of the more amusing consequences.

What do you think? Is it something you'd like to see in the newsletters? Do you have an amusing foggy moment of your own to share. Identities (and pride) can be protected!

*Craig*

## ME

ME – where did you find Me?

Was it in the virus that didn't go away,  
or wasn't I listening to the stress I was under,  
or did you just arrive out of nowhere?

ME – why did you find Me?

Was I going too fast in life and needed to  
slow down,  
or were my priorities wrong,  
or was I just unlucky?

ME – what have you taken from Me?

My job, many friends,  
loss of my own self worth,  
my independence, my life.  
You are with me always.

ME - what have you given Me?

Some friends who really care,  
finding blessings in small things,  
learning to take as well as give,  
pain and fatigue,  
the challenge of living with an invisible illness,  
the disbelievers.



*June*

## On-line discussion and posts

Catch up with links to articles posted by members of our Facebook page by reading the latest blogs on our website: <http://dgmeffm.org.uk/blog/>

Recent on-line discussion included:

- The desirability of having a Specialist nurse / GP / Consultant
- Fitness bands to monitor sleep etc
- The benefits of massage for treatment
- Vitamins, supplements and alternative therapies
- Giving up work and support available
- DWP assessments – successes and frustrations
- A 'brain fog' moment resulting in taking the dogs antibiotics was shared – thankfully this person has not grown any whiskers as a result of this mishap.
- [YouTube](#) video '8 Brocades Qigong Practice' was shared as an option for exercises which could be done seated.

## Pop-up Meetings

We would love to cover more of the region but we need your help. Arranging your own get-together is easy. Just let us know your chosen venue and the time and we will promote it on facebook and the website, and in the newsletter given sufficient notice. We can send you a copy of our logo so members will be able to identify you. It can be relatively impromptu. The Garden Wise Café get-together was a very enjoyable afternoon and well-attended, organised with only a week's notice, after the snow drifts forced the cancellation of our March Midsteeple meeting.

## Unrest in the Scottish Parliament

I was invited up to represent the Network at a showing of an excerpt from 'Unrest', the award-nominated film about ME. It was an awareness-raising event for MSPs, with the film followed by a few speakers and a discussion with Jen Brea, the film maker joining us on Skype from her home in the USA.

The film is a very honest portrayal of what life is like with ME, it's about the 'journey' with the illness, and it's partly a love story too. The excerpt was very moving, with many tears shed in the room. Afterwards a couple of sufferers told their own story and Jen spoke about the problems facing us. I managed to speak to her and thank her for all the awareness raising that she is doing. I also managed to speak a little about the PACE Trial and inform the MSPs of the problems it causes in our treatment guidelines and benefit applications and press for it to be replaced in Scotland.

Thirteen MSPs had attended, although not all stayed for the screening. Our South of Scotland region was represented by Joan McAlpine, Emma Harper, Claudia Beamish and Colin Smyth. Other MSPs sent their apologies.

I was particularly impressed with Joan McAlpine, who stayed right to the end, showed great concern and asked all the correct questions. Since then she has asked questions of the NHS Board here about our care, as has Finlay Carson, who, although unable to attend, asked a question in parliament for us, and also of the NHS.

It was a very useful event on many levels. From the initial contact with the MSPs when, on behalf of the Network, I was urging them to attend, to their interaction there, plus the opportunity to Network with other patient and support groups. It will also serve as a model for our own awareness events in this region for Awareness Week in May, more on that on page 7.

*Craig*

## Struggling at Work?

Recommended by one of our members, Working Health Services Dumfries and Galloway are an NHS organisation who are there to support the self-employed and those who work for small-medium sized enterprises (up to 250 employees) to remain in work despite a health problem, such as ME and fibromyalgia. They can organise free physiotherapy and counselling sessions. Their services can include employer liaison support, employment legal advice, work station risk assessments and advice on workplace adaptations. You can self-refer: Tel. Ailsa Black, Case Manager 01387 244626. Email [ailsa.black@nhs.net](mailto:ailsa.black@nhs.net). National free phone no. 0800 0192211 option 3



## Awareness Events

### Unrest in Dumfries and Galloway – RBCFT, Dumfries - Tuesday May 15<sup>th</sup> at 7pm

As you will see from the flyer dropping out of this Spring's newsletter we have arranged a public showing, in conjunction with Robert Burns Centre Film Theatre in Dumfries. There will be a showing of the entire film, to be followed by refreshments and a discussion, hosted by us, with Dr Charles Shepherd, medical director of the ME Association and a sufferer himself, joining us in the cinema via video link.

It will not be an easy watch, but it is a beautiful and acclaimed film and does much to show our plight.

The showing is a public event and part of the RBCFT's scheduled program. This was deliberate to reach as large an audience of possible non-members and non-sufferers. To be sure of a place you will need to book tickets online ([www.rbcft.co.uk](http://www.rbcft.co.uk)), by phone (01387 264808) or with the cinema or at the Box Office in the Midsteeple. The concession price (applying to all our members) is £5.30 and £7 full price. The discussion and tea and coffee afterwards are provided by the Network.



For those unable to attend our screening and discussion but still wishing to view the film, *Unrest* is available to buy on disc now, or from Netflix and the other TV streaming services.

### Professional Awareness-Raising Event

We have also arranged an awareness event for health professionals, NHS management, our local politicians, support charities and anyone else we can reach who needs to be made aware of the scale of the problem in this region and the effects of ME and fibromyalgia.

This will be a private showing of a 23 minute excerpt of *Unrest*, also in the RBCFT cinema on Friday 11<sup>th</sup> May. It will be followed by a discussion around the problems we face in this region. Jen Brea, the filmmaker will be joining us via Skype, and we will have some 'expert patients' to answer questions and provide the health professionals with the experience we have had here. We intend it to be very much a learning experience, pressing our needs, and hopefully will initiate further dialogue with those in a position to improve the services we receive in this region and to open the discussion about what more could be done for us.

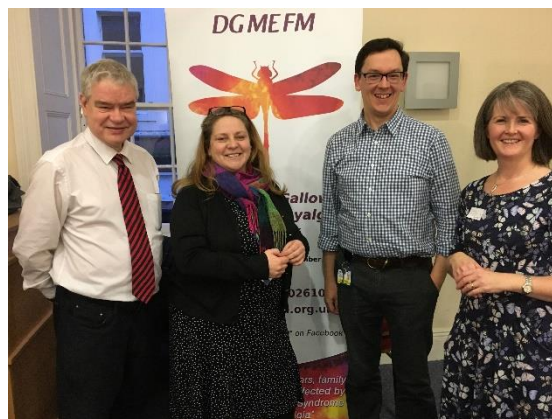


**Please display your *Unrest* film flyer somewhere prominent or ask your local shop, GP practice or pharmacy to pin it up.**

You can also do your bit for Awareness Week by wearing a blue (for ME) or purple ribbon (for fibro). They'll be available from us at our next Midsteeple meetings. Please also use the week to share your experience of the illnesses on social media and with friends. There will be plenty of memes and links posted within our Facebook page for you to further share.

## Meeting with AfME

At our Midsteeple meeting last December we got together with Action for M.E. who invited professionals working in health and social care to a roundtable meeting to examine the current care pathway for people with M.E. in Dumfries and Galloway. Chaired by Theresa from AfME, in attendance with our members were representatives from clinical health psychology (Ross and Alison), the community health and well-being social prescribing team (Danielle), D&G strategic planning (Viv), and Dr Gregor Purdie, Clinical Lead for ME in D&G.



*Gregor, Viv, Ross and Theresa*

Discussion was focussed on three areas – self-management; awareness raising and education with Health Professionals and others; and Primary Care and specialist services. This led to identifying priorities and action plans, amongst which include AfME undertaking to:

- produce a briefing for primary care health professionals highlighting appropriate approaches to treatment management;
- work with D&G Health Care and Strategic Planning to explore local partners to work with and develop a local peer mentoring project;
- increase the advice and support available for people who require to claim benefits by promoting Action for M.E.'s welfare advice line and by engaging welfare benefits organisations in awareness raising events about M.E. and its impact;
- target and invite third sector organisations to engage in its learning opportunities
- target health professionals in D&G to engage in their webinar series;
- through their webinar series address the issue of GP consultations and the effect of brain fog and other symptoms on communication, and to enhance health professionals 'caring conversations';
- produce a patient advice leaflet to support people to get the most from their consultations;
- introduce health professionals in D&G who have expressed an interest in the condition to other clinicians with a shared interest in Scotland.

*Dr Alison Wren, one of the Clinical Health Psychologist attending, has agreed to join us for a discussion about Cognitive Behavioural Therapy at our meeting in April (see front page).*



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