

Worthing Area Fibro Group



October 2011 Author Nichola Bond & Editor Tony Ede

I do hope your month has gone well and you have enjoyed and gained knowledge from the newsletters.

I have been away with my husband for the week so could not attend our September meeting. And no it didn't look like this heheheh shame.



It is important to get away on occasions to just do nothing so you can recharge your batteries. On the day we left to come home we drove out of the park where we stayed and found we had a puncture. Peter my husband dealt with it.

Now a day's most cars no longer have a spare wheel, they come with an inflation kit that will get you to your garage or home. If you are on the mobility scheme all you need to do is phone them up they put you through to RAC who will come out to you

in no time and either repair the damage or temporarily repair it and then you follow the van to the nearest Kwik Fit centre for a full repair a. Kwik fit is the only company that is contracted through the mobility scheme. No hassle no worry, job done.

Simon ran the meeting this month, and we had several new people attend, it was enjoyed by all.

Lupus: I found out my niece and nephew had lupus when they were young kids and I didn't put the fibro and lupus together until many years later.

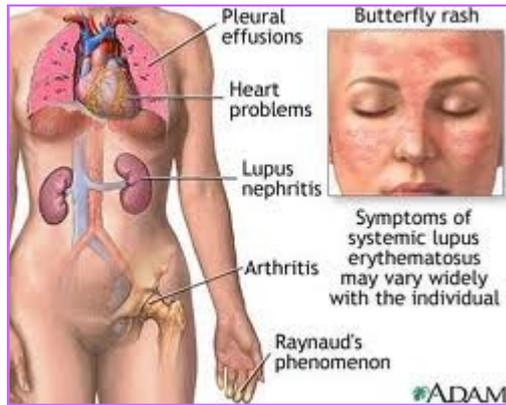
Fibromyalgia and Lupus are very similar-seeming illnesses that frequently go together. They share many of the same symptoms (pain, fatigue, brain fog), they're both marked by flare-ups and remissions, and they're both hard to diagnose. They're each frequently diagnosed as the other, and lupus appears to make you predisposed to fibromyalgia. Fibromyalgia, however doesn't seem to increase your odds of getting lupus. Even though the symptoms are so similar, what's going on in your body is different. Lupus is an autoimmune disease that causes inflammation, while fibromyalgia is a neurological condition that's not associated with inflammation. Lupus can attack your organs, while fibromyalgia can't. These problems require different treatments.



Our Charity that we are affiliated to is having its AGM at the **Chichester Park Hotel on October 29th (Saturday) at 1pm**. This is an opportunity for members and non members to come along and find out what the charity does for us and how you can help. There will be refreshments after the meeting and we are hoping to have a speaker to brighten up the proceedings.

Systemic lupus erythematosus. Alternative Names:

Disseminated Lupus Erythematosus; SLE; Lupus; Lupus Erythematosus



Definition: Systemic lupus erythematosus (SLE) is a chronic autoimmune disorder. It may affect the skin, joints, kidneys, and other organs.

Causes:

SLE (Lupus) is an Autoimmune Disease. This means there is a problem with the body's normal immune system response.

Normally, the immune system helps protect the body from harmful substances. But in patients with an autoimmune disease, the immune system cannot tell the difference between

harmful substances and healthy ones. The result is an overactive immune response that attacks otherwise healthy cells and tissue. This leads to long-term (chronic) inflammation.

The underlying cause of autoimmune diseases is not fully known. There are three major type:

- **Systemic Lupus Erythematosus** is the most serious form of the disease. It is a chronic, inflammatory, multisystem disorder of the immune system that may affect parts of the body such as the joints, skin, kidneys, heart, lungs, blood vessels or brain.
- **Discoid Lupus** primarily affects the skin, causing lupus face rash. A red, raised rash may appear and become thick and scaly. Lesions usually occur on the face or other sun-exposed areas and may scar.
- **Drug-induced Lupus** is caused by a small number of prescription medications. Usually when the medicine is stopped, the disease goes away. The most common drugs that can cause lupus are Procainamide (for heart problems), Hydralazine (for high blood pressure) and dilantin (for seizures).

It affects nine times as many women as men. It may occur at any age, but appears most often in people between the ages of 10 and 50. African Americans and Asians are affected more often than people from other races.

Symptoms:

Symptoms vary from person to person, and may come and go. The condition may affect one organ or body system first. Others may become involved later.

Almost all people with SLE have joint pain and swelling. Some develop arthritis. Frequently affected joints are the fingers, hands, wrists, and knees.

Other common symptoms include:

- Chest pain when taking a deep breath, Fatigue, Fever with no other cause, General discomfort, uneasiness, or ill feeling (malaise), Hair loss, Mouth sores, Sensitivity to sunlight, Skin rash -- a "butterfly" rash over the cheeks and bridge of the nose affects about half of people with SLE. The rash gets worse in sunlight. The rash may also be widespread and Swollen lymph nodes.

Other symptoms depend on what part of the body is affected.

More information will be put on our website.

Brain Fog/Fibro Fog in Fibromyalgia & Chronic Fatigue Syndrome



What Causes It & What to Do About It

Brain fog (also called fibro fog or cognitive dysfunction) is one of the most common complaints of people with Fibromyalgia (FMS) and Chronic Fatigue Syndrome (CFS or ME/CFS). For many, it can be severe and can have just as big an impact on their lives as pain or fatigue. In fact, some people say brain fog is more of a disability than their physical symptoms.

What Causes Brain Fog?

We don't yet know exactly what causes cognitive dysfunction in these conditions, but we have a lot of theories about possible contributing factors, including:

- Lack of restorative sleep
- Abnormal cranial blood flow or volume
- Brain abnormalities
- Premature brain aging
- Mental distraction due to pain

In both FMS and ME/CFS, it can be exacerbated when you're anxious, rushed, or dealing with sensory overload. Depression which is common in FMS and ME/CFS also is associated with cognitive dysfunction. Some studies, however, show that the severity of brain fog is not correlated with depression symptoms.

A lot of common medication for FMS and ME/CFS can contribute to brain fog as well.

Brain Fog Symptoms. Symptoms of brain fog can range from mild to severe. They frequently vary from day to day, and not everyone has all of them. Symptoms include: **Word use & recall:** difficulty recalling known words, use of incorrect words, slow recall of names. **Short-term memory problems:** forgetfulness, inability to remember what's read or heard. **Directional disorientation:** not recognizing familiar surroundings, easily becoming lost, having trouble recalling where things are. **Multitasking difficulties:** inability to pay attention to more than one thing, forgetfulness of original task when distracted. **Confusion & trouble concentrating:** trouble processing information, easily distracted. **Math/number difficulties:** difficulty performing simple math, remembering sequences, transposing numbers, trouble remembering numbers.

Some people may also have other types of cognitive dysfunction.

Brain Fog & Learning Disorders So far, we don't have evidence that our brain fog comes from known learning disorders. However, our problems are similar to those associated with disorders such as dyslexia (reading problems), dysphasia (speaking problems) and dyscalculia (math/time/spatial problems).

For some people, brain fog resolves with effective treatment for pain or sleep problems. However, not everyone can find effective treatments, which leaves many of us trying to manage it.

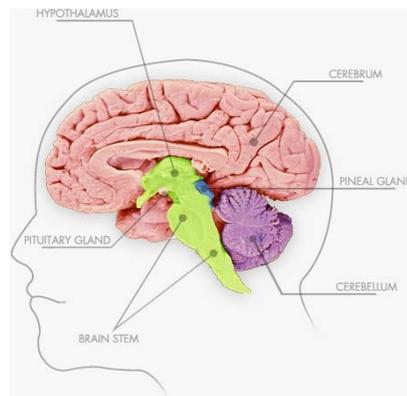
Common brain-fog supplements include:

5-HTP, B vitamins, Carnitine, Choline, Omega-3 (Fish Oil), Rhodiola, St. John's

Wort, SAM-e, Theanine. Brain friendly" foods, some of which are natural sources of the supplements listed above. Some of these foods are:

Fish (Omega-3), Canola or walnut oil (Omega-3), Eggs (Choline), Fruits & vegetables, Carbohydrates. Cognitive therapy also can help.

The Brain: Proteins and Amino Acids: Amino acids that come from the protein you eat are the building blocks of your brain's network. Amino acids can excite or calm your brain as well as nourish it throughout its lifetime.



How Amino Acids Reach Your Brain: Imagine if the people in your family could only travel to the next town if they were escorted by a lady in a pink dress, rode in a blue Ford Mini-Van and were allowed to travel on only one road. Sound like a difficult journey? Amino acids face similar obstacles and requirements in their journey to the brain. The fact is, if amino acids reach your brain at all, it should be considered a success. Not only do

brain cells compete with body cells for amino acids (body cells pull amino acids from the bloodstream more easily), amino acids must pass the protective blood-brain barrier. To top it all off, amino acids must be escorted through the blood-brain barrier by a certain molecule on a certain pathway in a certain “vehicle”.

Facebook: There are a lot of people that use the internet to talk to others, ask questions and type in how their day went. We have a Facebook account for our group so please have a go. As the USA is the leading country in research I talk and offer advice to people all over the world. It feels like a way to communicate with others that are going through the same thing so you feel you have some support. Even though it is easy to say I'm not interested in the computer the reality is it's here and it's not going away, so have a try and get speaking to others. You can learn things that may help you in your daily routine.

Website: A lot of the information that is talked about can be found on our own website www.fmswaws.org I got together with one of our members and a friend to create a great website. Pete maintains it and is always improving it and I send him information. If there is anything you would like to see on it please contact us the details are on the last page of the newsletter.

Holistic Treatments: As far as I know we are one of few groups that have our own therapist at each meeting. Her name is Ghennet and I went to college with her to study a range of holistic therapies.



That was many years ago. Ghennet offers a variety of therapies, for members of Worthing group she only charges £20.00 for a full treatment. At the meetings it is £5.00 for 20 minutes off which £1.00 goes towards the running of our group.

On arrival at the meetings just have a word with her to get yourself booked in. Have a word with other members to get feedback if you are not sure about having the therapy. I can and everyone else that goes to her say she is fantastic. Everything is confidential. She has her own room so it is very private too.

Medical Box: Prednisolone 25mg tablets.



Prednisolone is a corticosteroid. Prednisolone works by preventing or reducing inflammation. It is used to treat a number of conditions that are characterised by excessive inflammation.

Prednisolone suppresses the immune system and so can be used to treat autoimmune diseases. Prednisolone can help to prevent and to treat the rejection of transplanted organs.

People who take corticosteroids for a long period of time are prone to infection as their immune system can become weak. These infections may be much more severe than they usually would be and the symptoms that would usually be used to identify such infections can be hidden. For this reason people who take Prednisolone must be careful to avoid exposure to infections such as chickenpox and measles whenever possible. If you have been exposed to them, you must get immediate medical advice. You should continue to take your medicine unless your doctor advises you to stop taking it.

Talk to your doctor if you think you may have Lupus.

Alternatives: Lupus Erythematosus



Diet can aggravate the symptoms of lupus or contribute to its onset. Treatment may call for dietary alterations and supplementation for any nutrient deficiencies.

Food allergies and sensitivities have been implicated as a possible trigger of the disease. Many believe alfalfa sprouts are a common trigger of lupus symptoms; people who have had lupus symptoms may want to avoid eating alfalfa sprouts. An elimination diet can help to identify any other culprits. Here's how an elimination diet works: For two to three weeks, the patient's commonly eaten foods are eliminated from the diet. Common food allergens (such as wheat, eggs, milk, peanuts, and corn) are also avoided. If symptoms have subsided or not appeared by the end of this period, then the food challenges can begin. If the symptoms are still present, then more foods should be eliminated from the diet. Every two days, reintroduce (one at a time) the commonly eaten foods and common food allergens that you eliminated, noting if any symptoms appear. Continue in this fashion with the other foods.

Therapies: Herbal Medicine for Lupus Erythematosus -- Echinacea, feverfew, goldenseal, and pau d'arco are just a few of the helpful herbs. **Hydrotherapy for Lupus Erythematosus** -- Cold or hot compresses can be used for pain relief.

Mind/Body Medicine for Lupus Erythematosus -- Creative visualization, spirituality, relaxation techniques, biofeedback, and other mind/body treatments can strengthen the immune system, as well as reduce joint pain and ease accompanying depression. **Traditional Chinese Medicine for Lupus Erythematosus** -- Treatment may involve acupuncture, herbal therapy, dietary alterations, and exercise.

Important News

Meetings

Ferring Baptist Church Hall
Greystoke Road
Ferring BN12 5JL
Every third Tuesday of the Month.
Doors open 6.30pm start 7pm to
9.15pm
2011 Dates
20th September
18th October
15th November

Raising funds and awareness for your group:



We are looking for volunteers who will be happy to be involved with some fundraising for the group.

Group and Help Line No: 08448872394-
Email: beauty_within_15@hotmail.co.uk

Advertise:

We are looking for anyone with a business or event who would like to advertise in our newsletter for a small charge.

Please get in touch with Nichola
Tel: 08448872394

Internet:

Download Newsletter:

If you are on the internet you can download previous copies of the monthly newsletter via www.fmswaws.org
Membership leaflets are available at each meeting.

Please ask for information packs.

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Our Main Charity email:
Fibromyalgia
Sussex and Surrey Support
www.fms-sas.co.uk

Spiritual Readings

Available at reduced price for fibro members.

Please speak to Nichola

Healing is a gift that we all have.

It can help in many ways not just with Fibromyalgia. If you would like to know more please speak with Nichola at the group meetings or telephone her. Details are below.

Contacts:

Organiser of our Group, Co Leader & Author of your Newsletter:

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Disclaimer:

Information in this newsletter does not necessarily infer endorsement by the Worthing & surrounding area West Sussex Fibromyalgia Support Group. Any advice or recommendation of a medical or legal nature must always be discussed with a qualified professional.