



## Welcome to Our December 2012 Newsletter

**A Note from Alex:** Merry Christmas and Seasons Greetings to you all. Is it really that time of year again? Have you bought all of your Christmas presents yet, if not remember that if you purchase anything from [www.amazon.co.uk](http://www.amazon.co.uk) please go through our webpage <http://www.mesupportgroup.co.uk/> and click the Amazon link, as the group receive 5% commission on sales, but only if you use the link.

I can't believe that this is the last newsletter of the year and I hope you enjoy it as I've made another

word search for you to have a go at and if you get stuck the solution will be in next months newsletter.



**Who was it who wanted to have a GP knowing something about CFS?**

With thanks to Invest in ME ([www.investinme.org](http://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

## **Support Group Posts & Contact Information:**

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**Supported by:  
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.

**Please note that there will be no meeting in December.**

**Thursday 17th January – ME Clinic Staff** coming to enable people to chat with them.

**Thursday 21<sup>st</sup> February – Debbie MacIntosh,** will be talking to us about nutrition

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 7<sup>th</sup> January** 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](mailto: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](http://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.

## **Facebook Page:**

We are now on Facebook this is a closed group so only the members of Bury/Bolton ME/CFS Support Group can join. To find us on Facebook put in the following: <http://www.facebook.com/groups/buryboltonmecfs/> or alternatively visit our website at [www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk) and click on the "Facebook" link.

# **Bury/Bolton ME/CFS Support Group Meeting**

## **November 2012**

This months meeting was our Annual bring and share supper, which always proves popular. We had lots of lovely food to choose from and it gave us all a chance to sit, relax and have a good chat with each other.

We also had a Christmas cake to raffle off that one of our members kindly donated to us and we made £17 which has gone towards the groups running costs.

### **A Review of the Year by Alex Wootton**

It's been quite busy for our group this year; we started off the year with a book swap where we all brought in any books that we had read and paid 50p in exchange of a new book. I myself went home with more books than I had brought in and some of them are still in the pile at the side of my bed waiting to be read! From the book exchange we also managed to make £26.50 which went towards the groups running costs.

We have also been lucky to have some very interesting speakers this year ranging from Sarah Skinner who told us of the benefits of Aloe Vera, to Phil Samphire from Greater Manchester Coalition of Disabled People (GMCDP), I really enjoyed Phil's talk as he made me for the 1<sup>st</sup> time think in a different way about being disabled. He said that we should be proud to be disabled and we shouldn't hide away and that it took him in his self a long time to realise this. So if you are like me use your walking stick with pride and don't feel ashamed that you have to use one, as one day the people that may stare at you may also need to use one.

Professor Chew-Graham also came along to one of our meeting to update us on how the METRIC research programme has been going and it also gave her a chance to meet some of our members.

This year we also saw a big change to how our group is run as Pam Turner the Group Leader stepped down, after many many years service to our group, as she said at the time she is getting older (sorry to remind you of that Pam), and also her health isn't as good as it has been. I'm sure you also agree with me that we have and will always appreciate what Pam & Roy Turner have done for our group over the years and also hope that they both get more time to relax and take things a bit easier now Pam has stepped down. So now our group is run by the committee and our volunteers/helpers.

We had a big turn out for this years AGM and we thank you all for showing us your support as our committee members, volunteers and helpers are still troubled with their ME/CFS symptoms and sometimes find it difficult to carry out the task that they have volunteered to do. The AGM is one of the stipulations we have to comply with in order to run our support group and it makes it so much easier for us knowing that you are behind us. Yet again at the AGM we had another raffle where we managed to raise £42.00. I managed to collect free gifts when purchasing the stationary for the newsletter, so I hope that they have some more nice goodies to give away before our next AGM.

Lastly this year's diary ended with our bring and share supper, which I have been told from a few different members how much they enjoyed it, with a varied selection food and also how much there was! So I hope you managed to go home with a goodie bag. Unfortunately I had to miss this event. We hit the New Year 2013 off with our carers meal at the Red Hall (sorry but all the places are now booked), and the following week we start up our monthly Longsight social with the ME clinical staff, which I am looking forward to.

Lets hope that in the coming year ME/CFS will get some good press in helping other understand what a debilitating illness it is and how it impacts not only on us but our loved ones, there have been some very good articles in the press this year. The one that stands out in my mind is the article that was on the Daily Mail website (by Sonia Poulton: All in the Mind? Why critics are wrong to deny the existence of chronic fatigue) which they kindly gave us permission to reproduce in our June newsletter. And lets hope that the government also take us more seriously, that we are not work shy, we're are actually ill. Well we can all but hope can't we?

I hope you all have a happy and health Christmas & New Year.

## **ME Clinic Team Meeting**

Pam and Yvonne attended the bi-annual meeting with our ME Clinic Multi Disciplinary Team on Tuesday 13 November 2012.

Despite all the forthcoming changes to the Health Service, Dr Gaber remains optimistic and very determined to try to ensure that our clinic will continue to offer the best possible service to M.E. sufferers.

The recent appraisals done by the people who have been referred to the clinic show that sufferers have been very happy with the team and with the service that they have been given.

At our last meeting in April we had asked about supporting letters for ESA and DLA claims and we had an in depth discussion. Unfortunately, whilst Dr Gaber and the team are keen to ensure people obtain the benefits to which they are entitled, it is not possible for them to write a letter for everyone as the team see many hundreds of neuro rehabilitation patients. However at this meeting we took copies of Action for M.E. levels of severity scale and Action for M.E. Wellness Scale. Dr Gaber feels that these may be very useful for patients to take with them to their GP to illustrate the level of their symptoms and could be used to support claims for ESA or DLA.

The Clinic Team hope that patients will keep the copies of all their medical letters that they send to the GPs but if any further copies of these letters are needed they can be provided by the team and these can also be used to support claims.

Don't forget our Team will be coming to our January meeting.

## **Nom De Plume**

Most of my recipes are, in some way or another informed by M.E. Sometimes it is evident in the most subtle of ways, ways that a casual taster would I hope, be unable to detect. But when one is devising or making a dish for a special occasion, an occasion that demands in a whole host of ways, such as Christmas time then planning is essential.

I think I will always credit my ability to plan ahead to having M.E. Yet try as I might, the concept of pacing remains ever elusive. However for the sake of you dear reader, I intend to consider such a concept as a necessity when sharing my recipes, and so my first offering is I hope you'll agree, a rather fitting one since it can be tackled over a period of days. Not only does Panforte demand, indeed benefit, from the hands of a slow thoughtful cook but just like a lot of things that are left to marinate, the time one can afford this confection will I promise, be paid back tenfold; not only within the matured flavours that will be released but equally through the favourable responses you will receive by those you care to share it with. It is a sticky sweet marvel I promise. In order to come at something with a strong certain standing, one has to be afforded a little treat along the traitorous way. This earthy cake is just that. Panforte originates from Siena, and has been traced back to the 13th Century where it was so revered that it was used as a currency to pay Monks and Nuns for their labour. Later the dish is reputed to have been developed by Chef and food writer Enrico Righi in 1879, who presented the dense fruit cake to his Queen. Since then there have been many more variations, which along with Panettone, is traditionally served to loved ones during the Christmas and New Year celebrations. In my home, a large batch of these mini treats are made then lovingly wrapped in Grease proof paper and twine so they may be gifted to friends and neighbours. For me, Christmas is the sound of wrapping paper being torn apart to reveal much anticipated treasures, nestling by the flames of our parlours' fire with our cats, giving my vintage Silver nut cracker pride of place alongside piles of organic nuts and bright bright Clementines; and of course time enjoyed cooking for my precious loved ones.

Making especially decadent edible presents is one of the most rewarding pursuits I know, it is a means of expression, a way to give thanks, to pamper and to share. This is one version of many I have concocted. It is a sticky wedge of a cake which is best served on a silver tray alongside freshly ground coffee with a backdrop of your favourite Carols playing gently away. Merry Christmas!

## Nom De Plume Cont...

### Panforte

1 heaped tablespoon of organic dates  
1 heaped tablespoon of organic sultanas  
1 heaped tablespoon of organic cranberries  
1 heaped tablespoon of organic sour cherries  
1 teaspoon of candied peel (preferable home made and organic)  
3 heaped tablespoons of roughly chopped organic toasted nuts. walnuts, brazil, pistachio and pecan nuts work best.  
1/2 a teaspoon of crushed sea salt  
1/2 a tablespoon of ginger powder, a capful of organic vanilla essence or 1/2 a teaspoon of cinnamon powder  
300 Mls of agave nectar or golden Syrup  
100 Mls of water  
5 heaped tablespoons of organic corn flour

5 heaped tablespoons of organic finely crushed almonds  
100 grams of Lindt's 90% cocoa dark chocolate  
Finely grated rind of an organic unwaxed lemon or lime  
2 tablespoon of organic toasted flaked almonds  
1 tablespoon of fair trade unrefined icing sugar  
6 medium sized pieces of edible rice paper, large enough to line each of the mini baking tins  
2 mini cake tins (each with a 5 inch diameter) or 1 small tin (with a 10 inch diameter)  
Cling film, grease proof paper and twine to wrap.

We start by chopping and combining the dried fruit and mix of toasted nuts into a bowl. I like to ring the changes by varying the seasoning and type of dried fruits and nuts I use. This is often influenced by the quality of ingredients I can get and the time of year I decide to make it in. So, I urge you to indulge your imagination here, roughly chopped crystallised ginger works well, so too dried figs and apricots. Here I have opted for the tartness of sour cherries, so they can balance the otherwise exceedingly sweet heady depths of the Egyptian dates I am using. A similar intent when considering the seasoning too; as long as you think of contrasts in relation to the texture and taste of this cake then fear not, all will be well. I look on this cake as an edible landscape that reflects the season and mood of my times, it is therefore a recipe forever in flux and subject to whim and fancy. I ask one thing though, that you opt for the best quality of ingredients you can, which means steering clear of food that has been unnecessarily messed about with, such as when fruit is subjected to various oils and sugars, which in my opinion serve little purpose other than to add calories and extend shelf life.

I have to confess that for me, the purer an ingredient is, the better the results and so it is my humble opinion dear reader, that this dish demands no less of you than that. So while you allow your fruit and nut ensemble to become acquainted rest up for as long as you need, before attending to the next stage.

Mix the Corn Flour and water until transformed into a thick sticky paste and keep to one side. Using a copper or heavy-bottomed pan on a moderate flame, pour in the Agave Nectar, allow this to reach boiling point, now add the corn flour mix and stir continually until a smooth thick treacle-like syrup appears. Turn the flame very low, while continuing to stir.

Now comes the seasoning. I appreciate that it may seem strange to add salt, but let me assure you it is essential since it not only helps balance an otherwise exceptionally sweet cake, but the salt will also reveal the less assertive flavours, which otherwise run risk of becoming quite overwhelmed. So along with the salt, add the powdered ginger to the syrup that is by now gently beginning to cool. Take the pan off the heat while you gingerly add all the chocolate, once melted watch as the batter transforms into a glossy mass. Slowly mindfully stir in the ground almonds. The syrup should now resemble an exceptionally thick batter, which means it is ready to accept the fruit and nut mix. Having lined each baking tin with three sheets of edible rice paper. Pour the batter into each of your tins, smoothing the top with a dampened knife. Here I like to tempt the intended receiver, by customising the Panforte to suit their fancy. I have chosen almond flakes and the zest of a Citron with my Mum in mind. When suitably impressed by your little creations, bake your cakes at 300F for 30 minutes. The Panforte should not brown, which is why toasted almonds are preferable to raw ones as a suitable garnish.

## Nom De Plume Cont...

When your Panforte is done, remove the pan from the oven and allow to cool. Once wrapped in cling film the cakes can happily be left for a number of days. Before sharing, some like to finish off by trimming the excess wafers away, but I prefer a more rustic appearance. At any rate all agree that it benefits immensely from a generous dusting of icing sugar. When wrapped well in cling film, grease proof paper and twine, experience assures me that ones Panforte will keep happily in the fridge well into the New Year. As I hope you will too.

## ME Association Quick Survey

Taken off the ME Association Website Monday 3<sup>rd</sup> December 2012.

I thought this quick survey on the ME Association website was quite interesting.

*Novembers Question:*

**Have you consulted your MP (whole of the UK) about an ME/CFS or benefit related issue? If so, what was the response?**

*Answer:*

- Very helpful (10%, 45 Votes)
- Fairly helpful (9%, 40 Votes)
- Neutral (9%, 39 Votes)
- Unhelpful (18%, 83 Votes)
- Refused to help (6%, 27 Votes)
- Awaiting a response (4%, 16 Votes)
- **No - never contacted my MP (44%, 205 Votes)**

Total Voters: 457

## Word Search by Alex Wootton

Christmas

Tree

Pudding

Cake

Presents

Decorations

Family

Friends

Father Christmas

Holly

Mistletoe

Advent calendar

F	Q	S	G	J	U	E	K	A	C	D	G	P	D	S
A	A	D	F	H	T	F	K	G	R	N	C	U	X	G
M	F	T	B	S	V	H	N	D	X	J	D	D	D	M
I	D	B	H	O	L	L	Y	S	F	M	S	D	K	H
L	Z	V	H	E	D	F	F	J	I	D	S	I	M	D
Y	W	F	H	N	R	C	D	S	Z	G	N	N	N	E
S	G	K	E	I	F	C	T	S	H	T	H	G	S	C
S	G	K	E	E	K	L	H	W	T	H	S	G	H	O
S	T	N	E	S	E	R	P	R	W	G	J	K	H	R
S	D	G	H	T	K	T	E	D	I	S	F	H	D	A
S	D	V	O	X	B	E	B	D	X	S	H	M	N	T
F	G	E	M	R	D	V	H	E	F	B	T	S	D	I
D	C	H	R	I	S	T	M	A	S	C	B	M	D	O
S	X	F	C	V	G	B	H	U	J	M	N	B	A	N
R	A	D	N	E	L	A	C	T	N	E	V	D	A	S

## **Late Edition**

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

An argument has flared up after Professor Simon Wessley was awarded the John Maddox Standing Up For Science Award earlier this month. It was awarded because of the courage he demonstrated in speaking out about his studies on ME. Opponents such as Professor Malcolm Hooper and the Countess of Mar believe he should be stripped of this recognition because his scientific method was "poor". ME: bitterest row yet in a long saga – **The Independent** – **25 November 2012**

This article charts one woman's CFS/ME journey from being diagnosed in 2005. She highlights some of treatments, and explains the benefits of pacing plus changes to her diet. HEALTHY LIVING: ME can feel like a life sentence but now I don't see myself as ill – **Sheffield Star** – **14 November 2012**

A book of poems is going to be released by an ME support group from Oxfordshire. One of their members, said it was a great way to share experiences, and that reading was an absolute lifesaver during the time she was ill. One seven-year-old poet wrote, "Bed, tired, asleep, wake up, tired again." Book of poems written by ME poets – **BBC** – **4 November 2012**

To improve the way you manage your condition, this article recommends keeping certain items close to you. A good example was to keep bedding, pillows etc. close at hand in case you need them at short notice. Kittle: Tips on how to cope with chronic fatigue syndrome, fibromyalgia – **Kelowna Capital News** – **20 November 2012**

This is the second edition of a CFS treatment guide which was first written in 15 years ago. It has a wealth of information, and has been published as an electronic book. This allows for references and links to be easily accessible through the web. Book Review: Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition (eBook) by Erica F. Verrillo – **Seattle PI** – **2 November 2012**

Young people with CFS/ME experience higher levels of psychological distress than healthy controls and young people with other chronic illnesses. The researchers demonstrated that 38% of this population scored above the clinical cut-off on the Spence Child Anxiety Scale. Why do young people with CFS/ME feel anxious? A qualitative study – **ProHealth** – **5 November 2012**

### **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: [alex@mesupportgroup.co.uk](mailto:alex@mesupportgroup.co.uk), or if you are unable to email, post to Alex Wootton 49 Lepp Crescent, Brandlesholme, Bury, BL8 1HX



Whatever celebrations you'll be participating in this December, from everyone on the Bury/Bolton ME/CFS Support Group Committee and from our volunteers too, we hope you enjoy yourselves and keep well. And we hope to see you all in the New Year.