

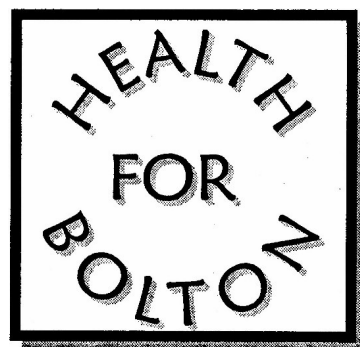
BURY/BOLTON ME/CFS SUPPORT GROUP

'Breaking the Isolation'

Newsletter 40

Summer 2009

Supported by



The Bury/Bolton ME/CFS Support Group was founded in
September 1990

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What does CFS or ME really stand for?

Using an acronym helps us to cut down on the lengthy words we repeat so often. Chronic Fatigue Syndrome is shortened to CFS and Myalgic Encephalomyelitis is, of course, shortened to ME. Despite the wide use of convenient acronyms, how many times have you seen one related to fatigue only to realise it's referring to something completely different?



So, in this issue we're running a competition to see who can supply us with the best ones. To start you off we've collected a few ourselves:

- CFS – Communicating For Success – appears on BT Vision's television channel
- "I love ME" – OK it's not an acronym, but when I see the symbol I wish they wrote what they really meant: I love Me!
- DLA – Is the Dental Laboratories Association (of course).

The best acronyms will be published in the next edition of the newsletter and the winning entry will get a £10 Amazon voucher. Please send all your entries to andmk1@gmail.com.

Social Meeting, 16th July 09

Our July meeting started early at 6:45pm so that our Yoga Therapist, Olivia, could take us for a brief half hour mini yoga session. It was very relaxing doing gentle stretches and movements, and best of all relaxation prior to our main meeting.

The social was most enjoyable with plenty of time to chat over cakes and a cuppa.

Don't forget the group gets 5% commission on all your purchases from Amazon.co.uk if you follow the links from our website, www.mesupportgroup.co.uk. Please pass this link on to all your friends who could use this also. Click on any Amazon images or the amazon.co.uk link in the left-hand-side navigation bar, and then make a purchase within 24 hours and we get money for referring you. Thanks to people making some large purchases we have made quite a lot from this. You can do all your gift shopping on Amazon.co.uk - they sell CD's, DVD's, shoes, books, electronics, games, home & garden items, kitchen gadgets, jewellery, exercise equipment and more. There is free shipping when you spend over £15 on most items. This is an easy way to support the group.

Would anyone like to receive the flyers and newsletter by email instead of post? Postage is our biggest expense so please let me know on 01204 525 955 or email dave@mesupportgroup.co.uk if you would like email instead of postal contact.

DISCLAIMER:

The observations expressed in our newsletter may not necessarily represent the views of the Committee or the Bury/Bolton ME/CFS Support Group.
All products and treatments featured are for information only.

Support Group Information Sheet

A reminder of who is what during 2009 with Telephone numbers for contact if required

Support Group Leadership

The 'Bury/Bolton ME/CFS Support Group' is managed by a Committee of 6 Members: -
Pam Turner, Margaret Benn, Ann Richards, Maria Sale, Sheila Myerscough and Kim Finney.

Support Group Posts

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Meetings Secretary:	Maria Sale	01204 575613
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Link Up Co-ordinator:	Stephen Walker	01204 842395
Librarian:	Carole Senior	stewalker@postmaster.co.uk
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OUR MEETING DATES FOR AUTUMN 2009

Meetings are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, usually on the third Thursday of each month from 7.30pm until 9pm, except in April, August and December when there is no meeting but our newsletter goes out. We started to meet here formally as a support group in September 1990 after several years when we met in each others homes. Simple refreshments are provided.

17th September 2009: We are having Debra Seddon, Dip.ONT, Nutritional Therapist, BANT registered. She will be talking about her successful battle with ME and the methods she used to overcome it. She has many ME clients and has several helpful ideas.

15th October: The speaker is Gail Sumner. Gail has spoken to us some time ago about her history of ME, she will be updating us on her work using the Perrin technique, and her other observations on ways of managing the illness.

19th November 2009: The Pre Christmas Social and Bring and Share Buffet Supper

SOCIAL GROUPS

Bury Socials: Sheila has now organised some Bury socials for the first Thursday of every month, (**except** for January when it will be on the 8th), 3pm at The Met, Derby Hall, Market Street, Bury. BL9 0BW.

http://themet.biz/location/find_the_met.pdf

It's not noisy and they have couches and sell snacks, soft drinks, etc. If you need any more information, please phone Sheila on 0161 7970026 after 12 noon (she is happy to phone you back as she is on a free calling plan).

Bolton Socials: Our Social Group meets informally on the first Monday of each month; our next meeting will be on **Monday 7th September** at **4pm**, continuing at our new venue:

The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY

This has already proved to be a popular venue. It has plenty of parking, good accessibility, comfortable seating, is relatively quiet and serves excellent chip butties! However if this does not suit you, or you have any ideas, we are still open to alternatives to try out. It could be a pub, café, coffee shop or similar, ideally we are looking for somewhere that is quiet and comfortable, in the Bolton area, with good accessibility and parking – so if you have any suggestions, or concerns that can be addressed, or just need more information before giving it a try, please email **dave@mesupportgroup.co.uk** or phone 05601 335037.

Remember that you can ring Pam if you wish to borrow our wheelchair or our light box.

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

BURY/BOLTON CFS/ME GROUP MEETING MAY 2009

DR RAYMOND PERRIN

We were very happy to welcome Raymond to our May meeting. Raymond has spoken to the group previously and this time he spoke about a recent gathering of ME specialists in the USA.

Raymond was recently invited to present his work at a conference in Reno, Nevada, at which many of the leading scientists in the ME field were attending. In all there were 75 lectures and 50 poster presentations describing what was happening all over the world. All the current research supports Raymond's work and his theories about ME.

Raymond's introduction to the world of American medicine and this conference, was via the Osteopathy Council. It was therefore a great honour for him to be asked to present 3 poster presentations. He then showed our meeting a poster illustration, covering his theory that the fluid mechanics in the brain do not work properly.

There were scientists from all over the world presenting at the conference. Raymond felt that Japan's Professor Watanobi led the way with his research programme.

Raymond explained his research and treatment method, which is based on sound scientific knowledge. It is based on the premise the fact that all ME patient have faulty lymphatic drainage systems. Despite this, some Doctors still did not accept the theories, even though it has had some success and is based on orthodox medical science.

Dr Perrin then explained the role of the lymphatic system in the body. The blood takes many toxins (poisons) round from all parts of the body, to the liver to be "detoxified" or purified. We also need a second detoxification system, the lymphatic system, as some larger molecules cannot be dealt with by the blood system alone. Large protein molecules need another way to be removed and some of these are called cytokines.

There is a lot of research being done on cytokines at present. These are chemicals which are needed in the immune system for fighting infection or inflammation. They attach themselves to the cell which is causing the damage, and if there are bacteria, a virus or foreign body, the cytokine will attack the invader. However, if we have too much cytokine activity there will be problems as they will try to attach themselves to the healthy cells as well.

This problem can be seen in people undergoing chemotherapy which involves cytokine activity on a large scale, the cytokines are injected into the body to kill off the cancer cells but they also have a damaging effect on the healthy cells. Cytokines can't drain through the blood; they have to drain via the lymphatic system. The brain and spinal cord is the only part of the body that doesn't have a lymphatic system. So, how does our brain cope with large molecules, or poisons, either from outside the body or from within? A membrane in our brains prevents these larger molecules from getting there. However, within the brain lies the hypothalamus, a gland controlling all the functions of the body. It does this by sending messages along the sympathetic nervous system in response to hormone levels. For example, if the hypothalamus detects your blood sugar is imbalanced, it will send out a chemical message to the pancreas to adjust the level back to normal. This process is called biofeedback, something which takes place all the time in our bodies.

Raymond said that women are affected more than men by ME because they have more hormonal activity. At the hypothalamus, there is no blood/brain barrier because it needs to be able to sample the larger hormonally influenced molecules. As a result, these larger molecules can enter the brain, but must also leave somehow as there are no lymph vessels in the brain. Instead there are small drainage holes, and at this point he showed everyone a picture of the cribriform plate. This is plate of bone with a series of small holes. This method of drainage is via the olfactory (nose and smell) nerve, auditory nerve, trigeminal nerve, and optic nerve down to the spinal column. With all ME patients, there is always a problem with drainage of the cerebro spinal fluid causing congestion or blockage. The problem may have been present from birth e.g. cleft palate. It may be due to trauma to the head or neck or from a malformed spine. As there is no drainage from head, neck and spine, there is a build up of toxins and a reduction of blood flow. This affects the sympathetic nervous system which can affect any part of the human body, which is why every ME patient has slightly different symptoms.

In his research, he had the difficult task of proving that there was a build up of lymph. He was very fortunate that a man came to him who had outwardly visible lymphatics as they appeared to be engorged, like varicose veins. Varicose lymph vessels were easy to spot as they were pale and flesh coloured carrying a whitish fluid. Raymond was then able to use photographs of his patient this as proof of the problem.

Now he is able to identify these engorged lymphatics in all of his patients although they may not be immediately visible. Another characteristic of most ME patients is Perrin's point, which is a very tender spot on the chest. The spot is produced by the blockage of the lymph drainage which causes irritation to the nerves. The solar plexus area is also tender, the spine has problems and the cranial flow between the brain and the spine is affected.



Jim was doing OK until his supplements fell on him

Raymond explained that the flow of fluid from the brain to the lymphatics is similar to the heartbeat at around 50 to 70 beats a minute. However, the thoracic duct into which the brain fluid drains only beats at around 4 beats per minute. Therefore, we have a rapid beat leading to a much lower beat and this creates a wave or third beat which is called the rhythmic pulse wave at around 12 beats per minute. In ME patients this process is disrupted because the sympathetic nervous system pushes fluid the wrong way. The idea of Raymond's lymphatic drainage technique is therefore to get the lymph moving in the right direction and to get these three waves back in synch with each other. Raymond has developed his theories and treatments over 20 years and with many different patients.

In America much of the research being done right now is aimed at developing a patented drug to cure ME once and for all. Raymond told the group of the Whitmore Peterson Institute which was set up by a lady whose daughter has ME. Dr Dan Peterson was also a founder, and like Raymond has 20 years experience in the field. Dr Peterson wanted to know why this severe fatigue had developed and has been researching the phenomenon since the late 1980s. The Institute, is funded from the US government and by charities and they are currently building a centre in Reno, Nevada.

Dr Anthony Kamaroff, the head of medicine at Harvard University, led the conference and summarised the main areas. Amongst other things he covered diagnostic tests for ME, the role of stress, infectious agents, cytokines etc. The vast amount of information has given Raymond much to go on. In fact since the end of the conference, he has spent the past 6 weeks absorbing all the 75 lectures and 50 poster presentations.

Raymond then went on to cover more aspects of the conference. At present, ME is identified by symptoms alone whereas researchers are looking for biological markers. If these markers could be found, it would enable drug companies to develop some form of treatment or cure.

However, researchers still need to identify biological markers to prove to the scientific world that ME has a real foundation. Perrin's Point for example, is a biological marker that has been developed independently. As a result, he has been invited to a conference in Turin this September to give a lecture to the world's leading psychiatrists and psychologists.

Dr Basant Puri is another doctor investigating the biological markers for ME. Raymond knows from his work with 100s of ME patients that there are signs that show ME is a physical illness. However, many patients are diagnosed using the Fukuda Scale, which is a list of symptoms developed by scientists for research purposes. Dr Kamaroff helped to develop the Fukuda Scale and he made it clear that it was only intended to be used for research purposes. Despite this intention, most UK patients are diagnosed by the NHS using the scale.

Lots of research is also being conducted around genes. Raymond agrees that this is very interesting, although he felt that the large investment in this area may not produce a solution. Sophisticated gene studies establish link between genes and diseases. ME patients however, may be affected by a number of other factors such as bacteria, viruses and toxins. Therefore, a simple link to a gene may not be enough and only a guide on how to treat ME.

There are biological markers which show that the body's neurotransmitters are overworking causing a build up after trauma, physical toxins, stress, organophosphates etc. These neurotransmitters, or neuropeptides, are chemicals which stimulate the nerves and there are far too many.

They also looked at levels of pain and the cytokines it produces in the body causing yet another build up of toxins in the body. Raymond wrote 5 years ago that if his theory of ME was correct, there would be too much acetylcholine in the brain and was

subsequently proved correct by Dr Puri's work. He also told us that during the American Civil War, Dr Costa discovered that physical overload (pain, stress, chemicals) caused ME like symptoms which was repeated during the Gulf War.

Raymond also referred to other areas of ME research:

- Dr Sarah Myhill's study of mitochondria - see Spring Newsletter 2009. Again he said this is useful, but there is mitochondrial damage in other illnesses.
- Electroencephalograms show that ME patients have different patterns of brain waves.
- Post Viral infections, this theory is that ME always follows an illness e.g. Epstein Barr Virus but Raymond knows it can start following a trauma such as whiplash injury. The virus is usually the trigger for ME but not the cause of it.

Raymond was impressed by Dr Bruce Carruthers who helped to develop the Canadian Consensus Document which is very accurate for diagnosing ME. It looks at ME in a much more holistic way instead of trying to find one single cause or cure.

There are many studies showing that many different viruses or bacteria are involved in ME e.g. Epstein Barr (Glandular Fever), Human Herpes Virus, enteroviruses. These studies are aimed at finding a drug to cure it and eradicate the virus. However, the problem is not the virus but that the immune system is not working properly.

So, what is the position with cytokines? Many patients with ME don't get full blown flu or colds because they produce too much of a substance called RNase L which attacks these viruses. At the same time, it also attacks the immune system and body lodging toxins deep inside the nervous system and the brain.

Does a patient's history of past infections provide an answer to all ME patients? There are many subsets of ME patients because many factors are involved. Stress before an immune activation will make you ill for much longer, there are lots of factors interlinked and so just treating a virus will not rid the body of ME. Raymond listed some of the factors involved as work related e.g. lifting leads to strain of the spine, sitting over a computer or desk also strains the spine and causes lymphatic blockage. He also said that endometriosis in women is linked to ME.

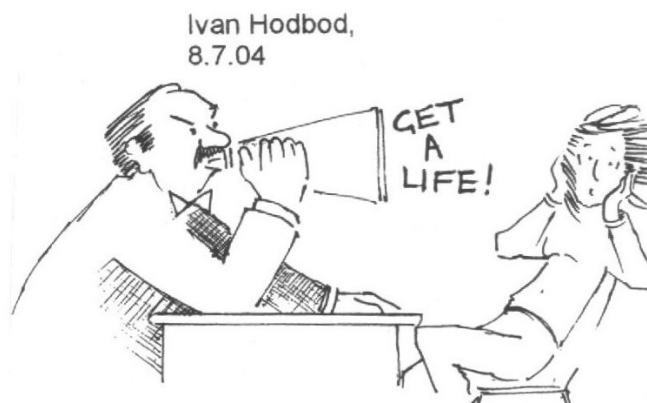
Raymond briefly explained many more of the lectures and he worked hard to give us a good insight into all of the good work being done to try to understand what is happening with ME. He also helped us understand what could be done to help us to manage the condition and even for some people to recover by using the treatment he developed.

Raymond finished his very informative talk by showing us a technique to help to reduce stress levels:

Sit comfortably, place your hands onto your thighs and use the forefinger of each hand to turn to tap the leg gently i.e. right finger taps right leg then left finger taps left leg. Close the eyes and then try to just concentrate on tapping for 3 minutes. It takes the mind off the stressful incident and helps to relax.

The summary of the Reno conference can be accessed via:

<http://www.iacfsme.org/IACFSMEConferenceMoreInfo/SummaryReno2009byRosamundVallings/tabid/373/Default.aspx>



He had yet to master the subtle nuances of cognitive behaviour therapy

Thanks to East Lancs ME/CFS Support Group
for these 2 cartoons.

BURY/BOLTON CFS/ME GROUP MEETING JUNE 2009

EMOTIONAL FREEDOM THERAPY - JULIE SHORTLAND

Julie is a holistic therapist who can offer a variety of therapies, but tonight she gave us information and a demonstration of Emotional Freedom Therapy (EFT) and Tapas Acupressure Technique (TAT). These are fairly new meridian energy techniques and have sometimes been called “emotional acupuncture” or acupuncture without needles. This system of therapy is based on the acupuncture system in which it is believed that the body has lines of energy which correspond to the various organs in the body. The idea of the therapy is to remove any blockage in the energy lines.

First of all Julie described Tapas Acupressure Technique which was devised by a lady called Tapas Flemming. Tapas needed help to deal with various sensitivities, and as she is a very religious lady she asked God for help and she believes that he answered by giving her ideas which helped her to develop her technique.

Basically the idea if this technique is to balance the seven chakras or energy centres in the body.

Using your dominant hand place the thumb and middle finger on either side of the nose, at the bridge, and place the forefinger on the brow. Place the other hand at the back of the head on the ridge. Now make the statement “I don’t believe this can work.” now drop the pose and then take it up again and say “I do believe this can work”. Hold that pose until you feel a shift.

The statements can be for example “I don’t have a lot of energy today” then “I do have a lot of energy today or “I feel really down today” then “I feel really good today”. Always start with the negative and finish with the positive.

Ideas may come of how to help yourself to feel better and to balance the chakras.

More information is available on the tatlife website with free downloads www.tatlife.com/

Julie then went on to tell us about EFT. This technique was developed by Gary Craig and Roger Callahan and they are so convinced that it works they feel all children should be taught the technique in school. Also they give full description and free manual download on their website www.emofree.com.

Roger Callahan has been working for two years with a lady who had a serious phobia about water, gradually he had managed to get her so that she could wash without fear but she was still afraid of rivers, ponds etc. One day he was walking with her in the grounds of the institute where he worked and they were not far from a pond. The lady complained she had stomach ache and Gary told her how to tap the stomach chakra which is near to the water chakra to get rid of her pain, when she said “its gone” and she had lost her fear of water and could get close to the pond. They have been so pleased with results such as this that they want to share it with everyone.

This technique is based on tapping various places in sequence.

Julie gave us a demonstration of how this works by first of all saying she was trying to relieve her own anxiety at speaking in public; then she asked everyone to think of something that caused a problem and to think of how severe it was on a scale of 1:10 i.e. Identify the problem. Now to begin repeat three times this affirmation---”I deeply and completely love and accept myself”, whilst at the same time tapping one hand with the other as in doing a karate chop, or whilst rubbing what she called the sore spot on your chest. You can find the sore spot by pressing gently the upper part of the chest midway between the armpit and the breast bone.

After completing the first sequence you then tap about seven times on each of the energy points whilst repeating the affirmation and reminder of the problem. The energy points are:

- 1 Eyebrow :- inner aspect near nose
- 2 Side of the eye :- away from the nose at the side of the head
- 3 Under the eye
- 4 Under the nose :- on the upper lip
- 5 On the chin :- halfway between the bottom lip and point of the chin
- 6 The collar bone :- about an inch from the notch
- 7 Under the arm :- about 2 or 3 inches down from the arm pit - on the bra line
- 8 On top of the head.

Once we’d done this procedure she asked everyone to think of their original problem and to evaluate it again, many people found the original number had now gone down indicating an improvement in their problem.

For those people who did not get a experience a benefit there is an additional procedure of tapping the top of the head, again repeating the set up affirmation but also saying that you are now addressing the remaining problem. Do the following nine actions.

- 1 Eyes closed
- 2 Eyes open
- 3 Eyes hard down to right
- 4 Eyes hard down left
- 5 Roll eyes in a circle
- 6 Roll eyes in other direction
- 7 Hum two seconds of a song
- 8 Count from one to five
- 9 Hum two seconds of any song

Then perform the original tapping sequence once again.

It is important to aim EFT at the specific emotional events in one's life that form the problem. Where necessary, be persistent until all aspects of the problem have vanished. Go on, and try it on everything.

Following the additional version, more people found their evaluation of the problem had reduced. Julie said that some of the reasons that it doesn't work are because people are not tuned in to the issue. They may be dehydrated, sensitive to something in the room or distracted because of an interruption.

You should repeat the sequences and clear your numbered rating down to zero before starting on another issue. Julie said that what you start with is not always the issue you end up with. For example, she was originally working on a weight issue and the problem finished up to focus on her sister, who died when she was two years old.

This technique starts with a negative, and moves on for you to my knowledge it. Then you can clear it out. When asked if she had treated anyone with ME Julie told us about a lady called Sacha Alenby who has written a book about Neuro Linguistic Programming and EFT. Sacha was thinking how awful her life was when she realised her emotions were so negative so she went to a therapist and developed the technique and was cured from her ME.

Another question was the cost of treatment? Julie offers a free 20 minute initial consultation and then charges £40 per hour. She also does workshops lasting two hours at £10 for the unemployed. It can be useful to work with another person in pairs, you don't have to tell the other person what it is exactly you are working on.

What if you can't tap yourself because of fatigue? You can either ask someone else to tap for you, or you can imagine tapping and think of the sound it would make.

Someone asked how many sets of tapping a person could do? Julie said you can do 20 minutes at a time or one round 20 times a day or just think it through.

When asked how she got into EFT, Julie said that she had done lots of group sessions such as reflexology and several other healing therapies at which she had heard about EFT. So she decided to learn more about it and has now done several levels of training. She is also taking courses in hypnotherapy.

Julie holds the belief that that all illness is caused by emotional blockage. This caused some reaction in the room, despite the fact that this is just one point of view. If you want to look further into this there is a list of information on the internet under mind/body connection. There are also very interesting books on the subject such as Quantum Healing by Deepak Chopra.

Julie can be contacted at Energy Balance on 07894 507053, based at the Nutricentre (inside Tesco), Middlebrook, Horwich.

Girlie Wisdom!

Women over 50 don't have babies because they would put them down and forget where they left them.

A friend of mine confused her Valium with her birth control pills ... she has 14 kids but doesn't really care.

One of life's mysteries is how a 2 pound box of chocolates can make a woman gain 5 lbs?

My mind not only wanders, it sometimes leaves completely.

The best way to forget your troubles is to wear tight shoes.

The nice part about living in a small town is that when you don't know what you are doing someone else does.

Thanks to Phoenix

NEWS IN BRIEF

Diagnostic test for ME?

Some of you may have read about a new diagnostic test for M.E. developed by Professor Kenny de Meirlier and Dr. Chris Roelant; which they claim solves the mystery of M.E.

Professor Kenny de Meirlier released news of this test in a press conference on Thursday May 28th, prior to his presenting his research to the 'Invest in M.E. Conference' the following day.

The test comprises of a urine test kit, which is designated for use at home and is only available privately at a cost of about £13.

The basis of the test is his hypothesis that people with M.E. are producing relatively large amounts of the chemical hydrogen sulphide (H₂S), and that it can be measured by the test.

Producing too much H₂S, which can act as a mitochondrial poison (mitochondria are the energy producing part of the cells) is claimed to be due to overgrowth of a certain bacteria in the gut. This combined with the presence of certain heavy metals e.g. mercury and nickel cause a toxic build up in the body. They claim that the problem can be treated successfully by changes in the diet, probiotics (good bacteria) and antibiotics.

However, Dr. Charles Shepherd, Medical Advisor to the M.E. Association adds a note of caution. He has looked at the information and heard the presentation, and while he agrees that it is an interesting hypothesis, the test itself cannot yet be regarded as a scientifically proven diagnostic test for M.E. He considers it needs further research and validation and then be published in peer reviewed journals.

Dr. Shepherd also feels that there will be problems if people start to use this test at home and then expect their G.P. to interpret the results and recommend prescribed treatments, including antibiotics based on the results; because the UK medical profession has not yet received any information about the hypothesis, the test, or the treatment.

The article written in the Telegraph is available at www.telegraph.co.uk/health/5407749/ME-proof-that-it-isnt-all-in-the-mind.html

The M.E. Association reply is available at www.meassociation.org.uk/content/view/875/161/

The Lightning Process — Another Perspective

Dave and Jean wrote this article for Hermes, after hearing Derek Vernons' March presentation.

The Lightning Process generates a lot of interest and controversy, because of its assertion that a full recovery from M.E./C.F.S. is possible, there is however a lack of substantive information on the actual process, as well as failure to provide any supporting quantitative data/studies.

It is encouraging to hear Jan Williams is undertaking some follow-up of those undertaking the three-day training in Greater Manchester. However, the apparent lack of any follow-up elsewhere in the U.K. is extremely concerning. We are concerned with what happens to the reported 15% to 35% for whom this approach is not helpful, some of whom we are aware of from our own contacts. Is it their fault they didn't try hard enough, or not have enough belief in this approach? This rather evangelical attitude towards sufferers who try this approach and who don't benefit is worrying. You may feel we are overstating the issue here but the rather secretive attitude being projected by those who have benefited from the Lightning Process flies in the face of the more open approach and sharing of information of therapies, which the Group has presented to the membership in the past.

We would agree the L.P. is not appropriate for those who are seriously affected with M.E./C.F.S. but it may be helpful for those in the latter stages of recovery, particularly where there is an emotional or motivational issue to be resolved. As we know, many acquire M.E./C.F.S. as a result of an immune system breakdown, which is usually due to some kind of viral infection (although they may be other causes). Therefore, the main root of their health difficulties is physical, rather than psychological. We remember the arguments of a few years ago when M.E. sufferers across the country strongly argued their health condition was not 'in the mind' but the result of a combination of physical factors, (which admittedly had an emotional and psychological impact). The L.P. appears to help some in terms of emotional, behavioural or psychological issues, just as the organisers of this training programme also train sports people and those in business in motivational techniques and positive thinking techniques. M.E./C.F.S. is more than demotivation and negative thinking, or what has been called 'being stuck' in the illness.

The basis of the Lightning Process is Neuro Linguistic Programming (N.L.P.). This approach is not new and has been around since the 1970s and works on understanding how we think, behave and change. If you look up N.L.P. on the Internet you'll find many training organisations that offer this, including the Lightning Process. You may find it useful to check out the Association for Neuro Linguistic Programming (www.anlp.org), which is a not-for-profit organisation. This has over 20 book titles for beginners who want to find out more about N.L.P.

We would argue, the complex and individualised nature of M.E./C.F.S. as it affects each person means a range of approaches need to be deployed in meeting such highly variable health difficulties. This is based on Jean's many years as a State Registered Nurse and as founder of the Stockport M.E. Group and Dave's 30 years as a lecturer and teacher-trainer in education, including running a Masters degree in Disability Studies.

We are open-minded about complementary therapies/alternative approaches but would strongly recommend for a balanced view on any particular approach, to contact either Action for M.E. or the M.E. Association, or alternatively, the M.E. Research U.K. Research Centre, which is chaired by Vance Spence, who spoke at one of our recent meetings.

The lack of published research or serious recognition by influential sources on the Lightning Process suggests that as a group we should be wary of being seen to endorse, or recommend such an approach. Therefore, it is important the Stockport M.E. Group continues not to advocate the use of any particular form of healthcare as outlined in the longstanding disclaimer included in every copy of 'Hermes'.

Dave Swindells and Jean Holt
With thanks to Hermes

Closure of Manchester Disability Benefits Centre

From 13th July, all new DLA claims have been processed at Blackpool. Ongoing DLA claims will still be dealt with at Manchester until 21st September, when all but ongoing Special Rules applications will move to Blackpool.

From 5th October, all new AA claims will transfer to a new AA Unit in Preston: all remaining claims will move over on 26th October.

New postal address

From 13th July, a new postal address has been used for all new DLA and AA claims, although envelopes containing the current return address [PO Box 32, Preston] will be diverted to the new destination. However, they may take a little longer to arrive, so using the new address is a better option, where possible. A stock of envelopes bearing the new details will be available shortly from your usual sources. The new address is:

DCPU Unit 4,
Pittman Way
Preston,
PR11 2DQ

Information about the new postal arrangements and our imminent closure can also be accessed online via the following link:

<http://www.dwp.gov.uk/about-dwp/customer-delivery/disability-and-carers-service/outreach-events-and-local/manchester/>

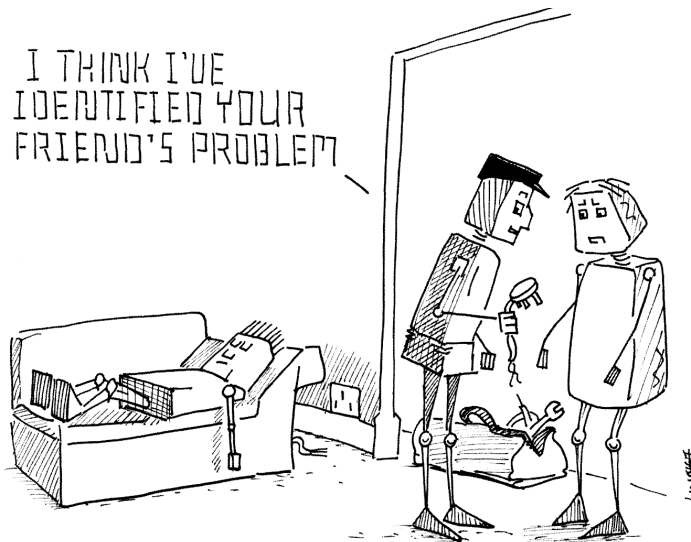
Form completion information

Manchester DBC is no longer able to offer a form completion service and alternate arrangements are now in place. For help over the telephone, or to arrange a home visit, please contact the Benefit Enquiry Line on 0800 88 22 00.

Editorial

Despite its popular perception as 'Yuppie Flu', ME/CFS is a serious, often disabling, chronic illness, causing impaired mobility and disability in the majority of cases.

Published research has demonstrated that the quality of life of patients can be seriously disrupted — more impaired than in MS, according to one Australian report — and the social consequences, as regards schooling, employment, relationships, financial security, future plans and personal worth can be severe; one estimate puts the cost of ME/CFS in terms of treatments, lost taxes and benefit payments at £3.4 billion per year in the UK.



My friend

In 2002, a report to the Chief Medical Officer of England said that ME/CFS was 'a genuine illness and imposes a substantial burden on the health of the UK population. Improvement of health and social care for people affected by the condition is an urgent challenge.' Unfortunately, seven years on from the CMO's report, little has changed for patients on the ground; the condition continues to be shrouded in mystery and metaphor, and remains invisible to all except the immediate family, largely unnoticed by health care professionals.

Most importantly, the illness is also ignored by the biomedical research community. Despite the seriousness and extent of the condition, comparatively little serious biomedical research has been conducted or is presently being undertaken anywhere in the world.

Given the extent of the problem — the recent NICE guideline gives a mean prevalence of 193,000 people with ME/CFS in the UK alone — this situation is bizarre, not to say tragic, particularly as some studies have already uncovered biological anomalies that might well help to explain many of the clinical features associated with the illness and indicate areas for therapeutic intervention (the findings of increased oxidative stress and of neutrophil apoptosis at the University Dundee, and dysfunction of the autonomic nervous system at the University of Newcastle are two examples).

Something that concerns me is the problem that exists at a funding level. Biomedical research is expensive: one medium-sized clinical trial can cost £300,000, while a major programme of research can last 5 years and cost £1 to 2 million. The ideal scenario would be for central (e.g., MRC and NHS R&D) funding of biomedical research to be provided through ring-fencing, making it easier to entice good established biomedical researchers into the field — so that a 'critical mass' of investigators could be encouraged to produce the 'critical mass' of biomedical data necessary to set the field alight. But this alone is not the answer. Experience has convinced me that the funding strategy for ME/CFS must mirror that of other illnesses which obtain most of their research revenue from private sources and ground-level fundraising. It is a huge task, but one that ME Research UK is determined to pursue.

Dr Vance Spence Chairman of ME Research UK

Thanks to ME Research UK

Lords Debate

The Welfare Reform Bill had its first reading in the House of Lords, 18 March, with a full debate on 29 April, after InterAction went to press.

Before the debate, Action for M.E. wrote to all members of the Lords, as it did to MPs, expressing the need for safeguards within legislation and regulations.

If the Bill achieves Royal Assent and becomes an Act of Parliament as we expect, it will be critical that people with M.E. record and report their experiences of the new, benefits-related back-to-work procedures, so that we have evidence on which to campaign at the review stage.

To help achieve this, Action for M.E. has produced a factsheet and 'diary' form for ESA applicants. Download them from our website or tel: 0845 123 2380 and ask us for a copy.

Thanks to Interaction

Carers Therapeutic Service

This wonderful service is provided by the Medi-Well Complementary Clinic, Tonge Moor Road, Bolton BL2 2DL. Jane Grundy and her team of practitioners have studied and practiced their chosen therapies for many years so she says they have a greater understanding of their patients' spiritual, emotional and physical health whilst also having the necessary experience and knowledge of how to adapt treatments that would be best suited for each patient. Under their Carers Therapeutic Service they offer Massage, Reiki, Indian Head and Reflexology. Her website is www.medi-wellclinic.com.

Carers living in Bury

If you are a carer and live in the Bury area you can take advantage of the Carers Therapeutic Service she offers on a Monday and Friday through Bury Carers Centre, Victoria Buildings, 9-15 Silver Street, Bury. Each session, which has to be pre-booked, lasts 30 minutes and costs £8. Bury Carers Centre has obtained funding to discount the normal rate for carers of £10. Telephone Bury Carers Centre 0161 763 4867 to book an appointment.

Carers living in Bolton

If you are a carer and live in the Bolton area Jane holds carers only pre-booked 30 minute sessions for £10 on a Wednesday at her Medi-Well Complementary Clinic, Tonge Moor Road, Bolton BL2 2DL. Telephone the Clinic on 01204 417213 to book an appointment.

For several months now I have really benefited from the treatments given by Jane and her team. She really supported me in the lead up to my hip replacement operation in February and once I had the ok from my consultant I have resumed my treatments. I usually go to the Bury Carers Centre, where you are warmly welcomed, but I have also been to her Wednesday Clinic at Bolton. Both are easily accessible using public transport. There is also plenty of street parking close to the Clinic in Bolton. Why not give it a try and enjoy some "me" time which can also benefit your health.

Yvonne Leech

Carers Direct

A new free telephone advice service for carers has been launched. It is the second component of the new Carers Direct support service for carers — help and advice is also available on-line through the NHS Choices website www.nhs.uk.

The free telephone advice line will open seven days a week and will provide a comprehensive service for carers wanting information and advice about benefits, how to get care and support, respite breaks, housing, equipment, etc. The number is 0808 802 0202. Please spread the word.

Thanks to Bolton CVS Jumbo Magazine

My experience with massage

About 10 years ago when my ME was truly awful I was advised to try seeing Raymond Perrin. I toddled along not knowing what to expect and was very surprised and pleased when I started to improve quite rapidly. This went on for some time and then I hit a plateau and stayed there for several years. I continued to see Raymond and his support was invaluable.

Then about two years ago I made a friend through the link up group and she told me how she had improved with regular massage. It was quite a stressful time for me and I decided to give it a go. I thought that even if it did not improve my ME it would be relaxing. I have continued for about 2 years with an hour long massage every two weeks or so.

The reason I am writing this is because I really do seem to be doing quite well. I am not cured or anything like it but I am much better and able to do more. During this time I have tried no other treatment and as I have been ill for 19 years it seems unlikely that I am improving spontaneously. I just wanted to share my experience with you so that you can make your own mind up.

I just go to my local beauty therapist for the massage and it costs £25 for the hour.

Susan Jane

'Just Four Quid' Campaign To Raise £1m For ME Research

Two charities are launching a recession-busting campaign to raise £1,000,000 for biomedical research into the much-misunderstood illness ME/Chronic Fatigue Syndrome. ME Research UK and the ME Association have joined forces in the 'Just Four Quid' campaign which will use the internet to encourage donors to take advantage of weekly money-saving tips, and then give some of the money they save to the appeal.

www.justfourquid.com has a daily blog. Every week, there will be a new moneysaving tip - some with potential to save hundreds of pounds. Participants will be invited to contribute some of their savings to the campaign. Visitors will also be encouraged to use the tips to help friends and family save money and in turn, make a donation. The campaign is focusing on money-saving as a means to raise money partly because of the recession but also because most people with ME/CFS are on restricted incomes due to their ill health and too unwell to take part in traditional fundraising activities, such as sponsored sports events.

The success of the campaign will rely on involving as many as possible of the estimated 250,000 people in the UK with ME/CFS - most of whom have no contact with any of the UK's ME charities. One of the first actions of the campaign will be to ask participants to locate other people with ME/CFS and invite them to join in.

"If all 250,000 people in the UK with ME/CFS gave just £4 to the appeal we'd reach the £1,000,000 target in next to no time. But nothing is ever that simple", said Tony Britton, publicity manager at the ME Association. "So we've designed this blog to help people save money on everything from their utility bills to their haircuts in the hope that, once they've saved a little, they'll give some of it back."

Inspired partly by the journalism of personal finance guru Martin Lewis, the "save a lot, give a bit back" approach could well become a model for charity appeals in these troubled times.

The Charity Commission has reported a fall in many charities' donations as the recession bites. But the 'Just Four Quid' Appeal aims to buck the trend by leaving participants better off by the end of the year - even though they've given little and often to the campaign.

Cool it

Why not invest in a Chillow?

Available everywhere online, all you have to do is fill the pillow (available in a number of different sizes) with tap water and it cools itself without power of any kind. Perfect if it gets too hot.

The Chillow® website says: The Chillow is a unique personal cooling pad, only two centimeters thick. It does not use power and is allergy free. The Chillow is activated only once by simply filling it with tap water. The water is fully absorbed into the patented foam core which creates memory foam like comfort that COOLS & SOOTHES. Enjoy a SOFT RELAXING SENSATION that eases you into deep sleep, soothes headaches and COOLS HOT FLUSHES. Once activated, it will keep on working, so it's always ready for use whenever you need it.

The Chillows are also available through Amazon, so you could raise funds for us at the same time as buying one. Go to the www.mesupportgroup.co.uk website and click on Amazon. You then order in the same way as going direct to their site but we get a percentage of the sale.

Thanks to AYME

CLINICAL NETWORK COORDINATING CENTRE (CNCC) MEETING

MAY 2009

At the Clinical Network Coordinating Centre Meeting in May, Colette Bennett the CFS/ME Educator gave us an update on a research project that she has been undertaking, which was reported in Interaction.

Colette wanted to find out whether the practice nurses in the Greater Manchester Area were motivated to adhere to NICE Guidelines for CFS/ME. Also to see what barriers there are which prevent practice nurses caring for CFS/ME patients. Finally to highlight the learning needs of practice nurses, with a view to developing a training package to meet their needs.

In order to do this she sent out a questionnaire to the nurses asking about their knowledge of the NICE guidelines for CFS/ME and the confidence of the nurses when assessing and treating CFS/ME patients in general practice. Information was requested about their awareness of evidence based practice; support from organisations; if training opportunities were available, how they would like training to be given and finally what would motivate them to treat patients with CFS/ME and what they see as barriers to this new role.

The questionnaires were given out at practice nurse forum meetings or posted to practice nurses in surgeries known to have patients with CFS/ME. 9 out of the 10 Primary Care Trusts in Greater Manchester took part and 20 surgeries per PCT were targeted.

30% of nurses responded and of these 82% reported poor or no knowledge of the NICE guidelines for CFS/ME and poor understanding of what evidence based treatments are available. However they were aware of the need for education and training to improve their clinical confidence and to feel motivated to care for CFS/ME patients. 3 needs emerged; the need for evidence based information and training; a better understanding of the condition and more flexibility in their work and organisational structure.

In conclusion Colette found that the nurses were well motivated and experienced but had no real awareness of CFS/ME as a condition or of the evidence based treatment that can help to manage the condition. It is not usual for CFS/ME patients to be seen by practice nurses although they do see patients with other chronic conditions such as diabetes.

The results of the survey show a lack of awareness of the NICE guidelines for CFS/ME and it seems that information has not been passed on effectively in primary care. One of the knock on effects of this is a resulting negative impact on diagnosis and management of the condition and referrals to the CFS/ME clinical service that are timely and appropriate.

This study has shown how difficult it is to contact a professional group employed outside the NHS. The results indicate awareness by practice nurses of the need for; education and training to implement NICE recommendations in general practice; the need for GP support to access education and training; and for GPs to provide care for CFS/ME patients as part of the multidisciplinary team.

We are so fortunate to have Colette working on our behalf with Gill Walsh at the CNCC. Both of them are passionate about the need for good quality services and support for ME patients and families.

As a result of this study Colette has made some recommendations.

1. To develop a link nurse system, this works well with other long term illnesses e.g. MS nurse, stroke nurse.
2. To develop an IT template for GP practice computers for screening and management of CFS/ME:- this kind of tool is used successfully for other illnesses.
3. To collect accurate information regarding the prevalence/incidence of CFS/ME to gain a more realistic picture of the level of health needs in this group; this would help to support the request for increased funding for a more comprehensive service.
4. To develop a standardised education strategy for all health professionals to care for patients with CFS/ME; especially training for GPs to encourage them to diagnose patients at an early stage, and for practice nurses so that they can manage their care safely in a general practice.
5. The delivery of education and training should be conducted in an audit cycle (checked regularly) to ensure the education package is evaluated and fit for purpose.

A copy of this report is available to anyone who would like to read more from:-

Colette Bennett
CNCC for Greater Manchester
Silk House
Holyoak Street
Newton Heath
Manchester
M40 1 HA
Tel 0161 219 9420 Fax 0161 219 9477
Email: Colette.bennett@manchester.nhs.uk

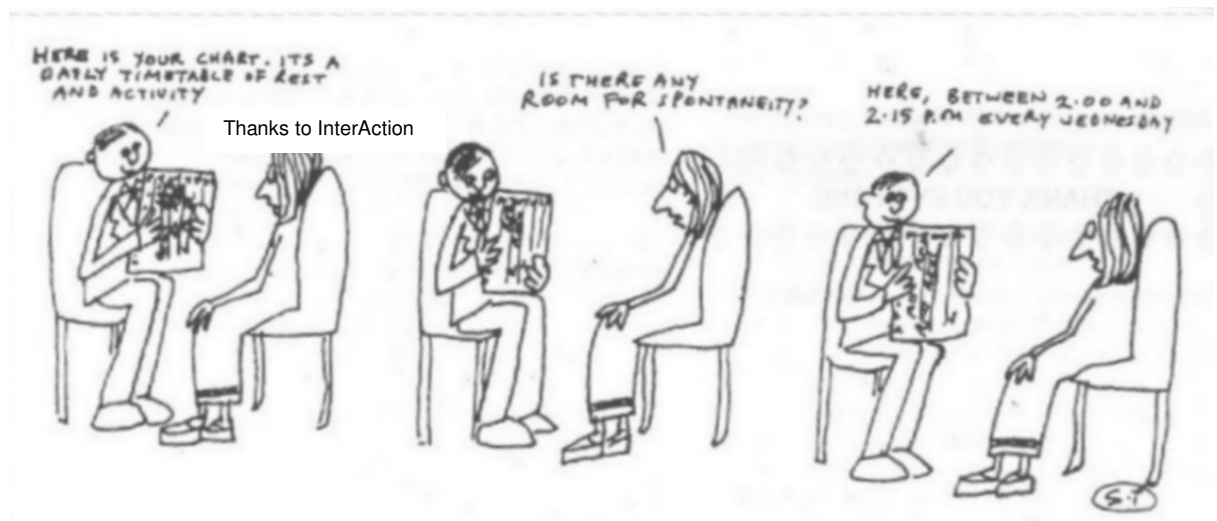
EXPERIENCING BREATHWORKS - PAT MCKENNA

Pat McKenna has had M.E for 30 years. She is only capable of short amounts of activity and then she will quickly become exhausted. The severe nature of her condition has meant that she has tried many different types of cure as well as ways of managing the illness. You name it and Pat says she's done it. From antibiotics to acupuncture, she's ticked off lots of "cures" and has spent large sums of money in her pursuit. However last year, she attended one of the club's meetings and was intrigued by a speaker promoting a therapy called Breathworks. Even during the presentation Pat was feeling unwell, but chose to stick it out. Whilst the session was going on, everyone was asked to do some meditation, and as a result Pat felt a lot better. She felt the immediate effect was enough to follow it up, and she enrolled on one of their eight week programmes.

When she got there she found out her classmates had many different types of illness as Breathworks is for anyone who has a chronic condition. In the first weeks she was encouraged to relax and was taught how to breathe properly. Then the class were encouraged to scan their bodies in order to locate areas of tension. After that they would work on those areas in order to let go and relax.

The course also addressed issues such as blocking, which is a situation or symptom you don't like and consequently run away from. At the lessons they were taught to accept these situations, to let go and say "goodbye" to them. In this way Pat could accept issues caused by her M.E. symptoms and let go of them without dwelling on them.

At each class they practised their breathing and meditation and later on in the programme they also practised some drama. The idea was that the



class could role-play situations, which were similar to real life, especially ones where they experienced pressure. The person who was experiencing the pressure would practice not reacting, controlling the situation and distancing themselves from it. In this way in real life they would be able to cope with pressure in a more constructive and controlled way. For ME sufferers like Pat, this was ideal as it would help them to pace their lives and daily activities.

The class were also taught about posture. They learned how to sit properly and all whilst breathing properly. Breathworks is therefore a collection of techniques designed to help you deal with your illness and some of the secondary symptoms that might occur because of it.

Pat felt that Breathworks provided her with many benefits and allowed her to manage her condition in a better way. Although she still has an underlying illness she is better able to control her life. Instead of fighting the illness she's learning to accept it more. Pat said "It showed me another way to cope with my illness and how to handle pain better by breathing and relaxation techniques."

Breathworks can be contacted at: <http://breathworks-mindfulness.org.uk/> or by calling: (0161) 834 1110.

SERIOUS ABOUT BEING LIGHT-HEADED

On 21 January, Professor Julia Newton, Newcastle University, was invited to present her latest research to MSPs at the Cross Party Group on M.E., in the Scottish Parliament. This is a summary of her work.

My research focuses upon understanding the autonomic nervous system and how abnormalities of heart rate and blood pressure regulation may lead to the symptom of fatigue.

Clinically, I head up the Falls and Syncope Service (FASS), which is an internationally renowned clinical unit based at the Royal Victoria Infirmary in Newcastle upon Tyne. The FASS is the largest autonomic testing laboratory in Europe and we see over 4000 patients a year, most of whom present to the clinic with falls, blackouts or dizziness on standing.

One of the common reasons why people experience blackouts (medically known as syncope), falls and dizziness is due to problems with the autonomic nervous system (called dysautonomia). I believe that there is a large overlap between these symptoms and fatigue and that the underlying physiological abnormality that links them is the presence of dysautonomia. The medical literature supports this view with over 200 research papers describing abnormalities of the vascular system, or its control, in M.E./CFS.

The autonomic nervous system controls all the actions that go on in our body that are outside conscious control. Functions such as making sure that the gut is working to digest our food, keeping us breathing and keeping our blood pressure high enough to maintain the necessary head of steam required to keep our organs supplied by blood.

Dizziness on standing

The autonomic nervous system needs to be very reactive to sudden changes. For example, when we stand up over 500 mls of blood drops into our legs by gravity, so there needs to be a microsecond response to compensate for this to make sure that we keep supplying our brain. These responses are controlled by the autonomic nervous system and if they do not happen adequately or quickly enough, then we might blackout or experience dizziness on standing up.

Blood pressure is the head of steam that gets the blood around the body and if this is lower then in extreme circumstances it will lead to blackouts - but I believe that if it is more subtle, this lower head of steam leads to reduced blood flow to many organs in the body and may account for the many and varied symptoms seen in patients with M.E. One question people often ask me is "Why is looking for dysautonomia not currently an accepted part of the management of M.E.?" I think this is partly because the concept of dysautonomia was first coined in the 1960s in studies involving diabetic patients.

This has led to a rigid view of dysautonomia that has changed little since the '60s with the dogma being that it is either there, or it is not.

Thankfully technological advancements have confirmed that this is a naive perspective and that rather than being an all or nothing phenomena, dysautonomia is in fact a continuum. I believe therefore that it is important that we re-evaluate the potential role of dysautonomia in fatigue associated chronic diseases particularly M.E.

My research team in Newcastle has performed a number of studies in patients with fatigue-associated chronic diseases. These groups include patients with chronic liver disease (primary biliary cirrhosis and non alcoholic fatty liver disease), early renal disease, and rheumatological diseases.

The team has developed and validated techniques that we are now beginning to apply to the study of fatigue in M.E.

In fatigue associated chronic diseases we have shown that fatigue is associated with dysautonomia, and that if we treat this, then quality of life improves. I believe that similar approaches to management have the potential to also lead to improvements in M.E., particularly as one of our recent studies has confirmed that an individual's experience of fatigue is the same in M.E. and in fatigue-associated chronic diseases.

We have shown that almost 90% of patients experience symptoms on standing (orthostatic intolerance) and that the more dysautonomia symptoms the patients have, the more fatigued they are (Jones et al., *QJM*). Which really makes you question, what is it about the physiology of standing up that is abnormal in M.E.? By understanding that, can we reverse it?

M.E. patients also have lower blood pressure compared to controls when we have measured it over 24 hours and the more fatigued patients are, the more their blood pressure drops through the night (Newton et al., *Psychosomatic Medicine*).

POTS

In addition, we have recently shown that 27% of those with a diagnosis of M.E. have a condition called Positional Orthostatic Tachycardia Syndrome or POTS (Hoad et al., *QJM*).

This condition is recognised by cardiologists and is diagnosed when people have symptoms when they stand up in conjunction with an increase in heart rate by 30 beats per minute or to above 120. The clinical studies we are doing in the unit in Newcastle will help us understand how common the overlap is between M.E. and conditions we recognise, and can treat, which will also allow us to develop specific treatments in the future.

Patients with M.E. have also participated in ongoing studies taking place at the Newcastle MR Centre. These studies have to date involved muscle and cardiac MR.

The initial muscle MR studies have been published and show that those with M.E. have difficulty removing acid from their muscles after exercise (Hollingsworth et al., *Clinical Gastroenterology and Hepatology*). Further studies are on-going to look at how this might happen so that we can begin to develop treatment to reverse it.

ME Research UK has recently funded a study that will allow us to develop a well characterised group of newly diagnosed patients who have attended one of the M.E. clinical services. In this study, all patients who attend the clinic will have autonomic function testing as a matter of routine. This will help us to determine how common autonomic nervous system problems are in this group and whether or not they can be detected in a clinic setting. The aim of this work is to help identify potentially treatable causes of fatigue and improve our understanding of it.

Assessment

When I was invited to speak at the Scottish Parliament to the Cross Party Group for ME., as a clinician seeing patients with M.E., I was asked to comment on which patients I felt should have assessment for dysautonomia.

I believe that there are two main groups who might benefit from assessment. Firstly, those with a history of loss of consciousness should be referred to an appropriate syncope service and secondly, patients with postural symptoms, i.e. a sense of lightheadedness on standing up, or in whom heart rate or blood pressure changes are detected on standing up.

I hope that as our knowledge increases, and understanding of the role of dysautonomia improves, this will lead to specific treatments and allow us to identify groups of patients, currently given the diagnosis of M.E. who might benefit from these treatments.

Professor Newton is based at Newcastle University. She has recently been promoted to the personal chair of Professor of Ageing and Medicine in the Institute for Ageing and Health.

Thanks to Interaction

A Sad Case Edgar Fawcett (1847-1904)

I can't understand why we don't like the things
It's wholesome and proper to eat;
I wish that I just hated candies and cakes,
And cared for potatoes and meat.
It frightens me sometimes, to think what I'd do,
If only I had my own way
In a candy-shop or a baker-shop,
With no one to watch me, some day.
For if anyone left me alone with a lot
Of candies and cakes at my side,
I firmly believe I should eat and should eat,
And should eat, and should eat, till I died.

Disorder Gamaliel Bradford (1863-1932)

My life is governed by the clock,
All duly mapped and plotted;
And only with a nervous shock
I miss the time allotted.

My course without has always been
Set straight to hedge and border;
But I confess that all within
Is vast and vague disorder.

In matters of style, swim with the current;
In matters of principle, stand like a rock

Thomas Jefferson 1743-1826

LYNDA AND PRISCILLA TAKE ON THE GREAT GLEN WAY



I've never been very good at sitting back and waiting for things to happen. (Does that sound familiar)? I have been planning for a while to try and cycle the Great Glen Way. Fort William to Inverness over a few hills. And decided that I should use this to raise awareness of the difficulties encountered by ME/CFS sufferers and also try and raise funds for ME Research. I will try and show that it is an illness that forces you to make choices that it doesn't necessarily mean you can't do active things, but then when you do do them there are repercussions.

I realised that I needed to try and maintain some muscle strength in order to function generally and also found that cycling was easier than walking. I try and do some exercise two or three times a week feeling that if I didn't then I would deteriorate further. It seems to have worked so far but I am only working within the constraints that the illness has placed on me. I have done the Pacing and CBT and will use these techniques to help me achieve this goal, but even with this level of graded activity there is a limit as to what I can sustain, and I hope that I will be able to continue at the level I have maintained this last year.

However my first priority has to be to be able to work and then after that to look after myself and my home, I only work part time, earning just enough to keep a roof over my head but not much more. I then choose what I do with any remaining energy. How I appear when I am visible to people belies what is going on when I am not. The questions that sometimes need asking about a sufferer are why do I see them so little? Why don't they go out? Why do they seem to hibernate in winter? Why is tired all the time such a limited view of what is really going on? I intend to write to my MP and other MP's in the area, try and get some media coverage and obviously raise awareness of what it really means. Currently it is just Priscilla, myself and my accomplice. More would be welcome, but they need to pay for themselves, although I will try and get group discounts.

I welcome any help and suggestions and hope that you will direct people towards my Just Giving page, which is on:

www.justgiving.com/lyndamarney1

I also have some sponsor forms if anyone prefers.

Introducing Priscilla

This New Year I won a duck which when searching for a name, as you do, I decided to call Priscilla after the film Priscilla Queen of the Desert. It seemed appropriate with her being pink and flashy. When I arrive in Inverness I may try and re-introduce her to the wild and see if I can lure Nessie out. She glows when put in water.

Just for Fun

As we look forward to the delights of an English summer to come, here is a thought for the season (Sorry Mr. Browning.)

Oh to be anywhere but England, now that April's finished off.

The crows have blocked the chimney, and there's bees up in the loft.

The air is full with pollen, it makes you want to sneeze.

There's rising damp in the basement, and arthritis in me knees.

Me eyesight's getting bleary, and me hair's all turning white,

First thing in the morning I don't half look a sight.

Still I carry on quite gamely keeping body and mind together.

The garden's killing me back and legs, and me skin has turned to leather.

It's the sun that's doing the damage, and the wind, and the rain, and the fog.

The lawn's overgrown, and the greenhouse smashed, and the garden's just a bog.

Still I love a good English summer, and watching the clouds a scurrying by,

I love the flowers, and bunnies and things, cept the birdie who pooped in me eye!

Thanks to Hermes

INFECTIONS

M.E./CFS cases are commonly triggered by a viral infection and the burning question is why, in some people, an initial infection persists - with serious consequences that can last a lifetime - while other people swiftly recover their health.

The Dubbo Infection Outcomes Study Group in Australia has followed 300 people with acute infection with Epstein-Barr virus, Q fever or Ross River virus, from the time of symptom onset until their recovery.

The Group's most recent report (published in *Clinical Infectious Diseases* 2008) shows that individual differences in genes that have critical roles in the immune response to infection - cytokine genes - have a key role in subsequent differences in the severity of illness, as well as its outcome over the longer term.

Specifically, the type of interferon-gamma and interleukin-10 genes carried by the infected person were important.

As the authors explain, the challenge faced by the immune system of an infected person is to respond with sufficient intensity and duration to control or eliminate the infecting pathogen, while minimising immune injuries.

People whose genetic makeup favours a more intense inflammatory reaction (at the start) are likely to experience more severe symptoms of infectious disease and a more protracted illness.

The challenge for medical science is to identify these individuals early and have a treatment plan prepared.

Lifestyle factors

Lifestyle factors are important risk factors for several diseases, such as cancer, heart disease and diabetes, but is this also true for M.E./CFS?

Well, academics at the Radboud University Nijmegen Medical Centre (*Journal of Human Nutrition and Dietetics*, 2009) explored the issue by collecting data from 247 M.E./CFS patients on lifestyle factors, smoking, intake of alcohol, fat, fibres, fruit and vegetables, body mass index (BMI), fatigue severity and functional impairments.

Of the patient sample, 23% smoked, 32% had a BMI greater than 25 (i.e. overweight or obese) and none had an alcohol intake that could be classed as unhealthy. In fact, 27% of M.E./CFS patients abstained from alcohol altogether, compared with around 14% of the general Dutch population, confirming an earlier study from 2004 and patients' own reports of alcohol intolerance.

Only 5% had a healthy fibre intake and approximately 70% had an 'unhealthy' lifestyle with respect to fat, fruit and vegetable intake, though the eating habits of the general Dutch population also reveal a similar 'unhealthy' pattern and overall the researchers found that patients tended to lead a healthier lifestyle than the general Dutch population.

But were there differences between patients with healthy and unhealthy lifestyles as regards fatigue severity or impairment of function? No, although a definitive answer would require a full population-based epidemiological study.

Nursing issues

The NICE guideline of 2007 accepted that most patients with M.E./CFS would be managed in primary care, a setting in which practice nurses are acquiring a greater role. A recent investigation from the School of Community-Based Medicine, University of Manchester (*BMC Nursing*, 2009) aimed to discover the current level of knowledge and understanding of the condition in 29 practice nurses using semi-structured interviews.

Qualitative studies like this do not rate highly in the hierarchy of research evidence, yet they can be very revealing indeed, as the results show.

There was considerable ignorance about and limited experience of the clinical features of the illness, its aetiology and appropriate management strategies. And some of the nurses' comments would make a crow blush. For instance, "I know so little you could write it on a postage stamp," "no time paid to it whatsoever, brushed over," "I think the money could be better spent."

So the authors correctly recognise that training must begin by addressing some current negative attitudes to patients with M.E./CFS.

However, in most there was an openness to training and a willingness to get to grips with issues, particularly in order to help patients.

Interestingly, the practice nurses who were most informed had gained their understanding about M.E./CFS through contact with patients, friends and personal experiences, rather than any formal training.

This is something we all recognise: that understanding and sympathy are kindled (and the desire to help awakened) when there is a personal connection, such as the severe illness of a family member.

Thanks to ME Research

ALL PARTY PARLIAMENTARY GROUP

Inquiry into NHS Service Provision for people with M.E.

Dr. Des Turner, chair of the APPG on M.E. has commenced an inquiry into service provision for sufferers of M.E. The aim is to evaluate the care provided by the NHS in England. The inquiry committee comprises Des Turner, Ian Gibson, Tony Wright, Andrew Stunell, Peter Luff and the Countess of Mar.

Apparently patient group surveys continue to highlight levels of concern by patients regarding both the services which are being provided and the way in which the NICE guidelines recommendations could result in an inflexible approach to management.

The inquiry committee wants to collect data from Strategic Health Authorities, Primary Care Trusts, from specialist treatment centres, directors of Public Health, patients and patient groups.

They want to know the service framework for caring for people with M.E., including children and those severely affected;

- the funding available;
- their estimate of how many sufferers live in each area and the degree of severity of illness; what funding is necessary to provide adequate healthcare for these patients;
- what happens to people with M.E. who need referral to hospital or other secondary service if there is no local service available;
- the ways in which patient outcomes are measured and seeing how this compares with how patients measure outcomes;
- what diagnostic criteria are being used;
- how are their health professionals in primary care (GP surgeries), secondary care (hospitals) and in specialist centres/teams, trained;

and lastly information about the range of interventions and symptom management strategies available.

Although the deadline for writing to the inquiry has passed, I can assure you that we have written on behalf of the group highlighting some of the concerns about lack of hospital facilities for severely affected patients, the need for respite care, lack of services for young people and the inflexibility of approach inflicted by GP's in general due to NICE guidelines.

Anyone wishing to look at a copy of our submission can obtain one by e-mail from Yvonne at

ryleech@talktalk.net

Watch this space for updates as we receive them.

Pam Turner

GETTING THE MESSAGE ACROSS

Once again AYME has managed to get a large article (4 A4 pages) into The Journal of School Nurses (Apr 2009 Vol4 No.3). Mary-Jane (AYME CEO) spoke at the conference of School and Public Health Nurses' Association at the end of last year following an initial article in their journal. We are delighted that they followed it up this year with such an informative article, which can only assist our children and young people struggling with their education. Part of the article is shown here

Myalgic encephalopathy: Sustaining an education.

Myalgic encephalopathy is the most common cause of long-term absence among school children. This second article concentrates on providing an education to children suffering from the condition that takes all their needs into account.

School nurses are the key to negotiating the fine balance between health and education for teenagers with myalgic encephalopathy/chronic fatigue syndrome (ME/CFS). The physical symptoms and psychosocial effects of ME/CFS can severely impair quality of life of young people as discussed in last month's article (Willows, 2009.) This article focuses on education for children and young people in ME/CFS.

ME/CFS has a huge impact on the education of young people. In a survey of members of the Association of Young People with ME (AYME) (2007), one third of children and young people with ME/CFS said they received no education for a period of time, 18% were in school part-time, 19% were receiving home tuition, 17% were in college and others were participating in correspondence courses.

Mary-Jane Willows, chief executive officer of AYME, said that there are great examples of education professionals including school nurses and home tutors supporting pupils with ME/CFS, but that they have also dealt with some heartbreaking cases of local education authorities (LEA) acting unreasonably, inflexibly and, in some cases, illegally, by not providing the support they are obliged to in law.

It is the duty of every LEA to provide suitable education for children with medical needs and it is no defence to say they cannot afford it. Section 19 of the Education Act 1996 says that LEAs have to provide a 'suitable' education for sick students. The court case R v East Sussex County Council ex parte Tandy (1998) says that LEAs cannot take money into account when deciding on what constitutes a suitable education.

It is the provision of 'suitable education' that is crucial for young people with ME/CFS. Due to the fluctuating nature of ME/CFS, the education of young people with ME/CFS must be geared to each individual, there is no one-size fits all.

Diagnosis

ME/CFS is diagnosed where there is debilitating fatigue, muscles and/or joint pain in multiple sites with evidence of (Turnbull et al, 2007):

- Inflammation
- Headaches
- Painful lymph nodes
- Cognitive dysfunction
- Malaise or 'flu-like' symptoms
- Dizziness or nausea.

Problems with both memory and attention were found to be the most common symptom for both children and young people with the condition (Davies and Crawley, 2008). The study by the Bath/Bristol Paediatric ME/CFS team demonstrated that children and young people with ME/CFS found it difficult to focus their attention on one piece of information, and that concentrating for a long time (10 minutes in some cases) was almost impossible. Difficulty recalling information was also described as a problem, such as remembering the location of keys or shoes, or perhaps a friend's birthday. Switching attention, divided attention and auditory learning were also found to be problems for young people with ME/CFS. These sorts of problems with memory and concentration also lead to a lot of stress and frustration for the young person and are obviously a challenge to educational professionals.

The Case Study shows how this challenge was met by one young person with ME/CFS during his secondary education.

Advice and support for parents

Families often feel alienated and in need of constructive support. School nurses can fill the gap by supportive and non-judgmental home visits. This is particularly vital when the young person is too ill to attend school and, all too often, these ill young people no longer feel a part of the school community.

The school nurse may bring messages from classmates and news from the school community. Families will need to feel they can voice their concerns, be listened to and believed. Home visits rather than a telephone call will make family members feel comforted and they will appreciate the supportive contact. This too will provide a vital link between the family and school when deciding what would be suitable educational provision. This may be in the form of home tuition provided by the LEA, tuition....

Thanks to AYME

If someone you know who is in need of help, will you gladly give it? I'm sure most of us would.

But – and be honest – when you find yourself in trouble or in need, how happy are you to let others do for you what you would do for them? Sometimes accepting help can be the most difficult thing in the world.

The poet John Donne said “as God loveth a cheerful giver, so he also loveth a cheerful taker, who takes hold of his gifts with a glad heart.”

And who can doubt a helping hand, from any quarter, is anything other than a gift from God?

RECIPE SELECTION

All-in-one Chicken Tray Bake

Serves 2

Ingredients

2 Tbsp Olive Oil	2 Chicken Breasts, skin on	375g of new potatoes, sliced
Large pinch of dried thyme or fresh if you have it		2 Garlic cloves, peeled but left whole
225g of mixed peppers	1 orange, cut into segments	100g jar pitted black olives in brine

Preparation and cooking time - ready in 30 minutes

Method

1. Heat oven to 200C/180C fan/gas 6. Heat 2 tbsp of oil in a large flameproof roasting tin, then fry chicken, skin side down, and the potatoes for 8 minutes or until the chicken skin is crisp and golden. Turn the chicken and potatoes, then continue to cook for a further minute.
2. Add the thyme and garlic, then stir to coat everything.
3. Roast everything for 15 minutes until the potatoes are soft. Remove from the oven and throw in the peppers, orange segments and olives and roast for 5 minutes more until the chicken and potatoes are completely cooked. To serve bring the tray to the table help yourselves.

Alternatives to chicken - use white fish fillets. Simply start with the potatoes and add the fish/tofu with the peppers.

Beef Stroganoff

Serves 4

Ingredients

350g (12 oz) rump steak, cut into thick strips	Salt and ground black pepper
75g (3 oz) vegan margarine	1 large onion, halved and thinly sliced
225g (8 oz) button mushrooms	4 tablespoons brandy (or sherry)
100 ml of beef or chicken stock	75 ml (3 fl oz) Soya cream
75 ml (3 fl oz) Soya milk	1 tablespoon of chopped tarragon
1 tablespoon of snipped chives	Mustard to taste

Method

1. Toss steak strips in black pepper
2. Heat 50g (2 oz) of margarine in a heavy based frying pan until hot and sizzling
3. Cook the steak strips in batches for a couple of minutes
4. Remove from pan and keep warm
5. Heat remaining margarine and cook the onion and mushrooms for a few minutes
6. Add brandy (sherry), stock and soya cream and milk
7. Leave simmering until the sauce thickens
8. Stir in mustard and tarragon and season with salt and pepper
9. Put beef into sauce, stirring until the meat is hot
10. Sprinkle with snipped chives

Serve with rice

Thoughts of the day

Thousands of candles can be lit from a single candle, and the life of the candle will not be shortened.

Happiness never decreases by being shared.

You don't stop laughing because you grow old. You grow old because you stop laughing.

Remember what the caterpillar calls a tragedy the master calls a butterfly.

Our spirit is indestructible and continues from eternity to eternity. It is like the sun, which seems to set only to our earthly eyes, but which, in reality, shines on unceasingly.

USEFUL SERVICES FOR PEOPLE WITH ME

Internet Services

The World Wide Web has allowed me to stay in touch with friends, meet people I'd never known before (including my boyfriend!), learn about my illness, and most importantly, retain some sense of independence. It's amazing how many things you can do and make happen just by sitting at a computer and clicking the mouse a few times. The following are a few services I have found while exploring what is available to help make my life easier.

Prescriptions

Some doctors' surgeries allow you to email them or their local chemist for repeat prescriptions, instead of having to go into the surgery. The surgery receives my email request and sends the request down to the chemist of my choice automatically, and usually within one or two days. There are also some prescription delivery services available on the NHS in some areas of the country, who will deliver your prescription directly to your home. Ask at your GP's surgery.

Boots (www.boots.com) provide various prescription services, include a repeat prescription home delivery or store pick up service (go to: "pharmacy and health" and then "prescriptions" on the Boots website).

Directgov

www.directgov.co.uk This is the new government website offering information about "public services all in one place", relevant to everybody, but there is also a section specifically for people who are disabled. From the main website you can easily navigate to the "disabled people" section, and from there find information about employment, financial support (including benefits advice), education and learning, transport (including the blue badge scheme), home and housing, health support, and the rights of the disabled person.

I have found the "Financial Support" pages the most useful - they give clear advice about the different benefits that you might qualify for, as well as eligibility criteria and an option to download the application forms so you can print them out and fill them in straight away.

Banking Online

Most banks and building societies enable you to bank online so that you can view a statement of your account history, going back months if you want to. You can move money from one account to another, set up standing orders and direct debits –especially useful for checking how much money is in your account without having to get to a bank or cash machine. Some internet bank accounts are exclusively online accounts and can only be accessed through the internet, whilst others enable you to also use your bank in the normal way as well.

Library Services

Some libraries have their own websites which you can access and use various library services. My own local library website has a complete catalogue of all books, cds etc. from all over the county so I can search for a particular book, author or keyword. I can find out within minutes which books are available and also which library in the county they are at. I type in my library card number and order whichever books I would like – to be picked up at my local library. I can check online to see when they are ready for collection but I can also get an automated phone call to tell me when they are ready for collection, and once they're on loan I can check when they are due back. If I want to keep a book for longer, I can renew them online.

It's worth checking to see if there are any special types of library cards for disabled people. My library has issued me with a housebound person's library card – meaning that I can keep books longer than other people and if I do happen to be a bit late returning a book I don't have to pay any late fees.

DVD Rental by Post

There are many different DVD rental services available - and more appearing all the time. Even the supermarkets have their own DVD rental services now, so it's worth surfing around to find the best price scheme for your needs. Most DVD rental services run in the same way.

I use Lovefilm, (www.lovefilm.com) rental, and have found them to provide an excellent service over the years. The service is very simple to use. Log on to the website and register and you have a free trial of 2 weeks during which time you can cancel at any time. After this time, if you decide to sign up properly you can pick from 6 different rental plans: 1, 2, or 3 DVDs at any one time.

Once you have chosen a plan, you look through all the DVDs available to rent (over 65,000 titles including new releases) and make up a list of any that you would like to rent, marking them as "high", "medium" or "low" priority) to your first class. When you've viewed the DVD you just pop it back into the envelope, seal it, and drop it in the nearest post-box. No stamps, no postage. As soon as Lovefilm receives the returned DVD, they will post out the next DVD on the list (first class), until you reach your monthly quota. There are no due dates, no late fees, and no hurried trips to the rental shop to return DVDs.

Shopping Online (Grocery)

Most of the major supermarket chains have a home ordering and delivery service. The websites are very easy to use and some even have a list saver option so if you buy the same things from week to week, you don't have to find them in the website all over again each time. The supermarkets charge a (fairly small) fee for packing your shopping and delivering to your door, but in most supermarkets you can choose which day and time slot you want your deliveries.

Postage Online

The Royal Mail website (www.royalmail.com) has lots of helpful services including a postcode finder and other information about postage. I don't know about you, but despite the general move to email, text messages etc., I still use the postal service a great deal.

A brilliant and fairly new service provided on the Royal Mail website is printing postage online. Being able to post things for myself at the postbox up the road, rather than getting someone else to do it for me is very empowering and makes me feel much more independent.

Education

Just because you are stuck at home with ME, it doesn't mean you can't carry on your education from home if you want to and are able to (within reason – remember your pacing!).

I was lucky enough to complete my A levels before ME struck but there are options out there for people who want to try improving their qualifications from home. Or maybe you just want to learn something completely different. The following websites include various options for studying from home:

* www.nec.ac.uk – National Extension College – offers GCSE's, A-Levels and other home learning subjects.

* www.learndirect-skills.co.uk - Learn Direct offers flexible learning (with funding help for those who need it) in subjects such as English and Maths.

- www.open.ac.uk – The Open University – offers university level qualifications from home in many subjects. The O.U. gives fantastic support for those who are disabled or long-term sick and can provide lots of financial support; exams can be taken from home if required.

The Certificate in Interpersonal Skills for Volunteers,

Run by the University of Wales, Lampeter (<http://www.volstudy.ac.uk>) has been revised for 2009 making it more relevant and accessible than ever before. The course has helped hundreds of people in the past improve their interpersonal skills. Most new students can take the course for as little as £99 or free* with the promotional code LAMP99 or for those on certain benefits. The course can be taken alone or make it part of a formal qualification like a diploma or degree.

There are lots of subjects out there to study from home. I have recently finished a two year writing course from home with www.writersnews.co.uk home study. Writing was something I was always interested in before becoming ill, but never had time for while I was at school and college. I have loved the sense of focus the course has given me, and it has even lead me to writing these articles. I would recommend a course (even a short one) to anyone with M.E who is well enough to give it a go; it gives you such a sense of achievement, and really does give you something to focus on other than the miserable symptoms.

Katherine Metcalfe

From the AYME Cheers magazine members own pages

POETRY CORNER

Goldfish by Linda Agar

I wish I was a budgie, a cat or even a dog.
Instead I am a goldfish with a mate who is a frog.
Everyday and every week and every flippin year,
I spend my time here in this tank, the water's not even clear.

A piece of wood, a silly toy and the bottom is full of gravel,
I wish I could escape sometimes, I'd really like to travel.
All I do when I am down to try to forget my troubles,
Is swim and fart then dash around to try to dodge the bubbles.

But never mind its feeding time, at least I'll fill my belly,
And if they turn the volume up, I might even watch the telly.

I wish by Helen Thomas

I wish I was a pop star with loads and loads of money.
Everyone interested in what I am doing, what I am saying, scrutinising and analysing my every word and doing.
No privacy in whatever I am doing. On second thoughts maybe not.

I wish I was never born, although I quite like chocolate and the feel of the sun on my face on a warm sunny day. I like the trees in blossom and the full moon shining in the sky and all the twinkling stars. So, no, that's not my wish.

I wish for the humility, courage, strength and compassion to live my life to the full, to face the challenges of day to day living, as well as deep dark parts, as well as joyous times, to be the best friend and confidante I can be to all I love and cherish. I wish to be the best I can be.

Dream - anon

Dream not too much of what you'll do tomorrow
How well you'll work another year.
Tomorrow's chance you do not need to borrow -
Today is here.

Talk not too much of some new endeavour
You mean to make a little later on.
Who idles now will idle on forever,
Until life is gone.

Swear not some day to break some habit's fetter
When this old year has passed away.
If you have need of living wiser, better,
Begin today.

The Sea Gypsy by Richard Hovey (1864-1900)

I am fevered with the sunset,
I am fretful with the bay,
For the wander-thirst is on me
And my soul is in Cathay.

There's a schooner in the offing,
With her topsails shot with fire,
And my heart has gone aboard her
For the Islands of Desire.

I must forth again tomorrow!
With the sunset I must be
Hull down on the trail of rapture
In the wonder of the sea.

For Beauty I am not a Star by Woodrow Wilson (1856-1924)

For beauty I am not a star,
There are others more perfect by far,
But my face I don't mind it,
For I am behind it
It is those in front that I jar.

ORIGINATOR OF H₂S THEORY SPEAKS

by cort on June 22, 2009

Dr. DeMeirleir made a big splash when he announced at a press conference that he had uncovered a new and important factor in chronic fatigue syndrome (ME/CFS) called hydrogen sulphide. What was lost in the flurry that followed was the fact that if it was not for an inquisitive mother of a daughter with chronic fatigue syndrome that press conference very well might never have happened.

Years before hydrogen sulphide had become even the smallest blip on the ME/CFS research community's radar screen a rather remarkable woman named Marian Dix Lemle was developing a theory suggesting that it could lie at the heart of this disease.

I first met Marian Lemle two years ago at the IACFS/ME conference in 2007. She had written a paper proposing that the excessive production of hydrogen sulphide gas had put ME/CFS patients into a kind of hibernation like state. I was a little taken aback by it - I had never even heard of hydrogen sulphide before and certainly not the connection with chronic fatigue syndrome. I bumped into her several more times over the next couple of years and each time her interest in the subject remained undimmed.

She got a short paper published, a remarkable accomplishment, I thought, for someone without a medical background. Then the news flashed across the Internet - big breakthrough in ME/CFS! I eagerly scrolled through the news - it was hydrogen sulphide! You could've knocked me to the floor with a straw. But where was Marian? I saw no mention of Marian. (Marian was cited on the last slide of Dr. DeMeirleir's presentation)

Marian Lemle had been in London. When she got back to the states I got a chance to talk with her. She just accomplished an amazing feat; opening a new field of inquiry in a disease doesn't, after all, happen every day - especially if you're a lay person. In truth if anyone was going to do something like this it was probably going to be someone like Marian Lemle. Previously a professional in the telecommunications field and an exhibited sculptor and painter, she is used to traversing and excelling in different fields. I asked her how this all came about.

"In Nov 2006 I attended a meeting in Washington where a prominent molecular biologist discussed an experiment where he gave H₂S gas to mice and watched their metabolic and heart rates plummet as they entered an apneic-like low-level sleep state in which one part of their brain was always monitoring the environment. When he pumped oxygen back into the chamber the mice completely recovered. I started thinking about the kind of enervated torpor-like state that CFS patients experience and I asked him if this could be related to CFS. He thought it seemed possible."

"From there I started turning over every clue I could. I prepared a short synopsis of my findings and asked the panel on 'The Brain in Chronic Fatigue Syndrome' at the IACFS/ME Conference in Miami in 2007 what they thought of my idea. One of the Japanese researchers (Dr. Watanabe or Dr. Kuratsune) thought it was an interesting question. The rest of them (including Dr. De Meirleir) showed little interest."

"A couple of months later Dr. Carl Peck, former Assistant Surgeon General and a friend of the family, approached me and asked to take a look at the paper. He said it was groundbreaking and helped me formulate the hypothesis. We periodically met over the phone to discuss drafts of the paper."

"I sent the paper to and talked to researchers at Johns Hopkins, the NIH and elsewhere. Eventually I talked to Dr. Suzanne Vernon, the Research Director at the CFID's Association of America (CAA) and Kim McCleary, the President of the CAA. Dr. Vernon thought the theory "made biological sense" and directed me to Dr. Richard Deth, a prominent researcher working on mercury in autism. She encouraged me to publish the paper. All three were very supportive."

"Dr. Deth told me that his work on thimerosal had led him to think about sulphur metabolism in autism, but he'd missed a possible link with regard to H₂S. He asked me for permission to share my ideas with his students and colleagues and I agreed. "

"I submitted the paper to the Journal of Medical Hypotheses early in 2008. The editor wrote back immediately and offered his help in getting a much shorter paper ready for publication. The abbreviated version of the original paper was e-published in September of 2008."

In retrospect the doors opened for Marian Lemle quite quickly; Dr. Peck, Dr. Vernon and Dr. Deth all quickly realized that Marian was onto something and were happy to assist her. I noted, though, how difficult it can be for a lay person to get the research community's attention.

While noting that that's often true, Marian observed that "In scientific discovery, many new ideas come from people on the outside who haven't been constrained by the thinking patterns that permeate the field." In fact we don't have to look far to find evidence of that in ME/CFS. Rich Van Konynenburg Ph.D. is in physics yet his ideas regarding glutathione and now methylation have sparked much interest in the field.

I mentioned Rich and Marian was quite emphatic that she felt that his work deserved more attention. She talked to Rich at the IACFS/ME conference and told me that he said "You're right!" It turns out that the H₂S theory fits in quite well with Rich's methylation theory.

The Gut Connection - Dr. De Meirler and Dr. Chia have been focusing on the gut for several years now. Marian, however, does not have a singular focus on the gut, although she thinks the story could "begin there, within the context of our genetic boxes". She notes the prevalence of gut dysbiosis (imbalance of intestinal flora) in CFS and is inclined to think of Lyme, salmonella and many other H₂S-positive infections as a manifestation of this underlying dysbiosis. She takes it even further, saying that certain people may be particularly susceptible to the effects of H₂S, having, "what, years ago was called "hyper-susceptibility" to Hydrogen sulphides".

I noted that the gut is 'consuming' more interest all the time but it turns out that it's only one organ of interest with regard to H₂S. Marian noted that "if the gut connection doesn't produce reliable results it may reduce interest in other areas... The story of H₂S goes far beyond what happens in the gut. H₂S is fundamental to life. Imagine, there is a parallel universe in the deep sea that relies on H₂S to sustain some extraordinary life forms. H₂S is to the deep sea world what oxygen and light are to life on earth. Who could have imagined this?"

"We may be fuelled by oxygen and light, but it turns out that H₂S is essential to our bodies as well. Hydrogen sulphide and oxygen may well turn out to be the yin and yang of homeostasis in our bodies".

Marian noted that "our mitochondria are descended from ancient eukaryotic cells, which appear to have retained that deep sea capability to use H₂S as an energy substrate."

This is the third prong of her theory. She stated that "Drs. Myhill and Moore appear to have confirmed the first part of my hypothesis- that CFS is a mitochondrial disease. Dr. De Meirler may prove the second; i.e., that H₂S dysregulation plays a key role. Now we must examine the role of H₂S in the mitochondria."

A Nitric oxide/mitochondrial connection? H₂S's ability to interfere with mitochondrial production has again brought the question of metabolic abnormalities to the fore in ME/CFS. The Pacific Fatigue Lab has documented that some chronic fatigue syndrome (ME/CFS) suffer a kind of metabolic implosion after exercise. At the last IACFS/ME conference a Spanish researcher presented preliminary findings of greatly increased levels of nitrates in ME/CFS patient's blood following exercise. Nitrates are derived from nitric oxide. Could H₂S dysfunction be the tie that binds with regard to nitric oxide and exercise metabolism?

Martin Pall believes nitric oxide plays a key role in a broad arena of disease (ME/CFS, FM, IBS, MCS). Italo Biaggioni is currently examining whether NO is causing the blood vessels to over dilate in ME/CFS patients. Some evidence suggests, however, that H₂S may even be the puppet master controlling NO's strings in our blood vessels.

H₂S is produced in the brain, pancreas, liver, reproductive tissues and it affects smooth muscle functioning in our blood vessels. Dysregulated H₂S production in any of them could cause dramatic effects.

The brain connection? The brain connection is particularly intriguing. ME/CFS patients often benefit from drugs (Klonopin) or practices (meditation, relaxation exercises) that slow down nervous system activity. In fact the whole class of CFS-like illnesses (Fibromyalgia, IBS, MCS, etc.) may be characterized by an over-active nervous system. Marian informed me that H₂S is produced in the brain by cystathionine beta synthase and cystathionine gamma lyase and its release in the brain is triggered by neuronal excitation.

Increased levels of H₂S in the brain may indicate that low blood flows in the brain have caused a free radical explosion in the blood vessels (resulting in cerebral ischemia). Interestingly, several studies have found evidence of 'hypo-perfusion' or low blood flows in the brains of the ME/CFS patients. Both Dr. Baraniuk's and Dr. Shungu's work suggests high rates of oxidative stress/mitochondrial problems occur in the brains of at least a subset of ME/CFS patients.

Marian also noted that the brain and gut share enough similarities that the gut is often referred to as the second nervous system or the 'enteric nervous system'. Does the neuronal excitation presumably found in the central nervous systems of

chronic fatigue syndrome patients extend to the gut as well? Could H₂S play a role in the irritable bowel problems so often seen? She added “We already know that it has been tied to ulcerative colitis and colon cancer.”

A Protective Mechanism? H₂S by itself is not ‘bad’; it’s a potent signalling molecule that triggers important reactions across the body. Interestingly in the case of cerebral ischemia H₂S is thought to have protective effects and this brings us back to the altered brain states in sleep, hibernation, torpor and all the states in between

Could H₂S outside of the gut be protecting patients from the damaging effects of ‘high’ metabolic rates. Could that torpor like state the molecular biologist described which so caught Marian Lemle’s attention in 2006 be protective? Could H₂S be stepping in to induce fatigue and thus shield patients from the effects of overexertion?

The Question As with all the intriguing theories in ME/CFS, the links abound. But will they stand up to rigorous scientific inquiry? (Will they get rigorous scientific inquiry might be a more applicable question.) Dr. De Meirleir has done something that Marian Lemle could never do on her own - capture the attention of the ME/CFS community. Before going public, he wrote her in an e-mail - “Your H₂S hypothesis was confirmed by us “and is working on extending it.” He’s developed a test for H₂S metabolites and has asserted that H₂S producing bacteria are indeed present in high levels in ME/CFS patients’ guts.

Treatment Marian Lemle is not a physician but she is a mother with an ill daughter. Has she tried to apply her theory to her daughter’s health? She said “I’m quite cautious with regard to treatments for my daughter”. She noted that the standard treatments for H₂S poisoning (usually from industrial accidents) include amyl nitrate (better known in the recreational drug community as ‘poppers’) and oxygen. (Injections of the sodium nitrite (used as a preservative in foods) are also used). Only the last is tenable for ME/CFS but she has concerns about providing oxygen to ME/CFS patients.

Another tack, which appears to be used by Dr. De Meirleir, is to isolate the bacteria in the gut and attack them with antibiotics while providing nutrients to heal the gut but she has hesitancy about using long-term antibiotics. Right now she’s watching and waiting to see how all this interest that she started resolves.

This can be seen with comments at <http://aboutmecfs.org/blog/?p=613>

CARERS' NEWS

If you are a carer and you are looking for some support, advice, information or perhaps you want to learn how to manage a bit better in your caring role, a new programme is now available across Bolton.

Free for carers aged 18 and over in England,

Caring with Confidence aims to help improve your health and wellbeing and that of the person you care for.

The programme is made up of seven sessions covering different aspects of a carer's role and you can choose which you want to do depending on your own circumstances.

Everyone is encouraged to start with **Finding Your Way** which gives you some more information about the programme, helps you look at what matters to you and which other sessions you might want to do.

You can then choose to do one or more of the following sessions:

Caring and Coping - Gives you time and space to look at the emotions involved in looking after someone, what strategies to use and what can be done to cope with stress more effectively.

Caring and Me - How to be fit for life and caring. Discussion and planning around a carer's own health and wellbeing.

Caring Day-to-Day - Looks at the essentials of looking after someone day-to-day, from medication to emergencies at home.

Caring and Resources - How you can maximise your income and access other resources which save you money as a carer.

Caring and Life - Invites you to take time out and think about how to juggle competing demands and how your caring role fits with other aspects of your life.

Caring and Communicating - Uses real-life caring situations to help you get the best from communicating with other people.

For more information about free local sessions in your area please contact:

**Scott at Crossroads Bolton on 01204 522366
or text/phone 07540 578789 or email scottcwc@btconnect.com**

Caring with confidence will:-

- Help you build on your strengths as a carer
- Give you the opportunity to share experiences and learn from others in similar situations
- Give you useful information, ideas and tips about looking after someone
- Help you decide what you might like to change about your caring role
- Provide travel and alternative care costs for those who need it while attending a session

Thanks to Bolton CVS Jumbo magazine

SOME CONTACT NUMBERS AND ADDRESSES YOU MAY FIND USEFUL

Benefits Agency Information Officer (Bolton) : 01204 367000 (Bury) : 0161 762 2000

Bolton Primary Care Trust : 01204 907724

Bury Primary Care Trust : 0161 762 3100

Citizen's Advice Bureau Bury : 0161 761 5355 Bolton 01204 900200/(213 Housebound)

Disabled Living : 0161 832 3678

DIAL Disability Information and Advice Line: equipment and gadgets and where to get them : 0161 703 8887

Bolton Community Voluntary Services: 01204 546010 Carers Support (Bolton) : 01204 363056

Bury Council for Voluntary Services : 0161 764 2161

Bury Carer Services : 0161 253 6008 and **Bury Carer Assessment** : 0161 253 7190.

Bolton Market Place - Wheelchair Service : 01204 361100

Shopmobility, Trafford Centre : 0161 749 1728

Basic Neurocare Centre, 554 Eccles New Road, Salford, M5 2AL : 0161 707 6441

Ring & Ride Bolton : 01204 388500 Bury : 0161 764 1999

Welfare Rights Advice Line : 01204 380460

Benefits Helpline : 0800 882200. **Completing Forms** : 0800 44 11 44

The Disability Rights Commission : www.drc-gb.org

Job Centre Plus : <http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled/>

Access to Work : <http://www.jobcentreplus.gov.uk/JCP/Customers/HelpForDisabledPeople/AccessToWork/>

General government guidance on entitlements : <http://www.direct.gov.uk/DisabledPeople>

ACTION FOR ME : 3rd floor, Canningford House, 38 Victoria Street, Bristol. BS1 6BY.

Tel 0845 123 2380 (or 0117 9279551). e-mail admin@afme.org.uk for general enquiries

Welfare Rights Helpline 01749 330136 9am to 1pm Mon Tues Thurs 9am to 12.30 Fri

e-mail pauline@afme.org.uk Telephone support - advice and information for anyone affected by ME (including non-members) 0845 1232314 11am to 1pm Mon to Fri

Web site www.afme.org.uk Young people with ME www.a4me.org.uk

ME ASSOCIATION, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks. MK18 4DF 01280 818968. Information Line: 0870 444 1836 (10am to 12noon, 2pm-4pm and 7pm to 9pm – every day) www.meassociation.org.uk/

M.E.R.G.E. MERGE : is the Myalgic Encephalomyelitis Research Group for Education and Support <http://www.mereseach.org.uk/>

BRAME : (Blue Ribbon for the Awareness of ME) 30, Winner Avenue, Winterton on Sea, Great Yarmouth, Norfolk. NR29 4BA. Tel/Fax 01493 393717. The BRAME campaign was launched to create a greater awareness and understanding that ME is a very real and debilitating illness. www.brame.org

CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION : 2, The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. This charity (formerly the Persistent Virus Disease Research Foundation) was established to concentrate entirely on research into ME and on informing the medical profession of any new findings.

NATIONAL ME SUPPORT CENTRE : Disabled Services Centre, Harold Wood Hospital, Romford, Essex, RM3 9AR. 01708 378050

The 25% ME GROUP : Simon Lawrence, 4, Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ ME Group for the Severely Affected ME sufferer. e-mail enquiries@25megroup.org

CHROME : (Case History Research on ME), 3 Britannia Road, London SW6 2HJ. This charity was set up to identify as many severely affected ME sufferers as possible in the UK and monitor the course of their illness over 10 years. The study will supplement medical research into the condition.

TYMES TRUST- (The Young ME Sufferers Trust) : P.O. Box 4347, Stock, Ingatestone, CM4 9TE, www.tymestrust.org Advice line 0845 003 9002 (Mon-Fri 11-1 or 5pm-7pm).

ME PUBLICITY CAMPAIGN : Russ Bassett, 7, Ridgefield, Watford, Herts. WD1 3TU. 01923 226253 Campaigning organisation dedicated to enhancing the rights and profile of the ME/CFS sufferer.

AYME : (Association for Young people with ME) Box 605, Milton Keynes MK2 2XD. 08451 23 23 89.

RIME Research Into Myalgic Encephalomyelitis : 10 Carters Hill Close Mottingham London SE9 4RS

THE NATIONAL ME CENTRE : www.nmec.org.uk/ lists many contacts.

INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS) : to help with North West NHS complaints: 0845 120 3735