

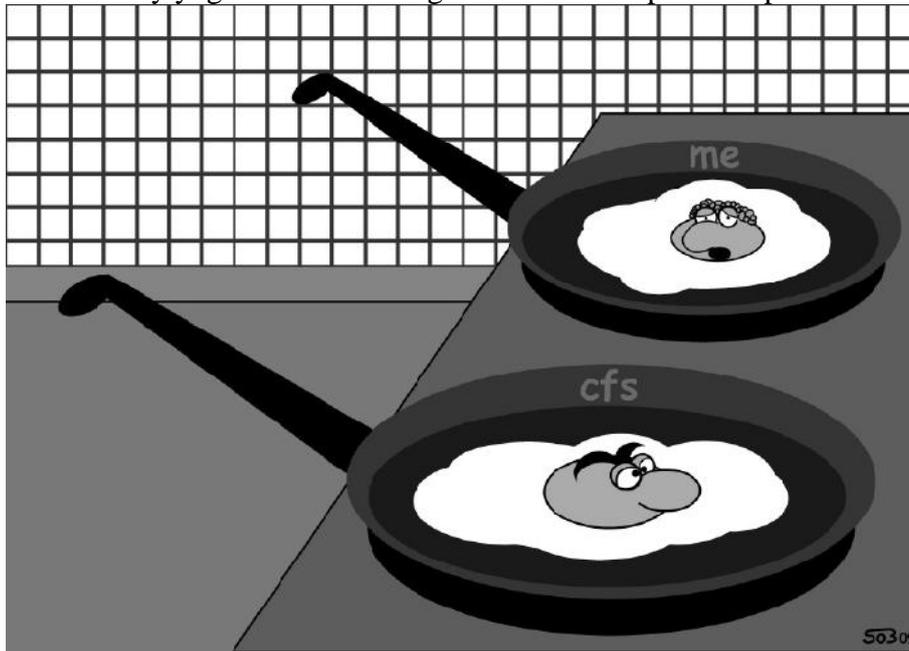


Welcome to Our February 2012 Newsletter

A Note from Alex: How did you find last month's word search, if you found it a bit taxing you can find the solution on the back page and a Sudoku puzzle that I have made up for you when you have time.

You will also find included with this month's newsletter the Agenda for this year's AGM (Thursday 15th March 7.30pm at the Longsight Methodist Church Hall) and the minutes from 2011's AGM,

with instructions on how to cast your vote for our committee members if you are unable to attend. Please note that the weekly yoga class has changed its times to 3pm- 4.15pm.



Does your brain feel as fried as mine does today?

With thanks to Invest in ME (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:

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**Supported by:
Health for Bolton and the
Big Bolton Fund 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 16th February 2012. – **Sarah Skinner** of Forever Living, will be talking about the benefits of Aloe Vera. We will also be carrying on with the book swap. A donation of 50p for each book you choose would be gratefully accepted (may be able to arrange discount for bulk!)

Thursday 15th March – AGM. For the full information & Agenda please see the enclosed leaflets with this newsletter. It also has details for casting your vote if you are unable to attend. We will also be holding a raffle full details also included on agenda. We would appreciate it, if as many of you can attend the AGM in order to show support for the committee and our support group in general. The AGM should last about an hour at the most.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 5th March 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. **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!**

Yoga Classes: Are **3:00pm-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 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 for information about meeting times and locations.

IF YOU ARE THINKING OF ATTENDING ANY OF OUR SOCIALS, WHETHER YOU ARE A NEW MEMBER OR A MEMBER WHO HASN'T BEEN ABLE TO ATTEND FOR A WHILE, PLEASE REMEMBER THAT YOU CAN BRING ALONG YOUR CARER OR A FRIEND. WE DON'T BITE, BUT WE UNDERSTAND THAT MEETING NEW PEOPLE OR IF YOU HAVE BEEN HOUSE BOUND FOR A WHILE, IT CAN BE QUITE DAUNTING GOING OUT BY YOURSELF AND WE'LL LOOK FORWARD TO SEEING YOU.

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

The New DLA & ESA appeal guides are just out. If anyone needs any of the Benefit & Works guides please contact Phil Seddon on 01204301713 or email phil@mesupportgroup.co.uk as he had taken over from Dave.

Bury/Bolton ME/CFS Support Group Meeting

January 2012

Our January Meeting was to be a book swap and Professor Carolyn Chew-Graham had asked if she could come along to talk to members about the METRIC Research Programme being undertaken by her team at Manchester University.

Unfortunately the day dawned with poor Professor Carolyn suffering from a very sore throat and cough so she had to postpone her visit to us.

However we had an update from Carol and Phil who had attended an input group meeting with the research team earlier in the day and from Pam and Yvonne who had attended a management group meeting the previous week.

METRIC is the ME Training and Resources in Primary Care and the aim of it is to provide GPs and Practice Nurses with information, training and resources to enable them to diagnose ME accurately and confidently, also to provide information for newly diagnosed patients.

The input groups and the members who have been interviewed in their own homes have given lots of information to the team regarding how they felt the doctors should discuss ME with their patients and what the doctors can do to help.

The research team have taken notice of everything that has been said and are in the process of developing an on-line programme of information, leaflets and DVDs for both doctors and for patients.

Carol and Phil saw some of the DVD at the meeting earlier in the day and said it was great to hear some of the things being said and to realise that it was something that they had said in one of their meetings. They felt that the research team have really listened to them and they are happy with the progress being made.

The update provoked an interesting discussion.

The book sale proved to be quite a success, the books were sold for 50p each, and several people including myself brought books in and took quite a few different ones home.

All together we made £26.50 on the sales. The book sale will be available again at the next meeting.

Requests For Your Help.

Yoga Grant

As you all know from last months newsletter we were successful yet again to receive another grant, so we can continue our weekly yoga sessions. To show our appreciation please could you write a few words of thanks either by e-mail or post to me. I know we asked you to do this a few months ago but this grant is from different funders/sponsors. We feel that it is important to let them know how much the weekly yoga helps you and what you get out of it. Email: alex@mesupportgroup.co.uk Address: 49 Lepp Crescent, Brandlesholme, Bury, BL8 1HX.

Do you live with a person with CFS/ME?

This study will investigate close interpersonal relationships in CFS/ME.

Why is this study being done?

We are interested at looking at the emotions, beliefs and behaviours of CFS/ME patients and individuals close to them (referred to as significant others), and differences in patient symptom patterns.

Who can take part?

Individuals with a current diagnosis of CFS/ME, who are aged 18+ and have a significant other (friend/relative) who would be also willing to take part in the study.

What happens to people who participate in the study?

Participation in the study will involve three parts. First, a research pack containing questionnaires about your CFS/ME will be sent to you. Secondly, the researcher will visit you to discuss your illness and your relationship with your significant other, lasting approximately 30-45 minutes. At approximately 6 months following the first part of the study, a second set of questionnaires will be sent for you to fill out and return to the researcher.

Confidentiality

All information which is collected during the course of the research will be kept strictly confidential. No information that is collected as a part of the research will be passed on without prior consent.

Assessments will be conducted by:

A PhD researcher working on the study.

If you are interested in taking part or would like some more information please get in touch with the researcher directly. Please telephone:

01613060444 or 07950806046 Email: Rebecca.band-2@postgrad.manchester.ac.uk

The College of Medicine's Workshop on CFS/ME **from an Integrative Approach** by Dr R Perrin

REPORT FROM DR RAY PERRIN DO PhD ON THE COLLEGE OF MEDICINE'S WORKSHOP ON CFS/ME FROM AN INTEGRATIVE APPROACH.

On Wednesday 18th January I attended a day's workshop on CFS/ME at Queen Mary College, University of London. I was asked by Michael Watson to attend on behalf of the BOA and it was a privilege to represent my profession in what turned out to be a thoroughly illuminating day. The event was run by The College of Medicine which is an institution that has been established to bring together all health care professionals including the complementary health practitioners, scientists and patients to bring about better medicine and a better health service.

The meeting at QMC was formed of a dozen practitioners including a homeopath, Chinese medicine specialists, reflexologists, researchers, carers and patients. It was a cosy group of individuals gathered to discuss CFS/ME and all the problems concerning patients and practitioners who are trying to battle this disorder that affect over a million individuals across the nation according to a recent study from the University of Bristol.

The workshop was ably chaired by Mrs Jennifer Archer from the College of Medicine. The first speaker at the meeting was Kings College Professor of psychiatry Simon Wessley. He and I have both been involved in CFS/ME since 1989 at different ends of the spectrum. Whilst my work supports the idea that CFS/ME is a physical disease, his work has often been viewed as interpreting CFS/ME as a psychological condition. However in this meeting he actually spoke language that addressed the audience looking at an integrative approach. CFS/ME he agreed was a real illness which flummoxed medicine in general. However when patients suffer with CFS/ME they also feel frustrated and eventually depressed because of their symptoms. They do less and less and their muscles become de-conditioned. This then leads to a reduced tolerance for activity which leads to frustration. Further failed attempts at activity lead to helplessness as the patient becomes further fatigued. He told the group that in The Eighties and Nineties most GPs believed it wasn't a real disorder. In fact he read out a referral letter he received from one doctor which was worded, "Please can you see this patient. There is nothing wrong with her. "

Professor Wessley told the group that at Kings College Hospital his unit were very successful at treating low mood and anxiety with CBT and muscle de-conditioning with graded exercise therapy. I did point out it was all to do with timing and that you cannot tell somebody who has pushed themselves for years which has finally ended in CFS/ME to push themselves further. He agreed and said that first they have to avoid overexertion when ones energy levels are high but at the same time they must try to do some activity when feeling unable to do much. In other words consistency and balance are the key to better health whilst avoiding the boom and bust mentality that plagues so many CFS/ME patients. It was wonderful to hear a man vilified by many for allegedly classifying CFS/ME as a form of depression saying his views have been wrongly portrayed by the press. He concluded with a humorous quote by a neurologist "If we could identify the problem with the brain we could tell patients it is not all in their heads!"

The groups were then divided into small groups of four to discuss the topics raised and develop ideas that could change how we view CFS/ME and manage it in future.

The following ideas were discussed:

Early diagnosis needs to be made with possible biomarkers and/or physical signs of neuro-lymphatic problems. There could be different levels of intervention in the NHS regarding the management of CFS/ME with the less severe patients using self help education tools such as books , CDs and websites and peer groups to improve their help and inform the patients of what treatments (conventional and complementary) are available.

The College of Medicine's Workshop on CFS/ME

From an Integrative Approach Cont...

Patients who are affected more could have low cost interventions focussing on the mind, muscle and metabolic changes and those with very severe symptoms should receive specialist care focussed on their particular needs.

There was also a presentation by Professor David Peters, clinical director of the school of life sciences at the University of Westminster. Prof Peters is not only a trained GP and musculoskeletal physician, he is also a qualified homeopath and an osteopath. He demonstrated the College of Medicine's on-line self-care library which he has developed which helps inform patients of advances and research of many medical conditions including CFS/ME.

There was a lecture on traditional Chinese medicine's approach to treating CFS/ME by Dr Andrew Flower PhD of Southampton University. He stressed the Chinese belief in balance and that CFS was a complex presentation of a number of different pathological syndromes and so one should treat the person and not the disease. The aim of the treatment on CFS/ME in Chinese Medicine is to drain the pathogenic factors and strengthen the energy within the body which supports my osteopathic concept of the disease and its treatment.

The final talk of the day was CFS/ME from the first hand perspective by Clare, a recovered patient. Clare was very ill for many years, housebound and unable to even feed herself. However with help from a number of therapists she gradually recovered. She commented that the two therapists who got her started on the road to regaining health were both cranial osteopaths. Since that time, she has found using techniques from neuro-linguistic programming (NLP) particularly helpful in building and maintaining recovery.

She spoke about her elation at getting up in the early hours in Dorset, where she lives, to take the train into London for the meeting. The joys of a normal day doing what she wanted and travelling to the Capital without the worry that tomorrow she will suffer. With CFS/ME it is post-exertion malaise that destroys patients' lives and now Clare appreciates every healthy moment and it showed in her exuberant, impassioned talk.

I thoroughly enjoyed the day and I could not help but think that an integrative approach to CFS/ME is the way forward for the NHS and that more of these seminars need to be arranged. In fact The College of Medicine is organizing a second workshop in Birmingham on 7th February. For more details go to the College of Medicine's website at www.collegeofmedicine.org.uk

Ray Perrin

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New Student Hub Forum on Action for ME

Action for ME is pleased to have launched a new student hub forum on their website at a time when many are in the process of applying to university or college.

http://www.actionforme.org.uk/get-involved/join-a-discussion-forum/student-hub-forum?dm_i=1HO,O4D6,1SU6NE,1Y47U,1

Designed especially for those with M.E. planning to attend university or college, or those already studying, it provides a dedicated place for peer support and friendship and joins other forums on their website, such as the popular M.E. Friends Online forum.

It greatly enhances the student hub on their website which contains a wealth of information on various aspects of being a student. Please do share with anyone who might find any of their discussion forums helpful.

Treating pain in CFS/ME – Conventional and Alternative by Andrew Levy

SUMMARY OF AN ARTICLE BY DR NEIL ABBOT, WHICH APPEARED IN BREAKTHROUGH MAGAZINE WINTER 2011. THE ADVICE IN THIS ARTICLE IS A GUIDE ONLY, AND YOU SHOULD DISCUSS YOUR SITUATION WITH A DOCTOR OR OTHER QUALIFIED HEALTH PROFESSIONAL.

The cause of pain in CFS/ME, is an issue which still hasn't fully been answered. However, some progress has been made after the publication of research from Glasgow Caledonian University. They analysed 50 CFS/ME patients and looked at their perceptions of alternative therapies in helping their pain. They also looked at their perceptions of complementary medicine, physiotherapy and pain management strategies. None of the patients had any other long-term physical or mental conditions. The team collected information on the pain associated with their illness, the treatments they had tried and how successful these had been.

The Results

Acupuncture was the most popular therapy, used by 23 patients. 14 of them said it helped relieve their pain. Eight patients stopped the treatment because it was too expensive, and six had difficulties travelling to a clinic. Information on acupuncture's effect on ME/CFS is cloudy, because most of the studies took place in China where the scientific quality of each study was "poor". However, other clinical studies have shown acupuncture to be helpful for conditions such as lower back pain, but only as a supplement to conventional treatments.

Massage followed acupuncture as the next most popular therapy, used by 18 patients. Only 5 experienced pain relief and the majority felt pain actually increased, especially the next day. Deep and firm pressure was used during the massage, although the researchers pointed out that more than 80 different styles of massage were available. They felt gentler pressure could be more effective for CFS/ME.

Out of 17 who tried reflexology, only 4 reported a benefit. Nine said it had increased the pain. The other therapies were tried by six or less, so an accurate assessment was not possible.

27 had received physiotherapy, although the variety of treatments were too varied to make any firm conclusions. However, those involving gentle exercise seem to be the most effective. Most patients had tried to manage the pain through some physical activity, with pacing and stretching the most successful. Graded exercise was often prescribed by physiotherapists, but 11 out of 12 reported an increase in pain.

Cognitive behavioural therapy helped 11 patients, but 13 said it was no use. 22 refused to have the therapy when offered.

Which one should you choose?

Dr Abbot thinks it's pot luck which alternative treatment or therapy may work. Scientific evidence is not conclusive and some may work for some but not for others. The research provides a snapshot of alternative treatments, but doesn't give a measure of how effective they can be. Even so the results show it could be worth looking into acupuncture, soft tissue massage and gentle exercise. Other methods of easing pain were having a warm bath, applying a heat source e.g. hot water bottle and lying down and drinking water.

The research team also pointed out the failure of conventional methods to provide effective pain relief. This is why patients will continue to look for alternative methods to help them. Dr Abbot recognises this, but hopes patients don't have to spend large amounts of money "on the more outlandish therapies that have little chance of working".

Treating pain in CFS/ME – Conventional and Alternative Cont...

PS: What conventional painkillers are available?

In a related article, Dr Alistair Miller offers some useful advice. He also points out that the cause of pain in CFS/ME remain unexplained. Effective drugs used for relieving pain for other illnesses or trauma may not be as effective in someone with CFS/ME .

Pain can be caused by inflammation (e.g. arthritis), pain in the organs (visceral) or through nerve damage (neuropathic). All 3 varieties could exist in a person with CFS/ME. So the best approach is to diagnose the cause of the pain first, and then treat it. On top of that, a patient should be offered reassurance, psychological support and the appropriate pain killers (called analgesic).

Different types of pain killers (analgesics)

Paracetamol: For most types of pain paracetamol acts as a powerful painkiller. It is safe in a normal dosage, no more than 4 grams per day, and there are virtually no adverse reactions.

Non-steroidal anti-inflammatory drugs (NSAIDs) : As their name suggests they act on pain caused by inflammation. Examples include Ibuprofen, naproxen and diclofenac. Side-effects could be indigestion, ulceration and gastric bleeding. NSAIDs can be taken with paracetamol to have an additive effect.

Opiates: If this doesn't work you could try the next level called opiate drugs. These drugs were originally developed from the opium poppy, and morphine is probably the best-known. Codeine is a weaker opiate, although diamorphine, i.e. heroin, is much stronger. Other opiate drugs include dihydrocodeine, pethadine, fentanyl, tramadol and dextropropoxyphene. The side-effects of opiates can vary. They affect the perception of pain and can produce euphoria. Once taken, the patient might be aware of the pain but might not be bothered by it.

Neuropathic painkillers: These drugs work on neuropathic pain e.g. damage to nerve endings. They fall into categories such as antidepressants (e.g. amitriptyline and dotheipin) or anti convulsant (anti-epileptic drugs such as phenytoin, carbamazepine and pregabalin). Amitriptyline may be helpful with CFS/ME patients, but at a much smaller dose than originally intended. It can help control the pain and help with sleep. Side-effects include dry mouth and urinary retention, but this will be lessened by a smaller dose.

Recommendations

The World Health Organisation describes an “analgesic pain ladder” on how to prescribe painkillers. The idea is to start at the bottom of the ladder prescribing the least possible dose and potency to control the symptoms. The ladder has three stages: 1) non-opiates such as paracetamol and NSAIDs, 2) weak opiates such as codeine or tramadol and 3) strong opiates. The prescription of each should not be mixed with another type of painkiller or other drugs. So Dr Miller concludes by saying that paracetamol is the safest drug to be taken in the long term. Adding ibuprofen maybe the next step, but watch out for the risk of an upset stomach. Finally low-dose amitriptyline could also be worth trying along with the alternative therapies and treatments mentioned above.

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 01204 793 846.

Amazon.

Don't forget if you are buying anything from Amazon our group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk.

Ministers Urged not to Pass the Buck. Acton for ME Website

18th January 2012.

Action for M.E. warned the Government today that the figures for individuals suffering from long term neurological conditions have been grossly under estimated as people with M.E. have not been included.

Yesterday, the Neurological Alliance <http://www.neural.org.uk/> - which represents 70 health groups – warned the Care Minister that there were already more than 200,000 people suffering from long term neurological conditions and that with an aging population this was a ticking timebomb for the NHS.

A study published last month by the National Audit Office <http://www.nao.org.uk/> highlighted delayed diagnosis, poor information, uncoordinated follow-up care and variable access to services regionally as all contributing to burgeoning problems for the NHS's future care of neurological conditions.

"M.E. currently affects 250,000 adults and children in the UK," said Sir Peter Spencer KCB - Chief Executive of Action for M.E., "and no other illness has such a devastating impact on so many people but has so little money spent on scientific research or the provision of specialist healthcare."

Care Services Minister Paul Burstow said: "We know that care for people with neurological conditions is not good enough and we must do more". The Minister added that government was considering investing in services like Telehealth to individualise long-term care.

Action for M.E. has advised Paul Burstow on the problems encountered by M.E. patients but were told that the decisions on providing their healthcare had been delegated to local healthcare commissioners.

Sir Peter Spencer said: "During my 38 years in the Royal Navy I had a very clear understanding that delegation of a task did not ever relieve me of the responsibility for seeing that it had been properly executed. The same principle must be applied to Ministers. Otherwise it becomes what is known in all three armed services as 'sloping shoulders' or simply passing the buck."

"ME is a neurological illness that has been neglected for far too long. It must be included in the Government's plans for a general improvement in the care of people with long term conditions and this will require much more than investment in Telehealth," he said.

The 'Tougher' New Blue Badge

Measures to crack down on drivers who park in spaces for disabled people came in to force on 1st January 2012. They include a new design of the 'Blue Badge' which is harder to forge.

They come at a price. If they wish, local councils can now charge up to £10 for a Blue Badge instead on the old cost of £2.

The badge will be electronically printed, much like a driving licence, and include new security features – a unique hologram, digital photo and serial number which will be easier for parking attendants to take down details through the windscreen.

Transport Minister Norman Baker said: "Motorists who pretend to be disabled to get free parking are frankly disgraceful. They prevent real Blue Badge holders from using parking bays designed for those genuinely in need and they cheat the majority of road users who play fair.

"Our new Blue Badge will be as secure as a banknote."

There are fears that the new eligibility rules will result in fewer people with ME/CFS being able to get a Blue Badge. If you have been denied one under the new rules then the ME Association would like to hear from you. Address: The ME Association, 7 Apollo Office Court, Radclive Road, Gwcott, Buckinghamshire, MK18 4DF or Email: administration@meassociation.org.uk

