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# Newsletter

Winter 2008

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## Future events

Please note that both sufferers and carers are welcome at the following group events:

### **Evening meet - Tuesday 24<sup>th</sup> February 7.30 pm**

#### **The Weyside Pub - Millbrook, Guildford, Surrey, GU1 3XJ**

The Weyside is just a ten minute walk from the centre of Guildford. Set in a beautiful location right on the riverside overlooking fields and trees this top class food house has a lot to offer.



### **Women's fair - Saturday 28<sup>th</sup> February 10am to 4pm**

#### **H G Wells conference & events centre, Church Street East, Woking, GU21 6HJ**

Soroptimist international of Woking & district (part of a worldwide organisation for women in management and the professions) invite you to a health fair.

The free event will focus on women's health issues and will also promote all aspects of healthy living and lifestyle. Soroptimist International have invited organisations involved in health promotion, research, support or general wellbeing to have a display stand or to give a demonstration of products or services. There will also be a Programme of short talks throughout the day. The Guildford ME Group will be providing a display stand.

### **Morning meet - Wednesday 25<sup>th</sup> March 10.30am**

#### **The Holiday Inn Hotel - Egerton Road, Guildford, GU2 7XZ**

The hotel, which has plenty of parking, is near the Royal Surrey County Hospital. At the roundabout before the hospital, turn left into the hotel car park. They have a large foyer area with plenty of comfortable sofas and large coffee tables.



From M25: take junction 10 and follow A3 to Guildford and exit at exit sign for Research Park & Onslow Village. At 1st roundabout take 3rd exit. At 2nd roundabout take 2nd exit. From south: A3 to Guildford and exit signposted for Research Park and Onslow Village. At roundabout take 1st exit.

### **Afternoon meet - Friday 24<sup>th</sup> April 4.00pm**

#### **The Seahorse, 52-54, The Street, Shalford, Guildford, Surrey, GU4 8BU**

Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham).

## **Audio-conference poll**

We would like to understand if scheduled audio-conferences would be appreciated by group members. They would be listed on the front of our quarterly newsletters and members would be able to dial into them using their phone to have general discussions with others on the audio-conference. The audio-conferences could be of particular benefit to those unable to attend the physical meetings.

Before the group provides audio-conferences we would like to confirm that there would be interest in them. As such, if you think you would like to use audio-conferences please email or phone using the following details, simply stating that audio-conferences would be welcomed.

Email Neil at: [rescue@F2S.com](mailto:rescue@F2S.com) (S for sugar) or phone Maggie on: 01483 890620

## **Tenpin bowling poll**

We have been considering activities for group members to attend, beyond the typical meetings. Obviously CFS/ME is limiting, however, we have thought that a number of our more able members might be able to attend tenpin bowling.

We would like to confirm that there are enough members able and interested in the tenpin bowling before we arrange it. As such, if you are interested could you please email or phone using the following details, simply stating that tenpin bowling would be welcomed.

Email Neil at: [rescue@F2S.com](mailto:rescue@F2S.com) (S for sugar) or phone Maggie on: 01483 890620

## **CFS and mitochondrial dysfunction**

**Dr Sarah Myhill has published a paper on mitochondrial dysfunction in ME/CFS in the International Journal of Clinical and Experimental Medicine. 22<sup>nd</sup> Jan 2009**

Here's the abstract:

Abstract: This study aims to improve the health of patients suffering from chronic fatigue syndrome (CFS) by interventions based on the biochemistry of the illness, specifically the function of mitochondria in producing ATP (adenosine triphosphate), the energy currency for all body functions, and recycling ADP (adenosine diphosphate) to replenish the ATP supply as needed.

Patients attending a private medical practice specializing in CFS were diagnosed using the Centers for Disease Control criteria. In consultation with each patient, an integer on the Bell Ability Scale was assigned, and a blood sample was taken for the "ATP profile" test, designed for CFS and other fatigue conditions.

Each test produced 5 numerical factors which describe the availability of ATP in neutrophils, the fraction compelled with magnesium, the efficiency of oxidative phosphorylation, and the transfer efficiencies of ADP into the mitochondria and ATP into the cytosol where the energy is used. With the consent of each of 71 patients and 53 normal, healthy controls the 5 factors have been collated and compared with the Bell Ability Scale. The individual numerical factors show that patients have different combinations of biochemical lesions. When the factors are combined, a remarkable correlation is observed between the degree of mitochondrial dysfunction and the severity of illness ( $P < 0.001$ ). Only 1 of the 71 patients overlaps the normal region. The "ATP profile" test is a powerful diagnostic tool and can differentiate patients who have fatigue and other symptoms as a result of energy wastage by stress and psychological factors from those who have insufficient energy due to cellular respiration dysfunction. The individual factors indicate which remedial actions, in the form of dietary supplements, drugs and detoxification, are most likely to be of benefit, and what further tests should be carried out.

The full paper is available for download from:

<http://sacfs.asn.au/download/IJCEM8120012.pdf>

# Serotonin's role in CFS

By Adrienne Dellwo, About.com

Updated: August 31, 2008

Serotonin is a neurotransmitter that helps regulate a lot of your bodily functions. Along with melatonin, it's especially involved in your sleep cycle. Melatonin helps you fall asleep, while serotonin helps you wake up feeling refreshed. At least, that's what serotonin and melatonin do in people who are fortunate enough to have the right amount.

A growing pool of research suggests that people with fibromyalgia (FMS) may have low levels of serotonin. Experts are split, however, as to whether serotonin levels are high or low in people with chronic fatigue syndrome (CFS or ME/CFS). Some studies show that the problem in ME/CFS may lie in low serotonin receptor activity, which could mean that the brain isn't using serotonin properly, even if plenty is available.

## Low serotonin

No neurotransmitter acts alone. They all work together in a complex web of activity that scientists are really just beginning to understand. Still, experts have been able to associate different neurotransmitter imbalances with certain conditions and symptoms and find some ways to help boost or decrease activity.

Serotonin activity takes place in several areas of your brain, and even elsewhere around the body (where it acts as a hormone). Those different areas of your brain use serotonin differently, and they also contain several different kinds of receptors that also influence how serotonin is used.

Low serotonin levels are associated with many physical and psychological symptoms. Examples of physical symptoms:

- Fatigue in spite of adequate rest
- Disturbed sleep
- Changes in appetite
- Hot flushes and temperature changes
- Headaches

Examples of psychological symptoms:

- Changes in libido
- Mood disturbances
- Depression
- Irritability

When serotonin levels are extremely low, additional symptoms may include:

- Muscle cramps
- Bowel & bladder problems
- Rapid, uncontrolled thought processes
- Emotional numbness
- Emotional or behavioral outbursts
- Escape fantasies
- Memory torture (dwelling on or reliving your most traumatic experiences)
- Thoughts of harming yourself or others

Several disorders improve with medicines that increase the availability of serotonin, including depression, insomnia, restless leg syndrome, irritable bowel syndrome, headaches, obsessive-compulsive disorder, anorexia, bulimia, social anxiety, phobias, Attention Deficit Disorder (ADD/ADHD), post-traumatic stress disorder, and alcoholism.

### **High serotonin levels & serotonin syndrome**

Naturally occurring high levels of serotonin aren't associated with many symptoms. However, taking too much of a drug that raises serotonin levels can cause a dangerous condition called serotonin syndrome. If you suspect serotonin syndrome, you should get emergency medical help as soon as possible.

Symptoms of serotonin syndrome include:

- Confusion
- Agitation
- Profuse sweating
- High fever
- Muscle rigidity
- Fluctuating blood pressure

With treatment, serotonin syndrome typically resolves within a few days. In rare cases, it can be fatal.

### **Altering the availability of serotonin**

Several prescription drugs on the market increase the amount of available serotonin available. In people with FMS and ME/CFS, the most common ones are selective serotonin re-uptake inhibitors (SSRIs), such as Prozac (fluoxetine), Paxil (paroxetine) and Zoloft (sertraline); or serotonin norepinephrine re-uptake inhibitors (SNRIs) such as Cymbalta (duloxetine), which is one of only two FDA-approved fibromyalgia treatments.

If you prefer natural treatments, the dietary supplement 5-HTP can raise serotonin levels, as can sunlight. We don't have a lot of research confirming that food can boost serotonin levels in your brain, and it could take prohibitively huge amounts to have the desired effect. Some that are commonly believed to help include:

- Carbohydrate-rich foods, especially before bed (for an energy boost during the day, add protein)
- Complex carbohydrates, including grains, beans and many starchy foods
- Watermelon
- Dark chocolate (only in small amounts)

While it's generally safe to experiment with these kinds of foods, don't expect miracles and avoid extreme changes to your diet. Be sure to make changes slowly, and track your dietary changes and symptoms in a symptom journal to get an accurate gauge of what may be helping. You should always work with your doctor to decide what methods to try and how successful your treatments are.

# **CFS/ME – by Dr Andrew Wright**

The following article is a question and answer session held between the Bolton/Bury CFS/ME support group and Dr Andrew Wright \* - 15<sup>th</sup> Feb 07

The first question asked was whether we are any nearer to finding out the proper cause of ME and why some people are affected but not others. Dr Wright replied that, yes we are nearer to finding the cause; this has been the most difficult thing because generally all people find six things that happen

## **1. Mitochondrial failure**

He explained that within every cell in the body except red cells there are the mitochondria, within which energy is made from the nutrients (from food) that are delivered to the cell via the blood stream. He compared the mitochondria to a battery and said when the battery is flat we can plug it in to be recharged and then when it is full of energy it can be used again in your phone or radio etc. The mitochondria make energy with chemicals instead of batteries; food supplies a chemical called the phosphate group which turns ADP (adenosine diphosphate) into ATP (adenosine triphosphate); by adding a phosphate group, then energy is stored. When the ATP releases the phosphate group it has obtained back in the cell energy is released just like discharging a battery.

In 95% of people with ME this process is disrupted so that they are not producing energy as they should. However, surprisingly, in 5% this process is perfectly normal, but that is a real difficult one. Why do they have ME, probably because mitochondrial failure is not the whole picture.

## **2. Inflammation**

Tissues in the body become inflamed by chemicals, usually called Cytokines, which are like messengers and are made by the immune system and are called T cells. They are necessary but they can be very inflammatory making things hot and red and tender e.g. joints and muscles, but also the brain can become inflamed and particularly blood vessels can become inflamed. He told us that when the men recently in the news who were damaged by drug test trials, it was because their bodies produced massive amounts of cytokines. In ME we produce too many cytokines and this causes the inflammation and the pain.

## **3. Hormone problems**

There are many hormone problems but a very interesting one is Kenny De Melliers work in Belgium which concerns Thyroid hormone. Many people benefit from Thyroid hormone even though the tests show their blood levels of thyroid hormone to be within the normal range. When you have ME you make an abnormal protein, because of a fault in the immune system (2-5 OAS-Like protein) and this is 98% the same in structure as T3 which is the Thyroid hormone which does all the work. So this abnormal protein could block some of the thyroid hormones from working and that also decreases energy and metabolism.

**4. There are problems with Vitamin D** which he didn't go into as it gets very complicated.

**5. Problems with the Autonomic Nervous System**, where you have too much of a "fight or flight" response.

**6. Problems with lymphatic drainage** which should drain all the toxins from the body.

This basically is the problem, all these things are going on, so what on earth can cause all of that? Dr Wright believes that the answer is "WEIRD BUGS" (Bacteria).

The thing about these weird bacteria is they are difficult to find using normal tests and are difficult to kill as well and it is a bit like treating TB. It is an infection that has to be treated for years to get rid of it and ME is similar, in that it will need long term treatment to eradicate the bugs. These bugs live within the cells in the body (intra cellular). In acute infection e.g. flu you will find bugs in the blood stream, very easy to find. The immune system recognises them and makes antibodies to attack them. But these weird bugs enter into the cells so the immune system does not recognise them. These difficult to find and difficult to kill, weird bugs, would explain all the findings and all the energy problems.

So why do some people become so ill? Dr Wright then said that you need to have genetic predisposition, the same bug could be given to 10 people but only one would develop ME because their genes react differently and that is the big problem, you are far more likely to get a chronic infection instead of getting rid of it straight away.

What are these “bugs”? Borrelia :- most commonly talked about as Lyme Disease where you get bitten by a tick and develop an illness virtually identical to ME. Dr Wright, here, mentioned the gene studies done by Jonathan Kerr and by John Gow and which show that what happens to the genes in ME is identical to what happens in Lyme Disease. It was thought that Borrelia can only be injected into humans by a tick bite, but work done by Bill Harvey in the USA has shown this is not true, it can be passed by mosquitoes and mites and even congenital transfer. He told us of a study done in Papua New Guinea where 57% of the research sample were positive for Borrelia, there are no ticks in Papua New Guinea, so they must have got it from some other source.

Borrelia is a big possibility for causing ME, and its shape shifts from its normal wriggly form, it goes inside the cells and becomes an L form and it can also become a dormant form which is a cyst like form which can be dormant for years.

The other big possibility is Chlamydia Pneumoniae which is a respiratory bacteria which causes sore throat, chesty symptoms and wheezing. This bacteria also has a complicated life span, including the cyst form.

These are the only two bacteria which have this complicated life with changes in form and both can cause all the symptoms.

Other bugs such as Staphylococcus, Rickettsia, Mycoplasma and some viruses e.g. Epstein Barr virus (glandular fever) and Chicken Pox and Herpes can act as triggers and set off the dormant bacteria. Any stress to the body can set off these dormant bacteria into the active form.

Dr Wright told us that the body only reacts to stress in one way, the fight or flight response where we produce adrenalin. It doesn't matter whether the stress is physical e.g. from an accident, or an illness or whether the stress is psychological, the body responds in the same way producing adrenalin. These bacteria grow very much faster in adrenalin.

A question was asked here about the Lightning Process and Reverse Therapy which both encourage people to get rid of stress. Dr Wright said that of course it depends on what it is that is stressing you most, if it is a psychological stress and you can relieve it, then that will help to curtail the growth of the bacteria. However, ultimately we need to get rid of the bacteria.

He also made comment that sometimes the holistic therapists get some very good results because of course they help to reduce stress levels.

Dr Wright uses two approaches to kill the bacteria:

- 1 herbal, a product called Samento which is made from a herb called Cats Claw
- 2 antibiotics, this would need to be long term and five studies have shown it can cure 60% of people and a further 20% will be helped significantly, but it is long term, possibly one – two years.

When asked whether it was generally accepted that this is the cure he replied that it is not at the present but he feels that it will be acknowledged in the not too distant future.

One of the major problems has been the lack of research studies done on people with ME. It has not, historically, attracted many scientists to do studies. He quoted the number of studies done on cancer are about 250,000, in heart disease 150,000, but in ME only around 3000. It is very common so why have there not been many studies? Probably because for a long time it was thought of as a psychological problem but now that view is not standing up to scrutiny. Dr Wright said that Prof Simon Wesley who was the main adherent to the psychological view would not appear in front of the Gibson Enquiry to defend his views. The Gibson Enquiry was done by an MP who chaired an all party working group of MPs to look at ME and to see why patients have had such a bad deal. The report, when published said, too much emphasis has been placed on psychological factors, there has not been enough notice taken of the basic medical research, and that many of the medical profession have had a poor attitude to ME patients. It also says that they don't feel that Lyme Disease is the same as ME, which Dr Wright says he agrees with, it is not purely the same.

He then said other measures such as mitochondrial support and anti inflammatory measures can help as well. Dr Wright said he has seen a few patients cured with six weeks antibiotic therapy- not many- but some.

A study done in a Dutch ME clinic, looked at 99 patients who had taken Azithromycin for six weeks and 60% had noticed an improvement in their condition. Azithromycin can kill these weird bugs, and along with stress, these bugs can cause all the symptoms of ME.

Unfortunately there is no NHS test to detect these bacteria but the work of John Gow and Jonathon Kerr, looking at how genes respond in ME, will hopefully lead to a diagnostic test for ME becoming available.

Another question asked was why the local Primary Care Trusts have suddenly taken an interest in ME and provided services: Dr Wright responded that it is due to patient power and all the pressure that has been put on them by our letters and meetings with them. He added that now, more is becoming known about the science of what is happening to patients with ME, it is becoming more interesting to the scientists and doctors and so more research studies will be done and there will be an exponential growth in knowledge.

The next question was "what is the Candida association?" – to which Dr Wright replied that he doesn't think that there is a Candida association. There are problems with glucose metabolism on many levels, and the problem is why does the brain crave sweet things. He said that he doesn't know but he doesn't think that it is Candida, he feels that it may be another weird manifestation of the inflammation, but he doesn't really understand it. He said that Candida can not explain the mitochondrial failure in ME and although Candida is present it is probably because the immune system is not in balance and it is an opportunistic infection which will grow when the immune system is not right.

A further question was to ask, in the absence of any diagnostic test, how the doctors actually diagnose ME. This is done firstly by excluding other illnesses, using the tests that are available and secondly by looking at the symptoms. Doctors usually use the Fukuda Criteria but recently the Canadian diagnostic criteria have been documented and this is a much better way of diagnosing as it not only lists the symptoms it also explains why things are going wrong.

Dr Wright made us laugh by telling us that there has been a conference in the USA about the name of the illness and the conclusion to which they came, was that it should be called ME/CFS.

Then it was asked if Interferon can help, this is a drug used in MS and which calms down an overactive immune system. Dr Wright replied that while it may help it will not solve the problem. He said that ultimately the best thing to cure ME is yourself, if you can get your immune system in balance yourself, that is the best way of doing it. Most people know what makes them feel better or what makes them feel worse.

He then went on to talk about the similarities in the inflammation levels seen in rheumatoid arthritis and the inflammation that occurs in ME and to tell us of some of the other things that can help to normalise the immune system and reduce the inflammation e.g. plant sterols such as SIMBA and BENECOL but also general antioxidants and minerals and vitamins.

It was then asked if there is a link between raised cholesterol and ME; to which he replied that Dr Vance Spence and the Vascular Biology Unit at Dundee have done studies of cholesterol. Total cholesterol is made up of 1) HDL which is good cholesterol and which is necessary for the body to function properly: 2) LDL which is bad cholesterol which forms the fatty plaques which cause narrowing in the blood vessels. What is important with cholesterol is the ratio of good to bad. So even if your total cholesterol is quite high, if there is a good ratio of good to bad cholesterol you are ok. Dr Wright said that cholesterol is dangerous when it is oxidised by chemicals within the body, called free radicals, which are made by every chemical process in the body and we use them to kill bugs and for hormone activation but if we make too much they damage fat particularly, and they damage DNA, so we use vitamins to fight the free radicals. Statins are used by doctors to lower cholesterol; they help to lower the inflammation in the blood vessels. There is now a problem of how much these statins should be taken as there can be problems with muscle pain. Most cholesterol is due to genetics but diet can help and use of plant sterols (Benecol) also antioxidants, vitamins and minerals, but he warned not to overdo Vitamin C, no more than 1 gram per day.

When asked if cholesterol can kill you Dr Wright answered by telling us of a study which has shown that men are helped by use of statins but women are not helped by use of statins.

When asked about using Co-Enzyme Q10, Dr Wright said that it can help in some cases, approximately 50% of ME sufferers have low levels of Co-Enzyme Q10. The preferred dose is 300 mg per day for one month, then reducing to 100 mg per day. He also said then when it comes to energy production there are so many things that can go wrong you may need other things as well.

Dr Wright then told us of studies done by a very clever doctor in USA called Bill Harvey; he has looked at Borrelia as a cause of ME but feels there is something else and he feels that it is Chlamydia Pneumonia. There is a very helpful website [www.cpnhelp.org](http://www.cpnhelp.org). Again he was talking about long term antibiotics and when asked if there are ill effects from long term antibiotics he said the main problem is thrush but generally they are well tolerated. Many illnesses are treated using long term antibiotics e.g. TB, Acne, prostatitis etc.



# Invest in ME

## Lost Voices

Invest in ME are offering a new book which we hope will help healthcare professionals, media, ME Support groups and people with ME in their quest to improve education and assist with publicising of the illness myalgic encephalomyelitis (ME).

The name 'Lost Voices' refers both to the fact that people who are severely ill with ME are generally not in a position to make themselves heard, and also to the way that the prejudiced denial of ME - as an 'aberrant belief' rather than a devastating physical illness - has meant that often others are incapable of actually hearing and seeing what is being said and shown - our voices drop into a void.

The book is an A4 landscape size with a laminated card cover with pictures, mostly in colour.

'Lost Voices' is primarily written by people affected by severe ME- whether as sufferers, carers or families.

The book provides the following -

- It provides an opportunity for people who are usually invisible and unheard to speak for themselves, so that their situation can be seen and understood more clearly.
- It clearly and movingly shows the evidence of the devastating impact this physical disease has on individuals and their carers and families.
- It will bring to more public notice the plight of ME sufferers.
- It will help change a widespread lack of comprehension based on general misinformation, vague definitions, guessed numbers and statistics, to the development of empathy and concern for those who are so ill.
- It can educate the medical profession, the public and others such as wider family.
- It will, hopefully, encourage a sense of community among ME sufferers and those supporting them.

The stories and photographs are provided by carers, families and, as far as possible, people with ME themselves. 'Lost Voices' represents different families, showing the impact of the illness on all family members and sufferers and carers.

### **Ordering**

Lost voices can be ordered from the following website address:  
<http://www.investinme.org/LostVoicesBook/Order.htm>

Postal orders can be made by sending a cheque and delivery address to:

Invest In ME, PO Box 561, Eastleigh, SO50 0GQ.

Cheques should be made payable to Invest in ME for £8.00 per book

## **Gupta amygdala retraining**

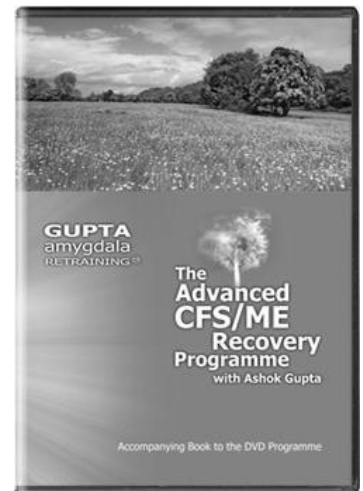
The following article has been taken from the Gupta amygdala retraining website. A few group members have experience of using the treatment and we will try to include some associated feedback in the Spring 2009 newsletter.



Gupta amygdala retraining™ is a new treatment for Chronic Fatigue Syndrome, ME, Fibromyalgia, and associated conditions.

The treatment has been developed by Ashok Gupta, a well-known researcher and therapist in the field of ME/CFS, who has dedicated the last 10 years of his life to understanding and treating the condition. He suffered from ME/CFS himself around 10 years ago, and has now been 100% better for many years. He runs a clinic in Harley Street in Central London, where he successfully treats patients with the condition.

His latest programme of recovery is now available as a fully interactive DVD programme, which contains 12 interactive sessions with Ashok at his clinic, giving you all the tools and techniques required to help you recover from ME/CFS & Fibromyalgia.



Although this is a drug-free therapy, Ashok clearly states that ME/CFS is a real physical condition, with real physical symptoms. This is based on his medical paper which was published in a medical journal in 2002. The explanation is based on the role of a brain structure called the Amygdala, which Ashok believes keeps the body in a permanent imbalanced state, causing all of the symptoms.

The techniques used in this programme are different to conventional techniques like pacing, CBT and the Lightning Process, and are drawn from many spheres of therapy. They incorporate NLP (Neuro-Linguistic Programming) techniques, meditative techniques, mindfulness techniques, yogic techniques, and many others. The tools and techniques have been custom designed to address the amygdala-based patterns which are occurring in ME/CFS, and therefore cannot come under one particular banner. Some of the processes can really only come under the banner of "Amygdala Retraining" techniques, and therefore it is difficult to describe the techniques without actually being taken through them.

Once someone has bought the DVD programme, there is follow-up coaching and support available with an experienced practitioner, who has been through the programme themselves and recovered 100% from ME/CFS.

The programme comes with a guarantee which means that you can return the DVD's and get your money back if you haven't noticed any improvements in your health after following it for 6 months, generally, those who follow the process, notice improvements within this time. It is important though that you feel that you are able to give the programme 100% commitment before purchasing it.

At time of printing price of the DVD's: £95

Order Line: 0845 4751 475

Website: [www.cfsrecovery.com](http://www.cfsrecovery.com)

# Yoga positions for CFS/ME

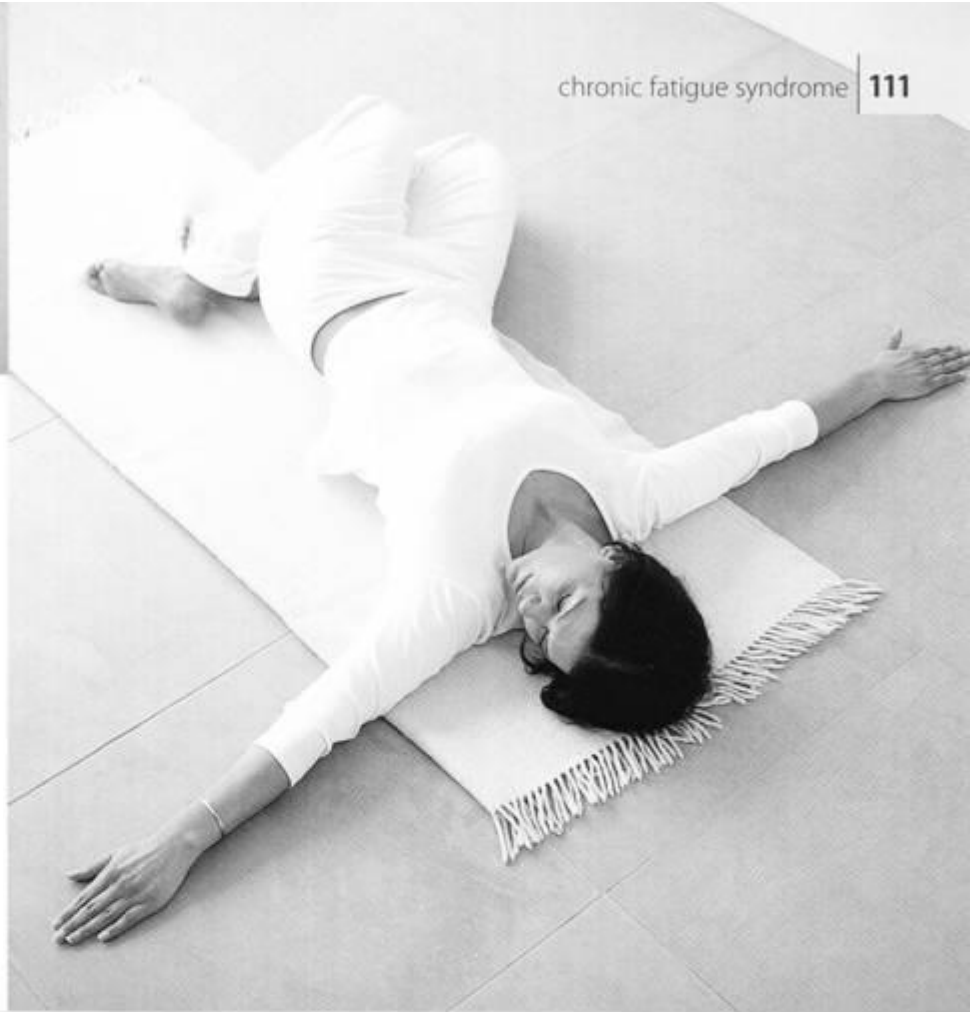
Continuing from last newsletters yoga position...the supine twist IV, forward stretch and straight-leg lift



## Supine Twist IV Supta Parivritasana

This twist is excellent for relieving tension in the upper back. In our experience, this part of the spine is almost always weakened in CFS sufferers, and this exercise helps to strengthen and straighten it.

1) Lie on the floor with your knees up and your feet together in front of you, and stretch your arms out to the side at shoulder level



2) Slowly lower your knees to the right, looking over your left shoulder as you do so. Press your right shoulder and upper back towards the floor. Over time, try to increase the distance between your feet until you reach a stage where on lowering the knees towards the right, the left knee is touching the right ankle. Slowly come up, pelvic tilt and repeat on the other side.

3) Repeat steps 1 and 2, this time raising the knees to your chest and then lowering them so that your knees are in line with your hips. Keep your neck straight and stay on each side for 4-5 breaths, easing the upper back to the floor as you slowly breathe out.



## Forward Stretch

### Paschimottanasana

**1** Sit up straight with both legs stretched out in front of you and inhale deeply. Bending from your hips, reach forward and grasp your toes, slowly exhaling as you do so. Stay in the stretch for 4–6 breaths, keeping a constant rhythm in your breath.

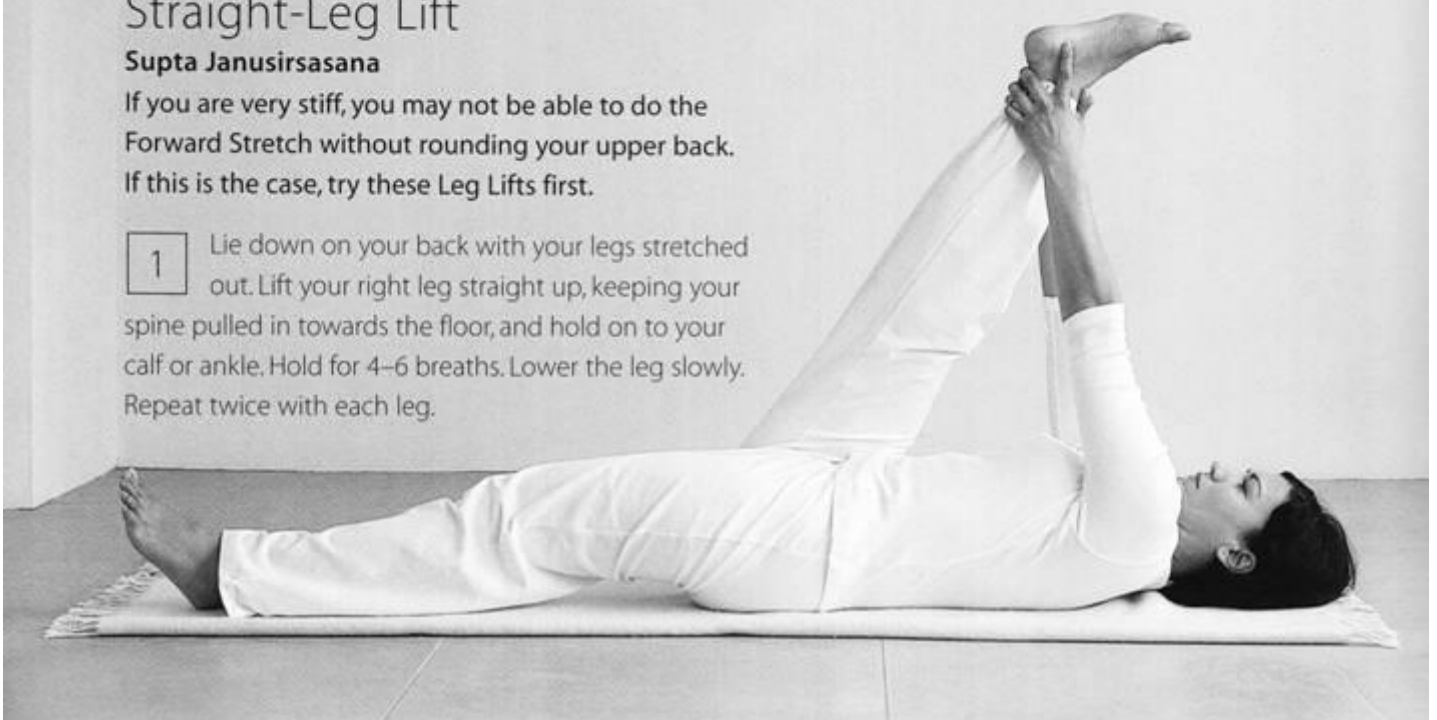
**2** Now repeat Step 1, this time folding further forwards. Keep your upper back straight. Always sit back slowly, straightening your spine first, then pulling the shoulders down and back and straightening the neck last. Try to lift your spine up on sitting back, to help keep your lower back free of tension. Now lie down and breathe normally.

## Straight-Leg Lift

### Supta Janusirsasana

If you are very stiff, you may not be able to do the Forward Stretch without rounding your upper back. If this is the case, try these Leg Lifts first.

**1** Lie down on your back with your legs stretched out. Lift your right leg straight up, keeping your spine pulled in towards the floor, and hold on to your calf or ankle. Hold for 4–6 breaths. Lower the leg slowly. Repeat twice with each leg.



# **The 4<sup>th</sup> Invest in ME international ME/CFS conference 2009**

The conference will be held on 29th May 2009 in London and builds on the successful biomedical research conferences organised by Invest in ME in previous years.



As in previous years Invest in ME aim to raise awareness of the neurological illness myalgic encephalomyelitis (ME/CFS) and we shall be focusing on severely and moderately affected patients with ME as part of our campaign for a national strategy for biomedical research into ME which will lead to treatment and a cure for this devastating illness - an illness which is about 5 times more common in the UK than HIV/AIDS - yet which has had little funding spent on biomedical research.

At the 2009 conference we will raise more awareness of severe ME - a group of patients who are not represented in research trials and misunderstood by healthcare services. Many believe that studying severe ME will yield treatments and cures for this illness and have repercussions for other services including management of ME

## **Who should attend?**

The conference will appeal to healthcare professionals, doctors, nurses, paediatricians, occupational therapists, researchers, ME support groups, people with ME and those working in social services, educational support and the media.

The conference provides an opportunity for people within government, health departments, social services and education to be able to be informed of the true nature of ME/CFS and of the current status of diagnosis, treatment and current/future biomedical research possibilities.

## **Conference registration**

Registration will be possible from 08.00 on 29th May. Included in the conference are morning and afternoon refreshments, and a hot lunch. A small quiet room adjacent to the lecture theatre will be available for some who may wish to rest.

The refreshment areas should be available as rest areas during the conference presentations and during lunch and breaks the lecture theatre should also provide a quiet area to sit and relax.

## **Conference venue**

The conference venue is at One Birdcage Walk in the heart of Westminster. The conference will be held in the magnificent Lecture Theatre of One Birdcage Walk.

This wonderful venue will make the day a relaxing opportunity to network with other healthcare professionals and patient groups/charities. Please note this conference is a TICKET-ONLY event - tickets must be purchased prior to the event.

## **Registration form**

Please see overleaf...

# Registration form

4th Invest in ME International ME/CFS Conference 2009  
29th May 2009 - One Birdcage Walk, Westminster, London

Post to:

Invest In ME, PO BOX 561,  
Eastleigh, Hants SO50 0GQ

Cheques payable to:

Invest In ME

<b>Personal information</b>					
<b>Name</b>					
<b>E-mail</b>					
<b>Phone</b>		<b>Fax</b>			
<b>Address</b>					
<b>Organisation (if appropriate)</b>					
<b>Indicate if Hotel Required</b>		<b>Wheelchair place requested (see "disabled access" in conditions)</b>			
<b>Ticket Details</b>					
<b>Choose one option below:</b>				<b>Until 20<sup>th</sup> March 2009</b>	<b>After 20<sup>th</sup> March 2009</b>
<input type="checkbox"/>	<b>Professionals</b>	<b>For professional healthcare staff and others</b>	<b>£100</b>	<b>£125</b>	
<input type="checkbox"/>	<b>Sponsor a GP rate</b>	<b>For GPs and healthcare staff registered via a local ME/CFS Support Group</b>	<b>£70</b>	<b>£100</b>	
<input type="checkbox"/>	<b>Charity rate</b>	<b>For charities and organisations</b>	<b>£70</b>	<b>£90</b>	
<input type="checkbox"/>	<b>Student rate</b>	<b>For students</b>	<b>£30</b>	<b>£40</b>	
<input type="checkbox"/>	<b>Concessionary rate</b>	<b>For people with M.E. or carers</b>	<b>£30</b>	<b>£40</b>	
<b>Conditions (please read overleaf)</b>					

**Important - Please Read These Notes:**

Submission of this completed Registration to Invest In ME (via the Submit Completed Registration form button below), will register the application for a ticket covering the requested attendance day(s) at the event entitled "The 4<sup>th</sup> International IiME ME/CFS Conference 2009". Access to the event venue will be limited to "Ticket-Only" and Personal Identification will be required for proof of identity. One completed Registration Form is required for each individual wishing to attend. Under the Data Protection Act (1998), you agree to your details being retained by Invest In ME for the purposes of managing this event.

**Disabled Access**

Disabled access is available but wheelchair places are limited by the venue owners and need to be reserved beforehand. IiME cannot guarantee that a wheelchair place will be available and applications are treated on a first-come-first-serve basis.

**Cancellation and No-shows**

No refunds will be considered for no-shows. Refund will be considered if written notice is received by 3<sup>rd</sup> April 2009. No refunds will be given after this date. Substitutions are welcome provided Invest in ME is informed and agreed at least seven days prior to the event.

Invest In ME is not liable for any loss or damage as a result of substitution, alteration, postponement or cancellation of the event due to causes beyond its control including, without limitation, natural disasters, sabotage, accident, trade or industrial disputes or hostilities.

**Concession Rates**

These are offered to individuals who are Registered Disabled, Unemployed, Benefits Recipients and individual ME Sufferers/Carers and Students. These concessionary places are limited and will be dealt with on a *first-come-first-served* basis. We will be maintaining a priority waiting list for those who, initially, have not been able to obtain a place.

**Disclaimer**

Invest In ME is not liable for any loss or damage as a result of substitution, alteration, postponement or cancellation of the event due to causes beyond its control including, without limitation, natural disasters, sabotage, accident, trade or industrial disputes or hostilities or due to the economic viability of the conference to be put in doubt. The views expressed at the 4th International IiME Conference 2009 by the presenters and delegates to the conference and any information material distributed are their own personal opinions that are not shared or endorsed by the Trustees of IiME. IiME accept no responsibility for the views expressed or any subsequent action taken.

The contents of any presentation should not be deemed to be an endorsement, recommendation or approval of such content by Invest in ME. The materials presented at the ME/CFS Conference 2009 do not constitute medical advice.

No medical recommendations are given or implied by Invest in ME.

Any person registering or attending the conference who may take any action or consider medical treatment or referrals should take detailed advice from their own medical practitioner.

IiME disclaims any implied guarantee about the accuracy, completeness, timeliness or relevance of any information contained at the conference. By registering for or attending the conference you agree that Invest in ME is not liable for any complications, injuries, loss or other medical problems arising from, or in connection with, the use of or reliance upon any information contained in the conference.

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