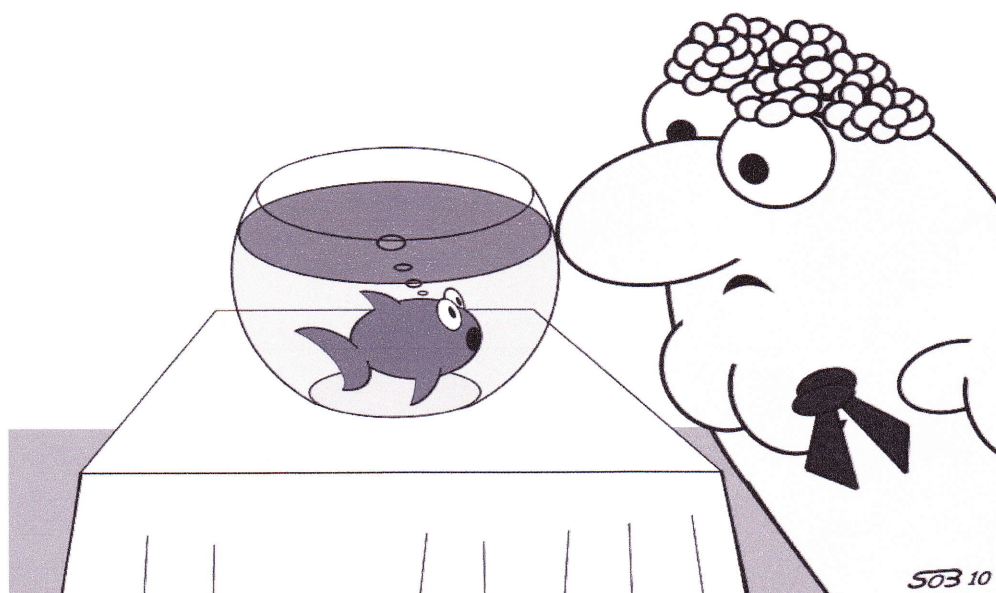


Welcome to Our September 2011 Newsletter



**I'M SO SORRY. YOU FEED ME AND CHANGE MY WATER TO KEEP ME GOING BUT NOBODY
CAN DO ANYTHING AT ALL FOR YOU.**

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

Support Group Posts & Contact Information:

Group Contact / Welfare & Benefits Advice:	Pam Turner	01204 793846
Treasurer & 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 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@gmail.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.

Thursday 15th September – Don Stenhouse, curator of natural history at Bolton Museum. He will tell us some amusing and interesting stories about the objects and will bring some objects with him. These might include fossils, seashells, butterflies, etc.

Thursday 20th October – Sara Grimshaw (Kirkman), Occupational therapist with our clinic, will talk about ways of making life easier.

Thursday 17th November – Pre-Xmas Social.

Please note there will be no meeting in December.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 3rd October 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. **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 6th October, 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. 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 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.

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

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk.

Who am I? By Alex Wootton

I thought seeing that I have taken over editing & distributing our newsletter, that I would let you know a little about myself as I have not been a member of our support group for very long.

I'm originally from Bury, but lived in Edinburgh for many years. My very first job was working part time on the tills at the small Tesco's in Bury (before the redevelopment of Bury's city centre), while I was at college.

Then I went working for a textile company in their laboratory; while I worked there I was working towards a degree in Textile Technology. Unfortunately, I was made redundant and in the early 90's the textile industry went in to decline. From there, I went on an unemployment scheme and was taught to type, as I could already use computers. I was then put on a placement, working in the office of the catering department at Fairfield General Hospital in Bury. A couple of months later, I was lucky again to land a job permanently, working as a receptionist in the Ante-natal & Gynaecology clinic. I worked there for 7 happy years and while there I went on many night courses, so I could further my career.

From there I went working in Manchester as a receptionist for a blue-chip data centre. Luckily for me, because I knew all about data protection, having had to sign it every year whilst working for the NHS, I started doing work for the HR department, covering for the site administrator and also helping the Finance department. So within six months I gained a great promotion and moved up to Edinburgh to become the Site Administrator/Finance Manager for a new site they were establishing. This was a great move for me as I had to set up all of the office systems, purchase everything for the site, as when I first arrived there we were working in portacabins next to the building that was being custom fitted for us, I remember having to go on to the site with a hardhat on so I could measure up the rooms for fixtures & fittings, desks, conference tables, even the china for entertaining clients. I was in charge of getting cleaning staff, catering companies, and flower/plant companies on contract to us. I also ended up chairing our monthly site meetings instead of the site manager who was my boss, as I was more organized and better than him at doing so, he said (he probably didn't want the extra work).

Yet again I was made redundant, but was given the option to go back to the Manchester site, but that felt like a backwards move to me and by this time I'd bought a lovely flat in the centre of Edinburgh.

I then ended up in the job of nightmares, working as an office manager for an environmental company. We feel I started with ME/CFS due to this job as I was over worked, with running up and down the country for meetings and for me to audit people. There was also a huge amount of computer work and I ended up with a bad hand injury, for the 1st time in my working career my spotless sickness record ended. I was off work for 3 months. When I finally went back to work I was treated so badly by management even though I was told by my consultant & GP that I must only work on a pc for the maximum of 2 hours a day and I was also told to make sure I didn't work through my lunch breaks and go home on time. For a company that would have you working 25+ hours in a day if it was possible it didn't go down well. My health was getting worse and worse, as I was in constant pain with my hand, and when I wasn't at work I was in bed totally exhausted. My parents were taking it in turns to look after me as I was unable to do anything, as at times when I was on my own, it got to a point that I would get so tired that I'd go without food, as it was to much of an effort prepare it.

I left this job as I went off sick again just over a year later with depression, and got myself a part time job (2.5 days) doing basic admin (for a homeless charity) and not having to manage staff. I did seem to start getting better but 15 months in to this job I was getting exhausted again, constantly getting one cold after another, sore throats, all of the glands in my neck constantly up, feeling sick, feeling hot and having night sweats, upset digestive system, not being able to concentrate and forgetting what I was in the middle of talking about, and no matter how much I slept I just didn't feel any benefit, I also had some nights that I just couldn't sleep and the more exhausted I got the less I could sleep, I also had the shakes & dizzy spells (on one occasion of dizzy spells I fell over

Who am I? Continued....

and broke my front teeth). During all of this time my parents were still taking it in turns to look after me, as all I was doing was going to work or sleeping. So in December 2005 I officially finished working, although I didn't work for the last 2 months. I thought all I needed to do was take it easy for a couple of months and planned to start looking for another job at the end of February 2006, as I had enough money to pay my bills till then.

The only problem was that when it came to February I was in bed most of the time only getting out of bed for meals or to use the bathroom. I was constantly having sore throats and every time I ventured out to the shops or the Doctors within a day or so I'd have yet another cold, I felt like I only had to look outside and I'd get another cold!

At this time my GP still thought that it was depression, but I was already on the happy pills and I didn't feel depressed, as I had been very depressed when working for the environmental company. My mum started searching on the internet to see if she could find out what could be wrong with me. Luckily for me my mum knew about ME/CFS because of Esther Rantzen's daughter. My mum came across the Action for ME website and they have a document that you can print out with all of the symptoms. <http://www.actionforme.org.uk/get-informed/about-me/Symptoms/range-of-symptoms>

So I printed it off and made another appointment with my GP and asked if my dad could go in with me. We discussed all of the symptoms with her and she agreed with me that this may be what was wrong and referred me to a specialist. We were very surprised that my GP never mentioned ME/CFS to me before as she told me she had quite a few patents already that had ME/CFS and she did believe in ME/CFS.

There was a long waiting list for the ME Specialists and I didn't get my 1st appointment until September 2006. From there it took until January 2007 for me to be diagnosed with ME/CFS, after having lots and lots of blood tests, having scans on my liver and other organs. And like with everyone else that has ME/CFS all of the results were clear/negative.

So then it came to discussing the treatment available! In the time between stopping working and was final diagnosed, I had gained lots of weight so I didn't have the opportunity to go on the PACE trials the Western General Hospital were running with Edinburgh University and was referred to the Thistle Foundation in Edinburgh who run Life Style Management Courses for people like us. This course is very similar to the Management course at the ME/CFS Clinic at Brightmet Health Centre.

In 2008 I decided that it was time to come back and live near to my parents in Bury, as on one occasion in the summer of 2008 my father became ill and I had to take him to A&E and he stayed in hospital for about a week. I had to then organize for my mum to get up to Edinburgh. All this time I was running on adrenalin and was very surprised that I did what had to be done. Needless to say a few weeks later when everything started to get back to normal again I ended up in a bad way again and just stayed in bed sleeping.

From this time in summer 2008 it took us until 2009 to sort things out and get my flat up for sale, finally selling my flat at the end of July 2009 and purchasing my new house in Bury August 2009.

I still miss living in Edinburgh, but my parents and I weren't really living our lives, and I have a much better quality of life in Bury. With living only a couple of miles apart instead of 200+ miles it makes it easier for my parents to come over and help me.

Just before I finally moved down to Bury I did some Google searches to see if there were any support groups in the area and came across our group, I didn't join the group straight away as I went down hill again, my parents and I all put this down to the move, as moving house when you are in good health is stressful enough. I'm so glad that I am able to help our support group as with being involved with it I don't feel lonely and going to the socials when I'm able to, helps me get out and stop looking at the same 4 walls.

If anyone wants to ask me anything or contact me please feel free. Tel: 01617615493 (Not before 12 noon please) Email: alex@mesupportgroup.co.uk

Library Update by Carole Senior

Thank you to everyone who has returned library books recently - especially those of you who posted items back to me.

We've added 2 new books:

- Beating Chronic Fatigue - Dr Kristina Downing-Orr
- Chronic Fatigue Syndrome: The Facts - Frankie Campling & Michael Sharpe (Thanks to Alex for this one).

We also have some new Benefits and Works Guides:

- Understanding Employment & Support Allowance
- Employment & Support Allowance Claims on Physical Health Grounds
- Employment & Support Allowance Claims: Mental Health & Learning Difficulties.

Library FAQ's by Carole Senior

Our library of books, CDs and DVDs is open to all group members and available at our Longsight meetings. We have few rules and I'm always happy to answer any queries but here are a few of the commonest ones cleared up.

1. How many books/CDs/DVDs can I borrow?

There's no set limit, just be realistic about what you can read or make use of at one time. Better to take 1 or 2 items that you will enjoy/find useful then exchange them for something else.

2. How long can I keep the things I borrow?

We don't have a specific period for loans but we would ask that you return items as soon as you are finished with them, so that they are available to other members. If you still have them after 6 months, I'll remind you!

The exception to this is if an item you have borrowed is requested by someone else, in which case I will contact you and ask you to return it as soon as possible.

3. What if I want to borrow something that's already out on loan?

If the book/CD/DVD that you want is not available, let me know and I'll organise its return as soon as is practical. When it's ready for you, I'll call and tell you.

4. What happens if I can't get to a meeting to return or collect an item?

If you can't make it to a meeting, get in touch and we can make alternative arrangements to pick up a book or get one to you.

If you need to contact me you can do it by phone [01942 810320] or e-mail carole.senior@tiscali.co.uk

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.

Researching CFS/ME can be Bad For Your Health.

By Andrew Levy

In late July CFS/ME grabbed the headlines because some researchers have been subjected to a campaign of abuse and intimidation. The story was raised on Radio 4 by Professor Simon Wessley of King's College who received death threats and threatening phone calls. The reason for the threats is because Professor Wessley views the disease as a mental illness whereas the activists believe it is mainly biological. "Sadly some of the motivation seems to come from people who believe that any connection with psychiatry is tantamount to saying there is nothing wrong with you, go away, you're not really ill," says Dr Wessely.

In the debate that followed, Doctor Charles Shepherd from the ME Association was keen to point out that government funded research was mainly used to look at the psychiatric aspects of the disease. "The anger, the frustration, is the fact that all this effort, all this government-funding, has just been going to the psychological side," he said.

The threats are not limited to Professor Wessley. Professor Myra McClure of Imperial College London was one of those scientists aiming to repeat the findings of the Lombardi study which suggested that the XMRV virus was a cause of chronic fatigue. However, when her team failed to confirm the study's findings she too was exposed to a torrent of abuse.

Unfortunately this abuse is leading to expert researchers avoiding this area. The Wellcome Trust's Dr Mark Walport said, "We clearly don't yet understand exactly what's going on, and if we're going to find out it needs good scientists to work on it," he says. "But why would any scientist work on it if they know that all they're going to receive is a torrent of abuse?"

A personal view from the author: The psychological problems that come with chronic fatigue usually set in once you know your life has been changed. You can't do the things you used to and it was very difficult for me to cope with that. I have a family, I liked doing sport, I liked working hard and I was a very active person. Suddenly I had to go from a very active life to doing not much at all, and this was bound to have a psychological effect. I remember being put on antidepressants at the beginning, but I was so determined not to take them that eventually I was strong enough to kick that. Anyway over the years I've tried many different types of therapy, and I am 100% convinced that's my disease is caused because of a biological reason.

Your Replies on Magnesium Treatment.

by Tracey Morris

Thank you to those people who replied to my plea regarding magnesium in a recent newsletter. Members agreed that magnesium can help in easing muscle aches and pains, moods, sleep and many other symptoms.

Several people suggested that **magnesium citrate** is a good, absorbable form. Solgar do a version and their supplements are free of preservatives, colours etc which can be helpful for those with sensitivities.

A popular choice of **magnesium malate** seems to be produced by Biocare and is available from them or Nutricentre (online or at larger Tesco stores). This is in capsule form which may be better for those who struggle to absorb nutrients as the powder can be removed from the capsule and stirred into water or juice.

www.nutricentre.com Telephone ordering: 020 8752 8450

www.vitaminuk.com Telephone ordering: 0800 056 8148 Action For ME member discount.

Epsom salt baths can be very helpful for aches and pains if done with care.

www.justasoap.co.uk produce larger sacks of gardening grade Epsom salts delivered to your door.

One member suggests that **acupuncture** is a good all-round tonic treatment that is good for helping mood, sleep, pain and detoxification which may therefore be an alternative to magnesium for some

people. Care needs to be taken in finding a qualified practitioner. As ME sufferers can struggle with detoxification, it may be better to start with a treatment every 2-3 weeks at first before increasing to once a week (if tolerated). Some people claim very good results from this.

An alternative to acupuncture which seems to give the same benefits (but without needles) is **laser pen treatment**, available from some acupuncture practitioners.

Reiki healing is another suggestion that may prove helpful for a range of problems including sleep. Reiki can be also be done as absent healing for those unable to attend a clinic etc.

If anyone has any further tips that may be of interest to others please contact Tracy 01204 592226 (10am- 1.30pm or 6.15pm- 7.30pm)

Bury/Bolton ME/CFS Facebook Page.

By Caroline Higson

Following popular demand, we are pleased to announce that our group now has a Facebook page! For those of you who don't know, Facebook is a social networking site that allows you to stay in touch with others and has over 750 million active users!

Please visit <http://www.facebook.com/groups/buryboltonmecfs/> to join. Alternatively, visit our website at www.mesupportgroup.co.uk and click on the "Facebook" link.

We currently have the "Yahoo Groups" chat forum, however, Facebook is the more modern and easier way to interact with others and has better functionality than Yahoo, which has proven to be quite unreliable at times. After discussing this with members, we have decided to keep the Yahoo group going for those who don't wish to make the move to Facebook, but it will be closed off to new members.

You can post messages, links to helpful websites, photos and even videos to the group! You can even chat live to other members who are logged in to Facebook at the same time! There are already 25 members and it's been nice to see people who we've not heard from for a while on Yahoo.

One member said "in the few days it has been running I feel less alone and have had fab advice" and others like being able to put faces to names, as many members have their photo up. There have been lots of lively discussions so far, such as suggestions for low energy activities and people swapping their experiences and advice on claiming benefits.

Facebook is the same as Yahoo in that you can get emails of messages sent to you so that you don't have to log in to view them. Being on a Facebook "group" is different to being "friends" with someone on Facebook. You will not see everyone's personal posts on this group, unless you are "friends" with the person posting the message. For a message to appear on the group's page, users have to specifically post a message on it, so it is like Yahoo in this way.

We have made this a "closed" group so that only members of the Bury/Bolton ME/CFS Support Group can join and everyone must be approved before they can see other members posts. Even though only members of the Facebook group and not the general public will be able to see what you post, please still be careful about divulging personal information!

Some members have expressed concern over security issues on Facebook, however, being registered on Facebook carries no more risk than being registered on Yahoo, or any other website. To ensure your security and privacy, it's possible to edit your settings to make sure you are best protected (there is a guide on our Facebook page on how to do this).

If you have any questions about the Facebook group, contact Alex and Caroline at alex@mesupportgroup.co.uk or caroline@mesupportgroup.co.uk. Please email dave@mesupportgroup.co.uk for any questions relating to the Yahoo forum.

We are a very friendly bunch and everybody is very welcoming, so please come along and say hello!