



**Merry Christmas and Welcome to the Last Newsletter for this Year. December 2011 Newsletter**



**I HAD HOPED HE'D FINISH DECORATING THE TREE BEFORE YOUR ARRIVAL, AFTER ALL, HE STARTED IT IN AUGUST!!!**

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.

**Contents of December's Newsletter**

About Bury/Bolton ME/CFS Support Group & Sponsors	Page 2
Dates for Your Diary	Page 3
Appeal for Committee Members	Page 4
Bury/Bolton ME/CFS Support Group Meeting November 2011	Page 4
Relapses and Flare-Ups	Page 5
METRIC Update	Page 5
News and Views (including Carers Meal update)	Page 8

**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, Margaret Benn, Ann Richards, Maria Sale, Sheila Myerscough & Kim Finney.

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

Group Contact / Welfare & Benefits Advice:

Pam Turner

Treasurer

:

Lynda Marney

**Lynda@mesupportgroup.co.uk**

Minutes Secretary:

Margaret Benn 0161 761 2723

Bolton CVS Contact:

Ann Richards 01204 521769

Meetings Secretary:

Maria Sale 01204 575613

Medical Sub-Group, Group Rep & Carers' Contact:

Yvonne Leech 0161 764 7822

Bury Socials:

Sheila Myerscough 0161 7970026  
(after 12noon)

Web Master:

Caroline Higson 01204 525955

**Caroline@mesupportgroup.co.uk**

Membership Secretary:

David Gore 07919 234256

**Dave@ mesupportgroup.co.uk**

Newsletters & Distribution:

Alex Wootton 01617615493

**Alex@mesupportgroup.co.uk**

Librarian:

Carole Senior 01942 810320

**carole.senior@tiscali.co.uk**

Door at Meetings:

Sue Forshaw 01204 883506

Roving Reporter:

Andrew Levy 0161 798 6183

**andmk1@googlemail.co.uk**

**Supported by:**  
**Health for Bolton, 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 19<sup>th</sup> January 2012, 7:30pm – Book Swap:** We thought in these tough times we'd help each other and raise a little money for the group, too. Bring along books you think others would like and hopefully pick up some books you haven't read. A donation of 50p for each book you choose would be gratefully accepted (may be able to arrange discount for bulk!) We will arrange to take any "orphan" books to a local market stall to raise even more, so please bring books that you think someone will want to read and that are in good condition. Social

**Thursday – 16<sup>th</sup> February 2012. – Sarah Skinner:** of Forever Living, will be talking about the benefits of Aloe Vera.

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 9<sup>th</sup> January 2012 at 4pm, at The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY.** It has plenty of parking, good accessibility; comfortable seating is relatively quiet and serves 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. For more information please phone 07919 234256 or email [dave@mesupportgroup.co.uk](mailto:dave@mesupportgroup.co.uk). **Don't worry about getting to the venue and not being able to find us – just phone 07919 234256 when you get there and we will find you!**

**Bury Socials:** These are continuing on the first Thursday of every month, the next will be **Thursday 2<sup>nd</sup> February 2012, 3pm at The Automatic, next to the Met theatre** (it is across the street from Yates, not the Met Café next to Yates), **Derby Hall, Market Street, Bury, BL9 0BW.** [http://themet.biz/location/find\\_the\\_met.pdf](http://themet.biz/location/find_the_met.pdf). If you need any more information, please phone Sheila on 0161 7970026 after 12noon.

**Yoga Classes:** Are **3:15pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX.** Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. 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.

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

**Please Note that we have changed the date of our Radcliffe Social in January 2012 to Monday 9<sup>th</sup> January due to it being a Bank Holiday Monday on our usual 1<sup>st</sup> Monday of the month. Also note that there will be no Bury Social until February.**

## **Appeal for Committee Members.**

**by Group Leader Pam Turner.**

I am making an earnest appeal to anyone who could possibly help by joining our committee.

We have reached a stage where some of our committee members wish to retire, after giving long and excellent service to the group. I shall also stand down from being group leader as my health has deteriorated and of course I am not as young as I used to be. I can honestly say that it has been both an honour and a pleasure to represent the group and I will be happy to remain on the committee and offer help when needed.

However we need more volunteers to become committee members in time for our AGM in March, so that they can be included in the postal vote for those members who can not attend on the night for the election process.

Please, please consider this request very seriously, if you wish your group to continue it is imperative that we have more support. No one will be asked to take on more than they feel comfortable with coping. We do have a good core of hard working committee members and several support workers but we need your help if at all possible.

We only have 3 committee meetings a year when we plan activities and committee members choose what they can do to help, so you won't be over whelmed.

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

**November 2011. By Alex Wootton**

I'd like to thank everyone who came along to our pre-Christmas social with "Bring & Share" buffet supper. We had a really good turn out; there were about 30 of us including some new faces. Everyone brought lots of lovely food, with Pam's stuffed cheese and onion jacket potato's and lots of cakes (with 'free from' options), so much so that people were taking home goodie bags me included.

We also had a raffle for a Christmas cake that has kindly been donated from one of our members. So a big thank you to Zara for donating the cake. We made £23 from selling the raffle tickets. We haven't drawn the winning ticket as yet as everyone was so busy enjoying themselves that we forgot to draw it. So the draw will take place at our next social held at the Sparking Clog on Monday 9<sup>th</sup> December and I will contact the lucky winner.

### **Keeping us Up To Date:**

**Please can all members make sure that we have your correct details so we can continue to keep you updated with our Newsletter or any other important information regarding our support group. Please call Dave on 07919 234256 or email [Dave@mesupportgroup.co.uk](mailto:Dave@mesupportgroup.co.uk) Thank you.**

### **Amazon.**

**Don't forget if you are buying anything from Amazon our group gets 5% commission when you shop at [www.amazon.co.uk](http://www.amazon.co.uk), but only if you follow the link from our own website [www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk).**

# **Relapses and Flare-Ups.** by Andrew Levy

This is a summary of an article written by Doctor Charles Shepherd in  
ME Essential - Autumn 2011

**WARNING: When you're reading this article do not take this information as medical advice. Instead, consult your doctor, or health care professional, and discuss with them first.**

CFS/ME is a unique illness affecting people in different ways. Some get better, get worse, fully recover or never recover. However some people reach a stage where the condition stabilises and it's difficult to make any more progress. If you're in this category, you may experience flare-ups which last a short period of time, or a relapse which is more severe and lasts a lot longer.

There are many different ways a relapse or flare-up can be triggered. If you know about them beforehand, you could take steps to prevent them. Or, if you know the cause of your decline you'll have a better idea of what to do. These are the areas you should look out for:

**Infection:** - This is the most common and predictable cause of a relapse. If possible try to avoid the cause of the infection. For example, wash your hands thoroughly or avoid places where there's lots of people. Keeping good food hygiene or taking good care of your teeth and gums are two other ways to prevent infection.

**Activity management:** - You must strike a balance between activity and rest. This includes mental as well as physical.

**Stress:** - Stress will worsen your condition, and continuous stress could cause a serious relapse. It can also harm your recovery prospects. So if you're managing other aspects of your illness, consider managing the stress is well.

**Symptom control:** - This is all about controlling symptoms such as depression, pain or sleep disturbance. If any one symptom is getting worse, it could lead to a worsening in your overall symptoms.

**Temperature extremes:** - if it gets too hot or too cold, symptoms can become a whole lot worse. This is linked to a place in the brain called the hypothalamus which helps regulate your body temperature.

**Trauma:** - If you fall, get assaulted or have an accident you could trigger a relapse.

**Antiseptics and surgery** - These can be traumatic events, and some people with CFS/ME report a worsening of their symptoms after surgery.

**Medication:** - Almost all drugs will have side-effects, and can lead to symptoms which we all recognise in CFS/ME. So if you've started a new medication and symptoms start to get worse, go back to your GP or pharmacist.

**Menopause:** - Many women with CFS/ME going through the menopause also report an increase in their symptoms. Menopausal symptoms can be the same as those of CFS/ME, for example temperature control and emotional lability. If this happens to you, it's worth discussing the use of Hormone Replacement Therapy (HRT).

**Vaccinations:** -They mimic the effect of an infection on the body's immune system. Therefore there is no surprise that some CFS/ME sufferers report their symptoms got worse after they took the vaccine. Vaccines are still very important in the prevention of many diseases. You should use them with care, and possibly avoid if you've recently been infected or are having a lot of flu-like symptoms.

## **How to cope with a relapse:**

The minute you know you're suffering from a relapse, you need look over your existing activity management programme. This means checking your physical and mental routine, and reducing the levels towards more rest. You may want to sleep more, or rest more. Go with it, as that's what your body is telling you to do.

You'll also need help and support from carers, family and friends. Even before the relapse, it's best for them to understand what is likely to happen so they can do more to help when it occurs. Once the relapse stabilises, you may need a period of convalescence followed by a gradual return to what's normal for you.

Getting back to your previous level will be difficult if a relapse has been severe or long-lasting. However stick with it even though it might be frustrating at times.

### **When to see the doctor:**

Contact your doctor if you get an infection which might require antibiotics. It's not true that people with CFS/ME should not take antibiotics. If you're not improving, see your GP again, and they may make some more investigations to see what the real cause is.

Finally, the ME Association has leaflets to help with various suggestions mentioned in this article. If you need more information please contact them at: 0844 576 5326 between: 10am-12noon, 2-4pm and 7-9pm.

## **METRIC – ME Training and Research in Primary**

### **Care by Pam Turner**

Yvonne and I attended a management meeting of METRIC at Manchester University on 16<sup>th</sup> November 2011 in order to look at the developments of the training and information materials that will be available for both GP's and for Patients when the research is completed.

The research group are always eager to listen not just to our views but also to the views of the people in the patient groups, including our Bury/Bolton Group, who meet regularly and to the people they have interviewed.

We saw the information leaflets that they are proposing to use, which will include help and advice on medication, pain management, sleep problems, diet, fatigue, exercise etc. The team were happy to have our comments and we feel that they will eventually have produced very valuable information to be easily available for GP's and for Patients.

There will also be DVD's of case studies of patients for doctors to see just what it is like to suffer from ME.

## **News and Views**

### **Carers Meal Update. by Alex Wootton**

I am please to announce that we have been given the grant for our carers' meal, which will be held on **Thursday 5<sup>th</sup> January 2012 @ 6pm at the Sparking Clog.** If you want to come to the carers' meal please can you fill in the form that was sent with last month's newsletter, or just write on a piece of paper, stating your name, menu choice and a £5 deposit for each person attending. I need all forms and deposits to be sent to me **no later than Monday 5<sup>th</sup> December 2011.**

My contact details are: Alex Wootton, Tel: 01617615493, E-mail [alex@mesupportgroup.co.uk](mailto:alex@mesupportgroup.co.uk)  
Address: 49 Lepp Crescent. Brandlesholme, Bury, B18 1HX.

### **Sparking Clog Menu:**

#### ***Starters:***

- Roast Parsnip and Caramelised Onion Soup (V) Served with a bread roll and butter.
- Pork and Plum Pâté, A coarse pork pâté with plum and brandy, garnished with a glazed sweet plum. Served with toast and butter.
- Prawn Cocktail, Prawns on iceberg lettuce with Marie Rose sauce, served with brown bread and butter.
- Breaded Mushrooms (V), Breaded mushrooms with a garlic mayonnaise dip.

#### ***Main:***

All our main courses are served with new and roast potatoes and a selection of seasonal vegetables.

- Roast Turkey, Hand carved by our chefs, served with sage and onion stuffing, bread sauce and cranberry sauce.

- Traditional Roast Topside of Beef, Classically served with Yorkshire pudding and horseradish sauce.
- Sea Bass with Roasted Tomato and Dill, Sea bass fillets served with a buttery sauce flavoured with slow roasted tomato and dill.
- Butternut Squash, Walnut and Cheese Tart (V), Butternut squash, walnuts, spinach and red peppers in a vintage Cheddar cheese pastry.

**Sweet:**

- Christmas Pudding, Served with brandy sauce.
- Millionaire's Ice Cream Cake, A crunchy shortbread biscuit base topped with layers of chocolate and caramel flavour ice creams and toffee sauce, finished with curls of milk chocolate and chocolate flavour sauce. Served with vanilla ice cream.
- Chocolate and Cherry Bombe, A rich chocolate crumb base with Belgian chocolate mousse and a soft centre of cherries in brandy. Served with cream.
- Tumbleberry Pie, A crisp pastry brimming with Bramley apples, raspberries, blackcurrants, blueberries and redcurrants and dusted with sweet sugar snow. Served warm with custard.

**Christmas Tree Festival. by Pam Tuner**

There is to be a Christmas Tree Festival (similar to a flower festival) held at St Matthews' Church, Little Lever on the 9<sup>th</sup>, 10<sup>th</sup> & 11<sup>th</sup> December (Friday, Saturday & Sunday) between 10am and 4pm. There will be a display of 10 or 12 Christmas Trees decorated with themes of Christmas Carols inside the church. Also there will be a café and craft fair and raffle for excellent prizes in the church house, situated in the car park at the side of the church.

The event is being held in order to raise funds for the restoration of the church as around £1 million pounds will be needed to complete all the work necessary.

It promises to be a lovely event and I hope some of you may be able to visit it and see the very creative and beautifully decorated trees.

**Money Saving Tips on Heating. by Alex Wootton**

**Are you worried about paying your fuel bills this winter?** I'm sure most of you are, as the price of everything is rising, while the money we bring in to our homes each month stays the same.

In looking for some good money saving tips I have come across The Home Heat Helpline. They can give you help and advice about paying your fuel bills. They can also tell you what deals or initiatives are available and ring your provider for you. There is a new initiative that is being rolled out (Warm Home Discount) but at the moment only a couple of energy companies have started this; eventually all energy companies will be providing this initiative.

This help line is for anyone and everyone. I called them and they found out that I could be on a much better tariff with my energy provider, so they contacted them while I stayed on the line. They told my provider what the call was about and when I was put through to my provider all I had to do was give them my account details, and they just updated my details to a cheaper rate. The helpline number is free. The Home Heat Helpline: 0800 33 66 99. [www.homeheathelpline.org.uk](http://www.homeheathelpline.org.uk)

Remember it's much better to have a few extra pennies in your pocket, than fill the energy provider's pockets.

**Simple Steps to Keeping Warm and Reducing your Fuel Bills:**

***Staying warm:***

- Draw curtains over windows at night to provide insulation for the room
- Keep outside doors shut and block up obvious draughts (including the letterbox)
- Move furniture away from radiators and heaters to allow heat to circulate around the room
- Open internal doors of any rooms which get more sun than others and let the warm air travel around your home

**Reduce your bills:**

- Turn radiators down in rooms which you only use occasionally
- Switch your lights off when you're not using them
- Turn appliances like TVs and phone chargers off at the wall rather than leaving them on standby when they're not being used
- Replace normal light bulbs with energy efficient bulbs which use 1/5 of the electricity. They may cost a little more, but they soon pay for themselves
- Regularly defrost your freezer to make sure it's operating at full efficiency

Also remember if you are receiving any benefits (disability living allowance, pension credits, council tax benefit, child tax benefit or income-based jobseeker's allowance) you may be able to apply for grants to insulate your home and improve your homes energy rating. Also all energy suppliers have monies put aside to help anyone who finds themselves in financial difficulty and can't pay their energy bills. So if you are disabled, over 60, have a young family, or are bringing up children on your own, there are special grants and services available to make sure you don't suffer.

**Radiator Heat Deflectors:**

Instead of purchasing expensive radiator heat deflectors why not make your own. All you need to do is save some "Tetrapak" drinks cartons, cut them open so you can flatten them, give them a good wash to clean them up and lastly cut to size and rejoin them with foil tape.

**Boiling Water:**

There are a few different ways in which you can save money when boiling the kettle. Just boil the amount needed or boil more than you need and put the rest in to a flask as it'll save you boiling the kettle several times a day if you drink a lot of tea or coffee. This is also a good idea if you are having a bad day and don't have much energy.

**Bins:**

I haven't bought any bin bags for my kitchen bin or my wastepaper bins in my house since I move back to Bury, as so many charities kindly keep putting their charity bags though my letter box. Don't get me wrong I give what I can to charity, but if I do have anything to give I organise for that charity to pick up my clothes donations etc as then I know they are going to the right place. So why not save up all of these bags and use them in your kitchen bin too. These bags are usually a bit smaller than the bin bags you would buy at the supermarket but I find them better as you can't overload them the same but have to empty them a bit more frequently.

For my other waste papers baskets, I use the carrier bags that my shopping has been delivered in. Which also makes emptying my bins much easier, as all I need to do is grab up the handles.

If anyone has any other good money saving tips or tips on how to keep warm over the winter period please drop me a line so I can share your ideas and experiences with our members. Here is a reminder of my contact details: Alex Wootton, Tel: 01617615493,

E-mail [alex@mesupportgroup.co.uk](mailto:alex@mesupportgroup.co.uk) Address: 49 Lepp Crescent. Brandlesholme, Bury, B18 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.