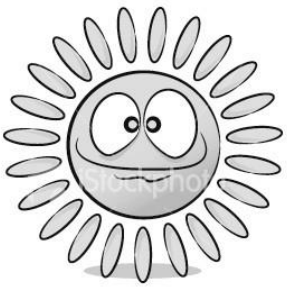
Guildford M.E. Support Group

Newsletter

Summer 2007



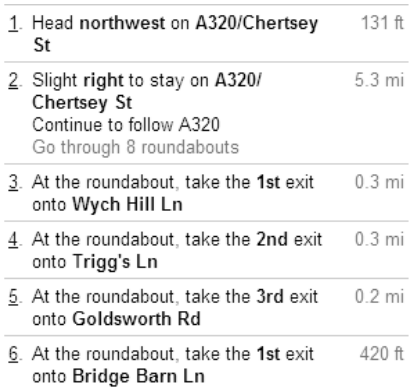
Future events

Afternoon meet

Wednesday 25th July (6pm onwards)

The Bridge Barn, Bridge Barn Lane, Woking, Surrey, GU21 1NL

Both sufferers and carers are welcome.



1.	Head **northwest** on **A320/Chertsey St**	131 ft
2.	Slight **right** to stay on **A320/ Chertsey St** Continue to follow A320 Go through 8 roundabouts	5.3 mi
3.	At the roundabout, take the **1st** exit onto **Wych Hill Ln**	0.3 mi
4.	At the roundabout, take the **2nd** exit onto **Trigg's Ln**	0.3 mi
5.	At the roundabout, take the **3rd** exit onto **Goldsworth Rd**	0.2 mi
6.	At the roundabout, take the **1st** exit onto **Bridge Barn Ln**	420 ft

Due to a combination of building work, weather and low participation, it was reluctantly decided to cancel the pool party that was intended for the 22nd June. We are, however, going to try to make it happen one last time this summer, as detailed below.

Pool Party and Picnic – Friday 31st August (12pm-onwards)

Alison Wallis' house, 22 Scotlands Close, Haslemere

The group will be providing both food and soft drink for the pool party and, as such would appreciate an indication of numbers in advance. Could you please phone Alison on 01428 654216 or email her at: alison@kiamara.freeserve.co.uk to confirm your intention to attend in advance of 20th June. Directions have kindly been provided by Alison below.

Take the A3 from London. Either take the turning for Haslemere at Milford, following signs for Haslemere (A286) or stay on the A3 until the next turning, signposted Brook – a small cut through to the A286 at the bottom of a hill – if you go this way go along this road for about half a mile until you come to crossroads and then turn right on to the A286 - this is the best way. It is best not to carry on the A3 to the Hindhead crossroads as there is congestion there at the moment as roadworks have started for the tunnel.

When you enter Haslemere, go up the High Street, turn right after the town hall and left up Shepherds Hill signposted Midhurst A286. Go up and down the hill the other side and at the bottom of the hill turn left into Scotland Lane and take the second right into Scotlands Close. No 22 is at the top of Scotlands.

Coffee morning – Friday 28th September (3pm onwards)

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. We will display a sign so that you can find us easily.

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.

10 DOWNING STREET

E-petition

Downing Street is providing a service to allow citizens, charities and campaign groups to set up online petitions that are hosted on the Downing Street website, enabling anyone to address and deliver a petition directly to the Prime Minister.

The following bold text is a petition (submitted by Konstanze Allsopp) relating to ME/CFS that has been signed by over 5,600 people to date.

We the undersigned petition the Prime Minister to get the Health Service and medical profession to accept the WHO classification of ME/CFS as an organic neurological disorder and not as a psychosocial syndrome.

To sign the petition go to the following website address:
http://petitions.pm.gov.uk/ME-is-real/

GP information packs

We have recently completed an ME/CFS information pack for GPs in Guildford and the surrounding areas. The pack will provide doctors with information on the Guildford M.E. Support Group, Woking CFS Clinic, Action for ME, ME association and guidance on the diagnosis and management of this illness.

Please use the form below if you would like to contact Cathy by post. Many thanks.

Name and address ……

…….....

…….....

Name of GP……..……

No. of packs required …….

Surgery …….....

It worked for Me

For our "It worked for me" section a new member, Jeannie Kent, has kindly written an overview of her son's health improvement through use of VegEPA and osteopathic treatment. In conjunction, James Kent, Jeannie's son has written with details of a local osteopath familiar with ME.

I joined your support group because I felt so alone watching my son suffering so much for over two years. I felt better knowing that others knew how I and of course he felt.

Your first newsletter arrived with the article about the Perrin treatment and a supplement. My son's wife and I nagged him to try these; his scepticism has stopped him so many times. This time though he had heard from another young man who had recovered from M.E. after weeks of the Perrin treatment. Eight weeks ago he began weekly osteopathic treatments and is taking the supplements daily. At first he felt well for the odd day, only to relapse into the same state as before. Then after three weeks he felt better for two days. Although his head said I feel well his body is so weak he was still unable to do much.

The fourth week he was feeling dreadful all week and we all began losing hope.
Now this week after eight treatments, he has felt so much better for so much longer. He has come out of his house and walked upright. He thought he must have grown in the last two years but he has been so bent over he has forgotten how tall he was.

This week I feel I have my son back as he was before this awful illness struck. He actually looks well. He is taking part in conversations again, something he had stopped doing because he stopped understanding. Even if it means paying for this treatment forever, it will be worth every penny. I am so grateful that I joined this support group, I would not have heard of the Perrin treatment without it. I know it is very early days for us all but the difference is truly amazing. Please add this to your next newsletter.

I keep meaning to log into the chat room, but miss the time slot each day. I cannot really put into words how I feel today. I want all the people who suffer so very much to know and I hope every one of them finds the right cure for them, as I am aware not all things help all people.

Thank you all, Jeannie Kent.

The following has been written by James, Jeannie's son.
Hi, My mother, Jeannie Kent, contacted you recently with my story of dramatic improvement after trying osteopathic treatment over recent weeks. I have gone from not being able to look after myself to being energised, relatively pain free, improved sleep and increased strength and mobility.

I wanted to send you some details as I know there are many sufferers in the area. I was treated at the Addlestone Therapy Centre by osteopath, Raj Bahbra. I have known Raj for many years from playing cricket with him (pre-illness) and he treats me with a tailor made osteopathic approach. He is pleased with the success and is considering getting officially accredited by Perrin but as yet is not.

His sessions are currently charged at £35 - with a 1 hour introductory session then weekly half hour sessions. I hope this is helpful and if you have any questions please feel free to contact me or Raj through the following website: http://www.addlestonetherapycentre.co.uk/

Thanks, James Kent

As a reminder of our Perrin article included on page 6 of our Winter 2006 Newsletter contact details for our local Perrin certified practitioner are:
The Southsea Centre for Complementary Medicine
Laurent Heib DO, 25 Osborne Rd, Southsea, Portsmouth, PO5 3LR Tel: 023 9287 4748
E-mail: sphenoid1000@yahoo.com

The Point of Health
Mr Laurent Heib D.O., 106 Winchester Road, Chandlers Ford, Eastleigh, Hampshire, SO53 2GJ
Tel: 023 80269809

The NO/ONOO cycle disease paradigm

The following three pages have been provided for those interested in the on-going scientific research in to ME/CFS. The NO/ONOO cycle disease paradigm is by Prof Martin Pall, who recently (May 07) lectured at the ME conference in Westminster. Prof Martin Pall works at the School of Molecular Biosciences, Washington State University, with a Ph.D. in Biochemistry & Genetics from California Institute of Technology.

Overview

Dr. Pall has long-term interests in biological regulatory mechanisms. His current research is focused on a theory he has developed on the cause (etiology) of chronic fatigue syndrome and the overlapping and related conditions of multiple chemical sensitivity, fibromyalgia, and post traumatic stress disorder. According to this theory, each of these is initiated by stresses that induce increased levels of nitric oxide and its oxidant product peroxynitrite, followed by a biochemical vicious cycle mechanism associated with chronic elevation of these two compounds and several other important parameters, known as the NO/ONOO- cycle.

Symptoms of these conditions are produced by both nitric oxide and peroxynitrite and treatment should focus on down-regulating this NO/ONOO- cycle mechanism. Vitamin B-12 injections, commonly used to treat these conditions, are proposed to act through the action of one form of B-12 (hydroxocobalamin) which is a potent nitric oxide scavenger. Dozens of biochemical and physiological observations provide support for this theory. The most puzzling features of these conditions are explained by this novel theory. Other diseases are also candidates for inclusion under the NO/ONOO- cycle paradigm.

In-depth

Chronic fatigue syndrome (CFS) was the first of these multi-system illnesses to be proposed to be caused by a vicious cycle that has recently been named the NO/ONOO- (no, oh no!) cycle and is still one where an increasingly strong case for this etiology can be made.

CFS appears to have the largest group of initiating short-term stressors where each may be expected to act to increase nitric oxide levels. Most of these are documented in a recent review and these and three others are documented in my book and elsewhere. The initiating stressors implicated in CFS cases are as follows:

- Viral infections
- Bacterial infections
- A protozoan infection, toxoplasmosis
- Carbon monoxide exposure
- Physical trauma
- Organophosphorus poisoning
- Severe psychological stress
- Ciguatoxin poisoning
- Ionizing radiation exposure

While the first two of these are implicated most commonly in the initiation of CFS cases, we need explanations for the apparent roles of all nine. The fact that all nine can initiate a sequence of events that leads to increased nitric oxide synthesis must be considered to be a striking coincidence that provides a key clue to CFS etiology. Indeed the genetic evidence implicating corticosteroid-binding globulin gene and the serotonin transporter gene in determining susceptibility to CFS also provides support for a nitric oxide role in CFS initiation because both of these genes can act to determine cortisol function and cortisol is known to lower the induction of the inducible nitric oxide synthase (iNOS) and therefore partially determine levels of nitric oxide.

Of the nine stressors listed above, the first three act primarily by inducing iNOS, as does stressor 9. Most of the others act, at least in part, by increasing NMDA activity which acts, in turn, through the other two nitric oxide synthases, nNOS and possibly eNOS .

Thus the common feature is the increase in nitric oxide, not the specific form or forms of nitric oxide synthase involved.

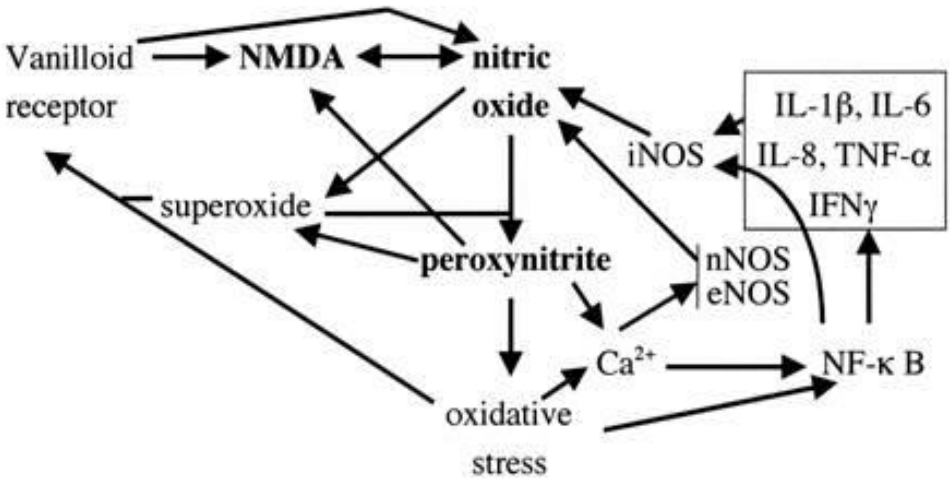
The connection between each of the first six and nitric oxide is very clear. I'd like to discuss the last three. Number 7, severe psychological stress has been mainly linked to nitric oxide synthesis through animal models of post traumatic stress disorder, where it has been shown to increase NMDA activity and consequently levels of nitric oxide.

Ciguatoxin exposure is known to greatly delay closing of certain sodium channels and this is known, in turn to be able to stimulate NMDA activity. The role of ciguatoxin in increasing nitric oxide levels is inferred, therefore, from the known role of NMDA receptors activity in increasing nitric oxide and its oxidant product peroxynitrite.

Ionizing radiation initiates cases of postradiation syndrome, a CFS-like illness. Ionizing radiation is known to act to stimulate the transcription factor NF- k B, leading in turn to increased iNOS activity and consequent nitric oxide.

It can be seen, from the above, that the pattern of evidence implicating elevated nitric oxide synthesis activity in the initiation of CFS cases is quite striking. How can nitric oxide act to initiate these illnesses? By acting mainly through its oxidant product peroxynitrite to initiate the vicious cycle mechanism, the NO/ONOO- cycle, that is responsible for chronic illness. The NO/ONOO- cycle mechanism is presented below in Fig. 1.

Figure 1



Vicious (NO/ONOO-) cycle diagram. Each arrow represents one or more mechanisms by which the variable at the foot of the arrow can stimulate the level of the variable at the head of the arrow. It can be seen that these arrows form a series of loops that can potentially continue to stimulate each other. An example of this would be that nitric oxide can increase peroxynitrite which can stimulate oxidative stress which can stimulate NF- k B which can increase the production of iNOS which can, in turn increase nitric oxide. This loop alone constitutes a potential vicious cycle and there are a number of other loops, diagrammed in the figure that can collectively make up a much larger vicious cycle. The challenge, according to this view, in these illnesses is to lower this whole pattern of elevations to get back into a normal range. You will note that the cycle not only includes the compounds nitric oxide, superoxide and peroxynitrite but a series of other elements, including the transcription factor NF- k B, oxidative stress, five inflammatory cytokines (in box, upper right), all three different forms of nitric oxide synthases (iNOS, nNOS and eNOS), and two neurological receptors the vanilloid receptor and the NMDA receptor.

Some of the specific CFS evidence is as follows:

1. Oxidative stress has been reported in 13 studies of CFS, published by seven research groups on four continents. Such oxidative stress is also supported by reports of glutathione depletion and cyst(e)ine depletion in CFS and by reported depletion of essential fatty acids in CFS. Oxidative stress is expected to lead to both glutathione/cysteine depletion and essential fatty acid depletion as I proposed earlier. Thus oxidative stress is probably the best documented change in CFS. Having said that, it is not a specific response to CFS! Many inflammatory diseases will lead to elevation of markers of oxidative stress and in addition, many cases of CFS (presumably among the more modestly effected) fall into the "normal" range of these markers. The same pattern occurs with many other changes that are reported in CFS, where on average there are statistically significant changes but many individual CFS cases fall well within the normal range.

2. Mitochondrial/energy metabolism dysfunction is part of the NO/ONOO- cycle mechanism because peroxynitrite attacks a number of components of mitochondria, and nitric oxide and superoxide also inhibit certain mitochondrial functions. 18 different studies provide evidence for mitochondrial and/or energy metabolism dysfunction in CFS. This again provides extensive evidence supporting NO/ONOO- cycle biochemistry in CFS. Among these are studies showing that agents predicted to improve mitochondrial function such as carnitine/acetyl carnitine, coenzyme Q10 and lipids designed to help regenerate the mitochondrial inner membrane are all helpful in the treatment of CFS. These provide evidence that not only is there mitochondrial dysfunction but that it contributes to the CFS pathophysiology.

3. Two studies report increased nitric oxide levels. In addition, studies of neopterin levels, a marker of high level iNOS induction reported statistically significant elevation in three of five studies of CFS, suggesting that iNOS induction contributes to the nitric oxide elevation. The hydroxocobalamin form of vitamin B 12, a potent nitric oxide scavenger was reported to produce statistically significant improvements of CFS-like patients in a placebo-controlled trial (20). Hydroxocobalamin has been used clinically to treat CFS-like illnesses for over 60 years, being used in at least 9 countries on three continents, mainly by IM injection. Patients report rapid improvement of their entire spectrum of symptoms in response of hydroxocobalamin injection. The pattern of apparent efficacy suggests that not only is nitric oxide elevated in CFS, but that it contributes in a major way to its etiology.

4. There are 10 studies that report that one or more of the inflammatory cytokines in the right, upper corner of Fig. 1 are elevated in CFS. These elevations are relatively modest suggesting that they contribute to but do not dominate the CFS etiology.

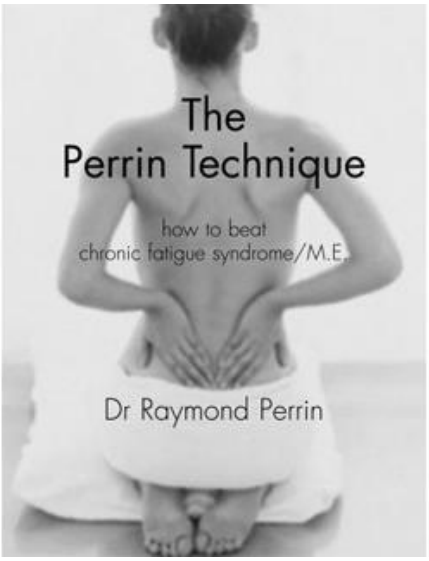
5. Two physicians and one research group report clinical observations supporting an elevation of NMDA activity in CFS, again supporting the NO/ONOO- cycle etiology.

While these are the main observations supporting a NO/ONOO- cycle etiology, there are some additional clinical observations from therapies that may also suggest elevation of cycle components. For example, some physicians have used agents known to lower NF- k B activity as part of their CFS treatment protocols and others have used the drug guaifenesin, a drug reported to lower capsaicin responses and therefore vanilloid receptor action. The drug thiacetarsamide was reported by Tarello to produce great improvement animal models of CFS and has been found by me to scavenge both nitric oxide and peroxynitrite. These studies suggest but do not prove both elevation of NO/ONOO- cycle elements and also suggest that lowering those elements produces improvement and that they may contribute, therefore, to the etiology of CFS.

For further information

http://molecular.biosciences.wsu.edu/Faculty/pall/pall_cfs.htm

On-demand Perrin Lecture



In our winter newsletter, on page 6, we provided information on The Perrin Technique. In our spring newsletter, we heard from Mair Ellis about her success with the treatment. Now in our 'it worked for me section' we hear another success story from Jeannie and James Kent.

As part of our ongoing coverage of The Perrin Technique we are now proposing to host a lecture given by Dr. Perrin himself. However, before we can justify the expense of making this happen we need to hear from you, our readers, if you would like to attend such a lecture. We won't be able to make the arrangements unless we hear from you.

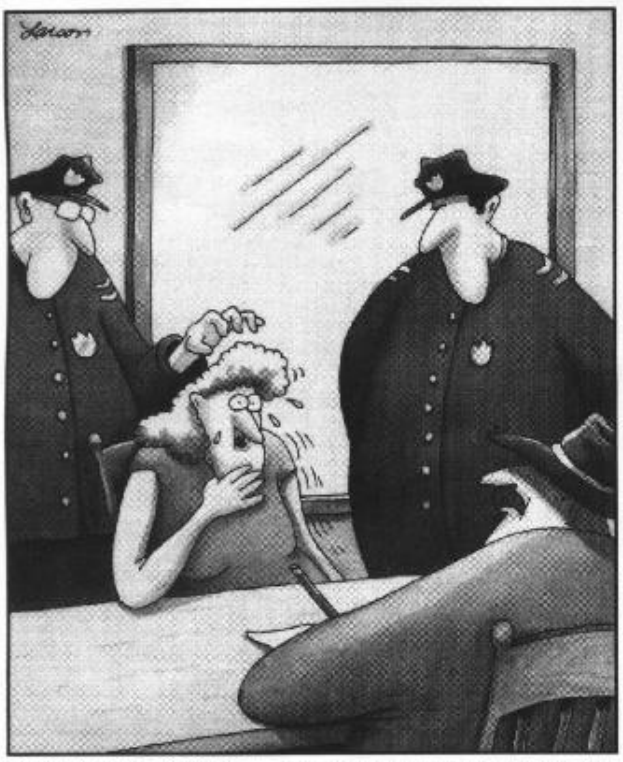
If you would like to attend the evening lecture please tell us by phone or email using the following contact details:

Tel: 01428 654216 Email: alison@kiamara.freeserve.co.uk

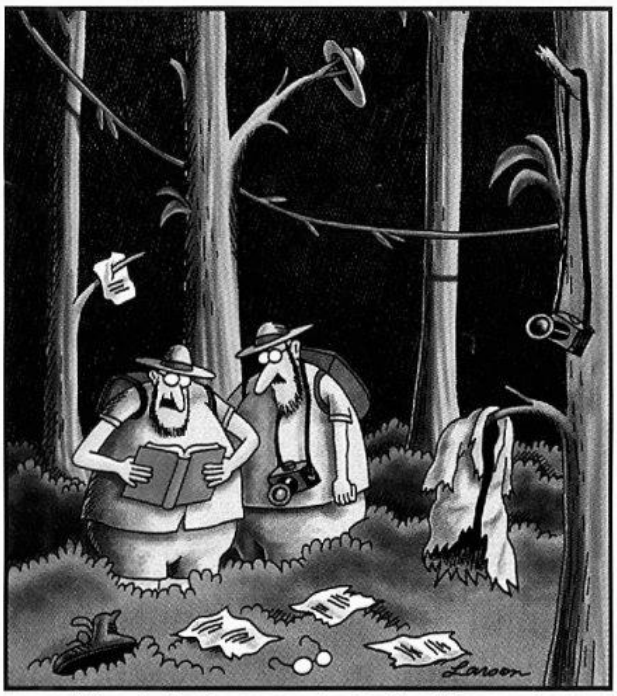
The book

Dr Perrin's book: 'The Perrin Technique' published by Hammersmith Press, is now available in bookshops. RRP £14.99. Recommended for all sufferers and any practitioner interested in finding out more about the technique.

Some humour



"Try to relax, ma'am. . . . You say it was dark, you were alone in the house, when suddenly you felt a hand reaching from behind and . . . *Johnson*! Knock it off!"



"Here's the last entry in Carlson's journal: Having won their confidence, tomorrow I shall test the humor of these giant but gentle primates with a simple joy-buzzer handshake."

Daily Mail article on The Perrin Technique

By Barbara Lantin - Last updated at 08:47am on 10th July 2007

At school, Lizzie Jolley was envied by her classmates for her energy and sporting success. Picked for most sports teams every year, she swam, played netball, hockey and tennis and gained a Duke of Edinburgh gold award.

At university, she added diving and sailing to her list of accomplishments. But within 18 months of graduating in 2001, she was so ill that there were days when she could barely struggle out of bed. Walking was difficult and serious exercise impossible.

"I would wake up feeling really groggy - as if somebody had hit me over the head with a baseball bat - and very depressed, which was really unlike me as I have always been a happy person,' says Lizzie, now 28.

"I knew something was seriously wrong but I had no idea what it was."

Lizzie's GP arranged for her to have some blood tests. When these came back clear, he diagnosed ME by process of elimination, as there is no definitive test for the condition. The symptoms persisted and Lizzie remembers Christmas 2002, one month after her diagnosis, as a low point.

"I could not exercise, go out with my friends or even enjoy a drink without throwing up. I thought this illness would be with me for life."

But by March the following year, Lizzie was on the road to recovery, thanks - she believes - to a technique devised by Manchester osteopath Raymond Perrin.

Perrin - who is not a medical doctor but gained a PhD for his work on ME - believes that the condition is caused by the body's inability to rid itself of harmful organisms and chemicals, including bacteria, viruses and environmental pollutants. He claims that his massage techniques stimulate the lymphatic system - the network of vessels that carry infection fighting cells round the body and remove foreign bodies - to drain these toxins away.

In one trial, published in the Journal of Medical Engineering And Technology in 1998, the symptoms of 33 patients treated by Perrin improved on average by 40 per cent, while the untreated group deteriorated by an average of 1 per cent.

In a second - unpublished - trial that specifically investigated muscle strength, ME patients who had a year's treatment regained far more strength than those left untreated.

Despite these trials, Perrin's approach remains controversial. It is not accepted by the medical profession and there has been no robust independent research showing that the lymphatic system is involved in ME. His book describing the technique was published last month.

ME - also known as chronic fatigue syndrome - is a debilitating illness that affects up to 250,000 people in the UK, around 55,000 of them so badly that they are housebound. Once labelled 'yuppie flu' and believed to have a psychological cause, it is now more widely recognised as a chronic physical illness, but what lies behind it is still unclear.

A number of possible causes are under investigation. Neil Abbott, director of operations at ME Research UK, says that ME may not even be one syndrome, but instead a collection of symptoms with different causes.

Conventional treatments, including cognitive behavioural therapy (CBT), exercise therapy, painkillers and antidepressants bring relief to some, but others find that they make little difference and turn instead to some of the huge range of complementary therapies apparently offering a promise of improvement.

For of these, including the Lightning Process described in Good Health earlier this year, there is very little scientific evidence.

Lizzie Jolley's doctor prescribed sleeping tablets to improve the quality of her sleep and CBT, both of which helped a little. In February 2003, Lizzie's mother was told about Raymond Perrin by a neighbour whose teenage daughter he had successfully treated for ME. After examining Lizzie, he confirmed the diagnosis.

According to Perrin, ME occurs when the body's nervous system is put under stress, causing the lymphatic system, which it controls, to work less efficiently. The stress may be caused by a physical problem, such as back strain or trauma; by environmental factors such as pollution or by an emotional upset such as a bereavement. In Lizzie's case, he thought that whiplash after a car accident while she was in New Zealand may have been a contributory factor.

Because the drainage pathways of the lymphatic system do not work properly, toxins - including bacteria, viruses, atmospheric pollutants such as cigarette smoke and petrol and waste products from food - build up. One final trigger, usually an infection, increases the toxic overload and tips the patient into the condition known as ME.

On Lizzie's first visit to his clinic in Manchester, Perrin gently massaged her back, neck, armpits and head.

"I remember when he held my skull he was so still that my mum thought he'd gone to sleep. It was as if he was in a trance. I slept the entire way back to Nottingham in the car and then all that night and the following day - about 20 hours, the best sleep I'd had in ages."

After a few weeks, Lizzie began to feel significantly better. First her eyesight began to return to normal, then her concentration improved, the muscles in her legs ached less and her exhaustion subsided.

In May, Lizzie ran a half marathon and this month she is attempting the gruelling Three Peaks Challenge, climbing the three highest mountains on mainland Britain in 24 hours.

"Without a doubt, I have now made a full recovery and I know that I could not have done it without the Perrin Technique," she says.

The Perrin Technique does not work for everybody, cautions Dr Charles Shepherd, medical advisor to the ME Association, who is sceptical about the approach.

"This is just one person's hypothesis and I am not convinced that the theory behind it is scientifically sound," he says.

"The trials that have been done are not of a sufficiently high standard to make people sit up and take notice. Patients may find this kind of treatment helpful when delivered by a sympathetic practitioner, but whether the underlying process actually has any effect on the disease is another matter."

Heather Walker, of the charity Action for ME, said: "As a matter of policy we do not recommend individual therapists."

All about sleep

Achieving sleep can be a common difficulty for those suffering from M.E. The summer heat can make the problem worse. The following article was recently written by Dr. Sarah Myhill, MD* and taken from www.chronicfatiguesupport.com

The need to sleep is of paramount importance in CFS/FM patients, and “you must put as much work into your sleep as your diet,” says Doctor Myhill, who specialises in nutritional and preventive medicine. Before considering drugs, she advises her patients to manage the physical essentials - “pressing the right buttons” to put your brain to sleep, helped by low-dose natural preparations such as melatonin and valerian root.

The physiological ‘history’ of sleep

Humans evolved to sleep when it is dark and wake when it is light. Sleep is a form of hibernation when the body shuts down in order to repair damage done through use, to conserve energy and hide from predators. The normal sleep pattern that evolved in hot climates is to sleep, keep warm, and conserve energy during the cold nights and then sleep again in the afternoons, when it is too hot to work and hide away from the midday sun.

As humans migrated away from the equator, the sleep pattern had to change with the seasons and as the lengths of the days changed. People needed more sleep during the winter than in the summer in order to conserve energy and fat resources. Furthermore, during the summer humans had to work long hours to store food for the winter, and so dropped the afternoon siesta.

But the need for a rest (if not a sleep) in the middle of the day is still there. Therefore, it is no surprise that young children, the elderly, and people who become ill often have an extra sleep in the afternoon - and for these people that is totally desirable. Others have learned to power nap, as it is called, during the day and this allows them to feel more energetic later. If you can do it, then this is an excellent habit to get into - it can be learned!

More sleep in winter, less in summer

The average daily sleep requirement is nine hours, ideally taken between 9.30 p.m. and 6.30 a.m. – that is, during hours of darkness, but allow for more in the winter and less in the summer.

Light on the skin prevents the production of melatonin, which is the sleep hormone essential for a good night's sleep. Therefore, the bedroom should be completely blacked out and quiet in order to give the best chance of quality sleep. Even people who are born blind still have a day/night rhythm - it is light landing on the skin which has this effect. Just closing your eyes will not do it!

After the First World War a strain of 'Spanish' flu swept through Europe killing 50 million people worldwide. Some people sustained neurological damage, and for some this virus wiped out their sleep centre in the brain. This meant they were unable to sleep at all. All these poor people were dead within 2 weeks, and this was the first solid scientific evidence that sleep is more essential for life than food and water. Indeed, all living creatures require a regular 'sleep' (or period of quiescence), during which time healing and repair takes place. You must put as much work into your sleep as your diet.

First, get the physical essentials in place

- We are all creatures of habit, and the first principle is to get the physical essentials in place.
- A regular pre-bedtime routine. Your 'alarm' should go off at 9:00 p.m., at which point you drop all activity and move into your bedtime routine.
- A regular bed time – 9:30 p.m.
- A busy day with the right balance of mental and physical activity.
- Not having a bed fellow who snores.
- Small carbohydrate snack just before bedtime (such as nuts or seeds) helps prevent nocturnal hypoglycemia, which often manifests with vivid dreams or sweating.

- Perhaps restrict fluids in the evening if your night is disturbed by the need to pee.
- No stimulants such as caffeine or adrenaline inducing TV, arguments, phone calls, family matters or whatever before bed time! Caffeine has a long half life, so none after 4pm
- Dark room - the slightest chink of light landing on your skin will disturb your own production of melatonin (the body's natural sleep hormone). Have thick curtains or blackouts to keep the bedroom dark. This is particularly important for children! Do not switch the light on or clock watch should you wake.
- A source of fresh, preferably cold, air.
- A warm comfortable bed. We have been brainwashed into believing a hard bed is good for you, and so many people end up with sleepless nights on an uncomfortable bed. It is the shape of the bed that is important. It should be shaped to fit you approximately and then very soft to distribute your weight evenly and avoid pressure points. Tempur^{R} mattresses can be helpful (if expensive), as are water beds.

Address other factors known to disturb sleep

- If your sleep is disturbed by sweating, then this is likely to be a symptom of low blood sugar.
- Another common cause of disturbed sleep is hyperventilation, which often causes vivid dreams or nightmares. This can now be tested for by measuring red cell carbonic anhydrase. However, I often use a benzodiazepine [“minor tranquilizer”] such as diazepam 2-5 mgs at night, which reduces the sensitivity of the respiratory centre.
- If sleep is disturbed by pain, then one must just take whatever pain killers are necessary to control this. Lack of sleep simply worsens pain.
- If one wakes in the night with symptoms such as asthma, chest pain, shortness of breath, indigestion, etc., then this may point to food allergy being the problem with these withdrawal symptoms occurring during the small hours.
- Some people find any food disturbs sleep and they sleep best if they do not eat after 6:00 p.m.

If you do wake in the night, do not switch the light on, do not get up and potter round the house, or you will have no chance of dropping off to sleep.

The hard part: getting the brain off to sleep

Getting the physical things in place is the easy bit. The hard bit is getting your brain off to sleep. I learned an astonishing statistic recently, which is that throughout life, the brain makes a million new connections every second! This means it has a fantastic ability to learn new things – which means it is perfectly possibly to teach your brain to go to sleep. It is simply a case of pressing the right buttons.

Getting to sleep is all about developing a conditioned reflex. The first historical example of this is Pavlov's dogs. Pavlov was a Russian physiologist who showed that when dogs eat food, they produce stomach acid. He then 'conditioned' them by ringing a bell whilst they ate food. After two weeks of conditioning, he could make them produce stomach acid simply by ringing a bell. This, of course, is a completely useless conditioned response, but it shows us the brain can be trained to do anything.

Applying this to the insomniac:

1. First, he has to get into a mind-set which does not involve the immediate past or immediate future. That is to say, if he is thinking about reality then there is no chance of getting off to sleep - more of this in a moment.
2. Then he uses a hypnotic (see below) which will get him off to sleep.
3. He applies the two together for a period of 'conditioning', for a few days or a few weeks.
4. The brain then learns that when it gets into that particular mind-set, it will go off to sleep. And then the drug is irrelevant.

However, things can break down during times of stress, and a few days of drug may be required to reinforce the conditioned response. But it is vital to use the correct 'mind-set' every time the drug is used, or the conditioning will weaken. I do not pretend this is easy, but to allow one's mind to wander into reality when one is trying to sleep must be considered a complete self-indulgence. It is simply not allowed to free-wheel.

Self hypnosis to form a conditioned reflex pattern

Everyone has to work out their best mind-set. It could be a childhood dream, or recalling details of a journey or walk, or whatever. It is actually a sort of self hypnosis. What you are trying to do is to "talk" to your subconscious. This can only be done with the imagination, not with the spoken language. [For a step-by step explanation, see the final section of this article - "Self Hypnosis - Like Learning To Drive With A Clutch" – which offers excerpts from a book on self hypnosis.]

I instinctively do not like prescribing drugs. However, I do use them for sleep, in order to establish the above conditioning and to restore a normal pattern of sleep, after which they can be tailed off or kept for occasional use.

Indeed, viruses can cause neurological damage (for example polio) and this could involve damage to the sleep centre. So often CFS patients in particular get into a bad rhythm of poor sleep at night, which means they feel ill for the day, which means they get another bad night. They are half asleep by night and half awake by day. Furthermore, their natural time for sleep gets later and later. They go to bed late and if they have to get up at the usual time, chronic lack of sleep ensues. Indeed, there is now evidence that the biological clock is dependent on normal adrenal function and we know this is suppressed in CFS. So often some medication is needed to facilitate sleep. Most CFS patients react badly to drugs in normal doses.

The personal sleep support 'starter pack'

I like to use combinations of low dose herbals, natural remedies and prescribed drugs to get the desired effect. Everybody works out his or her own cocktail which suits. This may have to be changed from time to time. I like to supply a 'starter pack' for patients, which has a selection of hypnotics (as outlined below, the supplements melatonin and valerian root, and the over-the-counter sedating antihistamine Nytol^{R}) to try so they can work out their best combination…

I am always asked about addiction. My experience is that this is rare, especially if drugs are used as above to develop a conditioned reflex. One has to distinguish between addiction and dependence. We are all dependent on food, but that does not mean we are addicted to it. We are all dependent on a good night's sleep for good health and may therefore become dependent on something to achieve that. This does not inevitably lead to addiction.

Addiction is a condition of taking a drug excessively and being unable to cease doing so without other adverse effects. Stopping your hypnotic may result in a poor night's sleep but no more than that. This is not addiction but dependence.

Beginning with natural preparations to help sleep

These all work differently, and so I like to use low dose combinations until you find something that suits. Choose from the following, and start with:

Melatonin 3 mg (one tablet) 1 to 3 tablets at night. [Melatonin is a supplement available over the counter in America. In the UK melatonin can be prescribed and is also available from the Internet.] Some people just need 1 mg. CFS/FM patients have a poor output of hormones from all their glands - namely the hypothalamus, pituitary, adrenals, thyroid and also the pineal gland. The latter is responsible for producing melatonin, the natural sleep hormone. It seems logical to me therefore to try this first.

Melatonin is a hormone produced by the pineal gland. It signals the time to go to sleep and its production is often faulty [especially] in CFS. Levels are slow to rise and slow to fall and this may well explain why these patients tend to drop off to sleep late at night and wake late in the morning. It is like having a form of chronic jet lag.

Melatonin is made from serotonin (the "happy" neurotransmitter) which in turn is made from 5HTP [5-Hydroxy L-Tryptophan, a supplement which studies indicate works by supporting production of healthy levels of serotonin]. This may be why 5HTP is helpful for sleep disorders.

The only precaution is that one or two of my patients have become depressed with melatonin, so be aware of this. On the container it also states melatonin should be avoided in autoimmune disorders... [and certain other conditions including epilepsy and leukaemia].

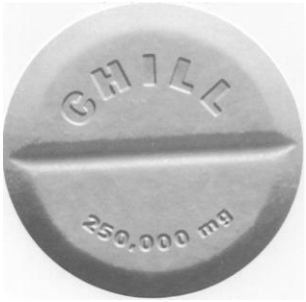
There is a test to measure melatonin production. The Melatonin Profile test measures salivary melatonin levels over 24 hours. Particularly Chronic Fatigue Syndrome patients have poor or delayed melatonin output, so they are unable to drop off to sleep quickly. If this test shows a deficiency of melatonin, then melatonin supplements are indicated.

Valerian root 1 to 4 capsules at night. This herbal supplement is shorter acting and can be taken in the middle of the night.

Nytol^{R} (diphenhydramine 50 mg). This is not a supplement, but a sedating antihistamine available over the counter. The dose is 1 to 2 at night. This is longer acting - don't take it in the middle of the night or you will wake feeling hung over. [It is "potentially dangerous" taken with alcohol.]

Prescription drugs, starting with sedating antidepressants

If there is no improvement with a combination of the above, or if there are intolerable side effects, then I would go on to a prescribed drug. I usually start with one of the sedating antidepressants, such as:



Amitriptyline 10 mg to 25 mg I would start with 5 mg initially. Most CFS/FM patients are made worse and feel hungover with "normal" doses.

Dothiepin. I do not prescribe dothiepin now because a study suggested that this had an increased risk of cardiac dysrhythmias compared to other tricyclic antidepressants.

Surmontil 10 to 30 mg at night.

Short acting temazepam 10 mg. This is useful but recently has been made a controlled drug. so doctors are understandably twitchy about prescribing it. It is controlled because some drug addicts were taking the gel and injecting it into themselves. Nowadays I tend to use instead **zaleplon (Sonata^{R})** or medium acting **zopiclone (Zimovane^{R})** 7.5 mg.

Diazepam is helpful if sleep is disturbed either because of hyperventilation (it reduces the respiratory drive) or for muscle spasms (it is a good muscle relaxant).

Different people will respond to different combinations of hypnotics. For example, one person may take a melatonin and two valerian at night, plus a zaleplon when they wake at 3:00 a.m. Somebody else may be best suited by 10 mg amitriptyline at night with a Nytol^{R}. Don't be afraid to try combinations - there are no serious side effects that I am aware of with any of these used in combination. However, don't change more than one thing at any time otherwise you (and I) will get confused!

One of my patients has found a wrist band that presses on the acupressure point in the wrist very helpful.

If you find your dose creeping up...

If you find your dose of hypnotic is gradually creeping up, then this may be because you have become less disciplined about establishing the conditioned reflex. Go back to the basics as above.

When your normal sleep pattern has been restored you can begin to reduce or tail off completely your hypnotic medication - but only if good quality sleep can be maintained. If your sleep begins to suffer, you must go back on the medication that worked before, because the need to sleep is of paramount importance in CFS/FM patients.

Self hypnosis – "like learning to drive with a clutch"

The following is lifted from a book on self hypnosis which works for some:

We know that the hypnotic state is characterised by extreme responsiveness to suggestion. You can use this information for conditioning yourself in self hypnosis. Here is a standard procedure to follow.

1. Lie down in bed, ready for sleep initially with your eyes open (the room needs to be dark). Mentally give yourself the suggestion that your eyes are becoming heavy and tired. Give yourself the suggestion that as you count to 10 your eyes will become very heavy and watery and that you will find it impossible to keep your eyelids open by the time you reach 10. If you find that you cannot keep them open and have to close them, then you are probably under self-hypnosis.

2. At this point deepen the state by again slowly counting to 10. Between each count mentally give yourself suggestions that you are falling into a deep hypnotic state. Give yourself suggestions of relaxation. Try to reach a state where you feel you are about to fall asleep. Give yourself the suggestion that you are falling more deeply down into sleep. Some may get a very light feeling throughout the body; others may get a heavy feeling.

3. Let us assume that your eyes did not become heavy. Then repeat the procedure. You can count to 100 if you need this period of time to assure an eye closure. The closing of the eyes is the first sign you are in a receptive frame of mind. Let us assume that you get the eye closure. Take a longer count to get yourself in the very relaxed state. Once you achieve this you should be able to respond properly. The difficult bit is not allowing your brain to wander off into other areas. You must work hard at concentrating on the counting and the responses that achieves.

4. If you respond properly, give yourself the "post-hypnotic suggestion" that you will be able to put yourself under later by counting to three, or using any specific phrase you desire.

5. Continue using it every day and give yourself the post hypnotic suggestion every time you work with it, that at each succeeding session you will fall into a deeper state and that the suggestions will work more forcefully with each repetition.

Each time that you work towards acquiring the self-hypnotic state, regardless of the depth that you have achieved and whether or not you have responded to any of the tests, give yourself the following suggestions: "The next time I hypnotise myself, I shall fall into a deeper and sounder state." You should also give yourself whatever suggestions you desire as though you were in a very deep state of hypnosis.

You may ask "If I'm not under hypnosis, why give myself the suggestions?" You do this so that you will begin to form the conditioned reflex pattern. Keep at it. One of the times that you work at achieving self-hypnosis the conditioned response will take hold... you will have self hypnosis from that time on.

It is like learning to drive a car with a clutch. At first you must consciously go through the process of putting your foot on the clutch and shifting gears. Usually there is a grinding of the gears and you feel quite conspicuous about this, but gradually you learn to do this almost automatically and you gain confidence in your driving ability. The same is true of hypnosis. As you work at your task, you gradually get the feel of it and you achieve proficiency in it.

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* Dr. Sarah Myhill, MD, is a UK-based CFS specialist focused on preventive healthcare, nutrition, and patient education. This material is reproduced here with permission of the author from Dr. Myhill's patient-information website (DrMyhill.co.uk) R Sarah Myhill Limited, Registered in England and Wales: Reg. No. 4545198.

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ME/CFS related adverts

Do you have a child with M.E?
We do!

Would you like to meet other parents in a similar position?

We are a small, friendly group who meet informally for mutual support and to share information.

Join us on the first Tuesday of every month, 7.45 – 9.00 pm at:-

St.Pius Church meeting room,
Laustan Close (off Horseshoe Lane East), Merrow, Guildford.

For further information or directions call Christine on 01483 503092 or e-mail Christine@awconsulting.co.uk

NHS Services for Chronic Fatigue

Epsom and St. Helier University Hospitals NHS Trust

Dr. Amolak Bansal - Consultant Immunologist

Initial assessments for diagnosis are made by a Consultant Immunologist or a General Practitioner with special interest or a Clinical Nurse Specialist.

Treatment options: Lifestyle Management Group Programme

One-to-one sessions with:

- clinical nurse specialist
- clinical psychologist
- occupational therapist

The Trust is the Chronic Fatigue Clinical Network Co-ordinating Centre for Surrey and South West London.

For further information, please contact the Chronic Fatigue Service Administrator on: 020 8296 4152

Potential medical treatments ?

The following summaries of medical treatments relevant to M.E. have been taken from the MEActionUK website at the following website address: http://www.meactionuk.org.uk/treatments.html

Guaifenesin

Guaifenesin is a common over-the-counter expectorant. It has been around for about seventy years, first as guaiacum and then as guaiacolate, and for about twenty years as guaifenesin. Guaifenesin seems to allow the kidneys to eliminate something harmful that has been stored in the body. One study found that with guaifenesin therapy, there was an increased excretion of phosphates and oxalates.

Guaifenesin is safe and even available in pediatric dosages. It is also sold as a prescription medication available in 600 mg caplets or capsules. It is important to ensure that there are no other medications mixed in with the guaifenesin, as there often are in cough and cold formulations.

A typical regimen is to start with 300 mg twice a day, and if there's no obvious change after one week, increase the dose to 600 mg twice a day for about a month.

Antidepressants

Tricyclics
Some of the most widely used treatments employed in the management of ME are sedating tricyclic antidepressant agents in low doses: amitriptyline or doxepin, 5 to 20 mg at bedtime. For unusually low doses, the liquid form of the medication is ideal.

Low-dose tricyclic agents have been proved efficacious in randomised trials of a similar illness (fibromyalgia) and in a number of sleep disorders. Many patients report that their sleep is less frequently interrupted and of better quality.

Interestingly, patients with concomitant depression do not report an improvement in the core symptoms of depression when given tricyclics in such low doses.

Readers should be warned that during the first week of therapy, even extremely low doses of tricyclics may cause them to feel groggy in the morning; this reaction is usually short-lived.

Others
Half or more of patients with ME (somewhat unsurprisingly) develop major depression in the months and years after the onset of their illness. Also, increasing synaptic strength may itself be of help in the symptomatic treatment of ME, as it is in other illness with neurological effects.

Tricyclic agents can rarely be tolerated in conventional antidepressant doses, but selective serotonin reuptake inhibitors are often better tolerated. Sertraline (Lustral), fluoxetine (Prozac), and paroxetine (Paxil) have been used the most.

Some clinicians have reported good results with the combined serotonin and norepinephrine uptake inhibitor venlafaxine (Effexor). However, the only randomized trial of antidepressant therapy in ME, which used fluoxetine, found no benefit in either the fatigue or depression. It is also worth reading the online article entitled "The Aftermath Of Prozac, Zoloft, Luvox, Fen-Phen, & Many Other Serotonergic Drugs" before deciding to try such treatments.

Vitamin B12 Injections

Although little controlled scientific research exists on the effectiveness of vitamin B-12 for the treatment of ME, many doctors and patients are trying this therapy. Two well-known ME researchers and clinicians, Dr. Paul Cheney and Dr. Charles Lapp, believe that it can be helpful for some patients in managing the symptoms of ME.

If you ask a G.P. for B12, s/he'll check your blood serum level and say it's normal. The stock method of measuring vitamin B12 levels is not going to reveal deficiencies of the coenzymes required for healthy neurological functioning, since it measures blood levels of vitamin B12 and not the Cerebro-Spinal Fluid level. It's the CSF level that's often extremely low in ME sufferers. This could be because B12 either doesn't get across the blood-brain barrier sucessfully, or else it's being consumed or destroyed at a phenomenal rate in the CNS.

Drs Cheney and Lapp recommend a trial dose of 3000 mcg (three mg) 2 to 3 times per week. If there is no response by the end of two weeks, give up: this treatment either works for you, or it doesn't.

Interestingly, transport of vitamin B12 into the brain can be disturbed or prevented by heavy metals such as inorganic mercury (have any mercury amalgam fillings?), cadmium or lead. These affect the blood-brain barrier by causing leakage and restricting the active transport of nutrients.

Oralmat

Oralmat is a Rye sprout based product originally produced for the treatment of Asthma. It contains a gluten-free, activated extract of Secale cereale (rye) in which are found phytoestrogens, genistein, matairesinol, Beta 1,3 glucan, coenzyme Q10 and squalene. It is reputed to be effective as an immune enhancer in cases of flu, allergies and conditions of impaired immunity.

This treatment is mentioned here because of its recommendation by AIDS sufferers as an effective immune modulator. It is pleasant tasting and the average user requires 3 drops under the tongue 2 to 3 times daily. It can also be administered to children over the age of 6.

Sterinol

Recent research indicates that the health-promoting benefits of a plant-based diet may be due to the presence of plant-derived cholesterol analogs known as sterols and sterolins. These compounds, which are ubiquitous throughout the plant kingdom, appear to have important immuno-modulatory and anti- inflammatory activities in human and animal physiology.