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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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The Laptop Analogy

Explaining ME/CFS to 'normal' people is difficult because there is no frame of reference, you can try the usual:

- 'Imagine you have a hangover combined with flu.'
- 'Imagine you just got run over but had no visible injuries and were expected to just pick yourself up and push through it.'

Those kind of scenarios are not a good explanation.

How many people get drunk enough to have a hangover if they are already suffering from the flu? and who really knows what it's like to be run over unless it has actually happened to them?

Normal people will never understand unless they get it themselves.

A geek on the other hand will instantly understand if you tell them that the human body is a laptop and when it gets ME/CFS that it may have contracted an invisible worm or virus that has changed a couple of registry keys and moved a few system files.

Now things don't work the way they once did, programs crash for no apparent reason, it runs hotter when there's no program on the go and everything is just so much slower and harder than it was before – it looks fine, all the virus and adware scans have come up empty but you know there is something wrong.

Even the battery fails to charge, it only ever makes it to around 10% even changing the cable or the way you use it has no affect on the constantly annoying pop up saying 'please switch to mains' – some days it doesn't even start up at all even though the power light blinks at you to show there is life in there somewhere.

...but the casing still looks brand new and you'd never know there was a problem if you hadn't used it previously – you'd just think it was a crap laptop.

So how do we fix this?

Sadly we don't. Humans don't get a re-boot or a re-install, we can't save our memory to a backup system and when things start breaking down completely we can't mend it with a new one (well, mostly).

We are stuck with this computer for life; We can uninstall a few social apps and conserve energy by shutting down the least essential processes, but basically that's it.

Sucks to be ME huh?

**Thanks to Vics, for sharing this extract from her blog with us.
You can read more of it at <http://rosevibe.me.uk/blog/>**

Latest news on XMRV

Recently we told you about an American study, which reported a link between XMRV and ME/CFS – and that the first attempt to replicate it in the UK had failed to confirm the original findings. Now two more studies, one in the UK and the other in the Netherlands have been completed, they too have found no evidence of XMRV in ME/CFS patients. Neither of these studies used the same methods and criteria as the initial one, there are still other groups around the world working on it and we will update you when we know more.

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 18th March 2009, 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.

Please note there will be no meeting in April. The next meeting will be Thursday 20th May, details to be confirmed.

Radcliffe Socials *CHANGE OF DATE***:** Our Social Group usually meets informally on the first Monday of each month, however due to the first Mondays of April and May being bank holidays, for these two months we are changing to the second Monday. Our next will be on **Monday 12th April** and **Monday 10th May** at the usual time of **4pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. For more information please phone 05601 335037 or email Dave@mesupportgroup.co.uk.

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

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 provide information, advice and support for people with any type of neurological condition and/or their carers. Guest speakers are in attendance most months.

Bury Neuro Support meets most 2nd Thursdays between 4-6pm at Bury Parish Church Hall (Community transport available).

Neuro Support 4 Salford meets most 4th Fridays (11am-2pm) at varying venues whilst building work is being completed at their regular meeting place.

Call 0161 743 3701 or visit <http://www.gmneuro.org.uk> for information about either group.

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

Bolton/Bury ME Support Group Meeting February 2010:

Sue & Eric talk about Qi Therapy

Sue and Eric are both musicians as well as Qi Masters and so they began their talk by playing us a lovely piece of music; Air on a G String. Then Eric started told us his story: he was a professional classical guitarist, living in Australia at the time he became ill. He was so exhausted and ill that he could no longer play his guitar; not having the strength to hold the notes; nor could he teach and he was having stage fright.

One day, when he was out he came across a Chinese Medicine shop and it took him two years before he actually went into the shop. Inside it was very modern and although he expected to find an old Chinese person with a long beard he instead found a very dynamic team of young charming Korean people who practiced Qi therapy. Eric said that 9 months later he was climbing the mountains of Korea, he became very friendly with the people there, they were so generous and kind and he was so impressed when he saw people getting better that he began to learn how to give the treatment. He said that Qi therapy is not only for healing, but also for happiness and a better quality of life. Eric said that by helping others we learn to understand ourselves, he said that they help you to become your own doctor. Eventually Eric went back to Australia and he managed to do a tour playing his guitar.

He then explained that Inner Sound help people and that is anyone who needs energy to help to heal themselves and to get back to the life they had before.

Sue then told us her story, which started when she had glandular fever as a student. When she got better she found a job in Manchester but found it stressful and realised her energy was low. She played in the Halle Orchestra and had good friends and a busy social life. She started getting muscle and back pain also shoulder pain and irritable bowel syndrome. She began to worry all the time about making a mistake and was so worried about her body that her heart wasn't in the music and she began to feel more and more negative. Then she contracted a virus and was admitted to hospital with rapid heartbeat, palpitations and chest pain and was very ill, she also had a lot of head symptoms, she was sensitive to light, couldn't watch television; had severe headaches. She was seen by several doctors and specialists who didn't know how to help her, so she tried lots of alternative therapies e.g. Reiki, reflexology and did a life style management course.

Sue thought she would be better after two years, then after four years and eventually it was 10 years later and she was still no better. She tried reverse therapy with no improvement and eventually it became a more spiritual journey and she even tried attending a Quaker Friends Meeting but still felt something was missing.

Eventually she was at a Mind, Body, Healing Exhibition with a friend and was very sceptical because she had tried so many things. Then she heard the very distinctive shoo noises made by a Qi Master practicing; he gave her a treatment and although it was quite uncomfortable because of the pressure on her abdomen she found that afterwards she could walk around the exhibition much more comfortably and that evening she found she had more peace and felt better. She went back the following day and had another treatment and the Qi Masters asked her to go to London to their centre. She wondered how on earth she could manage it but did go with her husband for a few days in which she had a further five sessions and was very much improved and managed to do some sight seeing.

After this Sue arranged for some of the masters to come to Manchester monthly to give treatments and a year ago the Inner Sound Centre was opened in St Annes Square, Manchester. Eric is Master Sung and gives treatments there.

They said the treatment works by the Master using his energy as a kind of laser to the patients, to unblock their energy channels. Eric has done this work for 14 years and said he has seen the same

patterns emerging from patients with many illnesses including M.E. He said that the Master finds where the blockage in energy is situated and then directs his energy to the point to get the flow started again. Eric said that he has left his guitar in Sydney because any good guitarist can do that but he wants to help people.

Eric then tried to show us a simple version of quantum theory on his computer screen; he said we must try to think from an invisible aspect. He said everything is made up of very small particles of vibrating energy atoms, neutrons and protons all working together. He said some energies are denser than others and vibrate at such a level they appear to be solid and so we can make bricks, tables, chairs etc but they are vibrating energy just the same.

He said we are energy and everything we do is energy such as thinking, making decisions, walking, actions but something is not working properly. He said emotion is a form of energy and eventually we put layer upon layer of energy according to our emotion.

Eric then explained that the inner force in our bodies which regulates such things as our heart rate, our breathing, the growth of cells is what the Korean Masters call Qi energy and this energy is meant to be in a constant cycle. He said that if it becomes blocked there is a dysfunction in the body and of course if it stops we wither and die.

He said the Masters do not give you energy but they restore the cycle of energy in your body. Eric told us that electrocardiograms and electroencephalograms are measures of the vibrating energy in our bodies. He then went on to show us a picture of the energy centres in the body which he said are known as chakras; he said that there are seven of these going from the base of the spine up to the head. Eric has worked with many, many people and said that when we are happy the energy flows well but if we are sad it doesn't flow properly. He also said we are designed, like a mobile phone, to perfectly allow the flow of energy through the body but if for some reason we have a shortage of energy perhaps because of a bereavement or other stress, this opens you up to problems and they get locked in and the body and spirit are not in line. He said there is also much damage to the planet now which can affect the balance in our bodies.

Eric showed us some very interesting pictures done by a research chemist called Mr Imoto who does experiments with freezing water. The crystals made as the water freezes can make very different shapes and when loving and gentle vibrations are fed into the freezing water the crystals are beautiful and symmetrical but when harsh sounds are fed in the crystals are jagged and asymmetrical.

He said the energy field around you can be opened up to help the flow of energy round the body. Eric said to cultivate a beautiful mind, with such things as positive meditation and calm peaceful music, such things that make the crystals become beautiful and symmetrical.

He said that we must work with the invisible aspects of who we are to restore the balance.

Eric and Sue then gave short treatments to everyone who wished to experience the technique.

Inner Sound is situated on:
2nd Floor,
20 St. Ann's Square
Manchester, M2 7HG

Telephone: 0161 834 5681

Email: manchester@innersound.org

Web: www.innersound.org

Cost: £50 for a treatment and a consultation with Master Sung(Eric), or £30 for a treatment and consultation with Master Jung (a lady). It may be possible to put on a full day of treatments for a reduced cost if 20 or more people are interested in going together.

There are also Qi classes which they said help you to breath away stress with sound vibrations: strengthen and heal your body using slow movements and breathing exercises to activate energy and blood circulation: release pain and emotions using meditation as a tool to heal your mind and change negative patterns.

All-Party Parliamentary Group on ME **Inquiry into NHS Service Provision for ME/CFS Interim Report**

You may recall some months ago that we told you that the Countess of Mar was heading a group of MPs setting up an inquiry into services for ME patients. We had only a very short time to send our comments and so Pam replied on behalf of all our group. The interim report has now been issued which includes the following recommendations (in bold) having received over 400 responses from service providers, charities, sufferers and carers:

Recommendation 1

There were a significant number of submissions from PCTs stating that they do not have accurate patient numbers. PCTs who do offer adequate services could only supply numbers of how many people are using their particular service. There will also be an unknown number of other sufferers within the community.

The Department of Health should undertake research to determine accurately the numbers of patients with ME/CFS.

Recommendation 2

It is clear from the evidence that there are probably sufficient numbers of patients involved and sufficient uncertainties about the nature and availability of services to justify a measure in addition to the NICE Guidelines.

A national service framework should be created to complement the NICE Guidelines.

Recommendation 3

The All Party Parliamentary Group felt that many of the concerns and experiences submitted as evidence by patients, carers and patient organisations would have been addressed had the Independent Working Group Report to the Chief Medical Officer (CMO) of 2002 been acted upon adequately.

The DoH should revisit the report to the CMO and ensure that the recommendations relating to service provision are adequately addressed and are implemented promptly.

Recommendation 4

Lack in consistency in treatment options offered to patients in different PCTs. The Group has ascertained this from the evidence supplied by PCTs and patients. The APPG finds the degree of variation in the availability and access to services unacceptable. Patient evidence also indicates people want services that are physician led, multidisciplinary, and are situated in locations that are easily accessible to those with significant mobility problems.

The APPG recommend the DoH take steps to remedy the variation and ensure that each PCT offers a full range of services promptly – a process that should involve meaningful consultation with local patients or patient support groups.

Recommendation 5

Through the evidence supplied to the Group, it is clear that there is a significant lack of services available for children and adolescents. Many services only offer treatment options to patients over 16, which has led to many children not receiving adequate care. This is unacceptable and can lead to tragic consequences.

The APPG therefore call on PCTs, Strategic Health Authorities and the DoH to undertake a detailed review of current services for children and adolescents to ensure that all receive adequate care and that all decisions are made in conjunction with personal carers, education authorities and social services where appropriate.

Recommendation 6

From correspondence with the Royal College of Physicians and the Royal College of General Practitioners, the Group is not convinced that medical students receive sufficient training on

ME/CFS, including how to clinically assess and diagnose these patients and advise on appropriate forms of management.

The Group recognises that ME/CFS does not have the same obvious impact as cardiovascular disease or cancer, but that it is necessary for medical students to receive adequate training in ME/CFS. The relevant Royal Colleges should ensure that students receive training in this disease.

Recommendation 7

There were a large number of submissions from patients that stated their experience with GPs was poor due to lack of awareness of the disease amongst primary care givers.

GPs should receive ME/CFS awareness training as part of their continuing professional development and ensure they are able to adequately recognise the symptoms of ME/CFS and deliver a correct diagnosis. They should also be aware of the various management pathways.

Recommendation 8

The Group noted evidence that there were serious concerns about acceptability, efficacy and safety with some treatments such as cognitive behavior therapy (CBT) and graded exercise therapy (GET). This may be due to the lack of training given to professionals but evidence was given that it was in part due to fixed attitudes about causation by some health professionals. The Group feel that it is inadequate for professionals to treat patients with ME/CFS when they have not been fully trained in the particular characteristic of this disease.

It is essential that all healthcare professionals i.e. dieticians, nurses, occupational therapists, physiotherapists and psychologists, involved in treatment should have adequate training in ME/CFS and the relevant professional bodies should ensure this occurs as a matter of real urgency.

NICE should carry out a detailed review of their management guidance on ME/ CFS, in particular the mounting evidence for the need to broaden the range of appropriate therapies beyond CBT and GET, and to specify that all such therapies should be delivered by specifically ME/CFS trained professionals.

Recommendation 9

As noted in the Gibson report, there has also been far too much emphasis in the past on psychological research and insufficient attention to biomedical research. The Group welcomes the recent MRC initiative to attract new researchers and new technologies in to this area.

However, the Group is sure that it is vital that further biomedical research is undertaken to help discover a cause and more effective forms of management for this disease.

Recommendation 10

It is clear from the evidence submitted to the Group that currently, ME/CFS patients receive little assistance in the complicated process of application for benefits and that refusal rates are worryingly high. Applying for benefits is an extremely prolonged and strenuous task, especially if patients are forced to appeal the original decision where their application was denied.

The Department of Work and Pensions should review its guidance to decision makers to increase the awareness of the specific difficulties faced by ME/CFS sufferers. Furthermore the Group recommends that ATOS Healthcare staff should also receive increased training to ensure that they are fully aware of ME/ CFS and the limitations that it places on patients.

Recommendation 11

The APPG is aware that many patients who are severely affected by this disease are receiving either inadequate care or no NHS care at all, which is clearly inconsistent with the NICE Guidelines.

Specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services and in-patient facilities for assessment and management.

Amazon Commission

A big thankyou to everyone who did their Christmas shopping on Amazon! For the last quarter of 2009 we received nearly £50 in commission fees on all your purchases! This remains an easy way to raise funds for the group, at no cost to us, so when you're next shopping on **amazon.co.uk**, please remember to go to **www.mesupportgroup.co.uk** first and click on the links to take you to amazon.co.uk and we will get money for referring you.

Equipment Hire: We have a wheelchair, an electric mobility scooter (small enough to fit in car boot for days out or holidays) and a light box. To borrow any of these, please phone Pam on 01204 793 846.

Link-Up: If you would you like to be in contact with other members of the Bury/Bolton ME/CFS Support Group by telephone, then you can by joining the Link Up Contact Service. It is very user friendly and it is free to all members of the Support Group. Two contact directories are sent out each year, one in the summer and one during the winter. It is a great way to contact people, compare experiences and most importantly make new and lasting friendships. For further information you can contact Stephen at stewalker@postmaster.co.uk /or call on 01204 842395 (Monday and Friday after 6pm).

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 or visit:

http://health.groups.yahoo.com/group/Bury_Bolton_ME_CFS_Support_Group/

Help us to be greener: If you would like to receive flyers and/or newsletters by email instead of post, please let me know by emailing dave@mesupportgroup.co.uk.

Benefits & Work Guides – UPDATE!

There is a new Benefit & Work guide that you might be interested in. It is an update on the previous guide to Work Focused Interviews, called:

“Knowing your rights at Pathways to Work interviews” – 12 pages

Why not have a look through the www.benefitsandwork.co.uk website and see if there is anything else there that might be useful to you. Along with their fantastic range of guides, there is also a large archive of their own news stories about disability and benefits related issues. Their website is full of invaluable information, but unfortunately far too much for us to relay to you in our newsletters.

Don't forget, our group's subscription to www.benefitsandwork.co.uk allows us to access all of this on behalf of our own members. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal and have already helped a number of our members.

If you need copies of any of the guides (or news articles off their website) phone Dave on 05601 335037 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. 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 you have a friend or relative who 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 a selection of the more popular guides available from the library at our meetings – 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), and you can afford to make a contribution towards the costs, it would be very much appreciated. Please see January's newsletter for the full list of guides.