Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

March 2016

Future dates

Open to all members and carers.

18th April 2016 (Monday) 7.30pm White Lyon & Dragon
Perry Hill, Worplesdon, Guildford, GU3 3RE
www.whitelyonanddragon.com
(not far along from the Worplesdon Hotel)

Offers Thai food. We sit in the bar area to the left rather than the restaurant area to the right.

12th May 2016 (Thursday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

15th June 2016 (Wednesday) 7.30pm The Britannia
9 Millmead, Guildford, Surrey GU2 4BE
www.shepherdneame.co.uk/pubs/guildford/britannia

Invest in ME - Colloquium & Conference 2016

The 5th Colloquium will take place on the 27th-28th May 2016 in London.
The 10th Conference will take place on the 29th May 2016 in London.

Colloquium

The Invest in ME International Biomedical Research into ME Colloquiums bring together researchers from around the world in a round-table discussion of ME research and ideas; and the sharing of experiences, data and plans. Last year 50 researchers from nine countries attended.

Conference

The conferences attract some of the most renowned speakers from all over the world and are valuable sources of education and information for healthcare professionals, doctors, nurses, researchers, ME support groups and people with ME.

Further details will become available at: www.investinme.org/IIME%20IIMEC10.htm

High-pressure oxygen: Researchers develop ‘very effective treatment’ for fibromyalgia

Source: http://preventions.co/high-pressure-oxygen-researchers-develop-very-effective-treatment-for-fibromyalgia

Tel Aviv University researchers have found that treatment in a hyperbaric (high-pressure) oxygen chamber improves the condition of women suffering from fibromyalgia – a syndrome characterised by chronic widespread pain and a heightened and painful response to pressure.

Between two percent and 4% of the populations in Western countries have the condition, and 90% of those sufferers are women. Until now, there has been no effective treatment for it.

The TAU-led team – which also included scientists from Assaf Harofeh Medical Center in Tzrifin, Ben-Gurion University in Beersheba, Tel Aviv Sourasky Medical Center, and Rice University in Houston, Texas – recently published its findings in the open-access journal PLoS One (Public Library of Science One).

The researchers developed an innovative and effective oxygen treatment that they say “improved significantly” the condition of 70% of the women who participated in the clinical study, and could alleviate the suffering of millions of (mostly) women around the world.

Until now, the exact cause of fibromyalgia – which is related to chronic fatigue syndrome – was unknown. Experts have said it involves genetic, psychological, neurobiological and environmental factors.

It is usually triggered by head trauma, a neurological infection or serious and continued emotional stress. However, because the exact cause was unknown, doctors have been treating only the symptoms, and even this has been largely ineffective.

Now, for the first time, the Israeli research has identified the primary factor causing the syndrome: the disruption of the brain mechanism for processing pain. The pain that is the condition’s main symptom appears to result from neuro-chemical imbalances – including activation of inflammatory pathways in the brain, which results in abnormalities in pain processing.

The brains of people with fibromyalgia show functional and structural differences from those of people without the condition, but it has been unclear whether the brain anomalies cause fibromyalgia symptoms or are the product of an unknown, underlying common cause.

“In previous studies in the hyperbaric chamber [at Assaf Harofeh], we found that a series of treatments significantly improves the condition of stroke and head-trauma patients,” said Dr. Shai Efrati, director of the Segol Hyperbaric Center and a member of the Segol School for Brain Sciences at TAU . “We found that high-pressure oxygen brings about the renewal and repair of damage in the brain tissue of these patients, even many years after the injury.”

As a result, the doctors decided to see if the technique was effective for treating other brain disorders, and chose fibromyalgia. Sixty women, ages 21 to 67, who were diagnosed with the condition underwent high-resolution brain-mapping (to show brain activity). They were then randomly divided into two groups: a control group that did not receive any treatment, and another treated with hyperbaric oxygen.

The treatment group underwent five exposures per week for an hour each over two months in the closed chamber.

The air inside had 100% oxygen at a pressure of two atmospheres, twice the conditions of regular air.

“The result was very encouraging,” said Efrati. “The condition of seven out of 10 improved so much that they are no longer identified as fibromyalgia patients.”

The team carried out more brain mapping on the treated women and made an important discovery. “We found changes in the brain that were compatible with the improvement in their clinical condition, and we identified exactly the brain regions responsible for fibromyalgia,” said the doctor.

“For all practical purposes, we identified the source of the syndrome and proved that fibromyalgia is harm to the pain-processing mechanism in the brain. In the oxygen chamber, the root of the problem – the damaged brain tissue – is treated, which is why it is so efficient. It is likely that in the future, we may even be able to diagnose the condition on the basis of the characteristics we observed in brain-mapping.”

The researchers are continuing to conduct comprehensive studies on renewal of brain tissue under hyperbaric conditions. Their next study will be on patients with light cognitive decline, which could be the beginning of dementia.

The brain-mapping technique the team used was done with technology developed by late TAU physicist Prof. Eshel Ben-Jacob, who had previously speculated that hyperbaric treatment could “help patients in the early stages of dementia and Alzheimer’s disease and prevent the patient’s decline.

Maybe in the future, we will be able to give the brain ‘anti-aging treatment’ that will fortify it and preserve its function until the patient’s last day.”

Hyperbaric Oxygen Therapy (HBOT)

Source: http://drmyhill.co.uk/wiki/Hyperbaric_oxygen_therapy_(HBOT)

Following on from the previous article, the following article is from Dr Myhill’s website and offers further information about Hyperbaric Chamber treatment.

This article was written by Jackie Scoones, a mercury poisoned sufferer who has seen clinical benefit from HBOT, and edited by Craig Robinson - first written and edited in March 2014.

What is HBOT?

HBOT involves breathing pure oxygen in a purpose built chamber for periods of an hour. This pure supply of oxygen is delivered at 1.5 to 2.5 times normal atmospheric pressure ATA.

For those who are interested, ATM is a unit of pressure equivalent to the weight of the earth's atmosphere at sea level. Absolute pressure (ATA) is the total ambient pressure on the system being calculated or measured. In essence, the crucial point is that the oxygen is delivered at a pressure in excess of that which you would experience in ‘normal everyday life’.

How does HBOT work?

Under normal ‘everyday’ circumstances oxygen is transported throughout the body only by the red blood cells. With HBOT, the pressure effect increases the oxygen carrying capacity of the blood stream. So, oxygen levels increase in all of the body's fluids, including the blood plasma and lymph.

There are many benefits which arise from this increased level of oxygen availability:

- The extra oxygen can reach damaged tissue and areas where circulation is diminished or blocked. This is of proven benefit in conditions where blood supply is impaired such as acute stroke or myocardial infarction.
- The white blood cells’ ability to kill infection(s) is enhanced because oxygen is itself both an effective anti-biotic and anti-viral.
- Swelling and inflammation are reduced. This is because the delivery of extra oxygen allows the rapid growth of new blood vessels into the affected areas and these are then available for healing and repair purposes.
- Recent studies are now suggesting that increased oxygen levels trigger the release of stem cells from the bone marrow. These stem cells have the potential to transform into any cell of the body and so there is the possibility that damaged tissues could be renewed.
- Through this therapy, and depending upon the pressure level, the body is provided with between a ten and twenty fold increase in normal oxygen delivery. HBOT is a simple, non-invasive and painless treatment.

Which conditions benefit from HBOT?

HBOT is of proven benefit in carbon monoxide poisoning, multiple sclerosis, cerebral palsy, cognitive disorders in the elderly, myocardial infarction (heart attack), stroke, burns, leg ulcers, coronary artery stents, radiation damage and (problem) wounds that are failing to heal. A comprehensive list of conditions that have been found to benefit from HBOT can be seen at

www.hyperbaricoxygentherapy.org.uk/search?q=research

where you will find links to the references supporting these many benefits of HBOT.

HBOT protects against infection and inflammation during surgery and accelerates healing. It may also relieve the pain and inflammation of arthritis.

Where can I obtain HBOT?

We are fortunate in the UK to have 2 organisations providing this therapy for the public. First, there is The British Hyperbaric Association, which has 13 Diving Chambers across the UK.

Secondly, for ME/CFS sufferers the Multiple Sclerosis National Therapy Centres are more affordable, and also more likely to help. This is a self-help charity with a network of 50 Independent Centres across the UK. The history of one such Centre in Cornwall is movingly described at:

www.merlinmscentre.org.uk/the-merlin-centre/how-it-all-began

To access information about oxygen therapy on the website of the MS National Therapy Centres us the following link:

www.msntc.org.uk/oxygen_treatment.php

Once you have had a look around the website, and if you decide that this is a therapy that you would like to investigate further, you can telephone 0845 367 0977 for more information and help of a general nature.

Or if you feel that you have definitely decided to check out this therapy in more detail, you can simply call your nearest Centre and arrange a visit - it will normally be the case that someone will be pleased to show you around and let you sit inside the HBOT chamber and explain how things work. Please note that these Centres are very used to dealing with severely disabled people and so there will not be a problem if you are a wheelchair user. For example, you can actually get into the Chamber whilst remaining in a wheelchair.

You can find your nearest Centre by going to ‘Find your nearest Centre’ and entering your postcode in the search box or by browsing the Directory of Centres. Although this charity primarily treats people with MS, it is the case that, given the wide range of conditions that benefit from HBOT, you will most likely find other CFS sufferers and people being treated for a wide range of varying conditions including, for example, sports injuries, autism and (post chemotherapy) cancer. It should also be noted that the Centres are all staffed by volunteers and the atmosphere is friendly and informal and there is no need to be apprehensive.

Website for the Guildford Centre:
www.samsoncentre.org.uk

In addition, and although there are regional variations with NHS funding, I am advised that the HBOT Unit in Whipps Cross, East London London Hyperbaric Medicine, the DDRC Healthcare in Plymouth and the HBOT Unit in Hull North of England Medical Hyperbaric Services Ltd all have many patients funded by the NHS.

What will the treatment be like and how much will it cost?

If you decide that you do want to go ahead with the treatment, you will be asked to become a member of the Centre. Each Centre is independent and so costs will vary. However, as a guide, membership is normally around £20 a year. The cost of each treatment varies but is approximately £12 - £15 a session. You will need your GP to fill in a form saying that you don't suffer from any ear/sinus problems.

The Centre Manager will usually seek advice from their own medical expert on your treatment programme. This is usually a block of 20 daily sessions. There are 3 different levels of atmospheric pressure - 1.5, 1.75 and 2.00 ATA, also called 16, 24 and 33 feet (indicating the ‘diving depth’ equivalent). You will start at the gentlest level and gradually proceed to the next level, until you find the pressure that suits you best. Once you have completed your block of 20 sessions, you can then decide how often to continue with your treatment, normally once or twice a week. The oxygen will continue to have benefits for about 3 days after each treatment.

How will the treatment help me and are there any side effects?

To begin with a quote from Petra Kliempt Medical Advisor to the Multiple Sclerosis National Therapy Centres - " Oxygen is our body's antibiotic dealing with inflammation and infection, moreover, it controls over 8000 genes and a course of 20 sessions increases our own stem cells eightfold."

Normal effects are an increase in energy and an increase in mental clarity and a sense of optimism and well-being.

The main side effect is that you may feel a little light-headed after the treatment for the first few sessions. It is therefore wise to sit down for about 10-15 minutes when you come out of the chamber and have a drink, until you are used to the treatment and know how it affects you. We are all individuals and will react differently to HBOT. You may also feel you want to rest for an hour or two afterwards. Overall the increased oxygen levels create a feeling of relaxation and optimism. It’s a pleasant experience. In order to write this article I did some research on the London and Midland Diving Chambers, www.oxygenhealing.co.uk . This organisation is associated with the British Hyperbaric Association. There is a big difference in prices - they quote £50-£300 a session, but I think the average is more like £150. They can "dive" deeper, each client has a consultation with a doctor before being treated and a doctor goes into the chamber with the client.

So, this represents a different level of service than that being offered via the Multiple Sclerosis National Therapy Centres and the cost clearly reflects this!

A course of treatment can obviously cost thousands of pounds, but HBOT treats some very serious conditions, including people who would otherwise lose limbs through amputation. The only reason I mention this organisation is that I am aware of individual cases of ME/CFS sufferers having had a course of 10-12 HBOT sessions at the deepest concentration and this treatment was the difference between them being bed ridden and becoming mobile. It wasn't a cure but it did create a big improvement in their condition and subsequently they were able to go to an MS therapy Centre for weekly HBOT.

However, I advise people not to start off at the ‘deeper levels’, although the idea of having a block of treatments at the deeper level might appeal to some people because they may want to see a ‘quick improvement’. It is wiser to go gently, and pace yourself, by starting at the lightest level and gradually building up to a level that is right for you. In addition, not everyone can tolerate the deeper levels, especially those with neurological conditions. Finally, and as noted, ‘going deeper’ also costs more money and so by pacing yourself, you will save your wallet as well as (potentially) your health!

I offer this information in the knowledge that HBOT offers an improvement for many chronic conditions. To my knowledge its hallmark characteristics are increased energy levels, reduced pain and inflammation and increased mental clarity and optimism.
I think it’s an ideal therapy for CFS... until a cure is found.

Article written by Jackie Scoones March 2014

Facebook Oxygen therapy group
If you are interested in joining a Facebook group which discusses these issues and has members who can help with their experiences and expertise, please consider sending a request to:-
‘HDOT (High Dosage Oxygen Therapy) For M.E, M.S, & Many Other Conditions’
If you wish to join, please visit Facebook Group weblink - HDOT (High Dosage Oxygen Therapy) For M.E, M.S, & Many Other Conditions. This is a closed Facebook group and so only members of this group can see your posts – this affords a level of privacy.

Comment by Dr Myhill
The cardinal symptom in CFS is fatigue. The commonest rate limiting step is poor mitochondrial function caused either by a deficiency of substrate (e.g. magnesium, co-enzyme Q 10, vitamins B3, vitamin B12 , carnitine etc...) or by blocking caused by substances from the ‘outside world’ (e.g. pesticides, toxic metals, VOCs) or by blocking caused by substances from the ‘inside world’ (e.g. such as products of the fermenting gut).

Of course, lack of oxygen would severely impair mitochondria, but the causes of such a lack of oxygen, such as severe anaemia or respiratory failure, are usually clinically obvious.
Less obvious causes of poor oxygen delivery would include hyperventilation or allergy. In hyperventilation the acidity of the blood is changed in such a way that oxygen binds so avidly to haemoglobin that it cannot escape to get to the mitochondria, where it is needed! Blood vessels and tissues can react allergically with oedema (an excessive build-up of fluid in the body's tissues), which may impair oxygen delivery.

The second major problem in CFS is inflammation which may be as a result of infectious, allergic or autoimmune problems. There are many interventions to tackle this, and for some, HBOT may be a helpful additional therapy for the reasons given above.

A further possible explanation has to do with the fermenting gut - many of the ferments such as alcohol, esters and aldehydes have a general anaesthetic like effect on the brain. The effects of general anaesthetics can be reversed by high pressure. So a response to hyperbaric oxygen could point to fermenting gut or toxic stress being an issue.

See Wikipedia link on Theories_of_general_anaesthetic_action:
https://en.wikipedia.org/wiki/Theories_of_general_anaesthetic_action

External links:

- **www.hyperbaricoxygentherapy.org.uk**
  Hyperbaric Oxygen Treatment Trust HBOTT - this is clearly a website worth exploring in detail. You will also be able to find a hyperbaric centre close to where you live.
- **http://mssussex.com/?page_id=155**
  Subsequent to the first writing of this page, a patient of mine has pointed out the website of the Sussex MS Centre to me. This centre offers HBOT and the website, in itself, is a useful resource.

Joint Hypermobility & Ehlers Danlos Syndrome

Source: www.cortjohnson.org/blog/2016/02/17/pain-fatigue-sleep-fibromyalgia-misdiagnosis

By Cort Johnson 17th February 2016

She was twenty years old – a competitive skier – complaining of muscle and joint pains, fatigue, gut problems, difficulty sleeping, cognitive problems, difficulty concentrating and tingling sensations. When she tried to exercise the pain in her shoulders and limbs would get worse forcing her to stop. She had difficulty urinating but no infections. When she chewed her mouth tended to ache.

Her blood work was normal. She had no sign of an autoimmune disease and her physical examination – with one exception – was normal. Her muscle tone was good and her reflexes fine. Her history was intriguing.

She'd experienced sprains and tendinitis in her wrists and ankles since childhood. When she was fourteen she was diagnosed with Raynaud's phenomenon, a disorder of sympathetic nervous system hyper-activation which causes reduced blood flows to the fingers. At fifteen she caught SARS and then infectious mononucleosis keep her weak and in bed for months.

She'd tried to resume training at sixteen only to be felled again and again by muscoskeletal injuries which responded poorly to treatment. One ski fall which altered the curvature of her neck worsened her fatigue and arthritis-like pain. When she started experiencing paresthesias or tingling sensations in her lower legs she was suspected of having a neurological or muscle disease but extensive testing (brain and spinal MRI's, four-limbs EMG, body bone scan, skull and jaws X-ray) revealed nothing. At this point she was diagnosed with fibromyalgia.

Over the next two years attempts to run and swim caused her so much pain that she was forced to stop. When she saw the doctor who wrote up this case report she was depressed, had trouble sleeping, thinking and had gained weight to boot. The doctor had her do one test which changed her diagnosis completely. Her main problem wasn't fibromyalgia or chronic fatigue syndrome or some mysterious muscle disease; he felt she had primary joint hypermobility syndrome (JHS).

Joint Hypermobility Syndrome

The main feature of joint hypermobility syndrome or JHS is the ability to flex your joints beyond the normal range.

Despite being present in approximately 5% of the population JHS was only first described in the medical literature in in the 1990's. Many people with JHS don't experience symptoms but those that can experience a range of muscoskeletal problems including tendonitis, bursitis, osteoarthritis, subluxations, prolapsed back discs, whiplash, TMJ and carpal tunnel syndrome. They also tend to experience severe fatigue (ME/CFS) and a generalized pain hypersensitivity (fibromyalgia) that extends beyond the joints that are effected. One study found that over 75% of people with Ehlers Danlos Syndrome – the most common kind of JHS – experience severe fatigue.

Autonomic nervous system problems are also common and can result in orthostatic intolerance including postural orthostatic tachycardia syndrome (POTS). People with EDS can experience fatigue, visual changes, poor concentration, discomfort in the head or neck, throbbing of the head, weakness and fainting when they stand.

Diagnosing Hypermobility Syndrome
Like ME/CFS and FM – two other diseases that can generate an enormous number of symptoms, JHS and EDS are often misdiagnosed.

Physicians who know of the Beighton score – a test you can take at home – use it to help them diagnose the condition. It should be noted that a high Beighton score by itself does not mean that an individual has a hypermobility syndrome. Other symptoms and signs need to also be present.

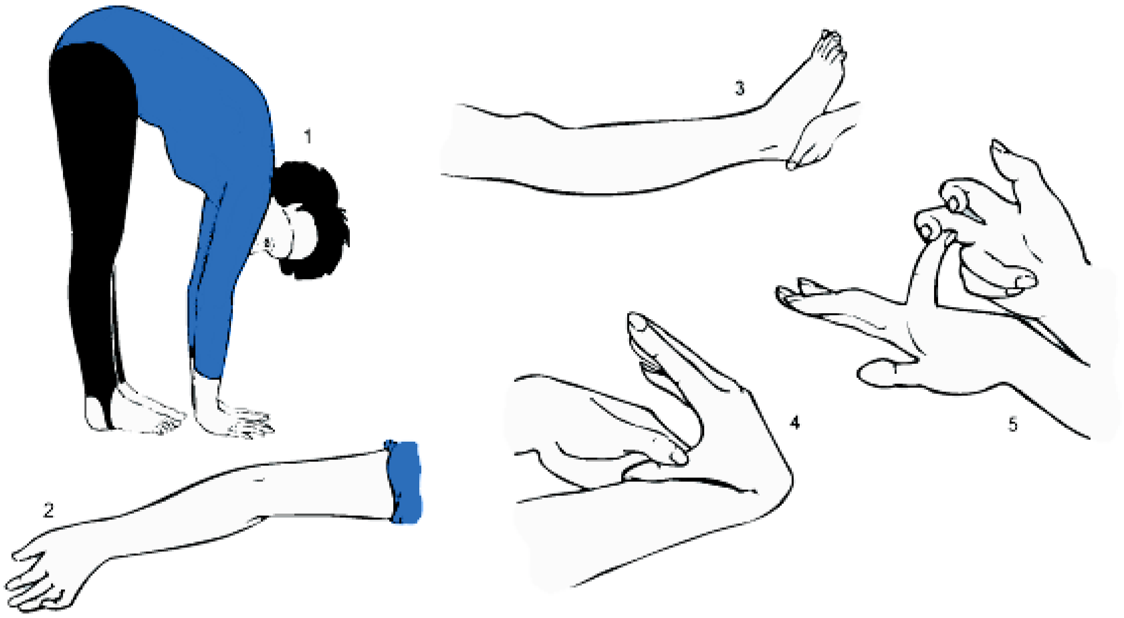
It should also be noted that a low Beighton score may not be accurate because the questionnaire doesn't ask about some areas in the body:
jaw joint (the 'TMJ'), neck (cervical spine), shoulders, mid (thoracic) spine, hips, ankles and feet which can exhibit joint loosening.

It's also possible to have JHS without having overt joint hypermobility. Because of changes in the connective tissue as we age some people who exhibit strong joint hypermobility as children no longer do so as adults. They may still, however, still experience the pain associated with JHS/EDS.

With those proviso's out of the way…..

The Beighton Score:

1. One point if while standing forward bending you can place palms on the ground with legs straight
2. One point for each elbow that bends backwards
3. One point for each knee that bends backwards
4. One point for each thumb that touches the forearm when bent backwards
5. One point for each little finger that bends backwards beyond 90 degrees.



The hypermobility questionnaire

Another quick tool to use is the hypermobility questionnaire. An answer of ‘Yes’ to two or more of the questions suggests hypermobility is likely present. Again, like the Beighton score, this does not mean that the person has a Hypermobility Syndrome. (Why some people are hypermobile and in pain while others are hypermobile and healthy is not clear.)

- Can you now (or could you ever) place your hands flat on the floor without bending your knees?
- Can you now (or could you ever) bend your thumb to touch your forearm?
- As a child did you amuse your friends by contorting your body into strange shapes OR could you do the splits?
- As a child or teenager did your shoulder or kneecap dislocate on more than one occasion?
- Do you consider yourself double-jointed?

The overlap between JHS/EDS and ME/CFS/FM

Thus, a person with ANS dysfunction wastes tons of energy regulating body processes that should be automatic. Dr. Alan Pocinki on EDS

Dr. Pochinki is an ME/CFS/FM doctor who has found such increased rates of EDS in ME/CFS that in a 2011 Solve ME/CFS Initiative talk he called it a “characteristic factor” of the disease. After rattling off a long list of similar symptoms (including post-exertional malaise) he stated that sleep studies and autonomic nervous system (ANS) findings in the two diseases are identical.

Pocinki’s talk on the ANS and EDS (“The Pseudo-scientific symptoms in EDS”) could have been taken right out of an ME/CFS/FM seminar. He believes that low epinephrine (adrenalin) reserves found in EDS cause a paradoxical response: the more depleted the ANS is the more exaggerated its stress response becomes.

He Pochinki described an ANS that just cannot find relief; Staci Stevens has described the ANS in ME/CFS in a similar way and many people with ME/CFS can probably relate. He used the metaphor of a car. A person with ANS dysfunction is constantly hitting the breaks and gas attempting to get his/her body where it needs to be. Instead, this person is getting surges of too much gas/slam on breaks/too much gas/slam on breaks/too much gas….and on it goes. Thus, a person with ANS dysfunction wastes tons of energy regulating body processes that should be automatic.

If you have ME/CFS or FM consider the possibility that you might have JHS/EDS as well. Pochinki’s basic treatment plan for helping to restore autonomic nervous system balance in EDS is an interesting blend of treatments used in FM and/or ME/CFS.

- better sleep – reducing arousals and increasing deep sleep;
- adequate – really – pain control, including appropriate exercise,
- physical therapy;
- adequate salt and fluid;
- minimize emotional stresses; and
- conserve energy, rest when needed and don’t “push through” fatigue.

He says that while not curative these simple measures help the majority of his ME/CFS patients.

To learn more about EDS check out the EDS media section of Health Rising, using the link below. You will need to sign up to Health Rising Forum before being able to gain access.

www.cortjohnson.org/forums/media/categories/ehlers-danlos-syndrome.46

Sleep Apnea

Source: www.britishsnoring.co.uk/snoring_&_sleep_apnoea/what_is_sleep_apnoea.php

> **Often ME/CFS comes with significant sleep problems. As such, it may not occur to look into the possibility of a secondary illness called Sleep Apnea – where air ways regularly close a night sabotaging both sleep and health. I refer to it as secondary because I wonder if ME may be causing throat muscles not to be taught because of a lack of general energy (ATP).**
>
> **Newsletter Editor**

What is Sleep Apnoea? (Sleep Apnea)

Obstructive Sleep Apnoea (OSA) is defined as the cessation of airflow during sleep preventing air from entering the lungs caused by an obstruction. These periods of 'stopping breathing' only become clinically significant if the cessation lasts for more than 10 seconds each time and occur more than 10 times every hour. OSA only happens during sleep, as it is a lack of muscle tone in your upper airway that causes the airway to collapse. During the day we have sufficient muscle tone to keep the airway open allowing for normal breathing. When you experience an episode of apnoea during sleep your brain will automatically wake you up usually with a very loud snore or snort, in order to breathe again. People with OSA will experience these wakening episodes many times during the night and consequently feel very sleepy during the day: they have an airway that is more likely to collapse than normal.

> **I have severe sleep apnea at 47 events per hour. But I did not have the waking in the night, although it is a core symptom of Sleep Apnea. For me, it was a severe issue of not being able to get to sleep and a travelling sleeping pattern.**
>
> **Newsletter Editor**

How do I know if I have Sleep Apnoea?

People with sleep apnoea may complain of excessive daytime sleepiness often with irritability or restlessness. But it is normally the bed partner, family or friends who notice the symptoms first. Sufferers may experience some of the following:

- Extremely loud heavy snoring, often interrupted by pauses and gasps
- Excessive daytime sleepiness, e.g., falling asleep at work, whilst driving, during conversation or when watching TV. (This should not be confused with excessive tiredness with which we all suffer from time to time)
- Irritability, short temper
- Morning headaches
- Forgetfulness
- Changes in mood or behaviour
- Anxiety or depression
- Decreased interest in sex

Remember, not everyone who has these symptoms will necessarily have sleep apnoea. We possibly all suffer from these symptoms from time to time but people with sleep apnoea demonstrate some or all of these symptoms all the time.

Diagnosing Sleep Apnoea

OSA can range from very mild to very severe. The severity is often established using the apnoea/hypopnoea index (AHI), which is the number of apnoeas plus the number of hypopnoeas per hour of sleep - (hypopnoea being reduction in airflow). An AHI of less than 10 is not likely to be associated with clinical problems. To determine whether you are suffering from sleep apnoea you must first undergo a specialist 'sleep study'. This will usually involve a night in hospital where equipment will be used to monitor the quality of your sleep. The results will enable a specialist to decide on your best course of treatment.

I approached my GP about Sleep Apnea, who referred me to the sleep clinic at Chertsey Hospital. They start by giving you a home-kit to wear one night. It includes straps around the chest and waist and a simple breathing tube that sits at the front of the nose. Also, an oxygen saturation monitor on the tip of the finger which attached to a wrist device. All easy to put on and not very intrusive. The kit is then returned to the hospital the next morning (or when you can).

If this detects sleep apnea then no further testing is needed. If nothing is detected then an overnight sleep test in hospital is likely to be offered. The in-hospital test looks for any other type of sleep problem that is harder to detect.

There is also a Sleep Clinic at Guildford Hospital.

Newsletter Editor

The ultimate investigation is polysomnography, which will include:

- Electro-encephalography (EEG) - brain wave monitoring
- Electromyography (EMG) - muscle tone monitoring
- Recording thoracic-abdominal movements - chest and abdomen movements
- Recording oro-nasal airflow - mouth and nose airflow
- Pulse oximetry - heart rate and blood oxygen level monitoring
- Electrocardiography (ECG) - heart monitoring
- Sound and video recording

This is a very expensive investigation, with few centres able to offer it routinely for all suspected sleep apnoea patients. A 'mini' sleep study is more usual, consisting of pulse oximetry and nursing observation. Home sleep study is becoming more popular.

Treating Sleep Apnoea

There are several forms of treatment for sleep apnoea. In mild and moderate cases weight loss and the use of mandibular advancement devices can be wholly successful. In moderate and severe cases mandibular advancement device or nasal continuous positive airway pressure (CPAP) are normally prescribed. CPAP is the gold standard treatment for OSA.

Central & mixed Sleep Apnoea

OSA is the commonest form of sleep apnoea, (about 4% of men and 2% of women) but there is also a condition called Central Sleep Apnoea (CSA). This is a condition when the brain does not send the right signals to tell you to breathe when you are asleep. In other words the brain 'forgets' to make you breathe. It can also be associated with weakness of the breathing muscles. The assessment for CSA is often more complicated than for OSA and the treatment has to be carefully matched to the patient's requirements. There is also a condition called Mixed Sleep Apnoea that is a combination of both obstructive and central sleep apnoea.

On the following page I have included some information about CPAP machines and contact details for local sleep apnea clinics.

Newsletter Editor

Contact details for local sleep apnea clinics

(Referral must be by GP)

Royal Surrey County Hospital
Egerton Rd, Guildford GU2 7XX

Respiratory Medicine – sleep service
01483 571122

GP referrals may be sent by post, fax or be made via Choose & Book.
They may also be emailed to rsc-tr.sleepteam@nhs.net

Prior to referral it would be helpful to have the following:
Epworth Sleepiness Score
FBC, thyroid function and HbA1c
Weight, BMI

St Peter's Hospital
Department of respiratory medicine
Guildford Road, Chertsey, Surrey, KT16 0PZ

Main switchboard: 01932 872000

Example CPAP machine – ResMed Airsense 10

The RedMed Airsense 10 costs about £520 and the AirFit F10 about £100. The ResMed Airsense 10 detects the air pressure you need at any time. The NHS will offer a free alternative, probably also from ResMed but might not offer variable air pressure or built-in humidifier.

The Guildford & West Surrey ME/CFS Group newsletters aim to inform members of relevant news and treatment options. Use of the treatments is done at your own risk.