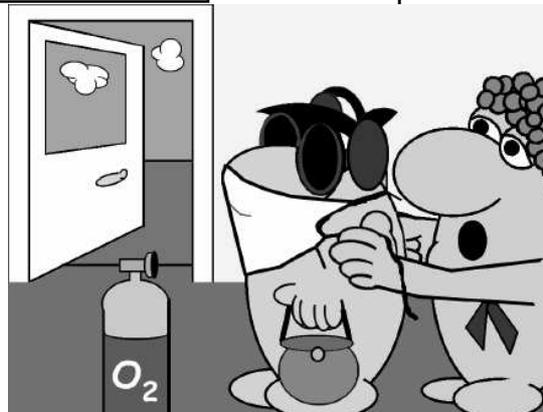




Welcome to Our March 2014 Newsletter

Note from the Editor Maxine: As I finish this newsletter I have just been informed I am having my Partial knee operation on the 12th March, with that in mind I will not be Editing Aprils Newsletter. Hopefully I will be back up to par for Mays'. Thank you for the feedback and hopefully you will keep it coming in on how I can improve the news letter. For anyone that has not sent in the tear off slip for the voting in the A.G.M. can you please do so as soon as you are able. And a gentle reminder that those that can turn up for the A.G.M. please do so.



Even though your sensitivities and your exhaustion are extremely bad today you shouldn't interrupt your routine - go and do the shopping!

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

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.

Thursday March 20th 7:30pm – Annual General Meeting followed by a raffle and social evening. We know this is not the most interesting of meetings, but it is essential to the running of the group. If you cannot attend on the night, please send in your ballot via email or post (was in last month's newsletter), as we must have enough votes to represent the members and make it official, or else hold it all over again! The last couple of years, the AGM business has taken no more than 20 minutes. Please come along and show your support and also help raise funds with the raffle. We have loads of great raffle prizes! Booze, chocolates, children's craft sets, puzzles, toiletries, cuddly toys, jewellery a years free membership, some of Alex's cards and even a chocolate fondue set!

No Harwood Meeting in April.

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: The Sparking Clog is set to reopen at refurbishment at the end of April, so all being well, our next Radcliffe social will be on Wednesday 7th May at 2pm

Prestwich Socials:

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. April's meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 9th April 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.** Apologies to those not online, but it is either this, or stops 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

**Bolton
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/>

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

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.

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. 01204 525 955, caroline@mesupportgroup.co.uk.

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.

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.

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 9UN

Wanted! For our March AGM on Thursday March 20th 7:30pm) The AGM business is usually over in 20 minutes the last couple of years, with a social evening after and a raffle. We are in need of **raffle prizes!** I have quite a few donated to me by people off our Facebook group and my support worker (thank you everyone), but more would be nice! If you have any unwanted gifts or goodies to donate to the raffle, please bring to the March Prestwich social, Longsight meeting, or drop off at my house in Harwood if near-by.

I am also collecting **used stamps** (one of our members also volunteers for the PDSA who collects them, and I am a member of the Hypermobility Syndrome Association who also collects them). I can also send off **old computer ink cartridges** to the M.E Association. Still also collecting **cat things** for a member who helps run a cat charity! In a somewhat bizarre request, I am also collecting **old egg cartons/boxes**, as my support worker has ex-battery hens on her allotment and is selling the eggs to help pay for their up-keep, and needs boxes to put them all in! Since we have 150 members, I thought I would put the word out in here, and become a rag and bone lady! Thank you for your help, our members have always been a very supportive and helpful bunch of people. Caroline-01204 525 955.

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.

Bury Medical Sub-Group Representative: Vacant

Carers' Contact: Vacant

Fundraising: Vacant

PR: Vacant

Writing the speaker reports at meetings: Vacant

Bury/Bolton ME/CFS Support Group Meeting Feburary 2014: Julie Stansfield from In Control

In Control was formed by families in Wigan struggling with the local authority and running up against bureaucracy and inflexibility. Julie's brother has mental health issues, others were children with learning disabilities and adults with disabilities. It's now a national charity who pioneered the concept of self-directed support, emphasising person-centred planning. They wanted to turn social care on its head: wanting local authorities to say "this is how much money you're entitled to" rather than "this is the service you can have", so that users can decide what THEY would like, not what someone else think they may need.

Wigan social services took on their suggestions, e.g., instead of a day centre, a job coach, instead of respite, a holiday with extended family to increase social skills and share care. That led to six projects with local authorities for adults with learning difficulties. These projects produce really good results: personal budgets didn't cost the authorities more, and sometimes less, and the users were much more satisfied. The idea was taken up by central government, with personal budgets/direct payments. In Control is keen to ensure that these personal budgets are not used as a cost-cutting exercise in these times of austerity. It is illegal for a local authority to give you less than meets your needs.

It can be difficult to get over the first hurdle of receiving a community care assessment when you're in crisis, but refer to last month's talk by Jeff Glasser to help. It is your right to have an assessment if you have a disability. Don't let them tell you you aren't eligible without an assessment. Then, you don't need to accept what is offered.

You can ask what the budget amount is, and organise whatever support suits you best. If

you are eligible you will have to have a financial assessment to see how much, if anything, you will have to fund. It's really complicated, and there isn't a simple formula, but takes account of income and savings (of more than £14,250, after which it's a sliding scale up to £23,250, above which you have to pay full cost). But it does not count the DLA/PIP mobility component, and must consider your outgoings and disability-related expenses, such as extra heating, water, electricity costs, or buying batteries or having your scooter serviced.

Prevention Fund: All local authorities have a requirement to make provision for prevention, to allow people to maintain their condition, say, if there is a danger they will deteriorate without help. Some have a prevention fund (inc. Bury, Oldham and Rochdale), some authorities may simply offer services. It can be useful for conditions like M.E. The fund was used by a woman whose husband has M.S: she paid someone to do the ironing so she could do her husband's personal care.

If you have a personal budget you don't have to employ people yourself, deal with national insurance, etc. You can use a care agency (there are some good person-centred agencies in the area), or use a broker. One broker is In Stream, based in Rochdale and run by an ex-accountant who is disabled himself. Brokers' fees are usually paid by the local authority on top of your personal budget. You can also pay a payroll company to work out the pay, contributions, etc. The cost of the payroll should be added on to you personal budget, so it won't cost you any extra personally. Breakthrough UK (www.breakthrough-uk.co.uk) or 0161 234 3950) offer broker services, payroll and personal budget support. They can also offer employment support to disabled people in Manchester and Liverpool. Penderels Trust, a non for profit organisation, also offer a payroll and employment advice service. Tel: 0845 6060 650 www.penderelstrust.org.uk

Disabled Facilities Grant: available in all local authorities for adaptations to the house. This is means tested. If you think you may qualify, contact your local social services department and ask for an Occupational Therapies assessment.

There was some discussion on complaining if you're not satisfied. You could use the complaints procedure, or you could contact your local councillor. Sometimes the only solution is to go to the head of department, director of social services or the council chief executive.

There was a discussion about what might be available in a crisis, e.g., someone who was released from hospital and couldn't manage at home, but was not offered any timely help at all. In circumstances like this, you should be offered re-enablement (sometimes called intermediate care). This is 6 weeks' services, jointly funded by the NHS and the local authority, so no-one has to pay for this. If you are not back to where you were at the end of this time you will receive a community care assessment.

In Control is part of the Partners in Policymaking network, and run courses to empower people to navigate through all of this. The course is 2 days a month for 6 months and is free. If you are interested, let us know.

There is loads of information on the In Control website (<http://www.in-control.org.uk>) including webinars. They also have lots of information leaflets on various topics on community care, and a free e-newsletter. You can call their head office on 01564 821 650.

Many thanks to In Control for coming to talk to us.

Caroline's Experience of Hiring a Support Worker

After many years of trying to get some help of social services, I was finally awarded some help. I wanted to get a regular person in that I could hire myself, rather than rely on an agency. For your support worker, you can hire anyone, as long as they do not live in the same house as you. So it can be a friend, family member, neighbour, etc.

The hiring process and the concept of payslips, National Insurance, employer's liability, sounded very complicated and daunting, but it's really not, though copious amounts of papers, red stickers and notes assist my M.E brain!

Hiring a support worker (the council call them "Personal Assistants", but I prefer Support Worker, it's more akin to her role): They put an add in a P.A agency to say what you are looking for. I said I wanted someone who could drive an automatic car, was vegetarian friendly and didn't mind cats! The ad ran for a month and they came to my house to show me the replies.

I contacted Janet to arrange an interview at my house. The Council provided a leaflet with handy questions to ask. I offered her the job and we had to sign some Inland Revenue forms to arrange for her to be paid.

Payment: The council added on an extra amount to my Personal Budget to pay a payroll company to sort out tax, National Insurance, etc, because I would not stand a chance at that! I had to set up an empty bank account which is solely to be used for my Council's Personal Budget money and no other money is to be paid in/out. You get audited occasionally.

The Council arranged Employers Liability cover for me. I just had to pay for it out of the money they gave me.

I get so many hours per week and I have to call them in every 4 weeks on a Friday to the payroll company, including any sick days and holidays. They send you a calendar with the days you should call so you don't forget. They generate a payslip which is posted to you, so you know how much to pay. The Council top up your bank account every month so you can pay your worker. You get extra money in your budget for holiday and sick cover to enable you to pay your worker for when they are off, and pay someone else to cover them. You can have more than one worker. The pay rate is set by the Council. At first I was very confused by the payroll process and had to call them and the Direct Payments team a few times to ask questions and to check I was doing it right! They were very nice about it though and I soon got the hang of it.

To keep track of our hours, I have a little log book. We write down the date, and hours done on that day, and tally them up as we go along. Sometimes we go over, in which case we will carry them over to the next month.

I would strongly recommend anyone who has a disability get a community care assessment off the Council. It's made life easier, and when I broke my foot, we would have been truly stuck without her too! The concept of Direct Payments and hiring a support worker and all the paperwork and responsibility sounds very complicated, but it's not too bad once you get the hang of it. You can also use a broker, as mentioned above, to deal with all the employment and payroll. You can also use an agency instead.

A Beginners Guide to ME by Jeff Glasser

I hope that my thoughts may help some others, having had ME for about 20 years & actually improved over the years, but not fully recovered.

Firstly try to find a sympathetic GP who has some interest & or insight into ME (the group has a GP directory with sympathetic GP's on). I have learnt along with my GP, remember you can change GPs.

Accept that your life is going to change, often drastically, but that ME will not kill you.

Explore if you have other co-existing conditions that are treatable, I discovered as others have that I have arthritis of the neck & spine as well as R.S.I in my right hand & arm. Certain exercise & massage help to relieve the pain to do with the arthritis; the R.S.I I feel is made worse by using the computer so much.

The new answer is technology and voice recognition. What a relief it was to find there were other answers. Therefore this takes away some of the stress & pain that I related inappropriately to ME.

Try to find some way to develop a more positive attitude, mine was to laugh at myself & the stupid things that I did and do even now, rather than withdraw even more, leading into greater depression.

Be open with people about the condition & the effects it has on me, such as the fact that I need frequent breaks to rest and sleep even in my own home when we had visitors, and that sometimes I cannot come out to play however much I want to.

To try to accept I cannot live life in the way I once did, setting myself impossible targets that others would never of expected in the first place of me.

To accept I have a disability, but then to obtain help to cope from all sorts of sources such as:

- Register with social services as disabled.
- Obtain a Blue Badge.
- Apply for a concessionary bus pass or taxi vouchers.
- Explore Shopmobility schemes.
- If employed, apply to Access to Work for assistance as soon as possible. Others who could help include The Shaw Trust, Disability Employment Advisors at JobCentre Plus, Work4ME.co.uk, and if in Bury, try Bury Employment Support and Training (B.E.S.T).
- Claim Personal Independence Payment, Employment Support Allowance, Attendance Allowance, and any other benefits you could be entitled to, but ideally let a professional assist with the filling in of the form and the gathering of information to support the claim, but look at the Benefits and Work Guides the group can send you.
- Ask for a Community Care assessment from social services, because you are disabled, and a Carers assessment for anyone who provides care to you (don't tell them initially what help you need help with, that's their job and you are entitled to the assessment by law).

- Ask for an assessment by an occupational therapist or contact Disabled Living Service in Manchester to see what help is available in practical terms, such as bottle openers, chairs, bath aids (don't go out and spend lots of money when you may be entitled to these free of charge).
- Check out with others what sorts of treatments seem to work, beware of expensive ones that nobody seems to improve from, or nobody else has heard of. Personally I have been receiving treatment from Dr Raymond Perrin and Gail Sumner for some years and it has worked for me, but that's only my experience.
- The biggy is try to PACE yourself and set realistic limits on what you can do. Yes you will have good days and sometimes get away with over exertion, but if you have a relapse through bloody mindedness how does that help how you feel? (boy do I know this one).

I found that a support network of people who I could ring and chat to even if I could not get out helped with the isolation, but also who would ring me, made me feel valued. The group has a Facebook page where you can hopefully find some friends who understand. Remember that you are still a person in your own right and not a victim, and are entitled to opinions and views about your life and society, as well as the things that are important to you, despite the fact sometimes stringing a couple of sentences together may be difficult to do.

I was reminded the other week that most of us did have a career and life before ME and some still do, so we still have things to offer to our friends, family, work and society, although we have to sometimes pick when and where. Obviously these are only some of my thoughts & may not be appropriate for others or maybe will provoke discussion, but at the same time I hope may ring a bell and help some along the path of coping with ME.

Guess what my back is now aching so will, close but be interested in people's comments.

NICE Guidelines Review - with thanks to Action for M.E

Action for M.E. has condemned the decision by the National Institute for Health and Care Excellence (NICE) to move its clinical guideline for CFS/M.E. on to a static list. This means the guideline will be due for review every five years, instead of every two. A promised review of the guidance is already long overdue, but this move means there will be no review until at least 2016.

Action for M.E. responded to a NICE consultation on the proposal following a survey of the views of members. NICE does not take submissions from individuals. Other M.E. charities also responded.

"NICE has arrogantly chosen to ignore the evidence put before them by us and others. This is yet another example of the neglect and injustice faced by around 250,000 men, women and children in the UK whose lives are ruined by this dreadful illness. "This is a bad decision. It is simply wrong."

NICE stated in their post consultation with regards to ME/CFS:

This guideline was reviewed in March 2011 where the decision was that it should not be updated at that time as no new evidence was identified which would suggest a significant change in clinical practice ... Since that review NICE is not aware of any important new

studies likely to publish over the next few years which would contradict the decision to move this guideline onto the static list. Having considered the criteria again in light of all comments received we do not feel that the evidence base is substantially evolving in this area at this time. In addition this guideline is not scheduled to form part of a Quality Standard at this time and is therefore not considered a priority for NICE to review.

ME Association Booklets sent to GP Surgeries

If you have a less than understanding GP, or one who is nice, but who doesn't know much about M.E or how to help you, remember that the M.E Association do free mail-outs of their good purple booklets "An Explorations of Key Clinical Issues". If you want them to send one to your GP surgery (anonymously), please get in touch with them: tony@meassociation.org.uk or 0844 576 5326. We have one in our library if you want to look at one, or they are £6 to purchase from the M.E Association. Several members can recommend them.

NHS home hearing and sight tests

The Outside Clinic offer NHS sight and hearing tests in your home. If you are aged 60 or over and are unable to go out without help or assistance, you are entitled to an eye test in the comfort of your own home from one of our opticians free of charge under the NHS. Call 0800 85 44 77 for information. My mother in law has used both services and found them helpful. Caroline.

Fitness To Drive

Several of our members have asked about driving licenses and whether you can still drive when you have M.E. Below is a Question and Answer article, written by Dr Charles Shepherd which appeared in ME Essential magazine in August 2013. Reprinted with thanks to The ME Association.

QUESTION: Like many people with ME I am still driving a car - but do not do so if I'm feeling unwell. Is there any official guidance on driving in relation to ME that I should be aware of?

ANSWER:

Firstly, I think it's important to point out that people with ME/CFS have a number of symptoms - muscle fatigue/weakness and cognitive dysfunction in particular - that can affect the ability to safely drive a car. And whilst a significant number do stop driving as a result there are others who should not be driving - even on an occasional basis. So this is clearly an area of personal responsibility where you have to consider not only your own safety but that of people who may be with you in the car, as well as any other road user. This is something you should discuss with your GP - who should be used to dealing with queries relating to medical problems and fitness to drive.

Secondly, in relation to insurance, it's important to check the small print in the policy where it refers to medical conditions. You will almost certainly find that you are obliged to inform the insurer of any condition that could affect your ability to drive - or words to that effect. This would obviously include ME/CFS. Failure to provide an insurer with this type of information could invalidate your policy, especially if a claim results from something that could be linked to your medical condition.

Thirdly, the DLVA produces very comprehensive guidance on medical conditions and fitness to drive. Ordinary UK driving licenses issued by the Driver and Vehicle Licensing

Agency (DVLA) state: 'You are required by law to inform Drivers Medical Branch, DVLA, Swansea SA99 1AT at once if you have any disability (either physical or medical condition) which is, or may become, likely to affect your fitness as a driver, unless you do not expect it to last more than three months.'

It is the responsibility of the driver to inform the DVLA. It is also the responsibility of doctors to advise patients that medical conditions (and drugs) may affect their ability to drive and for which conditions patients should inform the DVLA.

The DVLA issues very specific guidance on a large number of named conditions and in some situations (eg epilepsy) includes restrictions on the ability to drive. Interestingly, ME/CFS is not included in this list. However, problems such as excessive sleepiness, cognitive dysfunction (eg where this is affecting visual attention, easy distractibility, ability to multitask) and medication (eg antidepressants) are covered.

Detailed information on fitness to drive from the DLVA can be downloaded from the DVLA website: <https://www.gov.uk/driving-medical-conditions>

Bank Charge Refunds if in Hardship

If you are experiencing financial hardship. e.g. your only income is benefits, the bank cannot charge you bank charges. A member has used this below letter successfully to get bank charges waived. Remember to send in an income and expenditure sheet to show your lack of funds. With thanks to Fightback4Justice on Facebook. They have a template letter you can copy and paste on their website forum (<http://fightback.boards.net/>) or in their Facebook page "notes" section (<https://www.facebook.com/FightBack4Justice>).

Dear Sir/Madam,

I refer to the Lending Code guidelines to which you subscribe, issued in March 2011.

Due to [changes in my circumstances/xxxxx reasons], I have been experiencing serious Financial Difficulty since (month/ year).

I request that you stop adding interest and default charges to the above account. The interest and charges serve only to add to the Financial Difficulties I am currently experiencing. I draw your attention to paragraphs 224 - 227 in Section 9 of the Lending Code.

Furthermore, I enclose a Schedule of Charges which have been added to my account during this period of Financial Difficulty. I request that you refund the charges totalling £xxx which have been taken from my account.

I also enclose a schedule of my income and expenditure which demonstrate my current lack of disposable income.

Please give this matter your urgent consideration.

Yours faithfully, signed [name]

RSPCA Bolton Clinic

THE RSPCA in Bolton will be holding a Tuesday veterinary clinic now. (Thanks Maria). It will then be held every fortnight (Tuesdays) at the branch in St George's Road for pet owners on benefits, providing basic treatments including flea, worm, microchipping and vaccinations. For more details, call 01204 521160.

Non De Plume

By now you will have acknowledged the conviction I have in living an organic, fair trade life. I live this way believing it to be a positive investment in our planet and well being. There is a plethora of research to support my persuasion, but as the saying goes, 'the proof is in the pudding'. And it's on days like this that the power of clean living delivers the healing hand I need. Getting an infection on top of M.E triggers all sorts of anxieties. Some are lucky enough to bounce back with greater ease or at a faster rate than others. I am unable to stop, until I am overpowered by ill health, something I never advocate, but it is a useful explanation on how I handle myself. Appetite is often affected by sickness, allowing drinks to come into their own. In keeping with my organic existence, I seek most of my medication from the garden, kitchen and larder when possible. And this is a practice nurtured by a keen interest in Medieval and Ayurvedic cooking and health preparations. Both of which relay on herbs and spices that offer a mass of relief and support from common ailments. I grow many ingredients so I can call upon them easily, but my favourite spice has to be ginger. Ginger is warming, and has a powerful restorative effect that will aid nausea, a sensitive gut and sore throat. This tuber root is a relation to cardamom and turmeric too, and I will be including the later in the following recipe. Though powdered preparations offer a potent effect, in fresh form, a mellow subtle flavour will be perfect for the more inhibited amongst us. So sit back, sip gingerly and prepare to be soothed, and converted.

Remedy for two

- A pint and a half of organic unsweetened almond milk
- An inch and a half of organic unpeeled freshly grated ginger
- or two teaspoons of organic powdered ginger
- An inch and a half of organic unpeeled freshly grated turmeric or two teaspoons of organic powdered turmeric
- A tiny pinch of salt
- 8 whole organic black peppercorns
- Two and a half tablespoons of organic raw honey

On the hob's lowest setting, in a heavy based saucepan infuse all the spices within a pint of almond milk for 20 minutes.

Top up with enough almond milk to restore the liquid to its original amount.

Allow the saucepan's content to come to the boil then switch the hob off.

Now sieve away and discard the spices from the fluid.

Pour the infusion into two china cups and add enough honey to sweeten but not overwhelm the remedy's flavour.

Drink while hot.

Late edition – February 2014

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

Researchers have been looking into the effects of paracetamol on pain after exercise. The group of patients with Rheumatoid Arthritis showed reductions in pain both when taking a placebo and with paracetamol. The ME/CFS/FMS group showed some measures of worsening pain when they took the placebo. When this group took paracetamol, some only had an insignificant reduction in pain. Source: About.com – Exercise Pain in Chronic Fatigue Syndrome/Fibromyalgia vs. Rheumatoid Arthritis – Feb 19

A new study measured the amount of oxygen taken from the blood as it flows through the capillaries, on a sample of 440 people with CFS/ME (called oxygen extraction). They wanted to figure out why extraction is low and found the problem is in the mitochondria, the tiny structures inside cells, and used to produce energy. They also said the CFS/ME patients taking part did not show signs of physical deconditioning. Source: About.com – Exercise & Oxygen Shortage in Chronic Fatigue Syndrome – Feb 7

The Institute of Medicine is reviewing how CFS/ME is diagnosed and whether that label puts too much emphasis on fatigue over other significant symptoms. "There are many people — scientists, clinicians, advocates — who believe the name 'chronic fatigue syndrome' does harm to patients," said Dr Nancy Lee, a deputy assistant secretary in the Department of Health and Human Services. Source: Does Chronic Fatigue Syndrome Need A New Name? – Shots, Health News from NPR (blog) – Jan 30

This article covers the forthcoming events affecting CFS/ME; for example the Rituximab trial, publication of the Pridgen fibromyalgia antiviral study results and an antioxidant trial to improve brain functioning. These are only 3 of a very long list aimed at breaking new ground on the illness. Source: What's Up In 2014? A Look Ahead For Chronic Fatigue Syndrome – Phoenix Rising blog – Feb 10

The National CFIDS Foundation (NCF) has announced its latest research findings for chromosome damage in its fifteen-patient cohort. According to Gail Kansky, NCF President, "We feel that our grant funding for Dr Henry Heng has really paid some big dividends due to the fact that our selected patient samples displayed several key chromosome abnormalities." Source: National CFIDS Foundation's Research Finds Chromosome Damage in CFS/ME Patients – PR Newswire – Feb 25

Lucy's story is similar to many people whose lives are significantly changed after contracting the disease. After going through many of the issues CFS/ME patients face, she emerged to create a new life as a counsellor, mindfulness trainer and Acceptance and Commitment Therapist. - Having ME has made Lucy Dorey change her life for the better – Southern Daily Echo – February 18

"The medical understanding of long-term fatigue has changed. Previously, the condition was viewed as a typically male disorder; now it is perceived as a typically female disorder," explains Olaug S. Lian, a sociologist and professor at UiT The Arctic University of Norway. Originally CFS/ME was called neurasthenia. The male fatigue disorder that became a female disorder – Medical Press – February 20.....**end**

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.

Secretary's Report AGM 20th March 2014

So another busy year has gone by and it's AGM time again. While we have lost a few members others have joined, leaving our overall membership quite stable. We have kept March as our membership renewal date, the cost remains £8 and we would ask that our members renew promptly, also considering the Standing Order option.

We have held our usual 9 meetings at Longsight Methodist Church Hall, with a mix of guest speakers and socials.

- In May we heard from a physio from the hydrotherapy project at Bolton One. She showed us photographs of the sessions and a record of the feedback, which was somewhat mixed but generally positive and will be used in planning further courses.
- Representatives from Millercare Disability Aids spoke to us in June, left us each with a goodie bag and promised to look into a number of specific queries about equipment. [These promises were duly followed by action]
- July was a social and also marked Pam's 70th birthday. Charlene had made a beautiful, garden-themed cake which she cut into (very generous!) slices for us to enjoy.
- Dave Cook from Bolton Mountain Rescue gave us a fascinating insight into their work at our September meeting. Sadly he didn't bring any rescue dogs along!
- In October, as Bolton Healthwatch were unable to attend as planned, we had an extra social evening and Alex brought along some of her lovely cards.
- We held our traditional Bring-and-share supper in November, which gave us a chance to try different foods and have a good chat.
- Jeff Glasser, a group member, spoke to us in January about Community Care Assessments, sharing his professional knowledge and expertise.
- Finally, in February, [and when she had finally tracked us down!] we had Julie Stansfield from In Control, a charity who help people manage personal budgets and get support services in place.

Our monthly meetings are still being held in the Longsight Methodist Church Hall; we will let everyone know as soon as we have news of the change of venue to the church opposite. We are very fortunate to have the help of church member Kath Morgan at these meetings. She is giving up her time to help with setting up and clearing away and is our tea-lady. Kath has made herself an invaluable resource and we are very grateful.

Yoga sessions, and the grant which funds them, have continued and are generally well-attended. The Monday socials at The Sparking Clog in Radcliffe have also continued with a core of loyal attendees. However the offshoot socials in Prestwich have not been well attended and their future is in doubt, but have picked up in the last three months.

We were unable to hold our popular Carers' meal as our grant application was unsuccessful. It also takes a great deal of time and effort to organise this event, which will be a point to consider before possible grant applications in future.

A number of our members have taken part in Breathworks course in the past, reporting positively, and now we have our own course taking place in the church hall. We received matched funding to make this possible and demand for places was such that quite a few people were disappointed. However, if it goes well, we are hoping that the Breathworks trainers may be able to present second series of sessions later.

Throughout much of the year our group has been involved with the Metric study, in which Yvonne and Pam were instrumental from the start. Caroline took over as patient rep though we were unable to find a new carer rep. Other members were involved with the

Bolton patient group and some of us attended a final session at The Village Hotel, Bury where we were given an overview of the whole project, heard from the various parties involved and everyone was able to have their say. The team presented us with a cheque for £100 as a thank-you for our members' participation. We were also patient and carer representatives at a G.P conference the Metric team held.

Tracy produced a very useful contacts booklet, which was sent out to members and which received positive feedback. We will apply for a grant, with a view to updating and reprinting in future.

Our library now has several copies of the current Disability Rights Handbook, as well as updated Benefits & Work guides, which will be available for short term loan. Having lost a number of books over the last year, mostly due to members not renewing their membership or moving away and not providing a new contact number/address, the committee discussed a return to taking a deposit before lending items but decided against.

Bolton Primary Care Trust [PCT] has now been dissolved, replaced by a Clinical Commissioning Group [CCG]. We have been represented in this process, meeting with the new regime to discuss the work of our group. Both Bolton and Bury CCGs have sent out leaflets, containing information about our group and the ME/CFS Clinic, to the practice managers of all GP surgeries in the area.

We have continued our connection with the ME/CFS Clinic, represented at half yearly meetings by Pam, Yvonne and Caroline where there have been discussions about the concerns raised by our members, including the clinic's role in applications for benefits and the difficulties of re-referral.

Representatives from the group have also established our presence at other forums such as the bi-monthly ETAG meetings, Bury CCG board meetings and Bolton Health and Wellbeing meetings. Pam, Yvonne, Pat and Maria also met with Bury MP, Ivan Lewis and Bury CCG chairman Dr Patel, to discuss the difficulties faced by people with ME.

Committee Report AGM 20th March 2014

It would be hard to detail all the tasks done for the group by our small army of volunteers but they do so much, frequently at the expense of their own health and well-being, to help others and provide support. Grateful thanks to all of them; they are the strength of the group and without them it would not be sustainable.

A big thank-you to Pam and Yvonne, who have continued to attend Metric and Clinic meetings for us. While they are no longer active committee members they are still providing valuable advice and support.

Huge and heartfelt thanks to Kath Morgan, who gives up her time to help at our monthly meetings with the setting up of tables and chairs, the provision of refreshments and the clearing away of all of this. Thanks to Kath we now have our tea and coffee in proper mugs! She's even found us potential space for at least some of our library items to be stored at the church hall again. Thank-you Kath, we'd be lost without you now.

Alex has had to stand down as newsletter editor but continues with emailing it out and with maintaining the membership database. She also makes and sells beautiful greetings cards, proceeds of sales going to our group. Thank-you Alex.

Maxine has kindly taken over editing the newsletter and is doing a great job. The newsletter breaks the isolation for many, particularly those unable to attend meetings or socials, so we were delighted when Maxine offered to take over. We thank you.

Ruth is now handling the sending out of Benefits & Work guides by email and post. They have proved invaluable to many members in their fight for legal entitlements so thank-you Ruth.

We now have our very own admin lady in the form of Sara, who is responsible for mailing welcome packs to new members. She also prints and posts copies of the newsletter each month. Many thanks, Sara.

Huge thanks to Tracy, who compiled our very helpful 'useful contacts' booklet, sent out to members last year. An updated reprint is in the pipeline.

Thanks to Susan, who is our regular doorman and the first face new members see on arrival at a meeting.

Thank-you to Karen [aka Caroline Ward] who donated a portion of her book sales to the group.

Joanne has done some typing for us, as has Hilary who also wrote the interesting article about cruising for the November newsletter. Thanks to both.

Olivia continues to run our yoga sessions, which attending members report as being very helpful in easing symptoms and providing relaxation. Thank-you Olivia.

Lynda, our treasurer, is brilliant at keeping a sharp eye on our accounts. This is a huge, vital task, especially demanding at membership renewal time so many thanks to Lynda for her much appreciated efforts.

Maria is our meetings secretary, booking a range of interesting speakers for us. She has also attended ETAG meetings with Caroline and Pam, as well as playing a role in supporting members on our Facebook page. Thanks Maria.

Melanie has, with Maria, attended Bolton Health and Well-being meetings as well as meeting with the team at the ME Clinic. She has also, with Pam, written campaigning letters. Thank-you Melanie.

Thanks also to Carole, who keeps our library organized and the minutes book at committee meetings up to date.

Jeff is a recent addition to the committee, where he is able to share his knowledge and experience of benefits and support systems. He has spoken to the group and supported members with applications and appeals advice. Many thanks Jeff.

Caroline has many roles and is at the heart of much that happens in the group. She applies for most of the grants that help keep us functioning, attends many meetings as a group representative [Metric, ETAG, ME Clinic], manages our website and organized the current Breathworks course. She even hobbled to the December committee meeting and January's evening in Harwood with a broken foot! Huge thanks, Caroline, for shouldering more than your share of the work.

We owe a generous vote of thanks to all our sponsors, whose grants help the group to continue functioning: The Tesco Charity Trust; The Co-operative Members Community Fund; Comic Relief; Bolton Council/The Big Bolton Fund, administered by Bolton CVS who have always been very kind to us and are always on hand to offer advice and support. Thanks to the Metric team, who gave us a donation as their thank-you for our involvement in the study. Thanks also to those group members who gave up their time to take part. In

addition we have recently received a grant from Festival Medical Services which allow our newsletter to continue throughout 2014. Our thanks to all of them for their continued support.

Thanks finally to all our members, especially those whose help not been mentioned [apologies if anyone has been left out!] Together we are stronger and can work to break the isolation ME can bring.

Agenda for Bury/Bolton ME/CFS Support Group A.G.M
7:30pm, Thursday 20th March 2014

**At: Longsight Methodist Church Hall, Longsight, Harwood, Bolton,
BL2 3HX**

Agenda

- Apologies
- Minutes of last AGM
- Matters Arising
- The Secretary's Report
- The Treasurer's Report
- The Committee Report
- Nominations for the Committee
- Appointment of honorary Auditor for next year
- Any other Business
- Date and Time of next AGM
- Raffle

We would appreciate it, if as many of you can attend the AGM in order to show support for the committee and our support group in general. The last two years AGMs have lasted 20 minutes, so we have had ample time to have a social evening afterward.

If you feel that you could help, in any way possible, please let Carole Senior know, on 01942 810 320.

If you are unable to attend but would still like to cast your vote for the committee members please tick the names on the list below and return to Carole Senior, 182 Church Street, Westhoughton, BOLTON, BL5 3SX by the 17th March 2014. Please can you label the envelope with the words Ballot Paper on the left-hand side of the envelope? Alternatively you can send an email to caroles4@virginmedia.com, stating AGM Ballot in the heading and typing all of the names that you want to vote for. It is important that you are able to place your vote, as the rules for running a support group state that we have to vote each year and that we can show that are members are getting a say in who represents them.

Thank You.



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Alex Wootton
Jeff Glasser
Maria Sale

Carole Senior
Lynda Marney
Phil Seddon

Caroline Higson
Margaret Benn