September 2019

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome all,

It’s always good to meet members at our monthly and pop-up meetings, and it’s interesting to note the different turn-outs for the types of meetings. More came along than I’d have expected to our August Midsteeple meeting to inform the MSP of the problems we face. I note that other consultative meetings, where we have the chance of shaping policy are particularly popular. I wonder if it’s partly because we feel we aren’t listened to normally. It’s also cathartic to air problems, frustrations we face in a creative manner where we won’t be seen as complaining and moaning.

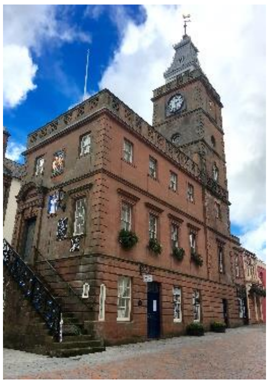
I hope that we provide a good balance of meeting topics and social get-together. Please let us know your thoughts or if you’d like to host one. I’m aware that there’s many people who can’t come along because of the distance in this region, or because they’re too poorly. If that’s the case please look into calling in the advice of AbilityNet (details on page 7) to connect up with us digitally.

It’s September so that means GiftDay, where we ask you if you can provide a small donation towards the running costs of the Network to do so. We’ve just been given a grant of £1000 from the Robertson Trust, and this will help with the ongoing costs, but does require match funding. I hope if further external funding follows we can begin to increase our work and support.

Craig Woods

Monthly Get-Togethers

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



Sept 5th The Pain Association speaker is no longer available for this meeting so we will theme discussion on Pacing: What are the stumbling blocks and the strategies you find helpful for keeping on as even a keel as possible. Share your experience and questions.

Oct 3rd This will include our **AGM.** Please come and join in discussion about the way ahead for the Network in the coming year.

Nov 7th Have a go at Iris Folding, maybe make a Xmas card - all materials provided. Or just join in for a cuppa and chat.

Refreshments will be provided at the Midsteeple meetings. Entry is through the Box Office door. We use the meeting room on the 1st floor. Press and hold the lift button to call it and press and hold the button until the door unlocks on the 1st floor.

The Midsteeple room has been confirmed as available to us until and including March 2020.

Pop-Up Meetings

Sept 15th Sunday From 1pm. Join us for a lunchtime get-together at **Castle Douglas Garden Centre Coffee Shop**. The Centre is on the edge of town heading out on the Dalbeattie road.

Oct 20th Sunday From 1pm. Another get-together at the Crichton Estate's **Easterbrook Bistro** (formerly Neuro's, it's on the far right hand side of the Easterbrook Hall, accessed from the side of the building). Come along and join us for lunch and a catch-up in this beautiful setting.

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

Registered Charity No. SC030641

Meeting with Colin Smyth MSP

We'd a good turnout for our August meeting (usually one of the quieter ones) which Colin Smyth MSP had asked to attend. He asked to hear about the issues affecting us and seemed genuinely interested and concerned to hear of all we encounter.

Problems accessing benefits, along with an uncaring system, and questionable form reporting was one of the biggest and most common issues. The other huge issue is the NHS and the lack of any specialist knowledge of ME and fibromyalgia in D&G. The problems accessing GPs, and finding an understanding and helpful doctor was experienced by everyone.

Colin thanked us for having him along and said that he'd raise the plight of our members at the next stakeholder meeting of NHS D&G.

Case for Change - Draft Document

In our February newsletter we mentioned that Julie Davidson from the Scottish Health Council could help us make a 'Case for Change', which would document the problems we currently face accessing suitable health care. Julie attended our monthly get-together and led discussion using a framework from the Voices Scotland programme, Chest Heart & Stroke Scotland.

The document below was drawn up from this discussion, and from posts on our Facebook page.

We envisage presenting our case to the four NHS localities and NHS management in D&G, politicians and the council too. However, before we finalise the document we would like to hear from you if you feel there is something important missing from it.

Please email admin@dgmefm.org.uk or write to us using the enclosed envelope addressed to our Treasurer (whether or not you wish to include a donation).

Making a Case for Change

Issues identified by members of Dumfries & Galloway ME and Fibromyalgia Network and members of the DGMEFM Network Facebook page.

What is the problem?

A lack of specialist knowledge of the conditions of ME and Fibromyalgia in Dumfries & Galloway.

<u>Getting a Diagnosis</u>

It can take a long time getting a diagnosis, often taking several years. It is felt by many people with these conditions that medical professionals are often unsure of the conditions and how symptoms can present themselves. There is not a specialist in this medical area, therefore patients are often diagnosed by their GP, who themselves can be unsure of the best way forward for the patient.

Support After Diagnosis

After finally getting a diagnosis there is often no support for patients and there are no specialist clinics. Finding a medical professional with expertise can be very difficult and patients are often left with no further advice on how to treat these conditions.
Finding a GP who has the knowledge and believes in these conditions can also be difficult. Patients are often left frustrated and upset after a GP visit as they can feel they are not believed or taken seriously. This can have a detrimental effect on their health, with the worry that all symptoms are being connected to their ME and or Fibromyalgia without being properly investigated. This can have serious implications if there is an additional disease or problem which goes undiagnosed.

How do you know the **problem exists?**
What is your **evidence?**

How we know a problem exists

There are numerous people using the DGMEFM Network's platforms, asking advice on many things to do with their condition, such as where to go to find a specialist or if other people have similar symptoms. They are also sharing experiences of GP or Hospital visits etc. These platforms are run by volunteers who themselves have these conditions. The aim is to give help and support to people who without it would find day to day life even more difficult or might not know how best to get help.

People using the network may:

1. Have been diagnosed with ME or Fibromyalgia many years ago
2. Have been diagnosed recently after years, sometimes decades, of symptoms
3. Be undiagnosed, but suspect they have ME or Fibromyalgia or both

Our Evidence

We estimate there may be up to 600 people with ME/CFS (1 in 250 of population) in D&G, and possibly 4500 (3%) with Fibromyalgia. The DGMEFM Network currently has around 350 full members, and a following of 250 on our Facebook page, many of whom are not full members of the Network. Both full and Facebook memberships have increased annually as more people become aware of the Network and share their experiences and symptoms, or that of family members, at our meetings and through Social Media.

Catherine Calderwood (Chief Medical Officer for Scotland) and Jeane Freeman MSP (Cabinet Secretary for Health and Sport) have both brought attention to ME. Catherine Calderwood believes almost half of the medical profession does not accept ME to be a real condition. Jeanne Freeman addressed the Public Petitions Committee at the Scottish Parliament as it considered a petition calling for a review of the level of support available to people with ME.

What has been the **patient/carer experience?**

Below is a list of some of the problems people with ME and or Fibromyalgia have experienced:

- Medical professionals can be dismissive of the symptoms and conditions
- Lack of consistency of advice from medical professionals for patients

- Not able to see the same GP for each visit
- Unable to find medical support locally
- Private Health Care diagnoses have been ignored by NHS
- Can be frightening for people being diagnosed – there is a lack of support / reassurance from professional or there is misinformation or no explanation about their condition
- Not being referred to a pain clinic
- Once diagnosed any new symptoms are presumed to be part of their ME and/or Fibromyalgia
- Some patients have been advised to exercise more but this has caused more harm to them and has in some cases worsened their symptoms

However there have been some positive comments from patients:

- “After I spoke to the right Doctor things moved quickly and have been great”
- “My GP seems to have a good understanding of my illness, he always listens to what I’m saying”

How has the **problem affected staff?**

- A huge amount of staff and patient time is wasted to repeat GP and Nurse’s appointments as people are misdiagnosed and given the wrong treatment. For example, both ME and Fibromyalgia can be misdiagnosed as depression.
- Staff may have felt frustrated or confused when results for tests for other conditions such as thyroid problems, Lyme disease or lupus come back negative.
- Where ME or Fibromyalgia has been diagnosed, staff can miss other conditions when patients return to GPs with other symptoms e.g. cancer, MS. These symptoms are often put down to their ME or Fibromyalgia even if the patient believes they are not normal symptoms for them and their condition.

What are the **national** guidelines on the topic?

- There is a Scottish Good Practice Statement on ME-CFS Quick Reference Clinical Guide https://www.scot.nhs.uk/scottish-good-practice-statement-on-me-cfs/ although this references Graded Exercise Therapy, the efficacy of which is disputed.
- The diagnostic, management and referral algorithm/care pathway in the Good Practice Statement offers good guidance but the group do not think GP’s have read it / are familiar with it
- The NICE guidelines are widely used although they are for England and also disputed https://www.nice.org.uk/guidance/cg53

What are the **local guidelines** saying on the topic? Are there any relevant **HEAT** targets in the Local Delivery Plan? Is there a Local Authority **Single Outcome Agreement**?

- There is no single guidance locally for ME and Fibromyalgia
- A letter from NHS Dumfries & Galloway, Chief Executive to MSPs stated people should receive care from their GP and they can be referred to:
  1. a consultant, but this is to *exclude* other illnesses
  2. specialists in Edinburgh or Glasgow
  3. specialists in Newcastle

  but this is not a clear pathway and patient experience to date does not reflect this process
- We are not aware of any local guidance or initiatives by Dr Purdie who was the Clinical Lead for ME in D&G NHS.

How exactly do you **want things to change?**

Increase awareness

- Make people who can change things aware of the problem
- Need support and understanding of the condition across health professions, especially amongst GP's as they are often the first port of call for people
- Have at least one person in a GP Practice with knowledge of ME and Fibromyalgia who can develop awareness (a Champion)

Belief in patients

- GPs need a patient friendly approach and willingness to listen
- Need flexibility regarding the choice of GP as some more knowledgeable than others about these conditions
- Ability to book longer appointments which would result in fewer appointments needed
- Medical professionals to work with 'expert patients' to learn from them
- Understand patients may have multiple conditions and not attribute new symptoms to existing ME or Fibromyalgia. Instead look at other possible conditions.
- Allowing patients to make choices about their treatment e.g. no enforced physiotherapy and psychology
- Alternative treatments could be explored e.g. acupuncture

Need for specialist knowledge

- Promote Scottish guidelines over NICE guidelines
- Have at least one specialist (doctor, nurse or otherwise) in the condition in each locality – someone a GP can refer a patient to
- To have an overall specialist in the region (someone with a special interest) who can learn from patients and Dr Purdie and support patients

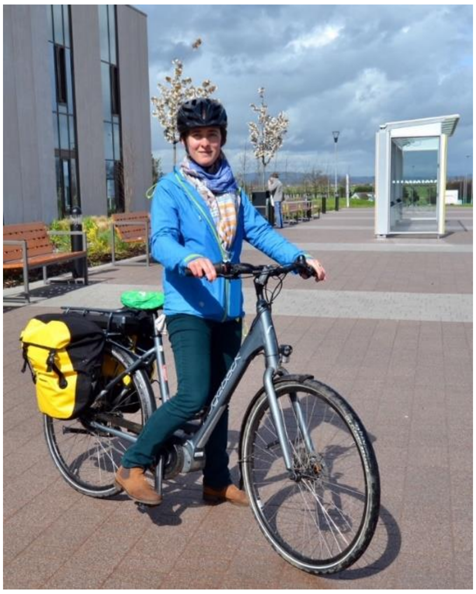
Support

- Appropriate care to the individual (ongoing support and care after diagnosis)
- Ongoing support, eg, group setting, by specialist professional. Consider some people can't travel – house/bed based
- Refer patient to DGMEFM Network for peer support.

The Earth is Flat

Firstly a little intro – I'm Rhian (rhymes with Ian! ☺). I was diagnosed with Chronic Fatigue Syndrome last year. I work for Sustrans, a sustainable transport charity and my job is helping NHS staff walk and cycle more. So when I started suffering with CFS/ME it did seem a little ironic! Like many with ME and Fibromyalgia I was used to a very active lifestyle. Thanks to advice from this group I caught my CFS/ME early and reduced my hours at work and took time to rest. I am now functioning at a higher level. One of the things I found invaluable is an electric bike and I'd like to share some information about them with you.

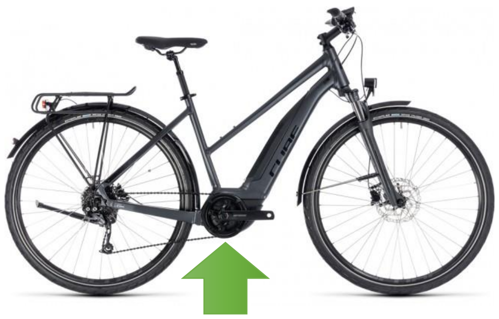
Electric bikes or e-bikes, technically called electric assist bikes or pedelecs, give you a little extra oomph. They flatten out the hills and are like travelling with the wind behind you. They are fitted with a battery and motor which gives you assistance when you pedal. There are a few variations but what they all have in common is you have to be pedalling for it to work, (you can't just sit on it) and the motor cuts out at around 15mph. Although you can still go faster than that, e.g. if you're going downhill.



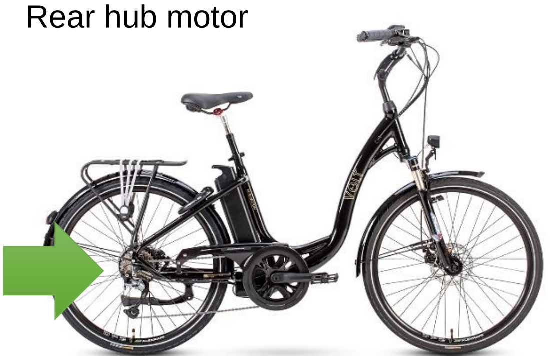
The main variations are to do with where the motor is. On a mid-drive motor the motor is where the pedals are. Typically these have sensors which respond to pressure you put down when pedalling. So when things get a little hillier and you pedal a little harder, the motor kicks in to help you up the slope. This type of e bike is very intuitive and is most similar to riding a regular bike, only easier!

There are also hub drive motors which are either in the back or front wheel. These type don't manoeuvre as naturally and can feel like you are being pushed or pulled along. However, for people where energy is more of a problem this can be quite useful as you are able to let the bike do a bit more of the work, depending on how you feel.

Mid-drive motor



Rear hub motor



For anyone thinking of buying an electric bike they are quite pricey. As with anything the more you pay the better the quality but the most important thing is if the bike will do the job you are needing it for. So if that's a mile pootle every couple of weeks there's no need for something very expensive. There are a couple of things that can help. If you are in work, your workplace may have a Cycle to Work Scheme. This allows you to buy a bike via salary sacrifice so makes it tax free, saving you money. There are various criteria you'll need to qualify for this so ask your workplace HR about it.

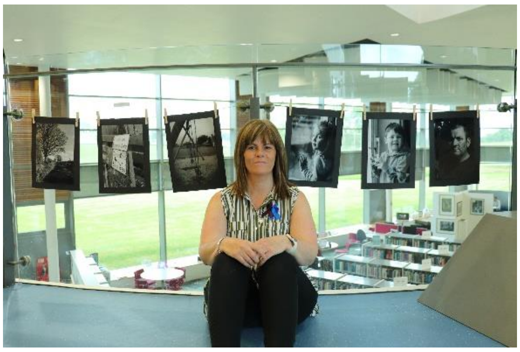
There is also a government scheme offering interest free loans to anyone buying an e bike. This is through the Energy Saving Trust and more information can be found here:
https://www.energysavingtrust.org.uk/scotland/grants-loans/ebike-loan
I highly recommend trying before you buy and having a go on both mid-motor and hub motor bikes.

Electric bikes are a different mode of transport all together. They take out the sweat involved in cycling but are not cheating. They are a pleasant way of getting around and at a speed to suit you. If you have any questions just get in touch – message me on Facebook (Rhian Davies).

Going Back to College

After having to give up work due to the Fibromyalgia, I found I was sinking into a black hole. I was unsure who I was and what my purpose was. I had always worked since I was 14 years old, now getting the shopping was like climbing Criffel. A very dear friend had encouraged me to get out and about with my camera and it was the best medicine. We didn't go far, just round about local beauty spots.
I never really knew what I was doing with the camera, just point and shoot and hope I got something that was in focus. I then came across an advert for Dumfries & Galloway College and that got me thinking, I could go back to college and study Photography.
One year on I have a NC Photography qualification and getting ready to start another year studying HNC Photography. I can honestly say it was the best thing I ever done, I've learned so much about the basis of photography and have so much more still to learn.

I've met some lovely people and made some great friends. I even had some of my photos in an exhibition at college with great feedback.
"Don't be afraid to try something new, you might surprise yourself"
Best Wishes to you all
Lesley Grieve

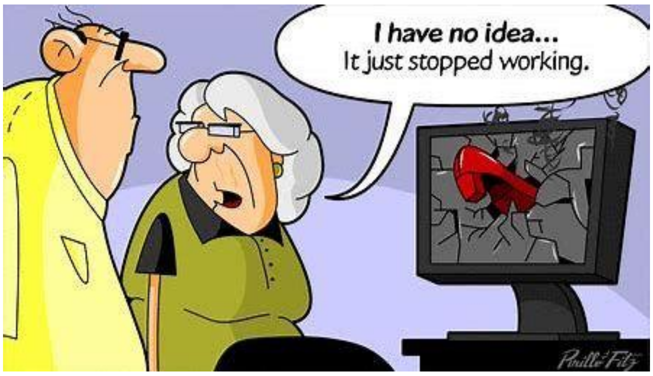


AbilityNet

Trouble using your tablet? Can't work your phone? Ready to smash your laptop?

Many of our members benefit greatly from the mutual support and friendship that is offered by the members of our Facebook group and by using our website to keep track of meetings and pop-up meetings. We are aware that not everyone feels comfortable or able to use technology to access the internet. With this in mind Lesley, Paul and myself recently met with Pat from AbilityNet to talk about their charity and to learn about the help that they can provide in helping older and disabled people of any age with technology. IBM and Microsoft fund them for this work, meaning there's no charge for users of the service, whether you're using IBM and Microsoft products or not. AbilityNet work with many large charities, including RNIB and Age UK and many of the volunteers in the charity are disabled and some have ME and fibromyalgia themselves which helps them to understand the problems we can encounter.

AbilityNet's ITCanHelp volunteers can help with things like learning to use your smart phone, tablet and computer. They can show you how to use and install apps and access our pages. They can help with setting up smart TVs and streaming. And if you're working they can help you with software and hardware to hopefully make your job a bit less painful. The volunteers are fully checked and vetted. In D&G it is most likely Pat who would visit – and she's very happy to be out and about in our beautiful region.



You can access the help by telephoning 0800 269 545. Someone will ask about the support you require and they will book an appointment for a volunteer to call you back or visit you. When you call say that you heard about them from us, please. More information on their website: www.abilitynet.org.uk.

Craig

Notice of Annual General Meeting (AGM)

Thursday 3rd October 2019, Midsteeple, Dumfries. 1pm to 3pm

Annual reports from Chair and Treasurer, and election of a new Committee. The existing Committee Members are each willing to stand for the coming year. However, we would appreciate a few more members to share the work and to raise our number above the minimum of five allowed by our Constitution. Committee meetings are held 3 to 4 times a year, with discussion between meetings on-line using Office 365, with each Committee member being allocated a license for that purpose.

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

If you, or someone you know, may be interested in joining the Committee please let us know in advance of the AGM either by speaking with a current Committee Member or by email to admin@dgmefm.org.uk. Existing members, new members, friends, partners, and family members would be welcome.

Following the business part of the AGM we want to hear your views on the future direction of the Network and ways in which we might, with funding, further our work.

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

Phone or WhatsApp: 07437 602610
Website: www.dgmefm.org.uk
Facebook: facebook.com/groups/dgmefm
Email: craig@dgmefm.org.uk (Chair)
paul@dgmefm.org.uk (Treasurer)
lesley@dgmefm.org.uk (Secretary)

OSCR
Scottish Charity Regulator
www.oscr.org.uk
Registered Charity
SC030641

Please let us know if you no longer wish to receive the newsletter, or if you wish to cease being a member of the Network (all your details will be deleted from our files). In either case, contact admin@dgmefm.org.uk or text or phone 07437 602610.