

Worthing Area Fibro Group



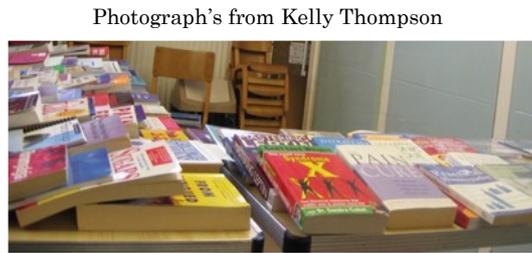
September 2010 Issue 10 Written and Produced by Nichola Bond,
Editor
Simon Stuart & Kelly Thompson

Hello to you all. We are excited to tell you that due to the growth of our group, plus taking on board the contents of the questionnaire, we have adjusted the format of our meetings slightly. We have created more discussion time with a shorter game time. You are all welcome to send me your ideas and thoughts to improve your support group. Please get in touch by email or phone myself Nichola or Simon our details are on the last page of your newsletter. Pictures taken of our Support Group.

Our Information Table.



Our Library



Photograph's from Kelly Thompson

Our Therapist Ghennet



At our August meeting Ghennet won the food competition she made her lovely scones with a hint of almond. She has won herself an hour long Holistic Therapy. I bought along some Jam & Cream and we all enjoyed our cream tea at break time. You asked if we can cook a savoury food which is a marvellous idea. When I was going through my paperwork I found some recipes which are suitable for those who have allergies. This gave me an idea to create a recipes leaflet to give out at the meetings. We need 2 or 3 people to join in the cooking competition, choose a recipe from our new leaflet. At the Fibro Conference in April the speakers spoke about food. Fibro sufferers should not eat Fruit, this can be upsetting news to some but for those of us like me eating fruit aggravates the yeast in the gut and create acidity which triggers of the cystitis and intercytistis which is to do with the Bladder lining being stripped away, we experience sore's in the mouth & pain in the gut to mention just a few. Fibro & food is a fascinating subject as the research has found a connection with a variety of foods and drinks connected with Fibro. This is a massive subject and it will be on - going. I will be up dating our new website with information for you. I advice all who are unsure about having an intolerance to foods, drinks, pollution, sprays etc to have an allergy test. I do have someone locally. Give me a call or text or email.



Charity Event.

We have been collecting all the money in from Dave Chidley's London Marathon, which he did for our group in April. A Fantastic £1000.00 & a few penny's was raised. We would like to say once again thank you very much to all that helped & of course a big thank you to Dave Chidley. His father is Allan Chidley who is a member and volunteer in our group.

Journey: Each time I write anything about my life experiences I find it hard to simplify them. However even though this is a challenge, I thought I would have a go in stages. Writing down your life experiences and reading it back to yourself helps to clear your mind, understand more about yourself & about your health. I also I remember some good events that had been lost. So where do I begin. While we are looking into food I'll start there. Food has played a big part of my life. My parents were chefs & I went to college to become a chef to. My parents owned several restaurants. I grew up in one in Ealing, London. I was put in my pram outside when I was little, I was then promoted to a play pen upstairs in the Bistro, customers would come up to see me. At the age of 10 I had learnt silver service and worked in the Bistro. When I was 15 yrs old I trained knew staff and could run the restaurant. My father was Grand Master Chef the youngest in the 1970's. He was our Royal family's chef, at the same time he worked in 10 Downing street. He also worked for foreign royalty. When I was 16 & at college I worked for foreign royalty. I worked with my parents once we moved to Arundel and then in later years was a publican. So I worked with food most of my life. It became a big shock for me when I found out I had become allergic & intolerant to Wheat, Yeast, Dairy & Sugar. I also had a back problem. At the age of 36 I had a big operation where they put in metal in my L4 & 5 Vertebrae. I was suffering with Candida Albicans and IBS as well as other health issues. I was put on a special diet for 3 months, which I did. I did not eat any foods with the above four ingredients. In those days it was difficult to find foods for me to eat. I looked at every ingredient on everything I picked up. I was at an advantage as I was bought up in the catering. My mother always cooked fresh foods at home. Thankfully as years have gone by the food industry have bought out more and more foods to suit various diets. When tackling this somewhat annoying subject you have to be 100% dedicated as the outcome will defiantly be a positive one.

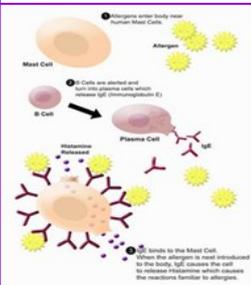
Confidence: There are different ways to become confident, one of them is how we look. Food can be a big factor as a lot of us comfort eat. Fibro can stop you from walking and doing exercises in the beginning and gradually we put on weight. What drives you to eat? How do you feel when you eat? Our skin is affected & we find ourselves suffering with other health issues. Your skin can be affected your thinking can become negative. Things that happen in our daily life will have a big impact on your life. What can you do to help yourself. Meditation, relaxing, talking can all help. Look in your wardrobe, have you cloths that are too nice to get rid of. I did, so I started to cut out lots of foods that were no good for me. I do have treats & I make sure when I do the rest of my meals are small and healthy. I started writing down what I was eating and how I felt at that time and how I felt after eating it. I began to take on board what specialist after specialist had told me, **Exercise**. How on earth was I going to do that as I was in so much pain? I went into the hydro pool every day and did my exercises the more I did it the more my confidence grew. Of course there were days where I couldn't get up out of bed ..Find the confidence in you to turn your health around. Build on your confidence. Ask a friend to come and join you, it's always easier when there are two or more. Go on our face-

Access your positive memories and boost your confidence.

Allow yourself a few moments to settle down, breathing easily and letting go of any tension in your body. Squeeze your first finger and thumb together and let that memory of a confident time fill your mind, pay attention to the details of that occasion, listen to any positive messages within it and notice how the body will respond with a sense of pleasant anticipation. Repeat returning to that memory 3 times, squeezing that finger and thumb each time as the memory and feelings become vivid.

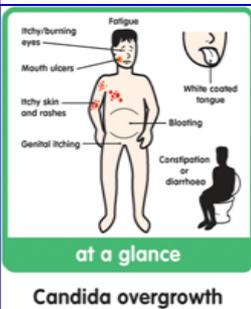
Boost your Confidence Cont..... It is something for you to use through your whole life. Start to do a little exercise before you get out of bed in the morning. Take a walk down to the shop instead of going in the car even if it takes longer. Take the surroundings in as you go, it is an experience seeing things you never knew were there. Take advantage of your confidence to give you the support to reach your goals. Make short goal lists that can be reached, and change them once you have achieved them. Live for the day. Enjoy the good simple things in life, you can't go back so don't regret, enjoy the now. Once you have taught yourself to relax by being confident you will feel happier. There will be tools to help you on our website over the next few months.

Allergies:



Allergies is a very common medical issue. They can range anywhere from relatively mild to severe to require emergency medical attention. Some allergies are caused by dust, molds, 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 people are completely unaware of their allergies. Allergy Testing: I have a leaflet going on to the website. **More information will be put on to our web site shortly.** For members who do not have a computer I can text over the details..

Candida Albicans:



Until very recently there has been little recognition of Candida and even less offered by way of useful and permanent help to fight it, for many people it is a condition which does quite literally ruin lives. In simple terms Candida in a healthy person is quite normal. When a person has Candida the fungus in the gut over populates it morph's to become a pathogenic invasive fungus. This can come about as a result of overuse of antibiotics, steroids, over eats sugar, wheat, yeast, dairy or experiencing extreme stress which hits the body's defences. **Look at the website for more information. If you would like a copy due to not having a computer please ask me and I can either post it out to you or bring it along to the next meeting.**

Celiac:

It appears that Fibro & Celiac share similar symptoms but does this mean we all have both. It also appears that many Fibro sufferers are not tested for Celiac automatically. Some may have a reduction in there fibro symptoms when on a celiac diet. If it helping you then go for it. If you have had a test & it has come back saying you are not Celiac, great one less thing to worry about. From personal experience I have had the test & am not a Celiac but have many people ask me about it. I have had a allergy test which includes pollution and toxins. I should not eat Wheat, Yeast, Dairy, Sugar & Citrus. After avoiding all these products I felt so much better. I have introduced foods back into my diet and slowly over the years my body is starting to rebel again. I am on holiday in Italy while I write this article & have had to avoid a lot of foods as I have been suffering terribly with pains, heart burn and bloated feeling. I have started on Rice Milk instead of soya. Once home I will have to stop all the foods I have a problem with as it is very bad at the moment. I have a friend who has all the symptoms of Fibro and has had the blood test to say she is a celiac. Her doctor is good but does not think she has fibro, she asked me for advice and i set to researching more about the relation between the two. It appears that there are many Fibro sufferers that do have Celiac. At the same time foods that I should avoid should be avoided by just fibro mites. It seems to me we all should look at our diets. When I was diagnosed 10 yrs ago there was no knowledge to look at it has taken all these years for us to have the information which is available to us. This is a very fundamental point that each fibro should seriously look into and hopefully diet can help our condition be easier to manage. Just think you should loose weight too. If you have any questions please email me on youandme1@sky.com or if you have any information that would be useful to other sufferers.

It takes a lot of will power to avoid foods you like but it is worth it in the long run.

Benefit Information...Disability living allowance: Many people are worried the direction that different benefits are taking; especially Disability Living Allowance (DLA) as many of us rely on this benefit for different things; cars (under motor-ability), daily adaptations, special foods, etc. For the elderly DLA can mean the difference between living at home or in a residential care. Richard Hawkes Chief Executive of Scope was recently quoted saying "DLA is not a benefit, but a basic recognition that it is more expensive to live as a disabled person in our society." Most of us had to fight to get DLA it is well known that it is rare to get DLA the first time around and you have to apply sometimes two or three times to receive it, some have had to go to tribunals and some people still not awarded DLA. The chancellor has recently announced that from 2013-2014 that ALL existing claimants of Disability Living Allowance will be subject to a medical as part of the coalition emergency budget changes, the new reform is to **"ensure support is targeted on those with the highest medical need"** and payments **"for as long as the claimant needs them"**. It has not been known yet when the assessments will take place and by which company but is estimates to save the government £1.4bn by 2015! Charities and disabled persons organisations are very unhappy at the news and believe it is likely to be expensive, counterproductive and could increase the burden on an already struggling local authority social care system. I recently had to fight 9 months to get the correct level of DLA ending in a tribunal which I won apparently for LIFE and it is worrying to know this will soon be meaningless. Are they going to have correct standards of tests for fibromyalgia? Which differs from person to person and day?

Source - Personal Knowledge Kelly Thompson and Disability Now (www.disabilitynow.org.uk)

Vitamins:

5 Things You Need to Know About Vitamin Supplements for Fibromyalgia.

1. Fibromyalgia Is Characterized By Widespread Pain.

This non-contagious disorder is characterized by chronic widespread pain, but its symptoms can vary greatly from person to person. From day to day, individuals may also experience a broad range in the intensity and duration of their symptoms. Fibromyalgia is not life threatening, nor is it degenerative, but its symptoms are persistent and greatly impact the sufferer's quality of life. Typical symptoms include muscle, joint or bone pain, difficulty sleeping, and fatigue. However, fibromyalgia sufferers may also experience headaches, facial pain, irritable bowel syndrome, and enhanced sensitivity to odours, noise, touch or bright light.

2. Vitamins Are Required.

Vitamins are characterized as organic compounds that organisms require in small amounts for nutritional purposes. Vitamins have many functions in the body, including functioning as antioxidants, regulators of cell growth and development, and as hormones. Vitamins are classified into two major categories: fat-soluble (absorbed by the help of fats) or water-soluble (dissolve easily in water), and are essential for normal development.

3. Vitamins Treat an Array of Fibromyalgia Symptoms.

The National Fibromyalgia Research Association recommends natural preventive treatment, including vitamin supplements, of the symptoms associated with fibromyalgia. Vitamins may be used to treat various fibromyalgia symptoms including insomnia, joint swelling, pain and fatigue. These supplements may also be used to boost the immune system.

4. Experts Recommend a Variety of Vitamins

Some experts believe fibromyalgia is at least partly due to a vitamin D deficiency and recommend a blood test to determine if your vitamin D levels fall within a normal range. Melatonin, a hormone involved in sleeping, levels may also be below normal range, as many fibromyalgia sufferers complain of difficulty sleeping. Magnesium and malic acid are often used to reduce both pain and fatigue. Individuals with fibromyalgia also commonly take B-Complex vitamins since B vitamins are known to support energy production in the cells. Additionally, low levels of calcium have been found in many fibromyalgia patients. Calcium supplements will also work in conjunction with other vitamins and minerals, for example vitamin C, to repair the damage caused by oxidative stress. Speak with your physician before adding any vitamins or supplements to your diet.

Vitamins Cont.....

5. Tell Your Doctor Which Vitamins You Use

Although uncommon, it is possible for a vitamin to interfere with other medications or to react adversely with its properties. You should compile a list of the names and doses of the vitamins you already take or are interested in adding to your diet in preparation for your next doctor's visit. It is also important to know that the health claims made by vitamin suppliers are not required to undergo evaluation by the Food and Drug Administration (FDA). Prescription medications, on the other hand, go through rigorous testing based on FDA guidelines to ensure patient safety and efficacy of the medication. Since the vitamin market is largely unregulated, it is possible that a vitamin may cause an undesirable or unknown effect. Your physician can help you determine which vitamins will be best for you.

Medical Box:



What Amitriptyline tablets are and what they are used for Amitriptyline belongs to a group of medicines called tricyclic antidepressant drugs. These medicines alter the levels of chemicals in the brain to relieve the symptoms of depression. Its an old fashioned antidepressant which has been found to relieve pain. **Amitriptyline is used for:** to treat the symptoms of depression. for the relief of bed-wetting at night by children. for pain relief to aid sleep. **What Amitriptyline tablets look like and contents of the pack** Amitriptyline tablets are circular, biconvex, film-coated tablets in the following colours: 10mg - blue. 25mg – yellow. 50mg - tan. Pack sizes are 28 tablets

Produced by Debbie Pidd

Book Review: Yoga for Fibromyalgia



I may have mentioned it once or twice (*like here, here, and here*) – I am a huge proponent of yoga. If I had to list the things that have improved my life the most over this past year, yoga would be at the top of my list.

I was fortunate to have a great instructor introduce me to a gentle and restorative type of yoga. She also suffers from Fibromyalgia, and through yoga has learned to find balance, energy, and productivity in her life again. Her transformation with yoga was so encouraging she eventually became a certified instructor and began paying her good fortune forward to eager students like myself. As my love and interest for yoga peaked, I began doing research and came across a great book on yoga tailored specifically for my needs: [Yoga for Fibromyalgia, by Shoosh Lettick Crotzer](#). And as fate, destiny, coincidence or whatever you call it would have it, the instructor who

taught me to love yoga, also uses *Yoga for Fibromyalgia* as the foundation for the style of yoga she teaches. How serendipitous is that?! *Yoga for Fibromyalgia* is based on the principles that “yoga’s physical practices are non-competitive and adaptable to any individual, including those with special needs, such as fibromyalgia.” The author, Shoosh, states clearly that it is her intention to help us find ways to improve our “quality of life by reducing stress, pain, fatigue, and muscle stiffness and by getting deeper sleep.” Don’t you just love her already? Produced by Nicole McGinlay

Our meetings: We endeavour to be informative & supportive; we have a lot of laughter and getting to know other each other. We encourage family, friends & carers to join us. I give a talk and a discussion time where we all get involved. Ghennet is our Resident Holistic Practitioner offers mini treatments throughout the meeting in a private room for a minimum charge. We ask for donations at the door which goes to the up keep of the group. A break is taken during the evening and you have a chance to talk with others while you have a tea or coffee. We also have a food competition where 2 or 3 different people each month make the same dish, then it is judged by someone in the group. The winner gets a Full Holistic Treatment. We have a great Library with CD as well as books. Raffle and information table. We give support at each stage of Fibro, counselling is available, hope, laughter, a social life & information. If you have any ideas that you would like to see at your group meeting and within your support net work then please email me with your idea’s.

Help: We are looking for members to help with raising awareness and funds for your group. It is not hard and you do not need to spend masses of time on it.

I will send you a letter already written out for you to give to your local business's, pub, club or sports venue, you can send them by email & hand deliver. Could you ask your local business's friends and family for unwanted gifts, gifts that can be used for a raffle. Please email me or phone me.

Email: youandme1@sky.com

Tel: 01903691723 or Mob 07796653477

We would like some help in the kitchen at our meetings please, just come in and offer a hand. Also at the end of our meetings we need help to put away the furniture, if you are able of course .

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: 07795563477.

Raising funds for your group: Does anyone like to raise money for your group. Please get in touch with me. My details are below. There are several events you can hold without being stressful like having all your friends round for coffee and asking for donations, opening your garden to the public, asking your local businesses if they would like to offer a free item to go towards your raffle. If you would but do not know how to, don't fear I have a information pack which can be sent to you to get you started.

Internet: Download Newsletter:

If you are on the internet you can download previous copies of the monthly newsletter via www.fmswaws.org

Our Main Charity email:

www.fms-sas.co.uk

If you wish to join the Fibromyalgia Surrey and Sussex Group & receive weekly information

email: webmistress@fms-sas.co.uk

Our Future Dates for your meetings are;

21st September,.....19th October,

.....16th November,

December Date to be arranged—



Christmas Lunch Offer!

As a thank you to you all in helping to create a supportive group, the group will put a % towards every member that books & pays to come to our Christmas Lunch. We will be having it at the David Lloyd Centre in Durrington. We will have copies of the menu from our September meeting & it will be put on to our website. If need be we can post it out to members that do not have the Internet.

More info will be printed in our October Newsletter.

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

Nichola Bond Mob :07796653477. Also used as a **Help Line.** Email: youandme1@sky.com

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

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

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