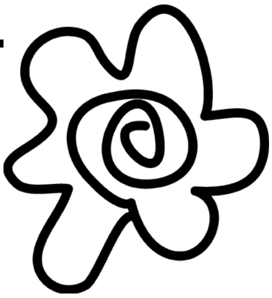
## Guildford M.E. Support Group

# Newsletter

### Spring 2007



## Future events

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

### Annual General Meeting - Wednesday 9th May (7pm onwards)

The White House pub
8 High Street, Guildford, Surrey, GU2 4AJ
On the riverbank by the side of the Town Bridge

### Pool Party and Picnic – Friday 22nd June (12 noon - 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 or email Alison on 01428 654216 alison@kiamara.freeserve.co.uk to confirm your intention to attend in advance of 20th June. Directions from Guildford below. Please phone Alison for directions from elsewhere.

**Directions from Guildford**

| | |
|---|---|
| 1 | Head northwest from Chertsey Street 0.2 mi |
| 2 | Continue on Stoke Road 0.4 mi 1 min |
| 3 | At the roundabout, take the 2nd exit onto Stoke Road 0.1 mi |
| 4 | At the roundabout, take the 2nd exit onto Stoke Road 0.1 mi |
| 5 | Turn left at Lady Mead 0.3 mi 1 min |
| 6 | Continue on Woodbridge Road 0.2 mi 1 min |
| 7 | Bear left at Middleton Road 0.2 mi 1 min |
| 8 | At Wooden Bridge Roundabout, take the 2nd exit into the Middleton Road entry ramp 0.1 mi |
| 9 | Bear left at A3 12.4 mi 20 mins |
| 10 | Turn left at Hindhead Road (A287) 2.0 mi 7 mins |
| 11 | Turn right into Church Road - signposted Midhurst A287(A286) |
| 12 | Go straight over at the traffic lights into Sturt Road 0.6 mi 2 mins |
| 13 | Turn left into Bell Road, just after 40mph sign, passing Coomers (builders' merchants) on your left. 0.2 mi |
| 14 | Turn left into Midhurst Road. 0.4 mi 1 min |
| 15 | Turn right at Scotland Lane 0.1 mi |
| 16 | Turn right at Scotlands Close 488 ft |
| 17 | No 22 is at the top of the road, last house on the right. |

## A thank you to Gillian Coleman

Our thanks go to Gillian Coleman for fulfilling one of the group's most involved positions over the past two years as both Secretary and Treasurer for the Group. While Gillian remains a committee member for the group, she is currently focusing on both family commitments and study.

At the same time as fighting her own M.E. Gillian has been on the frontlines of the group consistently working hard to keep it running. Her dedication and company will be very much missed.

As part of a return to better health in 2006, Cathy Gould, our past Treasurer, is now both our Secretary and Treasurer. Welcome back Cathy.

## Woking CBT Clinic continues

Despite the recent financial crisis in the NHS that threatened to close a number of specialist M.E. services throughout the country, we have confirmation that the CFS/M.E. Clinic in Woking will continue for the foreseeable future.

Based at the Woking Community Hospital, the Clinic provides Cognitive Behavioural Therapy (CBT), Graded Exercise and advice regarding work. The team is led by consultant Mr McCluskie and consists of a clinical psychologist, a physiotherapist and an occupational therapist.

A referral from your GP is required to attend the course. There is a secretary based at the unit for ten hours a week, who, can be contacted on Thursdays on 01483 846357. Alternatively, messages can be left on an answer machine.

## Gifts for our severe sufferers

The group has purchased a limited number of items which may be of comfort to our more severely affected members. An overview of the items is included below. If you believe that these might relieve your symptoms and you are short on money, please contact Cathy Gould requesting the item. Obviously, we would like to be able to distribute items to all group members, but, given our limited resources, we are only going to be able to provide for the most in-need members. As such, along with your request, please indicate why the item would be particularly helpful to you. Apologies in advance if this approach sounds awkward. Hopefully, however, it will result in our most severe sufferers receiving a useful gift.

Cathy can be contacted by post or email using the following:
Address: Cathy Gould, Westdene, Elmbridge Road, Cranleigh, Surrey, GU6 8NW.
Email: Catherineg_9@hotmail.com

### Item one – Sleepy bear

A luxurious soft pile fur character perfect for snuggling up to on a cold night. Microwave for two minutes, it stays warm in a bed for two hours. It is 12" tall, contains treated wheat grains, is fragranced with soothing herbs and embroidered with a logo on the chest.

Maybe of particular benefit to those experiencing aches and pains that the heat of the bear can soothe away.

### Item two – L-shape cushion

The V-shaped pillow is designed to help prevent back and neck pains and to provide the extra support right where it is needed. The pillow comes complete with a specially shaped poly-cotton case in one of four pastel colours: Blue, Yellow, White and Pink. Machine washable. If you are requesting this item, please remember to specify colour of preference from the four mentioned above.

# It worked for Me

**For our on-going column "It worked for me" Mair Ellis, one of our members, has kindly written an overview of her M.E. experience. In particular, she tells of the significant improvement she has experienced via use of The Perrin Technique.**

## BLOCKED DRAINS! - My Recovery and The Perrin Technique

I had suffered from M.E. for 21 years. Prior to its onset I had a successful job and was living in New York. I ended up back home with my parents looking after me, no job and no life.
Years later, married with three children, (in addition to two from a previous marriage) I embarked on yet another 'treatment' I hoped would be the answer. By this time I was pretty sceptical as I had tried many 'treatments' over the years, both medical and alternative, to no avail. I had struggled to bring up a family against all the odds but with very little in the way of quality of life for me. Virtually every day was a struggle, the life force had gone out of me and I forged on as best as I could (with a lot of help from my husband and friends) for the sake of the children. They had never known what it was like to have a healthy and reliably well Mum and often, understandably, resented it. They weren't the only ones. Things were also getting worse, as my immune system struggled more and more I developed bouts of pneumonia, which proved very difficult to get rid of.

That's when about a year ago, I went to see Dr Perrin. My husband came with me and we were both impressed by his frank and down to earth manner (no sales pitch here). He explained clearly his findings and the treatment. He then examined me and physically diagnosed M.E. This was the first time I had had a physical diagnosis. There were physical things on examining me that led to a diagnosis of M.E. and M.E. only. I think this is important, here was a physical diagnosis rather than a symptom led one.

He then gave us a rating for my M.E., I had a severe one and badly blocked lymphatics (or drains!), and told us he believed he could help but that it would take time. He was right. After my first treatment, I relapsed badly, lost my speech and was physically so weak that I needed a lot of help to get back in the car. So began a regular pattern of my husband driving me to Bushey, having the treatment and him driving me back. I wasn't much use after the treatment and as time went on I began to wonder if it was having any effect. In between seeing Dr Perrin I would see Laurent Heib (another practitioner trained by Dr Perrin) in Portsmouth and my husband would have to massage my lymphatics every day (as this was largely around the breast area this proved a real hardship for him!). This could be done oneself but it is better with a partners help particularly as they have more strength. There were other supporting aspects to the treatment but the massage is the most important.

Gradually, despite my cynicism, I started to improve. Last September, I felt sufficiently well enough to embark on a full-time HND course in Garden Design, which would have been unthinkable before. As my workload at college increased, it was a real struggle to stay on top of things but despite this, I have not relapsed and only experienced the same tiredness as every one else on the course. I am convinced that keeping up with the treatment has helped me to keep going. Probably if I had been content to take things easier for longer, my recovery may have been quicker, but it was never going to be easy with three children to look after and I needed the psychological boost. Family and friends around me thought it was a miracle I was able to keep going as if ever I had tried things before I always ended up relapsing. A friend told me recently in all the years she had known me, she had never known me not be in bed for at least one or two days a week. I have not been to bed through illness since September.

**Continued overleaf…**

One of the things I began to notice after a few months of the treatment was the disappearance in the pain in my breasts. This may sound odd, but I thought it hurt all women to lie on their breasts. It was only after it stopped being an issue that I asked friends who assured me this was not something they experienced. Also the front of my neck was a lot less lumpy and tender. There were many things that I had grown accustomed to that were not normal and began to disappear. My concentration (I had also been taking the VegEPA recommended by Professor Puri) was remarkably improved. I couldn't write a sentence without difficulty before and here I was writing dissertations!

There was still one aspect that continued to cause problems and that was the way my body reacted to the slightest stress or provocation (even a thought sometimes); it seemed to result in the over-production of adrenaline, creating a vicious cycle of more stress and adrenaline. This in itself was making the production of toxins worse so creating a constant need for the Perrin treatment to unblock the drains! I then heard about the Lightening Process and how it worked to address this problem. I spoke to Dr Perrin about this and he thought I should give it a go.

This too has proved very successful and I now feel I have control of my body back. When I notice the triggers that used to cause this stress reaction, I am able to use the mental tools the Lightening Process has given me to avoid the response. My body and I are now on top of this wretched illness and I, with the help and inspiration of God, am back in the driving seat and yes my drains are running freely!

### Further information

- Mair Ellis can be contacted by email at: mair@prismstrategy.com
- Further information on The Perrin Technique can be found at: www.theperrinclinic.com
- Further information on The Lightning Process can be found at: www.lightningprocess.com
- Further information on VegEPA can be found at: www.vegepa.com

## International ME Conference 2007

The second Invest in ME International ME/CFS Conference takes place over Two days – on 1st and 2nd May 2007 – in Westminster, London at One Birdcage Walk.

The conference will provide a chance to hear the latest news on epidemiology, aetiology, pathology, diagnosis, treatment and current/future biomedical research into ME/CFS from some of the most prominent experts.

The 1st May is the "pre-conference day" more informal than the actual conference and allows topics to be discussed in groups with the conference speakers. The 2nd May is the actual conference day which will cover Epidemiology, Aetiology, Pathology, Definitions, Diagnosis, Treatments, Protocols, Research and Paediatrics.

Conference speakers include: Dr.Abhijit Chaudhuri, Professor Kenny De Meirleir, Dr. Ian Gibson MP, Professor Malcolm Hooper, Dr. Byron Hyde, Dr Nigel Speight, Dr. Jonathan Kerr, Dr. Sarah Myhill, Ellen Piro, Professor Basant Puri, Professor Martin Pall, Dr. Vance Spence, Annette Whittemore, Dr. Terry Mitchell.

Both days are ticket only events. For pre-conference only £150, conference day only £150, both days £250. Concession Rates (£40, £40, £70 respectively) are offered to individuals who are Registered Disabled, Unemployed, Benefits Recipients and individual ME Sufferers/Carers and Students. These concessionary places are limited and will be dealt with on a first-come-first-served basis. A priority waiting list for those who, initially, have not been able to obtain a place is being used. Please refer to the final page of this Newsletter for the registration form and conditions.

# 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 Additional treatments from the same source will be included in our following newsletter.

## Armour Thyroid

'Proinflammatory' cytokines raise the temperature. So if you're in that group of patients who frequently experience low-grade fever, that's probably because of these proinflammatory cytokines. Thyroid medication is not suitable for such patients.

However, there is another group of patients where endocrine dysfunction predominates, and whose temperature tends to be low. For these patients, thyroid medication can be of help. Some practitioners prefer to use natural thyroid (Armour thyroid).

If you take your temperature when quite at rest, i.e. first thing in the morning, it should be somewhere between 98º F and 98.6 º F. If it is not, and is below 97.8 º F it is considered a positive indication. Frequently, it is really very low, even below 96 º C, if there is an adrenal/thyroid deficiency.

To do it really well, you should place the thermometer for ten minutes in the axilla (armpit) immediately on waking.

Thyroid supplementation should be used in a carefully increasing dose until the desired effect is achieved. Remember though, that if your body temperature's normal or high, it's probably not going to work. And there are other reasons for having a low temperature too (such as decreased ATP production), so (as will all treatments) it will not help everyone.

## DHEA

Most ME sufferers show suppression of the hypothalamic pituitary adrenal axis (HPA axis). As a result of adrenal suppression, sufferers tend to put out less cortisol, and also less of another adrenal hormone called DHEA.

It seems that, if you try to replace the cortisol, it doesn't work. But replacing the DHEA seems to bring about a small improvement in some sufferers.

The dose of DHEA is 25-50 mg for women, 50-100 mg for men, daily. It is best taken in the morning. DHEA is freely available without prescription.

## Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

The majority of patients with ME experience myalgias, arthralgias, headaches, and migratory paresthesias. For some, the pain is the most debilitating aspect of their illness. In most patients, nonsteroidal anti-inflammatory drugs (NSAIDs) seem to provide a measure of relief. The less expensive NSAIDs, eg. ibuprofen, seem to be just as effective as the more expensive ones.

## Opthalmic Drops

You may have read about SPECT scan findings showing decreased profusion in the frontal lobes of the brain. Vasocon is a simple vasal constrictor of the eye, but it causes a reflex vasodilation in the frontal lobes. A safe therapy that can significantly improve cognitive function in the short-term.

Naphazoline eye-drops (an alpha-adrenergic) are also reported to be of help.

## Myalgia Treatments

Note : Myalgic Encephalomyelitis has, as the name suggests, both myalgic (muscular) and encephalitic (neurological) components. What follows is drawn from both ME and FMS ('Fibromyalgia Syndrome') research, in the belief that the aetiologies underlying these diagnostic categories are closely related.

### Magnesium Sulfate

Just 2 cc of 50% magnesium sulfate once or twice a week can help ME sufferers with a myalgic emphasis. The problem with magnesium injections is that they burn like fire, so sometimes the treatment is worse than the disease itself!

### Oxytocin

Oxytocin is an anterior pituitary hormone which increases blood flow to the eye, to the brain, and to muscle. This tends to make the skin feel warmer and the body feel warmer. Some sufferers report thinking more clearly and seeing more clearly.

Approximately one-fifth of ME sufferers have a good response to oxytocin after failing to respond to other treatments.

### S-Adenosylmethionine

This precursor of adenosine has been shown to be an effective treatment for predominantly myalgic ME sufferers in three double blind studies. It works by correcting defects in adenosine metabolism.

### Gabapentin

Many ME sufferers report markedly reduced myalgia and an increase in energy after the first dose. It probably works by indirectly increasing the release of GABA.

## Candida Treatments

The yeast called Candida Albicans causes all sorts of problems for ME sufferers, including irritable bowel syndrome (diarrhoea and chronic flatulence) and 'leaky gut syndrome'. The latter can lead to severe encephalitic reactions after a meal and to food intolerances. To find out all about Candidiasis in ME, click here.

Fortunately, candidiasis can easily be resolved by appropriate treatment.

Diflucan is very effective for candidiasis, with or without Nystatin. Candida overgrowth occurs in the gut very frequently, so you may need to repeat this treatment regularly.

In the very worst cases of colitis and imbalanced gut flora, it is sometimes necessary to use a broad-spectrum antibiotic as well as Nystatin/Diflucan to clear the gut of its present occupants, and then immediately replace them with a course of probiotics.

## Spring competition

Due to recent donations to the group we would like to provide a competition. As such, please find below a “Spot the difference”. Just find and circle the seven changes in the second photo below and you will be entered into a draw for £25 of Marks and Spencers vouchers. The winner will be drawn from a hat at the Pool Party on the 22nd June (as detailed on page 1 of this newsletter).

HINT: both antennae count as one change

To enter your submission please cut along the line below and post, with the differences circled, to Cathy Gould at Westdene, Elmbridge Road, Cranleigh, Surrey, GU6 8NW.

## Readers section

**In response to a recent request, we are exploring the popularity of a new section of the newsletter called “readers section”, where our readers can communicate with the rest of the group with requests, advice, questions etc… If you have something you would like to submit, please email it to rescue@f2s.com**

**Our first request is from a fellow sufferer called Anna Kingston. To reply, please use her email address, supplied at the bottom.**

I got your address from the ME association support site because I'm wondering if you'd be able to help me with something. My name's Anna, I've had ME/CFS for around 13 years, from the age of 12, have relapsed twice (one of which was five weeks after starting Uni a couple years ago) and I'm really trying hard to build myself back up enough to go back there and get my biology degree. The trouble at the moment is that energy is very low and I also suffer from a severe anxiety disorder as part of the CFS which makes it really horrible to be at home on my own during the day while my parental types are at work.

So....what I'd really like to do now is to find someone around my own age (24), or even not, who also has ME/CFS and is from the local area, who I can spend part of one day a week with so as to feel less isolated, and also, to feel like I can talk about being ill with a bit so I don't just think I'm going totally mad! Ideally it would be someone who has a similarly low energy level who I can just hang out with at their home, not necessarily even talk much (tiring!) but just get some solidarity. With that in mind, I'm wondering if anybody suggests themself to you! Or if not whether there are any people you could pass this email around to. I live between Ripley, Send and Clandon, near Guildford, but could consider travelling to anywhere in the Guildford area.

Thanks muchly for your help in advance,
Cheers & All The Best
Anna Kingston :)

# Treat pain and Fibromyalgia at “The Park”

Our group has recently been contacted by Mr Kipp Clark, an advanced massage therapist/myofascial release practitioner, who practices in Hook, Hampshire (near Basingstoke) and specialises in the treatment of fibromyalgia and chronic pain.

Mr Clark works at the “Revive Health & Beauty Coffee House” at “The Park”, a health and fitness centre, with a country club feel, set within 40 acres of countryside in Hook. In addition to supplements such as Magnesium, MSM, 5HTP, Olive Leaf Extract, Zinc and Vitamin C, for Fibromyalgia sufferers, Mr Clark advises Myofascial Release therapy. An overview of Fibromyalgia and Myofascial Release therapy is included below.

## What causes Fibromyalgia?

Fibromyalgia is predominantly caused by widespread fascial restrictions all over the body. The fascia is the tough connective tissue, which covers every muscle, muscle fibre, nerve and organ in the body. In fibromyalgia sufferers, this 'web' of fascia has become dehydrated and tightened around sensitive structures of the body. 'Restrictions' (extra strands/areas of fascia which should not be there) also develop between areas of fascia. These fascial problems cause widespread pain, dysfunction, make movement more tiring and inhibit cell/tissue function and circulation. The reason fibromyalgia is poorly understood and difficult to diagnose is that fascial restrictions do not show up on any conventional medical tests (e.g. X-rays, MR1 scans, blood tests etc). Fascial restrictions also cannot be treated by conventional means (e.g. they cannot be treated by operations or medication).

Fascial problems can develop for many varied reasons including physical trauma/injury, muscular tension, stress/depression, dehydration, scarring/operations, emotional trauma/bereavement, postural problems and poor lifestyle. Some experts also believe that a viral infection may often be a precursor to fibromyalgia. Often it is however, not possible to identify the precise cause of fibromyalgia in an individual and a combination of various different factors is more likely to be the cause.

Fibromyalgia sufferers have also been found to have increased levels of 'substance p' in their bodies which makes their nervous system overly sensitive to pain (what would be a slight ache to most people can be severe pain to a fibromyalgia sufferer). It is also thought that some fibromyalgia sufferer's tissues may have become deficient in energy producing fuel. The body will then break down muscle tissue to provide the fuel needed for energy production which may also contribute to the pain, fatigue and fascial restrictions associated with fibromyalgia.

## Myofasical Release

Myofascial Release is a gentle yet extremely powerful therapy used to effectively treat the fascia of the body. If a patient has fascial problems associated with emotional trauma then these may need to be treated to help the patient fully recover, and 'move on'. Myofascial release can also bring about the natural self-healing process of 'unwinding'. The patient's body goes through a series of spontaneous movements to correct physical problems and to release unresolved emotional trauma, while being gently guided by the therapist.

## Indicative pricing and contact details

50 minutes session is £45
65 minutes session is £55

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