POST-VIRAL / CHRONIC FATIGUE SYNDROME

BURY/BOLTON ME/CFS SUPPORT GROUP

'Breaking the Isolation'

Newsletter 39

Spring 2009

Supported by

HEALTH FOR BOLTON

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

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ME AWARENESS WEEK

ME Awareness week will be from 11th May this year and we are hoping to have a display about ME at several venues, including Fairfield Hospital and possibly one of the large new health centres in Bolton

To coincide with this awareness week Yvonne has developed a patient held document which has information about ME in general as well as specific information about the individual patient's needs. This will be very useful to anyone needing to go into hospital for any reason, or needing care from any professional, e.g. social worker or helper. Copies of the patient held record will be available to download from our website or in hard copy form from Caroline.

Members of Bury Primary Care Trust and Bury Social Services are very impressed by Yvonne's document and are hoping it will be used throughout their services. Our ME clinic team are also impressed with the document and are hoping that we can have a launch in Bolton.

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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. 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 - in December alone we received £25 so thank you!

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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 caroline@mesupportgroup.co.uk if you would like email instead of postal contact.

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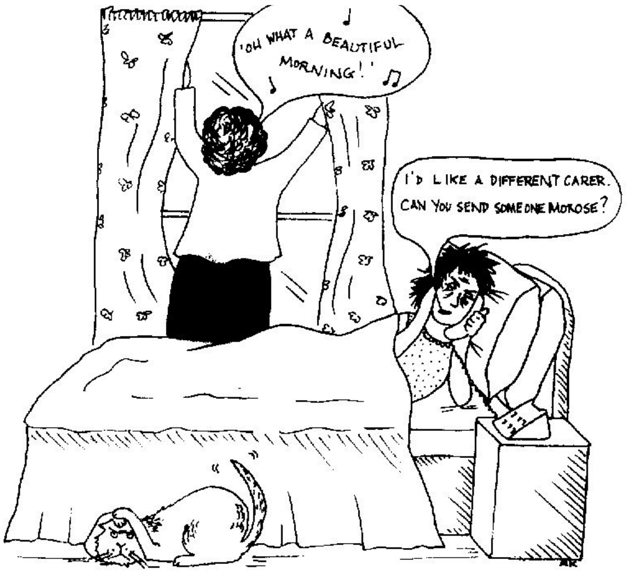
DISCLAIMER:

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.



Thanks to InterAction

Support Group Information Sheet

A reminder of who is what during 2008/9 with Telephone numbers for contact if required

Support Group Leadership

The 'Bury/Bolton ME/CFS Support Group' is managed by a Committee of 7 Members: -
Pam Turner, Margaret Benn, Ann Richards, Caroline Higson, Maria Sale,
Sheila Myerscough and Kim Finney.

Support Group Posts

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OUR MEETING DATES FOR SUMMER 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.

21st May 2009: Osteopath Dr.Raymond Perrin will visit us again and will be reporting on his latest research.

18th June: Julie Shortland will talk on EFT (Emotional Freedom Techniques) and TAT (Tapas Acupressure Technique) which belong to the Meridian Energy Therapies and are based on new discoveries regarding the connection between your body's subtle energies, your emotions and your health. This is often described as 'Emotional Acupuncture' (acupuncture without needles).

16th July 2009: Social Event

SOCIAL GROUP

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).

Our Social Group have been meeting informally on the first Monday of each month at the Sweet Green Tavern in Bolton. (127 Crook St. – go past the station on Trinity Street, through the lights and it's on your left.)

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 ME/CFS SUPPORT GROUP AGM 2009
GROUP LEADER'S REPORT

Once again it is my great honour and great pleasure to present the group leaders report; which gives me the opportunity to thank all our brilliant helpers and Committee Members which enable our group to exist.

A very special thank you must go to Caroline our multi-talented, web mistress extraordinaire who does such a magnificent job, as well as organising the printing and postage of newsletters and flyers. These are absolutely invaluable to our very many isolated and housebound members who really value the regular contact. We would be lost without her valued contribution and she has asked that special thanks also go to her little band of helpers, which includes Jean Higson, Rowena Preston, and Jeff Glasser. If anyone else can offer a little help such as folding leaflets or putting stamps on envelopes I am sure Caroline would be very grateful.

Special thanks go to a lady who has well and truly "saved our bacon" this year by stepping in at extremely short notice and taking over as treasurer; thank you so much to Kim Finney for taking on one of the key roles on the Committee and for keeping us on the straight and narrow.

Despite her own problems, once again we owe very many thanks to Yvonne, no longer a committee member but a very valued member of our support team, who attends so many meetings on our behalf. Also attending many meetings and doing another vital job on the committee is Maria Sale who plans our speakers and makes all the arrangements for them to be here for us. Once again this year has been particularly difficult for Maria but she has continued to give us her support - thank you so much.

Many, many thanks to our brilliant newsletter editor and producer, Tom, who has also had a very difficult year but has ensured that we have our excellent newsletter. A very big thank you, to you Tom.

Thanks also go to Carole Senior who has volunteered to be our librarian; this is a vital job which ensures that our books are recorded and available when people need information, so thank you to Carole.

Ste Walker has continued to update the Link Up Group which is such a comfort to many members and we thank him so much for this.

Thank you to both Mandy and Lynda who organise the Bolton Social Meetings and to Sheila who organises the Bury Social Meetings, these are very enjoyable.

Once again a serious thank you to Hilary for typing up my reports and articles and letters. If I had to pay her I couldn't afford her.

Many thanks to all our committee members for attending meetings and planning activities for the group.

Thank you to Sue our door lady, Pat McKenna who is always ready to help and to Lynne our tea lady who we hope is on the way to a full recovery after very serious condition this year.

And finally thank you to all of you who make the effort to come and befriend each other. God bless you all.

Pam Turner

BURY/BOLTON ME/CFS GROUP - AGM MARCH 2009
SECRETARY'S REPORT

This year, like last year, has been very busy and again, happily very successful; we are both proud and privileged to be able to represent all our members and try to put forward your views accurately.

Our membership remains between 140-150 members because as some members no longer need our support we usually have a similar number joining so the number remains the same.

We give a very warm welcome to all our new members and hope that as many of you as possible can join us at our meetings.

The nine meetings at Longsight Methodist Church have been reasonably well attended, but I would urge you to come along whenever possible so that we can all form new friendships and help each other. We have had some excellent speakers; especially Ross Percival from the Department of Work and Pensions who told us about claiming Disability Living Allowance. Also the talks by Stephie El Hassan about homeopathy and Derek Vernon's talk about the Lightening Process were both very interesting, as was the presentation by Isabel Dixon of Breathworks. Of course we were also very fortunate to have our old friend Dr Andrew Wright come to give us an update on his work in February.

The yoga sessions have continued throughout the year, free of charge, and remain funded by a grant for part of 2009. Once again I would encourage as many of you as are able to come along and feel the benefit of the relaxation, gentle stretches, movement and breathing exercises it really does help when done regularly.

This year we have had two Social Groups up and running. The Bolton meetings are held at the Sweet Green Tavern, near to Trinity Street Station on the first Monday of the month from 4pm to around 5.30pm. The Bury meetings are held at The Met, Derby Hall, Market Street, Bury, BL9 0BW on the first Thursday of the month at 3pm.

If we had thought that once our ME Clinic was up and running, things would be easier and we would have less meetings to attend, we were very much mistaken. We are now invited to attend far more meetings as more professionals have come to value the opinions and want to know more about the needs and the thoughts of both ME sufferers and carers. Although this can be hard work it is really very gratifying because we have developed an excellent working relationship with the wonderful staff at our clinics and with the management teams at both Primary Care Trusts.

Our ME Clinic has now been running for four years and continues to develop its services offered. There has been extra funding to increase staff hours and a pain management service is planned.

The Wigan, Leigh and Ashton area Clinic is now seeing patients with Dr Tarek Gaber being the doctor leading the service. We are so fortunate to have such talented and dedicated doctors giving support to both Wigan & Leigh Clinic and to our own brilliant Dr Andy Wright at Bury and Bolton Clinic, and to both sets of wonderful support staff.

Yvonne and I continue to attend the meetings of the Clinical Network Coordinating Centre and are happy to report that more services are planned for other areas in Greater Manchester. However the sad news has been that the Children's Service has been rather curtailed due to staff changes, it is hoped that this will be rectified soon.

Once again Yvonne continues to give unstintingly of her time attending many meetings as carer representative. Maria and Yvonne attend the NW Forum meetings where groups from the entire NW region meet to exchange information. Yvonne also attends the Bury Neuro Support meetings and along with Pat McKenna gave a talk to them about Pat's experience of being an in patient at Fairfield Hospital.

Yvonne and Pat also attended a training day at Pennine Trust Fairfield Hospital, which was for staff to listen and learn and to put patients first and foremost in their service.

We have been very fortunate that this year we have had grants to continue our group via the Bolton Community Voluntary Services. These grants from Health for Bolton have helped to pay for the Yoga classes and the newsletter and a grant from the Carers Fund of £750 has partly paid for our brilliant carers outing to Smithills Coaching House which around 80 people enjoyed.

Thanks also go to Darren Hayward for doing his sponsored run which raised over £700 for us, which also helped to pay for the outing at Smithills. I am sure that everyone who attended will agree that this was the highlight of the year.

We hope that our group will continue to go from strength to strength and value any help that anyone can offer and hope that you will let us know if there is anything we can do to improve your group.

Once again I reassure you that we do our best to represent your views fairly and accurately and we do believe that all the hard work is gradually paying off as ME is becoming more widely accepted by the wider medical profession.

THREE WISE WOMEN

If it had been three wise women
instead of three wise men.
They would have asked directions,
Arrived on time,
Helped deliver the baby,
Cleaned the stable,
Made a casserole,
Brought practical gifts, AND there would be
peace on earth.

Courtesy of Helen Crossan and our thanks to Phoenix

BURY/BOLTON ME/CFS SUPPORT GROUP MEETING 15th JANUARY 2009
ISOBEL DIXON- MINDFULNESS

We had an excellent turn out of 32 members for Isobel's enjoyable and informative talk about mindfulness.

Isobel came to talk to us about her experience of a Community Interest Company (CIC) called Breathworks. It is a not-for-profit organisation providing 8 week courses in Mindfulness to help people living with pain, long-term illness or stress to manage their condition and improve their quality of life. Breathworks is based at the Manchester Buddhist Centre in the Northern Quarter, five minutes from the city centre. Whilst the Breathworks programme uses some practices that have their origins in the Buddhist tradition, the courses are entirely secular in their presentation and approach.

Breathworks has grown out of the experiences of Vidyamala Burch. Originally from New Zealand, Vidyamala sustained a spinal injury when she was sixteen. Over twenty years ago she started exploring mindfulness and meditation techniques to manage her own persistent pain and in 2001 began offering those skills to others, initially with funding from the Millennium Commission. In 2004 she joined with two co-trainers to found Breathworks. Two main types of mindfulness courses are run by Breathworks - 'Living well with Pain and Illness' and 'Living well with Stress'.

Isobel has had ME for 17 years since she was 21. At that time she was a student of design and she became interested in alternative therapies to help her manage her illness. She went on to develop a career in meditation and relaxation and has trained in stress management. She has been involved in several projects, largely on a voluntary basis teaching different forms of meditation, stress management techniques and relaxation. She came across Breathworks in 2004 when she saw a poster for their mindfulness-based pain management courses and she thought it was really interesting that they were offering courses which included training in meditation for people with chronic illness. Isobel went along to the course and found the approach they offered both helpful and inspiring. So much so she later went on train to be a trainer for Breathworks.

One of the first things that struck Isobel was the different and refreshing approach to the idea of relaxation that the course offered. If you are in pain or discomfort and trying to escape that to achieve a feeling of calm and relaxation – frustration and disappointment can easily occur if you don't succeed. What Isobel found on the Breathworks course was that Mindfulness offers a different way of being with our experience. If we can allow ourselves to 'be where we are' including unpleasant symptoms of pain or fatigue, with a kind and accepting approach, often a natural state of relaxation follows. For most of us living with M.E there is likely to be a degree of pain or fatigue in our experience, a 'given', which in that moment we probably cannot change. On top of that, however, comes all of our reactions to this discomfort: frustration, irritation, sadness and so on. The Breathworks course helps us to develop a kinder more accepting response to the physical symptoms of our condition which we cannot currently change and offers techniques and training to help us work with and minimise what we call the 'secondary suffering' – all the ways we try to resist and push away our discomfort, physically, mentally and emotionally.

Isobel said she has found relief from practising mindfulness which she feels has offered her a gentler and more open way of relating to her illness. She said she had previously been so busy trying to push away all the unpleasant sensations; it was like having a battle every time she had a flare up – like being at war with her body/the M.E. She realised that this battle was actually adding additional tension and stress on top of the actual symptoms of the M.E and mindfulness has helped her find different ways of responding to the illness.

Then Isobel went on to explore mindfulness a little further.

We did a brainstorm of the audiences thoughts on what mindfulness might mean and some of the responses were 'understanding your own thoughts', 'being at peace with yourself', 'being aware', 'acceptance', 'being in the moment', 'being in control', 'focussing', 'being thankful for what you can do and being relaxed about what you can't do', 'empathising', 'beginning to have a choice about how you react'.

Isobel went on to discuss definitions of mindfulness. Mindfulness or 'mindful awareness', is a state of present moment attention where you can clearly perceive thoughts, physical sensations, emotions and events at the moment they occur without reacting in an automatic or habitual way. This means you can make choices as to how you respond to things and have a rich and fulfilling life, even when experiencing difficult circumstances.

Usually we attend to the activities of the moment with only a small part of ourselves, while our minds and thoughts are miles away – this could be described as being on 'auto-pilot'. We could see mindfulness as the opposite of auto-pilot.

One definition of mindfulness is "Paying attention in a particular way, on purpose, in the present moment, non-judgementally".

This definition comes from Jon Kabat-Zinn who established the hugely successful Stress reduction Clinic at the University of Massachusetts Medical centre in 1979 and along with his colleagues developed Mindfulness-Based Stress Reduction (MBSR).

Another definition is "The whole path of Mindfulness is this: whatever you are doing, be aware of it." Amy Schmidt.

Mindfulness also includes an affectionate and compassionate quality. On the Breathworks courses this idea is used to help participants develop a kind response to their pain.

It takes time to get a feel for mindfulness and practice to develop it and incorporate it into your life but the rewards are many. Often when we are in chronic pain or discomfort we get into the habit of blocking out our experience, but in blocking out the unpleasant we also tend to block out a whole band of pleasant sensations too. Mindfulness can help us to open up again – to gain a much broader, richer experience of life.

The best way to get a sense of mindfulness is through experiencing it directly. So we then did a 15 minute mindfulness practice called Body Scan in which Isobel brought our attention to different parts of our body. It was really relaxing and when it ended several people said they felt revitalised.

Isobel then went on to outline some aspects of the Living Well with Illness. Below are some aspects of the Breathworks course overview:

The course explores a variety of approaches to managing pain and illness along with the stress that often arises as a consequence of these difficult circumstances. The course provides a tool kit of resources that we can apply in our lives. The programme as a whole is based on the practice of mindfulness - which is explored progressively over the course.

Breath Awareness. By investigating our breathing habits we can learn to use the natural breath as an aid to managing our pain, illness or stress.
Body Scan. This helps to develop habits of greater ease and awareness of the body Adopting a comfortable posture (lying down or sitting) we 'scan' through the whole body with our awareness, using the breath to help us soften around areas of pain and/or tension.
Mindful movement. The importance of keeping our bodies in as good physical condition as possible, in order to stop a cycle of disuse, loss of function and more pain or fatigue. The course includes some gentle movements (based on yoga and pilates) in the programme. These have been specially devised for Breathworks by a very experienced yoga teacher and are suitable for all, being easily adapted as necessary so they are appropriate for people suffering from a wide range of physical conditions.
The Mindfulness of Breathing. This meditation practice helps us develop awareness of ourselves in greater detail. By resting in a space between suppressing our experience of pain or illness on the one hand, and over-identifying with it on the other, we can learn to make choices as to how we respond to our moment by moment experience.
The Kindly Awareness Meditation. This meditation practice helps us feel more positive, accepting and kindly towards both ourselves and others and helps us develop a sense of equanimity towards both the pain and pleasure in life.
Mindfulness of daily life (Pacing). By bringing awareness to the activities of daily life we learn to overcome the very common tendency of overdoing it on good days and then getting a flare up of symptoms and needing rest for long periods (sometimes described as boom and bust!). The course includes consideration of what pacing is and how we feel about it as well as

practical strategies for pacing more in our day-to-day lives.

3 CDs are included in the course price (Body Scan, Mindfulness of Breathing and Kindly Awareness practice) but are also available to buy at a cost of £10 each.

The Living Well with Pain and Illness Course is held at Manchester Buddhist Centre, it is 2½ hours on Wednesday afternoons. Cost is £200 waged, £150 low waged and £120 if on benefit. A limited number of bursary places are sometimes available.

Course start dates and further information about Breathworks, the courses, and mindfulness is available at the Breathworks website. For further enquiries and booking you can also contact the office on the number below.

Breathworks Community Interest Co.
16-20 Turner Street
Manchester
M4 1DZ
0161 834 1110
Email info@breathworks.co.uk
Website www.breathworks-mindfulness.co.uk

GROUP MEETING 19th FEBRUARY 2009

DR. ANDY WRIGHT

We were very pleased to welcome Dr. Andrew Wright once again to our meeting to talk to us about current research into ME, and to update us on treatments. Dr Wright is head of the Bolton and Bury NHS clinics, and has worked in the field of ME for many years.

Dr.Wright started by giving us an update on current research projects, and also told us about past projects and past attitudes to ME. He brought some slides along to illustrate some of the aspects to his talk, and these are available from him if you wish to see them.

This illness has not been high on the list of subjects to research by doctors and scientists, because it just isn't a popular subject. If you look up on the internet "pubmed.com", which is a list of published medical research papers, the number of papers on ME is down at the bottom of the list. There are many more on breast cancer for example, and of course that is a very serious and life-threatening condition, but ME is more common. Recent research has tended to have a psychiatric balance, and pubmed today shows plenty of papers being churned out on psychological aspects of ME.

Historical definitions of ME have been biological, but the change in emphasis came in the 1990s when the Oxford criteria came out in 1991, after work done by Dr. Simon Wessely and colleagues. The Oxford criteria acknowledge that fatigue is a major element of the illness; but some of the other descriptions of symptoms included in past definitions were excluded. In 1994, a panel of international researchers met to revise definitions of CFS and came up with the Fukuda definition. More recently the Canadian Consensus came out which is more specific and detailed regarding symptoms, but it is very unwieldy to use.

Recently, some research papers have emerged which are showing real physical problems. Dr. Wright explained some of the research done by Dr. Vance Spence, who was the head of Vascular Biology at Dundee hospital and who has ME himself. Dr. Spence has found some interesting things going on in people with ME. One project compares the results of MRI and SPECT scans and Dr. Wright showed a slide pointing out the difference in appearance of the brain between these two scans. A MRI scan shows just the structure of the brain and is good for detecting tumours or structural changes, but it is unlikely a MRI scan will show up any ME related abnormalities. You will be told, therefore, that your scan result is normal unless of course another problem shows up. It doesn't show the abnormal blood flow and other abnormalities peculiar to ME that a SPECT scan shows. Clearly a SPECT scan is more accurate than a MRI for showing up those abnormalities. He has also done work showing up something called cell apoptosis, which means cell death. Another project done by Vance shows vascular inflammation. All these projects show that a chronic infection is the cause.

Dr. Wright went on to talk about the gene research projects being done by Professor John Gow in Glasgow and Dr. Jonathan Kerr in London. These studies support the conclusions reached by Dr. Vance Spence i.e. evidence of chronic infection. Professor Gow's research does show a connection with Lyme disease, and Dr. Kerr's work has shown there to be 7 sub-types of ME. The idea would be to match treatments to sub-groups so would make treatment more targeted.

The conclusion of all this research is that chronic infection or infections are responsible and the immune system becomes unbalanced. The sort of bugs that can cause such infections are viruses, bacteria, worms, and the immune imbalance takes the form of some parts of it becoming under active, other parts overactive. The immune system has to move around so to speak depending which bug it has to tackle. Immune imbalance causes problems like hormone disturbance, inflammation, immune problems, poor function of the mitochondria which are your energy powerhouses in your cells, poor response to stress. Most people with ME will have thyroid problems, the incidence being 6 to 9 times higher than in a healthy person. Bugs can manipulate your immune system to survive, so cause chaos in the body.

One set of viruses that have been found to cause a problem are enteroviruses, and work done by a Professor Chia has found enterovirus to be present in the intestinal tract in 80% of ME patients compared to 20% of controls. Professor Chia's son had ME, and that is what prompted him to investigate the illness, and he treated his son with antivirals and interferon, and it resulted in him doing more research. It cost him a lot of money, around £6000 a month to do this. Another set of viruses implicated are the herpes family of viruses, and these can be treated with antiviral drugs, but the problem is they are not available here on the NHS. You can get them from the USA, but you have to pay for them.

Bacteria can also be a problem. People with ME can carry bacteria. Studies say that between two thirds and three quarters of people will respond to antibiotic treatment of between 6 weeks to 6months duration, but in reality it may not be as clear-cut as that as some people have not responded to antibiotic treatment. Reasons for this may be that there is something else going on as well and also bacteria are very clever at evading treatments. They have a way of making it very difficult for antibiotics to get inside them and kill them. They can also share genetic information with each other so they can outwit the immune system.

There has been work done by a Dr. Lawrence Klapow in America showing the presence of a worm infection in ME patients, and it has been known as Cryptostrongylus Pulmoniae. This worm has been renamed Varestrongylus Klapowi. Dr. Klapow is a biologist and has been ill himself and found on a blood test of himself an allergy to something, suggesting either an allergy or a parasite infection. The response for both is the same. He found it to be a type of worm, only about half a millimetre in size, so it's difficult to see, and for the last 15 years he has been researching it. Originally he thought the worm came from bats in the Far East, but now thinks it comes from goats, and is a mutation of a goat worm. There was an outbreak of ME in New York in the 1980s in people who had drunk unpasteurised goat's milk. A percentage of ME patients carry this worm.

So the problem is that there are possibly multiple infections to deal with and some people will have one infection, others may have several. It won't be until all the necessary tests and investigations are available on the NHS that a comprehensive search for all these bugs can be carried out on an individual. At present, tests are difficult and expensive and not available on the NHS.

There has been research on the actual behaviour of the

STEP 1 OF GRADED EXERCISE THERAPY WAS PROVING TOUGH ON KAREN.

immune system in people with ME by Dr. Lorrusso in Italy, looking at what is actually happening to the immune system. It is behaving like it is dealing with a chronic infection.

Trevor Marshall who came up with the Marshall Protocol, which some people might have heard of has been looking at how these bugs can prevent you making your own natural antibiotics, so that is another way they outwit the immune system.

Dr. Wright went on to explain about mitochondria, which are the battery chargers within your cells and are the means by which energy is produced. All your cells have mitochondria except red blood cells. Dr. Wright showed us a slide of mitochondria and said originally they evolved from plants. Fatigue is one of the most frustrating and unpleasant aspects to this illness and it has been discovered that the function of mitochondria is disrupted in ME. Dr. Wright explained that to produce energy, glucose from your food has to combine with oxygen obtained from breathing, and the two things combine in the blood stream, and you turn it into energy, water and carbon dioxide. That is aerobic respiration. However, when you can't make energy normally, you have an emergency method where you can turn glucose into energy without oxygen. Other chemicals in the body are used to force the process, and the by-product of that process is lactic acid, which causes a lot of muscle pain. This is known as anaerobic respiration because the process is not using oxygen. You have to wait until the body clears the lactic acid out. It depends on how fit you are as to how long it takes. In ME, the mitochondria are dysfunctional, causing the excessive build up of lactic acid, and the pain doesn't wear off. Dr. Vance Spence found that the amount of lactic acid in an ME patient was equivalent to someone who has done 4 hours exercise, and that the levels start at a higher point than in a healthy person.

A research project done by psychiatrists in New York, called the Mount Sinai project looked at the brain with what is called a functional MRI scan which is better that a normal MRI scan, and they also drew off some spinal fluid, and found that there were abnormally high levels of lactic acid in the brain and spinal cord compared with patients who have depression, and healthy controls. This build up of lactic acid in the brain can cause the cognitive problems many ME patients experience. The brain also uses a lot of energy to function, so if energy production is faulty, the brain isn't going to function very well. It is notable that this study has been done by psychiatrists and it is a good study. The study shows that, in the brain, oxygen is not combining with glucose and that there is poor blood flow. So the stress experienced by ME patients is not the same as in generalised anxiety. The study shows the higher level of lactic acid and oxidative stress, and poor energy production is causing the feeling of being unable to deal with stress.

Dr. Sarah Myhill, a doctor who has done a lot of work with ME patients, has produced a study with biochemist John Mclaren-Howard who used to be head of Biolab in London, looking at the process of aerobic respiration and the function of mitochondria. John has now left Biolab, and has his own company called Acumen. The chemical processes involved in mitochondrial function are quite complicated, and for those who are interested in the details of how it works, Dr. Wright suggested a website called: http://www.ijcem.com/files/IJCEM812001.pdf to look up those details. Dr. Myhill and John Mclaren- Howard took 71 ME patients and 53 controls and carried out an ATP profile on all of them and all the controls and curiously one ME patient showed a normal result. The other 70 ME patients had an abnormal result. Dr. Wright has seen the same pattern in his patients with a couple of patients he has given the test to showing a normal result. He believed something else was causing the problem with those patients. One of these patients in particular was very poorly. It is possible to categorise the degree of people's disability according to the results on the mitochondrial study, and Dr. Wright asked those who have had a ATP profile test done in the past to contact him about the results as it is possible to look at those results in a new light as a result of this study and possibly target treatment accordingly.

Dr. Bill Harvey in the USA has done a lot of work on Borrelia and Lyme disease, as he has observed these bacteria in patients with ME in an area of America which is not noted for having high numbers of ticks. Normally, you associate Lyme disease with a high proportion of ticks in an area as you contract Lyme usually after being bitten by an infected tick so Dr Harvey was coming to the conclusion that the Borrelia was being passed on by other means. The difficulty however is when you try to grow this type of bacteria in a laboratory; it is difficult to make them grow. Dr. Wright has received some images of Borrelia from a patient who is a microbiologist and he has left them in the culture for a couple of months or so, which is longer than usual and the classic spirochete shape shows up.

Research therefore does show interesting results, and it takes the guesswork out of finding suitable treatments. Dr. Wright feels that those doctors who have being trying to help people with ME have largely been doing that over the last 20 years or so. Once things start to become interesting, more people will research them, so perhaps in a few years time the number of ME research papers may well have jumped up the pubmed list a bit, and there will be more biomedical research papers appearing. The research shows that the problem is becoming "real", so things have changed, even though the patients and their stories have not changed. Unfortunately for the patient, that is the way medicine works.

Treatments

The NHS ME clinics work under the National Institute for Clinical Excellence (NICE) guidelines, which puts the emphasis on pacing and supportive psychotherapy. Some clinics put more emphasis on graded exercise and cognitive behaviour therapy, but Bury and Bolton have modified those therapies to suit the patients, and they also do some symptom control. The Bolton clinic is moving to Breightmet in the near future, so if you already have an appointment with the clinic it is likely you will be seen there. Unfortunately there is no car parking, and the room is quite a long way down corridors so not an ideal location for ME patients. The clinics hope to be offering a pain clinic in the near future run by Helen the physiotherapist. They are also going to be setting up a stress group run by Gill Walsh, who is the lead nurse for all the clinics at the CNCC (Clinical Network Coordinating Committee) to help patients deal with stress.

Dr. Wright explained that you can be referred by your doctor to the service, and you are eligible for referral if you live in the Bury/Bolton post code areas, or if you have a GP whose surgery is in those areas. The new location of the Bolton clinic is Breightmet Health Centre, Breightmet Fold Way, Breightmet, telephone 01204 462765. The secretary is Linda Webb. You get seen by Dr. Wright and the other staff. The OT can visit you at home, and the clinic will help you get aids in the home, and will help with benefit and pension claims.

Dr. Wright says that with some people you only need to treat one thing, and it all falls into place, with other people you need to treat a number of things before it all falls into place. If a ME sufferer does nothing and undertakes no treatments; the bottom line is that the prognosis for recovery is bleak, so doing nothing is not an option. If the research improves, it follows that treatments improve and more money will be spent on it. The illness will be dragged out of the "middle ages" and it will be properly recognised. Other illnesses like MS and Epilepsy were classed as psychological illnesses once, but research has proved a physical cause for both conditions. Things are improving and ME is being recognised as a physical problem and treatments will come on stream.

Dr. Wright took some questions.

A question was asked about MRI scans as their scan did not show any abnormalities. It is only a SPECT scan that will show the typical inflammation of ME and they are not routinely available on the NHS. The nearest machine in this area is at Liverpool, but the NHS usually will only do a MRI scan, which tends to show up only structural changes within the brain.

A question was asked about whether the lactic acid was in the spine as well as the brain and the answer is yes. The person asking this question made the point that exercise was not included in the list of treatments, but felt the type of exercise he was doing helped him. He started in a chair to gently help the spine and offered to help anyone who was interested in doing this as he felt it helped him. Dr. Wright said that a sub-group of patients are helped by some forms of exercise, but not "running around" types of exercise, as something so energetic could not be undertaken by ME sufferers. The physio at the clinic will design the right type of exercise suitable for individuals. For those who want to go privately to Raymond Perrin in Manchester or Gail Sumner, who works at the Markland Medical Centre at Westhoughton, for osteopathic treatment they can do so. They practise a form of osteopathy called lymphatic drainage and Raymond has done a lot of research on this in the past. There was an osteopath doing lymphatic drainage osteopathy on the NHS, and for 12 months you could go and have this treatment, but now it is no longer available as they stopped it about 5 years ago. Most ME sufferers are likely to have back or neck problems and osteopathy will help to sort those problems out.

Someone asked about the availability of SPECT scans. They are only available privately and will cost you about £500. However it only really shows up what is already known, but what it would be useful for is to find out someone's baseline level of brain abnormalities and then it can be used to see if improvements happen over a period of time while having treatment. However, a MRI scan could be useful to exclude tumours and MS. Dr Wright said that some patients do have what he calls a MS like syndrome, and at this point someone said that they had had a MRI scan which showed up as MS, but they also have ME and feel that really they don't have MS. The explanation for this is that there may be a similar cause, but presents as a different expression of the same illness according to some doctors. Dr. Wright knows of someone in Bedford whose MS was cured by antibiotics, so a bacterial cause was showing up as MS on the scans.

Someone mentioned the old "chicken and egg" problem, whether it is the bug or bugs causing the immune system to be wrong, or is it that the immune system was faulty in the first place to have allowed such infections to take hold, and Dr. Wright said he didn't really know. It is a conundrum that has been debated for a long time. However he did think that certain predispositions may encourage someone to be susceptible such as genetic factors (if your mother has ME you are more likely to have ME; partly because of being in the same environment, or partly because of congenital exposure to infection through the placenta, or it could be because the genes that control your mitochondrial function, which are passed down from the mother, could be faulty or problematic in some way), or environmental factors such as toxins, (people with heavy metal toxins will have difficulty in clearing for example Chlamydia Pneumonia infections).

A question was asked about tests for Borrelia infections, whether there were tests available other than a Western Blot and there is what is called a Standard Antibody test, but a study shows this only picks up between 20 and 50% of Lyme infections, so the test is not really that reliable. Dr. Wright mentioned a test called a Flow Cytometry test in which commercially produced antibodies are introduced to the Borrelia and attaches to the bug. The antibodies have a dye on them, and when they attach to the bugs it turns on the dye and it fluoresces and they are counted through the Flow Cytometer, so you can see how many infected cells there are. It is more accurate than the normal tests available on the NHS. You can have this done and Dr. Wright has used it.

There were two questions about whether other family members may be at risk of catching ME from a sufferer within the family or could a sufferer pass it on. There is an increased risk of having ME if your brothers or sisters have it, maybe for environmental reasons as you are all sharing the same environment. Dr. Wright mentioned that in the past there have outbreaks of ME in a given area or location such as at Lake Tahoe in America, and at the Royal Free Hospital in London in 1955, suggesting a common cause in those areas. Genetic factors could also play a role. But there is only a low risk of someone passing on an infection. Dr. Wright said that the general population carried the same germs and 1 in 4 carry the meningococcal meningitis germ in the throat, but people are not going down with meningitis all the time. The bugs are not in high numbers and the immune system keeps them in check.

A question was asked whether glandular fever is a culprit as there seems to have been a lot of people who say that having it has seemed to spark off ME. Glandular fever is caused by the Epstein-Barr virus which is in the Herpes family of viruses, and unfortunately with herpes viruses once you get them you will always have them, and they can reactivate.

Someone asked about the availability of antibiotics on the NHS, but they are not always available.

One final question was whether dental amalgams could be a problem and Dr. Wright suggested looking up Dr. Sarah Myhill's website and Dr. John Roberts, a mercury free dentist in Huddersfield as they have done a lot of work on this. Dr. Roberts has spoken to our group in the past.

Angela Glendinning

ALL PUNS INTENDED

'Two antennas met on a roof, fell in love and got married. The ceremony wasn't much, but the reception was excellent.

A dyslexic man walks into a bra.

Two fish swim into a concrete wall. One turns to the other and says, 'Dam'.

'Doc, I can't stop singing 'The Green, Green Grass of Home.' 'That sounds like Tom Jones Syndrome.' 'Is it common?' 'Well, It's Not Unusual.'

What do you call a fish with no eyes? A fsh.

Thanks to Central Lancashire ME/CFS Support Group

NEWS IN BRIEF

Smithills Post Christmas Carers Outing

This year we were extremely fortunate to have been awarded a grant of £750 from Bolton Adult Services, Carers Grant Funding, to enable us to have a Carers Post Christmas celebration. We thought that the end of January would be a good time to have an outing and give people something to look forward to after the Christmas rush.

When we applied for the grant, we had no idea how many people would want to come along to the outing, never having done anything on this scale previously: so we applied for enough money for 50 people to go for a nice Sunday lunch at Smithills Coaching House.

It very soon became obvious that 50 places would not be enough and so I contacted Smithills to see if we could increase the numbers of places booked. We increased it to 70 places and then found that we would have to increase it again, up to 85, and Smithills were excellent and most accommodating, they were very helpful and professional at all times.

We would, of course, have had a major problem, with the funding only being for 50 and we now had an extra 35 people. However because Darren Hayward had been so good as to do a sponsored Fell Run for us this year, he was very happy for the money raised to be spent on the outing.

As the day drew near, unfortunately some people had to cancel because of various problems and eventually there were 77 of us sitting down to lunch.

When we arrived there was a sign in the courtyard welcoming people to the ME Group lunch and staff had made the Hunting Lodge look lovely for our arrival. The Managing Director had arranged for there to be gluten free and dairy free food for those of us needing a special diet, and with the customary hospitality always given at Smithills, we were looked after in fine style.

We enjoyed an excellent three course meal plus cheese and biscuits for those who could find room for it, as well as a welcome drink, wine with the meal, a liqueur and coffee after the meal. Soft drinks were available for those unable to tolerate alcohol, so all our needs were met.

We had a really enjoyable afternoon where carers could switch off from their worries for a few hours and just relax and enjoy a meal cooked by someone else.

Sufferers were also welcome to come along with their carer and although very tired I'm sure all went home with happy memories. It was a brilliant way for so many people, both sufferers and carers to meet up and make new friends and contacts and to offer each other support. Truly breaking the isolation of this terrible illness.

Once again a very big thank you to Bolton Adult Care Services, to Darren Hayward and to Smithills staff for a wonderful afternoon.

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Annual General Meeting 19th March 2009

Many thanks to the 23 hardy souls who turned up to make our AGM the best ever.

The business meeting, report reading and election of the new committee was over in a record 20 minutes. This gave us plenty of time to have a lovely social get together and chat, much enhanced by the lovely home made cakes on offer. The cakes went down very quickly and were much enjoyed.

Thanks were given to Stephen Walker as he is no longer able to be a member of our committee due to other commitments. We are much indebted to Stephen, and to Caroline, because several years ago, when we were down to only two committee members they stepped in and saved the group from folding.

If anyone feels that they can be a helper rather than a full committee member they are welcome to come along to the three committee meetings held each year (April, August and December) and to help with things on an ad hoc basis.

Thanks to InterAction

Judicial Review of the NICE Guidelines

The National Institute of Clinical Excellence produced a set of Guidelines for the care and treatment of patients with CFS/ME. These were published during the summer of 2008 and will become legally enforceable in 2009. The full document is over 300 pages and does contain some very useful guidelines, however the major recommendations for treatment are for Graded Exercise Treatment (GET) and Cognitive Behaviour Therapy (CBT).

In a comprehensive summary of the current research findings in the United States by Margaret Williams (http://www.meactionuk.org.uk/A_NICE_DILEMMA.htm) we are left in no doubt that ME is a physical and not a psychiatric disorder. Ms. Williams goes on to show that the majority of personnel making the guidelines for NICE were psychiatrists or psychologists, many of whom had a vested interest in ensuring that the treatment of choice is GET or CBT. She also states that many of the experts in ME such as Williams Weir infectious diseases expert, Dr Abhyit Chaudhuri neurologist, Dr Nigel Speight paediatrician, Dr Jonathan Kerr consultant clinician, Prof. Julia Newton and Dr Charles Shepherd, were not allowed to be part of the committee making decisions. She also states that the evidence base upon which decisions were made ignored the many thousands of research papers which show ME to be disruption of biological function involved in the immune, endocrine and nervous systems. Instead relying heavily on just 18 clinical trials of which 5 were random controlled trials on CBT and a further 5 were random controlled trials on GET. As most of these studies did not include anyone who was severely affected by ME and used the Oxford criteria, she hypothesises that it's possible that none of the patients involved in these trials had ME.

This document by Margaret Williams makes very interesting reading and shows why it has been necessary for a band of dedicated people to go to the Legal system and request a Judicial Review of the NICE Guidelines.

In conclusion to her statements Ms. Williams quotes 2 letters , Hilary Patten wrote to the Sun in Dec 2008 " American research has proved ME is caused by a viral and bacterial infection. But over here, health guidelines drawn up by psychiatrists, only allow psychological interventions for sufferers. It is an absolute scandal."

Hayley Klinger wrote to the Times also Dec 2008. "Despite thousands of medical research papers showing immunocological, neurological endocrine, cardiac and gene expression involvement in ME, it is thought of as an illness of fatigue and even called chronic fatigue syndrome by the media and some doctors."

The Judicial Review is to take place in February 2009 and it is hoped that many ME sufferers will be present. The outcome of this review will have repercussions for all of us suffering from this terrible illness.

On Friday 13th March the case was dismissed with arguments to continue over costs.
Go to http://www.afme.org.uk/res/img/resources/Approved%20judgment%20NICE.pdf to see The High Court approved judgement in full (32 pages), or phone Caroline for a paper copy.
http://www.nicemecourt.co.uk/ is a good website run by people who attended the review.

Information for disabled people

www.direct.gov.uk/disability

Directgov is the website to visit for the latest information and services from government. It's clearly written, useful and the information is all in one place.

There is a large section for disabled people covering areas such as:

financial support
motoring and transport
disability rights
everyday life and leisure
independent living
home and housing

Find lots of information on everything from direct payments (arranging your own care and services), social care assessments and accessible technology to the Blue Badge parking scheme – including an interactive UK-wide map.

There are also contact details and links to charities and organisations supporting disabled people.

Information specifically for carers can be found at www.direct.gov.uk/carers

Library

New additions to our library include: Lost Voices by Invest in ME, NLP workbook, Joyful Recovery From Chronic Fatigue Syndrome/ME by Sash Allenby and Recovery from CFS: 50 Personal Stories" by Alexandra Barton. We've also purchased a Pacing booklet and DVD made by Shropshire PCT which is very good.

Welfare reform continues to be a major area of concern as the proposals on which we consulted move towards legislation. We are mildly encouraged that the White Paper, published in December, said that claimants of the new Employment and Support Allowance (ESA) would not be required to undertake activities inappropriate to their health. We are now lobbying hard to make sure that safeguards will be adequate.

No one knows how such safeguards will translate into practice. We therefore need help from everyone with M.E. who applies for ESA to tell us about their experience of the process. Collecting hard evidence about the impact enhances our campaign effectiveness, so please do keep a record of what happens and let us know. It is also hard to see how the draft legislation will affect carers. When this becomes clearer we will be asking carers about their experiences too.

Sir Peter Spencer Chief Executive **Thanks to InterAction**

New forum for ME charities

The Countess of Mar, a long-time supporter of people with M.E., met representatives from Action for ME, BRAME, ME Association, ME Research UK, 25% Group, Tymes Trust and ReMEmber on 8 October 2008 to identify areas of common ground. AYME and Invest in ME were invited but unable to attend. The Countess found that agreement exists on 80-90% of issues and concluded that there was therefore a case for creating a new forum for M.E. charities. When asked if she would lead such a group, she agreed to chair the next meeting.

The meeting was held on 18 November. It was decided to call the forum FORWARD ME and to adopt the aim of promoting effective joint working by M.E. organisations to maximise their impact on behalf of people with M.E. in the UK. The website address is www.forward-me.org.uk . It will promulgate actions and decisions taken and details of specific joint activities. **Thanks to InterAction**

Carers Trips

Coach trips depart from, and return to Deansgate near to the Post Office. Coaches will not pick-up or drop-off at other locations. Please note : All outings / events are for the benefit of CARERS and former carers, with priority being given to those currently caring.

Wednesday 22nd April National coal Mining Museum of England

Based around an 18th Century colliery to the west of Wakefield, you will have the opportunity to go underground into a real coal mine, and see for yourselves, the working lives of miners through the centuries. The one hour underground tour is included, when you will be provided with a safety helmet, battery and light. The temperature underground is 12°C, and warm practical clothing and sensible shoes are recommended. The site also includes a fully licensed cafe and bar, souvenir shop, and numerous colliery buildings, displays, and don't forget a visit to the retired pit-ponies and shire horse!!

We will leave Deansgate (outside the Post Office) at 9:30am PROMPT, returning to Bolton for 3:30 pm.

Please book early to ensure you reserve your place : 01204 363056

Thursday 21st May Haydock Park Races: The Princess Royal Trust for Carers Raceday.

Another 'back by popular demand' outing following our very successful 'day at the races' in July, last year. Enjoy free coach travel from Bolton to the North-West's premier racecourse, Haydock Park, with free entry to the Tattersalls Enclosure, for the Princess Royal Trust for Carers Raceday.

Once inside the racecourse, you will have access to the parade ring where you can choose your horse, and later (hopefully) see your winning horse being unsaddled in the winners enclosure. The Tattersalls enclosure features 3 raised viewing areas (one with seats) giving superb views of the racing.

Should you wish to place a bet, the Tote, Betfred and other bookmakers are within the enclosure and betting ring. Refreshments are available to purchase on course. The coach will leave from Deansgate (outside the main Post Office) at 12:30 pm prompt, returning to Bolton for approx. 6:30 pm. Early booking is essential, as places on this excursion are limited. 01204 363056. **Thanks to Bolton Carers Support**

Success

Marry the right person, this decision will determine 90% of your happiness and misery

Give people more than they expect and offer it cheerfully. Be forgiving of yourself and others

Be generous Have a grateful heart Discipline yourself to save money

Treat everyone you meet like you want to be treated Be loyal, honest, bold and courageous

Take good care of those you love Don't do anything that wouldn't make your Mum proud

(Linkline February 2009 also thanks to Bolton Carers Support)

‘E’ card contact

An 'E' card can offer basic information about the holder's needs- it can give the kind of medical information that helps the Police to assist them in locating a named contact and it may help in a situation where a service user may need to talk about a crime or an issue to the Police but may find it hard to communicate what is wrong. To hear more about the 'E' card please email:
James.HoIland@lancashire.pnn.police.uk or phone him on 01772 412870. James is the Community Support Officer and the contact point for obtaining an 'E' card.

Mobile Phones—life savers!

Did you know that your mobile phone can actually be a life saver? In an emergency the worldwide number for mobile is 112. If you find yourself out of coverage area of your mobile network there is an emergency, dial 112 and the mobile will search any existing network to establish the emergency number for you, and interestingly this number 112 can be dialled even if the keypad is locked. **Courtesy of Sporting Bears Car Club**

Premium rate phone calls

Use the website www.saynoto0870.com to get the company’s landline number and save money!
Thanks to Central Lancashire ME/CFS Support Group for the above 3 items

Disability Rights at work

If you are experiencing difficulties whilst at work due to health problems or disabilities, you should be able to get help from your line manager in the first instance and then HR. Good management teams should be fully aware of the Disability Discrimination Act, what this means to their firm and how to support their staff in conjunction with HR. This is not always the case. If you are having problems there are the following helplines and services that could help you.

The DDA helpline (tel. 0845 6046610) is run by the Disability Rights Commission and they can advise in individual cases.

The Advisory Conciliation and Arbitration Service (ACAS) (Tel 0845 7474747) is another possibility. They can advise on general industrial relations.

ACAS suggested calling the Equality and Human Rights Commission who put callers through to a specialist depending on the help required. Their contact details are www.equalityhumanrights.com
Tel 0845 7622633 or 0845 6046610.

Lastly another useful area of support is the Disability Employment Adviser at your local Jobcentre. The DEA can advise you or your employer of any "reasonable adjustments" that could be made for example, change or reduction of hours, change of duties or role, useful equipment, in work support or even working from home. They can also inform you about the Department of Work and Pensions Access to Work scheme which provides specialist equipment, e.g. lumbar support chairs. **Thanks to Sutton ME support Group**

Thanks to Carers contact

Is CFS/ME a physical illness?

There has previously been much debate as to whether CFS/ME is a physical illness or not. Some researchers have put forward the argument that it is a purely psychological disorder, citing in evidence the high rate of co-morbid depression. Others are sure that it is physical, citing the abnormal hormonal tests found in some of the triggers of the illness by certain infections. Both views are simplifications. The reality is that the disability of CFS/ME involves both physical and mental incapacity and it is important to ensure full consideration is given to all the disabling effects of the illness and an accurate assessment of care and mobility needs is made.

For the purpose of DLA, however, the current law means that a claimant cannot be eligible for a higher rate of mobility unless his/her disability is considered "physical"; for this purpose, CFS/ME is "physical"
Courtesy of Dept of Work & Pensions.

WELFARE REFORM

No one written off - or the nightmare before Christmas?

The premise of the recent welfare reform proposals seems to be that it is both desirable and possible for all but the most severely disabled to return to work. However, the DWP has acknowledged that the situation may be more complex for people with chronic fluctuating health conditions.

When the Green Paper on Welfare Reform, *No one written off: reforming welfare to reward responsibility*, was presented in the House of Commons on 21 July, Action for M.E. welcomed the Government's proposals to help people to remain in work, to simplify the benefits system and to increase the higher minimum income guarantee from £86.35 to £102.10 for those with the greatest need.

However, we had a number of concerns about the Paper. For example, there were proposals that related to the new Employment and Support Allowance (ESA) and Work Capability Assessment (WCA), about to be introduced in October, which had yet to be implemented and which had not yet been subject to monitoring and evaluation. New claimants of Incapacity Benefit (IB) and Income Support on the grounds of incapacity would be assessed for ESA instead and existing IB claimants will all be reassessed by 2013.

What would the new system mean for people with M.E. and carers? Would some be forced back into work who were not able?

We decided to explore the issues through a national consultation with people with M.E. and their carers. Working in association with the Disability Alliance and The Princess Royal Trust for Carers, we developed two surveys and an online discussion forum to collate feedback on the proposals.

1162 people participated in the surveys and 53 actively participated in the forum. Although this response was far better than we had anticipated, we recognised that the survey was largely restricted to those with internet access and, critically, those well enough to attempt it. All responses were collected, even if all questions were not answered. 886 people with M.E. and 65 carers completed questionnaires. Thank you so much to everyone who contributed. The public consultation ended on 22 October. The quantitative results of our surveys are available on a dedicated website at: www.actionforme.info/survey-results.html

Our full response and consultation report is available online at: www.afme.org.uk

What follows is a small extract from the survey results for people with M.E. Responses from carers will appear in the next issue.

Findings

Our findings will not surprise readers but we believe that it is the first time that so much narrative evidence has been confirmed statistically and through extensive written feedback. Our consultation clearly showed that:

- the majority of people with M.E. surveyed want to work
- the prospects of many people with M.E. who are currently out of work being able to return to paid employment are likely to be poor, no matter how well motivated they are, because of the degree of long-term disability they experience
- when people with M.E. do not work, it is because they are physically and mentally unable to sustain paid employment
- unless carefully planned by a qualified health professional, trained in M.E., in full consultation with the person with M.E., increases in physical, mental or emotional activity can cause serious set backs in the recovery of people with M.E.
- for those who can return to work, a 'graded return to work' must be centred around a person's health, not the needs or expectations of employers or benefits agencies, or the employee may well suffer a relapse
- the benefits assessment process places great stress on people who have often already lost a great deal to M.E.
- the existing welfare benefits system does not take informed account of people with fluctuating conditions and respondents were not confident that the new proposals would address this
- people with M.E. struggle hard to stay in work
- some employers are supportive of existing employees who get M.E. but only to a point. Many do not support people with M.E. to stay in work
- the greatest barriers people with M.E. face when they try to return to work relate to their health and the ability of employers to support people with a complex fluctuating condition
- people with M.E. who are well enough to do some paid work need adequate support and understanding.

Some statistics

When asked, 'Would you like to be in paid employment, 728 people with M.E. who were no longer in paid work responded. The majority (70%) wanted to work – and while some said they did not want to work because they were of retirement age (63 respondents), had caring responsibilities (18), were studying or planning to study (6) or did not need paid employment (5), the majority of those who commented (102) said, "I am just too ill."

Only 18% of respondents were currently in paid work. Of these, 79% had had to change their hours of work as a result of their illness, with a clear move to reduced hours. 45% had had to change their employment, with a marked decline in the number of people working as managers and a notable increase in the number now undertaking clerical work. 76% had had a relapse as a result of work.

Many people told us that even if their employer was supportive when they first became ill, after a year the support usually ended. When people with M.E. who had had to leave work were asked who advised them to leave, 35% (97 of 278 respondents) were advised by their employer's human resources/personnel department, 19% by their line manager and 22% by occupational health.

Participants who were in paid work were asked to rank the extra adjustments they would find most helpful.

- 42% said working from home would be the most helpful
- 37% said flexible hours
- 33% said having access to a quiet place to rest
- 32% said an understanding attitude amongst colleagues

Of those not in paid work, 90% said that they were not well enough 'today' to undertake paid employment. 68% expected to work again but only if their health improved sufficiently. 13% did not expect to work again because of their health.

Of 709 respondents not currently in work, 81 % had not worked for at least three years. 60% had not been in work for over five years and 20% for 3-5 years. Not all were on benefits.

The majority had been ill for some considerable time; 61 % or 605 respondents had been diagnosed six or more years previously. In terms of severity, 53% (or 521 respondents) were 30-40% well. The largest single group of respondents was 40% well. Of those who did feel well enough overall to do some paid work, 49% felt they could do just 1-5 hours work per week. When asked about how far they could travel to work, 47% or 178 of people with M.E. said that they would have to work from home.

When asked, 'Which three changes would make it easier for those people who have M.E. who could work, to return to work and remain in employment?', 849 people responded:

- 57% said availability of part-time, flexible work
- 56% said increased understanding of M.E. amongst medical examiners employed by the DWP
- 52% said increased understanding of M.E. amongst employers.

220 people who were not currently in work listed home working as the most helpful practical step that could allow them to work.

When asked, 'Have you participated in Pathways to Work?', 92% (825 of 899 respondents) said no. 4% did not know. Of the 5% (42) people who had participated in Pathways, while 16% had found it helpful (11 %) or very helpful (5%), 46% had found it unhelpful (7%) or useless (39%).

Welfare benefits?

79% of people with M.E. (481 of 611 respondents) who had taken part in a benefits assessment process said the process had affected their health. 48% (273 of 574 respondents) had had a relapse as a result of a Personal Capability Assessment.
Of 420 people who had participated in a benefits assessment in the past three years: 70% said tests for functionality and sustainability of activity were inappropriate; 63% said there was no recognition of the fluctuating nature of M.E.; 57% said that guidance for assessors was unsuitable; 53% had encountered prejudice or disbelief during the process; 48% said there was no consideration by the assessor of evidence from their own GP and 40% said that their GP's evidence was disregarded; 48% said there was an assumption that the claimant was capable of work and 41 % said there was an assumption that the claimant did not want to work; 37% had encountered an assumption that employers will employ disabled people and 58%, an assumption that employers are able to support disabled people.

Recommendations

We need to see a fundamental shift in attitudes amongst DWP assessors to illnesses like M.E. and amongst employers to taking on people who have a disability or chronic fluctuating condition. We made a number of recommendations in our consultation response to support this.

We also asked for clarification of the nature of the condition management programmes suggested as work-related activities to support people back into work, pointed out that the Pathways programme had not helped many people with M.E. back into work and strongly recommended that the wording of the ESA50 *Limited capability for work* questionnaire is changed, to reflect a wider range of conditions in which cognitive impairment is a key symptom. We also asked that contribution based ESA be reviewed so that contribution based claimants are not penalised for working by losing Housing or Council Tax Benefits. Action for M.E. will be monitoring the impact of welfare reform on people with M.E. to ascertain the effects on health and well-being.

Help with ESA and WCA

Action for M.E.'s new guide to Employment and Support Allowance and Work Capability Assessment, will soon be available to help new claimants. It will give basic information on ESA and details on how to complete the new ESA form.

Claimants on Incapacity Benefit or Income Support on the basis of incapacity should not request a copy until they receive an ESA50 questionnaire. Present claimants who receive the IB50 questionnaire will need to ask for the *Personal capability assessment pack: a guide to filling in the form.*

Statistics quoted reflect the number of people who responded to a particular survey question, rather than the percentage of people who participated overall.

Thanks to InterAction

QUICK GUIDE TO ESA

In October 2008, the Department for Work and Pensions (DWP) launched Employment and Support Allowance (ESA) and the Work Capability Assessment (WCA). A factsheet has been produced by Action for M.E. in association with the Disability Alliance to help people with M.E. to complete the claim process. What follows is an extract. Download the factsheet free at www.afme.org.uk

Employment and Support Allowance (ESA) has already replaced Incapacity Benefit — and Income Support on the grounds of incapacity — for new claimants.

Whilst it will have no immediate affect on many existing Incapacity Benefit and Income Support claimants, they may find themselves having to undergo the Work Capability Assessment (WCA) and it is expected that they will be migrated across to ESA (beginning with the under 25s) during 2009-2013.

Rules on entitlement

In order to claim ESA you will:

- have a limited capability to work
- be aged 16 years or over and under state pension age
- be resident in Great Britain

You will not be able to claim ESA if you are entitled to Statutory Sick Pay, claim or are entitled to Income Support as a lone parent or as a carer, or are entitled to Jobseekers Allowance.
There are two strands of ESA: contributory ESA and income-related ESA.

How to claim

In most cases, your claim itself will start with a phone call to Jobcentre Plus on 0800 055 66 88 (textphone 0800 023 48 88 for people with speech or hearing difficulties). You will need your postcode and identification such as your National Insurance number. You may also need to provide information about your rent or mortgage, any current employment, income and savings.

Some Jobcentre Plus call centres may send their initial questions out to you (the ESA1 form).

People who are unable to claim by phone can claim via a representative or interpreter, by completing a printed ESA1 claim form or face-to-face through most Jobcentre Plus offices. It is possible to apply online at: www.dwp.gov.uk/eservice

Once your claim has been processed you will receive the basic rate payment and will enter the assessment stage.

Assessment stage

The claims process will vary depending on the severity of the illness and the following summary is intended only as a general guide.

1. For the first 13 weeks (the assessment stage) most claimants will receive a basic rate payment.

2. During this period, all but the most severely disabled claimants are likely to be sent:
i a form (the **ESA50 questionnaire**) asking for more information about their illness or disability, which should be completed and returned within six weeks. Further information about completing this form is provided in our factsheet
ii. a letter asking them to go to a local medical centre for a Work Capability Assessment
iii. a letter asking them to attend a Work-Focused Interview (WFI).

3. The **Work Capability Assessment (WCA)** will probably take place about six weeks after the initial claim has been made. It will involve a face-to-face interview, in a medical centre, with a healthcare professional from Atos Healthcare, which will last up to 75 minutes. In exceptional circumstances it can be carried out within the claimant's home.
The WCA replaces the Personal Capability Assessment. It consists of three parts:
i. Limited Capability for Work Assessment (LCW or LCWA)
ii. Limited Capability for Work-Related Activity Assessment (LCWRA)
iii. Work-Focused Health-Related Assessment (WFHRA)

4. A **Work-Focused Interview** will take place about eight weeks after the ESA claim has been made. An adviser will discuss the claimant's benefit entitlement, work aspirations and available support.

Nearly all sick and disabled people who claim ESA, National Insurance Contributions Credits or Housing Benefit because they cannot work will have to have a WCA. Only people with the most severe levels of disability will not have a WCA. Others will have to go through at least two interviews, more probably five or more.

Following assessment

Following the assessment stage claimants entitled to ESA will be placed in either the Support Group (people have an illness or disability that is too severe for them to undertake any form of work-related activity) or the Work Related Activity Group.

Those in the Work Related Activity Group will be expected to engage with a personalised programme of back-to-work support. They will attend up to five further Work-Focused Interviews with a Personal Adviser, generally on a monthly basis, to agree an action plan of training or other personalised support intended to enable them to manage their illness and retain or obtain work skills.

The amount that a claimant then receives will depend on which group they are placed in.

Useful contacts

Disability Alliance
Free factsheets www.disabilityalliance.org
DWP Benefit Enquiry Line
Tel: 0800 882 200
Mon-Fri 8.30am-6.30pm, Sat 9am-1 pm
www.dwp.gov.uk/esa
Jobcentre Plus
www.jobcentreplus.gov.uk
Citizens Advice
See the phonebook
www.nacab.org.uk

Can you help?

Action for M.E. is appealing for people with M.E. to keep a diary of their ESA 'journey.'

A questionnaire has been drafted to get you started and it is available by post or to download from our website, www.afme.org.uk, along with our ESA factsheet.

Thanks to InterAction

MORE THOUGHTS FOR THE DAY

If you put "eat chocolate" at the top of your list of things to do today, you're certain to get at least one thing accomplished.

“I think the most important thing a woman can have-next to talent, is of course-her hairdresser”. Joan Crawford
Man walks into a Doctor's surgery with a strawberry on his head. The Doctor says "I will give you some cream for that".

Mommy Mommy there's a man at the door with a bald head.
Tell him your dad's got one!!!

Thanks to Central Lancashire ME/CFS Support Group

CHRONIC FATIGUE SYNDROME AND MITOCHONDRIAL DYSFUNCTION

The original article by Sarah Myhill, Norman E Booth and John McLaren-Howard is available online at IntjClinExpMed(2009) 2,1-16 www.ijcem.com/812001A.html

This article describes a study done on ME patients with the aim of improving their health by interventions based on the biochemistry of the illness. Specifically the study looked at the way that the mitochondria (the power pack of each cell) produce energy for all bodily functions and how this process is damaged in people with ME.

The study also shows that ME patients have several biological problems in a variety of combinations. When all these factors are combined, there is a remarkable correlation between the degree of mitochondrial dysfunction and the severity of the illness.

The authors state that "The ATP Profile" test (which shows mitochondrial function) is a powerful diagnostic tool and can show the difference between patients who have fatigue as a result of stress and psychological factors, and those who have insufficient energy due to cellular respiration dysfunction. The authors also state that individual factors indicate which things will help e.g. dietary supplements, drugs or detoxification and which further tests should be carried out.

In the full article the authors explain that two of the most characteristic and debilitating signs of ME/CFS are very poor stamina and post exertional fatigue. Sometimes fatigue is mainly mental and sometimes mainly physical. They say that fatigue is the same as lack of energy and that energy comes from the basic metabolic process of the oxidation of food.

They go on to explain that some people believe that the metabolism of people with ME/CFS is normal but the fatigue is due to psychological factors and then explain how this is thought to occur. An alternative explanation for the fatigue is that there is metabolic dysfunction with the result that not enough energy is being produced. There is considerable evidence that mitochondrial dysfunction is present in some ME/CFS patients. One consequence of this dysfunction is increased production of free radicals which cause oxidative damage, evidence of this is found in muscle specimens.

The authors state that some studies have not found mitochondrial dysfunction but they argue that this is likely due to the different diagnostic criteria in use e.g. Oxford criteria which is a definition proposed by psychiatrists and which states fatigue is present and other symptoms may be present but are not essential. However their study was done using the Centre for Disease Control (CDC) criteria and the Canadian Consensus criteria. This study is aimed to assess mitochondrial dysfunction with the primary aim of helping patients. They go into detail of how the mitochondria works to produce energy then go on to describe the method used in their study. The patients paid for their own ATP test and there are various charts which show the levels of mitochondrial dysfunction combined with the other biological factors involved.

Patients were assessed for diet, sleep problems, allergies and thyroid and adrenal problems. Advice was also given on pacing and only those patients who remained below a functional level of 7 out of 10 were then forwarded to the study of mitochondrial function.

In their discussion of the study and results, the authors say that the ATP profile results indicate mitochondrial dysfunction of the neutrophils in their patients and moreover the degree of dysfunction is strongly correlated with the severity of their illness. Neutrophils are the major affecter cells of the immune system so the observed mitochondrial dysfunction is bound to have a deleterious effect on this system. They note that increased apoptosis (early death of cells and production of immature cells) of neutrophils has been observed previously in people with ME/CFS.

The authors say that they cannot over emphasise the importance of a careful diagnosis using the CBC or even better the Canadian Consensus criteria. (Available at www.mefmaction.net/Patients/Overviews/tabid/122/Default.aspx).

In their conclusions they state that they have demonstrated the power and the usefulness of the "ATP Profile" test in confirming and pinpointing biochemical dysfunctions in people with ME/CFS.

Although their observations strongly implicate mitochondrial dysfunction as the immediate cause of CFS symptoms, they cannot tell whether the damage to mitochondrial function is a primary effect or a secondary effect to one or more of a number of primary conditions e.g. low levels of oxygen in the cells or oxidative stress. Mitochondrial dysfunction is also associated with several other diseases, but this fact appears to have been recognised only in recent years.

They recommend that the observations that they present should be confirmed in a properly planned and funded study.

ME RESEARCH UK

Action for M.E. and the InterAction team are delighted to introduce a regular new feature: news, views and research extracts from Breakthrough*, the magazine of ME Research UK. Read the whole magazine on their website (www.meresearch.org.uk) or contact them at: ME Research UK, The Gateway, North Methven Street, Perth PHI 5PP Tel: 01738 451234. E-mail: meruk@pkavs.org. uk . In the first article, Dr Neil Abbot considers the importance of a nutrient affected by levels of winter sunshine: vitamin D.*

Rickets is commonly thought of as the classic disease of vitamin D deficiency, but science is recognising that it is merely the extreme end of a spectrum of possible disorders; in effect, the tip of the vitamin D deficiency iceberg. The reality is that vitamin D deficiency remains common in the population.

In young people, at both the foetal stage and during childhood, vitamin D deficiency can cause skeletal deformities and growth retardation, and increase the risk of hip fracture in later life.

In adults, it can result in osteopenia and osteoporosis, and muscle weakness. Recent scientific work, centring on the discovery that vitamin D receptors are widely distributed in the body and can be found in most cells and tissues, has thrown new light on this vitamin and its role in a variety of key functions.

Most interest, however, concerns the part played by vitamin D or its deficiency on the risk of chronic illnesses, including autoimmune and infectious diseases, the common malignancies, and cardiovascular disease.

Why might this be important in M.E.? Well, as a chronic illness with immune, infectious and cardiovascular aspects, there is at least a possibility that vitamin D deficiency/insufficiency could be involved in the development or maintenance of the condition or its specific symptoms.

For example, vitamin D is known to affect vascular smooth muscle cell proliferation, inflammation, vascular calcification and blood pressure, all of which are involved in cardiovascular risk, while there is evidence that M.E. patients have associated cardiovascular symptoms, including attenuated heart rate and blood pressure regulation and – as a recent report from the University of Dundee showed – increased arterial stiffness.

Again, vitamin D inadequacy has been linked with impaired neuromuscular functioning and chronic pain, two important facets of the day-to-day experience of M.E. patients.

These considerations, including the fact that Vitamin D is known to influence inflammatory processes – whether as an inhibitory influence on TNF- and interleukin-1 production, or by reducing the activation of macrophages – intrigued researchers at the Institute of Cardiovascular Research, University of Dundee.

And their interest was further stimulated by a 2007 report of improvement in endothelial vascular function in vitamin D-deficient patients with type 2 diabetes after a single large dose of oral vitamin D2 — suggesting, albeit tentatively, that there might even be a therapeutic role for vitamin D in M.E. patients, whose endothelial vascular function has been found to be dysregulated by previous work in the unit.

But the first step in determining whether there is an association between vitamin D and vascular function in people with M.E. is to find out if the vitamin D levels really are lower than normal (since if not, there is no point in looking further).

To investigate this, ME Research UK has given a small 'extension funding' award to Dr Faisel Khan of the Institute of Cardiovascular Research to test vitamin D levels in already-collected samples acquired from two separate studies previously funded by our charity.

Dr Khan aims to measure the main circulating form of serum vitamin D (25- hydroxy-vitamin-D3) as well as the active hormone 1,25-dihydroxy-vitamin D3. These measures will then be related to previously-assessed vascular function in the two M.E. and control populations.

If an association is found, a subsequent intervention trial might show whether vitamin D supplementation could be a relatively simple, effective way of contributing to reducing risk of cardiovascular disease in M.E. patients.

In other illnesses, small scale intervention studies, aimed at increasing levels of 25- hydroxy-vitamin D in populations at risk of cardiovascular disease, have reported beneficial effects, and the same might be true for M.E.

What is vitamin D?

Vitamin D is a group of fat-soluble 'pro-hormones' which have no hormonal activity in themselves but can be converted into active hormones by the body. The two major forms are vitamin D2 (ergocalciferol) and vitamin D3 (cholecalciferol).

People get vitamin D from two sources. The first is ultraviolet B radiation from sunlight, which penetrates the skin stimulating the production of vitamin D3. The other source is diet, particularly fatty fish such as salmon and herring. Much of our vitamin D intake today comes from fortified products like milk or breakfast cereals, or from dietary supplements. An adequate intake for adults is 400 to 600 IU per day.

Vitamin D is important for the maintenance of organ function e.g. it regulates blood calcium by assisting its absorption from food and re-absorption in the kidneys; it is essential for a strong skeleton; and it has a significant influence on the immune system.

Thanks to InterAction

ME RESEARCH EXPLODING THE DEPRESSION MYTH

The idea that depression is at the root of the symptoms of M.E./CFS has been exploded in two interesting overviews.

The first, aptly titled *Don't assume it's depression (Journal of Clinical Psychiatry)*, was a systematic review of the scientific literature on M.E./CFS and depression conducted by researchers at West Virginia University.

Their initial premise was that since "at least 1 million Americans have CFS... yet more than 80% go undiagnosed, "it is important for clinicians to clearly identify the condition and differentiate it from other conditions, such as depression, which can cause superficially similar symptoms. From the literature, they found a basket of indicators – from the clinical history, physical and mental examinations, and diagnostic arena – which could be useful.

Crucially, they stress that a good history (taken by the examining physician) is more important than any available diagnostic test to diagnose M.E. /CFS and differentiate it from depression.

The list below shows the key points of difference, including perhaps the clearest indicator, the fact that M.E./CFS patients show frustration at their physical limitations and generally do not have the usual depressive symptoms of lack of enjoyment of life, guilt and lack of motivation.

Indicators of M.E./CFS:

- post-exertional malaise
- unrefreshing sleep/excessive sleep
- intense frustration at not functioning well
- less likely to interpret symptoms in terms of negative emotional states
- weaker and more pain complaints
- frequent or recurring sore throat
- tender cervical or axillary lymph nodes
- more non-REM sleep disturbances

Indicators of depression:

- feel better after exercise or activity
- insomnia/excessive sleep
- apathy and anhedonia
- more likely to interpret symptoms in terms of negative emotional states
- stronger and have fewer pain complaints
- more REM sleep disturbances

The second review *(Journal of the American Academy of Physician Assistants)* described how biological abnormalities separate M.E./CFS from depression, emphasising that while the conditions share certain symptoms, many others, such as sore throat, lymphadenopathy, arthralgias, myalgias and post-exertional fatigue, are not typical of psychiatric illness.

In addition, the review outlines some of the evidence for physiological differences, with two of the most important being sleep (reduced REM sleep latency in depression versus reduced slow-wave deep sleep in M.E./CFS), and hypothalamus and pituitary function (high circulating cortisol levels in depression versus low in M.E./CFS, compared with controls).

Economic impact of M.E./CFS

In 2006, an Action for M.E. survey showed that 77% of our adult members had lost their jobs because of M.E. and statistics commissioned from Sheffield Hallam University showed M.E. costs the UK £6.4 billion, based on an estimated prevalence of 250,000 people in this country with M.E.

Thanks to InterAction

AN ENLIGHTENING ARTICLE BY PHIL GREEN

In the summer of 2003, at the age of 42, I became increasingly tired, mentally and physically, until I took time off work beginning mid-September; I was exhausted. By mid October I was diagnosed as having post-viral fatigue syndrome at Royal Preston Hospital. I was told I should recover in about 6-12 months and referred to physiotherapy and psychology services to aid my recovery. However, in the next year my symptoms became much worse so that by September 2004 I was housebound and acutely sensitive to light and noise, and could not cope with anything remotely stressful. I became very isolated from my family and friends, suffered from deep depression, insomnia, acute anxiety and could not tolerate mental stimulus in the form of talking, reading, writing, watching TV or listening to the radio. In 2005 my condition was classed as 'severe' Chronic Fatigue Syndrome and I was retired on ill-health grounds.

For much of this time I felt hopeless about the prospects of any improvement; I tried a number of different treatments but nothing helped - indeed one treatment left me feeling much worse. I was fearful that any treatment that made demands on me would lead to further relapses. However, during 2007 I slowly come round to the view that I needed some form of intervention if I was to stand any chance of recovery, no matter how small. My wife worked closely with my GP to refer me to Queens Hospital in London which has a CFS inpatient service. After a great deal of work the Primary Care Trust agreed to pay for 4 weeks treatment and I was taken by ambulance to Romford early in May 2008.

The first improvement came within a week in the form of medication to help me sleep 7 hours a night without any apparent side effects, a wonderful release after years of poor sleeping. The team of staff also worked on de-sensitising me to light and noise so that after three weeks when my wife came to see me she noticed a real positive change in my symptoms and my outlook. In this time I was assessed and a report was sent to the PCT requesting funding for a further 4 months to allow me to get the full benefit of the treatment. I had not wanted to go to London because I thought I wouldn't be able to cope; but knew I had to give it a chance, and now I didn't want to leave. It was a great relief when the PCT agreed the extra funding.

During the summer I worked closely with a physiotherapist and occupational therapist and the gradual improvement continued. After years of the illness it was fantastic to make small but significant steps week after week, as did other 'severe' CFS/ME patients who had been at the centre when I arrived. In addition I could hold a conversation for half an hour twice a day and read for 2 hours a day. After nearly five months in hospital it was a relief to get home and see my family and to begin a more normal home life.

I still have to be careful and manage my activities so I don't relapse; I have four rests a day and go out for coffee or an appointment twice a week. Going to Queens has given me a new lease of life and I shall always be grateful for the time I spent there. More details on the treatment are available on the Centre's web-site at www.bhrhospitals.nhs.uk/cfs/cfs1.php
Phil Green December 2008

SCIENCE NOTES BY SELINA L WILKINSON: "I'M NOT LAZY"!

Aetiology, Exercise and CFS - Taken from: CFIDS magazine by Suzanne Vernon, PhD.
Recently published in the journal Psychosomatic Medicine is a paper by Simon Wessely et al entitled "Aetiology of Chronic Fatigue Syndrome: Testing Popular Hypotheses Using a National Birth Cohort Study."

Aetiology is the study of causation. Even though many investigators have searched for the cause of ME/CFS, it has proven to be elusive. There have been many explanations as to why scientists have not identified a cause, but the most likely one is that ME/CFS is a complex, chronic disease resulting from a combination of gene-environment Interactions.

Chronic diseases like ME/CFS are difficult to study, let alone to identify a cause because - as the name *chronic* implies and the definition insists upon - the disease occurs over time. The term *birth cohort* refers to a group of people enrolled in a study from birth and followed for a certain period to evaluate any number of issues across the lifespan. In this study, the investigators aimed to test a set of hypotheses about the cause of ME/CFS. They examined whether there were increased rates of allergy and asthma (referred to as atopic illness), decreased levels of physical exercise and/or increased childhood illnesses in people with ME/CFS.

The first step was to determine how many people in this birth cohort self -reported a diagnosis of ME/CFS. Of 2,983 participants, 10 men and 24 women (1%) reported a diagnosis of ME/CFS with fatigue symptoms starting between 41 and 53 years of age. When investigators looked at rates of childhood illnesses that resulted in school absence or hospitalization in these 34 people with ME/CFS, they were no different from the rest. There were also no differences in the rates of atopic illness. And rather than finding decreased levels of physical exercise, the authors were surprised to find that the 34 people with ME/CFS had higher than average levels of exercise throughout childhood and a lower body mass index prior to their ME/CFS diagnosis. Interestingly, these same people reported continued exercise even after they began to experience early symptoms of fatigue. So does this study identify the cause of ME/CFS as being exercise? No. However, it did a reasonable job of decreasing the possible importance of atopic illness, lifetime inactivity or exercise phobia as causes of ME/CFS. (N.B. Exercise phobia is the psychological belief behind Graded Exercise Therapy treatment - GET). In fact, the authors interpret that the drive to be physically active is a personality trait that predisposes people to ME/CFS.

As this particular British national birth cohort was designed to study fertility and obstetric issues, the information collected is relevant to these two health questions. So some potentially ME/CFS - relevant information may be missing. For example, the information on childhood illness is limited, and there is no information on illnesses - in particular infectious disease episodes - after age 15.

The question to raise is what might these researchers have found if they had the information and inclination to approach their investigation from a gene-environment perspective rather than a psychological one? There is sufficient evidence in the literature that points to genetic vulnerability for ME/CFS (especially the genetic research being carried out by Dr Jonathan Kerr). There is also extensive evidence documenting environmental events, such as infectious mononucleosis, that can trigger ME/CFS.

Now through this research we see a possible connection to body mass and lifetime activity.

Despite the psychological spin the authors put on the results, the findings in this paper validate what many in the patient community describe regarding activity levels prior to the onset of illness: "I was a runner. . ."; "I loved to hike. . . "; "until I got ME/ CFS." This is an important publication because of that validation. This paper also reminds us of the importance and possible impact of events that happen across the life-span.

Thanks to Central Lancashire ME/CFS Support Group for the above 2 articles

SAYING NO CAN BE POSITIVE

The Grace Charity for M.E has written guidelines to support M.E. sufferers who choose not to attend the NHS CFS/ME clinics, many of which promote mainly psychological therapies such as Cognitive Behavioural Therapy (CBT) and Graded Exercise (GET).

People with ME who are bed bound or housebound, and who are advised to have these therapies on domiciliary visits, and those pressurised to undertake CBT and GET by Private Health Insurers may also find this useful. Some of the key points of this document called SAYING NO CAN BE POSITIVE are summarized below. A complete list of references is given in the full document, which can be accessed from the Grace Charity website (www.thegracecharityforme.org).

1) The law protects patients from unwanted treatments. Medical practitioners cannot give a treatment to a patient without the patient's consent.

2) Private Health Insurers cannot force an M.E. client to undergo unwanted treatment before making a payment, unless those treatments are specified in the contract. Also, every individual has freedom to express views as stated by The Human Rights Act 1998. If an insurance company ignores a client's reasons for refusing CBT and/or graded exercise, a client could claim their 'freedom of expression' has been violated.

3) An M.E. patient cannot have their state benefits withdrawn for refusing CBT and graded exercise. U.K. law says that if a patient refuses suitable treatment without good cause, benefits can be withdrawn. However, CBT and graded exercise could be argued as unsuitable treatments for M.E. sufferers (see facts below and additional ones included in the complete document).

4) M.E. is a neurological disorder. It has been classified as such by the World Health Organisation in the International Classification of Diseases since 1969. Therefore psychological therapies could well be inappropriate.

5) The assumption that an M.E. patient can always do more is an erroneous one. There are overwhelming international research findings on M.E., which support multi-system involvement particularly of the immune, endocrine, cardiovascular and neurological system and evidence of metabolic dysfunction in the exercising muscle. The Canadian Criteria (2003) states that the worsening of symptoms after exertion is a principal symptom of M.E.

6) CBT and GET can worsen M.E. symptoms. In a survey of 3074 M.E./CFS patients conducted between 1998 - 2001, 22% of patients said CBT had made their illness worse and 48% reported that GET worsened their symptoms.

A survey by the 25% ME Group (for severe sufferers) of 437 patients, demonstrated that of the 39% of group members who had used GET, 95% had found this therapy unhelpful, whilst 82% reported their condition had been made worse by graded exercise. Some patients were not severely ill with M.E. until after graded exercise. In the same survey - 93% of those who had undergone CBT had found it unhelpful.

Thanks to Stockport ME Group

RECIPE SELECTION

Baked Orange & Cinnamon Custard

1 tsp grated orange rind • 1 tsp caster sugar • 1 egg (size 3)
1/4 pint /150 ml skimmed milk Pinch ground cinnamon

METHOD

Preheat oven to 350 °F/180°C Gas mark 4. Put orange rind, sugar and egg into a jug and whisk with a fork.
Pour milk into a saucepan, bring just to the boil then gradually whisk in egg mixture.
Pour into two ramekin dishes and sprinkle with cinnamon. Put dishes into a small roasting tin or shallow cake tin and pour enough boiling water to come halfway up the side of the dishes.
Cook in the oven for 20-25 minutes or until the custards are set. Leave to cool then chill in the fridge.

•

No Fat Malt Loaf

1 cup all bran 1 cup of sugar • 1 cup mixed fruit or sultanas
1 cup of self raising flour • 1 cup of milk

- Mix together and soak overnight.
- Put into a greased 1 lb loaf tin and cook for ¾ hour at 160/180 degrees until a metal skewer is clean

Thanks to carer support

Cheesy Beans

This is a recipe from former carer Dorothy Rowlands "We have been using this recipe for years in our family"
This recipe serves one person

Small can of baked beans One portion of mashed potato 2oz cheese

Grate the cheese into the mashed potato reserving a little for later. Mix well. Put the beans into the bottom of an ovenproof dish and put the potato mixture on top. Sprinkle the remaining cheese on top of the mixture and cook in the oven until brown and bubbling.

ENJOY THIS COMFORT FOOD!

Banana & Chocolate Cake

425g flour 2 tsp baking powder Half teaspoon salt 250 ml vegetable oil
450g sugar 4 eggs 4 bananas chopped 1 tsp vanilla essence
325 grams chocolate chips

Mix the flour, baking powder and salt in a bowl.
In another bowl beat the oil sugar and eggs (one at a time), beating well, then add the bananas and vanilla essence, add the flour then the chocolate chips. Grease the baking tin well, and pour in the mixture. Heat the oven to180c/gas mark 4.
Bake for 60 -65 minutes.

POETRY CORNER FEBRUARY 2009

Breaking through

Breaking through the trees so tall,
Gentle sunbeams softly fall.
Through the branches grey and bare,
Saying Spring will soon be here.

Glorious shafts of golden light;
Ending winter's freezing bite.
Weaving a way through their cold dark host,
Dispelling the mists of cold and frost.

We say farewell to the dismal days,
As Mother Nature mends her ways
And tender shoots so soft and green,
Are through the mossy carpet seen.

Softly stealing through the air,
The wakening sun begins to stir.
And once more, sweetly birds will sing
As gently, golden, dawns the Spring.

Friends- Abbie Farwell Brown (1875-1927)

How good to lie a little while
And look up through the tree!
The sky is like a kind big smile
Bent sweetly over me.

The sunshine flickers through the lace
Of leaves above my head,
And kisses me upon the face
Like Mother, before bed.

The wind comes stealing o'er the grass
To whisper pretty things;
And though I cannot see him pass,
I feel his careful wings.

So many gentle Friends are near
Whom one can scarcely see,
A child should never feel a fear,
Wherever he may be.

Only- by Harriet Prescott Spofford (1835-1921)

Something to live for came to the place,
Something to die for maybe,
Something to give even sorrow a grace,
And yet it was only a baby!

Cooing, and laughter, and gurgles, and cries
Dimples for tenderest kisses,
Chaos of hopes, and of raptures, and sighs,
Chaos of fears and of blisses.

Last year, like all years, the rose and the thorn;
This year a wilderness maybe;
But heaven stooped under the roof on the morn
That it brought them only a baby.

QUESTIONS THAT CAN HAUNT YOU

Can you cry under water?
Why does a round pizza come in a square box?
What disease did cured ham actually have?
How is it that we put man on the moon before we figured out it would be a good idea to put wheels on luggage?
Why is it that people say they "slept like a baby" when babies wake up like every two hours?
Why are you IN a movie, but you're ON TV?
Why do people pay to go up tall buildings and then put money in binoculars to look at things on the ground?
Why do toasters always have a setting that burns the toast to a horrible crisp,
which no decent human being would eat?
If corn oil is made from corn, and vegetable oil is made from vegetables, what is baby oil made from?
Did you ever notice that when you blow in a dog's face, he gets mad at you, but when you take him for a car ride, he sticks his head out of the window?

Thanks to Sutton ME/CFS Support Group

DEAR DOCTOR TEMPERATURE CONTROL

I would like some advice about coping in hot and humid conditions and how those affected can prevent a relapse, especially as now we are experiencing hotter summers. My last relapse due to temperature problems lasted up to a year and now I have to keep out of the sun, even if it is only 18°C.
Enquiry received via our Reader survey

Professor Anthony Pinching replies:
Thank you for this. As well as responding to your specific question, I will broaden my reply to wider issues about temperature control in M.E./CFS.

Many people with M.E. have problems with external temperature. This can be through effects on symptoms and functioning in different weather conditions, as in your situation. Or it may be a sense of not being able to control body temperature – sometimes feeling hot when it is cold, at others feeling cold when it is hot, and often varying from one to the other for no obvious reason.

Most people with M.E. also find it very hard to adjust to extremes in external temperature, whether it is very hot or very cold. This may reflect a general difficulty in adjusting to change in this illness.

(87% of the 2,000+ respondents to our 2006 M. E. – More Than You Know' survey reported problems with body temperature control; 66% reported these as severe; 85% reported wildly fluctuating body temperature).

However, apart from such extremes, people with M.E. frequently seem to have their own preferred external temperature for optimal function and comfort with their illness. In fact, most often, people seem to prefer warmer (and preferably drier) climatic conditions.

But for others, like you, cooler conditions are better. Some seem more affected by humidity than by heat. Patients with other chronic neurological disorders (eg. multiple sclerosis) also show variation in symptoms or function at different external temperatures – the usual preference being for warmer conditions. We are not sure of the biological basis for this, but it is perhaps not surprising that the complexity of the nervous system will be sensitive to ambient conditions.

The regulation of our body temperature depends mainly on the fine control of the autonomic (inner) nervous system. We know that this part of the nervous system may be affected by M.E., for example with the control of blood pressure leading to a tendency to faintness on standing up quickly. It is probably because the fine control of this system is disrupted in M.E. that so many people find it hard to get to a comfortable temperature. Obviously, this can lead to a lot of extra energy consumption, quite apart from the discomfort.

Most patients with M.E. do not however seem to have an actual increase in body temperature from their illness. But a few do have persistent slight low-grade fever, for no apparent other cause. This may be because of the increased levels of pro-inflammatory cytokines (immune chemicals involved in inflammation) that have been found in research studies.

You ask how to prevent a relapse due to such changes. A lot of this depends on your exact circumstances, but I can outline some general ideas. By the way, the Department of Health does offer useful public health advice during hot spells, and this should be checked for ideas that may help you.

In a hot summer, it is a good idea to shut south-facing curtains in the daytime, to reduce the effect on room temperature of sunlight coming through windows. If you are able to stay in north-facing rooms, or in areas that are more shaded externally, there will be less extra warming of the walls. Keep windows shut when the outside temperature rises, and open them in the cool evenings and at night time. Reduce to a minimum the use of all indoor power-emitting sources; especially in the rooms you usually use (don't forget that freezers emit a lot of heat). If you can afford even simple air-conditioning, it could help if you are very much affected.

It is obviously advisable to keep out of the sun, but also to avoid going out in the heat of the day. Take plenty of water to replace what you lose. If you put some water on the skin and leave it to evaporate, that can cool you down a bit. Cool showers during the day can also help, if you can manage them. Wear light and loose clothing. Fans can help too.

If your own housing limits your options, you may want to approach social services to assess whether there are any modifications that could be made which could assist in your specific circumstances.

Overall, there are no easy solutions, but knowing why there is an issue can help quite a lot. Common sense solutions are worth remembering, adapting them to your own needs.

Heatwave, a guide to looking after yourself and others during hot weather, is available from the Department of Health. Quote 40313/Heatwave and contact the DH publications orderline (8am-6pm, Mon to Fri) on: 08701 555 455.
E-mail: dh@prolog.uk.com. Online address www.dh.gov.uk/publications

Thanks to InterAction

RACING ON WITH WELFARE REFORM

What impact will the Government's welfare reform proposals, born out of a desire to cut the benefits bill, have now that the country is in recession? Heather Walker says: "We can guess but the truth is we don't know."

A lot has happened since July when the DWP published its Green Paper, *No one written off: reforming welfare to reward responsibility.*

Employment and Support Allowance has replaced Incapacity Benefit (IB) for new claimants and existing IB claimants will be transferred across by 2013 (see opposite).

The economy has taken a nosedive. Official unemployment figures reached a 10-year high of 1.86 million in October and some analysts say they will hit 3.4 million by 2011. The Telegraph is keeping a tally of how many people have been laid off since the autumn. Even top accountancy firm, KPMG, has offered its 11,000 UK employees sabbaticals or a shorter working week, to try to stave off redundancies.

Jobs are scarce

Yet the Government published its welfare reform White Paper, *Raising expectations and increasing support*, in December, less than two months after consultation on the Green Paper ended, drawing heavily on Professor Paul Gregg's review, Realising potential: *A vision for personalised conditionality and support.*

The Welfare Reform Bill itself was introduced in the House of Commons on 14 January and received its second reading 27 January. It should be through the committee stage, when it is reviewed by a cross-party panel, by the time this InterAction hits your doorstep.

Fast work

In his preamble to the White Paper, James Purnell, Secretary of State for Work and Pensions, acknowledged: "Some people say Government should slow down welfare reform because Government are entering a recession." But, he said, "The Government believes that Government should do the opposite – Government should increase the pace, because that means offering more support to people and matching it with the expectation that they should not fall out of touch with the world of work."

The Prime Minister, Gordon Brown, agreed: "Too many of our communities still bear the scars of previous downturns, never having recovered from the scandal of millions pushed into a benefits system that too often trapped its recipients rather than supporting them back into work."

OK – but there is no work, even for those able. Will welfare reform – or the realities of recession – lessen or increase the pressures and expectations experienced by people with long-term fluctuating conditions, trapped on benefits not by the system but by their health?

Welfare Reform Bill

The Bill has five parts: social security, disabled people and the right to control provision of services, child maintenance, birth registration and a section entitled miscellaneous and supplementary. Most of the provisions in the Bill extend to England, Scotland and Wales but not to Northern Ireland.

In a nutshell, the Bill says that:

- Income Support will be abolished as the Government aims towards a single working-age benefit
- lone parents, partners of people with younger children and "disabled people who could work with support," will be expected to take part in work focused interviews, training and/or other work-related activities to help them move nearer to the job market
- Government will set up pilot schemes in which the long-term unemployed will work for their benefits
- disabled people will have "a new right... to control how public resources are used to meet their individual needs" i.e. they will be able to request direct payments from public authorities in order to pay for certain services.

The Bill, together with explanatory notes, are available online at http://services.parliament.uk/bills/2008-09/welfarereform.html

What follows are some brief extracts, adapted mainly from the Government's own explanatory notes.

Working age benefits

Part 1 of the Bill aims to increase and individualise benefit conditionality (what claimants must do in return for benefits) and to reduce the number of working age benefits by abolishing Income Support.

Income Support claimants will be moved on to JobSeeker's Allowance (JSA) with differing degrees of conditionality or to Employment and Support Allowance.

Only those on Jobseeker's Allowance who are required to meet the jobseeking conditions, rather than those who have moved from Income Support, will be required to attend an interview with an employment officer and provide information and evidence of their circumstances, availability for employment and the extent to which they are actively seeking work.

Work-related activity

We already know that all but the most severely disabled people who claim Employment and Support Allowance will be placed in the Work-Related Activity Group, where they will be expected to attend a series of interviews with a Personal Adviser and agree and implement an action plan of work-related activity.

The most severely disabled people will not be placed in the Work-Related Activity Group but in the Support Group where these expectations will not apply.

Clause 8 of the new Bill allows the Secretary of State or their representative (e.g. a Personal Adviser employed by Jobcentre Plus or a subcontracted organisation) to specify a work-related activity which a claimant who is placed in the Work-Related Activity Group must undertake in order to receive benefits.

Work-related activity is defined as activity aimed at helping the claimant obtain work, remain in work or to be more likely to obtain or remain in work.

The Bill also provides a power for the Secretary of State to direct that a specific activity does or does not count as work-related activity, in the case of an individual. The explanatory notes say: "This is intended to stop claimants seeking to satisfy the requirement to undertake work-related activity by undertaking activity considered inappropriate for their circumstances."

A new subsection requires that any direction given to the claimant must be reasonable, having regard to the person's circumstances and that any direction given to the claimant must be recorded in the claimant's action plan.

Failure to undertake the specified activity without showing good cause within the allowed time would be sanctionable (i.e. could result in a reduction in benefit, by an amount and for a period of time prescribed in regulations).

Contributory ESA

The Bill amends the Welfare Reform Act 2007 in that:

- the number of tax years in which a person can pay national insurance contributions and qualify for ESA is reduced from three years to two, to align it with JobSeeker's Allowance
- the first contribution condition for ESA is met by the claimant having paid, or being treated as having paid at least 26 weeks of Class 1 or Class 2 contributions on relevant earnings at the base year's lower earnings limit (£90 per week in 2008/09) in one of the two tax years prior to the claim.

What does it all mean for M.E.?

Last October, Action for M.E., BRAME, ME and You Aberdeen and the Welsh Association of ME & CFS Support all responded to the initial Green Paper on welfare reform. Over 1162 people with M.E. and their carers took part in our consultation alone. Their views and experiences were presented to the Department for Work and Pensions in person and in a report which is available by post or from our website, www.afme.org.uk

Our findings were clear. The majority of people with M.E. would work if they were well enough. The greatest barriers they face when they try to return to work relate to their health and the ability of employers to make adjustments which are fundamental to their healthcare needs. In order to return to work, those well enough would need to do so far more gradually than most employers seem to expect, working flexible hours ideally from home when possible.

How feasible will it be, really, to support people with M.E. back into work in today's economic climate?

Not impossible – our survey showed that there are some enlightened employers out there and Action for M.E. is seeking funds to highlight and promote good practice.

But the fact remains that the prospects of many people with M.E. who are currently out of work, being able to return to paid employment, are likely to be poor, no matter how well motivated they are, because of the degree of long-term disability they experience and because of how little others understand the fluctuating nature of the illness.

In the White Paper, the DWP does promise to "ensure that a clear and comprehensive set of safeguards are built into the support we offer, making sure claimants are not required to undertake inappropriate activities. In particular, this power would never be used to force claimants to apply for or take up specific jobs, or to undergo medical treatments that would clearly fall foul of human rights legislation or violate medical ethics, professional codes of practice or clinical governance."

But the Paper also says that Government wants to reduce the number of people on incapacity benefits by one million by 2015. Once any changes required by the Welfare Reform Bill Committee have been implemented, the draft legislation will go to the House of Lords for consideration.

A copy of our consultation report has been sent to MPs, MSPs and Lords, with a letter urging them to work to ensure that the new system is properly monitored and that adequate safeguards are in place to protect people with M.E. from any unreasonable pressures or expectations which might be brought to bear as a consequence of welfare reform.

The big problem is that while ESA and the proposed system are so new, there is as yet no direct evidence of its strengths and weaknesses.

As a result, we need people who are subject to the new regime – especially those who claim the new ESA and those who will be transferred across from Incapacity Benefit, to provide that evidence – to keep a record of their experience and tell us what the process is like.

Thanks to InterAction for this article

FAVOURITE THINGS WITH JULIE ANDREWS

To commemorate her birthday, actress/vocalist, Julie Andrews made a special appearance at Manhattan's Radio City Music Hall for the benefit of the AARP. One of the musical numbers she performed was 'My Favourite Things' from the legendary movie 'Sound Of Music'. Here are the lyrics she used: (Sing It!) If you sing it, it’s especially hysterical!!!

Botox and nose drops and needles for knitting,
Walkers and handrails and new dental fittings,
Bundles of magazines tied up in string,
These are a few of my favourite things.

Cadillacs and cataracts, hearing aids and glasses,
Polident and Fixodent and false teeth in glasses,
Pacemakers, golf carts and porches with swings,
These are a few of my favourite things.

When the pipes leak, When the bones creak, When the knees go bad,
I simply remember my favourite things, And then I don't feel so bad.

Hot tea and crumpets and corn pads for bunions,
No spicy hot food or food cooked with onions,
Bathrobes and heating pads and hot meals they bring,
These are a few of my favourite things.

Back pain, confused brains and no need for sinnin',
Thin bones and fractures and hair that is thinnin',
And we won't mention our short shrunken frames,
When we remember our favourite things.

When the joints ache, When the hips break, When the eyes grow dim,
Then I remember the great life I've had, And then I don't feel so bad.

Ms. Andrews received a standing ovation from the crowd that lasted over four minutes and repeated encores

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.meresearch.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