



Fibromyalgia in Tonbridge

Support Group for West Kent

Telephone: 0844 887 2429 (local)

fibromyalgia.tonbridge@hotmail.com

Working with Fibromyalgia Association UK - Reg charity 1042582

NEWSLETTER - March 2013

Next meeting - April 13th

11am - 1.30pm

Tonbridge Baptist Church, Darenth Avenue, Tonbridge, Kent TN10 3HZ

Car park entrance is in Derwent Road.

Further meetings for 2013 at TBC

June 1st August 10th October 12th December 14th

Some social events will be added in due course

Guest speakers for 2013

APRIL 13th ALEXIS MILLAR - Functional Massage Therapist. More details on page 3.

JUNE 1st Dr. NICK READ - Gastroenterologist & Psychotherapist with the IBS Network.
CAROLINE WRIGHT - Therapist & Reflexologist of The Wright Foot Forward.

AUGUST 10th PIP SALMON - Physiotherapist in Women's Health with the MTW NHS Trust.

OCTOBER 12th PAM WRIGHT - Qualified life balance & health coach. Pam, one of our first speakers, returns help us celebrate our 5th birthday. Many of you will have read her book "The Fibromyalgia Coach", available from our library, and Pam has now published "The Ability Coach - taking the dis out of Disability".



DECEMBER 14th This will be our Christmas Social & Buffet



Membership renewals - these were due in January for 2013

Please note, this is the last Newsletter you will receive if you haven't renewed your membership



- Firstly, a huge thank you to Jackie Maddocks who has taken over providing refreshments at our meetings.
- Many thanks also go to Clare Macro of Clare's Cake Creations, who kindly donates the most delicious cupcakes for our group meetings.
- May I remind all who haven't yet done so, that all memberships were due for renewal from January 1st for 2013. A renewal form has been sent to all members. If lost, there will be forms available at the April meeting. Subscription for the year is £10. You may either bring them to the April meeting, or post them to Treasurer, Sue Ryall at the address on the form. Please DO NOT POST cash. Cheques should be made payable to Fibromyalgia in Tonbridge. Thank you.
- Apologies for the rather abrupt ending to our last meeting which was out of my control. I have been assured that all our future meetings will be in the Darenth room, which we used last year.
- At our first meeting of the year it was good to welcome Julie Nelson – Co-ordinator of the Maidstone & The Weald Fibromyalgia Support Group. Julie has been providing temporary cover as Kent's FMA Regional Co-ordinator, since Christine Brown's resignation last summer.
- At the present FMA UK are handling nominations for all posts of RCO and Assistant RCO nationwide, as required every 3 years by their constitution. I will update you with any changes affecting us in the South East region, once FMA UK has completed this process.
- I have arranged Guest Speakers for all our 2013 formal meetings and I trust that you will all enjoy listening to, and engaging with them.
- It was good to welcome both Elaine & Stella, two new faces at our February meeting.
- Happy Birthday to us!! That is we - Fibromyalgia in Tonbridge (FiT) - will celebrate our 5th Birthday this October. WOW.... where has the time gone & now we are "all grown up"! For our meeting on the 12th October, I am very pleased to announce that our Guest Speaker will be Pam Wright - Life Balance and Health Coach and author of "The Fibromyalgia Coach". Pam also writes a regular column in The Fibromyalgia Magazine for UK Fibromyalgia. It would be good to have suggestions from members of how else we can mark this milestone. Maybe we could have a Birthday lunch or tea party, with a cake & candles. Perhaps it would be an ideal opportunity to have an open meeting, for the public to attend. Let me know what you think.
- The Questionnaire, devised by our very own Susie Connor and sent to all members was discussed in full at the February meeting. It gave members the opportunity to have your say about how the group is working for you. There were various suggestions, and ways that changes or additions may be implemented from the feedback, have been discussed at our recent Committee meeting. We are looking in particular at how to give members more chances to chat with each other.
- FMA UK have written a fitting tribute in the sad loss of Christine Craggs-Hinton, who passed away in January, in Tenerife where she had lived with her family since 2007. Christine, herself a fibromite, was a friend of FMA UK and supported the fibromyalgia cause. Her first book "Living with Fibromyalgia" was published in 2000, the first British book on the subject. Her latest book "Fibromyalgia – Your Treatment Guide" has just been published, which I'm sure will be in great demand. I will certainly be purchasing my own copy.
- Please see information later in this Newsletter about the ASK meeting on April 17th The subject is Pain Control & Management, so useful for all.
- Tonbridge Taster Day - Sunday 23rd June. It would be great to have a stall at this event but, as discussed at the last meeting, if there is to be a real feasibility of FiT doing this, we will need MEN & MUSCLE on the day. Therefore we need positive feedback from volunteers, before I can consider making a booking.
- At our recent Committee meeting I shared with fellow committee members, my intention that, at some point during this year, I shall be stepping down from my role as Group Co-ordinator & Secretary. By our 5th birthday celebrations in October, I will have led the group for 4 years. At the moment I am not aware of anyone waiting in the wings to take over the responsibility for this busy role, so please let me know if you are interested. I am happy to discuss the requirements of the role, for consideration by anyone who would like to approach me informally in the first instance. In the meantime, I will work with you all to find the best way the group can continue to support members. Further details will follow in subsequent newsletters.
- Warm wishes to you all for 2013. I look forward to seeing you at future meetings & social events.



April 13th Guest Speaker - Alexis Millar

Alexis Millar trained for 3 years in osteopathy at the British School of Osteopathy in the 1980's. In 1999 she qualified in therapeutic massage, anatomy & physiology and aromatherapy. She is also a qualified Massage and Cancer Practitioner (Diploma 2011).

She helped with the administration of a "Special Needs School" for 'severely disabled children to young adults' and had a practice in Sidcup.

She moved to Tunbridge Wells, and works within the physio team of a local hospital (since 2007) with a variety of in-patients and out-patients.

Alexis offers massage treatments in your own home or at her Langton Green studio. Her clients include many people with chronic pain and immobility, as well as those recovering from surgery - including scar tissue massage. Her treatments involve a concise case history of medical or skin conditions, a body examination, followed by a specific therapeutic massage with a massage pressure suitable for each client. She gives both post-massage and postural advice.

You can contact Alexis by email: info@alexismillar.co.uk or telephone: 07769 809 270

Tribute to Christine Craggs-Hinton from FMA UK website

We have recently learned of the sad news that Christine Craggs-Hinton has passed away at the age of 60 at Tenerife's Hospiten Rambla. Christine leaves a husband, David, sons Mark, James and Mathew, her mother, Mabel and a brother, Glenn. Born in Bradford, and lived there for most of her life, Christine was forced to take early retirement from the Inland Revenue in 1992 because of her health after contracting fibromyalgia. Involved with the West Yorkshire fibromyalgia support group including writing its newsletter, she went on to write a self-help and information book on fibromyalgia, based on her experiences, and found a publisher in 1999. It was published in 2000 and became the first British book on the subject. To date, it has sold over 50,000 copies. She has since written several books on fibromyalgia with her latest book just being published.

Christine moved to Tenerife in 2007 because of its climate which led to her having a better quality of life with improved pain levels. Her husband said: "Christine struggled with her health for many years and because fibromyalgia is an incurable, painful, chronic condition, we found that she was so much better in warm, dry climates."

Christine has been a friend of FMA UK and many of those involved with the fibromyalgia cause. Her passing will be felt by many whom she has helped over the years. Our thoughts and prayers are with her family

Arthritis Support Kent

ASK meets monthly at St Philips Church, Birken Road, Tunbridge Wells TN2 3TE

ASK 2013 meetings – all are on Wednesdays, beginning at 2pm

6th March 17th April 15th May 12th June
11th September 9th October 13th November 4th December

NO MEETINGS in JULY or AUGUST

However, you are all welcome at St Philips throughout August for our coffee afternoons on Wednesdays at 2pm

ASK – April 17th Meeting

This meeting may be of particular interest to FiT members as the speaker is Lesley Harman SRN/CNS Specialist Pain Management nurse with Maidstone & Tunbridge Wells NHS Trust's Chronic Pain Clinic. This continues from Lesley's previous talk on pain management. The April topic is Injections and Psychological Strategy.

If any FiT members are interested in attending, but need transport, please contact Dawn or Susie who are planning to go.

Cognitive Difficulties

by
Susie Connor

One of the symptoms of fibromyalgia syndrome that many of our members have found most frightening when first encountered, is the cognitive impairment associated with FMS.

When you first.....

- find you are forgetting things persistently at home and/or at work
- have trouble concentrating when reading, listening or talking
- stop in the middle of what you are saying because you have forgotten what you are discussing
- stop in the middle of what you are saying, and look at the other person expecting them to continue, because you think *they were talking*
- use completely the wrong word in sentences without being aware of it
- constantly typing the wrong version of words with two spellings such as there and their... *and spell check's no use as they are both proper words!*

.....it is understandable that you start to worry that you are showing signs of dementia – whatever your age. The degree to which these problems affect each fibromyalgia sufferer varies enormously, but it is linked to sleep disturbance symptoms, caused by lack of 'level 4' restorative sleep.

Once you reach middle age, people will tell you "it's our age dear, I have the same problem" – but you *know* it's not the same thing at all. Somehow our brains just don't always 'join up the dots'. Personally, I can look at a date in my diary, see there is something there and still go ahead and book something else for the same time! If away from home I put things in my diary but forget to add them to the calendar and vice versa if at home. When I try to remember things, it sometimes feels as if there is literally a gap in my brain where the link just isn't working.

There are a couple of upsides to the situation for me. Firstly, I can happily watch the endless repeats on TV, because I might recognise the story as it unfolds but I can't remember what happens next. Secondly, I used to remember *everything* those around me said or did. This made forgiving and forgetting a difficult thing for me. Now when I wake it is as if the slate's been wiped clean. I start each day afresh and can't remember much from the day before, so worries don't pile up; upsets or annoyances with people don't get added to previous anger and build up the way they used to. It's a calmer, happier, more relaxed way to live life. Given the number of negative aspects there are to FMS, it helps to find a positive slant.

Fighting the Fog

There are a number of ways to improve brain function generally, which will also help FMS sufferers to fight the fog. These include:

Hydration – When you feel the need for a mental boost, drink some water to keep the mind alert. Coffee, even decaff, tea and soft drinks will give you a momentary kick but they actually dehydrate muscles and constrict blood vessels making you feel even more tired. Each cup of coffee takes the equivalent of two cups of water from the body's reserves. It's frequently seen in the elderly that dehydration can lead to increased confusion, but it can happen at any age.

Exercise – Although many of us are unable to undertake cardio-vascular type of exercise, anything which improves blood and oxygen flow to the brain will help e.g. walking, yoga, swimming or hydrotherapy in warm water.

Games – Work with dementia patients has shown that doing puzzles, quizzes, crosswords, Sudoku and jigsaws can increase mental cognition.

Stimulating environment – Colours can have a significant impact on the subconscious. The right colours can work to combat fatigue and pain. Find what works best for you and decorate rooms, particularly work areas, in colours which stimulate e.g. yellow, but don't over-hype the brain e.g. vivid orange or green. There are colour therapists who can advise on this. Smell is the strongest of the senses and various aromatherapy oils can have a stimulating effect on the brain e.g. lemon and peppermint.

Happy and positive thoughts – Memory function is adversely affected by stress, tension, anger, unhappiness and

overwork. Most fibromyalgia sufferers probably feel all these at times. Removing stressful influences and negative people from your life, wherever possible, and focusing on happier aspects, may help to improve memory function.

Watching TV – passively watching TV can be detrimental but, as with playing word puzzles, watching quizzes on TV and joining in trying to get the answers stimulates the mind as if you were playing a quiz game with friends.

The Internet – It has been seen in studies at UCLA, that surfing the net stimulates the decision making and complex reasoning centres in the brain. However, using computers too close to bedtime means the same stimulation may prevent you getting to sleep.

Foods – It is well-known that certain foods are good for the brain. The main source being proteins. Other foods help to provide vitamins and minerals and it is preferable to get these from food rather than supplements. Wherever possible organic and free range produce are better. Brain feeders include: Avocados, bananas, beans, beef, berries, Brazil nuts, broccoli, brown rice, Brussels sprouts, cabbage, cheese, chicken, eggs, greens, herring, lentils, mackerel, milk, oats, oily fish, oranges, peanuts, peas, pecans, potatoes, romaine lettuce, salmon, sardines, soybeans, spinach, tomatoes, trout, tuna, turkey, walnuts and yoghurt.

Two herbs which are considered to be the most beneficial for the brain are ginkgo biloba for combating poor concentration, poor memory and fatigue, and ginseng for helping the brain adapt to stress.

There are some products which are considered particularly detrimental to brain function such as alcohol, artificial sweeteners, cake frosting, chemical food additives & colourings, fizzy drinks, hydrogenated fats, nicotine, processed sugars and therefore, sadly, sweets.

Memory Problems or CRS - Can't Remember Stuff!

This article is from FMA's support group resources

Many individuals with fibromyalgia experience cognitive problems. Trying to remember a name, putting the wrong word in a sentence, forgetting what your boss just told you to do five minutes ago, misplacing things, an inability to concentrate on reading or studying, are common complaints by many FM patients.

Sometimes these problems in cognitive functioning are referred to as "fibro-fog". When fibromyalgia symptoms are flared, often memory and concentration problems will also be more severe. It is not fully understood why this occurs because the brain's processing system is very complex. It is known however, that poor sleep quality exacerbates cognitive problems. As you get better from a flare, difficulties with memory and concentration should improve.

If cognitive problems are really extreme, sufferers should discuss these symptoms with their GP.

Tips for coping with memory problems

- ▶ Use a desk calendar large enough to write in the activities you need to do each day. Check it every day.
- ▶ Make a list of important phone numbers for each phone in your house. Tape it to the wall or inside your cabinet so it doesn't "walk away", preferably right next to the phone.
- ▶ Keep a pad of paper next to your favourite chair with a pen to jot down notes to yourself.
- ▶ Buy a pocket recording message tape player that you can speak into and leave audio messages to yourself. Don't forget where you keep it!
- ▶ Talk to your doctor about your memory problems. He or she can determine if you need medication and/or if depression is contributing to your memory problems.
- ▶ Consider seeing an occupational therapist. These health professionals will often suggest excellent memory compensation techniques to use until your memory and concentration improve.
- ▶ Exercise your mind. The more you do to use your mind; you may find your memory problems decrease. Do crossword puzzles; try to read interesting articles or books.
- ▶ Try to avoid taking oral directions when travelling by car. Keep a notepad handy on which to write directions and any other important information you need to remember.
- ▶ Speak to your family about your memory problems. It will save you some worry!
- ▶ Don't feel bad when you ask someone to repeat something they just said. Tell them you have CRS (Can't Remember Stuff)!
- ▶ If your memory is interfering significantly with work you may need to talk to your supervisor or someone in the Human Resources Department. Explain the specific difficulties that you're having with your memory and ability to concentrate. Often it's better to get things out in the open. Allow yourself more time for projects at work or make the decision to do some extra work at home.
- ▶ Avoid stressful situations when you can. They often make memory problems worse.
- ▶ Leave tasks that require concentrated effort for those times of the day and/or week when you feel better.

- ▶ Divide tasks into smaller portions. Do a little at a time and they will seem more manageable.
- ▶ Keep lists! Try to keep your lists in a planner or at a specific spot in your house. For example, on a desk or table in the kitchen or another room you frequently inhabit, such as the family room. Some individuals find that Post-It notes are helpful.
- ▶ You need to train yourself to follow a routine with easily misplaced items. Strive for consistency. Once you have trained yourself, it will become automatic for you. Plus it will save you a lot of time and frustration. If you misplace something, you will ultimately find it. Don't be too hard on yourself. Simply recognise that this is part of fibromyalgia.
- ▶ Being generally forgetful is part of fibromyalgia. Some people can do well with memory tricks such as trying to associate a person's name or an object with a familiar object or something important. Writing things down forces you to focus on things you want to remember. You should give yourself "permission" to forget. Experiment to find out what your best memory technique is and use it. Fibromyalgia will certainly give you many opportunities to do this.
- ▶ You can train yourself to stop and review what you have to do and where you have to go, before leaving the house. That way you sometimes can remember anything you might have forgotten.
- ▶ Try to go through files, drawers, and wardrobes regularly to get rid of unneeded clutter that just frustrates you, with the goal of keeping everything simple and pared down to essentials.
- ▶ At times you may need to decrease your sensory input (noise, lights and interruptions) and give your body/mind a chance to restore communication links. Sometimes decreasing sensory input helps. That's one of the reasons we often need to turn off the radio in the car. It's easier to concentrate on our driving with fewer distractions.

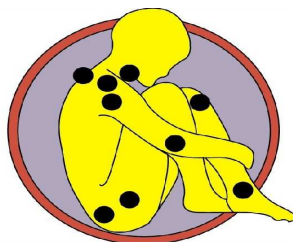
Reference: Taking Charge of Fibromyalgia by Julie Kelly M.S., R.N and Rosalie Devonshire M.S.W.



Our library of fibromyalgia related books, DVDs, CDs and other information may only be borrowed by **registered members** of FiT support group. The items must be recorded by the "librarian" on index cards/lists provided and returned at the following meeting.

We are always grateful for donations of any relevant books, particularly those that members themselves have found helpful. They do not need to be new. Second hand is fine! If you have any queries about the library please contact Susie Connor at meetings or by email: susieconnor@live.co.uk Thank you.

The inclusion of articles and features in this newsletter is for information only and does not necessarily infer endorsement by the Group/Association. Any advice or recommendation of a medical nature, given in this newsletter, should always be discussed with a medical professional. The Group/Association cannot be held responsible for omission and/or errors.



FIBROMYALGIA in TONBRIDGE

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TO CONTACT US

Support group helpline - 0844 887 2429 fibromyalgia.tonbridge@hotmail.com

Group co-ordinator - Dawn Weller - dawn_weller@hotmail.com

Newsletter Editor - Susie Connor - susieconnor@live.co.uk

Social events organiser - Vidette Purchard - happdet@aol.com