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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, Newsletters & Distribution:	David Gore	0560 133 5037 Dave@mesupportgroup.co.uk
Link Up Co-ordinator:	Stephen Walker	01204 842395 stewalker@postmaster.co.uk
Librarian:	Carole Senior	01942 810320
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 andmk1@googlemail.com

DISCLAIMER:

The observations expressed in our newsletter may not necessarily represent the views of the editor, the Committee, or the Bury/Bolton ME/CFS Support Group. All products and treatments featured are for information only.

**Supported
by:
Health
For Bolton**

Reminders

Equipment Hire: We have a wheelchair, an electric mobility scooter (small enough to fit in car boot for days out or holidays) and a light box. If you wish to borrow any of these, please phone Pam on 01204 793 846.

Link-Up: If you would you like to be in contact with other members of the Bury/Bolton ME/CFS Support Group by telephone, then you can by joining the Link Up Contact Service. It is very user friendly and it is free to all members of the Support Group. Two contact directories are sent out each year, one in the summer and one during the winter. It is a great way to contact people, compare experiences and most importantly make new and lasting friendships. For further information you can contact Stephen at stewalker@postmaster.co.uk /or call on 01204 842395 (Monday and Friday after 6pm).

Email Chat Group: Our Yahoo! Chat group is another great way of keeping in touch with other members between meetings. Unlike a conventional chat room, contact is made by email and/or message board, so you don't miss out if you are not online when a message is sent and can catch up at any time that suits you. On our Yahoo Group home page we have also built a large database of links to information and services that we have found to be useful.

To join, email dave@mesupportgroup.co.uk or visit:

http://health.groups.yahoo.com/group/Bury_Bolton_ME_CFS_Support_Group/

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.

Help us to be greener: If you would like to receive flyers and/or newsletters by email instead of post, please let me know by emailing dave@mesupportgroup.co.uk.

Benefits & Work Guides

Our group is a member of www.benefitsandwork.co.uk, allowing us to access their fantastic guides to a range of benefits and disability related issues. They are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge plus use of the Freedom of Information Act. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal. Our subscription allows us to make these guides available to our own members, so if you need anything phone Dave on 05601 335037 or email dave@mesupportroup.co.uk. We also have a selection of the more popular guides available from the library at our meetings – if you can't see what you need, please ask!

Please note that some of the guides are very lengthy (up to 88 pages) and so it can work out rather expensive for us to print and post them. To give you a rough idea what it costs us to print and post them to you, here are a few figures:

10 pages - £1.00	20 pages - £1.80		
40 pages - £2.70	60 pages - £3.50	100 pages - £5.50	200 pages - £11.00

If possible please help us to keep costs down by providing an email address we can send them to, if you do not have internet access yourself, perhaps you have a friend or relative who could help out. Alternatively, if you go to one of our meetings, social groups, or yoga classes, you could pick them up from there and then return to us to be used again. We don't want anyone to miss out and will do our best to accommodate your needs, but perhaps if you do need us to post any of the longer guides to you (or several of the smaller ones), and you can afford to make a contribution towards the costs, it would be very much appreciated. Please see last month's newsletter for the full list of guides.

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 18th February 2009, 7:30pm – Sue Hutchins on Qi Therapy.

Qi Masters are trained to understand the invisible mechanism of stress and disease. Their Qi treatments detect all imbalances and restores the invisible vital flow of the life force energy (Qi) inside us. When cleared of toxins, negative energy or blockages accumulated over a long period of time, our mind and body gradually return to an original state of vitality, reducing all symptoms of illnesses. They believe that most diseases (including M.E) stem from energy shortages, prompting an imbalanced state of mind (prolonged depression, anger, frustration, sadness etc.) Inner sound teaches a fast, accessible and effective method to regain energy and vitality through re-aligning mind, body and spirit. The Qi treatment is the most popular introductory technique to this method.

Thursday 18th March 2009, 7:30pm – AGM. For more information, please see the separate notice enclosed with this newsletter.

Radcliffe Socials: Our Social Group meets informally on the first Monday of each month, our next will be on **Monday 1st March 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 05601 335037 or email Dave@mesupportgroup.co.uk.

Bury Socials: These are continuing on the first Thursday of every month, the next will be **Thursday 4th March, 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 01706 829488, or olivia@oliviayoga.co.uk for more information.

Neuro Support Groups: These groups provide information, advice and support for people with any type of neurological condition and/or their carers. Guest speakers are in attendance most months.

Bury Neuro Support meets most 2nd Thursdays between 4-6pm at Bury Parish Church Hall (Community transport available).

Neuro Support 4 Salford meets most 4th Fridays (11am-2pm) at varying venues whilst building work is being completed at their regular meeting place.

Call 0161 743 3701 or visit <http://www.gmneuro.org.uk> for information about either group.

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

Bolton/Bury ME Support Group Meeting February 2010:

The Shaw Trust

Those of you who missed this meeting, missed a real treat. It was most reassuring to listen to two people who obviously take a great deal of care in their job and who are so helpful.

Neil Farmer spoke first to give us the background to the Shaw Trust, he is manager of the Bolton and Bury offices.

The Shaw Trust is an independent charity which has been in existence for over 25 years. It started in a small village in Wiltshire, called Shaw, where families with disabled members wanted better help to get them into suitable work. They became very experienced in this area and gradually the charity expanded and is now a national charity and even has branches abroad. They have over 400 charity shops mainly in the South and Midlands. Within the North West area, until two years ago, all their work was voluntary but it is now government funded to help people back into work. They focus on employment and training.

The Trust is the provider of Government Contracts for Pathways to Work and New Deal in this area. New claimants for Employment Support Allowance will usually have a medical but are then also required to see someone from the Shaw Trust. Neil said that he understands that for some people being told that they have to see an adviser from the Trust and have a series of five interviews can be frightening but he said to remember that the Trust is there to help; they are not there to force people who are not well enough back into work too soon. They want to help people and to give good service and advice so that when they get back into work it is sustainable.

It is important to the Trust that they learn as much as they can about different conditions so they invite in guest speakers to their training sessions; or they come out to meet people in groups like ours; or they learn from the individual client.

Natalie Flack then spoke about the way that they try to work with the individual and find their particular needs. It may be that someone has just been made redundant and needs help in producing a CV. The clients may have good work skills or they may never have worked before, each one is helped on an individual basis.

They are usually asked about their finances just to make sure that they are alright and can manage, if not the benefits advisors can help.

Natalie looks at what people have done, she assesses what they are capable of and tries to offer support such as CV workshops and job clubs. They try to source vacancies for clients rather than just looking in the paper, this is usually more successful. They work with the clients and try to give continuity, so you see the same advisor who can offer ideas and encouragement until you find a suitable post. There is an incentive of £200 job start plus £40 per week return to work credit for some jobs.

They also have an Access to Work scheme which helps by e.g. providing money for transport to work.

Natalie aid that the mandatory clients may be worried when they first come but that they try to reassure the client that they are there to help and even when they get a job they can ask

the Trust for help with any problem that occurs. For example the Open Work Steps. If someone gains employment under 16 hours per week they can still retain their benefit up to earning £90 but over 16 hours they have to come off benefit. Shaw Trust can help by contacting you regularly or coming into work to see you and ensure that you are not pushed too far or too quickly. This can be very important when you first go back as they can act as a go between for the employee and the employer.

Shaw Trust can also help people who are still in work but on sickness benefit; they can go with the person to negotiate a proper phased return. They develop an action plan with the individual.

Of course the DWP wants people off benefits and in work but the Trust does not force people into work, they want to help the individual and to make sure that when the time is right working will be a sustainable option. It is no use forcing someone into a job only to find a few weeks or months later they have relapsed. Relapse can happen but the support will still be there from the Trust.

Neil told us about the 104 week linking rule which means that if you were on a certain level of benefit and then tried to work but relapsed, you would not have to start again from a lower level but would be able to go back to the level of benefit you were on previously.

They get voluntary clients coming to see them who have never worked but would like the chance to be able to do so, even if it would be in the future.

In the question and answer session several people made comment about phased return to work being too rushed and people being pushed too far and of course Shaw Trust can help with this.

Many people are grateful for the help they receive and wonder why they didn't know about it years ago.

Neil said that although it is mandatory for some people to see them it is OK if they are not ready for work at that time, the help will still be there when they are able to think about work again. Also one person who has been seen by the Trust and has not been considered fit to return to work at present was told that they would be contacted again in three years. Neil said this was probably to link in with the period that benefits are reviewed.

There was a question about someone fighting an insurance company claim but Neil said that although they don't have any expertise in legal proceedings they will always give as much advice as possible and they would try to find someone with the expertise necessary for the client to contact.

When asked if there is a follow up programme Neil said that it totally depends on the individual, the first five meetings are mandatory but after that it is optional. These first five meetings do not need to be weekly, the Trust will try to be flexible, it is all about support for the client. There is no cost, the Trust will pay travel expenses.

Bolton Office is in Crompton Place Shopping Complex

Bury Office is in Europa Business Park (behind Tesco)

Wigan and Leigh helped by Work Solutions

Shaw Trust, tel: 0808 180 2001

www.shaw-trust.org.uk/support_for_individuals

Brian's Journey – Back From The Brink

Brian Hopkinson has had Chronic Fatigue Syndrome (CFS) for most of his adult life. Now 59, his symptoms first appeared in his teens, and by age 42 he had to retire from his job as a groundsman - gardener. Brian feels that the source of his illness was toxins in the chemicals that he regularly worked with. As patients with CFS are unable to detoxify effectively, this meant his body was unable to resist some of the chemicals he was working with. He supports this theory through research from Manchester University who proved that organophosphates, used in gardening, could not be detoxified by people with CFS. This was further backed up by different studies carried out on soldiers with Gulf War syndrome.

Brian's long journey to battle his illness also involved a court case against his employer starting in 2001. He fought the case based on the incorrect use of herbicides whilst doing his job. Although he was backed by his union, his legal team eventually advised him that the case had limited chance of success. In an effort to succeed, Brian changed his legal team, but despite this he didn't prevail, and with his health in decline he abandoned it altogether. The case took its toll on Brian. He was bedridden for six months, and housebound for a couple of years after that.

However, Brian was not finished and he discovered a Japanese healing technique called Reiki. Reiki was developed in 1922 and it involves treating the whole body applying healing energy through the palms of the practitioner into the patient. Brian felt that Reiki gave him the strength to build himself back up at a physical, mental and spiritual level. Coupled with a strict organic diet, he felt it helped to successfully detoxify his body.

Brian was treated locally in Whitefield, and although sceptical at first he soon felt the benefits. So much so, that after six sessions he was tuned to the healer and was able to administer healing by himself. He then subsequently trained in Reiki to achieve a level 1 qualification. By doing this, he could administer healing on himself in an effective and structured way. From February 2003 he was administering daily treatments on himself. After three years, he had lost four stone in weight and was back down to his ideal body mass index (BMI). But this wasn't enough for Brian, and in 2007 he took and passed the level 2 Reiki qualification.

In February 2006 Brian also discovered another treatment called MORA. Mora was developed in 1977 by the German physician Dr. Franz Morell and the electronics engineer Erich Rasche. After 20 years of research, they put forward a view that each person has a unique spectrum of ultra-fine electromagnetic oscillations running through their bodies. The chemical processes and information necessary for successful life are transmitted through this spectrum, and disrupting this will cause disease and ill health. Both scientists believed these oscillations could be detected, and therefore electronically treated to make a person better. Brian embarked on a treatment of MORA therapy, which helped improve his health even more. For example, his sensitivity to formaldehyde was originally 97%. After three years of monthly treatment, the same figure was down to 2.6%.

Brian is living a much better life today, and is the change man from the housebound person he used to be. He views Reiki as a spiritual form of healing with Mora providing a biological solution. Combine with a healthy diet, he believes his body is not susceptible to the toxins that can have such a devastating effect. Today, Brian is a fully qualified Reiki Master, and is happy to give a free taster session to anyone in the support group. Brian can be contacted on 0161 723 3589.

XMRV Update

Research published recently from Imperial and Kings' College London announced that they had been unable to find any trace of XMRV in 186 British CFS patient samples they tested. However, there has been widespread criticism of the methods used. Both Action For ME and the ME Association have commented that no single study can be conclusive. There are a number of other research groups, both in the UK and abroad who are also carrying out replication studies. So watch this space!

Chocolate Mousse Cake

This proved very popular at our December Bring & Share Social and several people asked for the recipe, so thankyou to Dianne for sharing it with us:

300g dark chocolate
275g caster sugar
165g unsalted butter
5 large eggs
1 tbsp ground almonds

- 1 Put the chocolate, sugar and butter in a bowl over barely simmering water and allow to melt.
- 2 Whisk eggs with the ground almonds until well mixed and use a spatula to fold into the chocolate mixture off the heat.
- 3 Pour into a 20-23cm cake tin (buttered and dusted with ground almonds). Bake in oven for 35-40 mins at 180°C/Gas Mark 4. Allow to cool (it may crack slightly) and dust with icing sugar. Serves 10.

Thoughts For The Day

- ❖ Worries are like babies – the more you nurse them, the bigger they become!
- ❖ If you find other people always smile before you do, you are not smiling enough. Beat them to it, smile first – it won't cost you anything and you will nearly always get it back!
- ❖ For safe keeping put your troubles in the pocket with the hole in it.
- ❖ Every good deed you do now is a golden thread in the blanket that will keep you warm hereafter.

SOME CONTACTS YOU MAY FIND USEFUL

Benefits Agency Information Officer: Bolton - 01204 367000 Bury - 0161 762 2000

Bolton Primary Care Trust: 01204 907724

Bury Primary Care Trust: 0161 762 3100

Citizen's Advice Bureau: Bury - 0161 761 5355 Bolton - 01204 900200 (/213 Housebound)

Disabled Living: 0161 832 3678

DIAL Disability Information and Advice Line: equipment/gadgets and where to get them: 0161 703 8887

Bolton Community Voluntary Services: 01204 546010 **Carers Support (Bolton):** 01204 363056

Bury Council for Voluntary Services: 0161 764 2161

Social Services: Bolton 01204 337841

Bury (town hall) – 0161 253 5000 (ask for adult social care team)

Bury Carer Services: 0161 763 4867 and **Bury Carer Assessment:** 0161 253 7190.

Basic Neurocare Centre (inc Assisted Gym): 554 Eccles New Road, Salford, M5 2AL: 0161 707 6441

Ring & Ride: Bolton - 01204 388500 Bury - 0161 764 1999

Welfare Rights Advice Line: 01204 380460

Benefits Helpline: 0800 882200. **Completing Forms:** 0800 44 11 44

Equality Human Rights Commission (was Disability Rights Commission): 0845 604 6610

JOB CENTRE PLUS: http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled_People_and_Carers/index.html

ACCESS to WORK: http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev_015798.xml.html

General government guidance on entitlements: <http://www.direct.gov.uk/DisabledPeople>

SHOPMOBILITY: Bolton – 01204 392946

Bury – 0161 7649966

Manchester Arndale - 0161 839 4060 Trafford Centre: 0161 749 1728

Bolton Market Place - Wheelchair Service: 01204 361100

ACTION FOR ME: 3rd floor, Canningford House, 38 Victoria Street, Bristol. BS1 6BY.

Tel: 0845 1232380 (or 0117 9279551), e-mail admin@afme.org.uk for general enquiries

Welfare Rights Helpline - 01749 330136 9am to 1pm Mon Tues Thurs 9am to 12.30 Fri

Telephone support - 0845 1232314 (11am to 1pm Mon to Fri) - advice and information for anyone affected by ME (including non-members). www.afme.org.uk or for young people with ME www.a4me.org.uk

ME ASSOCIATION, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks., MK18 4DF. 01280 818968.

Information Line: 0870 444 1836 (10am to 12noon, 2pm-4pm & 7pm to 9pm – every day) www.meassociation.org.uk/

BRAME: (Blue Ribbon for the Awareness of ME) 30, Winner Avenue, Winterton on Sea, Great Yarmouth, Norfolk. NR29 4BA. Tel/Fax - 01493 393717. The BRAME campaign was launched to create a greater awareness and understanding that ME is a very real and debilitating illness. www.brame.org

CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION:

2 The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. www.cfsrf.com

M.E. Research UK: The Gateway, North Methven Street, Perth, PH1 5PP. 01738 451234 www.meresearch.org.uk/

NATIONAL ME SUPPORT CENTRE: Disabled Services Centre, Harold Wood Hospital, Romford, RM3 9AR.
01708 378050 <http://www.nmec.org.uk>

The 25% ME GROUP: Simon Lawrence, 4, Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ ME Group for the Severely Affected ME sufferer. www.25megroup.org

CHROME: (Case History Research on ME), 3 Britannia Road, London SW6 2HJ. 020 7736 3511 This charity was set up to identify as many severely affected ME sufferers as possible in the UK and monitor the course of their illness over 10 years. The study will supplement medical research into the condition.

TYMES TRUST (The Young ME Sufferers Trust): P.O. Box 4347, Stock, Ingatestone, CM4 9TE, Advice line 0845 003 9002 (Mon-Fri 11-1 or 5pm-7pm). www.tymestrust.org

AYME: Association for Young People with ME, Box 605, Milton Keynes MK2 2X. 08451 232389. www.ayme.org.uk

INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS): help with NHS complaints: 0845 120 3735

COMMUNITY LEGAL ADVICE: 0845 3454345 www.communitylegaladvice.org.uk

www.writetothem.com - type in your postcode to find out who is your MP/MEP/councillor & how to contact them.

The Pensions Advisory Service (TPAS): 0845 6012923 www.pensionsadvisoryservice.org.uk

The Pensions Ombudsman: **020 7630 2200** www.pensions-ombudsman.org.uk/