

Welcome to Our February 2013 Newsletter



A Note from Alex: Is it really February where did January go? This months newsletter is almost like a bumper addition with me not being able to produce January's newsletter, due to the passing of my father, I'd also like to thank everyone for their support during this difficult time.

We have some interesting articles this month & a request for help by Dr Raymond Perrin on page 7.

You will also find included with this months newsletter the Agenda for this years AGM (Thursday 21st March 7.30pm at the Longsight Methodist Church Hall) and the minutes from 2012's AGM,

with instructions on how to cast your vote for our committee members if you are unable to attend



My personal weather forecast for today: walking on air and having brain fog. Obviously a low is in the offing.

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.

Bury/Bolton ME/CFS Support Group & Sponsors

www.mesupportgroup.co.uk

The Bury/Bolton ME/CFS Support Group was founded in September 1990 and is managed by a committee of six members: Pam Turner, Alex Wootton, Carole Senior, Maria Sale, Lynda Marney & Phil Seddon

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Health for Bolton and the
Big Bolton Fund via Bolton CVS**



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). Entrance is £1, tea, coffee, water, biscuits, etc provided.

Thursday 21st February – To be Confirmed, we will either have a guest speaker or if they are unable to attend we will have another book swap which has been very popular in the past. We will post on Facebook and our web page as soon as we have confirmation.

Thursday 21st March - AGM. 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 AGM should last about an hour at the most. Don't forget that we will also be holding a raffle. For the full information & Agenda please refer to pages 11 & 12 in this month's newsletter

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 4th March** at **the new time of 2pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. It has plenty of parking, good accessibility, comfortable seating and is relatively quiet. They serve very tempting chips that we just can't resist! For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. We usually meet at the oval table next to the bar.

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.

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.

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.

Equipment Hire:

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.

Bury/Bolton ME/CFS Support Group Meeting

January 2013

It was really wonderful to see 21 brave souls, including 3 new members, who turned out on such a bad night. Thank you all for coming.

Our speaker was Debbie MacIntosh and her talk was about the importance of a healthy breakfast. It was most interesting because it was so interactive and she kept asking us questions, as well as the many questions we had for her.

She started by asking us what we had for our breakfast and wrote the numbers on a flip-chart, with the headings "simple carbohydrates", "complex carbohydrates", "proteins" or "no breakfast".

She explained that simple carbohydrates are things like white toast or sugary cereals. Complex carbohydrates are wholegrain cereals like Wheatabix, wholemeal toast, porridge, or fruits and vegetables. Proteins include egg whites, bacon, beans, yoghurt, chicken and fish.

Simple carbs are broken down very quickly by the body and become sugar, which is quickly used up and shortly after leads to being hungry again and snacking, possibly on sweet things.

Complex carbs are broken down much more slowly, helping you to feel full for longer; Carbs are necessary for energy production.

Proteins are essential for building muscle and repairing the body.

The best type of breakfast would be a combination of complex carbs and protein, e.g. peanut butter or baked beans on toast.

Debbie explained that even when we are asleep we use energy for all the functions that our bodies carry on, such as heart beat, breathing and repairing, and we lose a lot of fluid through the night as well. It is most important that we start our metabolism with a healthy breakfast so that it can function properly.

She also explained that people sometimes skip breakfast when they are trying to lose weight, but this is a false conception as your metabolism slows down, your blood sugar drops and then you have sugar cravings which cause snacking. The blood sugar goes up quickly, so we produce insulin to use the sugar, but we can only use part of it as there is only so much insulin produced. The excess sugar is stored as fat. The blood sugar drops and the cycle starts again with snacking on sugary foods.

With a balanced healthy breakfast our body is supplied with vital nutrients without increasing the insulin and blood sugar levels, helping to avoid cravings for sugary food; this in turn helps the body to use its fat stores for energy. This type of breakfast rehydrates us, supplies energy, provides the body with vital nutrients and stabilises blood sugar levels.

Debbie also stressed the need to drink plenty of water throughout the day (at least 2 litres).

A healthy breakfast controls the overall appetite, and by preventing a "sugar rush" and snacking it assists in weight control. This is also important in helping to prevent such problems as diabetes and high cholesterol. Breakfast can provide all the essential nutrients the body needs to function:-

Macronutrients, i.e. proteins, complex carbs, fats and fibre

Micronutrients i.e. vitamins, minerals and trace elements.

Examples of good breakfasts include (don't forget there are dairy and gluten-free versions you can use):

Porridge made with semi-skimmed milk topped with fruit

Muesli, fresh fruit and low-fat yoghurt

Wholegrain breakfast cereal with semi-skimmed milk

Boiled egg with wholemeal toast and low-fat spread

Grilled mushrooms and tomatoes on a wholegrain bagel

Toast with baked beans or peanut butter.

You wouldn't expect your car to function without petrol, so don't expect your body to function properly without breakfast!

Employment Support Allowance (ESA)

Kim and Pam have been to see the MPs for Bury, David Nuttall for Bury North and Ivan Lewis for Bury South.

We have made them aware of the severe problems faced by claimants of ESA; the distress of the thought of a tribunal, the extremely poor so called assessments by ATOS and the fact that medical information is disregarded.

We have asked for their help and support to ensure a fair assessment and for there to be a medically trained person who understands the condition to be present at any assessment or tribunal.

They have both agreed to try to help the situation and Mr Lewis said that he will write a letter for any of his constituents who to come to see him, if necessary.

Carers' Outing

We recently had our Carers' Meal at the Red Hall in Bury, luckily the snow held off until just as we started to leave! We all had a lovely time, so a big thank you goes to Bolton CVS for their generous grant and to the Red Hall for providing us a wonderful meal.



NHS Commissioning

The new NHS Commissioning Boards will be taking over from April and we have been asked to comment on their priorities and pledges for action.

Yvonne and Pam have been to several meetings with Bury 3rd Sector and the new Commissioning Board members and commented on the plans and asked about the future of our ME clinic.

We have been told that there is no plan at present, to change the ME Clinic service, although there are always reviews to ensure the efficiency and value for money.

Melanie has contacted the Bolton Commissioning Board and is awaiting their reply about the future service for ME sufferers.

We were also asked to comment on a document outlining the National Commissioning Board plans for equality and access to provision of service. When we studied the plan there was no mention of ME services at all, although MS is clearly mentioned.

Melanie and Pam have asked the board for their service plan and are waiting for their reply.

Meanwhile, Pam has written to the Secretary of State for Health, the Rt. Hon. Jeremy Hunt MP to ask him to ensure, both nationally and locally, that the Boards know they must include ME Services in their plans. Ivan Lewis is also going to contact the ministers involved.

Nom De Plume January

Celeriac and Chestnut Soup

Christmas was especially difficult this time round. It was suddenly upon me and no matter how hard I tried, I continued to feel it was getting the better of me. I had the inevitable exacerbation of M.E symptoms to contend with, but the 4am consult with my Doctor on Christmas Eve had even me stumped. Ordinarily I would have had everything ready for Christmas. In fact if asked to elect a positive thing from having M.E, then without hesitation, I would declare how such an affliction has taught me to become a meticulous organiser in practically everything I pursue.

Indeed in previous years, presents are bought and wrapped, dried fruit steeped and countless jars of homemade pickles and preserves stand eagerly to attention inside my pantry, and all done well before September the 1st. But this year (or should I say last year), I felt as if I was treading water.

I confess that health wise things are really quite dire, and losing one of my nearest and very very dearest this year has totally devastated me. The profound loss resonates in the most undermining of ways, and yet suffering so keeps me connected to the loved one I mourn. And so one muses upon the fact, that despite the pain suffered, feeling hellish is less dreaded than feeling nothing at all. I continue in fickle attempts to keep busy both in mind and spirit, but somehow one returns to the fact that a void is within me and shall forever be thus. Wishing it away strikes me as a denigration of the person I have lost. Yet at least for the sake of others, one needs a means to keep going. And this is when the rattles of my enamel pots and pans call out the most. It is a cry that cannot be halted nor power overthrown. To refer to my kitchen as a place one merely cooks within is reductive and barely touches the parameters of its significance.

Nom De Plume Cont...

For me, those walls hold secrets, present ideas, challenges and evoke memories of the many lives I have lived and loved. I meditate through cooking, and despite the sorrow one endures, it remains a place of refuge and reinvention.

Christmas, we are told is about family, bounty, good will and celebration. I hold no religious conviction, but if I absolutely had to choose a belief system to suit best, then one might tentatively point to humanism. My aim, daily sounds simple enough, though like most things defined as such, its execution is far from simplistic. My aim is to try as best I can, to treat others, as I hope to be treated. This results each night in taking opportunity to reflect on good deeds done. Cooking for loved ones is always a good starting point. I have too much respect for my family's constitution to feed them nothing but rich decadent dishes, regardless of the time of year or nature of the event. I believe there is honour in using an array of healthy balanced ingredients, where local organic, seasonal food is used to prepare meals from. Of course life would be terribly dull without a few choice delights. And this Christmas was no exception. I witnessed my loved ones savouring my mulled wine which I'd laced with stem ginger, snacking on my adapted Sienese Medieval Panforte, and wiping the moist dark Christmas cake from the corners of their collective mouths, as I described the fruits I'd steeped in Ameretto many months before. Then to the tiny Frangipani sweets I had made and also gifted to neighbours. Each delicately housed within a neat little paper case, this too is another firm favourite of my family.

But what about January? A month many find themselves clawing back from the previous few weeks of excesses, be they concerning ones energy, nutrition or finances; alas, societal pressure manages to reign supreme around this time of the year. One could so easily condone the first month of the year to a time of drudgery once the first day of the year has been greeted and waved goodbye to. But that seems like an awful waste. Surely what is called for, is care and consideration, so one might reflect on the year past and the months ahead within a quiet and contemplative place. For the last few days I have observed a changeable forecast, where the weather has suggested everything from Heathcliff roaming the hills, to the atmospheric fogs seen from the late great David Lean's film Great Expectations.

The slow but constant simmer of an old pot on the range suits the winter months. I am sure that I am not alone in feeling tired and weary after the previous year's trials and tribulations. If so, then what is called for is rest, warmth and something restorative to serve up, which will echo the thoughtful considered manner we all strive to achieve. I think of such dishes as 'one pots'. A crude description I grant you, but one easily understood. Stews, warm salads, risottos, and curries all qualify. So too a soup, though the soup I have chosen to share, is I hope you will agree, a particularly restorative and mellow one. It has a creamy texture, which may suggest it is richer than its ingredients declare. When feeling low or at the very least in need of gentle soothing, this soup needs to be made. Upon inspection you will note that all the ingredients belong to this season, which will support any resolutions concerning ones finances, health or environmental convictions.

If like my husband, you perceive soup to be a rather worthy proposition, fear not as it can quite easily be corrupted by a multitude of toppings. There's the obvious ones, such as homemade croutons (made by tearing bite sized pieces away from a dry loaf of sourdough or better yet a loaf of spelt bread, which when drizzled with olive oil, copious amounts of lemon zest, smoked salt and freshly ground pepper and place under a grill or baked till the moist anaemic scraps are transformed into chunky shards of golden brown titbits), will convince the most reluctant of diners. Perhaps something else for the more adventurous might suit better, such as a generous spoonful of warm salad (dry roast a selection of multi coloured mini beets in their skins till soft, peel and finely chop. Combine these roots with the flower tops of chives, toasted walnuts and cherry tomatoes. Add to this a drizzle of raspberry vinegar, ground whole coriander seeds and if need be a little toasted sesame seed oil); I promise this will enthuse any palette you care to cook for.

Though Wheat and Dairy intolerant I could never serve any of my soups without some kind of Carbohydrate beside it. Wheat free mini scone dumplings (poached in the soup for maximum flavour and an excellent means of thickening ones soup), or a square of my special Corn bread which served straight from the oven is a remarkably light alternative to any Garlic bread or slice of bread and butter you care to mention. My suggestions will support a tired constitution in need of a slow release of energy whilst protecting what little energy reserves you have done so well to keep hold of.

Nom De Plume Cont...

The soup calls for the briefest of ingredients, here I envisage cooking for four adults. Should the unlikely event of having any leftovers present itself, the soup freezes like a dream, once cooled.

1 medium sized Organic Celeriac	The zest of an Organic unwaxed Lemon
1 tin of cooked Organic whole Chestnuts	Smoked sea salt & freshly ground black pepper to taste
1 tbsp of light Organic Olive oil	
1 litre carton of unsweetened Organic Rice milk	100-200 mls of filtered water to thin the soup should your preference require it.
1 tbsp of finely chopped Organic Sage	

Start by peeling away the outer skin of your celeriac, which until doing so may look a little disconcerting to the less familiar cooks amongst us. Once done, discard the peelings as they tend to trap soil and once the root has been chopped finely, one will appreciate the celeriac's fresh and nutty smelling core, as infinitely more favourable than the woody tentrical-like skin. In a generous sized pan place your diced celeriac, add to it the full contents of your tin of chestnuts. No need to concern yourself too much about chopping finely, as we shall be blending your cooked ingredients together. On a high heat, pour the olive oil onto your prepared ingredients. Once the Celeriac starts to brown, turn the heat down very low, and slowly lovingly, douse your celeriac and chestnut mix with half the carton's contents of rice milk. The efforts so far have produced what one might refer to as the base of your soup. Simmer until the celeriac is cooked through, whilst maintaining its shape. Remove the pan from the heat, placing it onto a surface suitable to blend your 'base' from. To do this I would suggest investing in a handheld blender, but if you prefer to use a liquidizer that will do fine. Experience tells me that the texture of ones soup can inform whether your diners enjoys or dislikes it. And so at this point I recommend you enquire which texture is preferred. All of your base lemon zest and sage could be blended into a smooth texture, to which one would then need to add enough of the remaining rice milk until the soup is light or thick enough to be enjoyed. Alternatively one could blend half of the 'base' lemon zest and sage, which when combined with the rest of the chunky mix and rice milk, will produce a stew like consistency. But whatever constancy is chosen, the soup needs seasoning. Retaining the root's subtle nutty taste is imperative, and this explains why I have opted for the simplicity of a really decent smoked sea salt and ground black pepper. It may seem obvious, but I am serious when I suggest you give due time to your seasoning, in doing so it will reward you, by fully enveloping the depths of your soup and your soul.

Urgent Research Request!

Dr Raymond Perrin urgently needs volunteers for some new research at his practice in Prestwich!

He is conducting a Practice Day to determine if ME can be diagnosed purely by his osteopathic methods, so he needs someone who has ME, between the ages of 18-60, and a carer (who is not a blood relative, is also aged 18-60, and does not have ME. It can be anyone else, such as a non-blood relative, neighbour, friend, etc). Neither of you must be known to Gail Sumner or himself. Both the person with ME and the carer will need to attend his practice on a Sunday and it will only take an hour of your time.

If you are able to participate in this exciting new research, please phone their clinic on 0161 773 0123 telling them you wish to participate in the Practice Day and you found out about it from the Bury/Bolton ME Support Group.

Summary:

Who? Someone with ME between 18-60 and a carer, who is 18-60, not a blood relative and does not have ME. Neither should be known to Dr Perrin or Gail Sumner.

Where? Dr Perrin's practice in Prestwich.

Why? To see if ME can be diagnosed using Dr Perrin's osteopathic methods.

When? On a Sunday (date to be confirmed) and it will take about an hour.

How do I sign up? Call the practice on 0161 773 0123 and tell them you want to participate in the practice day and that our group sent you.

Thank you!

Benefits and Work (who produce the excellent information on benefits) now have their own **Facebook** page, so if you have access you might like to follow them there for useful updates.

Late Edition

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

Ampligen, the first drug ever seeking approval to treat CFS recently hit another roadblock with the U.S. Food and Drug Administration (FDA). The FDA advisory panel did not recommend the drug to be sold on the market, largely because CFS/ME doesn't have clear biomarkers such as blood tests to define patients who most likely to respond to the drug. [Chronic Fatigue Syndrome Patients Need an Effective Therapeutic, Leading Expert Argues](#) - **Science Daily - Jan 25, 2013**

This article considers 3 drugs that may make progress in 2013. Their rout to market is a long on and one of the drugs covered, Ampligen, has already fallen by the wayside. [2013 Drug Outlook for Fibromyalgia & Chronic Fatigue Syndrome](#) - **About - Jan 11, 2013**

A new study looks at the rate of chronic fatigue syndrome (ME/CFS) in adolescents after Glandular Fever and reveals differences between the kids who fully recover and the ones who are left with ME/CFS. Looking at adolescents who had Glandular Fever, researchers found it was mainly the girls who continued to have symptoms long term. However, many of those who fitted the ME/CFS diagnostic criteria early on didn't have the disease when the researchers assessed them later on. [Post-Mononucleosis Juvenile Chronic Fatigue Syndrome](#) - **About - Jan 14, 2013**

Cognitive behavioral therapy (CBT) is a frequently recommended treatment for fibromyalgia (FMS) and chronic fatigue syndrome (ME/CFS). But should it be? What do we really know about it? Answers to those questions vary greatly, depending on which condition you're talking about, and which definition of ME/CFS you look at. [Cognitive Behavioral Therapy for Fibromyalgia & Chronic Fatigue Syndrome](#) - **About - News & Issues - Jan 2, 2013**

This is Katie Willocks' story of how she got better after contracting CFS in 2010. [Fighting back from fatigue](#) - **Blackpool Gazette - Jan 21, 2013**

This article reviews the diagnostic criteria for both myalgic encephalomyelitis (ME) (ie, chronic fatigue syndrome) and fibromyalgia (FM) and describes how to differentiate them from depressive and anxiety disorders, the psychiatric conditions with which they are most often confused. - [Identifying and Treating Common Psychiatric Conditions Comorbid with Myalgic Encephalomyelitis and/or Fibromyalgia](#) - **Psychiatric Times - Jan 18, 2013**

A letter to the Independent on Sunday by the Countess of Mar, Professor Malcolm Hooper and Dr William Wier pointing out that Professor Sir Simon Wessley's Maddox Prize was "awarded to the defender of a hypothesis with no evidence base rather than to someone who was upholding true scientific inquiry". [IoS letters, emails & online postings](#) - **13 Jan 2013**

Nom De Plume February

It was many years after Grandma had passed away that the gifts to Gramps stopped appearing. Never gregarious, this private modest lady, always skilfully managed to pursue the demands of her day with an apparent ease and contentment that's been hard to surpass. Her cool considered character could only ever be heightened when in contact with the young, impulsive and clumsy, middle eastern mix of my temperament. She, the well seasoned tree, leaned with great ease around the tornado of endless questions and restlessness that stemmed deep from my belly and out from my toes. Apart from the very occasional strained tone I'd overhear from time to time; it was a monologue of gentle self prompting, which served to refocus her thoughts; that I remember the most.

It was during a rare treat, when given permission to enter her priced kitchen that I would witness her heavy frame glide elegantly, effortlessly as she curated her space; where others would reduce this dance to an awkward juggle of hot pans and ferocious chopping. She enabled me to see domesticity as something other than an occupation of drudgery and boredom. For her and consequently me, a house and it's running is what helps to make a welcoming home.

Nothing prepared me for being left behind. I have always been a thoughtful soul, consumed by notions of identity and self image. So although I'd considered a world without her; an infancy of years meant I lacked the experience or skills that might have otherwise informed me of how I could emotionally survive.

Nom De Plume Cont...

Learning that she was terminally ill, she absorbed her fate, briefly discussed it, and then her emotions were quickly converted into action a private, delicate preparation ensued, intended, no doubt to spare her family from the pain of being left behind.

I always knew she was a hoarder, her larder continually spilt over into the cool dark cupboard within the spare room. Looking into this converted larder one would initially meet her very best gloves and handbags. Each respectfully lined up in the way that only someone who is used to having very little, will do. Below her prized accessories sat a deeper shelf, and it was from here that an array of edible treasures were stored.

It was easy to sense how much respect she afforded her things by the way they were treated each thing laundered, neatly piled up, and secreted away until a just occasion presented itself. And the tins she stored below her accessories, we're given equal reverence.

As a keen allotment holder, Gramps' efforts rarely gave reason to rely on anything shop bought, but after close vetting, the odd exception was permitted. And so an arsenal of tinned and greaseproof papered goods, proudly sat together. Whenever I had chance to peep into that dark heady and enticing place, I did. The experience for me was akin to Lucy's as she walked naïvely into the snowscape land I'd later read about in 'The Chronicles of Narnia'.

Grandma's Christmas pudding, wrapped in muslin, string and parchment paper that was always made with care and expertise, nestled proudly beside tins of Salmon, Peaches and Mandarins. Only the rarest of produce unlikely to prosper anywhere but 'overseas', was permitted in their home.

I can't ever claim that hunger motivated my riffling. I think instead, it was a desire to understand this quiet secretive lady, who was like no one else I'd ever known. Demanding answers to satisfy my curiosity were hardly ever met, but through close observation I did have opportunity to learn.

And so, learning from Gramps that he had continued to receive presents from her, some three years after her passing, could only ever intensify my fixation on her. To others there seemed no rhyme nor reason to where she hid his treats. But I had the benefit of many years of observation under my belt. Every nook and cranny frequented during her cleaning had, I confess, been mentally noted and secreted away deep within me.

Be it ego or curiosity, I felt the need to test myself. So on occasion I would indulge my fingers to wander and creep about. On my tip toes I stroked the tops of framed pictures, the cavities of each folded towel, and the depths of Grampy's suit pockets. Upon each efforts I was justly rewarded by finding a little wrapped package, which I duly placed back for Gramps to find.

Gramps had suffered a punishing terrain of experiences that dogged him from conception to marriage. His partnership with Grandma represented the end of all that. They never failed to rescue one another from the past. No wonder they held each other so tightly, with such respect and necessity. Of course there was no indication of any past trauma, it took a very close eye to sense any upset.

The first time I ever observed food being savoured was by Gramps. He would salivate, praise and savour with a vigour I hadn't experienced before. Soon I came to understand that certain foods had the ability to completely undo him Meat, Chocolate and Ice cream. Each one of these things represented states he'd rarely known, such as financial stability and enough abandon to afford oneself a touch of decadence here and there. Perhaps that was part of Grandma's attraction- she a professional cook and Chocolatier.

During these February days we are all encouraged to consume confection. Palettes are such that the complex bitter depths of Cacao (quite different to the milky, fatty impostor used to make cheap chocolate bars from), can feel quite overwhelmed by the real deal. But Cacao has a rich long history, and its nutritional and medicinal properties aid its benefactors well. Such is its strength that even a few nibs will transform both savoury and sweet recipes with a sense of time and place that belongs to the heritage of the Mayans.

For the more tentative amongst us, who favour corner shop confection, I offer you a gentle introduction into my world of Cacao. In return I ask you to approach this offering with enough reverence and flexibility to challenge your taste buds..

We begin by gathering the necessary ingredients which can within reason be determined by ones fancy

300g of Lindt 90% Cocoa, Dark Supreme Noir
2 heaped tablespoons of either Agave Nectar,
organic runny honey or golden syrup

2 heaped tablespoons of organic toasted and
flaked almonds, hazelnuts or brazil nuts
1 heaped tablespoon of organic dairy free
margarine or organic butter

The fine zest of an organic orange or if preferred, the seeds found within the cavity of an organic vanilla pod
a pinch of finely ground smoked Salt Unrefined fair trade Cacao Powder or Unrefined fair trade Icing sugar

Nom De Plume Cont...

If you are a fan of dried fruit then elect 2 heaped table spoons of both organic sour Cherries and organic Apricots.

Should the tried and tested 'fruit and nut' combination not appeal, then simply exchange these choices for a handful of chopped marshmallows and toasted coconut flakes.

One can gleefully indulge ones imagination for this dish by experimenting and raiding the inside of ones own pantry; as long as the basic building blocks remain in place, namely the quality and high percentage of Cacao used. Consider too the origin of your nuts and fruit. Toasting one's own nuts will not only inform your treats flavour, but will also deliver an exquisite aroma to taunt you and your fellow diners.

The first thing to do is gather & prepare your ingredients. So whatever needs toasting, chopping or weighing out, needs to be done first. Once you're surrounded by your arsenal of ingredients you can begin to combine them in the following order.

Using a Bain Marie (a heavy based saucepan in this case, a 1/4 full of barely simmering water that also has a smaller pot placed inside it), is needed to place & slowly melt your Cacao from. Do this with great care as Cacao easily burns, rendering it grainy & quite useless; so take the pan off the heat as soon as the cacao begins to melt. Once your bar has transformed into a smooth silky liquid, it is time to add your smokey salt, flavouring essence and golden syrup, stir till the Cacao has accepted your offering. Now add your vegan margarine. Put the pan back on the heat if need be, until all these ingredients have melted and merged happily together. Encourage this along by slowly stirring your pot, remembering to appreciate the sheer alchemy of your pursuit.

Now add the toasted nuts, dried fruit or any other ingredients you have chosen to use into your Cacao mix. Remove the inner pot from your saucepan, taking care not to burn yourself. Wipe away the water from the outside of your Cacao pot and pour its contents into a plastic container that is ridged enough to support and shape your mixture as it is left at room temperature to set over night. The needy amongst us can hurry this process along by refrigerating your Cacao for around 4/5 hours. It may alter the Cacao's bloom rendering it a little dull but as we intend to dust it's surface this needn't cause concern.

Once hard to the touch, your Cacao is set, so place a sheet of greased proof paper under your container and manipulate the mould until the Cacao block slides out. Chop your block into bite sized pieces and using Cacao powder, dust it with abandon. Then set yourself some well deserved time alone, to reflect on your hard work as you savour with increasing expertise over your new found love for Cacao...

Happy Valentines day!

Ampligen for ME? by Pam Turner

There is a report in Action for ME, Interaction Issue 82, Christmas 2012 regarding a research hypothesis about ME, which helps to explain many of the symptoms which affect sufferers. It says that G Morris and M Maes write that ME/CFS is considered to be a neuro-immune disease which is characterised by activated immuno-inflammatory pathways, including increased levels of pro-inflammatory cytokines, nuclear factor kB (NF – kB) and aberrations in mitochondrial function including lowered ATP. These processes may explain typical symptoms of ME/CFS e.g. fatigue, malaise, hyperalgesia and neurologic and autonomic symptoms. It would explain why ME sufferers show post exertional malaise following mental and physical activities.

Cytokines are substances secreted by specific cells in the immune system.

Mitochondria are the power pack within every cell in your body, they use the food and oxygen provided in the blood and turn it into energy. If the mitochondria are not working properly, you can not manufacture energy so none of your body can work properly because all muscles including the heart, lungs, brain, and digestion need energy in order to do their job properly.

If this research is proven it will provide many answers regarding what is going wrong and why we are so ill following even very minor activity.

Amazon.

Don't forget if you are buying anything from Amazon our 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.

15th March 2012 Bolton/Bury ME/CFS Group

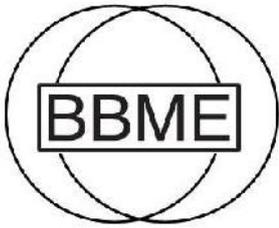
AGM Minutes

Present: Pam Turner, Sue Forshaw, Pat McKenna, Tracey Morris, Ann Richards, Yvonne Leech, Alexandra Wootton, Shirley Wootton, Sue Stephenson, Paula Stephenson, Carole Senior, Lynn Wright, Phil Pearson, Amanda Gore, Gill Mesce, Sara Drage, Diane Knowles, Melanie Bainbridge, Ann Lindsay, Angela Cassidy, Phil Seddon, Lynn Seddon, Lynda Marney, Jean Longworth, Dorothy Sheppard, Galena Steels & Susan Courtney.

Apologies: Bernie Bateman, Christine Farrington, Rohinton Bakti, Mike Parnell, Rosalind Smith, Mark Smith, Angela Glendinning, Neil Glendinning, Tom & Lois Nicholson, Caroline and Ste Higson, Mike and Christine Barnes, Andrew Levy, Shirley Horrocks, Karen Ruth Markovitz, Chris Hill, Maria Sale, Sarah Bainbridge, Karen Scull &, Hilary Smith.

1. Minutes of last AGM held on 17th March 2011 - The minutes of the previous AGM were accepted as a correct record.
2. Matters Arising - There were no matters arising from the previous minutes.
3. Secretary's Report - Pam read out the Secretary's Report.
4. Financial Report - Lynda presented the accounts and Treasurer's report.
5. Group Leader's Report - Pam read out the Group Leader's report which had been circulated to all members and which contained the information that she would step down from the Group Leader and Secretary positions with immediate effect. She would continue as a committee member. The Committee members will discuss the way forward in regards to the processes and responsibilities for dealing with day to day business at the next committee meeting
6. Election of Committee - There were no further nominations for membership to the committee. Yvonne Leech proposed and Sue Forshaw seconded the proposal that the six members standing for the post of committee member be accepted and all voted in favour. The elected members are: Pam Turner, Alex Wootton, Carole Senior, Maria Sale, Lynda Marney & Phil Seddon.
7. Appointment of Honorary Auditor - Alex Wootton proposed and Lynda Marney seconded the proposal that the Honorary Auditor should be Lisa Fletcher for the coming year. All voted in favour of the motion.
8. Any Other Business - There was no other business.
9. Date and Time of Next Meeting - The next AGM will be held at 7.30pm on Thursday 21st March 2013.

The meeting closed at 9.00pm following a raffle and social event



Bury/Bolton ME/CFS Support Group

"Breaking the Isolation"

Agenda for Bury/Bolton ME/CFS Support Group A.G.M

7:30pm, Thursday 21st March 2012

**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

Carole Senior

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 AGM should last about an hour at the most.

If you feel that you could be on the committee, or that you are able to volunteer to help the group in any way no matter how small, please let Carole Senior know by 1st March 2012.

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 14th March 2012. 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 alex@mesupportgroup.co.uk 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 for electing new or re-electing committee members that have put their name forward to be on the committee, as the rule 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.

.....✂.....

Alex Wootton

Carole Senior

Margaret Benn

Maria Sale

Lynda Marney

Phil Seddon

Tom Bridge