BBME

Support Group

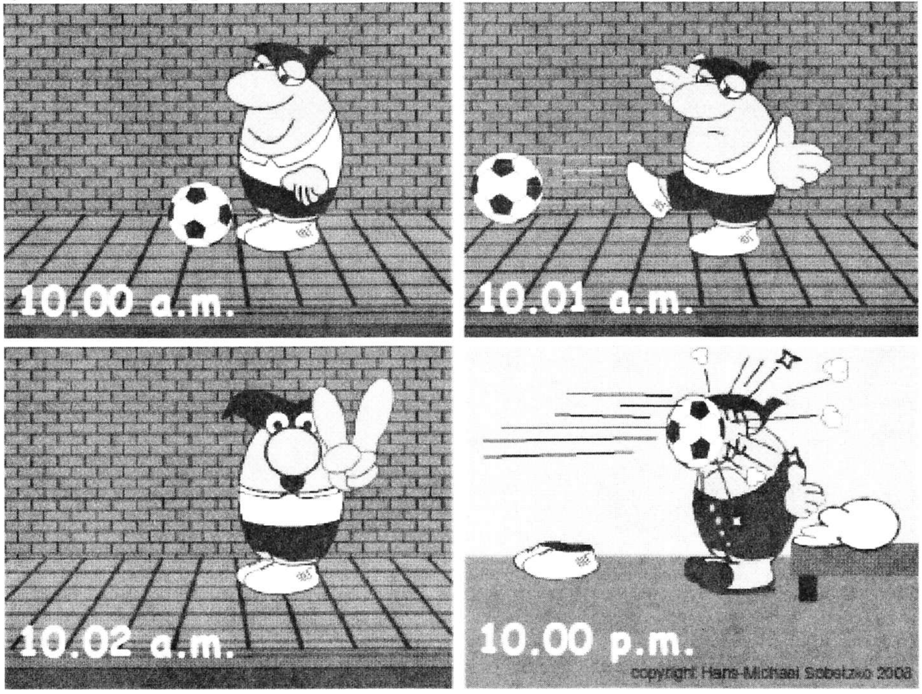
"Breaking the Isolation"

Welcome to Our July 2012 Newsletter

A Note from Alex: The other day I was looking at some back issues of our newsletter and it suddenly dawned on me that I have been editing and distributing the newsletter for 12 months now, so it just goes to show that time does fly when you're enjoying yourself, as I would have said I'd only been doing this for 6 months not 12!!

This month we have included Action for ME's Classification on the NICE guidelines on Degrees of Severity & the Wellness Scale for people with ME.

Also this month we have a lovely Thank You from Pam & Roy Turner (page 5) for the gifts we presented them with for all of their hard work & dedication that they have shown to our support group over the years. Lastly please note there will be no yoga on 31st July & 7th August.



It often takes hours before the effects of any activity finally hit 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.

Contents of July's Newsletter

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.

Issue: 74 **July 2012**

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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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 19th July – Phil Samphire from Greater Manchester Coalition of Disabled People (GMCDP) followed by a social.

Please note that there will be no meeting in August.

Radcliffe Socials: We meet informally on the first Monday of each month; our next will be on **Monday 6th August** 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 **3:00pm-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'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.

Please note that there will be no Yoga on Tuesday 31st July and Tuesday 7th August.

Our lending Library has had to be removed from it storage at the Longsight Church Hall, due to their renovations, so for the time being Carole can only bring along a select amount of books to the meetings. If there is a particular book that you would like to borrow from our Library please contact Carole Senior prior to the next meeting. To find an up to date book list please refer to our webpage. With next months newsletter you will receive an up to date book list along with other Library information.

Bury/Bolton ME/CFS Support Group Meeting June 2012

Philippa O'Callaghan from The Red Cross – by Tracy Morris.

Philippa began with an overview of projects the Red Cross are involved with. Most of us are aware of the work they do abroad in times of crisis but less is known about how they help people locally. They are not allowed to advertise through the media and this can make it difficult to reach people who may need their help. The Red Cross charity receives no Government funding and relies on grants, donations, legacies and fundraising. They have only 10% of paid staff with all other work being done by volunteers. They try to provide their services free (although donations are always appreciated) and any charges are kept as low as possible. Volunteers are always welcome.

In an emergency the Red Cross can provide a short-term "care in the home service" where volunteers are sent in to help people after a hospital stay, during times of illness or a family crisis. Volunteers may be needed to befriend or to help with cooking and shopping while an individual recovers. They are not allowed to issue medication or to provide personal care eg toileting (although they can help people to and from the bathroom). This can be useful while waiting for other agencies to set up more long-term care.

The Red Cross also offer two hour First Aid courses to groups (although these could be done in two parts), and the people present at our meeting felt that this would be very useful for our members. Philippa will look into this for us.

The Red Cross can help with the carers' assessment process and it was suggested that going through this in advance may allow people to access care services more quickly in an emergency as the details are kept on file until needed. Our group members who have been through the carers' assessment found that it was not a difficult or distressing process but it can take time to organise and so doing it in advance is essential to ensure care is available in a crisis. It was also advised that in answering any questions during the process you should answer according to how things are on a bad day.

A new (limited) project being offered is therapeutic neck and shoulder massage which is done over clothes (to help people deal with stress) and this can be done for a group or in the home. The above are available in both the Bolton and Bury areas.

Red Cross Medical Loan Service.

This service is available to all and involves the short-term loan of equipment (eg wheelchairs, shower seats, trolleys, perching stools etc) in times of crisis, in order to allow people to keep their independence. They ask for a donation for equipment loan (unless you are registered in their carers' card scheme when it is free – see later) and may ask for a deposit eg £20 for wheelchairs (available in all types and to suit all sizes and needs) which is refundable or which could be used as your donation. There is then a minimum fee per week after that. This service could be helpful for those returning home from hospital, needing mobility aids to go on holiday, or while waiting for more long-term provision from health or social service agencies.

If you have a specific need Philippa recommends ringing up to ask if they can help. She comments that if they do not have the equipment they often know how to get it. In an emergency (and if the equipment is available) they may be able to get it to you (or you could send someone to pick it up for you) that same day.

The Red Cross take their equipment back when the patient no longer needs it in order to loan it out to others and will take unwanted equipment that other agencies will not re-use, eg mobility aids (but not toileting aids).

Red Cross Transport and Escort Service.

This service offers independence to those who cannot get out easily and their trained, CRB-checked, and insured volunteers can provide door-to-door assistance eg getting to appointments, socialising, shopping etc. The volunteers use their own vehicles or adapted ones (eg a minibus with a ramp) and can provide more than one volunteer if needed. This can be a single arrangement or regular service. Philippa says the help they offer is better than other schemes eg they take people to Christies for cancer treatment with their carer and the volunteer remains with the carer while the patient receives their treatment. This can be of great comfort and support to the carer at a very worrying time. They do ask for a contribution to their costs and a transport charge based on mileage (usually cheaper than a taxi).

Red Cross Carers Care / Card Service.

This service is only provided in Bury currently although there is a similar scheme available in Bolton run by the authority for those who have had a carers assessment (through Social Services) and so the qualifying criteria may be more restrictive.

The service in Bury is part council and part legacy funded and they work closely with other agencies eg Age UK, Bury Carers' Centre and St. Johns Ambulance in order to give the most effective service possible. All

GP surgeries in Bury should have details of their work and there is also a carers' scheme at the hospital. Most people do not see themselves as carers but the Red Cross definition of a carer is very broad and is simply that someone is dependent upon them. An estimated 19,000 carers live in Bury. Sometimes there can be three generations of family all caring for each other at different times and this scheme also involves neighbours, other relatives or friends. To be part of this scheme either the carer or the dependent must live in Bury but other contacts can live out of the area.

In Bury this service provision is not dependent upon a carers' assessment. A carer simply applies for an emergency carers' card which asks for the details of the dependent, plus any other emergency contacts eg relatives or neighbours, and the carer then carries this card with them. The details are stored centrally and if ever the carer has an emergency the Red Cross have details of who needs help and any alternative carers are contacted. If there are no other carers available then the Red Cross may provide the help themselves. In the two years that the scheme has been running no-one has needed to use it but everyone involved agrees that it gives them reassurance in the event of an emergency.

In addition, those carer cardholders who need home help or transport can get this without the need to make a donation. Outings and newsletters are also available to give carers support from others who may be in a similar situation.

Leaflets detailing these services will be kept in our library.

To find your nearest Red Cross facility go to www.redcross.org.uk or call 0844 871 1111 (switchboard).
Regional office: 01772 707 300

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Message In A Bottle Scheme – The Lions.

This scheme gives the emergency services information on medication, allergies and emergency contact details if they are called to the home of someone living on their own. The bottles are available from hospitals, local surgeries and chemists free of charge and contain 2 stickers (for front door and fridge), plus the information sheet. The completed sheet is placed inside the bottle and kept in the fridge until needed. The stickers alert the emergency services to the fact that the information is there.

A Big Thank You from Pam & Roy Turner

Dearest friends I can not begin to tell you how very surprised I was at the meeting on Thursday when I was presented with the flowers, gifts and gift token to mark my retirement as Group Leader.

(Left photo Pam just after our presentation & above Pam & Roy with their gifts. The rose bush is called Fellowship which sums up our group.)

It was a very well kept secret and I had no idea that there was to be a presentation. I was very humbled and very touched at the gifts and cards and the lovely messages in the beautiful card that Alex had made. I would like to thank all of you for the friendship and love that we have shared over many years and to say that it has been both a privilege and a pleasure to have been Group Leader, I feel truly honoured. I hope to continue as a member of the committee and to help as much as my health will allow so you will still be able to contact me. Roy also sends his sincere thanks to you all. With much love and many thanks from Pam and Roy

NICE Classification on the Degrees of Severity & the Wellness Scale for People with ME. from Action for ME's Website 3rd July 2012

Degrees of Severity

The National Institute for Health and Clinical Excellence (NICE) acknowledges that the physical symptoms of M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.
Its **guideline** on CFS/M.E. outlines three levels of severity – mild, moderate and **severe** – as follows:

Mild

"People with mild CFS/M.E. are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week."

Moderate

"People with moderate CFS/M.E. have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed."

Severe

"People with severe CFS/M.E. are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise."

Want to monitor fluctuations?

As M.E. is a fluctuating illness, using a severity or **wellness scale** may help you to monitor your health over time.

Wellness Scale

There are a number of scales designed to help people to monitor their health over time.

Examples include the Hummingbirds' three-part **Ability and Severity Scale**, Association of Young People with ME's functional ability scale, Dr David Bell's **Disability Scale** and a scale in Dr Charles Shepherd's book, 'Living with M.E.', which is available from the **ME Association.**
Below you can find a version which we call a wellness scale.

You may wish to print out **a PDF copy** and/or keep a note of your 'score' in **your activity diary**.

How are you today?

100% well

I have had no symptoms when resting or following activity for at least three months.

90% well

I have no symptoms when resting. Occasionally, mild symptoms may follow activity.

80% well

Occasionally I experience mild symptoms when resting. The symptoms are more noticeable following activity. I can't do some activities which require physical exertion.

70% well

My symptoms are mild when I am resting. I can't do some tasks which involve physical exertion.

60% well

My symptoms are mild or moderate when I am resting. My ability to carry out normal daily tasks varies.

50% well

I experience mild to moderate symptoms at rest and moderate to more severe symptoms following physical and/or mental exertion. I can't carry out any strenuous physical tasks but I am able to perform light activities for several hours a day, as long as I have adequate rest periods.

Wellness Scale Cont...

40% well

When I am resting my symptoms are moderate. Following any form of physical or mental exertion, my symptoms become moderate to severe. I can't carry out any strenuous duties, but I can carry out light activities for one to three hours a day, as long as I have adequate rest periods. I am not usually housebound.

30% well

I experience moderate to severe symptoms when resting. Severe symptoms follow any physical or mental activity. I can do light tasks for one or two hours during the day. I am often confined to the house and may require wheelchair assistance at times.

20% well

I experience moderate to severe symptoms at rest. I may only be able to carry out a few physical activities relating to personal care such as having a wash. I am often unable to leave the house and may be confined to a wheelchair or bed for much of the day. I can't concentrate for more than short periods of time.

10% well

My symptoms are severe, even at rest. I am bedbound and housebound for much of the time, have real difficulties with many aspects of my own personal care and need a great deal of practical support. I have significant problems with memory and concentration.

0% well

I experience severe symptoms on a continual basis. I am bedbound and incapable of living independently and need a lot of practical and social support.

YOU AND ME- New young people's group in Manchester

by Rosie Heaton

Do you sometimes wonder if you could be doing more? Ever feel a bit lonely? Live around Manchester, and are aged 11-17?

Then this article is for you. I am setting up a social group for teenagers and young people, which will be for people with M.E but not based around it. The main aim of this group will be to have fun and make friends in a normal teenage way.

I'm Rosie, I'm 15 and in the past few years that I've had M.E, I've realised how easy it can be to be left behind. Well, that's about to change. I think that it helps to focus on what we can do, rather than what ME stops us from doing and for this reason I've decided to start up this group.

I'm a Brownie and guide leader, and I love it! I'm also doing my GCSEs at the moment. I think we're lucky to live in a place where there are so many opportunities; last week I was welcoming the Olympic torch to Salford with the guides after sleeping over at a shopping centre!

I got ill when I was 8, following meningitis and have been in and out of education since. I now attend a health referral unit and while I still get payback I can manage a lot more than I could previously. A lot of my friends from my mainstream school have moved on, which is why I think that this group could be a good idea as I understand how that feels. I'd like to make up for the things I've not had the chance to do, while involving others.

At the moment I am contacting different M.E charities in the hopes to gain their support and build up the numbers, so even if you would just like to talk to someone who understands to begin with, feel free to contact me. If you are interested in coming along to the group, email me on rosieheaton@hotmail.co.uk and I'll get back to you straight away.

The main aim of this group is to make friends, so if you'd like to bring a friend to a meeting that'd be absolutely fine, and hopefully we'll do things like going to the cinema, getting a pizza or going bowling but the options are still open.

You and Me ♥

I have had my low points over the past 7 years but now that I'm doing better I'd like to try and get this group going, I think it'll be fun.

We also have a Facebook group - search "You and m.e" and request to join! ☺

Survey on CBT, Graded Exercise and Pacing

by Alex Wootton

The ME Association is currently running a survey on their website to find out peoples feelings about CBT (cognitive behaviour therapy), Graded Exercise and Pacing with the results of this survey they are hoping that they will be able to influence the next review of the NICE Guideline on ME/CFS treatments, which is due to be announced next year.

I filled this in on line as soon as it was available and also contacted them requesting a paper copy hoping that I could attach it to our newsletter like I have done with other short surveys. Yesterday I received the paper copy and was amazed that the quick survey on line when transferred to paper becomes a 64 page survey. Which means it is too costly for me to replicate it and send it with your newsletter. However if you would like to participate in this survey please click this link: https://www.surveymonkey.com/s/MEAssociation alternatively you can request that they send you a copy of it by email for you to download and print it off yourself by emailing Gill.Briody@meassociation.org.uk . If you don't have an email address, and have difficulty reading from a computer screen or don't have a printer, you can ask for a paper copy to be posted to you by writing to Gill Briody, Ramsay Research Fund, ME Association, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks MK18 4DF, or phoning Tel: 01280 818964. Please make sure that you send back your filled in survey by the middle of August. To date according to their website over 500 people have already taken part in this survey.

Late Edition

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

Doctors Gerwyn Morris and Michael Maes recently published a paper suggesting a model for CFS/ME. Their model recognises many abnormalities reported in people suffering from CFS/ME affecting the immune and nervous systems. It suggests that initial infection leads to a state of chronic immune activation, driven by oxidative and nitrosative stress. This leads to further damage even when the initial infection has been cleared. **A neuro-immune explanation for the remitting/relapsing nature of ME/CFS – Prohealth - June 22, 2012**

The International Association for Chronic Fatigue Syndrome and Myalgic Encephalomyelitis (IACFS/ME), the largest group of American physicians and researchers dedicated to CFS/ME, has **released updated care guidelines** directed at primary care physicians and other health care providers. It's a complex 42 page document covering everything from brain abnormalities to anxiety and depression. **Scientific Organization Releases Chronic Fatigue Syndrome Guidelines to Educate Health Care Providers – PR Newswire – May 29, 2012**

A new study has claimed that blood pressure can be an indicator of CFS/ME. Researchers found that variations in blood pressure were higher in people with CFS/ME in a resting state. They also found that indicators in your nervous system will also be reduced. They also found that when CFS/ME patients stood up, their blood pressure change was lower. This links in with existing knowledge about getting dizzy when you stand up because blood pressure does not change enough. **Blood Pressure Problem as a Biomarker of Chronic Fatigue Syndrome – about.com – June 20, 2012**

Support groups exist throughout the UK, and are designed to help patients and carers alike. reMEmber is the group based in Sussex doing just that. to raise funds, they recently held a concert with a local singer called Michael Gverney. Michael has already raised lots of money for charity, and wanted to help this worthy cause. The group were also helped by the owner of a local venue to host the evening. **Come Fly With Me – Sussex Living – June 8, 2012**

The Leicester Mercury recently ran a short piece about CFS in the area. Dr Trevor Friedman spoke about the misconceptions and the importance of cognitive behavioural therapy. He also recognised the issues some patients have when their GPs are not fully informed about the condition. **Thousands Suffer From Condition – Leicester Mercury – June 11, 2012**

A study published in the journal Cancer shows a link between CFS/ME in elderly people and a type of cancer called non-Hodgkin lymphoma. The risk of catching this type of cancer was 29 times greater if you had CFS/ME. However, the risk of contracting other forms of cancer did not increase. **Cancer Risk Linked to Chronic Fatigue Syndrome – about.com – June 8, 2012**