



A HAPPY  
NEW YEAR

**and Welcome to this Years 1<sup>st</sup>  
Newsletter.& our New Look.**

**January 2012.**

**A Note from Alex:** Please note that we have quite a few changes with the Support Group Posts and their Contact Information. Also please note that the Bury socials are not being held at present. Yet again this

months newsletter is full to the brim with what I hope you'll find are interesting articles.



**ONE GOOD THING THOUGH IS THAT EVERYONE ELSE HAS ALREADY FALLEN OVER BEFORE  
I'VE EVEN MANAGED TO LEAVE THE HOUSE.**

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, 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 <b>lynda@mesupportgroup.co.uk</b>
Parents' Contact:	Kim Finney            01204 882826
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 7647822
Web Master:	Caroline Higson      01204 525955 <b>caroline@mesupportgroup.co.uk</b>
Membership Secretary:	Phil Seddon            01204301713 <b>phil@mesupportgroup.co.uk</b>
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**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.

**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 6<sup>th</sup> February 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!

**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.

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'LL 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, THANKYOU.

**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 .

# **Group Updates**

## **Would you like a social in your area?**

It has been discussed at a committee meeting, that members may like to have a social afternoon meeting in a variety of venues in either Bolton or Bury.

If you would like a social group to start up near to you, please let us know. If you know of a suitable venue, preferably not one that we have to pay for room hire, e.g. quiet pub or coffee shop; and if you could help by hosting the meeting until a few members become regulars. These meetings are not formal so they don't need organization or leading, they just need to have someone there if people turn up for a chat.

We can discuss this further at the AGM if enough people are interested?

## **Yoga Grant**

We have been successful yet again to receive another grant, so we can continue our weekly yoga session. To show our appreciation please could you write a few words of thanks and either e-mail or post them to me, as we feel that it is important to let them know how much the weekly yoga helps people and what they get out of it. Email: alex@mesupportgroup.co.uk Address: 49 Lepp Crescent, Brandlesholme, Bury, BL8 1HX.

## **January's Carers Meal 2012**

Our carer's meal went ahead last week at the Sparking Clog in Radcliffe. We had a great turn out with 61 members and their carers attending.

We all enjoyed our meal even though the night turned out to be much later than most of us expected.

Pam and I have already received some feed back from members who attended, saying how much they enjoyed themselves and how nice it was being able to meet other members, or catch up with members that they haven't seen in a while that they were able to let their hair down and have a good laugh. I can tell you that I heard quite a lot of laughter throughout the evening and I don't think it was down to the jokes in the crackers.

# **Blue Badge News**

## **from Action for ME Interaction Issue 78, Christmas 2011**

As of Sunday 1<sup>st</sup> January, the maximum fee a local council in England can charge for a Blue Badge will increase from £2 to £10 and, in addition to applying directly to your local council, you will also be able to apply online through [www.direct.gov.uk](http://www.direct.gov.uk)

In November Action for M.E. learnt that Greenwich Council is withholding Blue Badges from people with M.E. Sir Peter Spencer wrote to the council, pointing out that this contravenes the Equality Act 2010 and asking that it be rectified immediately. A response was still awaited as InterAction went to press.

Following consultation, the Welsh Government has yet to announce details of its proposed price increase (up to a maximum fee of £10) for the Blue Badge scheme. It also plans to introduce new IT to improve administration and cut fraud and misuse.

In Scotland, your local authority can charge up to £20 per application for a Blue Badge. In Northern Ireland, the Blue Badge fee is £2.

## **Channel 4's Programme Food Hospital. by Alex Wootton**

On the 13<sup>th</sup> December 2011 Channel 4's Food Hospital Episode 7, showed the case of a woman called Steph, aged 25, who has been suffering from ME/CFS for 13 years. She asked the programme for help as she had just finished all of her studies and gained her degree and wanted to be able to go out to work.

For those of you who haven't watched this programme the patient has a consultation with 2 people: Lucy Jones and Dr Gio Miletto, a prior to their meeting Steph was asked to fill in the Piper Fatigue Questionnaire (to see a copy of this please go to: <http://www.ntfactor.com/survey/> Please note that if you fill in this questionnaire you will get your results and then be advised to purchase the medication that this website is trying to sell) where she scored mainly 9's & 10's.

They then gave Steph the following advice: eating at regular times, as she used to skip breakfast and eat a very late lunch, eat 45g of dark chocolate with 85% in coco solids per day and to follow the rich in Glutamine diet that they worked out for her.

After 1 month she was invited back to their clinic to let them know how she got with their advice and if she had any change in her symptoms.

The chocolate didn't work for her, but eating at regular times and having smaller amounts of food throughout the day really worked for her. So much so that she managed to increase her swimming from once a week to 3 times a week and she was able to get a job.

## **Channel 4's Programme Food Hospital. Cont...**

I feel as though Steph didn't suffer from ME/CFS as she wouldn't have been able to turn her life around so quickly. I think she was suffering from Low Blood Sugar (Hypoglycaemia). I also feel that she and this programme have done us an injustice as there are so many of us that suffer badly from ME/CFS that we are always having to justify how debilitating this disease is. Never mind all of the hard work that the ME/CFS Charities have and are still doing in trying to teach and educate the masses on what difficulties we have to overcome each day. After this programme was aired I went straight to Channel 4's website to state how they have done us a disservice.

I have also found the following statement that Action for ME issued on their website the following day: *Sir Peter Spencer, Chief Executive, Action for M.E., has sent a letter to Tanya Shaw, Commissioning Editor, Channel 4, raising concerns about last night's edition of the Food Hospital.*

*In his letter, Sir Peter points out that viewers "might have been given the misleading impression that M.E./CFS may be explained in part by low blood sugar levels when in fact it is a complex and debilitating illness, which the NHS recognises as being as potentially disabling as multiple sclerosis, lupus, rheumatoid arthritis and congestive heart failure."*

To see this programme for yourself and also see what other peoples thoughts and opinions are please go to <http://www.channel4.com/programmes/the-food-hospital/4od#3264137>

If you have any thoughts or opinions on this article I have written or anything else in the newsletter then please get in touch and let me know and I can publish it in a later issue.

## **Did Darwin have M.E.?**

### **Letter from Paul Lack printed in Action for ME Interaction Issue 78, Christmas 2011**

Charles Darwin, originator of the theory of evolution by natural selection and author of *On the Origin of Species*, fell ill in his thirties shortly after returning from his crucial voyage on the *Beagle*. No one at the time knew what was wrong with him and it has puzzled historians and biographers ever since.

Robert Youngson, a consultant ophthalmic surgeon and physician, picks up the mystery in his intriguing booklet *Darwin's Mysterious illness* (available from [www.huxleyscientific.co.uk](http://www.huxleyscientific.co.uk) for £4 plus £1.50 p&p).

Darwin "appeared quite well" but suffered "headaches, severe fatigue, abdominal pain, flatulence, violent shivering and vomiting attacks, insomnia, tinnitus, depression and other symptoms brought on, by nothing more than minor exertion, excitement or anxiety."

Sound familiar? Youngson concludes, as I suspect many readers have, that Darwin may well have been suffering from M.E./CFS.

A contemporary, John Tyndall, commented that Darwin's illness had allowed him to "ponder a great deal." The raw material from his voyage on the *Beagle* was all there – but it had all been there for many others before him, who had not realised where it was pointing.

Perhaps it was that enforced rest, that need to live inside your own head that people with M.E know so well, that enabled Darwin to take the extraordinary mental steps that changed the world forever.

## **Me? It's all about M.E**

*What it's like to be accused of being lazy, or faking illness to claim benefits? That's what M.E means to many. Jacqui Morley of the Blackpool Gazette reports:*

Stephen Foster, of Layton, dreams of becoming a writer. His short stories have already won rave reviews at Blackpool Writer's Circle. That's because he writes from the heart and about what he knows.

And what he knows best is how marginalised people can become as a result of disabilities; that others tend to judge by trappings of disability, or shy clear of those exhibiting symptoms of such, and seldom see beyond it. That's why Stephen is telling his story today, as part of his campaign to promote a website, and allied helpline, which exists specifically to help others with myalgic encephalomyelitis – M.E – particularly younger people.

Famous M.E. sufferers include the novelist and former yachtswoman Clare Francis, the Duchess of Kent and Emily Wilcox, eldest daughter of Esther Rantzen and her late husband. Desmond Wilcox.

Stephen, of Addison Crescent, explains: "For the past 15 years my body has been slowly degrading, resulting in being in a wheelchair and, on some occasions, bed-bound." The reason for this is a condition better known as M.E which was classed as a neurological disease of the central nervous system by the World Health Organisation since 1969.

## Me? It's all about M.E Cont...

"It's not a new condition, it can be traced back as far as 1750 and was referred to as febricula (little fever) and it is now believed that some leading public figures who have passed into history such as Florence Nightingale and Charles Darwin suffered from this illness.

"Currently it is estimated that 250,000 people in Britain are affected by it, and it can affect any age in many different ways. There have been more than 1,000 proven scientific biological studies on areas of this disease worldwide.

"Eighty per cent of brain scans on M.E patients show damage or lesions in certain areas of the brain, with reduced blood flow, mass cellular death and reduced grey brain matter.

"It is worth making that point because some people call it lazy syndrome – and reckon we're faking it.

"It's severely debilitating with painful muscles and joints in very painful spasms. It causes problems with short term memory concentration, maintaining attention, also affects the central nervous system, causing clumsiness and problems with your equilibrium, causing many to fall, or other symptoms such as migraines, sleep disturbance, irritable bowel syndrome, mood swings, and clinical depression.

"These are ALL symptoms I deal with every day of my life, reducing my ability to cope with a normal daily routine, and meaning I need the help of around 20 pills a day to allow me to have some quality of life.

"in 2006, Sophia Mirza was the first person to officially die of M.E in the UK. She was told it was all in her mind, and died soon after being released from hospital. During her autopsy, two leading neurologists found swelling in her brain and spinal fluid, 75 per cent of her brain's ganglia destroyed and mass cellular death.

"Her mother has still not received justice for daughter's death, or even an apology.

"The blood of M.E sufferers show increased cytokines (immune cell messengers), decreased growth hormone, other reduced hormone levels, and reduced amounts of a chemical required for normal energy with low blood flow through the body's internal organs, especially the heart.

"But the worst thing I and many M.E sufferers face is the stigma – because to the outside world many of us look as if nothing's wrong.

"We're labelled lazy and even benefit cheats and it has cost me friends, by far the hardest pain I have to deal with, but lazy people don't get M.E. it can strike, hard working fit people.

"Before I was diagnosed I went through hell, many doctors didn't believe in M.E and called it Yuppie Flu. No one test confirms M.E, you go through a process of elimination.

"I had psychiatric therapy to prove my illness was not in my head, and for years went without proper medication to help me fight what was happening, and that caused other problems.

"I'm not alone, thousands go through this, are discriminated against, and depression can take over in a big way.

"Through the M.E Association, Association of Young People with M.E there are people who help, online groups such as To Me or Not to M.E [www.tomeornottome.yuku.com/forums/72](http://www.tomeornottome.yuku.com/forums/72) look at life in an upbeat way with lots of laughter.

"In 2002 the Government recognised M.E and started funding research but not a penny went to biological research or treatment. Dr Charles Shepherd, author of Living With M.E, and Dr Sarah Myhill, adviser to Action for M.E, have helped others cope.

"The message is don't let M.E get the better of you but hit it head on. I'm in a motorised wheelchair, have lost a promising career, and old friends, but have gained new friends. I write poems, a novel, and have a loving family.

"M.E may break your body, but not your Spirit."

### M.E – the facts

- Myalgic encephalomyelitis (M.E) is characterised by a range of neurological symptoms and signs, muscle pain with intense physical or mental exhaustion, relapses, and specific cognitive disabilities.
- The cause is unknown, there is no accepted cure or universal treatment.
- Some of the most serious cases are said to involve teenagers aged between 13 and 16.
- Predisposing factors to developing ME are thought to include: having other suffers in the family, due possibly to previous infections such as glandular fever or hepatitis; exhaustion and mental stress, for example, athletic over-training or stress from work or school.

## **ME Association Quick Survey**

Taken off the ME Association Website Monday 9<sup>th</sup> January 2012.

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

*Question:*

What has happened to you alcohol intake since developing ME?

*Answers:*

- No longer drink alcohol (48%, 240 votes)
- Decreased (34%, 172 votes)
- No change (7%, 34 votes)
- Increased (3%, 13 votes)
- Never drunk alcohol (8%, 40 votes)
- Total votes 499.

## **HYPOTHALAMIC FUNCTION**

**From ME Essential Autumn 2011 Issue No 119. Ask the Doctor with Dr Charles Shepherd**

**QUESTION:**

I often read about how hypothalamic dysfunction is thought to be involved in ME/GFS but know virtually nothing about the hypothalamus - apart from the fact that it is a tiny structure somewhere in the brain. Could you explain what the hypothalamus does and why this is relevant to ME/CFS.

**ANSWER:**

The hypothalamus is a pea-sized gland that sits in the middle of the brain just above the brain stem. This is roughly at the level of the top of your nose. The hypothalamus helps to direct a large number of vital body functions as a result of information that it receives through the nervous system, its blood supply and even what you smell. The hypothalamus is particularly sensitive to changes in light and day length, blood-borne hormones, stress and infections.

In relation to ME/CFS, the most important functions are:

- Linking the nervous system to the endocrine (hormonal) system and helping to stimulate or inhibit the output of hormones such as thyroxine (from the thyroid gland) and cortisol (from the adrenal glands)
- Links to the autonomic nervous system, which controls heart rate and blood pressure as well as speeding up or slowing down activity in the bowels and bladder.
- Temperature control - where it acts as a human thermostat by setting a desired and stable body temperature. If necessary, it can stimulate heat Production to raise the body temperature or produce sweating to cool the body down.
- Regulation of appetite and thirst
- Circadian rhythm - where it controls sleep and wake patterns throughout the day

As you can see, all these activities relate to symptoms that can occur in ME/CFS. And an association between ME/CFS and hypothalamic dysfunction has been strengthened by numerous research studies that have looked at the way in which the hypothalamus controls the output of various body hormones - cortisol in particular.

Further research in this area is clearly needed and it would be interesting to obtain a better understanding as to how a triggering infection in ME/CFS might then result in a permanent upset to the delicate control mechanisms that this key part of the brain carries out.

### **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.

## Keeping my Brain Going. by Alex Wootton

My brain just isn't what it used to be!! I'm also sure that most of you are exactly the same, but after I stopped working I found that I had nothing to stimulate my brain, as there is only so much day time TV you can watch. So over a long period of time I have been trying different things to try and get my concentration back, and I really think its helping. I know what I'm going to say wont work for everyone as we are all different, but you never know. I can hear you all asking what have I been doing? Word searches, nothing very glamorous but I find that I really enjoy doing them.

There are quite a few word search books that you can purchase from the newsagent or the supermarket, and the beauty about them is that you can spend as little or as long as you feel your able to concentrate on them. Some of the book are pocket size and the writing is small, but the bigger books are much better for eyes that don't focus that well.

I have now moved on from word searches to brain games on the Nintendo DS, like Brain Training with Dr Kawashima, Sudoku, Mahjong puzzles and classic word games. I'm not saying go out and buy one of these as there are other puzzle books you can purchase or even do a search on the website for free games, as you don't have register and pass on any of your personal details.

So why don't you try the word search below that I have made, and it's all to do with our Support Group, sorry there are no prizes, but I hope you enjoy it.

### Word Search. by Alex Wootton

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

BURY BOLTON  
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