

***Welcome all,***

June brings the long hours of daylight - which I love - and thoughts of summer holidays. Whether we have the wherewithal to get away ourselves (energy or funds) or whether we have children in school or nearby (to create a noise!) it probably will affect us.

For me the light late into the evenings and the strength of the sun on my body is a very refreshing thing. It may be cool yet, but I can feel it clearing away the dark, depressive winter and lifting my spirits. When the weather is good there's no better place to be than our beautiful region.

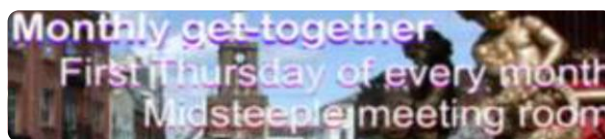
I've been fortunate enough to be away on holiday and have found that the changes have affected my ME hugely. I travelled while relatively unfit and have found that pushing myself resulted in a lot of extra pain and cognitive dysfunction, but also increases to my fitness levels and stamina. Of course it was easier to risk overdoing it when being looked after, knowing there will be dinner on the table, breakfast brought to my bed and everything will be tidied up behind me. Most of all though I feel mentally refreshed from a change of scene, and for me that is worth the extra pain and the recovery period. I feel even a small break can really help us to get through the more difficult days. Energy is in such short supply that we rarely do anything purely for enjoyment rather than out of necessity. A day or two staying with friends, to a night in a hotel, to a trip to the seaside can be very uplifting.

While I was away ME and fibro Awareness week happened. I packed my ribbon and wore blue. I do hope everyone joined in and shared information about their illness on social media. Understanding is improving, but there's still a long way to go.

*Craig Woods*

## **Monthly Get-Together**

Check our websites for 'pop-up' meetings at cafés:  
[dgmefm.org.uk](http://dgmefm.org.uk) or [facebook.com/groups/dgmefm](https://facebook.com/groups/dgmefm)



There are no guest speakers invited to our usual meetings over the summer months. Join us for informal chat on the **first Thursday of each month** from 1 – 3pm at Midsteeple, Dumfries.

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.

## **The Sussex-based ME/CFS charity ReMEber held a meeting on 14<sup>th</sup> May with presentations by consultant immunologist Dr Amolak Bansal (research) and ME Association medical adviser Dr Charles Shepherd (management).**

Dr Shepherd produced a summary from this meeting of the key points on both research and management – especially those that relate to the way in which some of the current research findings on infection, immune system dysfunction, muscle/mitochondrial function, etc, link in to practical patient management. The summary also includes information from the meeting on the role of stress, activity management and drugs that may affect the underlying disease process in ME/CFS (e.g. antivirals, steroids and rituximab). For the full summary see: <http://goo.gl/jw3dYM>

### **On Rituximab**

Dr Bansal provided a comprehensive update on the current situation regarding the proposal to carry out a clinical trial of rituximab here in the UK to see if this could replicate the benefits that have been reported from the Norwegian trial.

However, feedback relating to people in the UK who have been treated with rituximab in America, as well as US citizens who have been treated with rituximab, has been nowhere near as positive as the results that have been reported from Norway. Consequently, questions are now being asked as to how a UK trial could/should proceed and whether this is the right time to commence a UK trial.

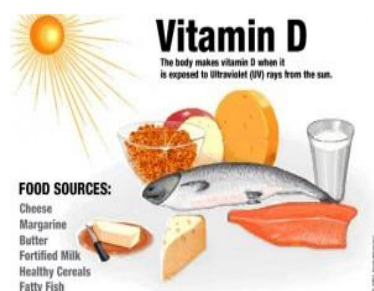
Dr Bansal noted that it is possible that the failure of these people to respond to rituximab could be explained by different trigger factors being involved in the Norwegian population, and/or that there is something different about the patient selection process in Norway.

On **Management**, Dr Shepherd spoke about what he regards to be the 10 key components that need to be included in any patient management programme: Early and accurate diagnosis; find a good doctor; drugs that can help with symptoms; balancing activity and rest; dealing with emotional and mental health issues; employment and education; state benefits; social care and support; vitamins, minerals and supplements; and alternative and complementary sector.

In particular, on **early and accurate diagnosis**, Dr Shepherd emphasized that:

- doctors do not have to wait six months before they can diagnose and treat people with ME/CFS – in most straightforward cases this can and should be done by three to four months from onset of symptoms
- there is a list of essential baseline ‘blood test’ investigations that should always be checked before a diagnosis of ME/CFS is confirmed
- there are a number of other investigations that should be arranged in patients where a symptom is atypical or is more severe than would be expected in ME/CFS (e.g. significant joint pain, severe sleep disturbance)
- obtaining an early and accurate diagnosis has many advantages – most important being the development of an individual management plan once a diagnosis (or working diagnosis) has been confirmed.

On **vitamins, minerals and supplements** he said that there is currently very little sound research evidence to demonstrate that mineral or vitamin deficiencies occur in ME/CFS.



One important exception is the possibility of vitamin D deficiency in people with moderate or severe ME/CFS who are housebound and not being exposed to sunlight and may also have dietary modifications/restrictions.

There is also very little evidence from clinical trials to show that vitamins, minerals and supplements are of any significant benefit in ME/CFS. Possible exceptions include carnitine, eicosapentaenoic acid (EPA) and Ubiquinone 10 (Co-Enzyme Q10)

Exclusions diets, including the FODMAP diet, may be helpful where there are irritable bowel syndrome type symptoms but more radical changes to diet can cause more harm than good.

Do not go 'gluten-free' until a screening test has excluded coeliac disease.

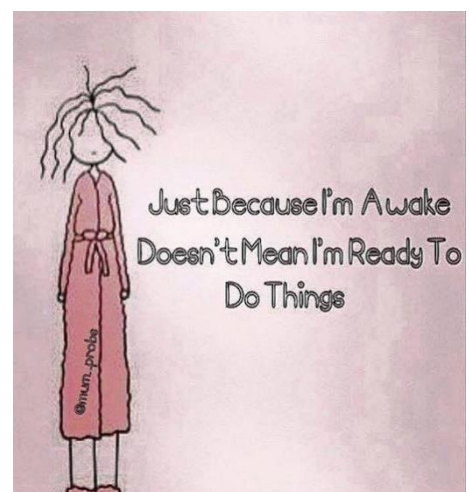
## **My Top 12 M.E Coping Strategies**

*by Jay McCarthy, Creative Director/Producer of Broken Puppet Theatre Company.*

These are basically the things I found out the hard way over a 6 year period, and I'm still learning...but I wish someone told me all this at the beginning of my illness, so I hope this may save a few people some time and spoons! ...

- 1) Explain to your family and friends that your autonomous central nervous system is faulty, and cannot properly regulate things like your temperature, or signaling in general between your brain and body. Explain that this also affects your immune system, and that your muscles simply do not have the capacity to store or generate energy the same as theirs can. It helps if people know as much as possible about how it affects you physically, even if there is not yet enough science to prove the underlying causes.
2. STOP FIGHTING IT, Sooner rather than later. This illness gets worse the more you try to ignore it and keep powering through, so depending on how ill you are feeling, you must learn to slow down to the pace your body is dictating. Hands down, this is the most debilitating and infuriating aspect of the illness. And has a psychological/emotional impact which also must not be ignored. Wrapping your head around the fact that the more you push against it to keep going, the worse you will get, is one of the biggest challenges.
3. Tell someone at work. Even just 1 trusted colleague, so they can help support you while you are there, or help advocate if things get to a stage where you have to talk to your boss. Consider whether your full time job brings enough joy and light into your life, because when you are having a flare up and still working, you will spend 100% of your 'spoons' doing it, leaving none for anything else. Sometimes a reduction in hours or instigating pacing at work, by switching tasks between mental/cognitive and physical activity can help. Your boss does have a responsibility to make reasonable adjustments to help you under disability legislation, but I know how hard it is to speak out at work, so do it in your own time.

4. Check out 'The Spoon Theory' by Christina Miserandino on 'butyoudontlooksick.com' it is very helpful for understanding pacing and explaining it to others.
  5. Make sure your doctor knows that you are conducting your own research, and get your heads collectively around the notion of 'symptom management'. They don't have any answers, but they do have prescription pain meds, which are sometimes the next best thing!
  6. Keep in touch with other ME Sufferers, or people with other chronic/invisible illnesses. They are the best people to relate to and support you on a rough day, as 'they just know', without you needing to say anything.
  7. The key is adapting, learning to go with the flow, accepting the unpredictability, instead of living in fear of it.
  8. Prioritise. Everything. This illness will force you to make a lot of tough decisions about your life, who you spend your 'spoons' with, who and what is really worth the 'Payback' from spending too many, and who is really there for you when it counts. It is painful on both physical and emotional levels, but you CAN learn to live with it, and even if your life changes a lot over the next few months or years, IT WILL GET BETTER.
  9. Learn to ask for and accept help. We are notoriously bad at this, culturally speaking. We feel like a burden. But actually asking for help with specific things can be good, not only for you, but also for whoever you ask, who often feel as helpless as we do and genuinely feel better if they are able to help you in some way, no matter how small.
  10. Learn how to rest properly. Mind and Body. Without guilt. Rest for us is as important as breathing. Really. It's frustrating, and way more stressful than you'd expect. Learning to have quality 'down time' is critical for extending long term access to the good things you'd rather be doing. You miss a lot. You get used to it. And it's a weird catch 22, because also, the more you rest, the more you get to do later!
- The bonus in at 11...Express yourself. For me that is usually creative writing and making theatre, for you it could be music or dance or blogging or talking it out...but whatever shape it takes, it is crucial to your mental health and general mindset to find workarounds that let you still be and feel like you. The one you think you might lose to this illness if you aren't careful. You're still you. Do everything you can do to protect your core self. It's more important than you realise. That doesn't mean you won't grow or change as a person, because you probably will, but try to stay true to yourself, even as it is adapting.
12. Deliberately aim to do something that makes you feel like you're not completely useless. Be a voice helping others to understand. Because not all of us can be, and we give ourselves such a hard time about what we can't do, we sometimes forget to look for and acknowledge what we can!



## Capability Scotland

We were pleased to welcome Karen Pirrie, a Support Worker from Capability Scotland, to our May get-together. Karen talked with us about their work and how to access the service in our Region. They cater for people aged 16 to 65 who have a physical disability, and they include ME and Fibromyalgia as qualifying criteria.



The service is free, apart from the costs of activities. They are a charity funded through NHS and Social Work, but also hold fund-raising events.

What do they provide?

- They run local groups.
- Help service users who want to stay in employment and offer guidance to employers.
- Help service users get into college and access training.
- They are a person-centred service, so happy for users to give them ideas as to what would help.
- They appreciate that not everyone wants to be part of a group and so will offer 1 to 1 services.
- They organise social events for service users and family members, open for suggestions.
- Work closely with other departments to get the most for their service users.
- Complete risk assessments on service user homes and for venues.
- Maintain a database to signpost service users to other services.

They accept self-referrals or through GP, Social Worker etc. We have added a link to their referral form on our website: <http://dgmeffm.org.uk/national-links/>



"Sometimes it's okay if  
the only thing you did  
today was breathe."

~ unknown

Sketches in Stillness.com

no oranges

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Contact: Carron Alison, Service Manager  
Dumfries and Galloway Integrated Service,  
Nithbank, Bankend Road, Dumfries, DG1 2SD  
Tel: 01387 244481 or 075721 28264  
Email: [carron.alison@capability-scotland.org.uk](mailto:carron.alison@capability-scotland.org.uk)

Ask them for their newsletter which shows the  
wide range of their activities - phone as above or  
email: [D&Gservice@capability-scotland.org.uk](mailto:D&Gservice@capability-scotland.org.uk)

**Would you like a 'pop-up' meeting with other DGMEFM Network members  
at a café or venue near you? If so, do you want help to arrange it?  
Phone: 07437 602610 or email: [admin@dgmeffm.org.uk](mailto:admin@dgmeffm.org.uk)**

## **Living with Fibromyalgia**

In 2009 I went through a very stressful time at work. At that time, I was employed with the Scottish Prison Service and had worked full time as a prison officer since 1998.

Due to the stress, I had a Haemiplegic Migraine and it was after this that I started to have symptoms of Fibromyalgia.

From April 2009 to June 2012 I was a regular attendee of my local GP, I knew there was something wrong, but my doctor could not pin point what the problem was. I was made to feel like it was all in my head and that I was a hypochondriac. I changed my local GP as I knew there was something wrong with my health and that it was not all in my head! My new GP sent me for an endoscopy, physio and blood tests and eventually in June 2012, I was sent to the Rheumatologist and was diagnosed with Fibromyalgia.

The Rheumatologist gave me an information booklet and said there was nothing more that could be offered to help me, my local GP put me on Amitriptyline and told me there was other medication that I could try but other than this, nothing more that could be offered to me.

I was so relieved I had been diagnosed with Fibromyalgia, which sounds bizarre, but I knew that it was not going to kill me and I was adamant I was not going to let Fibromyalgia get the better of me. So, I researched the condition and as a result of all the research I completely changed the way I lived my life!

I changed my diet, no more sugary drinks, tea, coffee, alcohol or processed food; regular exercise (which was walking the dogs or bowling); having a weekly treatment, eg Shiatsu, acupuncture, massage or a Myofascial Release treatment, and the main thing - pacing myself each day.

I felt I was coping with this horrendous condition very well. I still had the occasional bad flare up, but these would only occur for one or two days per month. On these days when I was very unwell I could not attend work. In February 2015, my work told me that they could not accept my sick days and they would have to look at dismissing me through capability. The most days off I had in a year was 17 days! I fought the decision of being paid off and was treated very poorly, but nothing could change their decision and I was faced with reality of losing a secure job. I had no idea what I was going to do and went through a very stressful time as I did not know how I was going to pay my mortgage, other financial commitments or who was going to employ me after being sacked due to my ill health!

I am a firm believer that everything happens for a reason and everything will be alright in the end and if it is not alright, then it is not the end! So I made the decision that this was not going to beat me! I would turn this negative into a positive and change my life for the better.

In July 2015 I started a 5 week dog grooming training course in Somerset and after passing my City and Guilds course with flying colours, I started my own dog grooming business in the town and I have never looked back!

*Claire Shaw*



## The benefits of an infra-red sauna.

An infrared sauna is not like a proper Swedish sauna with steam that makes you sweat profusely. The infra-red sauna uses infrared heaters to create infra-red light and the skin surface will absorb the radiant heat.



It looks like a cabinet made from wood and glass, you sit on a bench and can relax in the heat. Especially in the winter, when it's cold and dark in Scotland, it will give you a great feeling of well-being. Our sauna has a CD player in it, so now I can listen to whale sounds as well!

You can adjust time and temperature, but people with ME are often not good with the heat or change in temperature, so you have to build up the amount of time you are in the sauna and the temperature slowly over a period of time. Of course you have to drink a lot and that helps the detoxification process.

If you can't sweat from exercise due to health problems (something people with ME are very familiar with) an infrared sauna will make you melt! Your body gets cleaned out, you get rid of unwanted toxins and your skin will start to glow. It's good for the blood circulation and some people lose weight, but I never came slim out of this sauna! Some people use it for pain relief. I don't have ME myself, my husband has, but if I have been working in the garden all day, so my body hurts, it's heaven to be in this sauna. My Andy feels less back pain and just loves to be in it, so he can relax completely (and has some me-time, away from his wife!). He uses it as a part of his pacing process, along with a healthy diet and Tai Chi.

Relaxation is very good for the heart, soul and mind. If you have ME, you need that very much. There are more ways of course to create relaxation, this is just one of the possibilities. Some people say an infrared sauna is expensive (they vary a lot, but we have a Chinese cheepie for around £800 and it works great), but if you don't eat out, don't drink, don't do big holidays (which most people with ME can't do), you maybe save quickly a lot of money. There is also a cheaper option, like an infrared bag, they cost a just a couple of hundred pounds and don't need much space.

Keep going!

*Maya Berwick*



## Snippets from our Facebook page.....

..... some of the recent themes and discussions shared by members in support of one another.

- Stress and anxiety with PIP applications and reviews
- Numeracy difficulties
- Green smoothies
- Coping with pain; reactions, benefits & side effects of medication – gabapentin, pregabalin, tramadol, amitriptyline
- Vitamin D deficiency
- Sleep problems
- POTS (Postural orthopaedic tachycardia syndrome)
- Massage and other therapies
- Gluten-free diet
- Alcohol intolerance



## Pacing and Exercise

There have also been questions and comments on our Facebook page about exercise. The Physiotherapist at the ME Clinic in Keswick gave advice that ME/CFS sufferers should exercise in a way that requires little effort and keeps the heart rate relatively low.

The Borg Category Rating Scale		
Least effort		
6		
7	very, very light	
8		
9	very light	
10		
11	fairly light	ENDURANCE TRAINING ZONE
12		
13	somewhat hard	
14		
15	hard	STRENGTH TRAINING ZONE
16		
17	very hard	
18		
19	very, very hard	
20		
Maximum effort		

He referred to the Borg Scale which is a simple method used for rating perceived exertion, and recommended keeping exercise within the region of 8 to 10, and no more than 12 on this scale.

9 corresponds to "very light" exercise. For a healthy person, it is like walking slowly at his or her own pace for some minutes.

He also recommended that heart rate when exercising should be kept at or below 60% of 220 less age. So, for a person aged 40 years this would be  $(220 - 40) \times 60\% = 108$  maximum beats per minute. These are broad-brush guidelines for ME/CFS and don't take account of any other illnesses, conditions or medication affecting the person.

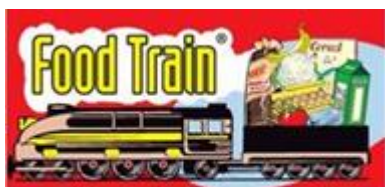
*Paul Thompson*

## Wanted: Blogger(s)

We have added a 'blog' page to our website - <http://dgmefm.org.uk/blog> which we would like to use to give a regular (e.g. monthly) anonymised summary of discussion and articles posted on our Facebook page. This will allow non-Facebook members, and the wider public, to see topics of concern and interest currently affecting us. If you think you could help with this please get in touch with our secretary, Kim.

[kim@dgmefm.org.uk](mailto:kim@dgmefm.org.uk)





Supporting local older people at home.

This charity ordinarily offers a service to older people (aged over 65) however they are now accepting referrals from people aged over 50.

Anyone aged over 65 can self-refer, but at present those aged 50 to 65 must apply through their local Social Work office.

The Food Train is a grocery shopping, befriending and household support service for older people in Dumfries & Galloway. The original weekly activity of grocery delivery remains unchanged during the last 20 years but the scope of work is much wider now, covering health improvement, food safety advice, nutrition advice, financial advice signposting, home and community safety advice, physical and mental health care advice. Their aim is to help older people who, through age related ill health, frailty or disability, are unable to manage their grocery shopping, by providing a shopping delivery service with additional household support and befriending service where required.

Food Train Friends is a service offered by Food Train, and offers a variety of befriending options including telephone contacts, home visits, regular group activities and outings on pre-planned programmes. Their vetted befriending volunteers provide informal low level social support services where clients pay a small annual charge for membership. Befriending happens on a regular basis, so customers can rely on companionship, a friendly face and someone to talk to. The service aims to reduce loneliness or social isolation in local older people and to encourage mobility and promote independence where possible. Due to high demand for their services and limited resources of volunteer befrienders, they prioritise customers who live alone at home and are lonely or socially isolated, particularly for their home visiting service. *At present the Food Train Friends service is not available in DG5, DG6, and DG7.*

Contact: Mrs Helen McAnespie, Regional Manager, Dumfries & Galloway

Phone: 01461 207778 or 0790 2186 454

Email: [helen@thefoodtrain.co.uk](mailto:helen@thefoodtrain.co.uk)

Address: 2-4 Bank Street, Annan, DG12 6AA

Website: [www.thefoodtrain.co.uk](http://www.thefoodtrain.co.uk)

## Fund Raising

Our thanks to Denis Turner and to Elaine Waugh for their continuing efforts to raise funds for the Network.

Denis entertains in the café area at Garden Wise in Dumfries every second Thursday of the month. He has raised nearly £240 for us since last August.

Elaine has recently sold honey and jams raising almost £100.

## Do you shop on-line?

Many major retailers and marketplaces such as Amazon and eBay give charity donations on purchases made through Easyfundraising, at no cost to the purchaser. We have 18 supporters whose shopping has raised over £200 for us so far. Please join in by registering with <https://www.easyfundraising.org.uk> and choose DGMEFM Network as your Cause. Thank you.



## Network Leaflet

We are keen to create a leaflet with useful local information for current and new members.

The plan is for this leaflet to be made available as a welcome to the network and to signpost members to key local information, for example who best to contact for help on allowances, employment rights for those still able to work, helpful services provided by other departments / charities, how to get the most from your GP etc.

As many of our members have had their condition for a considerable period of time, who better to contribute to the creation of this leaflet but our current members. **Please think about what is important to you and what would you like to see in a local Network Leaflet.**

Please send your items / ideas to [kim@dgmeffm.org.uk](mailto:kim@dgmeffm.org.uk) who will be pulling this leaflet together.

Thank you in advance.

Kim Jakobsen  
DGMEFM Network Secretary

<b>Dumfries &amp; Galloway ME and Fibromyalgia Network (DGMEFM Network)</b> Phone: 07437 602610 Website: <a href="http://dgmeffm.org.uk">dgmeffm.org.uk</a> Facebook: <a href="https://facebook.com/groups/dgmeffm">facebook.com/groups/dgmeffm</a> Email: <a href="mailto:craig@dgmeffm.org.uk">craig@dgmeffm.org.uk</a> (Chair) <a href="mailto:kim@dgmeffm.org.uk">kim@dgmeffm.org.uk</a> (Secretary) <a href="mailto:paul@dgmeffm.org.uk">paul@dgmeffm.org.uk</a> (Treasurer)	<b>Wigtownshire FM/ME Support Group</b> (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.
<b>ME Association</b> 7 Apollo Office Court, Radclive Road, Gawcott. MK18 4DF ☎ 01280 818964 <a href="http://www.meassociation.org.uk">www.meassociation.org.uk</a> Email: <a href="mailto:admin@meassociation.org.uk">admin@meassociation.org.uk</a>	
<b>Action for ME</b> 42 Temple Street Keynsham, Bristol. BS31 1EH ☎ 0117 927 9551 <a href="http://www.actionforme.org.uk">www.actionforme.org.uk</a> Email: <a href="mailto:admin@actionforme.org.uk">admin@actionforme.org.uk</a>	
<b>FMAUK (Fibromyalgia)</b> Studio 3007, Mile End Mill, 12 Seedhill Road, Paisley PA1 1JS ☎ 0844 826 9022 <a href="http://www.fmauk.org">www.fmauk.org</a> Email: <a href="mailto:charity@fmauk.org">charity@fmauk.org</a>	
<b>Tymes Trust</b> (For younger people with ME) P.O. Box 4347, Stock, Ingatestone CM4 9TE ☎ 0845 003 9002	
<b>Financial Inclusion and Assessment Team</b> D&G Council's benefits and money advice service. ☎ 03033 333008 email: <a href="mailto:fiatreferrals@dumgal.gov.uk">fiatreferrals@dumgal.gov.uk</a>	

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