

Worthing Area Fibro Group



Written and Produced by Nichola Bond 14th edition—February 2011

Group Information

Our first Event for the year 2011 was on our first meeting of the year 18th Jan. What a fantastic turnout, we were packed. A big thank you to Simon for his presentation which was very professional and Christine our fundraiser, who both were wonderful in helping me put the event together. Never forgetting all the volunteers for helping in their individual jobs to get the event up and running. The idea of the event was to invite anyone that had an interest in Fibro and to educate sufferers, their family, friends, carers, work colleague and even neighbours. As you can see from the pictures it was a great event.



Our aim as a support group is to give you our hand of friendship, with information, finding a way to helping you. We offer support, knowledge, lend an ear to listen, laughter and whatever you need from your group. Talking to likeminded people can give so much to the individual because Fibro can be a lonely condition. We want to reach out not only to sufferers but to their family and friends. Your support group welcomes partners, family members, carers, work colleagues and professionals to have time and space to air your thoughts, learn more about the condition and your body, learning skills to help your day to day life.

Taking back your Health

Today and in the past, many of us have relied on our doctors to put things right when we have fallen ill. Most of us have found disappointment in what the NHS have or I should say have not provided for us with. This statement is a strong one however it has to be said. I am not saying they have never helped. I am saying that Fibromyalgia patients have not received a package of permanent support so they can learn to live a life with Fibro. I have heard good and bad stories and I am sure there are others out there that can relate to that. It is time to take back the responsibility for our health. We are born, we are taught to walk, talk, eat, wash; at what point are we taught at home about the human body and how it runs, what is needed to keep a healthy mind body and spirit? To be able to recognise when something is wrong and have a good idea what it might be. We rely on our doctors to give us some medicine and make us better. Of course we need our doctor and I must say mine is wonderful however we need to take responsibility as well. So how does that work? Where does it go to make us better? All these questions. Do you know the answers?

Support

Unfortunately the NHS does not have the resources to give us the support we need after being diagnosed. Apart from possibly six sessions of hydrotherapy pool treatment and you may be put on a pain management programme. I recommend you take what is on offer. You need to learn as much as possible not just about Fibro, about pacing and everything that comes with it but you should learn about your body. The Doctor is your first port of call normally. It is up to you to talk to your doctor about your options. I use the word options because your doctor has to refer you to a specialist which is related to your health condition. Once diagnosed the specialist and doctor should refer you to a local support group. We appreciate that these are few and far between and that is one reason why I wanted a website so those of you who find it hard to get to the group can read and get inspiration from the knowledge on the website. We also have our information and helpline for those who need to hear a voice or someone who understands the trials and tribulations you go through each day. We have a coffee morning on the last Monday of the month from 10.30am to 12.30pm; please contact me on the help line for details of venue. Tel: 088448872394. This is for you. The advantages of learning about your body are massive and you may not need to go to the doctor first. Having the knowledge and listening to what your body is telling you will give you a more positive inner strength.



Lets look at your Muscles.



There are approximately 640 skeletal muscles within the typical human, and almost every muscle constitutes one part of a pair of identical bilateral muscles, found on both sides, resulting in approximately 320 pairs. Nevertheless, the exact number is difficult to define because different sources group muscles differently, e.g. regarding what is defined as different parts of a single muscle or as several muscles. So it ranges from 640 to 850.

The muscles of the human body can be categorized into a number of groups which include muscles relating to the head and neck, muscles of the torso or trunk, muscles of the upper limbs, and muscles of the lower limbs.

Most of us do not think about the smaller muscles which are for instance in our ears, there are two.

Around our eyes there are three main ones. We wonder if we are the only fibro sufferer with a twitch from the

eye area or part of our tongue can get pins and needles or numbness, the muscle of a tongue is divided into two. We have strange aching feeling in the wrist and lower arm. Sometimes even getting a numb patch on our face. The human body is a wonderful being and has many interesting capabilities like repairing it's self, however it needs a positive mind to help it along it's way. If you consciously think of a low mood and take time to see how your mind reacts, then take time out to feel what your body is feeling, then do the opposite and see how your body will react to your mood.

Worthing and West Sussex Fibromyalgia Group

Medical Box: Antidepressants Ease Fibromyalgia Symptoms



Medications Helped Fibromyalgia Sufferers with Pain and Fatigue. Antidepressants may help people living with the chronic pain of fibromyalgia experience fewer symptoms and improve their quality of life, new research shows. The study, lead by Dr. Winfried Hauser, of Klinikum Saarbrucken in

Germany, found that fibromyalgia patients had less pain, fatigue and depression while on certain antidepressants. Tricyclic and tetracyclic antidepressants helped the most people to reduce pain, fatigue and sleep disturbances, according to the report published in the Jan. 14, 2009, issue of the *Journal of the American Medical Association*. Medications used in England to treat fibromyalgia are painkillers, muscle relaxants and antidepressants. The painkillers are used to allow the patient to function and include over-the-counter medications such as Paracetamol or prescription painkillers such as Codeine. Muscle relaxants are used to aid in sleep and include medications such as Carisoprodol and Tizanidine. Antidepressants are prescribed to fibromyalgia patients not for their mood altering qualities, but rather for their ability to increase the number of neurotransmitters.

Amitriptyline is used for pain relief and depression. It works especially well for night time sleep. It also help to boost your Serotonin which helps to make you feel happier. Not everyone is the same if you do not get on with this drug there others that can help, just ask your doctor. By asking him more questions you will feel more positive with what he or she is giving you, don't just say thank you and leave. You have no idea what it is and what exactly it will do to your body. It is not necessary to go into it so much you are scared to take them but to have a better understanding after all it is not the doctor's body it's yours.

Alternative medicine: Fibromyalgia - Two herbal answers to your body's ailing stress response

Some experts believe that the body's normal responses to stress are imbalanced in patients suffering from fibromyalgia. Your adrenal glands, which are situated just above your kidneys, are your body's primary stress responders, and the outer part of your adrenal gland, known as the adrenal cortex, helps your body cope with chronic stress. Your adrenal cortex is under the control of your pituitary gland, which is, in turn, under the control of a part of your brain known as the hypothalamus. This stress-responding trio is called the hypothalamic-pituitary-adrenal (HPA) axis.

In fibromyalgia patients, the HPA axis has been found to function abnormally: The hypothalamus and pituitary overreact, and the adrenals don't respond, as they should. This results in what is known as adrenal exhaustion, which can cause a range of debilitating symptoms like fatigue, irritability, depression and insomnia. Licorice (*Glycyrrhiza glabra*) can help correct this problem. It prolongs the life of the hormone cortisol which helps you respond in times of stress and reduces the burden on tired, overworked adrenal glands to manufacture more of it. The recommended dosage is one to three deglycyrrhised licorice root extract capsules a day. Korean ginseng (*Panax ginseng*) can also help improve the HPA axis response. It increases energy levels and endurance and helps fight stress. The recommended dosage is 500mg a day.

Allergies:



Allergies are on the increase.. They can range anywhere from relatively mild to severe to require emergency medical attention or trying to live with them. Some allergies are caused by dust, mould, pet dander, or pollen. Food allergies can often cause serious reactions too, including anaphylaxis, which is an allergy so severe that the patient may cease breathing. Most people with allergies have simple air born allergies.

They can affect as many as 1 of 2 people, although some are completely unaware of their allergies. From my own experience, my older daughter's and friends I have found most

of the troubles come from major stress which changes the cells in the body thus creating an allergy or intolerance.

The only way to find out what you are allergic to is by either having an allergy test done on the NHS, private or do a process of elimination yourself. You have to be determined to last the course as it can be very challenging at times. I have gone through them all. I found out I had an allergy to Wheat, Yeast, Dairy and Sugar.

What else is there to eat you might be saying? I lived on raw and cooked vegetables, goats and soya products, plain yoghurt, seeds and almonds, wheat free pasta, meats except beef and pork because at that time they were the meats with the most antibiotic injected in it and this upsets the Candida and flora in your digestive system. No alcohol or juice as fruit as these are fungal, it feeds the Candida in our gut which over grows and can eventually go into the bloodstream, creating tiredness, fatigue, confused thinking and many more problems. I could only eat bananas and my mum used to make the odd loaf of bread with out the wheat and yeast of course. I did this for 3 months and only drank filtered water.

How it helped me I can not say in enough words. I lost weight, my skin cleared up, I had clear thinking and I was so positive it was fantastic. This was 15 years ago and I still have the allergies actually I have more now. As life goes by you go through many enjoyable times and unpleasant times which your body reacts with stress. Over the last few years I have tried to do the same diet but found it so difficult as my strength and determination is not what it used to be.

It has been a struggle to get to where I am now however I am slowly getting there 'wherever there is'. Hehehhe You have to have a sense of humour to live with all these issues but it has been hard no doubting that. We all have to go through life as it is a learning process to gain a sense of who you are and what you know. Eating is a well documented challenge for many and I can say I have been at all sorts of levels and experienced more than I would care to know. It has given me an inner strength to improve my life and help to improve yours. I only drink bottled water and have been doing so for 3 months, I have found a big difference in my pain levels. I would like to give you a challenge and do the same.

I can recommend a lady who does allergy testing or you can go see your doctor. Remember you are entitled to see the specialist of your choice so stand your ground with respect. Please let me know how you have got on.



Time for you:

Do you not think you deserve some time out? How are you going to do that? Days are full with different things and as women we usually have to look after the house, shopping, kids, work, a man if you've got one, the pet and maybe the bills. I can give you a few pointers.



1. On the weekend or day off: cook a few dishes on a larger scale. Once cold - portion them out for each child and adult size, label them with what it is, size and date. Put them in the freezer. So when you get in from a long day or are too tired to cook all you need to do is defrost them in the microwave and then heat them up. Have a food thermometer and make sure the food is 65% or above not too much more otherwise it will go hard. If you don't have a microwave make sure you write a note and put it on the fridge so each morning take out what you want for dinner. Make your choice on the day before as mornings can be a harder time to remember. If you just don't have the energy get someone close to you to do the cooking and stock your freezer.



2. Make a decision that you will take time out to indulge yourself without spending any money. Wait until you have time that will not be interrupted, plan what you want to do. If you enjoy hot water take a bath with some soft relaxing music, put some nice smelling bath salts, put several candles around the bath and room, lock the

door if you can if not put a chair or stool in front of the door, this is because it can give you confidence you won't be interrupted and so you will relax more. Turn off your mobile phone and silence your home phone. If you feel you need to let your family and friends know what you will be doing for security and peace of mind.

3. Maybe going out to a park where you can walk and only the birds and small animals are there to share it with you.

4. You might find going out to a friend's house for a chat, meal and relaxing will help.

5. Taking time out with your husband or partner, going for a meal or to see a film.

6. Meditation is the best one and you can do it anywhere that is quiet. In the bath, in bed or in a room in your house that you know you won't be disturbed.

7. Some find a gentle hobby relaxes them.

Not everyone will be able to relax the same way. What is important when living with fibro is to have a routine and put **your time** in it and live for the day. This is a great way to not think about what you have to do tomorrow and crowd your mind even



Benefit Info: As there are a lot of changes being made the best info I can give you is a website that answers your questions clearly.

Citizens advice bureau—Advice guide www.adviceguide.org.uk

BBC website— www.bbc.co.uk

Direct Gov—www.direct.gov.uk

Pain Research: There was a very interesting programme on BBC2 on Monday evening 10pm 'The Secret World of Pain'. Did anyone see it? It is on BBC I Player until the 15th Feb 2011. Did anyone record it on to a hard copy?

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

18th January. Awareness meeting

15th February

15th March

19th April

17th May

21st June

19th July

16th August

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

Tel 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

Last Monday in every month is our regular Coffee Morning

10.30am to 12.30pm

Dates

31st January . 28th February. 28th March.

25th April. 30th May. 27th June. 25th July.

29th August. 26th September. 31st October.

28th November.

Call Help Line for information on venue.

Internet:

Download Newsletter:

If you are on the internet you can download previous copies of the monthly

newsletter via

www.fmswaws.org

Membership is Free - however it is strongly advised to purchase the extensive over 40 pages of information, leaflets and some freebees in the packs.

Membership leaflets are available at each meeting.

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Our Main Charity email:

Fibromyalgia Sussex and Surrey Support

www.fms-sas.co.uk

Contacts:

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

Nichola Bond Tel No: 07796653477 Email: beauty_within_15@hotmail.co.uk

Help and information Line. 08448872394

Game Master & Co Leader: Simon Stuart: 07806 808862 Email: simon10pq@sky.com

Webmaster: Pete MacKean 01903739596 Email: petemackean@sky.com

Fundraiser: Christine Brunton...07905189163

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.