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**March 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.

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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.

**17<sup>th</sup> March 2011, 7:30pm – AGM.** We would sincerely beg as many people as possible to attend the AGM, in order to show support for the Committee and to tell us your views and ideas. We will keep the business part of the evening as short as possible so that we can have time to socialise and try out the cakes and biscuits (wheat/dairy free catered for!) The AGM usually lasts about an hour.

**Don't forget, there is no meeting in April, the next will be Thursday 19<sup>th</sup> May.**

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 4<sup>th</sup> April 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> April, 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.

**Dr Charles Shepherd**  
(Medical Adviser to The ME Association) will be speaking at the Stockport ME Group on **Friday 8<sup>th</sup> April.** Doors open **10:30am** for an 11am start, at The Toby Carvery, 271 Wellington Road, Heaton Chapel, SK4 5BP.

**Carers Outings:** During February we had two more carers outings thanks to our grant from Bolton Adult Services administered by Bolton CVS. They were both pub lunches, held on Sunday 6<sup>th</sup> February and Sunday 20<sup>th</sup> February at the Ainsworth Arms. The food was very good and everyone had an enjoyable time in good company and with no preparation or washing up to do afterwards. A real treat and much appreciated, so thank you very much for our grant.

## **Bolton & Bury CFS/ME Service Update**

Today I have attended the 6 monthly Service Development meeting. As usual it was a very constructive meeting. I can report that during the current absence from the Service of Dr Wright his clinical role is being undertaken by Dr Gaber, who is a Nero Rehabilitation Consultant and the clinical lead of the Ashton, Leigh and Wigan CFS/ME Service. Dr Gaber has been closely involved with our service from the beginning and some of you may have met him when the team have come to our Support Group Meetings.

All new referrals from GPs will be looked at by Dr Gaber and the initial consultation will either be with him or where the diagnosis is clear he will refer the patient directly to a member of the multi disciplinary team.

Dr Gaber has reviewed the medical notes of all the existing patients and these patients will continue to be seen by the appropriate member of the multi disciplinary team or discharged back to the care of their GP if appropriate. If any member of the team has any medical concerns about an existing patient this can easily be escalated to Dr Gaber for advice and if necessary intervention.

Current waiting times for the service are meeting the 4 weeks target and I am impressed with the ongoing commitment of the team during this difficult time. The Service will continue to run on this basis until such time as Dr Wright's position in the Service has been decided, although the timescale for this is still not known.

Also remember, once you have been discharged from the Service if you need further advice or review you can always self refer back to the Service within 12 months of your discharge. After that you will need to be referred back to the Service through your GP.

Yvonne Leech, 1 February 2011

## **Disability Living Allowance Renewals**

If you're receiving Disability Living Allowance, you may have been sent a renewal form to make sure you still need to keep on claiming. The Manchester area is one of three areas in the UK where the new form is being tested. The new form was cut from 40 to 4 pages. However, this led to problems as people were not being asked for enough information to restate that claim. So back in October 2010 it was increased to eight pages, and the trial goes on.

If you are making a renewal, and have received one of these new forms, we'd like to hear from you. This way we may be able to help of the members in advance of their renewal notices. Please contact: [andmk1@gmail.com](mailto:andmk1@gmail.com) .

Anyone can register for free email updates from Benefits & Work, just visit their website ([www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)) and click on the link to 'Free Stuff' on the left hand menu.

# **Bolton/Bury ME Support Group Meeting February 2011:**

## **Emma King - Holistic Therapist**

Our February meeting was a very relaxed one, thanks to our speaker Emma King.

Emma told us that she is an aromatherapist and at present is doing a part time course in order to be a teacher. She said that she had been learning a little about ME from Maria and when she saw a copy of the Canadian Consensus Document she was so interested that she bought one. Emma told us that she works with a lady who suffers from ME and she gives her massages, although the lady likes a lighter massage than normal.

Emma started her talk by taking us through a relaxing visualisation. Starting with an awareness of our breathing, in through the nose and out through the mouth, eyes closed. Then she asked us to tense the muscles in our legs and feet and then to relax them and notice the difference. Our visualisation was to see ourselves walking down a country lane where we could see flowers and trees and could feel the warmth of the sun. Then we imagined looking right where we could see a flowing river with gently bubbling water which ripples under a bridge. We were asked to walk onto the bridge and look down at the water flowing beneath us. Then we looked to our left to find an open box and into the box we put all our worries and cares and anxieties, then close the box and throw it into the water and see the river swirl it away. After a few moments Emma asked everyone to open their eyes and asked if we felt rested and relaxed.

Emma then continued by telling us that aroma means smells and therapy is a treatment that is applied to the body. However the oils do not have to be applied to the skin, she said it works just as well by smelling it as it goes up into the brain and the hypothalamus. A question was asked, if you have no sense of smell does it still work? To which Emma said that it does.

Oils can be used in an oil burner or in the bath but should not be used neat in contact with the skin. They are best diluted in a carrier oil.

Emma then did a guessing game and passed around small samples to see if we could identify the essential oil. It was very difficult because the essential oils are distilled for a long time and do not always smell of the original source.

She told us that aromatherapy was first used in Egypt when they used frankincense and myrrh for embalming and they acted as preservatives. The archaeologists can still find traces of them when they do their excavations. Also Native American Indians used oils in their dances and rituals.

A very interesting fact that she told us was that in France a cave had been discovered where the recipes for aromatherapy cures were found written on the walls. Also that a French professor who was a chemist was working and burned his hand, as he was rushing to get to some water his hand brushed against some lavender and it helped it to heal. From this he became very interested in the properties of plants and oils and started to develop it. Then a French nurse was encouraged to take on the practice of aromatherapy and it has continued to develop.

Emma then did a demonstration of a head massage, this can be done with or without oil. Then she encourages quite a few people to do a hand massage on themselves and showed them how to do it.

She once again warned about using oil that is not diluted and said a good way of using, for example lavender oil, is to put it onto cotton wool and put it inside the pillow case. Or to make little muslin bags with lavender seeds inside hem, lavender is used for relaxation and sleep.

Emma can be contacted by phone (07913 708419) or email ([emma@empathyholistics.co.uk](mailto:emma@empathyholistics.co.uk)) and will try to answer any questions.

A most relaxing and enjoyable evening.

## **The Lancet publish the results of the PACE study, 18 February 2011**

by Tony Britton on February 18, 2011

### **TRIAL SHOWS THAT COGNITIVE BEHAVIOURAL THERAPY AND GRADED EXERCISE THERAPY ARE SAFE AND EFFECTIVE TREATMENTS FOR CHRONIC FATIGUE SYNDROME**

Despite previous evidence that both cognitive behavioural therapy (CBT) and graded exercise therapy (GET) can be effective treatments for chronic fatigue syndrome (CFS), some patients' organisations have reported that these treatments can be harmful and instead prefer pacing and specialist medical care (SMC). The PACE trial, published *\*Online First\** and in an upcoming *Lancet*, shows that while CBT and GET have positive effects on CFS when combined with SMC as compared to SMC alone, adaptive pacing therapy (APT) with SMC is no more effective than SMC alone. The *\*Article\** is by Profs Peter White (Barts and The London School of Medicine, UK), Trudie Chalder (King's College London, UK), Michael Sharpe (University of Edinburgh, UK) and colleagues. The trial is funded by the UK Medical Research Council and various departments of UK governments.

CFS, sometimes called Myalgic Encephalomyelitis (ME), is a long-term, complex and debilitating condition that causes fatigue and other symptoms such as poor concentration and memory, disturbed sleep, and muscle and joint pain. The cause of the condition— affecting some 250,000 people in the UK alone—is unknown.

SMC consists of advice about CFS, including avoidance of activity extremes, and rest and self-help strategies. APT is based on the theory that CFS is an irreversible condition that leaves patients with a limited amount of energy, and that individuals adapt their lives to this available energy through use of a daily diary. CBT is based on the premise that cognitive responses (fear of engaging in activity) and behavioural responses (avoidance of activity) are linked and interact with physiological processes to perpetuate fatigue. GET helps a CFS patient gradually step up their level of physical activity to counter the deconditioning that has set in as their activity has fallen. Walking is a popular choice for this.

In PACE, 640 patients were assigned to one of SMC alone (160 patients), SMC/CBT (161), SMC/GET (160) and SMC/APT (159). After a follow-up of one year, mean fatigue and physical function scores had improved more after CBT and GET than after both APT and SMC alone. Serious adverse reactions to treatment were recorded in two APT patients (1%), three CBT patients (2%), two (1%) GET patients, and two (1%) in the SMC-only group.

The group plans to report in the near future on cost-effectiveness of these various treatments, and say that since even CBT and GET only offer a moderate improvement in symptoms, research into new effective treatments must go on.

The authors conclude: “We affirm that cognitive behaviour therapy and graded exercise therapy are moderately effective outpatient treatments for chronic fatigue syndrome when added to specialist medical care, as compared with adaptive pacing therapy or specialist medical care alone. Findings from PACE also allow the following interpretations: adaptive pacing therapy added to specialist medical care is no more effective than specialist medical care alone; our findings apply to patients with differently defined chronic fatigue syndrome and myalgic encephalomyelitis (ME) whose main symptom is fatigue; and all four treatments tested are safe.”

In a linked *\*Comment\**, Dr Gijs Bleijenberg, and Dr Hans Knoop, Expert Centre for Chronic Fatigue, Radboud University Nijmegen Medical Centre, Netherlands, say: “The central role of cognition in relation to fatigue might explain why graded exercise therapy is effective and adaptive pacing therapy is not.” They note that in adaptive pacing patients learn to focus on the fatigue in order to stop “in time”, which does not seem to help, while in graded exercise patients learn that they are able to do more than they thought possible.

They conclude: “Remarkably in this context, confidence in the treatment at the start is substantially lower with cognitive behaviour therapy than it is with adaptive pacing therapy. Despite lowered confidence in cognitive behaviour therapy, this therapy is more effective than is adaptive pacing therapy. Patient’s confidence in treatment can only change if a change in abilities is perceived, which generally seems to happen in cognitive behaviour therapy.”

With thanks to The ME Association ([www.meassociation.org.uk](http://www.meassociation.org.uk)) for their kind permission to repost.

## **ME Association press statement about the results of the PACE study**

by Tony Britton on February 18, 2011

### **“Results are at serious variance to patient evidence on both cognitive therapy and exercise therapy”**

This is the response from The ME Association to the results of the PACE trial, which were published in The Lancet on Friday 18 February 2011

An abstract of the paper can be found here:

[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60096-2/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60096-2/fulltext)

The Lancet press release can be found here: <http://www.meassociation.org.uk/?p=4621>

The MEA will be producing a more academic response to The Lancet in due course.

All of the comments below can, if preferred, be placed as quotes from Dr Charles Shepherd, Hon Medical Adviser.

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### **Headline comments from Dr Charles Shepherd, Hon Medical Adviser at the MEA:**

**“The largest ever clinical trial into the effects of CBT, GET and adaptive pacing therapy (APT) has produced results that are clearly at serious variance from those reported by the largest ever survey of patient opinion on these forms of treatment.**

**We find the trial results extremely worrying because pacing, in the form that the MEA recommends, may as a result no longer be offered as a treatment option in NHS clinics. And at the same time, NICE may well strengthen its inflexible and unhelpful recommendations regarding CBT and GET.**

**We also fear that the way in which the results are already being reported in media headlines – eg Got ME? Just get out and exercise, say scientists – will lead some doctors to advise inappropriate exercise regimes that will cause a serious relapse.**

**This is not a good day for people with ME/CFS.**

**They have a complex multisystem illness that requires a range of treatment options based on their individual symptoms as well as the stage and severity of their illness.”**

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### **Additional comments from The ME Association**

The ME Association does not accept the over-simplistic conclusions that CBT (cognitive behaviour therapy) and GET (graded exercise therapy) are safe and moderately effective treatments for everyone with ME/CFS.

We continue to maintain that the results from large and repeated surveys of patient reporting (see additional information below) into the possible value of these two approaches to management provide a far more informed and unbiased view of both their safety and effectiveness in what is a complex multisystem disease with a wide range of clinical presentations.

Equally, we do not accept some of the seriously flawed reasoning behind the use of CBT and GET in ME/CFS.

The use of these two treatments in the PACE trial has been based on the belief that ME/CFS is caused by a combination of abnormal illness beliefs and behaviour, where fear and inactivity can result in physiological changes. We believe this is wrong. Firstly because there is now considerable and compelling evidence involving neurological, muscle, hormonal and immunological abnormalities to demonstrate that ME/CFS is a complex biomedical condition which is not the result of inactivity and deconditioning. Secondly because the vast majority of people with ME/CFS do not have abnormal illness beliefs and behaviour.

The form of adaptive pacing used in the PACE trial is not the same as the model we recommend and which is favoured by the overwhelming majority of people with ME/CFS. The form of pacing advocated by the MEA is not based on the theory that CFS is an irreversible condition and that people rigidly adapt their lives to this fact through the use of a daily diary.

The MEA accepts that CBT can sometimes be of some help to some people who are having difficulties coping with some aspects of ME/CFS. We also accept that activity management, which involves gradual and very flexible increases in both physical and mental activity, plays a key role in any management plan.

But we also feel that far too much time and money has been repeatedly spent on research into CBT and GET over the years and that the time has come to start using these financial resources to discover the underlying biomedical causes of this illness, along with really effective forms of treatment. This is why we welcome the MRC (Medical Research Council) initiative to provide £1.5 million of ring-fenced money for research into the biomedical aspects of ME/CFS.

### **Background information:**

\* Our most recent survey of patient opinion on management options, which involved over 4,000 responses, was carried out at the same time as the PACE trial was in progress. The numbers involved exceed those in the PACE trial. Full report available here:

**[http://www.meassociation.org.uk/?page\\_id=1345](http://www.meassociation.org.uk/?page_id=1345)**

\* Results for CBT: 25% improved; 55% reported no change; 20% made worse (sample size=2137)

\* Results for GET : 22% improved; 21 reported no change; 57% made worse (sample size = 997)

\* Results for pacing: 71% improved; 24% no change; 5% made worse (sample size=906)

\* A similar study to the PACE trial, which was carried out in Spain, and published in January 2011, found no benefits from CBT and GET when compared to standard medical care. Abstract can be found here: **<http://www.ncbi.nlm.nih.gov/pubmed/21234629>**

\* Physical deconditioning does not seem to be a perpetuating factor in CFS – research abstract from paper by Bazelmans et al available here **<http://www.ncbi.nlm.nih.gov/pubmed/11200949>**

\* MRC announcement of ring-fenced funding for biomedical research into ME/CFS can be found here: **<http://www.meassociation.org.uk/?p=4085>**.

\* A further MRC announcement and press release is due next week.

### **The PACE trial**

\* The randomised controlled trial compared CBT, GET, adaptive pacing therapy and specialised medical care.

\* The assessments took place in hospitals in Bristol, Edinburgh, Oxford and London.

\* The trial was largely funded by the Medical Research Council and cost over £4million.

\* The MEA has been opposed the PACE from the onset.

\* NICE are currently considering whether they should review their guideline on ME/CFS to take account of the PACE trial results.

**With thanks to The ME Association ([www.meassociation.org.uk](http://www.meassociation.org.uk)) for their kind permission to repost.**

# **£1.5 million for M.E. research**

27 January 2011

## **MRC announces £1.5m to encourage further M.E. research**

The Medical Research Council (MRC) has announced £1.5m funding “for research into the causes of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).”

A [press release](#) on the MRC website today says:

“The Medical Research Council (MRC) is committing £1.5m for research into the causes of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/M.E.). The aim is to promote new and innovative partnerships between researchers already working in the CFS/M.E. field and those in associated areas, such as pain and fatigue. The aim is also to encourage and support more high-quality CFS/M.E. research proposals.

“CFS/M.E. is a complex and debilitating condition with a diverse range of symptoms. Profound physical and mental fatigue is the most well-known, while others include pain, disturbed sleep patterns and concentration and memory problems. Each patient experiences their own personal combination of symptoms. CFS/M.E. affects around 250,000 people in the UK.

“The funding call will focus on one or more of six priority areas identified by the MRC’s CFS/M.E. Expert Group in consultation with research leaders in related areas and representatives of two major CFS/M.E. charities [ie. Action for M.E. and the ME Association]:

- Autonomic dysfunction (malfunction of the nervous system)
- Cognitive symptoms
- Fatigue
- Immune dysregulation (eg. through viral infection)
- Pain
- Sleep disorders

“Full details of the funding call will be published here by mid-February 2011 following consultation with the [MRC CFS/ME Expert Group](#): “The deadline for submitting proposals will be around June 2011, to allow time for new partners to discuss and develop their research ideas.”

Action for M.E.’s Sir Peter Spencer has welcomed the news, saying:

"Money for research into the biology of this misunderstood and debilitating illness has been urgently needed for some time. I am especially grateful to the MRC for recognising this during this time of economic cutbacks. The men, women and children - some as young as four - who battle daily with M.E. deserve to know what causes their head, muscle and joint pains, their shattering exhaustion and their other symptoms. More research is vital if we are to find not only the cause but more effective treatments and a cure."

**With thanks to Action For ME ([www.afme.org.uk](http://www.afme.org.uk))**

## **Reminders**

**Equipment Hire:** We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on .

**Email Chat Group:** Our Yahoo! Chat group is another great way of keeping in touch with other members between meetings. Unlike a conventional chat room, contact is made by email and/or message board, so you don't miss out if you are not online when a message is sent and can catch up at any time that suits you. On our Yahoo Group home page we have also built a large database of links to information and services that we have found to be useful. To join, email [dave@mesupportgroup.co.uk](mailto:dave@mesupportgroup.co.uk) or visit:

[http://health.groups.yahoo.com/group/Bury\\_Bolton\\_ME\\_CFS\\_Support\\_Group/](http://health.groups.yahoo.com/group/Bury_Bolton_ME_CFS_Support_Group/)

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