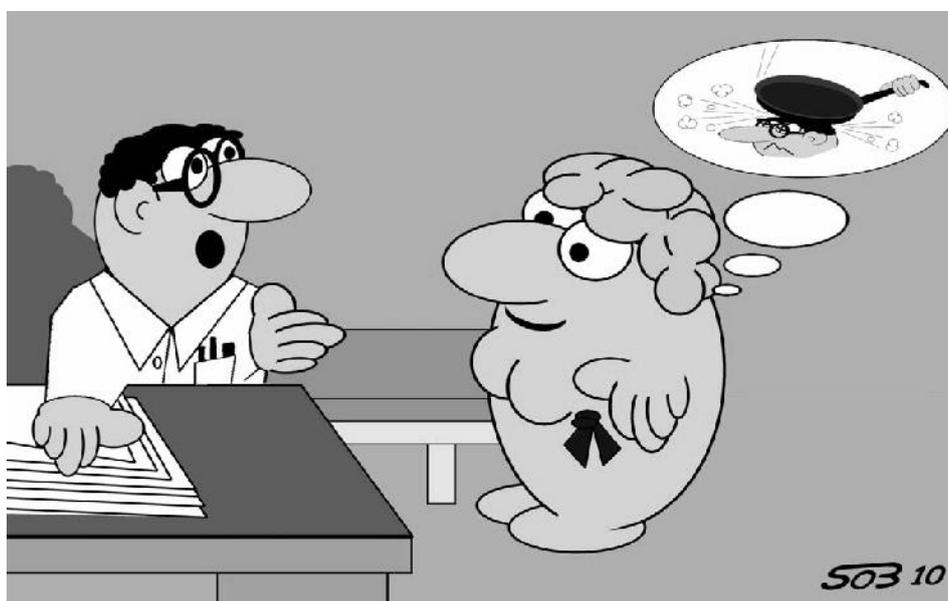


## Welcome to Our July 2011 Newsletter



**TRY CONCENTRATING ON SOMETHING YOU'D REALLY LIKE TO DO AND I'M SURE YOU'LL  
FEEL MUCH BETTER!**

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.

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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.

# **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, 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:	David Gore	07919 234256 <b>Dave@ mesupportgroup.co.uk</b>
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Librarian:	Carole Senior	01942 810320 <b>carole.senior@tiscali.co.uk</b>
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 <b>andmk1@googlemail.co.uk</b>

**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 21st July 2011, 7:30pm – Social**

**Please note there will be no meeting in August.**

**Thursday 15<sup>th</sup> September – Don Stenhouse**, curator of natural history at Bolton Museum. He will tell us some amusing and interesting stories about the objects and will bring some objects with him. These might include fossils, seashells, butterflies, etc.

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 1<sup>st</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 7<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 07746 197511, 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. Call 0161 743 3701 or visit [www.gmneuro.org.uk](http://www.gmneuro.org.uk) for information about meeting times and locations.

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

# **Bury/Bolton ME/CFS Support Group Meeting**

## **June 2011**

We had arranged to have a speaker from the Job Centre to tell us about the change over from Incapacity Benefit to Employment Support Allowance; Unfortunately they informed us that due to staff changes it would not be possible to have a speaker this month but may be possible later in the year.

Very kindly one of our members talked to us of his experience of being assessed for E.S.A. and gave us some pointers and things to be aware of when attending medicals.

He said that you will be observed when approaching the building so that the way to walk and the distance you walk can be assessed. Also when you are sitting in the waiting room you are observed so if you are uncomfortable either move about, or stand up, or ask for a more comfortable place to wait.

It is also important, during the medical or assessment, if you are asked to perform a task or asked if you can perform a task, that you always explain fully why it is difficult for you e.g. too painful or loss of movement in joints etc. Do not assume that the doctor will know how painful it is, always explain everything.

If you don't agree with what he/she is saying or writing tell him/her calmly and clearly, I do not agree with what you are saying and I want you to make a record of the fact that I do not agree.

So thank you to our member for an interesting and informative talk.

## **Grant from Greater Manchester Foundation.**

We have been very fortunate, once again, to have been given a grant of £1000 towards the cost of our Yoga sessions.

I would be very grateful if as many people as possible could either write a small note and send it to Pam or e-mail a message of thanks to Dave.

If you do use the sessions please add a little bit about how they help you.

The staff from the foundation can then pass on your good wishes and responses to the people who donate the money for them to allocate, in this case it was from The Red Nose Day Fund.

Thank you very much everyone, if we show how much it is appreciated then there is more chance we may get a grant next time we need one.

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

# **Mandatory Work Experience for Some on JSA**

The following Article has been taken from Action for ME News 27th May 2011.

Sarah Lawrence, Action for M.E.'s Welfare Rights Adviser, writes:

On 25 April new regulations came into force that will affect some people claiming Jobseekers Allowance (JSA). The regulations introduce a new scheme called the Mandatory Work Activity Scheme (MWA).

People who are put forward for this scheme by their Jobcentre Plus adviser will have to work for up to 30 hours per week for a four week period

They will continue to receive their benefit without any other financial incentive and will still have to seek work. As yet it is very difficult to know who will be selected and we have yet to see how this programme will work in practice. We would be very interested to hear from anyone who is selected to participate in the programme.

The fear is that with many people failing to satisfy the Work Capability Assessment, (the new test used to determine whether someone is fit for work) some sick and disabled people may have no alternative but to claim JSA.

There is then the risk of being required to participate in MWA.

At present there is little detail about the selection process and Jobcentre Plus staff have discretion about who they put forward.

On the Department for Work and Pensions (DWP) website it says that from 17 May:

“Jobcentre Plus advisers can refer jobseekers that need additional support to get back to work onto mandatory work activity. Where advisers believe a jobseeker will benefit from experiencing the habits and routines of working life, they have the power to refer them to a four week placement.

“This could be in a wide range of roles, including doing maintenance work for housing residents, renovating and recycling old furniture, working in a local sports club or supporting charitable organisations.

“The scheme, which will be delivered by a range of organisations from the private, voluntary and third sector has now started in London, the East and Yorkshire & the Humber and will be available throughout the country by the beginning of June”.

If claimants refuse a placement or fail to complete one without good cause they may have their benefit sanctioned for up to 13 or 26 weeks.

In the DWP decision maker's guidance, it states that if a claimant has failed to participate in the scheme the decision maker must take into account the circumstances of the case and this includes the claimant's physical or mental health condition.

It goes on to say that claimants would have good cause for giving up their places if it would have - or would have been likely to have - put their health and safety at risk if they had continued to participate in it.

## **Mandatory Work Experience for Some on JSA Continued...**

A Social Security Select Committee report recommends that MWA is not implemented and raises a number of concerns in their report to the Secretary for State.

It says that MWA is designed to target the small number of people who are doing little to comply with the requirement to actively seek work. The committee is concerned at the lack of detail available about the nature of the placements and believe that the quality of provision may vary.

A further concern is the amount of discretion given to the personal adviser and worries about people still having to seek work whilst participating in these placements. They also comment on the severity of the sanctions. They recommend that if MWA does go ahead, three key recommendations are implemented, based around the selection of participants, placements and sanctions.

## **PACE Trial Results An Overview**

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(Adapted from Action For ME (AFME) "Interaction" Vols 75 & 76.)

The PACE trial (Pacing, graded Activity and Cognitive behaviour therapy – a randomised Evaluation) reported their first paper on Feb 18th 2011. The trial was to examine the effectiveness of 4 therapies in the treatment of ME/CFS. These were: Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET), Adaptive Pacing Therapy (APT), and specialised medical care which covers treatment of symptoms (e.g. pain relief) without any other additional therapy.

Since the results have been published there have been conflicting reports in the media as to what they prove. Some aspects of the media have suggested that the positive results for CBT and GET suggest that ME is all in the mind. Others accept that this is a distortion of the results by journalists.

It was hoped that the results may lead to a revision of NICE guidelines which have been criticised due to the emphasis on GET & CBT. These hopes have proved unfounded. If misinterpreted, the PACE results could cause inappropriate revisions in the Dept. for Work and Pensions Guidelines, the 2013 NICE guidelines 53, and may have implications for health insurance.

The only thing that all parties seem to be agreed upon is that the results highlight the need for further high quality biomedical research. PACE suggests that there are currently no single treatments which result in complete recovery, improvements in all of the therapies tested were fairly marginal, and that some participants showed no significant improvement at all.

AFME backed the PACE trial partly to achieve recognition for pacing as a therapy that is consistently highly rated in many patient surveys and is free and accessible to all (especially those with no access to a specialist ME clinic). In a recent survey pacing was considered helpful by 80% of responders in comparison to 50% for CBT and 45% for GET (with some reporting that the GET made them worse). Yet within the PACE trial GET and CBT seemed to be better tolerated than was expected and pacing did not seem to perform as well. Also PACE found that serious adverse reactions to the treatments were rare (a view not necessarily backed up elsewhere).

It is noted by AFME that the authors of the PACE report are respected clinicians who did not come to any sensational conclusions but in fact were very cautious in their claims and even highlight some of the significant weaknesses of their own study. Clinical trials are designed to answer very

## **PACE Trial Results An Overview Continued...**

specific questions by testing ideas under strict conditions to see if they then hold up in reality. They admit that one trial alone proves nothing and that the results only become more compelling if several studies replicate the results.

One major criticism of PACE is the use of the “Oxford definition” in the selection of the participants. This is not as specific as either the Fukuda or Canadian definitions and could therefore include people with other forms of fatigue. Also, the most severely affected sufferers were excluded and anyone who failed to complete the trial, e.g. due to relapse, was not included in the final result. Their exclusion skews the results, making them appear more positive than is justified, and means that it is not possible to accurately apply the results of the trial across the whole ME population.

Possibly it is the type of research used which has produced such differing views. Fatigue and physical functioning can be measured by the researchers whereas other aspects of the illness and the judgements of patients themselves are much harder to quantify. When patients were asked which treatments made them feel “much” or “very much” better after 1 year of therapy both CBT and GET appeared to help 41% of participants each, APT 31% and specialised medical care 25%. Using a different statistical technique patients showed improvement (but only modest improvement in fatigue and physical function) with GET achieving a 61% success rate, CBT 59%, specialised medical care 45% and APT 42%.

The adaptive pacing strategy used in the trial is a specific form of pacing which involves no effort to push an individual with regards their energy or activity and this method seems to have been less effective than either CBT or GET. Graded activity pacing is the more usual therapeutic approach recommended in ME. It goes beyond APT and aims to manage the “boom and bust cycle” by setting suitable activity baselines and goals, monitoring and modifying the programme. This allows greater control over the illness by including periods of activity and rest, reducing setbacks, and allows slow “pacing up” under specialist supervision. Principles may need to be adapted for more seriously ill patients.

Within the PACE trials both CBT and GET incorporated pacing by the use of sustainable activity baselines and goal setting. . This could be an important point. Is it the combining of pacing with baseline setting etc that makes the therapy more successful? Practitioners find that when increasing activity levels it can be better to under-do, rather than over-do, an activity but on a regular basis as this allows for sustainability and gradual improvement. The skills of the CFS/ME therapist involved in such pacing programmes could be why there are often such varying results and why some doctors believe that as many people as possible should be assessed and offered therapy through specialist clinics.

One explanation for the fact that serious adverse consequences of the treatments were rare in the trial is that all the therapists involved are more highly trained than in general practice. Also it is accepted that what is described as “standard medical care” is in fact not the same as that provided by the average family GP and that the patients on the trial received a huge amount of input not normally available to NHS patients.

PACE findings suggest that GET or CBT may be of help to some people with mild to moderate disease. The benefits of pacing are often subtle and not easily measured. All the therapies were only moderately effective in isolation. This is an important finding when GET and CBT are the two main therapies recommended by NICE. In reality, ME services use a combination of pacing, GET and CBT but AFME believes the trial shows that patients need a real choice of treatments. PACE proves that much more research needs to be done into the biology, mechanisms, and possible treatments of CFS/ME

## **Survey On NHS ME Services.**

Action For ME (AFME) are currently conducting a survey into NHS services and CFS/ME clinics. This survey is open to anyone who has an opinion on local service provision, not just AFME members, and is short and simple.

Budget cuts, NHS reform and also possibly the types of advice and treatment offered at some of these ME clinics have led to closures. Others may be under threat.

AFME believe that NHS services vary across the UK and are concerned that there may be, in some cases, an over-emphasis on CBT and GET rather than patient choice and individualised care. However, they also believe:

- that these specialist CFS/ME clinics legitimise ME
- that most people depend on the NHS for their needs and so the NHS services available should meet those needs
- early referral to a specialist clinic can give earlier diagnosis and a better prognosis
- people with ME should have the option of seeing a specialist in a multi- disciplinary clinic if they so wish.

If you agree, then now is the time to get involved. If you have attended a local clinic and received helpful advice or treatment then now may be the time to let people know of the importance of such local knowledge. If you feel that services in this area or nationally could be improved then now is a good time to get your opinion across.

A copy of the questionnaire is enclosed with this newsletter. All replies need to be returned to the address printed on the form by Friday 12th August.

For those of you who receive this newsletter via email here is the link to the survey:

<http://www.afme.org.uk/interaction.asp>

## **Withdrawal Of Treatments.**

Many thanks to those people who have been in touch regarding the loss of their treatments recently. Some changes are still coming to light as people attempt to get repeat prescriptions. Do please get in touch if you are having difficulties getting any of your usual treatments so that we can collate the information.

If you have found an alternative to any of your medications please make contact so that we can share ideas with other members.

If anyone has suggestions regarding dealing with pain (general or fibromyalgia), sleep, digestive or thyroid-type symptoms please ring and I will attempt to compile a list of helpful tips / supplements etc that may be of some use if treatment is stopped.

Tracy 01204 592226 (10am-1.30pm or 6.15pm-7.30pm)