



Bury/Bolton ME/CFS Support Group

**7 Burghley Drive,
Radcliffe,
Manchester,
M26 3XY.**

September 2010

We are delighted to tell you that we have been awarded £728 from Bolton Adult Services via the Bolton CVS for a carers pub lunch. Thank you to everyone who sent in emails in support of the suggestion.

Some people preferred a pre-Christmas lunch and some people preferred a meal in February, so we will offer you the choice of dates.

It will probably be necessary to have several dates, as we would not be able to fit our usual large crowd in a pub all on the same day.

Please return the tear-off slip below, to Pam Turner at the above address, indicating your preference of date, so that we can approach the pub with some realistic idea of numbers for booking purposes.

We will probably combine the December social on Monday 6th December for our first outing and have a meal at 4pm at the Sparking Clog.

The options for February would be Sunday Feb 6th at 3pm or Sunday February 20th at 3pm, at the Ainsworth Arms on the Bury & Bolton Road.

.....

Name of Member..... Age.....

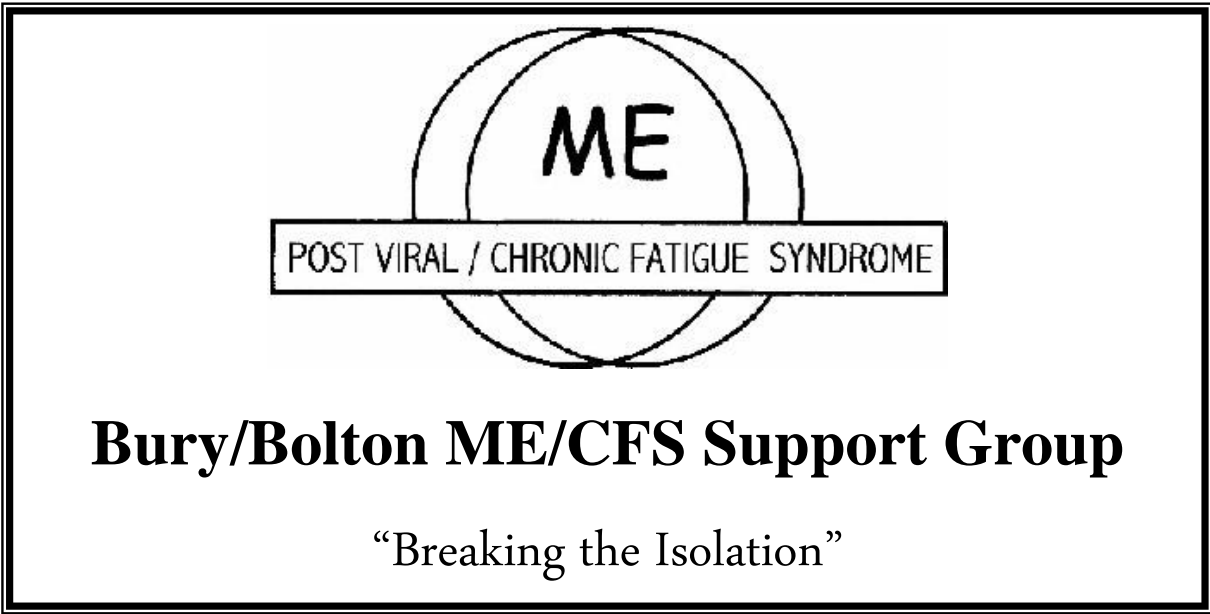
Name of Carer..... Age.....

Address.....

.....Postcode.....

1st Choice of Date.....2nd Choice of Date.....

(Please give an alternative date if possible, so that if too many people opt for the same date, we have some flexibility. We would anticipate that a pub could only accommodate approximately 25-30 people at a time.)



Issue: 52

September 2010

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	07919 234256 Dave@ mesupportgroup.co.uk
Librarian:	Carole Senior	01942 810320 carole.senior@tiscali.co.uk
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 andmk1@googlemail.co.uk

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.

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 16th September 2010 – Petra Barlow, holistic therapist.

Petra's 16-year-old son has ME and she will speak about their experiences of various treatments. Petra has very kindly offered treatments to carers at a 50% reduction. She offers massage, Reiki, aromatherapy, Indian head massage and Hopi ear candling, among others.

Thursday 21st October 2010 – To be confirmed.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 4th 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 7th 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 01706 829488, or olivia@oliviayoga.co.uk for more information.

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

Email Newsletters: This year's membership renewals saw a large increase in the number of people opting to receive their newsletters by email rather than post. Thankyou to everyone who has done so; this saves us a considerable amount of time and money. If anyone else would like to try this, but is concerned they might not like it, don't worry, if you prefer the old way we would be more than happy to change you back. To opt in, email: Dave@mesupportgroup.co.uk.

The Rough Guide to Accessible Britain

The latest guide is now out and once again is **FREE** to anyone who has a Blue Badge or receives DLA Higher rate Mobility (normal cost £6.99). To order your copy: phone **0800 9537070**, or visit www.accessibleguide.co.uk.

At last a breakthrough!

I'm really excited, and this time I think I've really cracked it. I've had CFS/ME for 7 years, and for 7 years I've looked for a cure. I've tried loads of different treatments and most of them didn't work. The best ones were management techniques such as pacing, cognitive behavioural therapy and sleep hygiene. However, they were never going to cure me.

I've spent thousands of pounds on prospective cures, and although disheartened I never intended to stop doing something to get better. Word-of-mouth is always good and that a support group I'd heard about an excellent doctor. In late 2009 I made sure I got a referral to his practice and things got better from there. He recommended that I take low-dose naltrexone (LDN) and I started doing this in March. The idea with LDN is to slowly increase the daily dosage over time as there is limited research into its effects. I was told that it could kickstart my immune system and help me fight off the infection I probably had.

Whilst taking LDN, I took a daily diary of my symptoms and noted that I was swinging from good to bad health as per normal. I almost gave up taking it, when I got the go-ahead to increase the dosage even more. The effects were immediate and startling. I felt human again and could do much more than I used to do. My family were amazed that the real me had reappeared!

At the same time, I was also encouraged to take a blood test, which would test various aspects my cell's energy production. When the results came back I was delighted to find that there were a number of problems. For example, I had a low level of Glutathione. This substance fights off free radicals and is an antioxidant. The test also revealed problems affecting different genes and their ability to either protect from infection or efficiently produce energy. As a result, I was asked to take 3 other supplements in addition to the LDN. However the effects of the supplements would take time to have a positive effect.

I'm really optimistic for the future and I'm delighted that there is a biological explanation for my symptoms. I'm already thinking about reclaiming the life I used to lead, but I know that I'll have to build up my ability slowly and surely. I'm also relieved to know that it's not "all in my mind".

My opinion of chronic fatigue is that the syndrome really is a collection of different health issues which are likely to be unique in each patient. Therefore, it's important anyone with chronic fatigue to go much further in terms of continuing to test and rule out everything until they find a positive cause. Only then can you take real curative treatment and get back on the road to a rich and happy life.

If you need more information about my experience I'm happy to discuss what I've just been through. Please contact me, Andrew, via e-mail: andmk1@gmail.com or call me on 07933 922375.

Editor's Comment: Please note, that Low Dose Naltrexone is not the answer for everyone. We are aware of a number of our members who are taking it or who have tried it - as with many other treatments, some are finding it helpful, some found it unhelpful and others found that it made them worse.

Art Classes

The popularity of the visit by Hugh Templeton to teach us to paint was discussed at the committee meeting.

If anyone would be interested in a series of 6 lessons on a bi monthly basis please contact Pam by phone or by email to Dave. If enough people show an interest we will try to arrange some sessions.

The Lightning Process

During the course of the year I have been able to listen to a talk by Derek Vernon at SMEG (March 2009) and to read two articles (Dave Swindells/Jean Holt and Hayley Misell) in HERMES about the Lightning Process. I would now like to put forward an opinion from someone who has done the Lightning Process, but has seen no benefit from it.

I did the Lightning Process in May 2009. And even during the three day course I noticed an improvement in how I felt, both mentally and physically. Immediately afterwards I was lucky enough to spend two weeks at the home of a good friend (who said she noticed a positive difference in me) and then spent two weeks on holiday, an occupation which has always made me feel better! After that I returned to my "everyday life", using the Lightning Process technique as instructed by my practitioner on the course.

The first two weeks there was a definite improvement in my symptoms. I could measure this empirically by how much more I was getting done, compared with two months previously. However, there was never any "take up thy bed and walk" effect; I still couldn't tolerate alcohol, loud noise and busy places and I didn't take up break-dancing; I was just planning and using more of my time more effectively. I also worked hard at implementing the Lightning Process in my life. Then during the third week, I noticed that my symptoms were returning. It started with an inability to order my thoughts and then tiredness crept back in. I'd set myself a list of goals to be achieved every day, from simple things like not sleeping during the day and doing the dishes to more taxing activities like searching the internet for information about a possible new career.

As the days went past the symptoms got worse and, one by one, I failed to achieve my goals. I seemed to be sliding down a slippery slope with no way of stopping myself, not even using the Lightning Process. Finally, one Monday, I slept all afternoon on the sofa. The exhaustion, along with the aches and pains and the mental fatigue were all back. The arrangement with my LP practitioner was that I could have two follow up sessions on the telephone, so I felt it was time for the first of these. And here I was in for a rude shock. My practitioner, whilst so good at putting across the LP theory and practice on the course, seemed totally unable to realise the seriousness of my condition and, in my opinion, dismissed the problems I was experiencing out of hand. A second telephone conversation a week later was equally disappointing, with the practitioner's suggestions for what I should be doing having no relevance to my symptoms and what I was capable of.

I continued to deteriorate until I was actually worse than I was before I started the training programme. It got so bad that I had to return to my parents' to be looked after and I didn't pull myself back to my "normal" level of CFS/ME until after a winter holiday in Thailand. And since then, regrettably, I find myself in the same

condition as before I did the Lightning Process, the techniques of which have now joined my long list of “things I would do if I could find the energy“.

However this does not mean that I would write off the Lightning Process as a means of tackling CFS/ME. It is wrong of LP sceptics to say that the Lightning Process treats ME as a psychological illness or “all in the mind”. That is certainly not the case. However, I would say that the relationship between patient and practitioner IS important. Having been wrongly diagnosed with depression in the early days of my ME, and having been on the merry-go-round of never seeing the same doctor for more than six months, I have experience of too many psychologists and doctors and I know that a good relationship between health practitioner and patient is fundamental to the effectiveness of ANY treatment. Research into the placebo effect also shows this to be true. Also, I think that worries about the “secretiveness” of the Lightning Process are entirely unfounded. Many people, myself included, have spent a lot of money on ineffective medicines and professional advice and are very wary of throwing good money after bad. Even so, you cannot expect to understand everything about a possible cure; at the end of the day you either take a leap of faith or you don't.

My criticism of the Lightning Process professionals is that LP is surely marketed too much as a “miracle cure”. No wonder many people are sceptical. I can't believe that everyone else as has had an easy ride to improved health, whilst I alone have had to face, for me, too severe difficulties. Recovered ME sufferers might well bear this in mind too; not everyone will have the “easy” ride that they have had. A second criticism is that not enough attention is paid to post Lightning Process support. Don't get me wrong, there is some support on offer, but I do think that the needs of individuals need to be tailored for. In my opinion, the Lightning Process shouldn't be a three day course with optional monthly meetings afterwards, run by private practitioners with no accountability, but an NHS run and monitored scheme which offers support on a long term basis. Hopefully one day we will get there.

So would I recommend the Lightning Process? I think everyone has to make their own decision about doing this training programme. But if you do decide to try it: DO ask about what support you can expect after the Lightning Process has finished. DO take along a parent, your partner or a close friend. You may well need someone who knows exactly what the Lightning Process is about to support and encourage you when your LP practitioner has signed you off, or if, as in my case, that relationship breaks down.

DO be open-minded and positive about the Lightning Process, but DON'T concentrate on the miracle stories - you might not be one of them and the way back to health might not be short and straightforward.

Jon Clements

From ‘Hermes’, with thanks to Stockport me Group, for their kind permission

Bury Neuro Support

Linking Listening Informing Speaking out

invites

People with any neurological condition or
injury and their carers/relatives to a

Special Open Meeting

Neuro Services for Bury, Oldham and Rochdale

Thursday 9th September 2010

4 – 6 pm

The Kay Room, Bury Parish Church BL9 0LA

Speakers from Neurosciences Centre, Salford Royal,
Pennine Acute Trust and Greater Manchester Neurological Alliance

**Come and hear about the latest developments and share
your views and experiences**

If you would like to attend please ring or email us and let us know.

Please note office closed for staff holidays 16th – 30th August 2010

Tea, coffee & biscuits provided – costs covered by raffle

GMNA, Innovation Forum, Frederick Road, Salford M6 6FP
Tel: 0161743 3701 Email: info@gmneuro.org.uk Website: www.gmneuro.org.uk

Registered Charity No 1098127

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. When they relaunch in September, after their summer break, both groups will be expanding to include service users from other nearby areas.

Bury Neuro Support currently meets most 2nd Thursdays 4-6pm at Bury Parish Church Hall but, if there is enough interest, may extend to **Oldham and Rochdale** and perhaps rotate meetings through these areas. Discussion of this and Pennine Acute Trust Services at the 9 September meeting.

Neuro Support 4 Salford will now include **Manchester & Trafford** and meets most 4th Fridays (11am-1pm) at BASIC, 544 Eccles New Road, Salford, M5 5AP.

Call 0161 743 3701 or visit www.gmneuro.org.uk for information about either group.

Bolton Neuro Voices are keen to welcome ME/CFS group members to an important review of local neuro services at 11am-1pm on Wed 8 September at Friends Meeting House, Silverwell St, Bolton BL1PP. More information from Vicki (01204 418668) or Marie (01204 594004).

GREATER MANCHESTER NEUROLOGICAL ALLIANCE

NEURO SUPPORT 4 SALFORD

Linking Listening Informing Speaking out

NEXT MEETING

Friday 24th September 2010 at 11am-1pm

The Neurocare Centre, 554 Eccles New Road, Salford M5 5AP

STOP PRESS

Re-Launch of Group – 24th September 2010

Neuro Support 4 Salford, Manchester & Trafford

“Benefits”

Attendance Allowance
Disability Living Allowance
Carers Allowance

Speaker Phil Carter - Partner Liaison Manager

Manchester Central Local Pension Service

Neuro Support 4 Salford is to include residents from
Manchester and Trafford from September 2010

Notes to remember: This group will not be meeting July/August 2010

Tea/Coffee provided – costs covered by our monthly raffle

**Something new for U if you have a neurological condition
or injury or care for someone who has**

You may be: Younger or older Diagnosed recently or some time ago
Confident or shy Busy or with time to spare
Keen to meet others or just wanting to stay in touch

Whatever your situation, please get in touch or just come along to our next meeting!

**For further information, please contact Yvonne Trace
GMNA, Innovation Forum, Frederick Road, Salford M6 6FP**

Tel: 0161 743 3701/2 Fax: 0161 743 3530

Website: <http://www.gmneuro.org.uk> Email: info@gmneuro.org.uk

Registered charity no. 1098127

Benefits & Work Guides

Our group has renewed its membership of www.benefitsandwork.co.uk, allowing us another year of access to their fantastic guides to a range of benefits and disability related issues.

The guides 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. The group's subscription allows us to make these guides available to our own members. Please look through the list below and if you need anything phone Dave on 07919 234256 or email dave@mesupportroup.co.uk.

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. After each guide listed below, is the number of pages in brackets, 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 a friend or relative 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 have some of the more popular guides in our library at the meetings, but if you can't see what you need please ask. 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), if you can afford to make a contribution towards the costs, it would be very much appreciated.

DLA & AA

The best possible Attendance Allowance claims on physical health grounds (44)
The best possible Disability Living Allowance claims for adults on physical health grounds (61)
The best possible Disability Living Allowance claims for adults on mental health grounds (53)
The best possible Disability Living Allowance claims for children on physical health grounds (65)
The best possible Disability Living Allowance claims for children on mental health grounds (58)
70 questions you are likely to be asked at your DLA medical (5)
The best possible way to challenge a DLA or AA medical report (28)
The best possible support for clients with DLA and AA appeals (41)
Appealing against a DLA decision (16)
Giving persuasive information about how far you can walk (13)
Challenging the claim a bottle or commode will replace the need for help (8)
DLA renewal claims (6)
Changes of circumstances for people claiming DLA (8)
Letter claimant to decision maker requesting reconsideration because of additional evidence (3)

Incapacity for Work

The best possible incapacity for work claims on mental health grounds (43)
The best possible incapacity for work claims on physical health grounds (48)
Exempt but sent a questionnaire (7)
60 questions you're likely to be asked at your incapacity medical (3)

ESA

Understanding Employment and Support Allowance (43)
ESA claims for mental health and learning difficulties (88)
ESA claims on physical health grounds (65)
ESA appeals (35)

Permitted Work (6)
Knowing Your Rights at Pathways to Work Interviews (12)
Work Capability Assessment Score Sheet (12)

Other

If I do any work can I continue to claim my...? (4)
Caution, it may not count as voluntary work (5)
Am I covered by the Disability Discrimination Act? (9)
Which benefits can I claim? (9)
Reasonable adjustments: Employers and Jobseekers (8)
Work and benefits for people with long term health conditions (7)