

**Issue: 43**

**December 2009**

**[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 (after 12noon)
Web Master:	Caroline Higson	01204 525955 <b>caroline@mesupportgroup.co.uk</b>
Membership Secretary, Newsletters & Distribution:	David Gore	0560 133 5037 <b>Dave@ mesupportgroup.co.uk</b>
Link Up Co-ordinator:	Stephen Walker	01204 842395 <b>stewalker@postmaster.co.uk</b>
Librarian:	Carole Senior	01942 810320
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 <b>andmk1@googlemail.com</b>

**DISCLAIMER:**

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

## 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 THERE WILL BE NO MEETING IN DECEMBER**

The next meeting will be Thursday 14<sup>th</sup> January, when we are hoping to have a speaker from the Shaw Trust. This organisation helps people who are on sickness-type benefits back into work. If you are a new claimant for ESA (the replacement for incapacity benefit) you may already have had some sessions with them. Eventually all of us on such benefits may have to attend such sessions. At the moment we're still awaiting confirmation of this speaker, watch this space.

**Radcliffe Socials:** Our Social Group meets informally on the first Monday of each month, our next will be on **Monday 4<sup>th</sup> January 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:** Apologies for the miss-print in our Summer newsletter, this social will not be on the 8<sup>th</sup>, the next will be **Thursday 7<sup>th</sup> January, 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.

### **PLEASE NOTE THERE WILL BE NO YOGA ON 29<sup>TH</sup> DECEMBER, CLASSES WILL RESUME AS NORMAL ON 5<sup>TH</sup> JANUARY.**

**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.**

## **Our Yoga Therapy Sessions**

We are very fortunate to have Olivia as our tutor at the yoga sessions. As well as already having her qualification as a British Wheel Of Yoga teacher, she is now in the final stages of her Yoga Therapy Training. This additional training gives her a much deeper understanding of the effects of illness on the body and she has many yoga tools that she can offer to help relieve symptoms.

Very often, pain can be caused by tension in the muscles. Seemingly simple things like breathing properly and using relaxation techniques can bring some relief from this type of pain. However these techniques are not as simple as they seem and need good explanation and plenty of practice.

Olivia uses gentle exercises to help with mobility and to gain a little strength in the muscles, but the sessions are not just about exercise. It is important to try as many of the different things that Olivia offers, because you never know which one will help you. We have recently been doing 'chanting', which really means just making a humming vibration along with the movements. At first everyone was embarrassed, thinking "I can't sing", but the noise helps you concentrate on the breath and lengthens it. At the same time it creates a vibration, which in turn releases tension. One of our members found that after a session using this technique, she released a lot of pent up emotion and anger, which resulted in her having much less pain from trying to keep it in.

Not everyone likes every element of yoga equally, some are happier with the relaxation, some like the exercises and some are beginning to like the chanting. What is important is that there are many things that Olivia herself has found to be useful and she is offering them to us, so that we can choose which suits us best. It is not solely an exercise class, it is so much more, sharing, companionship and support.

We would encourage any of you to come along and try to see if some, or all of it, is helpful to you.

### **DLA Update**

We recently told you about the threat to DLA from the government green paper 'Shaping The Future of Care together'. We have now received confirmation from the Department of Health that DLA will not be removed for under-65s. So well done to everyone who joined us in writing to MPs and taking part in the Benefits & Work campaign – it shows we can make a difference! Unfortunately it's not quite over yet though, the fight goes on for the over-65s keep their DLA or Attendance Allowance.

### **Bolton/Bury ME Support Group Meeting November 2009: Pre-Christmas Bring & Share Social & Quiz**

Thank you to everyone who attended for helping to make this a really enjoyable evening. We shared an excellent range of delicious food and had lots of fun with Lynda's quiz.

# Lynda's assault on the Great Glen Way – Sept 09



What the hell possessed me to dream up this plan? I blame it on the NHS and society in general. When I was doing the Life Management Course at Lever Chambers we were asked to set goals so this was mine. I also wanted to show the world that contrary to popular belief sufferers from ME/CFS were not lazy and idle and that I was representing people who deserved so much better than the deal that had been dealt them. Whilst any chronic illness is bad enough for anyone who suffers from it this one is particularly difficult because it is often not obvious physically to the outside world, and the cognitive difficulties people have again tend to be much more apparent to the sufferer, I mean someone who doesn't know you will never know if you were a nuclear physicist or a sporting legend, they won't know who you were or what you aspired to, they only can judge on what they say. I have certainly learned to be more tolerant as a result of this illness.

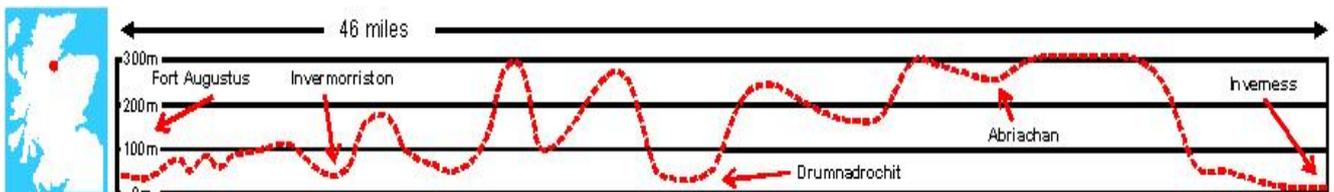
I set off with two stalwart companions (and of course Priscilla the duck) on September 1<sup>st</sup>, from Fort William. Thirty five gruelling miles later with a devilish detour we arrived in Fort Augustus, barely able to string a sentence together, and only keeping going through sheer pigheadedness, somehow ate a nice tea after my late afternoon nap, then back to bed to rest for day two. This would make or break me, assuming I could do anything at all the next morning.



## Day 2

So who could play me in a film?

A lovely day in terms of weather and scenery, again had a lot of ups and downs literally.



As you can see what goes up did come down, you can't see the round and round bit though, we got above the tree-line and I got sunburned for a change. It took about 7 hours to cycle 23 miles buoyed up with jelly beans - I knew my brother's fell running expertise would come in useful. We were doing quite nicely, I was tired but sure I would get a second wind at some point and I really wanted to achieve this. We had some lunch in Invermorriston, which had been hard work but Priscilla loved the bridge. Then I hit the wall, it was so steep that once I had stopped I couldn't start again, so walked up most of it. There were also

some more steep rocky paths to cycle down that made me fear for my bones. We had a sharp shower but other than attracting a few midges it was a lovely day, just very hard work.

Surprisingly I wasn't as tired as the previous day although I had a long sleep again before our evening meal. That was a really nice evening although I can't say I contributed much, but the food was lovely. My companions sampled the local beers with great gusto.

### Day 3

Cursed with the ME sufferers problem of not sleeping well I am usually awake about 5:30 so had some wait before my brother had put his tent down and my other friend was ready. So I had some time to look at the change in the weather. Priscilla was the only one who gamely wore her



ME t-shirt, the rest of us were smothered in waterproofs, but that didn't help much, at one point some of us were pouring the water out of our shoes, but I couldn't get away from the fact that I was on the last leg and I was going to make it. We sheltered for a while whilst we had a drink and a sandwich in a barn. I imagine it was a bit like Mary might have felt in Bethlehem, it gave me chance to put my brothers spare fleece on and warm up and to recover from the nightmare that was the hill out of Drumnadrochit. We climbed about 1000ft in about a mile, the only blessing being it was a tarmac road so the cycling was easier, or should I say pushing. My Ipod was

such a saving grace keeping my spirits up all the time, because unlike walking it is harder to talk to people whilst you are riding, and the weather prevented that. After the barn rest though we made very good time and were in Inverness just after lunch. We were met by Brenda and Elspeth from the Inverness Fibromyalgia and ME support group and they were incredibly kind, allowing some drowned rats to change and then feeding them and warming them, knowing myself how hard it is to do extra out of your allotted energy ration it meant a lot to me. It also probably prevented me suffering more, since we had nowhere to stay until the train later that evening.

We managed to raise £1,200 in total and I had some very generous and heartwarming donations and letters, I'm not sure what I managed to prove since my abilities sick are greater than what some well people do, but I hope that maybe I have raised a few questions in peoples minds. I have never written so many letters in a long while, and I think the House of Commons will be pretty sick of me by now. I just hope it did some good. I certainly loved the experience and the sense of achievement, as well as having the opportunity to remember who I was.

What next?



## Smithills Outing

Once again we were very fortunate to be awarded a grant by Bolton Community & Voluntary Service from Bolton Adult Care Services. The grant was for £900 and was given so that carers could be given an enjoyable outing.

As we enjoyed our outing to Smithills earlier in the year, we decided to return, this time on Remembrance Sunday, 8<sup>th</sup> November. Once again the staff were most helpful and the service was very good.

The lovely thing about being awarded the grant is that it allows us time to be together, to make new friends, to share good ideas and to offer each other support.

It was really lovely to see everyone enjoying themselves, chatting happily and being looked after for a change.

Thankyou for all coming and for making the day a success.

### Gut and Psychology Syndrome

We have a new book for our library, as recommended by Gail Sumner. 'Gut and Psychology Syndrome' is written by Dr Natasha Campbell MD, Master of Medical Science (nutrition). It explains the link between some neurological disorders, the food and drink that we take and the condition of our digestive system. It contains basic information for beginners, as well as in depth information for those at an advanced level. It also contains many recipe ideas.

## 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 .

**Amazon:** The group gets 5% commission when you shop at [www.amazon.co.uk](http://www.amazon.co.uk), but only if you follow the link from our own website [www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk) - look for the link on the left hand menu.

**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](mailto:dave@mesupportgroup.co.uk).

**[www.moneymadeclear.fsa.gov.uk](http://www.moneymadeclear.fsa.gov.uk)**

0300 500 5000

For help and advice on all sorts of financial matters, including benefits, taxes, pensions, mortgages, loans, etc, etc, etc...

**[www.turn2us.org.uk](http://www.turn2us.org.uk)**

0808 802 2000

A new charity helping people access money available to them, through benefits, grants, etc.

**Bury Carers Centre** has new contact details:

Suite One, Victoria Buildings,

Bury, BL9 0EU

**0161 763 4837**

**[burycarers@yahoo.co.uk](mailto:burycarers@yahoo.co.uk)**

If you are a carer and have not been in touch with them already, please do so, to receive invaluable support for yourself.

**(Bolton Carers Support are still at:**

**01204 363056, [boltoncarers@btconnect.com](mailto:boltoncarers@btconnect.com))**

## **Benefits & Work Guides**

Our group is a member of [www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk), allowing us to access 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, so please look through the list below and if you need anything phone Dave on 05601 335037 or email [dave@mesupportroup.co.uk](mailto: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 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.

**WE NOW HAVE SOME OF THE MORE POPULAR GUIDES AVAILABLE FROM THE LIBRARY AT OUR MEETINGS – IF YOU CAN'T SEE THE ONE YOU WANT, PLEASE ASK!**

### **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)

Getting the best from Work Focused Interviews (11)

### **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)

## **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 - 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](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/)