DGMEFM Network

Support for ME, CFS, Fibromyalgia

September 2017

Welcome all,

There's a lot of news this issue – within the Network and in the world of research. First of all thank you to all who completed the survey which was sent out in place of your June newsletter. The information from this will help to guide the future of the Network and will help us to apply pressure where needed to those who may be able to help provide for our needs.

Our AGM is fast approaching. We have ideas about how we can better help you – and initial returns from the survey show that you do too, but with all committee members suffering from either ME or fibromyalgia it is not an easy task to begin to implement. If anyone feels able to come on to the committee or take up a role or run a project we'd be most grateful to hear from you. What we really require is someone fit and able – an arm-twisted spouse or parent perhaps?!

There's been a complete contrast in research news coming from either side of the Atlantic. Here the psychologically-based PACE Trial scandal deepens, with the UK press, not usually known for their informed articles on ME, beginning to pick up on it, while in the USA biomedical research is shedding light – and hope - on a very complex illness.

Craig Woods

Monthly Get-Togethers

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

Sept 7th Our usual get-together with the theme 'medication and supplements'.

October 5th **AGM.** With annual reports and election of a new committee, there will be time for discussion of the way ahead for the Network in the coming year, and the usual social chat.

November 2nd This month the theme is 'diet and nutrition', with guest nutritionist, Karen Scobie.

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

October 15th Sunday 1 - 3pm 'pop-up social at **Castle Douglas Garden Centre Coffee Shop.** There will be the usual menu of meals and snacks, and specials of the day. The Centre is on the edge of Castle Douglas heading out on the Dalbeattie road.

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

Contact us:
Phone/WhatsApp - 07437 602610
email - admin@dgmefm.org.uk

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The following article, abridged from the Daily Mail, accurately reports the current situation around the PACE Trial, which is beginning to make news in the UK, having been mostly ignored by the media to date. The UK press isn't known for its accurate, fair or unbiased coverage of ME/CFS to date, being largely (mis)informed by the doctors behind the PACE Trial. The article also touches on the new research funded by the equivalent body in the USA to the body which funded the UK trial. This was a bio-medical trial and showed up many problems with cytokines and inflammation, which holds out hope of a blood test, anti-inflammatory pain relief and also of immune-modulating drugs providing a treatment. More about this follows the Daily Mail article.

Craig

Why are doctors and patients still at war over M.E.? | 15 August 2017
Abridged ***From Mail Online, by Jerome Burne, 15 August 2017.***

How the best treatment for the debilitating condition is one of the most bitterly contested areas in medicine

For years there's been a long-running and bitter debate between doctors and patients about its cause and how to treat it.

The lack of a clear physical cause meant many doctors dismissed it as all in the mind. This infuriated patient groups who insisted it was all too real and the result of an infection or immune system failure.

Even now, when it is generally accepted that ME/CFS is a genuine condition, it remains one of the most angrily contested areas of medicine. But the battle lines are no longer drawn just between patients and doctors: the medical community itself is at loggerheads.

THE ISSUE: THE BEST WAY TO TREAT ME

This has huge significance for the estimated 500,000 people in Britain affected by it. The official NHS treatment for their condition is delivered by psychologists and involves a combination of cognitive behavioural therapy (CBT) and graded exercise therapy (GET) which involves doing a little more each day.

The idea is that doing regular aerobic exercise would help patients a lot, but that they are held back by 'fear' of activity: the CBT is meant to overcome this.

Many patients and doctors claimed this combination provided little if any benefit.

This dispute has now broken out into the public arena in an extraordinary fashion. Two weeks ago the Journal of Health Psychology published what was effectively an attack on the official NHS treatment.

INSULTS TRADED BY BOTH SIDES

Three editors resigned from the journal in protest at this stance. In a leaked email, one of the resigners was described as a 'disgusting old fat neo-liberal hypocrite' and an 'ol' sleazebag' by an editor who supported the journal's approach.

But the insults swing the other way, too — recently, a scientist described patients critical of the CBT approach as 'borderline psychopaths' and likened them to animal rights activists.

The row is about a trial published in The Lancet in 2011 that helped form the official guidelines on treating the condition.

This was a large trial, called PACE, involving 641 patients, costing £5 million. It was paid for by the Government and carried out by psychologists at Queen Mary University in London.

PACE found that patients being treated with the combination treatment — 14 sessions with a therapist over a six-month period — improved by 60 per cent, while the 'recovery rate' (which implied a 'cure') was 20 per cent.

But a new analysis of the data has suggested that patients experience just a 20 per cent improvement, and only 5 per cent are classed as recovered.

PACE TRIAL REANALYSIS
Dr Charles Shepherd…
'This has cast serious doubts on the recovery rates being claimed,' adds Dr Charles Shepherd, honorary medical adviser to the charity the ME Association (Dr Shepherd was also a member of the Chief Medical Officer's Working Group on ME/CFS and the Medical Research Council's Expert Group on ME/CFS research).

'The trust of patients has been lost. PACE needs to be withdrawn.'
In fact, patient campaigners have been claiming for years that the psychological approach is profoundly wrong because it implies the problem is the way the patient thinks about it. They consider that they're suffering from a physical disorder.

The re-analysis of the PACE data has set the cat among the pigeons. A challenge to evidence supporting a NICE-approved treatment is unusual, not least because the data was only made available after a protracted battle by patients.

Ever since its publication in The Lancet, the PACE trial had been questioned by patient groups. They wanted to see all the data the trial had gathered to check the statistics.

For five years patient advocates and some doctors sent letters and Freedom of Information requests to the researchers — Professor Peter White (of Queen Mary University of London), Professor Michael Sharpe (Oxford University) and Professor Trudie Chalder (King's College London) — without success.


Jonathan Edwards

Grounds for refusal included risk of revealing patient identities and claiming the demands to hand over the data were vexatious or a form of harassment.

Indeed, one expert witness for the researchers drew parallels between these ME/CFS 'activists' and animal rights groups, suggesting there was a serious risk of violence to researchers if the data was released. But then the Information Commissioner's Office became involved and the university was ordered to cough up the data. It refused and then spent more than £200,000 to have the order dismissed.

This was rejected by a tribunal (as for the claim of threats being made, under cross-questioning the expert witness admitted there hadn't been any).

When the trial data was finally re-analysed and checked by two independent academics, Philip Stark, a professor of statistics at the University of California, Berkeley and Professor Bruce Levine from the Department of Biostatistics at Columbia University, it '**revealed that the study contained little evidence that CBT and graded exercise add anything to standard medical care in terms of patient recovery**', according to Professor Levin.
This was backed by Jonathan Edwards, an emeritus professor of connective tissue medicine at University College London.

'The results of the re-analysis shows that the call for access to the PACE data for independent analysis was justified,' he said. 'It confirms that this study failed to provide reliable evidence for useful, sustained benefit from either CBT or graded exercise therapy.'
Sir Simon Wessely, Regius professor of psychiatry at King's College London, has long been identified with the psychological approach. When he was asked about the data re-analysis last year, he was quoted as saying: '**OK folks, nothing to see here, move along please**.' He added that patients did improve and that the treatments were moderately effective.

The Journal of Health Psychology gave the original researchers the right to respond to the criticisms — they said they stood firmly by their findings, and that 'the PACE trial… along with other studies provide patients, healthcare professionals and commissioners with the best evidence that both CBT and GET are safe and effective treatments'.
But what about the 'biological' theories of ME/CFS and the new research published recently suggesting a link with raised levels of molecules linked to inflammation?

Commenting, Dr Alan Carson, reader in neuropsychiatry at the University of Edinburgh, said what wasn't clear is whether a higher level of these molecules 'necessarily make you feel worse'.

He added: 'It's highly unlikely it will lead to a blood test any time soon.'

Yet Professor Edwards, who has described the PACE trial as 'poorly designed, poorly executed and inappropriately interpreted' believes that studies are needed.
'Here in the UK we've spent far too much on the psychological aspect,' he says. 'Understanding the biology is what's going to lead to an effective treatment.'
Professor Edwards, a rheumatologist, has previously found that patients with ME/CFS as well as rheumatoid arthritis reported great improvement when they were treated with the powerful anti-inflammatory drugs used for their arthritis. A trial of this is now under way.

Meanwhile, PACE continues to have support among psychiatrists and psychologists. It seems unlikely that it will be withdrawn, and so the struggle between the doctors and patients continues.

Meanwhile NICE, whose guidelines shape our treatment and benefits, are currently considering reviewing their guidelines on ME/CFS. These have been largely based on the, now debunked, PACE Trial and, to date, they have been reluctant to revisit it. The weight of evidence showing the very poor science behind PACE is forcing their hand. The ME Association have been pushing hard for an update and are becoming more hopeful that they may be reviewed. This is vital for us sufferers in

this country – and a better example could not be found of how they shape our life than that given to us by a member. He has been ill for 18 months and had been receiving PIP. Recently he has had a diagnosis of ME/CFS and he phoned the DWP up to inform them of this and of his deteriorating condition. He promptly had his benefits removed – for all he had worsened. PACE and the NICE Guidelines promote CBT and graded exercise and suggest that we are merely deconditioned. This outdated theory has got to be banished to the history books for our lot to improve.

Craig

Stanford researchers identify biomarkers associated with chronic fatigue syndrome severity

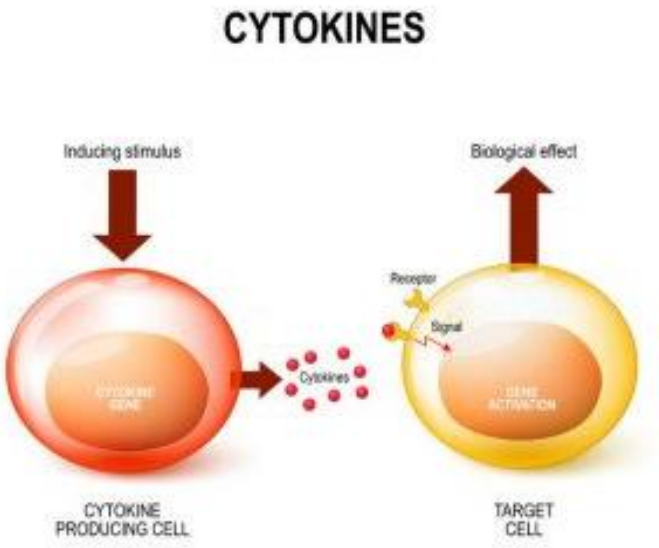
Researchers at the Stanford University School of Medicine have linked chronic fatigue syndrome to variations in 17 immune-system signaling proteins, or cytokines, whose concentrations in the blood correlate with the disease's severity. The findings provide evidence that inflammation is a powerful driver**.**

Dr Charles Shepherd, Hon. Medical Adviser, ME Association comments:
"This study was funded by the National Institutes of Health in America (equivalent of the MRC here in the UK) and published in the prestigious *Proceedings of the National Academy of Sciences*.

The research was carried out by a group of well respected ME/CFS researchers at Stanford University School of Medicine, California, including Professor Jose Montoya – who I have met on several occasions. The findings, which largely relate to specific abnormalities in various immune system chemicals called cytokines, confirm and add to our existing knowledge of immune system dysfunction in ME/CFS.

As with immune system research that has already been published, the findings support a key role for low level immune system activation in ME/CFS and that the consequent overproduction of certain 'pro-inflammatory' cytokines could help to explain the ongoing flu-like and infective symptoms that are so characteristic of ME/CFS.

This study also looked at how the pattern of immune system abnormalities changed in relation to both severity and duration of symptoms. As a result, we are clearly getting closer to finding biomarkers that are actually diagnostic of the disease – which is very encouraging given the long delays that people with ME/CFS currently face with obtaining a diagnosis and receiving appropriate management advice.



"As the researchers also point out, these findings could help to select patients who might respond to various types of immunotherapy drugs that can 're-set the immune system thermostat' and dampen down an overactive immune system response with the production of symptom causing cytokines."

"A very welcome and encouraging development for people with ME/CFS."

My GP and 'What Matters To Me'

I think I have a good relationship with my GP but it is not a one side relationship which I guess is why I think it is good. I also haven't been with my GP very long, although I must explain that you should not read anything into that.

When I first went to see my GP, I wrote down all my symptoms, or at least the ones I could remember ☺ I had been on pain medication for a couple of years which had started to affect my stomach and since I had been warned of this possible side effect, I had not been too phased. My GP acknowledged that I needed to continue on my pain medication so wished to address my stomach problem which he did with another medication and some tests. There are always side effects with medication never mind adding multiple medications into the mix. It wasn't long before I decided my new medication combination wasn't helping. I should explain, at this point I had not been diagnosed with Fibromyalgia.

So I started to think what was important to me and how to explain this to my GP so he could adapt his care and treatment for me. I also had to consider my own expectations, having pain for over 20 years it would be highly unlikely that my GP would have a magic pill to make it all better.

At each visit, I would write down what matters to me, which was really what I was hoping to get out of my visit. If I had any questions or if I had any new symptoms I would also write these down to save me forgetting. This did mean that my focus or wants changed for example did I want my GP to reduce my pain, improve my 'sleep' etc. I also had to be careful that I did not misdirect my GP by focusing on a symptom that although I wished to be acknowledged was not the main reason for my visit. I would also follow my GPs guidance which meant if he asked me to try medication for a set period of time, I did and would faithfully report back. In fact, I tested quite a few different medications with the support of my GP including one that was not offered to me but one that I gave sound reasoning for him to consider its usage. We discussed referrals either initiated by him or me. When he offered me the diagnosis of Fibromyalgia he printed me off some brief literature.

My GP words of wisdom are:

- Prepare for your GP appointment, ask yourself what matters to you and what you want out of your visit;
- Keep a note of your symptoms and when you get any new ones so you can update your GP;
- If you don't understand why your GP has you on a particular medication or if tests have been completed, what the results are and what they suggest, ask;
- If your GP is happy with their diagnosis there may not be a need to refer you on unless your GP feels this will help with your care and treatment;
- Don't assume your GP will offer you the same care and treatment as someone else, we are all different with different needs and one size does not fit all;
- If you are not coping, talk to your GP and explain what exactly it is that you are not coping with so they can consider how they can help you.

I no longer take regular pain medication and no this does not mean I don't have pain or that the pain is of an insignificant level. My condition is hard work, can be completely debilitating at times and relentless but I am not ready to give in yet and I hope that you don't either.

Kim

If you feel able to share your own story, please e-mail admin@dgmefm.org.uk

What Have We Discovered Which Helps?

Recently a few of the monthly Midsteeple meetings have had a themed discussion. April's was based around what we, ourselves, have found which helps us.

There was a mix of ME/CFS and fibromyalgia sufferers attending, but quickly it became obvious that for all of us, pacing, resting, avoiding stimulation/noise and finding our 'baseline' and not exceeding it was all vital in either helping, or at least in not worsening the symptoms. This probably isn't a surprise for any of us who have been ill for a while, but it may come as news to the newly ill, who may still be attempting to exercise their way out of it.

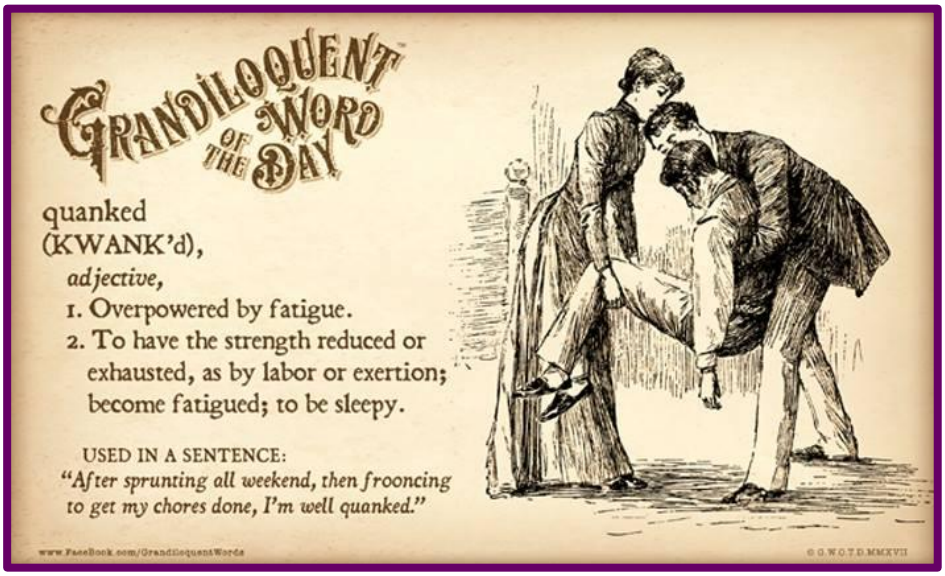
Stopping the symptoms worsening in the first place through pacing/rest was the most important aspect but besides that there were a few other things which helped. Finding the right painkiller was important but difficult – various people had various effects and side-effects and it had taken most of us a few attempts to find something which worked. Pregabalin seemed to be the one which most people with fibro had success with, followed by anti-inflammatories in those with ME.

Of the vitamins B12 and vitamin D (especially in winter) were mentioned. Diet played a part with some 'trigger' foods needing to be identified and cut out (you can find out more about this in our November meeting). Aloe vera helped one member. Of the alternative therapies, (gentle) massage, reiki, pilates, yoga and warm water hydrotherapy helped most with fibromyalgia, with warm water actually worsening ME. Of the alternative treatments acupuncture had quite a pronounced effect on a few of us, although the practitioner needs to know what they are treating. TENS machines, which work in a similar way to accupuncture had a limited beneficial effect in a few of us. Reflexology had limited effects with one person finding it pleasant and another painful.

Coping strategies were important to psychological well-being and also providing welcome distraction from the pain. Finding something enjoyable to do, which wasn't too exhausting, helped a lot. Some found escape in music, the enjoyment of pets, some in knitting and other crafts, some in quiet get-togethers with friends.

Of course our experience was limited to the things which we have tried, with many more things we may not be aware of – or may not have access to, which may help, but which we have no experience of. Frustration was expressed at how little GPs were willing to experiment, with even low risk and cheap therapies like B12 injections being ruled out for most who asked. In everything, with the exception of pacing and rest, it was acknowledged that the beneficial effects was limited. There was no one thing which was transformative, but lots of small things which added up to help provide some relief.

Craig



An Immune Disease? Low Dose Naltrexone (LDN) Fibromyalgia Study Suggests FM Has Inflammatory Side

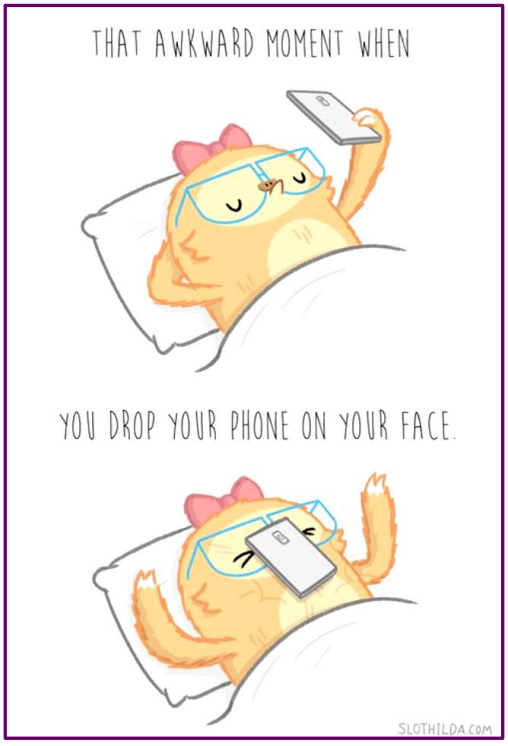
Low dose naltrexone (LDN) is becoming more and more widely used in fibromyalgia (FM) and chronic fatigue syndrome (ME/CFS). You can chart that use right back to Jarred Younger's two small FM trials in 2009 and 2013. Now Younger's back with a third trial that aims to do two things: a) further validate LDN's effectiveness in FM and b) attempt to understand what in the heck this unusual substance is doing in FM patients.

LDN could be working in a couple of ways in FM. It could, by blocking opiate receptors, cause a kind of paradoxical shift that spurs the production of feel good brain chemicals called endorphins. Younger's past LDN studies suggested, however, that LDN could be reducing inflammation – something not ordinarily associated with FM. His 2014 study, for instance, found that FM patients with higher levels of a factor associated with inflammation called ESR benefited more from LDN.

Younger believes LDN is blocking receptors (TLR4 or others) which are triggering the production of pro-inflammatory substances on microglial cells, creating a "neurotoxic" milieu that results in pain amplification. The many neurotoxic substances microglial cells create (pro-inflammatory cytokines, substance P, nitric oxide, and excitatory amino acids) could, he believes, account for the wide range of symptoms in FM and ME/CFS.

While the study was small, its findings meshed with those from past studies. It indicated that LDN works well for some, but it's not a panacea: Younger found a 15% reduction in FM associated pain and about a 20% reduction in overall symptoms. (Younger's previous study found about a 30% reduction in pain in about 60% of the participants. Younger is not satisfied that the optimum dose for LDN in FM has been found and hopes to do a study to resolve the dosing issue).

The main finding was that LDN actually did result in reduced levels of many pro-inflammatory cytokines which Younger believes are driving the pain process in FM.



Younger hopes to use the data from this study to do a larger double-blinded study. Much bigger LDN/FM studies are needed and one is underway. A 140 person trial in Norway should wrap up at the end of this year. (LDN use in Norway has increased dramatically recently).

From an article by Cort Johnson | Jul 10, 2017 | HealthRising.org blog

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Beneficial effects have also been reported in people with ME/CFS. Has anyone in the group with fibro or ME taken LDN and could tell us how they got on?

LDN is available by private prescription in Scotland after a telephone consultation from Clinic 158 in Glasgow - telephone 0141 357 7357.

Mark Davis finds the strongest evidence yet for ME/CFS immune activation and hunts for the trigger

This is one of the most significant findings since the results from the first rituximab trial.

Using a completely new, cutting-edge approach Stanford's Professor Mark M Davis has produced the most dramatic evidence yet of immune activation in ME/CFS. At the recent OMF Stanford Symposium, he showed unpublished evidence that the immune activation in ME/CFS, in the form of activated (CD 8) T cells, is on a par with that seen in cancer, MS and infection. That's a much bigger effect than has been seen in ME/CFS cytokine studies where the changes are altogether more subtle.

Davis is already looking for the specific antigens (small proteins recognised by the immune system) that are triggering the immune activation, again using new technology. So far, he says he's found one candidate from the new work, but he wants to verify the findings before revealing more details. Identifying the offending antigen or antigens could potentially provide a target for drug treatments.

Davis is pretty new to the field of ME/CFS, but he is a researcher with a remarkable reputation: an immunologist and professor at Stanford whose work is widely quoted by other researchers.

However, Davis has yet to confirm a definite antigen, and of course, has yet to publish these results. Even so, these are remarkable findings as they stand. One of the great strengths of this research is that it builds on work already done with several other diseases, helping to put the new findings in context and connecting ME/CFS to mainstream research. This is one to watch.

From an article by Simon McGrath ME/CFS research·Friday, 18 August 2017

Pain Association Dumfries & Stranraer Group

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, unless you want to attend their 5 week Intensive Self-Management Programme (not listed below).
If you would like more information or have any further queries, please phone the Pain Association on 0800 783 6059. www.painassociation.com/1-2/dumfries-and-stranraer-group/

Dumfries: Mitchell Room, Holiday Inn, Bankend Road, Dumfries, DG1 4ZF	**Stranraer**: Conference Room, Wigtown Locality Office, Victoria Place, Stranraer, DG9 7HX
• Tue 12th Sep 10.30am - 12.30pm: Understanding Emotions	• Wed 13th Sep 10.00am - 12.00pm: Understanding Emotions
• Wed 18th Oct 10.30am - 12.30pm: Improving Sleep	• Thur 19th Oct 10.00am - 12.00pm: Improving Sleep
• Wed 15th Nov 10.30am - 12.30pm: Goals & Baselines	• Thur 16th Nov 10.00am - 12.00pm: Goals & Baselines
• Wed 13th Dec 10.30am - 12.30pm: Improving Confidence	• Thur 14th Dec 10.00am - 12.00pm: Improving Confidence

Dumfries & Galloway Advocacy Service

Do you need help to have your voice heard with Health or Social Services or the Council? Advocacy promotes equality and social inclusion and helps those who feel vulnerable or who have been marginalised in society. The Advocacy service is free, confidential, and independent and aims to 'promote empowerment of adult residents of Dumfries and Galloway who require help, in whatever context, to understand the options open to them, to enable them to make informed choices and/or to make their own views known.'

Phone: 01387 247237 **Website:** www.dgadvocacy.co.uk

Notice of Annual General Meeting (AGM) Thursday 5th October 2017, Midsteeple, Dumfries 1pm to 3pm

Notice of
AGM
Thursday 5th October
Midsteeple, Dumfries
1 – 3pm

There are three main areas covered at the AGM, which would be useful to share with members in advance:

1. The Trustee Annual Report is provided for approval.
2. The audited Annual Financial Report is provided for approval. Election of an Independent Examiner is completed.
3. Dissolution & Election of the Committee takes place.

Committee Members (minimum of 5, maximum of 15) should be able to communicate either through Facebook or e-mail and be available to attend Committee meetings at least three times a year. In addition to election of Committee Members, election of Office Bearers is also completed for the following positions:

- Chairperson
- Treasurer (The current treasurer wishes to stand for election)
- Secretary (The current secretary has given intent not to stand for further election although will continue for a third year only if the position remains unfilled)

Items which require approval will be by show of hands. Election of committee members and Office Bearers, require nomination and a second.

If you are interested in being either a Committee Member or an Office Bearer, it would be good to confirm this in advance of the AGM either by e-mailing admin@dgmefm.org.uk or confirming with either a current Committee Member or Office Bearer. An electronic copy of the Network's Constitution can be provided on request.

DGMEFM
Dumfries & Galloway
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SC030641 | www.dgmefm.org.uk

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