

Seasons Greetings

**Welcome to Our
December 2013 Newsletter**

A Note from Maxine: We wish you a Merry Christmas and a Happy New Year. From everyone at BBME News Letter Team.



Hells Bells! If only I felt this awake during the day!.

With thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

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Dates For Your Diary

Longsight Meetings Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). There is a car park and blue badge parking on the street and the building is wheelchair accessible. Entrance is £1. Tea, decaf coffee, water, biscuits, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

There is no meeting in December.

Thursday 16th January 7:30pm. Social evening.

Neuro Support Groups: These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about meeting times and locations.

Yoga Classes: Are **3:00pm-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. Contact Olivia on 07746 197511, or olivia@oliviayoga.co.uk for more information. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

Radcliffe Socials: **No meeting in January** meeting at the Sparking Clog as this falls on New Year's Day.

Also **February's meeting** at the Sparking Clog is cancelled due to refurbishment, next date to be confirmed.

Prestwich Socials:

Unfortunately, due to poor attendance, our Prestwich socials at the Orange Tree are in danger of being cancelled. We understand people may be unwell, or have other things on that day, but they were set up in response to demand and if numbers do not improve, we may have to stop these and just have our Harwood and Radcliffe meetings. Now the weather is going colder, numbers may drop even further.

Someone has to commit to attending every month to be there, and on more than one occasion, they have been the only one there, and due to their own poor health, this is not fair on them. **December's meeting is still going ahead.** January's meeting is provisionally set for the usual second Wednesday of the month - Wednesday 8th January at 2pm. Please check on Facebook first to check it is still going ahead, as that's the quickest and easiest way, or call Maria on 07867862341 if you are not on Facebook. We are sorry to have to do it this way for now, apologies those not online, but it is either this, or stop them altogether.

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.



Supported by

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Council**



Reminders

Social Media. Please follow us on twitter on: @BBMECFS. Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecfs/ Don't forget our own web page <http://www.mesupportgroup.co.uk/>

Urgent Volunteers needed for: Writing up an overview of what speakers said at the meetings, there is a tape recorder to help. A short summary is fine with highlights of important bits. Someone still needs to write this please and we really struggle on the night to do this.

We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) you think you can contribute, or are up for a certain task, please contact Caroline. We are really struggling to keep the group going; we are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 01204 525 955 for more information.

Note from Maxine: We all have ME/CFS and to put this news letter together only takes a small amount of my time. I have nominated Wednesdays and therefore everyone knows that's the day I need information. Then I send this on and others take over. Please can you get involved with your group?

Newsletter Articles: Please carry on sending us anything you would like to share with the rest of the group, whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Please send your contributions to: maxine@mesupportgroup.co.uk , or if you are unable to email, post to Maxine Fairhurst, 33 Heath Avenue, Summerseat, Bury, BL0 9NU

Equipment to Borrow: We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk but only if you follow the link from our own website www.mesupportgroup.co.uk. Please remember this for your Xmas shopping!!

Benefit and Work guides: Remember, for anyone filling in benefit forms or if you have appeals/tribunals, we have excellent guides available via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Radar keys: We have Radar disabled toilet keys available at cost (£2.35, plus 50p if posted, or you can pick up at our Harwood meetings). Small headed or large headed (for those with dexterity problems). Contact Caroline on 01204 525 955 or email caroline@mesupportgroup.co.uk

Helpful GP's: Don't forget, we have a list of helpful GP's! There are only 13 on it at the moment, but if you have a sympathetic or helpful GP, please let us know, as people ask us for one in their area all the time. Contact Caroline on 01204 525 955, or email: caroline@mesupportgroup.co.uk.

Bury/Bolton ME/CFS Support Group Meeting

November 2013

Thanks to all those who attended our pre-Xmas bring and share supper. As usual, there was a good spread of sweet and savoury food and we all went home with plenty of left-overs after having a lovely chat. The raffle of a Christmas cake, donated and made by Zara Irani, was won by Yvonne Leech (well done Yvonne, not only have you have won Woman of the Year, you also won our raffle...quick!...enter the Lottery before the year is up!). Many thanks also goes to Kath for helping us out tremendously on the night. There is no Harwood meeting in December, so we hope to see you there again on January 16th 2014.

Sad News

We are very sorry to have to report that one of our longest standing members, Alice Doyle, has passed away, aged 86. She was a lovely lady who came to our meetings for years, up until a few years ago, and to the carers meals. In 2007, we threw her an 80th party at one of the Harwood meetings, with some cake, flowers and balloons. Our condolences to her daughter Christine and the rest of her family during this sad time.

This is a wonderful blog entry from Hannah Ensor, an author, cartoonist, and wheelie.

Copyright Hannah Ensor 2013, please be sure to visit her website, www.stickmancommunications.co.uk for her humour filled take on life with a disability.

12 Tips for Dealing with Able-bodied People

Having read a few blog posts recently about how to interact with people with disabilities/not be able-ist which I didn't entirely agree with, I thought this one (written to me, from my perspective, based on my experience and observation, with a bit of silliness. May not be applicable/relevant to all) was overdue:

1. **You are an ambassador for people with disabilities.** Whether you like it or not. You might be one of very few people with visible difference that an individual meets, so how you react will colour there perceptions of disability and future interactions. Your reaction matters to your future, so be nice.
2. **Offers of assistance can be refused politely.** Even when it is the 9th offer and all you've done wheel easily round your favourite shop. Sometimes you will need help, sometimes others will need help so you can't afford to make people scared to ask. Assertive is fine, but aggressive is not. It helps to start by thanking them for the offer...then give a firm, respectful refusal.
3. **Kids are curious.** They are learning about the world, and when they look at you they are usually trying to learn. Have a simple answer to the "why are you in a wheelchair" ready. Like "I can't walk very well." Or



4. **Not everyone is comfortable around wheels.** Political correctness may have taught them not to say lots of things, but forgotten to tell them *"it's a person, show politeness and consideration and all will be OK. If it turns out they are truly nasty, that is nothing to do with disability and everything to do with them being human."* This often shows itself in stupid comments, avoidance, patronising comments, and/or addressing questions/comments to an able bodied companion rather than you. Do not take it personally or take offence - this makes them even scared-er, awkward-er and worse-er next time. If you think you can say something that will help them relax, do so.
5. **Try not to exclude walkies from your conversations.** When out with a mix of wheelies and walkies, conversation and interaction is easier with people on your level - in this case, other wheelies. Although this is due to practicality rather than a disdain of walkies and is perfectly innocent and accidental, try to remember to direct some comments up to the walkies and include them otherwise they feel left out.
6. **Do not be offended by 'I wish I had a chair' comments.** It might fall under tip number 4. Or it might be due to achey legs, or due to a disability you hadn't noticed. Remember that time when you were disabled but pre-wheels, and you said to a wheelie about wishing you had a chair, meaning it literally and that you were seriously considering getting one, and they bit your head off? **DON'T MAKE THE SAME MISTAKE!** Or it might be because they have seen how awesome your chair is and are feeling a teensy bit put out that you just nipped past them with such speed, grace and agility. In which case, grin and admit that there and then, you had the advantage.
7. **Never yell at someone for parking in a 'blue badge' space.** There are thousands of invisible disabilities which give a valid reason to use those spaces. Shouting abuse at someone who has parked legitimately can cause lasting damage. It is not worth the risk. A polite, friendly 'Have you put your blue badge out?' is inoffensive for legitimate users and can be far more effective long term for illegal users than a stropky/aggressive reaction - cos aggression makes people become defensive so they don't actually think about their action, just about that stropky disabled person who was totally unreasonable. Unless that person is a friend/relative who has nicked your badge. Then yell all you like.
8. **Avoid the temptation to use the word 'crip' at every opportunity.** You might be comfortable with it, in some contexts prefer it to 'disabled', and quite like the fact that it is 'un-PC' but some people find it genuinely offensive. No hard and fast rules here - many people are OK with it, just try and be aware of reactions and don't keep using it if it seems to cause offence.
9. **You do not hold exclusive rights to the lift/elevator.** Able bodied people have many reasons to use them too. Like 'because they decided to.' Just wait your turn and try not to run anyone over.
10. **Don't bite people who pat you on the head.** Head-patting might be infuriating, patronising and insulting, but biting gets you arrested. Don't do it.
11. **People are more likely to walk into you.** They just are. It's nothing personal, it's because when in a wheelchair you are usually below their natural line of sight and not everyone is good at noticing things in their peripheral vision.
12. **Able bodied people are people first and foremost.** So if they behave in an unacceptable way remember that first and foremost they are a person, just like you. They make mistakes too. Treat them with the respect with which you would like to be treated

METRIC Carer Representative Needed

You might remember from previous newsletters, that we are involved in the METRIC study (an online training resource for GPs and information pack for patients about ME/CFS that was trialled in Greater Manchester and Lancashire). Pam and Yvonne acted as patient and carer representatives for the project, and they will soon be stepping down from their roles and need someone to take their place in February. The team will be carrying on with

the METRIC study and working on expanding it and keeping it updated. I am going to be the patient representative, but we still really need a carers representative please. Are there any carers in the group, or does anybody have a carer who is willing to help please? The meetings are at Manchester University (off Oxford Rd) every 2 months, usually on the middle Wednesday from 11am-12:30pm. Maybe some emails in between and a couple of events to attend at the end of the project if they can. They are a team of about 6 researchers (sounds scary, but they are very nice people!) and we give our views from our different perspectives of the illness, to the project. They pay travel expenses and there's lovely gluten-free home baking at the meetings to tempt you! I will be travelling in my car from Harwood, Bolton, (only round the corner from our Longsight meetings) so if you can get to my house, we can go together, or I can possibly pick you up on the way (I will be getting my carer to drive me).

I went to a couple of meetings to shadow Pam and Yvonne to see what it was like and I had no need to be nervous, they just want people who live with it daily, so they can hear our views and scribble down ideas. Somehow, they take these away and come up with stuff!

This would be a great opportunity for a carer to get their views and input across and to get involved in something that can really make a difference. Any questions, please ask, but we really need a carers representative. Call Caroline on 01204 525 955 or email caroline@mesupportgroup.co.uk with any questions.

A big thank you to the METRIC team for their recent donation to the group, which they surprised us with at the METRIC patient and carer event!

G.P Complaints

Has anyone received bad treatment off a G.P regarding M.E? This can be about them not acknowledging it exists, or is a physical illness, providing symptomatic relief, not referring you onto the M.E clinic, or just dismissing you about it in general, etc. We are looking for examples to give the NHS commissioners (anonymously, informally, not as proper complaints or naming the G.Ps or yourselves). We just want to make them aware of the kind of things that are going on still, despite all the safeguards that are supposed to be in place. Please email to caroline@mesupportgroup.co.uk or phone 01204 525 955. Examples will be made anonymous and will not name specific GPs. This is really important, please come forward!

Earl Howe Letter

We have a letter from Earl Howe, Parliamentary Under Secretary of State at the [Department of Health](#), to Ivan Lewis MP, stating that ME/CFS is a recognised disability. This letter could be useful if you are having problems obtaining a blue badge, benefits, adjustments in the workplace, etc. If you would like a copy of it via email or post, please contact Caroline in the usual ways.

Nom de Plume.

The alchemy of winter means that when aromas escape our ovens, they quickly infuse our homes. This joy will power the restoration of any floundering heart. Such musing enthuses the usual drudgery of preparing my cake tin at Christmas time. How innocently it looks up at me, as if to deny it's potential with a coquettish wink. Unlike the meditative, knowledgeable hands of my grandma, my fingers work too quickly, too impulsively. Rarely able to savour the present, I remain destined to focus my effort elsewhere. Hard as I try, attempts to slow my thinking down, to escape anxiety usually fail me. For now I remain in the realm of overdrive rather than that of stagnation. Here I describe two extremes and extremes are never comfortable states for me to inhabit. They almost always demand exclusivity, and a pitch of dedication which quickly shuts everyone else out. !

Recently half-listening to Radio Four, a particular comment pricked my interest! "If you are working quickly then chances are, you are not enjoying what you are doing". Weeks later,

and I continue to give this idea a lot of thought. Living with a chronic illness means that time can gradually become corrupted. For as long as I can remember in order to maintain a semblance of normality, I have had to plan, plot and anticipate the needs of loved ones as well as myself. Helping others forms a massive part of my self-concept. And without the skills to organise myself accordingly, I fear I would have rendered myself redundant!

Having begun to seriously muse upon this quote, I see that this kind of plot-making has been pushed to the point of distortion. Now fear overwhelms spontaneity, which ultimately means there is rarely opportunity for anything new to prosper. Much time has been spent wandering along this path and now I am quite lost. Routine has fixed me firmly in place that I am too disturbed and tired to find my way out. Experiencing emotion demands energy, so I justify safeguarding myself against fatigue by existing quietly and subduedly as I can, creeping from one encounter to another!

That is why food, and the aroma it produces matters. As we prepare to sit together or reminisce on our own, we will all share the effects of the food we eat. It may be experienced quickly and unexpectedly and so catch us quite off guard. Or it may be anticipated and positively welcomed through the annual cooking of a favoured recipe. But through one means or another and perhaps for just a fraction of a moment, we will all find our states altered as we remember and appreciate times past.

Merry Christmas one and all.!

INGREDIENTS:

- 100g of dairy free margarine
- 1 large ripe organic banana
- 3 extra large organic free range hen eggs
- Approx 1200g of dried fruit (steeped last month in spice, dark rum and marmalade)
- 100g of toasted organic almond flakes
- 50g of toasted organic hazelnuts
- 75g of organic pumpkin seeds
- 25g of organic sunflower seeds
- 75g of coarse polenta and 75g of rice flour
- OR 150g of rice flour
- 1 and a half teaspoons of baking powder (optional)!
- 20cm/8in cake tin
- Approximately 1/4 of a roll of Grease proof paper!

Preheat the oven for 30 minutes at 160C/300F/Gas 3.

Preparation:

During this time, prepare your cake tin by lightly greasing it before lining it's bottom and sides with greaseproof paper. To do this, trace an outline of the tin's bottom, making three circular discs. Two will be used to line the bottom of the tin, with the third intended to cover and protect the cake's surface during its slow long bake.

Now to the sides, wrap a length of the paper around the tin, until each end of the paper meets. Cut and fold to make a double sided length. Along the edge of the unfolded end, make a series of one inch slits all along its length.

Fold the slits inward to form a type of foot that will follow the curve of the tin when manipulated.

Insert one of the three discs into the tin, followed by the long length, arrange into place. Put the second disc on top of the feet, which will help to keep everything in place. Once the tin has been lined, the height of the paper lining should extend that of the tin's by approximately two to three inches. Finally, fold the third disc in half, and half again. With scissors snip the tip off. Unfold the disc to reveal a hole within its centre. Keep this to one side for later. !

Method:

1. Now to the cake. In a food processor beat the margarine and banana until light and fluffy.
2. Gradually add each egg into the mix, do this over a 5 to 7 minute period. It is important not to rush, as a slow introduction will rid your cake of any overwhelming smell and taste of raw egg.
3. With a spatula, gently transfer the batter from the food processor into a large mixing bowl.
4. Mix into this, the steeped dried fruit we prepared last month leaving behind any free liquor.
5. Now add the nuts and seeds. Sieve into your bowl the baking powder and whichever flour suggestions you have chosen to use. Meditatively stir your ingredients until evenly distributed. Add some of the liquor if the batter appears too dry. Spoon the mixture into the cake tin and carefully level off its top, gently place the third paper disc on to the cake mix.
6. Bake for about two hours or until a skewer inserted into the middle comes out clean.
7. Remove from the tin and cool on a rack.
8. Choose to either, lightly brush the top of your cake with apricot jam which will slowly set an arrangement of nuts into place. To dress the cake's rim tie a bowed ribbon around it.
9. Alternatively cover the whole cake with a thin layer of jam before encasing it within a sheet of marzipan followed by fondant icing and festive figurines.

Late Edition

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

This is a review of drugs that could be prescribed to treat CFS/ME and Fibromyalgia in the USA. It covers Ampligen and Northera to treat CFS/ME, and Lyrica and Cymalta for Fibromyalgia. These drugs are still far from being approved and there is a number of issues to overcome before they become widely used. **Source: 2013 Drug Outlook for Fibromyalgia & Chronic Fatigue Syndrome – About.com – 28th November**

On November 20th the New York Academy of Medicine held a conference called, "Diagnosis, Treatments and New Developments in ME and CFS". It was run by CFS expert, Dr. Derek Enlander, and included experts and patients presenting the latest research and opinions. Amongst the presentations, researchers showed that Graded Exercise Therapy may not help CFS/ME, but can make it worse. A team from Mt. Sinai Medical Centre also revealed that the illness is related to the immune system, but much more than was originally thought. **Source: Hemispherx Biopharma Sponsors Chronic Fatigue Syndrome Conference at Mount Sinai Medical Center in New York – Gobewire News – 19th November**

A video has been produced by cardiologist Dr. Frans C. Visser, about heart symptoms in CFS/ME. Most patients experience a pounding heartbeat, called tachycardia, at one point or another during their illness, and may end up making a trip to A&E, particularly when it appears as a new symptom. **Source: ME, Chronic Fatigue Syndrome, and Palpitations - Dr. Frans Visser, Cardiologist – Prohealth – 20th November**

Blogger Cort Johnson discusses balancing Christmas with CFS/ME. She talks about managing your expectations of how the holidays could be. She also covers issues such as not needing to live up to the identity of who the fit and healthy you should be. The blog also covers many other issues such as sharing the workload and delegating jobs. **Source: Surviving the holidays with chronic fatigue syndrome and fibromyalgia. how do you do it? – Cort Johnson's Health Rising blog – 26th November**

New Year Tip

At the start of the New Year, get an empty jar. Every-time something good happens, even if it's just something little, write it down and put the note in the jar. At the end of the year, open the jar and read all the great things that happened! You'd be surprised at the good things that happened that you forgot about. – That sounds like a nice idea I think I might try that after my year so far, Maxine.

**Whatever celebrations you'll be participating in this December,
from everyone on
the Committee and from our volunteers too, we hope you enjoy
yourselves and keep well.
Have a happy and healthy 2014, and we hope to see you soon.**

**Please, don't forget to use the Amazon link via our website
www.mesupportgroup.co.uk to buy your Christmas presents!**

