

**Issue: 60**

**May 2011**

**[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:**

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Meetings Secretary:	Maria Sale	01204 575613
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**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 19th May 2011, 7:30pm** – Jean Kay will do a session on card-making, providing materials for a couple of different types of cards.

**Thursday 16th June 2011, 7:30pm** - Anne Gent from Job Centre Plus will speak about some of the changes to ESA and new assessments. Please note: Anne will NOT be able to deal with individual cases, she will only be able to talk about the changes in general.

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 6<sup>th</sup> June 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 2<sup>nd</sup> June, 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 07746 197511, or [olivia@oliviayoga.co.uk](mailto: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.

### A reminder about Dave's contact number

Please note that although this is a mobile number, it is not his personal mobile and he does not always have it with him. Also, it has no voicemail & he may not always notice any missed calls, so if you are unable to get through at first, please do be patient and try again later.

For lovely handmade greetings cards, please visit: "Butterfly2honey Cards For Charity" on Facebook. If you quote "Sparking Clog" the profit will go to our group.

Last month we sent out the annual membership renewal forms with the newsletter. Thank you to everyone who has already returned theirs to us and rejoined.

For anyone who hasn't already done so, please don't forget. If you have forgotten whether or not you have renewed, or have lost your form and need another, you can call Dave on 07919 234256 or email [Dave@mesupportgroup.co.uk](mailto:Dave@mesupportgroup.co.uk).

# **What I'm really thinking: The woman with ME**

**The Guardian, Saturday 12 March 2011**

Twenty years coping with the symptoms of ME is bad enough, but 20 years of coping with people's reactions to it adds insult to injury in the most literal sense.

First was the era of "yuppie flu", when people you'd never met before felt entitled to interrogate you as to the validity of your illness and your presumed psychological deficiencies. Nowadays I get either the "you need to pull yourself together" brigade, or the alternative types who ask what my illness means, and are sure I could be well if only I understood what it was trying to tell me. Well, if I haven't figured that out in 20 years, that must mean they think I'm pretty thick. Then there are the ones who say, "But you always look so well." Of course I look well when I'm out and about; it's because that's a day when I'm well enough to drive. They should see me on the other days.

Of course, this is largely about the rudely healthy being in denial of the reality of illness.

Yes, it's scary to think you could wake up with a cold one day and never be well again, and there's little you can do about it. But don't try to force me to collude with you in trying to deny that it happens.

What I mind most, though, are the people who listen to my story with such sympathy, but then take equal time to describe the horrors of their current cold/flu/chilblains. My usual response? "Don't worry too much about feeling ill, it gets easier after the first couple of years." That shuts them up.

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## **Employment & Support Allowance – Benefit & Work Guide Updates**

You may have seen on the news that there have been some recent changes to employment and support allowance. In March the updated Work Capability Assessment (WCA) came into use and so anyone who now receives a form to fill in will receive a different one to that which you may have been used to in the past. Thankfully our friends at Benefits & Work have produced updated ESA guides:

**Understanding Employment and Support Allowance (42 pages)**

**Employment and Support Allowance claims on physical health grounds: a guide to the work capability assessment. (70 pages)**

**Employment and Support Allowance claims for Mental Health and Learning Difficulties: a guide to the limited capability for work assessment. (75 pages)**

If you would like a copy of any of these guides (or indeed any of the other B&W guides) please contact Dave on 07919 234256 or email [dave@mesupportgroup.co.uk](mailto:dave@mesupportgroup.co.uk).

As usual, it costs us no extra to send them to you by email, however due to the size of the documents, if we need to send them by post we would be grateful if you could contribute a donation towards the costs. For example printing and postage costs us: £2.50 for 40 pages, £3.50 for 60 pages and £5.50 for 100 pages etc.

There is also lots of useful information on the Benefits and Work website ([www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)), plus a very informative email information service that you can sign up to for free.

## **Can you help to support the running of our Group?**

Recently we asked if any of you could help with the running of the group. We had a couple of volunteers to whom we are very grateful however we are still looking for more.

The majority of the tasks required for our group to function are covered by a very small number of people and unfortunately this is not sustainable in the long term.

We do understand that due to health difficulties our members are limited in what they can achieve and have numerous other commitments and responsibilities, but even if you can only offer a little please do not underestimate how much difference that would make to us.

Here is a list of some of the tasks that you might like to consider:

### **Group Leader**

- Book room for meetings (once per year around Oct/Nov).
- Open room and chair monthly meetings.
- Chair committee meetings (three times per year, April/August/December).
- AGM – once per year chair meeting, write up minutes and write Group Leader's and Secretary's reports.
- Take telephone enquiries from members and potential new members.

### **Newsletter**

- Compile and edit newsletter.  
(This can be a small monthly newsletter like we have now, or a larger quarterly newsletter like we used to have. The articles come from a number of other sources, so you wouldn't need to write any, unless you wanted to.)
- Produce monthly update fliers (if we revert back to quarterly newsletters).
- Photocopy newsletters (on photocopier provided), then collate and staple newsletters together OR take to Staples for printing (if photocopier not wanted in home).
- Label and stuff envelopes, then post.
- Send out newsletters by email (for members who have opted in).

### **Membership**

- Keep the membership list up to date.
- Produce mailing list/address labels for people who receive newsletter by post.
- Produce mailing list for email recipients.
- Make up welcome packs and send out info to new members.

You will need to have your own computer, but the group will pay expenses to cover your printing costs, or can provide a printer.

### **Grants**

The group's annual income from membership subs is approximately £1700. This covers some of our costs, but our total annual expenditure is usually around £4500-£5500. The remainder of our funding comes from grants. Our running costs include essentials such as newsletter printing and postage, stationary, insurance, room hire. We also need money for our weekly yoga sessions, which although not vital are preferable. There are also the carers outings, which are non-vital, but much appreciated. So we need someone who can:

- Look for possible grants for money (we have a member who can help with the filling out of application forms).

- If grant money received, keep a record of expenditure and complete sign off.

### Miscellaneous

- Respond to requests for Benefits & Work Guides (by email and post).
- Photocopy library leaflets (1200 twice per year) OR taking to Staples for printing.
- Laminate library posters (72 twice per year).
- Write monthly newsletter article about the talk at our main meetings.
- Write up other relevant news for newsletters.
- Get tea, coffee, milk and biscuits and bring to monthly meetings.
- Get plastic cups and glasses for monthly meetings.
- Set up room for monthly meetings and tidy away tables/chairs afterwards.

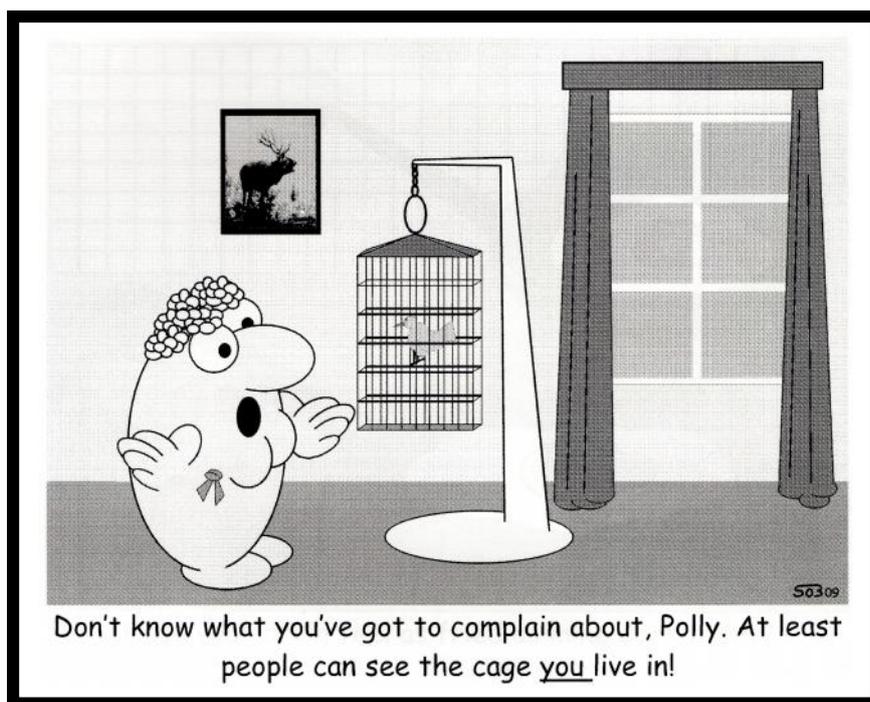
The following are not essential, but we would prefer to maintain if possible:

- Organise carers outings (if applicable grant received).
- Attend meetings with ME Clinic staff.
- Attend other meetings as requested, e.g. by CVS (Community Voluntary Service), Health Authority, Neurocare, or Manchester University.

We appreciate that some of these tasks might look rather daunting, but if we have enough people then we can share them out into manageable amounts and perhaps even have people take turns depending on how they are feeling. Or do you have a partner or family member who might be able to take part?

We would welcome additions to our committee, but we also welcome helpers who do not wish to be part of the committee.

If you can help in any way, big or small, please do get in touch with either Pam or Dave to discuss what you might be able to do.



With thanks to Invest in ME ([www.investinme.org](http://www.investinme.org)) for their kind permission to reprint this cartoon from the calendar available to download from their website.

# **STOCKPORT ME GROUP**

## **TALK BY DR. CHARLES SHEPHERD 8<sup>TH</sup> APRIL 2011.**

A few members of the Bury/Bolton Group travelled to Stockport on Friday 8<sup>th</sup> April to hear a talk being given by Dr. Charles Shepherd, who is the Hon. Medical Adviser to the ME Association. It was a beautiful sunny day, and there were a lot of people there who were obviously interested to hear what Dr. Shepherd had to say.

Dr. Shepherd started by telling us of his own experience of suffering with ME. He had had a fulfilling job as a hospital doctor, was fit and well, was able to play squash, and then he suffered a bout of chicken pox in the early 1980s, and the ME started from there. He has been Medical Adviser to the MEA for some time now and has worked for people with ME over many years.

Dr. Shepherd divided his talk into four main headings:

### **RESEARCH: WHERE ARE WE NOW AND WHERE ARE WE GOING.**

Dr. Shepherd stressed the need for research as crucial. There are three stages in ME, known as the 3Ps – predisposing /genetic factors which may contribute to someone being more susceptible to getting ME; precipitating/triggering factors such as an infection (infections are usually the culprits, whether viral or bacterial); and thirdly perpetuation. What is it that keeps it going? It is this third factor that medics cannot agree on. There are two main models to try and explain this, the psychiatric model and the biomedical model. The psychiatric model fits in with psychological treatments, and research up to now in this country has been dominated by this model. The biomedical explanation asserts that there are ongoing problems in the immune, the central nervous and endocrine systems.

There has up to now been very little impetus from the Medical Research Council to fund research into the biomedical model, with research along those lines being done largely by charities. A working group was set up in 2008 chaired by Professor Stephen Holgate, Professor of Immunopharmacology at Southampton University. Dr. Shepherd was invited to sit on this working group and the aim of the group was to advise the MRC on future research strategies. The result is that £1.5 million has been made available as research grants to suitable applicants for strictly biomedical research. A list of areas to be looked at has been agreed.

Dr. Shepherd talked about the Ramsey Research Fund, which was set up in memory of Dr. Melvin Ramsey who was a doctor at the Royal Free Hospital in London at the time of the ME outbreak in the hospital in 1955. The RRF is setting up a bio bank at University College Hospital, London. Blood samples will be collected from people with ME who form part of the ME Observatory patient database and this might help to narrow down which medical criteria they fall into e.g. Canadian Consensus, Fukuda etc. Professor Peter Behan who is a well known researcher in the ME field is doing a study on people who fit into the Canadian criteria. The bio bank should be set up by July and there will be a tissue bank as well. The RRF is also funding a study into mitochondria function in muscles being done by Professor Julia Newton at Newcastle University, with the results now being analysed, and Dr. John Gow at Glasgow Caledonian University has been funded to carry out gene studies.

Dr. Shepherd mentioned the PACE Trials and the recent announcement of the results and said that the pacing results were not really convincing, and that the MEA had not been in

favour of the trials while they were being carried out. The worry is that NICE will want to adopt this form of pacing, but fortunately the guideline will not now be reviewed until August 2013. He mentioned the Lightning Process and the XMRV research and felt regarding the former that the trial of LP should not be done on children when it hadn't been done first on adults, and he felt with the latter that the jury is still out on XMRV as studies subsequent to the original Lombardi et al research done in 2009 did not show up the virus. Further research on XMRV is needed.

#### MANAGEMENT OF ME:

It is important to get a proper diagnosis and investigations done. As the cause is still unknown there are no cures or effective drug treatments. A range of drugs can help e.g. painkillers, sleep medication. Orthostatic intolerance is often a factor in ME and is caused by the malfunctioning of the CNS. The Tilt-table test is done to test for this. A survey was done by the MEA into what treatments people found most effective, and a lot of treatments were covered, including complimentary therapies. Proper pacing and energy/activity management is also important. Dr. Shepherd isn't convinced about a lot of complimentary therapies, but felt that Acetyl-L- Carnitine might be of benefit. He did mention Vitamin D deficiency, and felt that you should really be tested for this as taking too much Vitamin D is harmful. The MEA does a booklet on clinical guidance known as the Purple Book and is available from the MEA.

#### BENEFITS:

Benefits reform is being undertaken to drastically reduce the number of people on benefits. The new Employment and Support Allowance (ESA) is difficult for ME sufferers to get because of the way in which the form has been designed. It does not account for the fluctuating nature of ME. Since the introduction of the original descriptors for the Work Capability Assessment, legislation came into being on 28<sup>th</sup> March 2011 which revises these descriptors and has resulted in the removal of some of the original ones. Included in the ones removed is the one concerned with cognitive dysfunction e.g. short term memory loss, poor concentration etc. which are relevant to people with ME. A bid during a House of Lords debate to get this bill annulled failed. Dr. Shepherd is a member of the sub-group for Professor Harrington who has been compiling a report on the issues to be taken into consideration on how ME affects people. If you are refused benefit it is worth while appealing as the success rate is quite high. The appeals process is independent of the Department of Work and Pensions. The DWP is tending to rubber stamp what Atos, the company doing the work capability tests, decides. The MEA does provide a guide to filling in the ESA form and information on ESA is provided in the ESA section of the Disability Alliance Handbook.

#### THE MEA:

Dr. Shepherd mentioned that the MEA continues to provide information and support for sufferers, and there is literature you can buy from them, plus a listening and information line called ME Connect, number is 0844-576-5326. The website for the MEA is [www.meassociation.org.uk](http://www.meassociation.org.uk).

There was time for questions but it isn't possible on this occasion to cover them here unfortunately. The talk was very enjoyable and my husband and I stayed for a meal again in the Toby Restaurant.

Angela Glendinning.

## Health club offer

The Sebastian Coe health club at the Jarvis hotel in Blackrod, Bolton is willing to negotiate a discounted price for our members to use their (very!) heated pool, Jacuzzi and sauna.

Bernie Bateman has felt much better after using these facilities, and thinks others would benefit. She says that the very warm water in the pool and hot water in the Jacuzzi help to relax the muscles, while supporting your joints. She was able to do some simple stretches in the pool, similar to yoga. The Jacuzzi jets promote improved lymphatic drainage (supports the Perrin technique) and blood circulation. Bernie says she had much improved sleep that night and reduced muscle pain the following day. Just sitting in the Jacuzzi feels similar to hydrotherapy and could be used by people with limited mobility, especially as it is next to the changing rooms. A mobility scooter could be used to get to the changing rooms. The facilities are extremely quiet, unlike public pools.

Many of us would not pay a monthly fee to a health club, due to the unpredictability of the illness. The manager is willing to reduce the cost of individual visits (currently £8) if enough people express an interest. We hope to knock it down by several quid.

We need as many numbers as possible to take to the manager. There is no obligation and your name will not be given to the health club. The bigger number we have the more bargaining power we will have.

If you are interested, please contact Maria Sale by e-mail ([maria113@talktalk.net](mailto:maria113@talktalk.net)) or by phone on 01204575613 Alternatively you can text Bernie, on: 07932185945.

The Jarvis hotel is on the A6 near junction 6 of the M61, near the Reebok and Middlebrook retail park. It is 10 minutes from junction 17 (Whitefield and Prestwich) on the M60.

If we are successful, other health clubs could be approached for a similar deal, so it would be worth registering even if this isn't your nearest club. Let's see if we can use our numbers to get a bargain.

## Do I really have CFS/ME?

Many CFS/ME patients are constantly looking for a cure. They try all sorts of things from taking supplements to sophisticated blood tests. However, trying lots of different therapies may not always be the answer. It can be a costly exercise trying different treatments which may be way off the mark. Therefore, getting re-diagnosed may provide an instant solution, and could lead to a rapid recovery.

Recently, we've heard of one CFS/ME patient who, in their desperation, started a diet without any carbohydrates whatsoever. Almost immediately they started feeling much better, and on further medical advice they were successfully tested for Coeliac Disease. Coeliac Disease is an auto immune disease caused by Gluten in the diet. If you have the disease, Gluten triggers an immune reaction damaging the lining of the small intestine.

Other parts of the body may be affected. People may also suffer a range of other symptoms such as hair loss, weight loss, joint pain, tiredness, headaches, nausea, vomiting and many more. It's easy to see why some of these symptoms could be confused with CFS/ME.

If you haven't already had this test, then maybe now's the time.

**Exclusion diets may do more harm than good. If you don't have enough carbohydrates, it can have a negative effect on your health. So if you're thinking of changing your diet, please take advice from your doctor first.**