



Welcome to Our April 2012 Newsletter

A Note from Alex: I'd like to thank everyone who attended this year's AGM (and also a big thank you to Sue & Paula Stephenson for also donating 2 lovely prizes to go along with the prizes I collected and we managed to raise £42). To be able to run our support group we have to hold an AGM therefore it was more formal than our usual meetings. You will find, in this months newsletter, all of the information from our AGM which include: the minutes, the group

leaders report and the secretary's report. Please remember there is no meeting at Longsight this month.



Today, she adhered exactly to the exercise programme her GP set her. Trouble is, she didn't manage to adhere to his predicted outcome ...

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 Aprils Newsletter

About Bury/Bolton ME/CFS Support Group & Sponsors	Page 2
Dates for Your Diary	Page 3
Bury/Bolton ME/CFS Support Group AGM March 2012	Page 4
Group Leader's Report	Page 5
Secretary's Report	Page 5
Time for Action Campaign	Page 6
DWP Starts Calling ESA Time-Limit Claimants	Page 7
Our Tips on Benefits Appeals	Page 8

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, Alex Wootton, Carole Senior, Maria Sale, Lynda Marney & Phil Seddon

Support Group Posts & Contact Information:

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**Supported by:
Health for Bolton and the
Big Bolton Fund 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.

Please note that there will be no meeting in April.

Thursday 17th May – Debbie McIntosh, who is a nutritionist. She will explain why good nutrition is so important in this disease, and for everyone

Thursday 21st June – Philippa O’Callaghan, from the Red Cross. she will explain their equipment loan service and their carers' care scheme (the latter runs in Bury only at the moment).

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 14th May 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 **2:45pm-4:00pm 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 the next two Radcliffe Socials at the Sparking Clog are to be held on the 2nd Monday of the month due to the usual Monday’s being Bank Holidays.

Thank you to everyone who has already returned their membership renewal forms to us. For anyone who hasn’t already done so, please don’t forget. If you can’t remember whether or not you have renewed, or have lost your form and need another, you can call Phil Seddon on 01204301713 or email phil@mesupportgroup.co.uk .

Bury/Bolton ME/CFS Support Group AGM

March 2012

Our March meeting was, as usual, our AGM. It was lovely to have a turn out of 27 members who all enjoyed the social and raffle which followed the formalities.

Thank you all so much for coming along to support your committee and of course each other.

Thank you also to those of you who sent their apologies and postal votes, although one or two forgot to put their names on them.

The postal votes are very important because when we ask for grants the sponsors like to know that we truly represent all our members and ask how we keep in contact.

Thank you all once again for your support during my time as Group Leader and I hope that you will continue to support your committee.

Love to all of you.

Pam

15th March 2012 Bolton/Bury ME/CFS Group

AGM Minutes

Present: Pam Turner, Sue Forshaw, Pat McKenna, Tracey Morris, Ann Richards, Yvonne Leech, Alexandra Wootton, Shirley Wootton, Sue Stephenson, Paula Stephenson, Carole Senior, Lynn Wright, Phil Pearson, Amanda Gore, Gill Mesce, Sara Drage, Diane Knowles, Melanie Bainbridge, Ann Lindsay, Angela Cassidy, Phil Seddon, Lynn Seddon, Lynda Marney, Jean Longworth, Dorothy Sheppard, Galena Steels & Susan Courtney.

Apologies: Bernie Bateman, Christine Farrington, Rohinton Bakti, Mike Parnell, Rosalind Smith, Mark Smith, Angela Glendinning, Neil Glendinning, Tom & Lois Nicholson, Caroline and Ste Higson, Mike and Christine Barnes, Andrew Levy, Shirley Horrocks, Karen Ruth Markovitz, Chris Hill, Maria Sale, Sarah Bainbridge, Karen Scull & Hilary Smith.

1. Minutes of last AGM held on 17th March 2011 - The minutes of the previous AGM were accepted as a correct record.
2. Matters Arising - There were no matters arising from the previous minutes.
3. Secretary's Report - Pam read out the Secretary's Report.
4. Financial Report - Lynda presented the accounts and Treasurer's report.
5. Group Leader's Report - Pam read out the Group Leader's report which had been circulated to all members and which contained the information that she would step down from the Group Leader and Secretary positions with immediate effect. She would continue as a committee member. The Committee members will discuss the way forward in regards to the processes and responsibilities for dealing with day to day business at the next committee meeting
6. Election of Committee - There were no further nominations for membership to the committee. Yvonne Leech proposed and Sue Forshaw seconded the proposal that the six members standing for the post of committee member be accepted and all voted in favour. The elected members are: Pam Turner, Alex Wootton, Carole Senior, Maria Sale, Lynda Marney & Phil Seddon.
7. Appointment of Honorary Auditor - Alex Wootton proposed and Lynda Marney seconded the proposal that the Honorary Auditor should be Lisa Fletcher for the coming year. All voted in favour of the motion.
8. Any Other Business - There was no other business.
9. Date and Time of Next Meeting - The next AGM will be held at 7.30pm on Thursday 21st March 2013.

The meeting closed at 9.00pm following a raffle and social event

Group Leader's Report AGM 15th March 2012

It is with a mixture of sadness and relief that I take the opportunity to say thank you to all our excellent committee members and helpers. Sadness because from tonight I shall no longer be continuing as group leader; I can honestly say that it has been both a privilege and a pleasure to have such an honour. Relief because as I get older, my own health is deteriorating and I know that I cannot continue doing quite so much. The committee members have all been wonderful and have rallied round to ensure that I am not over burdened and I thank them for all their care and consideration.

There will be more changes on the committee this year as several members will also be standing down. Kim has done a wonderful job as treasurer but is not able to continue, so she leaves with our very grateful thanks and we welcome Lynda who has kindly agreed to take on the task. Kim is happy to remain as Parents Contact. Dave is also unable to continue and we cannot thank him enough for all his past commitment; we are again fortunate that Alex has volunteered to take on the task of organising the newsletter and Phil has agreed to be our membership secretary. Margaret, our minutes secretary, Ann and Sheila are also unable to continue due to ill health but will continue as helpers rather than committee members. Our grateful thanks for all your efforts in the past.

Once again Maria has done a good job of bringing us interesting speakers, thank you Maria. Carol has done a grand job as librarian and will be joining the committee as minutes secretary, thank you Carol.

A big thank you to Pat, our lovely tea lady and unofficial "agony aunt" and to Sue our door lady. Thanks are also due to some of our "back room boys and girls" who do various necessary but often unrecognised jobs, so thank you Angela and Phil for ensuring that the libraries get their supply of leaflets and posters. Thank you to Andrew for writing us many interesting articles for our newsletter, to Caroline for keeping our Website up to date and to the mentors for our chat room and Facebook site. A very big thank you to Hilary for doing my typing and for completing application forms for the grants we have been awarded.

Yvonne has been a mainstay of this group for many years and despite poor health has continued to help and support me by attending many meetings to ensure our profile remains high and our voice is heard, many thanks Yvonne.

We had thought that we would have to change venue but have been assured that although the building we now use will be demolished we will be able to continue our meetings here at Harwood Methodist Church.

Finally thank you all for making my time as group leader both fulfilling and enjoyable. Thank you for supporting one another and please keep on supporting your group.

Secretary's Report AGM 15th March 2012

This year has been, once again, both busy and eventful, we now have over 180 members.

We have had our usual 9 meetings at Harwood Methodist Church which have included several social evenings and our ever popular and enjoyable pre Christmas bring and share supper. The speakers at our evening meetings have been varied and interesting especially the talks by the curator of the natural history exhibits at Bolton Museum, and Sara Kirkman, the Occupational Therapist from our local ME Clinic. Our book swap/sale was a new venture and as such was successful also the card making was much enjoyed.

Yvonne and Pam have continued to attend the multidisciplinary team meetings with the Bolton/Bury ME Clinic staff and have been very reassured by their dedication and determination to ensure the future of the service.

Amazon.

Don't forget if you are buying anything from Amazon our 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.

Secretary's Report Cont...

Many of our members have either been interviewed or have joined a patients group in order to help with a research project by staff at Manchester University. The METRIC (ME Training and Resources in Primary Care) project aims to develop an on line package for GPs so that they can diagnose ME accurately and confidently. This will be a three year project and the resources being developed will be introduced and, hopefully, used in the coming year so that an evaluation can be undertaken in the final year. Professor Dr Carolyn Chew-Graham came to our February meeting and gave us an interesting, informal update on the research project and answered questions.

Our Social Meetings at the Sparking Clog on the first Monday of the month have been continued and have a regular number of members joining in. However the Bury Social meetings have been temporarily suspended due to ill health.

We have been extremely fortunate again to offer our weekly Yoga sessions free of charge thanks to grants from 1. Manchester Guardian Charitable Trust; 2. Comic Relief via Manchester Community Foundation and 3. Health for Bolton and the Big Bolton Fund via Bolton CVS. We cannot thank these organisations enough for their generosity in these difficult times.

Once again we were very fortunate to have been awarded a substantial grant from Bolton CVS to enable us to have a lovely Carers Outing Christmas Party.

As well as our website we have a new venture on line with our Facebook site and I am assured that it is going well.

Time For Action Campaign – by Tracy Morris

As reported in our last newsletter, Action For ME (AFME) have launched a campaign for anyone who believes that there is still too much ignorance, injustice and neglect of ME within society generally and, more specifically, within Government, NHS, Dept of Work & Pensions etc. The “Time For Action” campaign is open to everyone. Sufferers, carers, family, friends, neighbours etc are all invited to take part by signing either the simple online petition or the postal alternative (hopefully enclosed) to indicate the strength of feeling surrounding the current ME situation. AFME hope to reach a target of at least 10,000 votes by ME Awareness Day (Sat. 12th May) in order to achieve maximum impact. The campaign will act on several fronts:

Ignorance: People do not understand how chronically disabling a condition ME is. This can include immediate family members, society generally and the people making decisions on our behalf e.g. NHS, Government. etc. We still do not know what causes ME or how to cure it.

Injustice: People are not getting the welfare support/social care they are entitled to and are at risk of losing benefits. Most lose their jobs due to ill-health. No other illness affects so many people in such a devastating way with so little money spent on specific research or provision of healthcare.

Neglect: 250,000 people in the UK are affected by ME but successive governments have done little to address the situation. Many patients are isolated and abandoned by the medical profession and social services. Too little research has been undertaken that may help find the answers we need.

AFME aim to campaign to highlight all of the above until the Government commits to putting things right. They also aim to invest in pilot studies to increase scientific research on the biology of ME, will continue to offer support to those with ME through their online ME centre and telephone support lines, and will launch new services to educate GPs, employers, teachers etc regarding the illness. AFME need our support to register the strength of our disapproval at the current situation. The members of the All Party Parliamentary Group (APPG) have been alerted to the campaign in order to further increase pressure on the Government.

If you agree with the above, you can register your support now online at: www.actionforme.org.uk/time-for-action (Twitter and Facebook options also available), or use the postcard supplied with our postal newsletters. Additional postcards are available at our group meetings or direct from AFME on **0845 123 2380** or **0117 927 9551**. (They advise that photocopies are acceptable. This may be easier if you are sending a few in a stamped envelope as they will be less robust than the originals). Please inform your friends and family and enlist the support of anyone who has seen your struggles with ME first-hand.

Time for Action Campaign Cont...

The more people who support this campaign the more successful it is likely to be. I can't remember the last time there was a national campaign of this nature (although I may have missed it!), but it certainly isn't an everyday occurrence.

PS. The NICE guidelines are due for review next year. The more people are aware of the problems faced by those with ME in the run up to this process, and the more facts and figures the national charities/MPs etc have to argue their case, the more likely they are to succeed.

If you know of any other surveys/campaigns or petitions that you think may be of interest to others please contact our committee members with the details. In this way we can inform anyone who would like to have their say.

Other Campaigns by AFME.

AFME are campaigning to get the Government. to suspend the Work Capability Assessment (WCA) programme for those with fluctuating conditions such as ME. An independent review has acknowledged the concerns of AFME and other disability campaign groups that the WCA is failing people with certain conditions and resulting in the unnecessary suffering of having to go to appeal. Information on this and other campaigns can be found at **www.actionforme.org.uk/currentcampaigns**

In addition, AFME are asking all PCTs to identify the current level of provision offered for ME (and to compare this with provision over the last 3 years). The initial figures suggest PCTs are failing patients but a full report is to be prepared when all the figures are in.

DWP Starts Calling ESA Time-Limit Claimants

from Work & Benefits March Newsletter.

The DWP has begun telephoning claimants whose employment and support allowance (ESA) is due to end because of the time-limiting of contribution-based ESA for claimants in the work-related activity group (WRAG). Payments will cease for some claimants from 30 April 2012.

Claimants are now only entitled to 365 days of contribution-based ESA if they are in the WRAG. Time spent in the assessment phase which is immediately followed by being placed in the WRAG counts towards the 365 days. The new rules are retrospective, meaning that people who have already spent a year in the WRAG on contribution-based ESA will lose their benefit from 30 April unless they are entitled to income-related ESA.

Claimants in the support group will not be affected and payments of income-related ESA will also not be stopped.

The first payments are due to end on 30th April and the DWP have begun telephoning claimants whose payments are expected to end between 30 April and 3 June. They are being informed of the ending of their payment and asked if they wish to apply for income-related ESA.

Claimants whose payments are due to end after 3 June will be given eight weeks' notice.

Income-related ESA is means-tested. Claimants who have too much income (depending on their circumstances), capital of £16,000 or more or whose partner works for 24 hours a week or more are unlikely to qualify for income-related ESA.

The DWP claim that around 60% of those affected by the changes will be entitled to some income-related ESA.

Claimants whose condition has worsened may be able to ask for their award to be looked at again if they consider they should now be in the support group, where the time limit does not apply.

Newsletter Articles

Please carry on sending us anything you would like to share with the rest of the group, whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Please send your contributions to: alex@mesupportgroup.co.uk, or if you are unable to email, post to Alex Wootton 49 Lepp Crescent, Brandlesholme, Bury, BL8 1HX

Our Tips on Benefits Appeals

We often get asked for advice by members who are facing the DWP appeals system, either because they have been refused ESA/DLA or because they feel they have been awarded the benefit at the wrong level.

With the increasing numbers of people being migrated from Incapacity Benefit to Employment Support Allowance, the number of appeals waiting to be decided has grown to the point where waiting times have grown significantly. Not only does this leave the claimant suffering ongoing hardship, but with the new rules time-limiting contribution based ESA to a year for those placed in the Work Related Activity Group rather than the Support Group (who can continue receiving ESA after 12 months), we are even hearing from members who's benefit will run out before they reach their appeal date.

If you are in this sort of situation you might want to consider writing to your MP to ask for assistance. This sort of thing is well within their remit and they can be brilliant at helping to sort everything out quickly without the need to go to tribunal.

We cannot stress enough though, that is very important to have your own medical evidence that demonstrates why you should be entitled to either ESA or DLA at the correct rate. If you don't have medical evidence to prove your point then you are unlikely to make any progress via this route. Keep in mind that your MP might not be familiar with the exact qualifying criteria, so you need to explain simply and clearly why you disagree with the DWP's decision, the ways in which the ATOS medical report is inaccurate (if that is the case) and how your own medical evidence demonstrates this. You could also explain to them what stress and hardship the ongoing situation is causing you and the problems with waiting so long for the process to take its natural course.

MPs have to reply to their constituents. Some are better than others when it comes to wanting to help, but it is well within their powers and if they are reluctant at first don't be afraid to push them. The reason they are so effective is that the DWP has to respond to an MP promptly. Sometimes the DWP will reply to the MP with the standard speech (that you have probably already had) which the MP will relay to you. If that happens, you can write back to your MP again telling them why you are not satisfied with that response and get them to convey that to the DWP - at which point the DWP will generally do something.

Don't forget to read through the brilliant Benefits & Work guides on claiming and appealing, they really are full of fantastic advice. Our group has subscribed to Benefits & Work so that you don't have to, so if you need any of the guides please contact Phil Seddon on 01204301713, or email phil@mesupportgroup.co.uk.

There is also a lot of valuable information on their website, but most useful of all is their forum www.benefitsandwork.co.uk/forum. Here you will find postings from people who've had similar problems and there is never a shortage of helpful advice and solutions - and if you sign up you can post your own questions.

Another useful resource is the Disability Rights Handbook, published annually by the Disability Alliance and available directly from them (www.disabilityalliance.org, 020 7247 8776). There is a copy of it in our own library at our meetings, or you could ask at your local library. Although it doesn't go into as much detail as the Benefits & Work guides on some areas, it has information on the whole range of benefits – and if you do find yourself in the unfortunate situation of having had your money stopped, it can help you understand what else might be available to you. For example, once contribution based ESA has run out, you might be entitled to income related ESA (similar to Income Support) but the qualifying criteria are much stricter and it is often unavailable to people who have a partner who works – all the more reason for those people who should be eligible for the ESA Support Group to be correctly placed so that they can continue to receive the benefit indefinitely (subject to the usual ongoing reassessments).

Please note that the advice in this article is only intended as general guidance and although we have done our best to make sure it is accurate, it should not be relied upon in place of proper expert help and advice. Your local Welfare Rights or Citizens Advice Bureau are there to help you will all benefits and appeal related matters.