



**Issue: 50**

**July 2010**

**[www.mesupportgroup.co.uk](http://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        |  |
| 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<br>(after 12noon)                       |
| Web Master:                                       | Caroline Higson   | 01204 525955<br><b>caroline@mesupportgroup.co.uk</b> |
| Membership Secretary, Newsletters & Distribution: | David Gore        | 07919 234256<br><b>Dave@ mesupportgroup.co.uk</b>    |
| Librarian:  | Carole Senior     | 01942 810320<br><b>carole.senior@tiscali.co.uk</b>   |
| Door at Meetings:                                 | Sue Forshaw       | 01204 883506   |
| Roving Reporter:                                  | Andrew Levy       | 0161 798 6183<br><b>andmk1@googlemail.co.uk</b>      |

**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.

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**Community Foundation for Greater Manchester**

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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 15th July - Hugh Templeton** will conduct his ever-popular watercolour workshop. You won't need any materials, and should go home with a completed painting.

**Please note there will be no meeting in August.** The next meeting will be Thursday 16<sup>th</sup> September, details to be confirmed.

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 2<sup>nd</sup> 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. For more information please phone 07919 234256 or email [dave@mesupportgroup.co.uk](mailto: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 5<sup>th</sup> August, 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](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](mailto: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. 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-1pm) at BASIC, 544 Eccles New Road, Salford, M5 5AP.

Call 0161 743 3701 or visit [www.gmneuro.org.uk](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.

**For anyone who hasn't already done so, please don't forget to send in your membership renewal forms. If you do not renew, this is the last newsletter you will receive, also you will not be eligible to attend the 20<sup>th</sup> Anniversary meal. If you have forgotten whether or not you have renewed, or have lost your form and need another, please call Dave on 07919 234256 or email Dave@mesupportgroup.co.uk.**

## **Bolton/Bury ME Support Group Meeting, June 2010:**

Several times each year, instead of having a guest speaker at our Longsight meeting, we have a social - and our June meeting was one such occasion.

Although our guest speakers are always very interesting and attract a lot of questions from the audience afterwards, once they have finished people are always very keen to talk amongst themselves – often to the point where we are trying to clear chairs from under people in order to vacate the hall on time! For many people, especially those who do not attend our informal Radcliffe or Bury socials, or use the internet to keep in touch, this is a very valuable opportunity to share experiences with other people with ME/CFS. So it was nice for everyone to be able to have a good long chat this time – and of course enjoy some delicious cake!

It is always useful to swap stories about our experiences, whether that be symptoms, latest treatments/medications, benefit applications, or employment problems – and if anyone has a specific problem they need support with, there is always someone there who can help. This is particularly beneficial for our newer members, but can be very worthwhile for our longer term members too – perhaps you have reached a point where any issues you have had have been resolved as best as can be, but you may find it a very therapeutic experience to talk about this with newer members, in order to try and help them avoid any of the stress, troubles, or pitfalls that you might have endured.

Of course, we don't just talk about ME, so if you want to take your mind off things this is also the place to be. We talk about anything and everything, but it is good to be able to do so in an environment where people truly understand us and our needs

Added to that, with our library full of very useful books on a wide variety of helpful subjects, available to borrow, these meetings really are beneficial to all who attend.

For anyone who has never been to one of our Longsight meetings, perhaps you might consider it in future.

**For anyone who wants to attend the group's free 20<sup>th</sup> anniversary meal in September, don't forget to send your booking form to Pam as soon as possible .**

**We have copies of a Tymes Trust publication: "The GPs Good Guide to Education for Children with ME". If you would like one of these please contact Dave.**

## **PACING V WORK: THE IMPOSSIBLE DILEMMA?**

*In our last issue, clinical specialist physiotherapist Peter Gladwell responded to InterAction readers' thoughts and experiences of exercise. He and his colleague, specialist occupational therapist Bev Knops, now turn to a letter from Ed who, like many people with M.E., is forced to balance his illness with his need to work.*

In an extract from a long, passionate and courageous letter, Ed writes: I work as a head gardener; I manage five staff and an historic garden. I do this work because I enjoy the physicality of it, or I did until a virus flattened me three years ago. I managed to reduce my hours but the job is still at the edge of what I can manage. Exercise for me is functionality.

I do only what I have to do; that was the hardest lesson. I was in a hole, getting up and going to work was like climbing a mountain every day but not doing so was even worse. The aching and lethargy just got worse with inactivity and it was that much harder to keep going if I stopped.

Weekends were the worst as my routine ceased, the opportunity and motivation to exercise was absent and I couldn't seem to find an alternative. This would leave me shattered, if with less pain, on Monday morning. As the week progressed I was able to do more until Thursday or Friday when I began to tire, leaving me shattered and in pain on Saturday.

I could walk about 150 yards on flat ground but meeting the gentlest of slopes I would slow and stop like a wave on a beach. I would work for short periods and rest my legs and that is how I coped.

In the first year I could sleep for England; my life was work, sleep, cook, sleep, work. I started to get joint pain which really scared me, mostly wrists and ankles. I would be unable to walk or pick things up or use a knife and fork. Stairs were hard. I used to go upstairs once a day, to bed, and would take them sitting, one step at a time and then rest.

I became selfish, harder to live with, but I coped by saying NO. I maximised my routine to minimise the unexpected or novel. I find new situations far more tiring. I discovered D-ribose and aching muscles no longer dominated my life!

My stamina is better, as is my strength, but some combinations are killers: bending and working, working too fast, overheating (very bad) and allowing my attention to be divided. Progress is pitifully slow but I am now more able; I can jump gates without my legs crumpling and leaving me in a heap on the ground. I have found that a low dose of an SSRI seems to help muscle stamina.

### **Bev comments:**

Despite the struggle Ed has experienced trying to sustain work; he has developed a range of useful coping strategies that may be transferable to others in different occupations.

Many of our clients consider either a temporary or permanent reduction in working hours which will minimise the risk of overexertion. This may leave enough energy to participate in other activities or at least avoid collapse on returning home after work. Obviously employees are concerned about a reduction in pay; however, it is possible to negotiate part-time hours with full pay – temporarily, anyway.

Regular rest breaks are so useful. Negotiation with employers for more frequent rest breaks, and timing these according to their own needs rather than a pre-determined schedule, may be possible. Where to take good quality rest breaks in a busy, noisy work environment? I have worked with people who successfully rest in toilets and stairwells. Personally I would prefer to retreat to my car. Use of an iPod or similar can block out background noise, and can also be used to listen to relaxation recordings during a break.

Ed writes that he coped by saying no. Being able to say no to additional work tasks, particularly when you feel pressurised to prove you can continue to work effectively, is difficult. However, we

have found that this ability, plus other communication skills are particularly beneficial in sustaining work and working relationships. Good communication with employers, and in particular line managers, is essential. It may be helpful to organise a meeting with your employer to discuss how you are currently coping and what changes may enable you to sustain work. This seems to bring greater understanding than focusing on barriers, or assuming that employers should know how to help. Remember you still have valuable work skills – don't be afraid to discuss those, too.

Ed also mentions how important having a routine has been. Pacing in the work place can be a huge challenge but the structure and routine of work can also support pacing. I have several clients who can pace beautifully at work during the week but it all goes to pot at the weekends.

[www.direct.gov.uk/en/DisabledPeople](http://www.direct.gov.uk/en/DisabledPeople) has a section on employment rights and the Disability Discrimination Act, with information on reasonable adjustments. The RADAR guide Doing Work Differently has also been helpful for many people. You can find it at [www.radar.org.uk](http://www.radar.org.uk) in the Campaigns section, or call RADAR on 020 7250 3222.

Peter adds: I agree with Ed that he does not need to be adding extra physical activity, because his job as a gardener is already demanding to the extent that he finds his work more of a struggle towards the end of the week.

I would offer Ed the opportunity to learn a gentle stretching program, which can be helpful to maintain a balance of movement and rest at the weekend, but this would be an 'optional extra' for him to consider. I would also encourage him to meet one of our occupational therapists.

*We asked other people with M.E. how they managed to cope with working. Here is what some of them had to say:*

### **Ros Lemarchand**

I was a single mother when I first became ill and had a house and mortgage. So I couldn't afford not to work. At the beginning I took considerable time off sick and reconsidered my situation.

I changed my job. I found easier and less stressful work. As travelling to work was time consuming and very tiring I decided to work nearer home. In fact, I was lucky to get something on my doorstep. I rested as much as possible before and after work.

Unfortunately that was not always possible as there were responsibilities and things that had to be done. Despite all this I still found myself having to take time off more and more until I had a complete relapse again.

I think it's extremely difficult if impossible to work with this illness due to its unpredictable and variable nature. Pushing oneself to work is not good and the long term detriment to health is usually the result.

### **Lynne Parfitt**

I have two small children so I work weekends from 9am to 6pm. Having to cope with this, sometimes, can all be too much. I do not have a great sickness record but my boss is fantastic. I told her as soon as I had the diagnosis and she is really understanding. I am a team manager of 12 people. At first I was coping really well, but then I was getting worse, so I told my team what was going on. I was super nervous, but they were brilliant and really supportive. However, that changed things as I was now known as "that" girl, and I hated this as I already had labels (mum, wife, etc) when I really just wanted to be myself.

I found that by letting people in can be hard at first, but then you have that added support network that you can rely on and, when I'm feeling rough, they can help.

### **Kate Rhodes**

For several years I worked 18.5 hours a week, but around 18 months ago I was forced to reduce to 12 hours. For the first six months there was no-one to pick up the hours I had dropped, so I was effectively attempting to do the same work in less hours. My employer wants to help, but as it is an

extremely small office it is hard for them to be flexible, and as it's a charity, I feel guilty about letting them down.

I am now struggling again, but doubt my employer can reduce my hours further as the lady I jobshare with can't take on any more hours. My doctor has done a u-turn and is no longer supportive, and the Citizens Advice Bureau have advised me that I would probably be turned down for ESA. I don't know what to do - I need to give up for the sake of my health but financially I don't know that I can. I also worry that if I was at home all the time I might become lonely and depressed.

I would recommend trying some voluntary work first in order to establish how many hours they can sustain, without having the same level of commitment as paid work. If possible, spread the hours out across the week. In paid employment, check out how much holiday you get and plan it in at regular intervals across the year. I also take some unpaid leave each year to top up my holiday allowance.

Work gets the best of me, and I have no energy left to see any friends - so don't necessarily work the maximum number of hours you can, as you also need to have time and energy left for doing something enjoyable.

### Amanda Challans

In terms of balancing work with my illness, I found that I could work from home from my bed. I struggled to lift my laptop onto my lap a lot of the time because it was quite heavy, so my employer has provided me with a super light laptop which made things much easier. I'm lucky because I have a very supportive employer, but you don't get it if you don't ask - so if there's any equipment you need, there's no harm in asking for it! Make sure you mention the words 'health and safety' and that should start the balls rolling! Most of all I think it's really important that you make sure you are working on something you enjoy, and that you take the pressure off yourself to get back to work as quickly as possible, else it will only take a lot longer!

### Anita Tovey

For pacing and work, I find restricting the amount of time I spend on my laptop essential. I do a certain amount then leave it on charge and do something else that doesn't require looking at a screen. Rest breaks even for 5 minutes are essential too.

With our thanks to InterAction



## **POTATO PANCAKES – FREE FROM GLUTEN/WHEAT/DAIRY**

1 cup of cooked mashed potatoes      ½ tsp salt      ½ tsp baking powder  
1 cup of grated raw potatoes      2 tsps margarine or veg oil

Mix all of the ingredients (except the oil/margarine) together in a bowl. Heat a frying pan with the oil/margarine. Spoon the potato mixture into the frying pan, making pancake shapes. Cook until golden brown, turning occasionally. Serve plain, or with your choice of topping.

## **NATIONAL CARE SERVICE**

On 30 March the Government released a new White Paper called "Building the National Care Service". This paper ruled out earlier proposals to change the provision of Disability Living Allowance and Attendance Allowance that had been outlined in the Green Paper "Shaping the future of care together".

Because these proposals caused a huge concern for people with M.E., Action for M.E. responded to the consultation with a national survey. The result was our Future of Care report in 2009, in which we asked the Government to "commit to keeping the current disability benefits in place especially for people with chronic fluctuating illnesses such as M.E."

Action for M.E. is pleased to read that the new White Paper "rules out any changes to DLA (Disability Living Allowance) or AA (Attendance Allowance) in the next Parliament to fund the second stage of the reform". However, we will continue to seek opportunities to ensure that the concerns of people with M.E. are taken into account as the plans progress.

**Taken from InterAction with our thanks**

**Pam Turner** says thank you to everyone who wrote or who contacted their M.P. or the Department of Works and Pensions about the suggestion of taking away D.L.A. and A.A. away from us. As you can see by the above article taken from the summer InterAction our campaign has been a success. Well done everyone.

Please carry on sending us anything you'd like to share with the rest of the group. It doesn't matter if it's a few lines or a few pages, it all counts! It could be recipes, tips, your experiences, book reviews etc. Please email your contributions to: Dave@mesupportgroup.co.uk, or post to Pam Turner (7 Burghley Drive, Radcliffe, M26 3XY). Alternatively, if you have an idea, but you prefer not to write about it yourself, then please contact Andrew (0161 798 6183 or andmk1@gmail.com) and he will discuss it with you and write it up on your behalf.

**Don't forget, if you want to share something like a poem or a newspaper/magazine article with the group, before we can publish it in our newsletter we will need to obtain permission from whoever holds the copyright - if possible it would be a big help if you could do this for us.**

## **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](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](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](mailto:admin@afme.org.uk) for general enquiries  
Welfare Rights Helpline – 0845 1228648 - Mon 9-5, Tues 9:30-12:30 & 3:15-6:45, Wed 1:30-4:30, Thurs 9:30-1:00  
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](http://www.afme.org.uk) or for young people with ME [www.a4me.org.uk](http://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/](http://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](http://www.brame.org)  
**CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION:**  
2 The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. [www.cfsrf.com](http://www.cfsrf.com)  
**M.E. Research UK:** The Gateway, North Methven Street, Perth, PH1 5PP. 01738 451234 [www.mereseach.org.uk/](http://www.mereseach.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](http://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](http://www.tymestrust.org)  
**AYME:** Association for Young People with ME, Box 605, Milton Keynes MK2 2X. 08451 232389. [www.ayme.org.uk](http://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](http://www.communitylegaladvice.org.uk)  
[www.writetothem.com](http://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](http://www.pensionsadvisoryservice.org.uk)  
**The Pensions Ombudsman:** 020 7630 2200 [www.pensions-ombudsman.org.uk/](http://www.pensions-ombudsman.org.uk/)