March 2016

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome all,
It's been another eventful few months for the Network. We've gained two letters!

Many years ago we picked up many new members when a local fibromyalgia group folded. Although we were then purely an ME group, we made for common bedfellows. As you'll see on page 2, there are many, many crossover symptoms and, like ME, there's little NHS understanding or support. Recently more people seem to be getting diagnosed with fibro whereas in the past they'd probably have been diagnosed with ME or CFS. It's possible to have both – as a few unlucky members know only too well. With over half of those attending our meetings suffering from fibro we felt it was time to officially recognise the illness in our name.

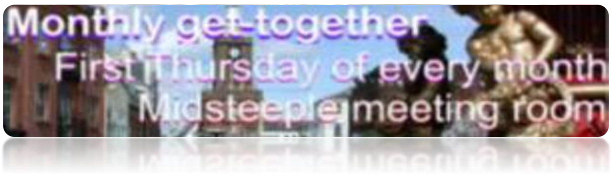
At the February General Meeting we had a great turnout of 20 and the vote was overwhelmingly in favour. We are now the **Dumfries and Galloway ME and Fibromyalgia Network**!

Meanwhile our meetings continue to grow in popularity. Besides the Midsteeple meetings we had an excellent Christmas lunch at the Three Crowns Bistro and a fun get-together at the Granite Kitchen in Dalbeattie. As our regular meetings have been a little heavy on business recently our next few will have no speaker to give us time to discuss those issues and problems we need to share, as well as have our usual laugh and joke.

Craig Woods

Monthly Meetings

Check our websites for 'pop-up' meetings at cafés:
dgmefm.org.uk or facebook.com/groups/dgmefm

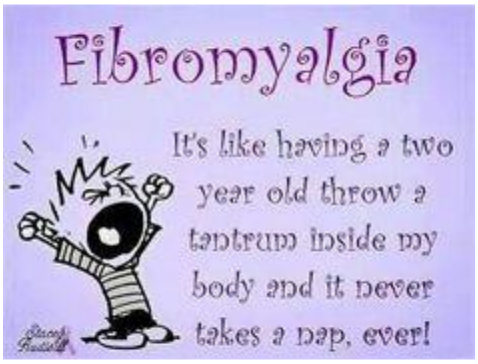


March 3rd	1 – 3pm at Midsteeple, Dumfries. Our usual social get-together with no speaker.
April 7th	1 – 3pm at Midsteeple, Dumfries. Our usual social get-together with no speaker.
April 17th	**Sunday** 1 – 3pm at the **Granite Kitchen, Dalbeattie**. We have reserved the area at the back of the café. Join us for a cuppa or more from the Granite Kitchen's menu.
May 5th	1 – 3pm at Midsteeple, Dumfries. Our usual social get-together with no speaker.

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. Entry is through the blue Box Office door. Stay for as much or as little as you'd like. Use the Facebook page to request or offer transport.

Registered Charity No. SC030641

Can anyone tell me the difference between M.E. and Fibromyalgia?

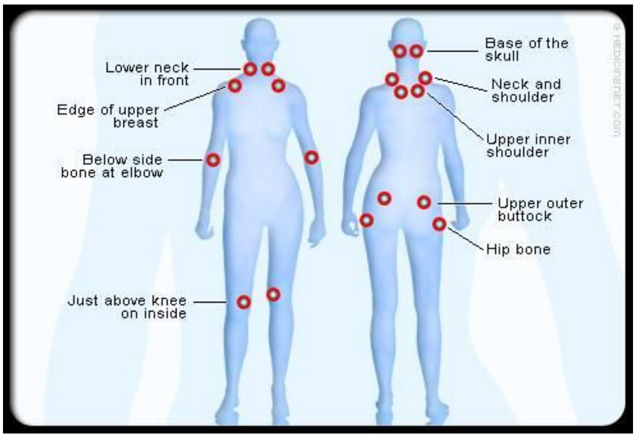


Dr. Shepherd, Hon Medical Adviser to the ME Association, replied to this question posted on the MEA's Facebook page.

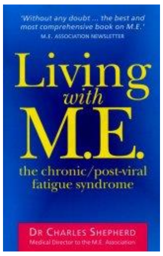
'My personal view is that there is a considerable degree of clinical overlap between ME/CFS and FM - but they are different conditions. So some specialists who see patients with ME/CFS-like symptoms (ie muscle pain, fatigue, cognitive dysfunction etc) will make a diagnosis of ME/CFS whereas others (rheumatologists in particular) may make a diagnosis of fibromyalgia in the same person.

Some people have what I think is best described as a fibromyalgic component to their ME/CFS, whereas in other cases a diagnosis of pure FM would be more appropriate. One important difference is that you have to have pain (often symmetrical/the same on both sides of the body that is in localised areas or 'tender points') to have FM whereas musculoskeletal pain (localized or widespread) is not always present in ME/CFS.

FM tender point map:



The situation is clearly unsatisfactory and can be very confusing for patients.



I cover the similarities and differences between ME/CFS and FM in some detail on pages 106 - 108 of 'Living with ME'.
(ISBN-13: 978-0091816797)

If you want to pursue the possible FM component I suggest you ask your GP for a referral to a specialist referral service for ME/CFS, or to a rheumatologist.
Contact details for all the UK services can be found on the website: www.meassociation.org.uk

If you need more help with your pain (regardless of diagnosis) and if the GP cannot help, another option would be to ask to be referred to a hospital pain clinic.

MEA have an information leaflet covering the general management of pain in ME/CFS and FM and leaflets covering specific drugs - amitripyline, duloxetine, gabapentin, pregabalin - that may be prescribed for pain relief in ME/CFS.'

Dr Charles Shepherd

Change of Diet......Change of Health

Like all ME sufferers my fatigue at best was debilitating and at worst being in bed for days.....

Last September I changed my diet on the advice of a nutritionist. She totally believes that what we eat has a huge influence on our health. When our digestive system is working well our general health improves. Before I tell you about the changes I made I know this is not a change of diet that fits all or a cure for our condition, and that ME sufferers react to foods with the same frustrating inconsistency as they do medications. I just want to tell you how the change of diet has helped me an ME sufferer for 7 years.

Firstly I had to give up all the white stuff, like white sugar (in all its forms), rice, flour and pasta and replace them with brown. The brown sugar being unrefined. After 3 days my energy levels improved and after a week I was delighted that I could get up earlier and go to bed later with no ill effects.

Two weeks on I had to introduce as much raw food as I could to my diet. Eating raw food before your meals whether it be an apple, portion of homemade coleslaw or half a raw carrot kick starts your digestive system to prepare for what we are about to eat. My nutritionist believes that we have not evolved enough yet for our bodies to tolerate all the processed foods that we eat today.

After a couple of months of not eating any processed foods at all and sticking to everything home-made or organic, raw foods before meals and brown rice, flour, pasta and sugar my energy levels have improved significantly and my IBS has more or less disappeared. I know many of you will be thinking I don't have the energy to completely change the way you shop, cook and eat, but all I can tell you is that it is hard at the start because of the fatigue, but for me it was just so worth it. I now look at processed foods as a poison for my body.

Once you have got to this stage the nutritionist says that as long as you stick to 70% good healthy eating you can have the other 30% eating the likes of takeaways, even cakes and biscuits with white sugar should you wish to do so without too much ill effect.

I could write much more, but Paul won't want me using up all the newsletter space Lol....

If anyone would like more information, please do not hesitate to contact me on 01387 264334 or 07512 786487.

Elaine Waugh

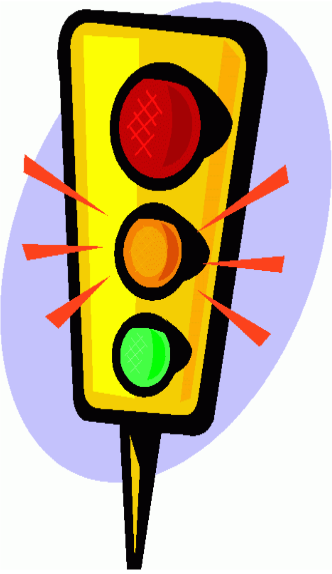
College Training Restaurant, Dumfries

A small group of us went for lunch recently at ‘Zest’, the College Training Restaurant. The 3 course meal was excellent and well worth the price of £7.50. We will definitely go again. If anyone would like to join us on the next occasion, yet to be arranged, please get in touch with Claire Shaw on 07850 343994 or email handsomeharry@hotmail.co.uk. Zest is only open on a Wednesday or Thursday as that is when the students are in college, and it would be 12.30pm arrival.

Pain and Pacing

From a conversation on our Facebook page…….

Pacing is a great help……it's like a traffic light system, or car engine warning light…..you can take your time and do a little, taking rests when need be, and when you reach the amber warning stage that's the time to have a proper break......stop what you're doing and have a good half hour break…..then if you feel you can, you could try a little more.



If like me you push on through that amber warning light, then sure you'll get a bit more done…..but you'll definitely get to the red light warning stage where you've gone well over the safety mark…..and you'll be in your bed in agony for days or more!

If you think of it this way; if the red light were to come on your car engine and smoke was pouring out of the bonnet, would you ignore it and keep driving on at same speed? Probably not!…..so why take the risk with our bodies?

I've learnt this kind of thing from attending Pain Association Scotland Chronic Pain group that meets monthly on the Crichton estate at a room at the Holiday Inn….or what used to be called the Aston Hotel. You don't need to be referred by a GP or such and there's no pressure to go each month.

There's a topic each month on a subject such as Pacing, Sleep, Nutrition, Coping with change, etc. It's an informal group run by someone from Pain Association Scotland but it's us, the chronic pain sufferers, who give our views and insights into what has helped or what makes us more pained etc. Well worth going to.

When we try to do too much the process is called Boom and Bust. Mind you, doing too little is also not helpful as our muscles will diminish. It's good to even do seated gentle stretching movements. YouTube is a good place to find short videos of how to do safe gentle movements seated. It's the same as doing crosswords or puzzles to keep our brain muscle active….we also have to keep some gentle safe movement in our body muscles.

Elaine Patterson

Branding

With the Network's name change we will also be rebranding and attempting to give the Network a cohesive and recognisable identity. We've been working with Daniel, an intern at Third Sector, on a 'look' for us.

From Facebook and group discussions we decided on a dragonfly as a suitable logo. It is coloured using an image of a silk painting by Paul called Earth's Core, as is the headline banner on the front of this newsletter.

DG ME FM

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

Purple is a colour often associated with Dumfries and Galloway and the swirling mix of contrasting hot and cool colours is, perhaps, a little reminiscent of some of the pain and emotions we go through as we cope with these illnesses.

We hope it will create a striking, and instantly recognisable, look for the group which can be used across facebook, the website, this newsletter and leaflets. There's still some finessing work to do, but look out for something similar to this in the near future.

Craig Woods

From The Open Mind website: *'The dragonfly, in almost every part of the world symbolizes change and change in the perspective of self realization; and the kind of change that has its source in mental and emotional maturity and the understanding of the deeper meaning of life'*

Rag Rugging

These photos are of 3 'rag rugs' at various stages of production, the latter having been finished off as a cushion. Elaine, June and Paul, all members of the ME Network are learning rag rug making and made these with me, Penny. I design and make rag rugs and textile art. I used to teach rag rug making but as I too have ME found I couldn't keep teaching. It struck me recently that this craft is good for people with ME as it is easy to learn, uses cheap materials (old clothes etc) and is fun. If anyone else would like to learn, I could teach a small group (3 or 4 people) for a couple of hours in either Dumfries or The Stewartry. You could contact me by email at pennylilley@gmail.com or phone 01556 504909, or via Paul Thompson at paul@dgmefm.org.uk

Penny Lilley

June says: *'I can't do very much because of the ME, but I can do this. I'm really enjoying it and Penny is such a good teacher.'*

This is a wall hanging that Penny made using one of the techniques.

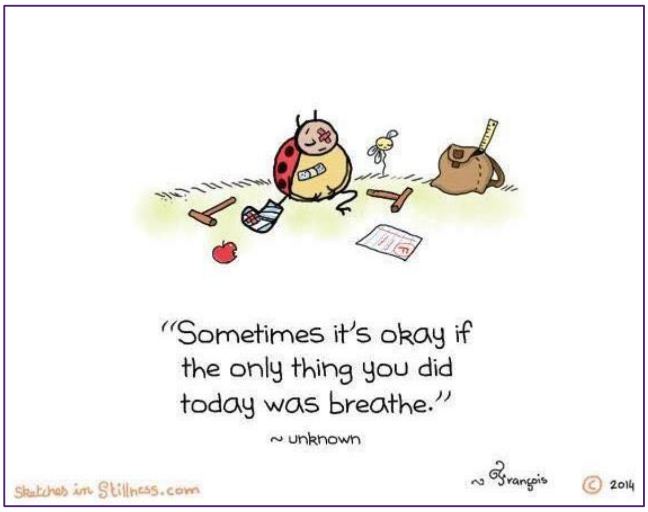
Does anyone else have low oxygen uptake?

I have one of those small oximeters that give a reading for both oxygen uptake and pulse - I bought it after being kept in hospital longer than I wanted because my uptake was always below the norm (95-100%). I also have low blood pressure and pulse rate; always have had. When I go into hospital now, I make a point of telling them about my low oxygen uptake, blood pressure and pulse.

There was a great deal of excitement a few years back about an American lab (Pacific Fatigue Lab) who found that ME (CFS) sufferers became and remained exhausted/fatigued unlike any healthy controls. They conducted a standard test used in the athletics world on a person's VO2 Max (a way of measuring the body's efficiency at utilising oxygen when exercising) on ME sufferers, and then did the same test the following day. It showed that ME folk just didn't recover from exercise - far from it; it made them much worse. This test is accepted worldwide in sports (can't be faked) and the hope at the time was that it could be used as a diagnostic test, proving something was badly awry with ME sufferers' metabolism. The test is still in worldwide use and it is far more accurate than the 'step test', yet its application to ME patients seems to have been forgotten about, even though it is closely linked to mitochondrial abnormalities. If your body can't utilise its oxygen intake fully or properly, you're in trouble - and permanently fatigued. It certainly is a test that would prove the ‘psychobabblers’ wrong; perhaps that's why it isn't being used. An oximeter (mine was just under £20) tells you instantly what your oxygen uptake is and your pulse rate too. Hospitals use better quality units - it's that little device like a fat clothes peg they clip onto one of your fingers. If your oxygen uptake is below 95%, then you are below the norm and if it drops below 90%, you've got problems. There will be folk with nursing experience that will be very familiar with these devices.

The Pacific Fatigue Lab research is still easy to find on the web. Quite a few GPs seem unaware of this being something patients can buy and use. There's loads of these devices available - just don't buy the cheapest, which are on eBay by the hundred. Mine is called 'OxyWatch' from 'ChoiceMMed'. (Ebay item no. 301841498498, sold by 'pulmolink' @ £16.49. Unless you really go up market, this is adequate for the accuracy of reading for home use). They don't last forever, but are an instant guide to a very important part of your metabolism and if you keep a diary of your illness, you can see how your oxygen uptake correlates to how bad you are feeling.

Steve Boyle



An OxyWatch has been purchased and will be brought along to meetings (so long as I remember). Ask if you'd like your measurement taken. *Craig*

The Carers Centre, a caring place for carers.

Twelve years ago I moved from Holland to Scotland. Reason; love (can you hear the violins in the back ground?). My Andy and I finished the house, so I learned how to put up ceilings and mix concrete. We rented the house out and shipped us and our bike and side-car to South America. We camped and travelled on dusty red tracks into the Amazon and got attacked by leaf cutter ants, who destroyed our tent. The side-car took us over the Andes to Ushuaia. We found out that we were able to live from very little and that money doesn't automatic means happiness. We also experienced great hospitality from people that have very little themselves. But that is another story...

If you are going to travel to certain countries you need inoculations, we got loads. Maybe it caused Andy's ME/CFS, maybe not, we never got to know. His troubles walking, speaking and many other symptoms never got explained or a name attached to it. It almost drives you mad when you can't get the pieces of the puzzle together. But at the moment we are not occupied any more with finding answers to the 'WHY-question'. Andy benefits from pacing and Tai Chi, a diet and the dog, lovely me, a positive attitude to life and his will power. If he wouldn't do or have this, all his symptoms flare up.

January last year a friend said to me; 'Do you know you are a carer'? Until then I never had thought about myself as one. Me a Florence Nightingale? Neh, for me it was completely normal to do what I was doing, but him saying that opened a door months later.

On the windows of the carers centre in Dumfries are the letters' CARERSCENTRE' spelled out on the top windows. I always thought that it was a place for training professionals.
Last summer I think I almost hit a wall and I didn't want to get totally burned out, so I walked - surprising myself - into the door of the carers centre. Now it gets tricky.
What happened was that the lady, her name is Ross, behind the desk offered me a coffee in a very big mug. I thought; 'They want me here, otherwise she wouldn't give me such a big mug!'
She offered me a seat and her two ears and I suddenly felt very peaceful and also tearful. Now she got me in her 'trap'; I realised I needed more than I got that moment, I needed to change things for myself.
She told me about the services of this carers centre, gave me leaflets, I got registered so I would get emails, and invited me to a coffee morning where I could meet the other expert carers. If I wish I could become a member of the writing club or have an appointment with a lovely lady that could give me a massage or skin treatment...I couldn't believe it, I was in carers heaven!

So I walked into the carers centre door in July last year and now it's January and lots of things have improved. I am a big fan of the coffee morning; all kind of ages, sizes and characters attend, all with lots of experience, humour and a great supportive attitude. It inspired me to make more time for myself and to be more social, outgoing and creative. All these things make me feel better and if I feel good my Andy benefits from that as well.
The emails from the carers centre are very useful, you get to know about things you otherwise wouldn't get to know…….it can be financial stuff, the men’s shed, or education for example. But the main thing I learned is that you can grow by sharing experiences and that you can feel good by helping other carers with listening and humour.

What else does the carers centre offer? (I pinched this from their leaflet):

*Information and Advice
*Grants and short breaks
*Assistance to access a Carers Assessment
*Training and Education
*Alternative Therapy and Relaxation
*Life after Caring
*Young Adult Carers (18-29)
*Carers support in hospital
*Advocacy
*Benefits Advice
*Health and Wellbeing
*Activities and Groups
*Help to access a counselling Service.
*Young Carers Project for young people (7-18) who help to look after a family member *Sunshine Group for parents of children with disabilities and their siblings

So, where to find the Carers centre?

The carers centre is based in Dumfries at 2-6 Nith Street. A drop-in service is available on Mondays, Wednesdays, and Fridays (9 - 4 pm) so there is not always the need to make an appointment. However, if you do need to speak privately with a staff member, it may be best to call first.
The Carers Centre service is provided throughout the region and there are Carers Support Workers based in Dumfries (01387 248600), Wigtownshire (01671 401152), Stewartry (07902002963), Upper Nithsdale, and Annandale & Eskdale.
Email address: info@dgalcarers.org

Don't hesitate, just go for it if you want to contact them.
With thanks to Andy and Ross. And keep going, even if it is at a low speed, Maya.

Maya Berwick

Carers’ Discount Scheme

Dumfries and Galloway Council has launched a new Carers’ discount scheme offering a 50% discount off some of its leisure and sport services. The scheme, open to those receiving Carers’ Allowance or holding a Carers’ Emergency Card, include swimming pools, fitness and health suites and public skating. Those eligible can start receiving this discount by taking their Carers’ Emergency Card or proof of receipt of Carers’ Allowance to any Dumfries and Galloway Council Leisure and Sport facility.

To find out more about the Carers’ Emergency Card please contact the Dumfries and Galloway Carers Centre by phone or email as above. The emergency card scheme aims to make sure that no-one receiving care is left unsupported if their Carer falls ill, has an accident, or faces an emergency.

Many thanks to all those contributing to this newsletter. It’s great to see our readers getting engaged with useful and interesting information. But don’t stop – articles, snippets, ‘funnies’, contributions and suggestions for articles (to paul@dgmefm.org.uk) are very welcome for our next issue! *Craig*

The Art of Letting Go

Written by Lisa Lorden Myers (US author), on her website Living with CFS & Fibromyalgia

'…………………….we often measure our worth in the currency of how much we *do*. Yet the typical goals declared on January 1st of each year may be more unrealistic than ever.

In his book, *Don't Just Do Something, Sit There,* Richard Eyre explains how some of the traditional wisdom about self-improvement is outdated or inaccurate. He argues that we need new paradigms to "reflect our world as it really is, and our lifestyles as they really ought to be." This is particularly true for people who are debilitated by chronic illness. Perhaps we need to rethink these annual goals and look to the New Year with a spirit of "Anti-Resolutions"—that is, to release ourselves from the obligation of things we are not able to do and consider alternatives more supportive of healing and well-being.

Let's look at some typical January 1st declarations and how they might be transformed to better fit the lives of people with Chronic Fatigue Syndrome or other chronic illness:

I will exercise for one hour every day, no matter how I feel.
→ *I will listen to my body, avoiding exercise that results in a worsening of my symptoms.*

I will wake up an hour earlier each morning.
→ *I will try to rest an hour each day.*

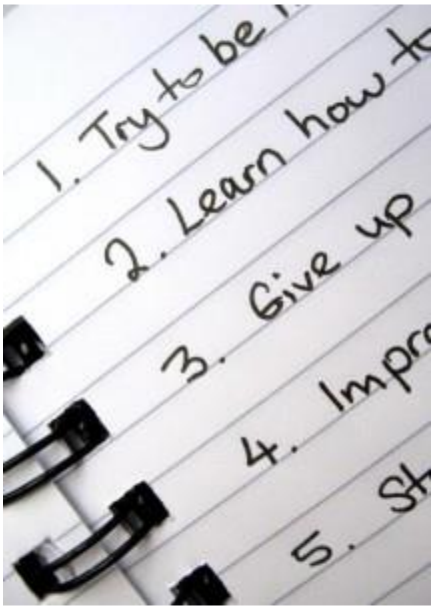
I will work harder to get that promotion this year.
→ *I will acknowledge my health is more important than that promotion this year.*

I will manage my time so that I can do more.
→ *I will pace myself to allow for rest and recovery.*

I will be more generous to others with my time and energy.
→ *I will be more protective of my time and energy in order to take better care of myself.*

I will return phone calls promptly.
→ *I will answer the phone less frequently.*

I will accomplish all the items on my To-Do List.
→ *I will eliminate some of the items on my To-Do List.*



The "transformed" list of resolutions may look quite different from the traditional one. But is it any less important? And is it any less challenging? It's funny how determination and will power can be so difficult to apply to the goal of doing less, instead of doing more. We may know how to commit ourselves to goals and work to achieve them, but can we have similar determination to rest and to heal?

Can our will power be devoted to "letting go"? Perhaps the New Year is a time to re-focus ourselves less on *doing*, and more on *being*. Consider making your own such list of "anti-resolutions" that focus not on getting things done, but on improving your health and quality of life. Or you may not want to make any resolutions at all.

This year, the most empowering declaration for us might be that we will make no resolutions, set no quantified goals, and rely on no concrete measures of success. Instead, we can open our bodies and minds to be healed and open our hearts to contentment and peace.

Healing requires no resolutions—it requires only that we live each day the best way we know how, listening to our bodies, and nurturing our souls. Even if we abandon every resolution we've ever made, perhaps we will start to experience the healing value of letting go.

Lisa Lorden Myers

ME and Fibro Awareness Week, 9th-15th May

May 12th is Awareness day, chosen as it is the birth date of Florence Nightingale, who is thought to have suffered ME or fibromyalgia.

Go BLUE to show your support. Perhaps you could dress in blue, light your house in blue light, paint your face blue... or maybe just wear a blue ribbon?

Please also use the day to share information about ME or fibromyalgia and to tell people how it affects you and your life. Perhaps you could write a letter or share a post on social media?

ME and fibromyalgia are maligned and misunderstood illnesses. Let's help change that.

Dumfries & Galloway ME and Fibromyalgia Network (DGMEFM Network)
Phone: 07437 602610
Website: dgmefm.org.uk
Facebook: facebook.com/groups/dgmefm
Email: craig@dgmefm.org.uk (Chair)
kim@dgmefm.org.uk (Secretary)
paul@dgmefm.org.uk (Treasurer)

Wigtownshire FM/ME Support Group
(An independent group)
Meetings on the last Thursday of each month (except December) from 12.30 – 2.30pm at
Turning Point Scotland, Burns House,
32 Harbour Street, Stranraer.

ME Association 7 Apollo Office Court, Radclive Road, Gawcott. MK18 4DF ☎ 01280 818964
www.meassociation.org.uk Email: admin@meassociation.org.uk

Action for ME 42 Temple Street Keynsham, Bristol. BS31 1EH ☎ 0117 927 9551
www.actionforme.org.uk Email: admin@actionforme.org.uk

FMAUK (Fibromyalgia)
Studio 3007, Mile End Mill, 12 Seedhill Road, Paisley PA1 1JS ☎ 0844 826 9022
www.fmauk.org Email: charity@fmauk.org

Tymes Trust (For younger people with ME) P.O. Box 4347, Stock, Ingatestone CM4 9TE
☎ 0845 003 9002

Financial Inclusion and Assessment Team D&G Council's benefits and money advice service.
☎03033 333008 email: fiatreferrals@dumgal.gov.uk