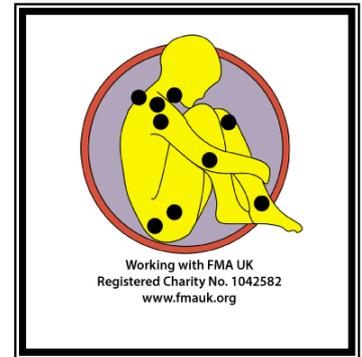




Welcome to Our December 2015 Newsletter.

Note from the Editor Maxine: Please remember no main meeting this month but the Prestwich social is at the Church Inn for December and changes venue in January 2016. Please read post below.



Monthly focus.



Amazon

Sorry to say it so loud, but CHRISTMAS!! Yes, I can't believe it myself, but it's nearly here already. Seems like just yesterday I was buying Easter Eggs. Don't forget when you're panic-buying or splurging in the New Year sales, that the group gets a small commission on your Amazon.co.uk purchases.

To get the commission, you must first go to our website, www.mesupportgroup.co.uk and click on any of the Amazon links you see about, there's one on the left side all the time. You have to visit our site first each time you buy something for the transaction to be eligible. It's incredibly easy to do, takes seconds, but gets us about £150-£170 each year, which is fantastic. We really appreciate your support, thank you! Caroline

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). The building is past Morrisons/Home Bargains/Brightmet Health Centre on the right hand side as you go into town, very near the junction before you turn onto Crompton Way from Bury Rd.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

No main meeting in December, but please join us at Prestwich!

Yoga Classes: Are 3:15pm-4:15pm on Tuesdays at the Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Please contact our instructor Lisa. Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

Prestwich Socials: *****PLEASE NOTE CHANGE OF VENUE. *****Due to parking problems at The Church Inn, from January our Prestwich social will move to **The Woodthorpe, Bury Old Road, Prestwich, M25 0EG**. This is a very roomy pub, with ramp access, a disabled toilet, a variety of comfortable seating and free parking outside. It also serves a range of full meals and snacks if anyone is hungry. We meet on the **second Wednesday** of the month at 2pm, so the next meeting is **Wednesday 13th January 2016**. (Depending when you are reading this, please note that the December 9th social is going ahead at The Church in as previously advertised.)
Please try not to turn up too late, because if numbers are low and those attending are not feeling very well on the day, it would be a shame if you missed us.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.



DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

November Pre-Xmas Supper Social

Many thanks to all those who braved the wind and rain to attend our bring and share supper. We had a lovely assortment of food, and welcomed members, old and new. One members brownies are always a sure-fire hit, so here's the recipe again, by popular demand:

VEGAN BROWNIES

150 g self raising flour (gluten free if required)
37g cocoa powder (tesco's own is vegan)
2 teaspoons Orgran no-egg replacer
175g caster sugar
185g baking fat (Trex, vegetable suet, etc)
4 tablespoons golden syrup
6-12 tablespoons water (depending on consistency when mixing)
half teaspoon vanilla essence
200g vegan choc (chopped into chunks)

Save 50g of the choc for the topping.
Mix the rest together well.
Spread evenly into a deep tray lined with baking paper.
Cook for 25-30 mins at 180C

STANDARD BROWNIES

225g self raising flour (gluten free if required)
400g caster sugar
225g melted butter
60g cocoa powder
1 teaspoon vanilla essence
4 eggs
50ml milk
200g plain choc chips

Save 50g of the choc for the topping.
Mix the rest together well.
Spread evenly into a deep tray lined with baking paper.
Cook for 30-40 mins at 180C

Do you have any recipes to share? Please send to maxine@mesupportgroup.co.uk.

If you're a bit nervous about coming to the meetings, remember you can bring family, friends and/or carers for support. We understand how scary it can be meeting new people, but we don't bite and have a lot of experience and knowledge between us! If you want more information about the meetings, call Caroline on 01204 525 955 or email caroline@mesupportgroup.co.uk

Our Awareness Merchandise Stall

Remember that we have a small stall at the main meetings, selling various awareness items at reduced cost.

We have a variety of bumper stickers for boot access, invisible illness and uncooperative bodies from the brilliant Hannah Ensor of Stickmancommunications.co.uk who draws cartoons about living with a disability! Also from her range are her books on POTS, hospital stays and life as a wheelie (wheelchair user), which are spot-on and light hearted. We also stock lanyards, posters and keycards for ME/CFS, Fibromyalgia and brainfog, to help explain to others quickly when your brain has gone for a long walk somewhere else.

From the ME Association, we have trolley coin keyrings and ME Alert wallet cards and blue ribbons for awareness. For the fibro warriors, we have phone charms, pens, yellow awareness ribbons, rubber awareness duckies, pin badges and more.

The items are bought at wholesale prices, so that you can purchase them at reduced cost to buying them elsewhere, but still helping our group out a little.

If you are desperate for stuff, but can't get to a meeting, most of the stuff is light, so we may be able to post it out for you at cost, energy depending.

The stall is awesomely managed by Louise and Soph, and a big thank you to them for looking after it so well.

Caroline's Close-Shave Update



Caroline raised a total of £601 for Bolton Destitute Animal Shelter and donated 17 inches of hair to The Little Princess Trust. She's received certificates for both. The hair is growing back very quick and is ridiculously easy to manage (no more injured wrists, mangled hair brushes, or struggling to wash and dry it. Would recommend to anyone!)

Huge thanks to everyone to contriuted, the group member donations are a large portion of the amount raised. Caroline welcomes any excuse to visit the shelter and see all the fur-babies, so any late donations appreciated! Thank you.



Phenomenal Two-Letter Word!!

Sent in by a member. Author unknown.

I'm sure you will enjoy this. I never knew one word in English language that can be a noun, verb, adjective, adverb and preposition.

UP

This two-letter word in English has more meanings than any other two-letter word, and that word is UP.

It's easy to understand UP, meaning toward the sky or at the top of the list, but when we awaken in the morning, why do we wake UP?

At a meeting, why does a topic come UP? Why do we speak UP, and why are the officers UP for election (if there is a tie, it is a toss UP) and why is it UP to the secretary to write UP a report? We call UP our friends, brighten UP a room, polish UP the silver, warm UP the leftovers and clean UP the kitchen. We lock UP the house and fix UP the old car.

At other times, this little word has real special meaning. People stir UP trouble, line UP for tickets, work UP an appetite, and think UP excuses.

To be dressed is one thing but to be dressed UP is special.

And this UP is confusing: A drain must be opened UP because it is blocked UP..

We open UP a store in the morning but we close it UP at night. We seem to be pretty mixed UP about UP!

To be knowledgeable about the proper uses of UP, look UP the word UP in the dictionary. In a desk-sized dictionary, it takes UP almost 1/4 of the page and can add UP to about thirty definitions.

If you are UP to it, you might try building UP a list of the many ways UP is used. It will take UP a lot of your time, but if you don't give UP, you may wind UP with (UP to) a hundred or more.

When it threatens to rain, we say it is clouding UP. When the sun comes out, we say it is clearing UP. When it rains, it soaks UP the earth. When it does not rain for awhile, things dry UP. One could go on and on, but I'll wrap it UP, for now . . . My time is UP!

Give A Dog A Bone

The Give A Dog A Bone Charity may be able to help you if you need an animal companion to keep you company, but cannot afford the adoption fee, or ongoing food costs. In November 2013, Louise Russell (pictured, right) set up a registered charity to support the over 60s to afford a rescue pet companion.

Her mission was to support individuals through loneliness, and animals through homelessness, by bringing the two groups together.

It seemed like a simple solution to her, to two of societies prevailing problems - loneliness in our ageing years and the rising number of animals in shelter.

If money is a genuine barrier to rehoming an animal, the charity can pay the rehoming fee and continue to support on a monthly basis, if need be, with the cost of pet food.



To date, the charity has been extremely successful and has helped 80+ animals and individuals to have a brighter future! They will consider applications for almost any pet, the help is not just limited to cats or dogs.

The charity has supported many people in various ways, including finding volunteer dog walkers for individuals who were too ill to walk them, emergency foster care for animals whose owners were taking into hospital and new homes for animals whose owners had died or were suffering from terminal illness and were worried about their pet companion.

Examples of their recent successes include rehoming Romanian dogs from a high kill shelter. Many Romanian shelter dogs live in terrible conditions and have many health problems. They also helped a 74 year old woman with the rehoming fee and pet food costs each month so she could give a stray dog a home. A lady who had recently been widowed and now felt alone and scared, had assistance from the charity so that she could adopt Ben, and she's smiling again now.

Louise was recently awarded with the Prime Minister's Point of Light Award for her outstanding contribution to volunteering.

They are still only two years old, so need your help with donations, fundraising and spreading the word. Registered Charity number SC044440

Website: <http://www.giveadogabone.net/about-us/>

Facebook Page: search "giveadogabone.net"

(link: <https://www.facebook.com/giveadogabonenet-545275872224672/>)

Phone: 07969 742 858. Email: Louise@giveadogabone.net

For the record

Response to headlines suggesting ME 'is all in the mind' Image

Response to headlines suggesting ME 'is all in the mind'

Articles on Wednesday 28th October in the Daily Mail, the Daily Telegraph and others reported that new research on ME/CFS showed it to be a disease that was "all in the mind", and that the research contradicted the view that ME/CFS is "chronic and cannot be alleviated".

The study, published in The Lancet Psychiatry, was a long-term follow-up to a study that suggested that cognitive behaviour therapy and graded exercise therapy were moderately effective ways of treating some people with ME/CFS.

Lead author of the study, Michael Sharpe, Professor of Psychological Medicine, University of Oxford:

"The study did not find that ME/CFS is 'all in the mind' – in fact it didn't look at causes of the disease at all. People think that if these kinds of treatments help, it is saying something about the nature of the illness, which of course isn't true. This study tells us nothing about the cause of the illness, just how to help people who have it. 'All in the mind' is also a

hugely misleading description of conditions that might be associated with psychological and social factors.

"The study did not contradict the view that ME/CFS is a chronic illness. These treatments, which we have found previously to be moderately helpful, are not a cure, and they do not benefit everyone. But the good news is, the benefit of these treatments is still apparent two years later, and they do not lead to a relapse of the illness. This new finding should reassure patients who want to try these treatments."

Document type: For The Record

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- See more at: http://www.senseaboutscience.org/for_the_record.php/214/response-to-headlines-suggesting-me-is-all-in-the-mind#sthash.XhnlLxdU.dpuf

Help Yourself Sleep by Dan Leigh

If you can't sleep, don't stay in bed/lying down...

In fact if you're not asleep after half an hour - get up!

Go and finish washing/drying the pots, hanging up/putting in the washing, or anything else that doesn't require much concentration.

Get your things ready for tomorrow.

Write down what you're thinking. Like, on paper, with an actual pen or pencil... A biro works best because it is smooth and there no distracting sound.

Have a cup of milk or milky drink, perhaps warm with a small snack like toast with mashed banana.

Remove all screens from the bedroom - it doesn't help your brain when getting into sleep mode and also if you've got it in another room it removes the temptation of checking your phone or writing something down on it.

I've read somewhere that lavender is soothing so I bought a couple of bags of dried lavender [already made-up] from Amazon and placed them strategically them in my bedroom.

Keep your bedroom cool. Open the window throughout the day. Keep the heating low. One can purchase cool gel pillow mats - I just got one, it came today - I will endeavour to let you know it goes.

Create a going-to-bed routine. Do whatever you like that helps you relax and switch off i.e. no reading, no screens and no chatting online. Settle in for a bit of 'me time'. Soak your feet. Have a short bath or shower. Not only does this help the muscles relax, but the transistion from hot soak/waterfall to cool bedroom encourages the body into sleep mode.

So when you get tired again, go back to bed, get all comfy, and then do the 4-7-8 yoga breathing technique - I was sceptical at first about this, however it is imporant to slow the

heart rate down after you've been moving about and also synchronises the body into the breathing pattern most optimal for sleep. It's simple:

1. Place the tip of your tongue behind the ridge of gum behind your front teeth
2. Take a deep breath and breath out for as long as you can
3. Breath in through your nose for a count of 4
4. Hold for a count of 7
5. Breath out through your mouth for a count of 8
6. Repeat this 4 times.

The 4-7-8 technique is also good for whenever one may get frustrated or stressed or in need of a relax!

The final snippet is creative visualisation. Think of a relaxing place [it could be literally anything!]. Picture it with your mind - one of mine is a beach in hawaii with white sands, palm trees waving in the breeze and the relaxing soundtrack of geysers. And one of those really comfy-looking long deckchairs - hopefully I'll get there some day!!!

Think about all the little details. Go nuts - it's free!!

This article is the culmination of everything I do and use to help me sleep. As well as going to a sleep management workshop courtesy of the mental health charity Mood Swings, this piece has no doubt been inspired by countless articles read in the wee hours of the morning [because I couldn't sleep!]. It started as a facebook comment to a friend who could not drift off...

The group also has some books on the subject, available at the main meetings.

Benefit and Work Guides

Please don't forget that we have benefit information guides that we may distribute to members via a purchased group publishing license. Please do not photocopy them, upload to the internet, or redistribute to non-members. Due to the cost in photocopying, it would be appreciated if they could be returned after use.

The email versions save us pennies and volunteer energy.

If you would like one, please call Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk

DLA, PIP & AA. No one aged 16 or over can make a new claim for DLA, you must now apply for PIP. Only people claiming for a child under 16 can make a new claim DLA.

Personal Independence Payment:

Claiming Personal Independence Payments (PIP) (70)

Example PIP Diary Extracts for CFS (3), FM (2), arthritis (3), mobility (3), anxiety & depression (2), blank template (2)

PIP Appeal Submissions (33)

Ways to Challenge a PIP Medical Report: Over 50 Grounds of Appeal With Sample Texts (24)

I've Been Awarded PIP, What Else Can I Claim? (12)

Attendance Allowance: Attendance Allowance Claims On Physical & Mental Health Grounds (44)

The best possible support for clients with DLA and AA appeals (44)

Disability Living Allowance: DLA for adults physical/mental grounds (60)

DLA claims for children on mental/physical grounds (67)

70 questions you are likely to be asked at your DLA medical (5)

The best possible support for clients with DLA and AA appeals (44)

Appealing against a DLA decision (19)

DLA adult renewal claims on physical (58) and/or mental health grounds (50) Changes of circumstances for people claiming DLA (8)

Giving persuasive information about how far you can walk (13)

Challenging the claim a bottle or commode will replace the need for help (8)

Employment Support Allowance:

Being transferred from Incapacity Benefit to ESA (22)

ESA claims for mental health difficulties (86)

ESA claims on physical grounds (84)

ESA Appeal Submissions (26)

ESA Mandatory Reconsiderations and Appeals (40)

Permitted Work (6)

Pathways to Work Interviews (10)

Other:

Which benefits can I claim? (9)

Getting help with your benefits (12)

Getting better treatment from the DWP (12)

If I do any work can I continue to claim? (4)

Caution, may not count as voluntary work (6)

Am I covered by the Disability Discrimination Act? (9)

Reasonable adjustments: Employers and Jobseekers (9)

Work and benefits for people with long term health conditions (7)

Bedroom Tax Case-Law Round-Up (7)

Late edition - November 2015

Here's a brief roundup of some of the recent articles covering CFS/ME and Fibromyalgia during November.

Researchers at the University of Leicester say visual stress may be a sign a person is suffering from ME/CFS. People suffering from the disease are more likely to experience what is known as pattern-related visual stress, resulting in exhaustion and discomfort when faced with repetitive patterns with stripes, for instance when reading lines of text. As a possible indicator, such stress may help doctors diagnose CFS, which is currently difficult to accurately diagnose. – Visual Stress Could Be Sign of Chronic Fatigue Syndrome, Study Finds – Tech Times – November 30 2015

After 25 years living with ME/CFS researcher Leonard Jason maintains a strong focus on improving the diagnosis of the disease. He analyses numerous cases, and symptoms, to get to what exactly constitutes a case of ME/CFS. Yet ongoing controversy over diagnostic criteria shows how much there is still to learn about it. For example, in 2011 Jason and his team showed that the most commonly used criteria identified only 79% of patients with ME/CFS. These findings underpin Jason's repeated calls for US government bodies to test any proposed disease criteria using patient data, and his continued dismay that they do not. Jason is still researching this important area, but it's a long term project making slow progress. – How to diagnose chronic fatigue syndrome – Philly.com – November 21 2015

This piece covers the role of diet in managing Fibromyalgia. The link between fibromyalgia and diet is emerging but it remains a new area of research. Unless we consider nutrition supplements as “natural,” there are currently no proven natural remedies or treatments for Fibromyalgia, from a dietary aspect. However, there are a few steps you can take yourself that may help prevent symptoms from escalating in the first place. For example keep a food and symptom diary, eliminating certain foods and reintroducing them slowly to see if any make symptoms worse. They also recommend trying to keep your overall weight down and make use of supplements such as Q10 and D-Ribose. - Fibromyalgia And Diet: A Beginner’s Guide To Natural Treatment – Care – November 26 2015

A new drug being tested in clinical trials to treat Fibromyalgia, called Tonmya, is showing promise for sleep improvement and pain reduction. Tonmya is being evaluated in the 500-patient Phase 3 AFFIRM study in Fibromyalgia. The main outcome measure for this study is a pain responder analysis, which means patients report a minimum of a 30% reduction in pain from their baseline after undergoing treatments for 12 weeks. The drug is taken every night, and researchers are finding that patients are experiencing improvements in sleep. – Sleep Improvement for Fibromyalgia Sufferers Possible, Study Shows – National Pain report – November 23rd 2015

The Metro published 18 things only you will know if you have ME/CFS. I’ll reprint the first five: 1. Your body can become so exhausted that the simplest of tasks can seem virtually impossible to complete, no matter how hard you try. 2. You are very much used to people asking you ‘How are you tired? You slept for ages!’ It’s the most annoying thing someone can say to you. 3. You make sure you’re always dosed up on supplements and coffee to get through the day, but even that has minimal effects. 4. And you’ve tried every fatigue remedy possible. And yes, they do all taste disgusting. 5. You’re constantly dealing with dull headaches and aches across your body. – 18 things you’ll only know if you suffer with chronic fatigue syndrome – Metro – November 13 2015

A teenager who has been fighting for treatment after being diagnosed with ME/CFS more than a year ago says his life has been turned around after finally been awarded funding. Robert Hawkins, from Halifax, couldn’t go to school, see his friends or play sport after being struck down by the condition. His mother Michelle said, “It’s been a very long journey. We are so glad obviously it’s now come to this decision where Robert can now get the treatment he desperately needs in order for him to help get through day to day and for him to get about basically the best way he can.” His treatment will include assessments, a rehabilitation programme and regular physiotherapy at Manchester Children’s Hospital which Robert hopes will make a big difference to his quality of life. - Teen living with Chronic Fatigue Syndrome awarded funding to battle illness – ITV - November 10 2015

