



Issue: 49

June 2010

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 caroline@mesupportgroup.co.uk
Membership Secretary, Newsletters & Distribution:	David Gore	07919 234256 Dave@mesupportgroup.co.uk
Link Up Co-ordinator:	Stephen Walker	01204 842395 stewalker@postmaster.co.uk
Librarian:	Carole Senior	01942 810320
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 andmk1@googlemail.co.uk

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**

Supported by:

Community Foundation for Greater Manchester
Managed by the Community Development Foundation
Funded by the Office of the Third Sector

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 17th June 2010 – Social.

Thursday 15th July - Hugh Templeton will conduct his ever-popular watercolour workshop. You won't need any materials, and should go home with a completed painting.

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

Bury Socials: These are continuing on the first Thursday of every month, the next will be **Thursday 1st July, 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.

If you need any more information, please phone Sheila on 0161 7970026 after 12noon.

Yoga Classes: Are **3:15pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 01706 829488, or olivia@oliviayoga.co.uk 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. Guest speakers are in attendance most months. Call 0161 743 3701 or visit <http://www.gmneuro.org.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.

Please note that there is a new contact number for Dave: 07919 234 256. This number is for all membership, newsletter and Benefits & Work Guide enquires.

For anyone who hasn't already done so, please don't forget to send in your membership renewal forms. If you do not renew, next month's July newsletter will be the last you receive, also you will not be able to attend the 20th Anniversary meal. 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.

Please carry on sending us anything you'd like to share with the rest of the group. It doesn't matter if it's a few lines or a few pages, it all counts! It could be recipes, tips, your experiences with ME, book reviews etc. Please email your contributions to: Dave@mesupportgroup.co.uk, or post to Pam Turner at 7 Burghley Drive, Radcliffe, M26 3XY. Alternatively, if you have an idea, but you prefer not to write about it yourself, then please contact Andrew (0161 798 6183 or andmk1@gmail.com) and he will discuss it with you and write it up on your behalf.

Bolton/Bury ME Support Group Meeting May 2010:

The Alexander Technique

Charles Tully made a welcome return visit, after many years, to once again tell us about the Alexander Technique.

He started by saying that it is about the choices you make and how you look after yourself. The technique is not a cure but it enables us to recognise that we have a series of choices which will enable us to feel better.

Charles works with many athletes and performers and can help them to change habit patterns which helps them to perform better. He explained that the technique is about poise and balance and thought.

We pick up habits all our lives from early infancy and Charles asked us to imagine a two year old, bright and alert, sitting up straight, eager to learn and lively. Then we pick up habits from family, we go on to try to fit in with groups picking up body language. He then explained that if you adopt a certain pattern such as slumped shoulders, head down it will very often affect your mood and you feel down. Life events can cause habits to form, e.g. If you have an accident and develop a limp whilst you are injured, the limp can often remain long after the injury is gone and we are better.

Charles explained about muscle memory; if we do a certain action more than 30 times we get muscle memory, e.g. If you hold your hand or shoulder in a particular way it starts to form muscle memory and becomes painful, this is repetitive strain injury.

The key is to try to be relaxed and do things differently. He demonstrated how difficult it is to change pattern by asking us to fold our arms, then fold them with the other arm on top and note how difficult it feels. The more you practice doing it differently the easier it becomes.

Then he asked us to guess how heavy is a head and said it is about 10lbs in weight, he passed round a bag weighing 9 1/2 lbs to show how heavy it feels. Then he explained that it is most important to have good alignment of the head taking the weight down the spine, through the legs to the feet. If it is out of alignment the back will move to accommodate it and we have pain. Stress causes the neck muscles to tighten up and this puts the head out of alignment.

Charles explained that even when we think about an activity the muscles begin to respond; he then described the most comfortable way to sit. Head up, sit with your weight on your sitting bones and this aligns the back and is comfortable. Mechanically we need the alignment. Let the arms drop down by the sides with the weight falling through the hands to the floor. It is important to keep the shoulders down as this takes the strain from any activity.

Always think about the process of movement and choose to move efficiently and this saves energy, be aware when you are tightening up and when you need to stop. Looking after yourself is very important. Many aches and pains can be from tension and relieving tension can help.

There was then some questions and discussion about comfortable positions for sleep and for driving.

Charles told us that Alexander was a performer and an actor who found that he was losing power, so he watched himself in a mirror and saw where he was tensing his muscles and by making changes he improved his performance.

Then he told us the number one secret for helping to relieve back ache; he asked for a volunteer to lie down on the floor with books under her head to keep the neck in alignment. He said that if

we adopt this position, building up, to about 20 minutes a day it realigns the back and relieves pain, the knees should be bent upwards to take any strain off the lower back. Charles then did some very gentle movements of the hands, arms and shoulders of the volunteer to show how gentle are the manipulations and movements used by the practitioner to help us to think differently and to help us to make the choices both physically and mentally which let us look after ourselves better.

Charles works in Bolton on Wednesdays and reminded us that he is a teacher and not a therapist. Sessions last for between 45 minutes to an hour. Charges are £35 during the day or £40 in the evening.

Charles can be contacted on 0161 947 9184

Charlestully@ntlworld.com

www.charlestully.co.uk

St Cyril's Rehabilitation Centre

Chronic Fatigue Syndrome CFS/ME Specialist In Patient Rehabilitation Programme.

Patients with severe ME can now be referred for in patient treatment and rehabilitation at St Cyril's Rehabilitation Unit, Countess of Chester Hospital, Liverpool Road, Chester.

The staff have recently had courses of training about ME/CFS and are therefore able to accept referral to the Unit. Referral is particularly welcome if it is via the local community ME/CFS rehabilitation teams to enable collaborative working and sharing of findings. However self referral or referral from health care professionals are considered.

The Rehabilitation Programme will be tailored to the individual and may include all or any of the following:- 1. Desensitisation programme, 2. Talking therapy which may include Cognitive Behavioural Therapy, counselling etc. 3. Graded activities; very slow and gradual increase in the level of activity supported by occupational therapists, physiotherapists and psychologists. 4. Thorough medical review including review of pharmacological interventions, pain management, sleep management, identification of allergies, mental health assessment and further investigations. 5. Assessment of the psychosocial situation, the team will address any significant issues with the patient, social services and the local ME/CFS services.

Team input during admission:

Medical review: 3 times a week; consultant ward round once a week; occupational Therapy once a day; physiotherapy once a day; psychology twice a week; assistant therapist four times a day; dietetics once a week.

Poetry Corner

If only life came packed, with manuals we could read,
A list of clear instructions and all parts guaranteed.
But oh, life's not so simple, no useful hints or tools
We have to muddle through it without the help of rules.
Yet one thing that we do have are others by our side,
To help support and cheer us, in whom we may confide.
For as we share our knowledge, so ignorance takes
flight,

By working close together we'll surely get it right.

By Margaret Ingall

Tragedy

That morning when my wife eloped
With James our chauffeur, how I moped!
What tragedies in life there are!
I'm dashed if I can start the car.

by Harry Graham 1874-1936

Exercise Revisited

In December 2008, Peter Gladwell, Clinical Specialist Physiotherapist at the CFS/M.E. Service, Frenchay Hospital, Bristol, asked InterAction readers for their thoughts and experiences of exercise. Here Peter responds to some of the issues raised.

Definitions of exercise vary, but most people tend to think of exercise as being the same as physical exertion: pushing the body to the maximum, in order to build fitness. In our clinic, however, the starting point with exercise is to redefine it in a more useful way.

A helpful definition is to think about exercise as 'any movement which is performed with the aim of improving your health.' Using this definition, many gentle movements can count as exercise. Even sitting up in bed can be thought of as an exercise.

However, daily activity may not always help us to make the most of our abilities, which can be usefully thought of as the 'four Ss': Strength, Stamina, Suppleness and Stability. I have met many patients who have made progress by focusing a small amount of energy on one of these categories, which they recognised were important for them as an individual.

Yoga v mini trampoline

Jo wrote: I've had M.E. twice. The first time was in 1992-95. I avoided exercise, rested as much as possible and made a full recovery. I was fortunate in that I was a student at the time, whose GP and course tutors were supportive and I could relatively easily adapt my daily activity to my energy levels.

My second experience of M.E. began in 2006, when I was 32 and I'm now recovering. This time I was referred to an NHS-run treatment programme. It consisted of a half-day group meeting once a month or so, at which nurses gave information and advice. We were grouped according to our levels of activity and, as I was still able to work part-time, I was with others who worked or studied at least part-time. A great deal of emphasis was placed on exercise.

I was sceptical but wanted to show willing. However, in the format of the meetings there was no time for individual attention and no specific advice was given. We were told we could choose pretty much any type of exercise, as long as we built it up gradually. Suggestions included marching and standing. I was confused about the difference between exercise and the sort of activity I was doing on a daily basis anyway, getting myself to and from work and so on. I think others were too but we didn't get clarification.

I had a mini trampoline at home, so decided to use that. I thought I was being very careful, starting with just a few bounces and increasing by one bounce each day, but after a few weeks I'd developed a pain in my hip. At the time I didn't think it had been caused by the trampolining but I stopped anyway.

The pain became quite severe and continued over several months. I took painkillers and tried osteopathy, acupuncture and physiotherapy. The physiotherapist said that the problem had most likely been caused by the trampolining. She said my muscles would have been very weak because of the M.E. and that trampolining had caused certain muscles to go into spasm. Building up gradually didn't stop me getting injured, because the exercise itself was unsuitable.

Eventually, I discovered that very gentle yoga (using an Angela Stevens CD) was effective in alleviating the pain, although I still have occasional discomfort over a year later. I believe that the yoga also helped my overall recovery from M.E. Speaking to others on the treatment programme, I found a number had also had problems with the exercise they'd tried. Interestingly, one of them told me that the nurses had advised her against yoga.

My belief now is that exercise can be beneficial but needs to be approached with caution. I think where graded exercise programmes are successful it could be where the patient finds an exercise they enjoy and the enjoyment itself is healing. All too often M.E. takes the fun out of life.

I remain sceptical that it can be beneficial to 'force' yourself to do something physically demanding when you feel ill with M.E. Although I tried to be disciplined about doing yoga every morning, I varied my routine according to how well I felt, even if that meant I only did the relaxation section. If I felt really ill I'd have a day off, but it wasn't hard to motivate myself because it seemed to be generating such noticeable improvement.

When I first started, I was shocked at how difficult even the most basic movements were and I realised just how weak I'd become, despite having remained reasonably active. So I think exercise can be useful in helping regain strength.

Over the last year I've been substantially better and have returned to working full time. I have had relapses but yoga has helped with these too.

I'm quite concerned about the treatment programme I attended. I think the advice given was misguided, if not dangerous, and people were made to feel they wouldn't get better unless they went along with it. I'm glad that Action for M.E. is looking at this issue.

Peter comments:

Thank you for your letter, which was one of a number which mentioned yoga. I think you were very unlucky to develop hip pain. It sounds as if you did the sensible thing in starting gently and building up slowly. Unfortunately, hip pain is quite common and can affect people with or without M.E. In most people it is probably 'multifactorial', in other words a wide range of factors affects whether an individual develops it at a particular time, or not. This is the first case of hip pain following use of a mini-trampoline which I have heard of, so I wouldn't like to put anybody else off who thinks that they may enjoy using a mini-trampoline, as long as they start gently and build up slowly.

I am pleased to hear that you have gained benefit from a gentle approach to yoga. There are, of course, different levels of yoga, some of which can be very strenuous. It may be that the nurse who warned against yoga was not aware of the gentler forms.

Yoga can be started with only one posture. It can help to think about the simplest version of the easiest posture to start with, even if it feels too easy. If somebody starts with too little exercise and finds that it is sustainable, then they have learned some very useful information which they can build on. If somebody starts with too much exercise, and finds that it is unsustainable, the information which they have learnt is less useful and the experience is often unhelpful. I agree with you, it definitely helps to incorporate exercise with other self-management strategies, especially pacing, but also relaxation.

However, I don't think we're in a position yet to be strongly recommending one form of exercise over another! One person may prefer to start with yoga, another with walking, another with Tai Chi. I think it is useful to remember that each form of exercise is likely to be more helpful with some of the 'four S' categories (strength, stamina, suppleness and stability) than others: this allows an individual to think about their own needs.

Sometimes, a gentle stretching program can be worth exploring, because it is low-energy, relaxing to do and can help with suppleness, balance and coordination. These forms of movement can help some people to maintain the equilibrium between recuperative rest and movement on a quieter day.

Pushed beyond my capabilities

Mrs Drake writes: Regarding exercise, I have found from painful experience that all exercises must be performed slowly with the body as relaxed as possible and when a new exercise is added (or an existing one increased) it should not be repeated for at least 48 hours. If any particular exercise

causes discomfort it should be stopped immediately and not attempted again for 24 hours. In the past I have suffered setbacks through being pushed beyond my capabilities by a physiotherapist who would not accept my explanation that my exercise tolerance is inconsistent and I need to stop before getting tired. Pacing is vital. I now flatly refuse to push myself beyond my capabilities for anyone.

Peter comments:

I am very sorry to hear that you have suffered setbacks. You have worked out that exercise which causes discomfort is not sustainable for you. That might sound patronising and obvious but strangely, it doesn't seem to be a 'blanket rule' for everybody. People can experience the illness very differently. A reader called Ed, whose experience will be published in the next issue, is a good example. He said: "Getting up and going to work was like climbing a mountain every day but not doing so was even worse. The aching and lethargy just got worse with inactivity and it was that much harder to keep going if I stopped."

Many people with M.E. experience pain at rest – and also experience pain if they need to perform basic activities. From what we know about the nature of this pain, it doesn't seem to indicate tissue damage (which is what acute pain, which we often experience with tissue damage, is designed to do).

I really like your idea of doing exercises in a relaxed manner. I also agree that pacing is vital. Action for M.E.'s guide on Pacing offers some clear ideas about setting a baseline for activities, whether they are physical or mental. This can be a good starting point for somebody who is trying to work out what their baseline for a physical activity or exercise might be.

I often talk about "paced exercise" with the patients that I see. It can be difficult to know how much to do at first and as you recognise, exercise

tolerance in M.E. can be inconsistent. This is particularly the case because of post-exertional malaise, which someone will only find out about in the days after the exercise.

In the next issue, Peter will respond to a letter from Ed who, like many people with M.E., is forced to balance his illness with his need to work.

With thanks to InterAction

Microwave Cake-in-a-Cup (gluten/dairy free)

So simple and easy to make in just a few minutes.

4 tablespoons self-raising flour (gluten free or standard)

2 tablespoons cocoa (or for a plain cake, another 2 tablespoons flour)

4 tablespoons sugar

1 egg

3 tablespoons water

3 tablespoons vegetable oil

Mix well with fork.

Add a **handful of choc chips** or chopped chocolate.

Spilt between 2 mugs or large cups (with enough room for the mixture to more than double in size).

Microwave for 2 mins each (on 800W, so adjust time for other wattages).

Allow to cool and tip out.

Benefits & Work Guides

Our group is a member of www.benefitsandwork.co.uk, allowing us to access their fantastic guides to a range of benefits and disability related issues. The guides are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge, plus use of the Freedom of Information Act. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal. The group's subscription allows us to make these guides available to our own members. Please look through the list below and if you need anything phone Dave on 07919 234256 or email dave@mesupportroup.co.uk.

Please note that some of the guides are very lengthy (up to 88 pages) and so it can work out rather expensive for us to print and post them. After each guide listed below, is the number of pages in brackets, to give you a rough idea what it costs us to print and post them to you, here are a few figures:

10 pages - £1.00	20 pages - £1.80	40 pages - £2.70
60 pages - £3.50	100 pages - £5.50	200 pages - £11.00

If possible please help us to keep costs down by providing an email address we can send them to. If you do not have internet access yourself, perhaps a friend or relative could help out. Alternatively, if you go to one of our meetings, social groups, or yoga classes, you could pick them up from there and then return to us to be used again. We have some of the more popular guides in our library at the meetings, but if you can't see what you need please ask. We don't want anyone to miss out and will do our best to accommodate your needs, but perhaps if you do need us to post any of the longer guides to you (or several of the smaller ones), if you can afford to make a contribution towards the costs, it would be very much appreciated.

**Please note there is now an additional ESA guide: 'Work Capability Assessment Score Sheet'.
This will be useful to anyone who needs to understand how the points system works.**

DLA & AA

The best possible Attendance Allowance claims on physical health grounds (44)
The best possible Disability Living Allowance claims for adults on physical health grounds (61)
The best possible Disability Living Allowance claims for adults on mental health grounds (53)
The best possible Disability Living Allowance claims for children on physical health grounds (65)
The best possible Disability Living Allowance claims for children on mental health grounds (58)
70 questions you are likely to be asked at your DLA medical (5)
The best possible way to challenge a DLA or AA medical report (28)
The best possible support for clients with DLA and AA appeals (41)
Appealing against a DLA decision (16)
Giving persuasive information about how far you can walk (13)
Challenging the claim a bottle or commode will replace the need for help (8)
DLA renewal claims (6)
Changes of circumstances for people claiming DLA (8)
Letter claimant to decision maker requesting reconsideration because of additional evidence (3)

Incapacity for Work

The best possible incapacity for work claims on mental health grounds (43)
The best possible incapacity for work claims on physical health grounds (48)
Exempt but sent a questionnaire (7)
60 questions you're likely to be asked at your incapacity medical (3)

ESA

Understanding Employment and Support Allowance (43)
ESA claims for mental health and learning difficulties (88)
ESA claims on physical health grounds (65)
ESA appeals (35)

Permitted Work (6)
Knowing Your Rights at Pathways to Work Interviews (12)
Work Capability Assessment Score Sheet (12)
Other
If I do any work can I continue to claim my...? (4)
Caution, it may not count as voluntary work (5)
Am I covered by the Disability Discrimination Act? (9)
Which benefits can I claim? (9)
Reasonable adjustments: Employers and Jobseekers (8)
Work and benefits for people with long term health conditions (7)