



Newsletter

Autumn 2008



Future events

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

Morning meet - Tuesday 25th November - 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.

Christmas Dinner - Thursday 11th December - 7pm

Prezzo , 8 Queen Street, Godalming, Surrey, GU7 1BD

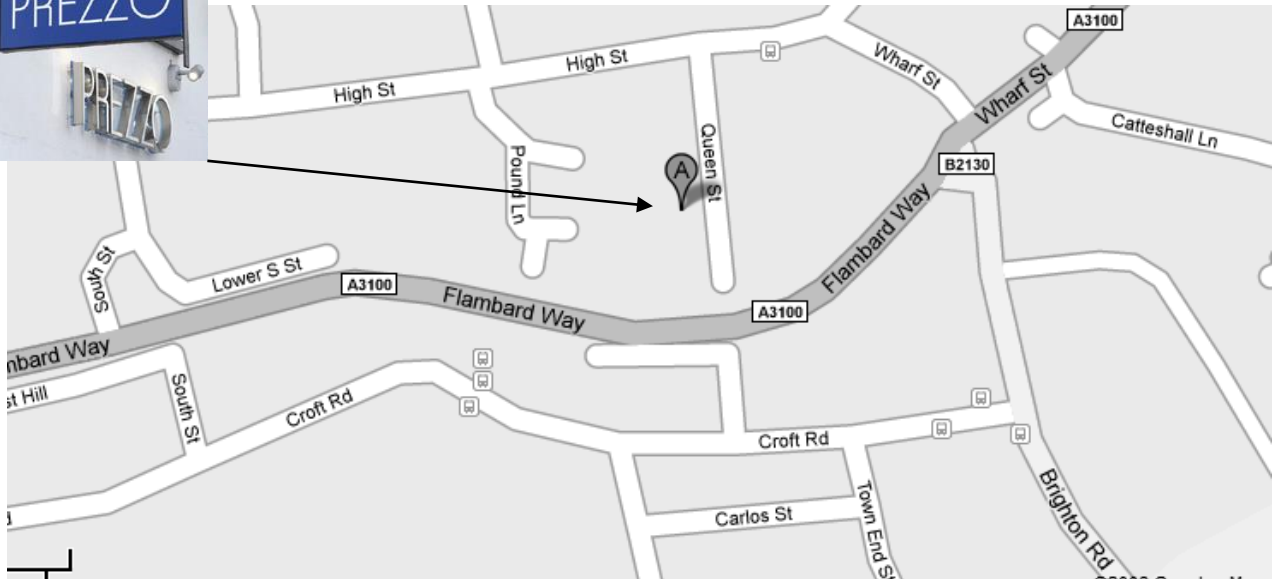
Prezzo offers Italian cuisine and use only the best seasonal products, many of which are imported directly from Italy. The menu includes pizza, pasta, risotto, grilled meats, fresh salads and frequently changing specials.



We have booked a number of seats. Please ring Cathy to reserve a seat well in advance of the night. No deposit required. Tel: 01483277790

Directions from Guildford

- | | |
|--|--------|
| 1. Head northwest on A320/Chertsey St toward North St . Continue to follow A320 | 0.2 mi |
| 2. Turn left at A246/York Rd | 0.2 mi |
| 3. At the roundabout, take the 1st exit onto A322/Onslow St Continue to follow A322 | 0.3 mi |
| 4. Slight left at A3100/Park St Continue to follow A3100 Go through 5 roundabouts | 3.9 mi |
| 5. At the 6 th roundabout, take the 2nd exit onto Bridge St | 0.2 mi |
| 6. Turn left at Queen St | 236ft |



Afternoon meet - Thursday 15th January – 3.30pm

Worplesdon Place Hotel, Perry Hill, Worplesdon, Guildford, Surrey, GU3 3RY



There is a wide range of food and drink available for those who are interested.



At Beefeater our passion is chargrilling. We only use the finest cuts of steak from traditionally reared cattle fed predominantly

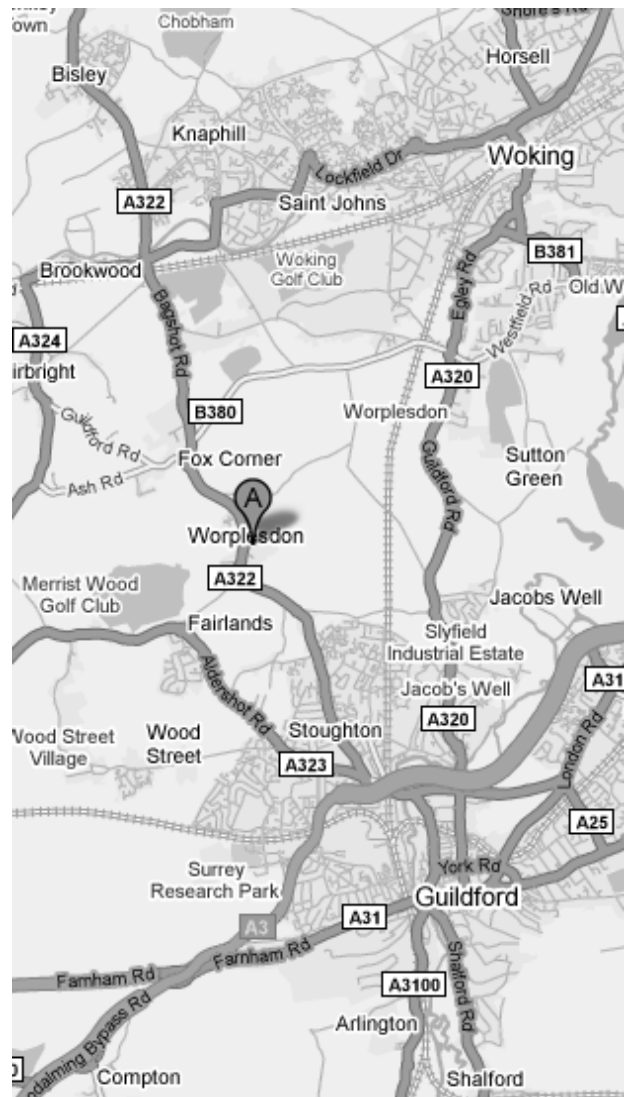
on grass to ensure exceptional flavour and tenderness. Our steaks are expertly prepared by a British family run firm of butchers and matured for a minimum of 28 days before being seared on the chargrill for that special Beefeater taste!

You'll also find succulent chicken, fish and lamb grills as well as fabulous salads.

Directions:

From A3 take the A322 towards Bagshot, upon entering Worplesdon the Hotel is on the right.

From M3 (J3) take the A322 south towards Guildford, continue along A322 into Worplesdon the Hotel is on the left.



An afternoon organised by reMEMber

(ME Charity based in West Sussex)

Written by Hilary Adams, our Publicity Officer.

Part 1 - Lifting your spirits – 7 tools for coping with illness

This is a summary of a talk given by Jan Alcoe, a health writer and trainer, who has had and been successfully treated for cancer.

There is a dark side to illness - it brings change and turmoil into one's life, with familiar roles falling away and the patient feeling a sense of separation from normal life. It can cause anxiety and a feeling of being out of control. The sense of loss can be profound – the loss of what we used to be and do. It is frequently an emotional roller coaster with feelings of wanting to give up, feelings of anger and internally it can be very draining. It is difficult not to be negative and we also fall prey to the negativity of others, all of which fuels the sense of separation. This affects our physiology and can affect our decision making.

There is also a lighter side to illness – it can bring opportunity and for some may be a big wake up call. It is possible to enjoy the gentler pace of life, to prioritise and appreciate our natural surroundings. We may be able to develop more meaningful relationships, to take up or return to creative hobbies and to deepen our spiritual awareness. Fulfilment arises from being in the moment and from fostering a sense of learning about oneself. There are seven helpful tools which can help to give a sense of authentic being and of greater patience, even when used only for a few minutes. These tools can help with:

- lessening of pain, anxiety and distress
- a growing sense of inner peace and stability
- an increase in positive and resourceful thinking and behaviour
- greater resilience in body and emotions

Meditation

This is about finding a time for silence and the power of peace. It can improve sleep, increase positive thoughts and it promotes that feeling of peacefulness. If it is difficult to still your mind, focus on positive and peaceful thoughts which can relax and recharge. Meditation gives the opportunity to discover inner peace and to stay positive in difficult situations.

Visualisation

What we see in our minds can be an enormous help or hindrance. We need to visualise positive outcomes. These need not just be in pictures, we can use all our senses to envisage good health. Use positive words to counteract negative words. Positive visualisation can be deeply relaxing which can help us to feel safe and more in control. It boosts immunity and resilience.

Appreciation

Anger, resentment and other negative emotions can help to feed illness. Appreciation and giving thanks can boost immunity and self-esteem. The body is always trying to restore balance so we should appreciate its efforts and give thanks for any treatment which may change the way we feel. We should appreciate those around us too – it makes them and us feel better. Appreciation of our surroundings and the beautiful things in our lives and showing gratitude boosts the way we feel. Appreciation creates an atmosphere of mutual respect and good feelings.

Creativity

Giving voice to our unique creativity is healing on all levels and when we are ill may be the time when we are moved to express this creativity. It is not about the outcome, it is about the process. It can take us to a restful inner place where we connect with ourselves at a deeper level. We can explore our feelings and revitalise ourselves. Being creative allows us to express ourselves in our own unique way, free from worry and guilt.

Listening

Practising deep, open-hearted listening is a very different sort of listening which deepens our connection with others. We need to be calm, find inner peace and be fully present to create an atmosphere of mutual caring and tolerance. We need to listen with our whole selves – this benefits the listener as well as the receiver.

Play

We need to enjoy the benefits of fun and laughter. People often feel they must be serious in the presence of illness. But a sense of fun has so many benefits – play takes us out of our normal roles and into a light-hearted place. Laughter has so many benefits – it reduces pain, improves immunity and reduces stress. A sense of humour makes difficult things easy and heavy things light. Play also enables self-learning.

Reflection

We need to make time for meeting ourselves. We have an opportunity to make time and reflect – we may see illness as part of our journey rather than as separate. It is a chance to focus on how far we have come rather than how far we have to go. Reflection allows us to let go. We can look at our strengths and achievements and come to a place of acceptance. We can learn from our mistakes and let go. We can accept and come to enjoy whatever we do. Acceptance of illness is not a state of giving up but a state of grace.

In all that we do, we should nurture ourselves, without feeling guilty!

Part 2 - Talks by Dr Harvey & Dr Willie Weir - a brief summary

Dr Harvey

Dr Harvey is an American doctor who had some interesting things to say about chronic illness, fibromyalgia in particular, and nutrition.

Dr Harvey works around making treatment better, more gentle and peaceful for patients and he works particularly with the relatively new science of psychoneuroimmunology. He has been dealing with a large group of FM patients. He explained that every part of us is connected to every other part of us. He spoke briefly about clinical hypnosis and referred to data which showed that stress molecules in the bloodstream can be altered by clinical hypnosis. We can alter the feeling of stress by changing our mood or with a hug.

All such tools are good but we have to have the energy to put them into practice. The single most important thing to which we should pay attention in our physical health is nutrition. We have three reasons to eat: physical hunger, emotional hunger and celebration. If we spend every day drinking coke and eating lots of beef and dairy then we will never have much energy or get over inflammatory illness. The western diet is inflammatory, especially beef, dairy and egg yolks – they produce inflammatory cytokines. If we can change our nutrition, this is a major opportunity. We need to do what is nutritionally useful. Chocolate cake once in a while is fine – but cake, coke or dairy every day is not so fine.

Dr Harvey found that a mostly plant-based diet made the biggest difference to the group of FM patients. He recommended keeping off aspartame and MSG and also keeping off apples and citrus fruit for a month. The fruit can then be added back to see if it has an adverse effect.

Inflammation makes illness worse and coping with illness harder. Everyone needs a multi-vitamin and mineral supplement with B12. Dr Harvey added one other thing – it is essential to find someone with whom we can share our feelings, in case we are eating for emotional comfort.

Dr Willie Weir

Dr Weir talked about CFS/ME as a disease characterised by neuro-immune features and virus infection. His background was at the Hospital for Tropical Diseases where it became evident that many patients remained ill even though the original tropical disease was dealt with. Dr Weir acknowledged that western medicine, if it can't find out what is wrong, will tend to say that it is something wrong in the patient's mind!

Dr Weir made clear that ME is a physical illness – it is not psychosomatic nor is it a faulty illness belief..... Descartes proposed that mind and body are separate entities which then spawned a tradition of psychiatrists who look after the mind and physicians who look after the body. There is a tendency to ignore the influence of the mind on the body.

If we set aside this divide and look solely at the work derived from Jonathan Kerr's work, this shows quite definitely that it is a physical disorder. (Dr Weir did mention that there are plenty of alternative causes of fatigue which should be investigated.)

There is a prevalence of about .5%; it is more common in women and it may be of gradual or sudden onset. Most people have a preceding virus but they may have had something else (such as salmonella gastroenteritis). Vaccinations also precipitate this condition in some people. There therefore appears to be some sort of immunological challenge.

Studies of the pathogenesis include studies of the immune system (chronic immune activation is one area Jonathan Kerr has particularly focused on), nervous system endocrine system, cardiovascular system, psychological function and genetic predisposition.

There is clearly something going on in the nervous system which contributes to symptoms. Some studies focus on the endocrine system and the impairment of communication between the hypothalamus, the pituitary and the adrenals. Looking at the cardiovascular system, there are problems with orthostatic intolerance and blood pressure. There may also be some impairment in psychological function which is why psychiatrists have tended to seize on it and make it their own.

A genetic predisposition has been deduced from twin studies. JK's hypothesis is that many insults trigger this illness but it can be triggered by a road traffic accident or by surgery. There appear to be various initial processes which lead along a pathway to the end result of the illness itself.

JK looked specifically at gene expression. We all inherit genes from our parents – our bodies are made up of billions of cells, all of which contain a complete set of genes from our parents. A liver cell has a complete set of genes as does a cell in a thumb – so why does a liver cell continue to be a liver cell? This is because the genes which would cause it to become something else are switched off. The immune system is slightly different - it has hyper-variable genes because it has to deal with all sorts of threats. It is good at dealing with all the common infections it may come across. In order to deal with these, the immune system has to switch on certain genes which were previously dormant and which will be switched off again later.

The basic premise for JK's research is that patients have had an infection and the immune response that was switched on, has failed to be switched off again. There is an ongoing inappropriate immunological process. He harvested white cells and looked at the activity of certain genes in the immune system; there was inappropriate activity in ME patients. Dr Weir used the analogy of the Keystone Cops who ran around after crooks and sometimes dealt with innocent bystanders quite unconstitutionally....The immune system is running around on alert when there is no actual crook to chase.

What JK has also found is that, when he looked at clinical sub-types, some patients say that fatigue is the main problem with no muscle pain, whereas others have significant pain. For others cognitive impairment is much more significant. There are clearly different sub-types, probably about 7.

Scientifically, there is a need to look at more samples to firm up the idea of clinical sub-types correlating with genetic sub-types. Probably some patients switch from one sub-type to another over time. Probably some overlap with Gulf War Syndrome. The Cartesian divide is no longer valid – the mind and body are interlinked and there is terrific interaction between the two. The effect of infectious disease on the psyche can be very significant – the initial stages of typhoid can cause a rambling delirium and spaced-outness. Social reflexes may be ok ('how are you?' – 'I'm fine') but greater interaction may be a problem ('what did you have for breakfast?' 'I caught a plane')...Patients are so often referred to a psychiatrist before an infection is identified. Dr Weir referred to work done by David Tyrell – he examined the psychological status of a group of people who had been given a cold. If they were psychologically stressed, the cold lasted longer, the illness was more severe and they excreted the virus for longer – so clearly the immune system was affected – it was not just the patient's perception.

Dr Weir expressed the view that there will be further research into the immunological abnormalities and that eventually there will be a cure. But currently we are dealing with a complex disease with chronic ongoing activation of genes in the immune system. How can we shut our own system down? There has to be an ultimate persuader to shut things down and this is the basis of meditation techniques.

Christmas Cartoons



A 3 phase concept of ME

The following article includes intensive scientific information, however, if you bear with the article it still provides concepts suitable for the layperson.

Source: <http://cfs-ireland.org/recovery.htm>

Clinical studies show that 10% or less of CFS patients make a full recovery. Despite the seriousness of the illness, a few thousand people around the world have fully recovered from ME/CFS. Considering the fact that approximately 90 million people around the world have ME/CFS, this means only a very small percentage have fully recovered. High-tech diagnostic equipment and tests followed by special medical treatments have played a significant part in these recoveries. There is a medical and clinical pattern in these recoveries, this fact offers hope to all of those currently suffering from CFS. In this section we will analyse this medical and clinical pattern and the recovery process.

Actual recovery process - what are we dealing with?

Scientific research and medical evidence has shown and is continuing to show us that Chronic Fatigue Syndrome is a multi-factor illness. CFS also has three distinct stages as outlined by Dr. Paul Cheney. Dr. Paul Cheney runs a specialist CFS clinic in the USA and has treated 5,000 CFS patients over a 15 year period. He has helped hundreds of patients recover from CFS.

The findings of Dr. Paul Cheney and researchers and scientists around the world show that CFS progresses in three stages over time. This accounts for it's multi-factor nature and it's complexity.

Phase 1 RnaseL abnormality

- Some biochemical or biological event leads to the following:
 - (i) cleavage of the 80 kDa form of RnaseL into 37 kDa RnaseL. An accompanying high LMW RnaseL (37 kDa) to HMW RnaseL (80 kDa) ratios found in CFS patients
 - (ii) cleavage of STAT1-alpha protein, and accompanying STAT1-alpha deficiencies
 - (iii) cleavage of p53 protein, and p53 deficiencies
 - (iv) abnormal caspase activity and disrupted cell apoptic process
 - (v) cleavage of RnaseL leads to the presence of RnaseL fragments. 3 RnaseL fragments have been found to be significant:
 - Fragment 1**, an ankyrin binding repeat domain which is known to interact with various transport proteins. It is capable of NF-kappaB mimicry ;
 - Fragment 2**, the 2-5A binding fragment that has catalytic activity and thus is able to degrade RNA ;
 - Fragment 3**, shares homology with chain A of Cdk6 (Cyclin dependent kinase). It of Cdk6 chain A mimicry ;
 - Research article:** *Total Exposure: Expanded Model for RNaseL Fragmentation in CFS Uncovered; The National CFIDS Foundation Announces the Use of Elastase Inhibitors as a Potential Treatment for CFS Patients (2003)*
 - (vi) Cell Apoptosis (cell death) increases initially in CFS and then is inhibited when the levels of RnaseL related fragments reach a certain point
 - (vii) cleavage of Actin ;

All of the above factors (i) to (vii) above interfere with the 2-5A synthetase / RNaseL pathway which is part of the anti-viral and anti-mycoplasma defense mechanism in cells. RnaseL destroys both viral messenger RNA and human messenger RNA. An over-active RnaseL destroys human messenger RNA preventing synthesis of essential human proteins and putting cells into significant dysfunction. Research by Suhadolnik, De Meirleir and De Becker show that the abnormal RnaseL in CFS is over ten times as destructive as normal RnaseL, and this destructive phase continues indefinitely for years.

The drug Ampligen effective in many cases, because it treats the RnaseL abnormality

- Effects of Rnase L (37 kDa RnaseL) :
RnaseL destroys both viral messenger RNA and human messenger RNA. An over-active RnaseL destroys human messenger RNA preventing protein synthesis within cells and putting cells into significant dysfunction. Research by Suhadolnik, De Meirleir and De Becker show that the abnormal Rnase L (37 kDa RnaseL) in CFS is over ten times as destructive as normal Rnase L, and this destructive phase continues indefinitely for years.

Abnormal Rnase L (37 kDa RnaseL) and RnaseL fragments disrupt human messenger RNA, protein synthesis within cells and other cell functions, mitochondria function, the liver, the immune system, the kidneys, HPA glands, growth hormone production, muscles, brain and nervous system.
- Infections by one or more of the following:
Viruses: HHV-6a virus, EBV, CMV, Coxsackie viruses, Stealth virus (from a subclass of retroviruses called "spumaviruses"), JHK virus, Parvovirus B-19 infections, Enteroviruses in spinal fluids, blood, brain, nerve tissues, muscles
Mycoplasmas: M. fermentans, M. pneumoniae, M. hominis, M. penetrans, M. pirum, M. incognito. in spinal fluids, blood, brain, nerve tissues, muscles
Chlamydia: Chlamydia pneumonia in spinal fluids, blood, brain, nerve tissues, muscles

Phase 2 Cellular toxicity due to xenobiotics

RnaseL (37 kDa RnaseL) by destroying messenger RNA and blocking protein synthesis disrupts the production of liver enzymes and leads to impaired Liver detoxification. This leads on to a build-up of toxicity in the body which forms Phase 2 of CFS. The body is poisoned both from metabolising food and from toxins within and outside the body. Mercury fillings in particular will worsen this toxicity, as it interferes with glutathione. This increased level of toxicity damages the brain, in particular the hypothalamus and sub cortex, leading to cognitive dysfunction, "brain fog" and constant exhaustion. The injury to the hypothalamus leads to a HPA axis dysfunction and a deficiency of key hormones - growth hormone, cortisol, female sex hormone, and anti-diuretic hormone. The damage to the sub cortex affects balance, thinking, memory and concentration. This toxicity is increased by infections due to a depleted immune system, the toxins produced by microbes worsen the patient's condition further. This toxic build-up can last from two years to ten years or more.

There is an abnormally high build-up of lactic acid in the cells of CFS patients. Scientists already know that if mitochondria can't function properly, pyruvate is converted to lactate acid and other organic acids. This explains the intracellular acidosis and extracellular alkalosis found in CFS. Alkaline blood in CFS inhibits oxygen transport to the mitochondria. Glutathione reduction in CFS induces an increase in citrate levels, which can inhibit 2,3 DPG. A deficiency of 2,3 DPG leads to a reduction of oxygen to the mitochondria.

The mitochondria dysfunction is a key factor in CFS as it leads to a serious depletion of energy throughout the entire body in CFS patients.

Phase 3 Dynamic injury phase

The build-up of toxicity in the body becomes cumulative over time, damaging the brain, mainly the subcortex and hypothalamus in the brain, the pituitary gland and adrenal gland, the immune system, muscles, cell functions, mitochondria & ATP production, and nervous system. This ongoing damage has a particularly devastating effect on CFS patients, causing severe fatigue. Thus patients remain in a state of sickness over many years. This toxicity leaves people highly susceptible to premature deaths from cancers, opportunistic infections and heart attacks.

These phases are a general guide. Some patients may have symptoms from two phases, though one phase will be dominant. Not all patients will share all of the same symptoms even if they are in the same phase of the illness. This may be due to genetic differences, different environmental and toxic exposures, different exposures to infectious agents, different diets and lifestyles, etc... The multiple dysfunctions and abnormalities involved in each CFS patient must be identified.

Article continued at <http://cfs-ireland.org/recovery.htm>

Therapeutic postures

Therapeutic yoga can help to eliminate the symptoms of CFS and restore wellbeing. It has two main effects on the body. First, it increases blood flow to the parts of the brain that control mental and emotional health, thus helping to tackle symptoms such as depression, sleep disturbances, lethargy, panic attacks and lack of concentration; it also activates the pituitary gland, which secretes feel-good chemicals called endorphins. And second, the postures combined with a focus on breathing increase the blood supply to the muscles (removing lactic acid and reducing muscle ache) and the various organs, improving physical wellbeing. Yoga is therefore a great regime for rehabilitating the body following CFS.



Complete Breath

Ujjayi Pranayama

Most people with CFS have developed poor breathing habits; as their bodies weaken, so do their breathing mechanisms. A deep breath often creates immediate dizziness as they do not have a normal level of oxygen in their bloodstreams. So, developing better breathing habits is very important in their course of treatment.

- 1

 Sit in a comfortable position (or lie down if you are new to yoga). Take a deep Ujjayi breath without force. Hold your breath for 5 seconds. Increase this gradually to 10 seconds.
- 2

 Raise your ribs and contract the pubis and anus to lift them upwards; this is known as an Anal Lock or Mula Bandha. You may now feel a little tension in your head. To counterbalance this, lower your chin to your sternum in a Chin Lock or Jalandhara Bandha, which should help to relieve the tension. Try to feel every inch of your lungs and skin filling up with air, keeping your face, neck and arms completely relaxed. Breathe out slowly, relaxing both locks. Resume normal breathing for a few seconds and then practise the Complete Breath again. Repeat 10 times, then lie down in the Corpse Pose (see pages 46–47).



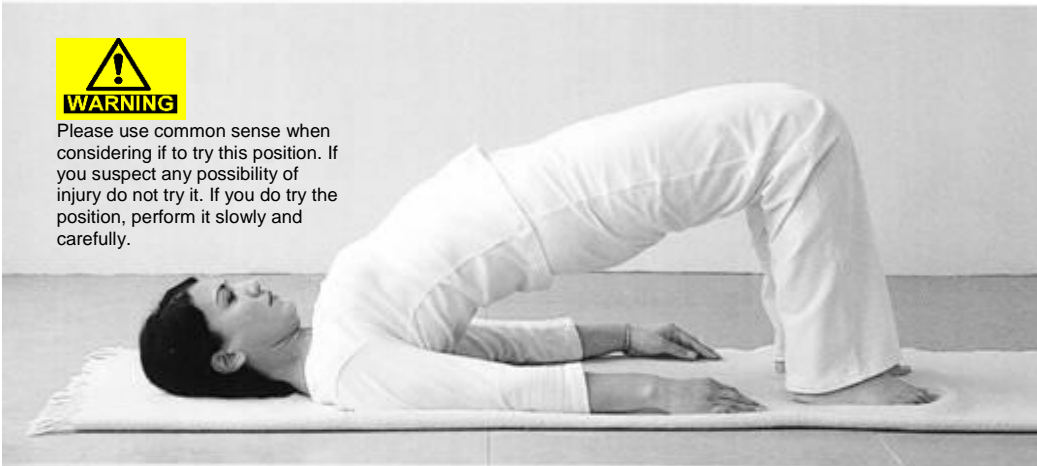
Embryo Pose III

Pavanmuktasana

- 1 Lie on your back. Breathe in and bring your right knee to your chest, pulling the knee towards you.
- 2 Breathe out and straighten your leg if possible; otherwise avoid this stage. Then breathe in and bring your knee to your chest again.
- 3 Breathe out and lower your foot to the floor, slowly keeping your mid-spine towards the ground as the leg is straightened. Repeat 5 times on each leg. Over time, repeat the same exercise with both knees to your chest.



WARNING
Please use common sense when considering if to try this position. If you suspect any possibility of injury do not try it. If you do try the position, perform it slowly and carefully.



The Bridge

Setubandhasana

- 1) Lie on your back with your arms by your sides, your knees bent and your ankles below your knees, hip-distance apart. Breathe in and peel your back off the floor until just your head, shoulders and feet are in contact with the floor. Keep stretching your neck while your back is lifted. Come down slowly on breathing out. Relax. Repeat 5 times.
- 2) Repeat step 1 but this time raise your arms up over your head, stretching your arms away from your shoulders.

Local Yoga for ME

The Guildford ME Group has become aware of two local Yoga courses for ME. One of them we have called “Eileen in Winnersh” the other “Carly in Merstham”.

Eileen in Winnersh

Interested in a remedial Yoga class, combining breathing, mainly floor work and meditation/relaxation. A small group of ME/FM people are enjoying this non-profit making class. To make the class more cost effective we would like to invite others with chronic illness who would like to join.

On Fridays 13.30 – 14.30, term-time recommencing September 26th

St Mary's Church Hall, Church Close, Winnersh

Please contact Eileen - 0118 9786480 eileenshoosmith@yahoo.co.uk

We have raised some funds and have a donation from The Ascot Round Table to subsidise it. Cost will be £2.50 session until funds are used up.



Random image from Internet

Dates this term Sept 26th Oct 3rd, 10th, 17th, 24th, H/T, Nov 7th, 14th, 21st, 28th Dec 5th, 12th

Bring padded/yoga mat, cushion and blanket for relaxation.

Carly in Merstham

Yoga class – extra gentle, suitable for people with CFS/ME

Canada Hall, Battlebridge Lane, Merstham Mondays 11am – 12pm

A warm and friendly yoga class suitable for people with CFS/ME. Or for those who just need a much more gentle and relaxing approach. The class will include simple asanas (postures), pranayama (breathing) and a lovely relaxation. Carly is an understanding teacher who has been trained to teach people with CFS/ME.

Starting 3rd November 2008

Please contact Carly to book and to discuss your needs.

Tel: 07804 613 132

Email: yoga@gingerpai.com

Website: www.gingerpai.com

Mats are provided but if you have your own please bring it. Wear comfortable clothing. It is best not to eat a heavy meal before yoga. A blanket for relaxation and a cushion would be useful to bring. Please arrive early to complete medical questionnaire. (If you have any concerns please call before you come and consult your GP.)



The benefits of Klonopin

Please note that Klonopin is a serious medication and must only be considered with a full appreciation of the risks involved and under appropriate medical supervision.

Article by Carol Sieverling, ImmuneSupport.com, 10-12-2001

Editor's Note: The following is based on an interview conducted by Carol Sieverling with Dr. Paul R. Cheney, M.D., Ph.D., and the article "CFIDS Treatment: The Cheney Clinic's Strategic Approach" (CFIDS Chronicle, Spring 1995). Dr. Cheney gave permission to share this information, but has not reviewed or edited it.



Many CFIDS specialists prescribe the drug Klonopin. In the October 1999 issue of The Fibromyalgia Network, nine CFS/FM specialists summarized their most effective treatments, and six included Klonopin. Interestingly, the three who did not are primarily FM specialists.

Dr. Cheney prescribes Klonopin to address a condition associated with CFIDS called "excitatory neurotoxicity." To explain this condition to patients, he draws a line with "seizure" on the far left and "coma" on the far right. A big dot in the middle represents where healthy people are when awake. A dot somewhat to the right of the middle indicates where healthy people are when asleep – slightly shifted toward coma. He highlights in red the left portion of the line, from seizure to the middle, and labels it "Neurotoxic State" (damaging to the brain). He highlights in blue the right portion of the line, from coma to the middle, and labels it "Healing State."

In CFIDS, an ongoing injury to the brain shifts patients toward seizure. A dot to the left of the middle, marked "injury," represents the position of CFIDS patients. This puts us in the red "Neurotoxic" zone. When we shift toward seizure, we often experience "sensory overload." It's as if our brain's "radar" is too sensitive. Our neurons (nerve cells) are sensing stimuli and firing when they should not. This causes amplification of sensory input. Light, noise, motion and pain are all magnified. At the beginning of their illness, many patients report feeling exhausted, yet also strangely "wired." The "wired" feeling is the slight shift towards seizure that occurs as a result of the excitatory neurotoxicity.

Cheney frequently uses the term "threshold potential" when discussing excitatory neurotoxicity. (Think of the threshold - bottom - of a doorway. The lower it is, the more accessible it is. When it is at floor level, everything can enter. When it is raised, access is restricted to taller people. If it is too high, no one can enter.) Threshold potential refers to how much stimulus it takes to make neurons fire. If the threshold potential is too low, even slight stimulation is "allowed to enter" and is detected by the neurons. This causes the neurons to fire, resulting in sensory overload. If the threshold is dropped to nothing, all stimuli get through and the neurons fire continuously, resulting in a seizure. If the threshold is raised, only stronger stimuli can make neurons fire. A healthy person's threshold potential naturally rises at bedtime, promoting sleep. If the threshold potential is too high, you feel drugged or drowsy. If the threshold potential is raised extremely high, coma results.

Two receptors in the brain, NMDA and GABA, determine the threshold potential. During the waking hours of a healthy person, NMDA and GABA should be equally active. This balances the person in the middle of the seizure/coma continuum. NMDA stimulates, and GABA inhibits. If NMDA increases, one moves toward seizure. If GABA increases, one moves toward coma.

In CFIDS, NMDA is more activated than GABA, lowering the threshold potential. This causes neurons to fire with very little stimulation, resulting in sensory overload. This condition of excitatory neurotoxicity is dangerous. Dr. Cheney emphasizes that in an attempt to protect itself, the body will eventually kill neurons that fire excessively. He states that brain cell loss can result if this condition isn't addressed.

How can the brain be protected against excitatory neurotoxicity? Klonopin. This long acting benzodiazepine has been Dr. Cheney's most effective drug for CFIDS over the years. He believes that Klonopin and the supplement magnesium may be two of the most important treatments for CFIDS patients because of their neuroprotective qualities. He recommends two or more 0.5 mg tablets of Klonopin at night.

Paradoxically, very small doses (usually a quarter to a half a tablet) in the morning and mid-afternoon improve cognitive function and energy. If the daytime dose is low enough, you'll experience greater clarity and think better. If the daytime dose is too high, you'll become drowsy. Adjust your dose for maximum benefit, taking as much as possible without drowsiness. Adjust the morning dose first, then take the same amount mid-afternoon if needed, then take three to four times the morning dose at bedtime. Dr. Cheney recommends doubling the dose during severe relapses.

Dr. Cheney most frequently prescribes the combination of Klonopin and Doxepin, along with the supplement "Magnesium Glycinate Forte." Magnesium Glycinate alone is a good choice for the more budget minded(www.ImmuneSupport.com sells it as "Magnesium Plus".) A common dosage of magnesium is 200 mgs at bedtime. Too much magnesium can cause diarrhoea, though glycinate is usually the best tolerated form.

Cheney prescribes Doxepin in the form of a commercial elixir (10mg/ml). At low doses, this tricyclic antidepressant acts as a very potent antihistamine and immune modulator. Doxepin acts synergistically with Klonopin to assist sleep, and may improve pain. Patients tend to be very sensitive to Doxepin, which can cause morning fog and fatigue if the dose is too high (5 to 10 mg or higher). He recommends starting at two drops a night and gradually increasing the dose until "morning fog" becomes a problem. Most patients can't tolerate more than half a cc.

On a handout entitled "Neuroprotection via Threshold Potentials," Cheney lists six substances that can protect the brain. Under the category "NMDA Blockers" Cheney lists:

1. Parenteral magnesium and taurine (intramuscular injections of magnesium and taurine, usually given with procaine) 2. Histamine blockers (Doxepin Elixir) Under the category "GABA Agonists" (increases GABA) Cheney lists: 3. Klonopin 4. Neurontin 5. Kava Kava 6. Valerian Root

Klonopin is taken "day and night"; Neurontin "night, or day and night"; kava kava "daytime only"; and valerian "nighttime only." The first four are by prescription, the last two are herbs. In my limited experience, only certain patients are put on magnesium/taurine injections, and then only for a limited period before switching to oral supplements.

Many myths abound concerning Klonopin. When asked about these myths, Dr. Cheney shared the following information.

Myth 1: The generic is just as good

When the generic Clonazepam came on the market, many patients switched to it because it was less expensive than Klonopin. Cheney then began hearing that most patients had to take more Clonazepam to get the same effect. Generics aren't exactly identical to the original products, and with most drugs the slight variations don't matter. However, most CFIDS patients can tell the difference between Klonopin and its generic form, Clonazepam. Most find Klonopin to be more effective.

Myth 2: Klonopin is addictive

Dr. Cheney was adamant that Klonopin is not addictive. In treating thousands of patients, he has never seen a patient become addicted to Klonopin. He reviewed the definition of addiction, stating that it involves: (1) psychosocial disruption, (2) accelerated use, (3) inappropriate use, and (4) drug seeking behaviour.

Dr. Cheney said a case might be made that Klonopin is habituating. It's true that it can't be stopped suddenly. You must taper off of it gradually. However, he was cautious about even calling it habituating. The process of tapering off a drug is not the same thing as withdrawal, a term that implies addiction.

Dr. Cheney said to keep in mind that Klonopin is given for a physiological problem – excitatory neurotoxicity. It's prescribed to adjust the threshold potential: to keep neurons from firing inappropriately and being destroyed. He stressed that Klonopin should never be given unless you intend to raise the threshold potential. He stated, "Problems arise when you begin to use benzodiazapines for reasons other than threshold manipulation." However, CFIDS patients have a "threshold potential aberration" and need Klonopin (or something similar) to avoid brain injury. Dr. Cheney has never seen a recovered patient have difficulty coming off Klonopin. He stated, "When you no longer need the drug, coming off it is very easy."

On the other hand, trouble arises when someone who still has an injured brain tries to come off Klonopin. It's like a thyroid patient stopping their thyroid medication. Dr. Cheney warned, "All hell breaks loose". However, it's not because the drug is addicting, and it's not withdrawal. The condition still exists, and the body lets you know it has a legitimate physical need for the drug. Cheney stated, "When a CFIDS patient who is still experiencing the underlying mechanisms of brain injury goes off Klonopin, there is a burst of excess neural firing and cell death. That's the havoc we hear about that is mistakenly called withdrawal."

Myth 3: Klonopin disrupts stage 4 sleep

Dr. Cheney said that he honestly doesn't understand this concern. He believes Klonopin might disrupt the sleep of people who take it for conditions other than the threshold potential aberration found in CFIDS. He also acknowledged that if you are looking just for drugs to facilitate sleep, Klonopin is certainly not the first one to come to mind, nor should it be used to induce sleep in "ordinary" patients. It's not a sleep drug per se. However, a large part of the sleep disorder of CFIDS is excitatory neurotoxicity and the resulting shift toward seizure. If you treat this condition with Klonopin, then you have treated a large part of the sleep disorder in CFIDS. Most importantly, he said he simply does not see stage 4 sleep disruption in his patients on Klonopin.

Towards the end of this discussion on Klonopin, Cheney smiled, and remarked, "But suppose I'm wrong about the brain injury and the threshold potential aberration and the shift toward seizure? What if I'm wrong about your need for Klonopin? I'm absolutely sure I'm right, but what's the worst case scenario? Do you know what long-term studies on Klonopin have shown? Reduced incidence of Alzheimer's Disease. Alzheimer's Disease is a complicated and convoluted way of knocking out your neurons, and Klonopin protects your neurons. Now it's believed that Klonopin didn't actually stop Alzheimer's. It just delayed its onset so long that everyone died of something else before they ever got it - which is to say you won't get Alzheimer's. You'll die of something else first."

The last question Cheney addressed concerned the dose: what happens if the dose is too high? He said the only down side was that if you took a little too much (we are not talking overdose here) it would shift you toward coma on the continuum. It would shut your brain down to some degree, and thus impact your ability to function. This is inconvenient, but it's not harmful. In fact, it shifts you into the "healing state" on the continuum. You may feel like a zombie, but your brain is protected and your neurons are not getting fried. However, not being able to function isn't an option for most of us, so we need to find the maximum dose that doesn't make us drowsy.

Dr. Cheney emphasized that Klonopin, Doxepin, and magnesium are very, very good at protecting the brain from cell death due to excess firing. However, they can't stop the underlying mechanisms of CFIDS that are injuring the brain in the first place.

Though it can't stop the underlying mechanisms causing the injury, Klonopin can protect your brain and keep your neurons from being destroyed. Then, as Cheney put it, "When you come out on the other side of this, you'll have more of your brain left."

Surge of chi exerciser



Having experienced a year of improved ability on the day following each of my Perrin treatment sessions, I believe that manual drainage of the lymph system can help ME/CFS sufferers. I learned from a group member that the 'surge of chi exerciser' could be used at home regularly as a form of manual lymph drainage.

Within 20 minutes of using the exerciser for the first time I was deeply asleep for 15 hours. In the 4 years of having ME I had not experienced a deep sleep, only excessive dreaming. I am now a number of weeks into using the exerciser and getting to sleep has continued to be easy for the first time in years and the sleep is of a far better quality. While this is a different benefit to that experienced from the Perrin treatment I am hopeful that my better quality sleep and continued use of the exerciser will deliver further benefits.

The exerciser is available from Amazon for £198.25 where an ME sufferer has provided a positive review. A possible explanation for the sleep improvement could be from the following listed benefit of the exerciser...

"If the parasympathetic and sympathetic nervous systems fail to ensure balance of function, insomnia, excessive dreaming, digestive problems, stomach pain, palpitation, anxiety, constipation, neurasthenia and extensive forms of aches and pains as well as mental stress may surface. The influence of the exerciser on the sympathetic nervous system can restore the vital balance to the nervous system, resulting in restoration of health from such conditions".

Written by the Newsletter Editor – Neil Perrett

Chi Machines provide a form of passive exercise that allows all ages to enjoy a stimulating workout in the comfort of home. They originated in Japan 15 years ago - where they emerged from the understanding within shiatsu and elsewhere about the value of swinging the feet to create a harmonic response through the torso. Often referred to in the West as 'Chi Machines' - after the original Japanese model found its way to the West under this trade-marked product name – they have a long history, and many fans.

Rhythmic movement

The rhythmic movement generated by the Chi Machine acts to both release tension in the back and shoulders, and to stimulate respiration and the nervous system, giving a distinct boost of chi energy - while the user lies down and focuses on letting go to the motion and completely relaxing..!



Based on a tried and tested model

The Japanese realised that benefits of Chi Machines occurred at many levels. The concept was recognised as a remedial medical device by the Ministry of Health & Welfare in 1990, and with their health-conscious and busy lifestyles, the Japanese quickly became enthusiasts. This newly found way of exercising became known in Japan as kingyo undo - or 'goldfish exercise' - and its popularity then spread to the Chinese, who realised the strong connection with 'chi' energy.

Second generation of Chi Machines

A second generation of Chi Machines was developed for Western physiques about 5 years ago, as the US market demanded more robust and sophisticated products. These new products adopted a heavy-duty DC motor for a smoother ride, a longer life and the capacity for better control, based on adjusting the speed of oscillation.

The Surge of Chi Exerciser is based on a tried and tested model that had become the top selling model in the US, with electronic programming that allows the user to adjust running speed during use, and converted for use with European voltages. The ability to control speed not only allows each user to find a speed that resonates with their own body, but opens up use to a much larger audience - including many with conditions that would prevent them using the high fixed speeds of first-generation products, yet who have benefited greatly from receiving the stimulating and relaxing exercise provided by regular use. What is 'Chi'?

'Chi' (also spelt 'Qi') is the Chinese word for 'life force energy', and is known as 'Ki' in Japanese. It is the subtle energy which can be considered to be the fundamental fuel for all life. The Chinese and Japanese have recognised the central importance of Chi in mediating all the processes of life for thousands of years. Traditional Chinese medicine is based on the key understanding that in a healthy body this subtle yet powerful energy is being channelled to all the organs of the body on a regular cycle - and that any blockage of this flow will inevitably result in ill health and other disabilities.

Many traditional approaches to supporting good health in Asia - including the age-old medical systems of China, Japan, Thailand and India - emphasise that balance is best maintained within the body through encouraging the flow of this vital energy throughout the body. These approaches recognise the wisdom in nature's design, and seek to bring back the healthy balance that children enjoy.

The body has a marvellous inbuilt capability for self-correcting action, but this can become blocked through habitual abuse - poor posture, poor diet, inadequate sleep and rest, and excessive stress can all lead to failure of the body's natural self-regulatory mechanisms.

Many of the therapies we now enjoy in the West - such as acupuncture, reflexology, shiatsu and the other wonderfully invigorating forms of Asian massage - share this basic understanding of the need to keep energy moving, and the inherent capacity of the body's systems to keep functioning efficiently when given adequate exercise and other forms of stimulation. Traditional Chinese Medicine aims to ensure the smooth flow of chi through the body's meridians. This approach is based on the belief that illness is generally caused by an imbalance of chi - 'tai chi, for example, is practised daily by millions of Chinese - more as a form of preventive healthcare than as a martial art.

How the Surge of Chi Exerciser works

The Surge of Chi® Exerciser is placed on a firm flat surface, normally the floor. Use of a mat or rug, such as a yoga mat or comfortable rug, is recommended, though a clean carpeted surface is fine too. The user simply lies down and places their ankles on the cushioned footrest, which swings from side to side after the motor is turned on. This rhythmic motion creates a 'figure of eight' movement up and down the spine. The sideways movement of the footrest has a slightly elliptical trajectory, which provides a gentle twisting of the hips and spine.



This wave-like movement up and down the back replicates the spinal movement of fish and other animals as they move around. The gentle massage of internal organs, musculature and body tissue provided by this motion has many effects including deeper respiration, stimulation of the nervous system, and improved circulation of the blood and lymph systems.

The Surge of Chi Exerciser also stimulates the flow of 'chi' throughout the body, and most people feel this as a tingling sensation in their limbs and torso, coupled with a heightened sense of well being, from their very first use of the Exerciser.

Is it good for back problems?

One of the great potential benefits is the release of tension in the back, shoulders and neck. This is especially helpful if you use the Exerciser regularly, as it will help to relieve the build-up of tension that often accompanies continuous bad posture or other possible causes for back problems. However, it should not be used as a substitute for the many excellent therapies which professional practitioners make available. In particular, you should not use the Surge of Chi Exerciser immediately after you have suffered a back injury. There are many practitioners able to assess your back problem comprehensively. They are best qualified to work on injuries and persistent conditions that need special attention.

What is 'passive exercise'?

The Surge of Chi Exerciser provides a direct form of exercise that we call 'passive' because the user is lying down in a completely relaxed state. They are not expending any energy in giving the body the exercise it needs. The exercise happens in a very balanced way, as the body responds naturally to the movement of the feet from side to side. More importantly, the main impact of this exercise is the rhythmic flexing of the back, shoulders and neck. Most adults in today's society rarely enjoy this type of exercise in their everyday lifestyles, even if they manage a workout in the gym, go jogging or play sports.

Some might think that the old maxim 'no pain, no gain' should apply when it comes to getting exercise. But the body's need for exercise goes beyond philosophy. Nature based its health maintenance design on the stimulation that happens when all the different parts of the body are exercised. The exercise benefits of the Surge of Chi Exerciser are focused on the torso, rather than the arms and legs - flexing of the torso or trunk of the body stimulates all the major organs and nervous system.

Of course we do not claim that use of the Surge of Chi Exerciser can simulate all the different types of exercise that can be enjoyed in sports or the gym. Nor can it substitute for the more targeted stimulation given by professional therapists. There are many well-qualified practitioners who are able to assess your health condition comprehensively, and to work on areas that need special attention. We strongly recommend that you seek advice from your Doctor or therapist if you are suffering from a recurring or chronic physical condition.