



Fibromyalgia in Tonbridge

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Affiliated to Fibromyalgia Association UK - Reg charity 1042582

NEWSLETTER JAN/FEB 2012

ALL 2012 meetings will be held on the 2nd Saturday of alternate months

February 11th April 14th June 9th August 11th October 13th December 8th

Saturday 11th February meeting 11am - 1.30pm Tonbridge Baptist Church, Darenth Avenue, Tonbridge TN10 3HZ **This month we do need to make a prompt start** so if you can arrive a little earlier that would help but of course you can join in at any time. Our guest speaker will be Stephen Elsdon, CEO of the local charity Compaid. He will talk to us about the work of the organisation and the services they offer.

NEWSFLASH - Margaret and Ron Robson **WILL** be coming to our meeting - see Dawn's Desk. Margaret will give us a talk on how the Alpha-Stim can help with pain relief/relaxation/mental focus

Our library of fibromyalgia related books, DVDs, CDs and other information will be available for members to peruse and borrow. There will also be the usual raffle, time for Dawn's notices, refreshments and the opportunity to chat with fellow 'fibromites'.

Raffle prize donations are always needed and gratefully received, thank you.

ON SALE AT MEETINGS

Enamel FMA (UK) badges	£1.50	Plugmates	£0.50
Fibromyalgia awareness wrist bands	£1.50	Cherry Active drink with dispenser	£12.00
Fibromyalgia awareness ribbons	£0.50	Cherry Active drink refill	£10.00

If anyone has ideas for fund-raising or potential sponsors please call Group Co-ordinator Dawn Weller on 0844 887 2429 or via the group's email address:

fibromyalgia.tonbridge@hotmail.com

Membership Subscriptions

Just to remind members that membership renewal forms have been sent out and subscriptions (£10) are due this month. **ALL** members need to complete and return their form please.

Subscription payments may be made in person at the February meeting, or by post to Treasurer, Sue Ryall at the address on the form.

Cheques should be made payable to Fibromyalgia in Tonbridge. **Please do not post cash.**

DAWN'S



DESK

- Happy New Year to you all & to your families. With the festivities now firmly behind us, we can look forward to Springtime, the Queens Diamond Jubilee celebrations & the Olympic Games. Due to circumstances beyond our control we will be meeting on the **second** Saturday of alternate months throughout 2012. February & April meetings will be in the DARENTH ROOM at TBC. This is the room on the Darenth Avenue bus stop side of the church.

- It was with great pleasure at our December meeting that I was able to hand over a cheque for £545.00 to group Treasurer Sue Ryall, from Waitrose store in Tonbridge. This was our share of the proceeds of the Waitrose Community Matters scheme, collected in store for the month of September 2011. We extend our thanks to all of the customers who kindly donated their charity discs to support Fibromyalgia in Tonbridge. The donation will be used in many ways to continue running the group, supporting members & their families, ensuring we remain in touch with our members. Our sincere thanks are extended to Hazel Barnes of Waitrose who runs the scheme in store.

- It was lovely to see four new faces at our December meeting; Carolyn, Stephanie, Tracey & Julia. We look forward to seeing you in February & hope that you will register as members of FiT.

- Research Partnership with PIP Health.

Information can be found on the FMA UK website: www.fmauk.org "From the Trustees"

In the future FMA UK will be working with a research company to better understand people's experiences of Fibromyalgia. Through the partnership they hope to be able to increase awareness of Fibromyalgia and work with healthcare providers to help improve how the disease is diagnosed and treated.

PIP Health is a research company that aims to increase understanding of patients and improve the care they receive. They do research, mostly through online surveys and use the results to represent the voice of patients with healthcare providers, who pay them for their research. They will also be doing research for FMA UK, which we can use to raise Government, medical community and media awareness of Fibromyalgia.

For every person who signs up to take part in research through this link PIP will donate £1 to FMA UK and a further £1 for every survey completed. So, please sign up for PIP Health now and help us improve healthcare for others with Fibromyalgia.

Please log on to: <http://www.piphealth.com/Default.aspx?id=31&ids=454345&ref=chfb> Thank you.

- Those of you with Internet access may already be aware of the Benefits and Work Publishing Ltd website www.benefitsandwork.co.uk It is an invaluable resource in relation to a whole wealth of benefit entitlements, giving very practical guides for new applications and excellent advice on the appeals process. FiT has taken up professional membership for the next twelve months to access all available information. If you don't have the internet, please do not hesitate to contact me if you would like me to find specific information on your behalf. If you wish you can take out individual annual membership for £19.45. Email: info@benefitsandwork.co.uk

- Fibromyalgia Conference & Pampering Weekend - Easter weekend April 6th -9th inclusive
There is still some availability of rooms at the Chichester Park Hotel, Chichester where the conference is being held. The cost of 4 days/3 nights is £179 per person (sharing a twin room). A deposit of £90 per person is required when booking. Price includes full board/conference/ workshops

The hotel has a warm indoor pool. Please see flyer for further details. It's attached for those on email, otherwise contact Dawn for a copy. Or contact: Simon Stuart - Fibro Conf 2012 Booking Manager email: simon10pq@sky.com or phone 01243 817400.

● Margaret & Ron Robson

Those of you who have been members of the group since FIT was launched in Autumn 2008, will be aware that Margaret Robson - Co-ordinator of the Medway Fibro support group was instrumental in setting up our Tonbridge group, bringing member volunteers together to run the group. Margaret & Ron will soon be moving to Eastbourne and Margaret has therefore resigned from her post as Regional Co-ordinator for the South-East area.

Christine Brown has agreed to cover the Kent area, until such time as a new RCO is elected. Christine is based in Nottingham & has extensive knowledge of FM, having been local and regional co-ordinator for many years. Christine also brings together the work of all the Regional Co-ordinators on behalf of FMA, so is a very busy lady.

Margaret will be travelling back to run the Medway group meetings until the end of September if necessary, until new volunteers are found. Anyone wishing to keep in touch with Margaret on a personal level can still use her same email. I have invited both Margaret & Ron to our February meeting if their prior engagements permit.

● Arthritis Support Kent have their next meeting on Wednesday 15th February at 2.30pm. Venue St Philips Church, Birken Road, Tunbridge Wells TN2 3TE. You can contact ASK on 01892 534341

● e-petition For the DWP to recognise fibromyalgia as a real disability.

If you have internet access, please sign this e-petition submitted by Rachel Patterson. Responsible department: Department for Work and Pensions

"It's time the DWP recognised Fibromyalgia (FM) as a genuine disability. The impact this chronic condition has on the sufferer's life is enormous and for too long we have had to suffer in silence as a forgotten minority. The DWP does not yet acknowledge this as one of their 'listed' conditions for the application for DLA, and their medical test does not allow for the many debilitating symptoms of this severe condition. . FM reduces a person's ability to function physically and cognitively and as a consequence work life suffers to the point where sufferers lose their jobs and are unable to support themselves or their families. The government must now take action to help FM sufferers by getting the DWP to recognise this condition and adapting their assessment methods accordingly so those affected by FM can live with dignity and receive the support that is currently lacking"

<http://epetitions.direct.gov.uk/petitions/12627?mid=57>



DECEMBER 2011 MEETING – Guest speakers

At our last meeting we were given two excellent talks by local therapists Caroline Wright and Claire Amos. Carolyn introduced us to reflexology & meditation and Claire demonstrated her work as a chiropractor. Caroline and Claire both have nursing backgrounds and are now independent practitioners within their chosen fields.

Caroline Wright - The Wright Foot Forward.

Carolyn is experienced in reflexology, indian head massage and hypnotherapy. She is also qualified in neuro-linguistic-programming, having gained a Diploma with Distinction, which is accredited and recognised by the Royal College of Nursing. Neuro-linguistic programming (NLP) is an approach to communication, personal development and psychotherapy that was created in the 1970s. The name refers to a stated connection between neurological processes, language and behavioral patterns that have been learned through experience, and can be organised to achieve specific goals in life. Caroline also specialises in stress management, anxiety, fears and phobias.

In addition to her busy practice, Caroline works voluntarily for a few sessions per week at the Hospice in the Weald. She provides hypnotherapy, reflexology and massage for patients with cancer and other long term degenerative diseases. She often integrates hypnotherapy with reflexology to help reduce stress for certain conditions, often enabling clients to reduce their medication. Caroline undertakes continual personal development through attendances at master classes and seminars. For more information or to make an appointment contact Caroline on 07855 731416 or email enquiries@thewrightfootforward.co.uk

Claire Amos practices as a McTimoney Chiropractor at **Crowborough Chiropractic & Nutritional Health** and can be contacted on 01892 668852. The McTimoney method is well known for being a precise, whole body approach to chiropractic care. The gentle nature of the McTimoney method makes it suitable for people of all ages. UK members of the McTimoney Chiropractic Association are registered with the General Chiropractic Council.

Chiropractic is a straight forward method of adjusting the bones of your body to improve the alignment of your skeleton, and through this process to rebalance the body to help the nervous system to work more efficiently, to relieve pain and discomfort, and increase mobility. A misalignment of the joints can occur for many reasons; some of the most common are incorrect lifting, car or sporting accidents, falls, stress and poor posture. These can lead to pain, numbness, pins and needles, or restricted mobility.

Claire used a model of the spine to demonstrate the way it works, where it should remain fixed and where flexible, and to show us the effects of poor posture and injury, such as compression of discs and trapped nerves. She demonstrated some simple exercises for improving the balance of the spine – to be undertaken slowly and carefully by fibromites.

The following conditions, common in people with fibromyalgia, can benefit from chiropractic care:

- Back, neck and shoulder pain
- Pain, discomfort and stiffness in joints
- Migraine
- Muscular aches
- Arthritic pain
- Sports injuries (not so likely with FM!)



HANDLING STRESS

A lecturer, when explaining stress management to an audience, asked; 'How heavy is this glass of water?' Answers ranged from 20g to 500g. The lecturer replied, 'The absolute weight doesn't matter. It depends on how long you try to hold it'.



audience, raised a glass of water called out ranged from 20g to 500g. matter. It depends on how long you

If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case, it's the same weight, but the longer I hold it, the heavier it becomes.'

He continued, 'And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden feels increasingly heavy, we won't be able to carry on. As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden.'

So, before you return home tonight, put the burden of work down. Don't carry it home. You can pick it up tomorrow. Whatever burdens you're carrying now, put them down for a moment if you can. Put down anything that may be a burden to you right now. Don't pick it up again until you've rested a while.'

KEEPING POSITIVE

“Every day may not be good, but there is something good in every day”.

(Donnie Kuhn, Sr)

Keep a little pocket diary by your bed.
good things from the day.



Each night before you go to sleep, write down 3

They need not be major events. Sometimes you might have to try a little harder to get to 3, but hopefully even on your worst days, the memory of things as simple as blue sky on a cold winter day, an emailed joke or TV programme that made you laugh, time spent chatting with a friend, before you go to sleep, will lift your spirits and set you up for a better night's sleep. The more often you do this, the more your mindset will shift to the positive in life, and lift some of the burden of being in pain.



Here are some great attitudes and thoughts for helping with the burdens of life and keeping positive, in spite of the challenges you face.....

- * Acceptance is the first step on the path to happiness.
- * A truly happy person is one who can enjoy the scenery on a detour.
- * Happiness is not so much a matter of having everything you want, but of being happy with what you have.
- * Accept that some days you're the pigeon, and some days you're the statue.
- * Always keep your words soft and sweet, just in case you have to eat them.
- * Always wear stuff that will make you look good if you die in it.
- * If you can't be kind, at least have the decency to be vague.
- * If you lend someone £20 and never see that person again, don't stew - it was probably worth it
- * It may be that your sole purpose in life is simply to be kind to others.
- * Never put both feet in your mouth at the same time, because you won't have a leg to stand on.
- * Nobody cares if you can't dance well. Just get up and dance. If you can't stand, sit and wave your arms about. If that hurts too much, close your eyes and imagine yourself gliding around serenely, or bopping the night away.
- * When everything's coming your way, you're probably in the wrong lane; so rethink & try changing lanes.
- * Birthdays are obviously good for you. The more you have, the longer you live.
- * You may be only one person in the world, but you may also be the world to one person.
- * Some mistakes are too much fun to only make once.
- * We could learn a lot from crayons... Some are sharp, some are pretty and some are dull. Some have weird names, and all are different colors, but they all have to live in the same box.

TOP TIPS for FIBROMITES

This month's tips from one of our members

If you have children, explain to them simply about fibromyalgia and how it affects you, so they can understand why you need them to help you on your more challenging days*

Pace yourself

Drink lots of water

Do a little exercise regularly and build up slowly - not all in one go

Not more than three coffees per day

Do something you like every day and don't feel guilty about it!

* I think this is a topic that would help many members and I will be researching it for a future issue. I would really appreciate any members letting me know their own top tips, so that we can all share them. Also, please let me know if there is a subject that you would like covered in our newsletters.



SOME INTERESTING WEBSITES

fibrotv.com

Creator, Jen Reynolds says "FibroTV is a weekly Podcast designed to bring the chronic illness and chronic pain community together in a POSITIVE way. It is a place to educate family, friends, the public, about fibromyalgia. I have had fibromyalgia since I was a young teen and a lot of the support sites are very negative which is to be expected because of the symptoms of fibromyalgia syndrome. But I want people to use this place to encourage, dream, hope, believe that even though fibromyalgia can be debilitating we need to focus on our abilities not our disabilities. I am in no way implying that you can think your way out of this syndrome but I do believe if you focus on the positive things, it will have great benefits to your over all health. What is so awesome about this is that it is FREE! Being positive will work better than any pill you can take! Your thoughts are in your control, and they can be very powerful. So lets start the positive healing!"

As well as the podcasts FibroTV.com has blogs, inspirational stories and live chat which can be followed on the website, with Twitter and Facebook

overcomingpain.com

Author Mark Grant MA says "Inside these pages you will find a collection of information and resources to help you apply this knowledge to your healing ranging from free tip sheets to a comprehensive self-healing program - Change Your Brain Change Your Pain (book and CD)".

Overcoming Pain approaches life with chronic pain problems from the psychological perspective, based on the way we can retrain our brains to perceive things differently.

fibromyalgiasyndrome.co.uk

John Rowlinson explains "FibromyalgiaSyndrome was formed to offer a unique reference point on the symptoms and treatments for joint pain and fibromyalgia. The FibromyalgiaSyndrome website is designed and written to help support people with fibromyalgia, and their families, friends and colleagues. It provides an approachable and easy-to-read introduction to fibromyalgia syndrome, and gives no-nonsense information about living with this potentially long-term disorder".

This website explains the facts, symptoms, medical aspects and treatments for fibromyalgia in a way that is easy to read and understandable for the non-medic. It may be particularly useful for those who have been recently diagnosed.

painsupport.co.uk

Author Jan Sadler introduces the website "If you're in pain - this is the site for you. Find advice and support - and relief from pain. The PainSupport website is packed with pain relief techniques for those with chronic pain. There is also a regular email **Newsletter**, a lively **Discussion Forum** and a **Contact Club** for making new friends, plus our **Shop** for books, relaxation CDs and downloads.

Jan Sadler, author of 'Pain Relief Without Drugs', designed the PainSupport website for anyone with pain of any kind, their family, friends and carers. If you are looking for pain relief, friendship, support or information, this is the site for you! All the ideas and techniques on this website can be used to enhance any medical treatment you may be having. No matter where your pain - back pain, neck pain, knee or leg pain, arthritis, sciatica, fibromyalgia, or pain from any other condition, there is help for you here, on the PainSupport website.

This site is run by Jan Sadler who lives with chronic pain herself. Each month she produces a newsletter distributed free of charge via email. Jan writes articles, from her own experience, that tackle a major aspect of long term illness each month.

NB – these websites are listed for your information only. This does not infer endorsement by Fibromyalgia in Tonbridge Support Group.

THE PAIN SUMMIT 2011

The Pain Summit 2011 took place on Tuesday 22 November at Central Hall, Westminster. The Summit was well attended by a wide variety of delegates, ranging from health care professionals to commissioners, academics and patient groups. The morning session included addresses from Earl Howe, Professor Sir Bruce Keogh and Professor Dame Carol Black, combined with accounts from patients and professionals and two panel discussions. Delegates then split into smaller groups to attend workshops on the themes of 'Education', 'Public Health: The Wider Context of Pain' and 'Quality Commissioning' in order to discuss the issues that these subject areas raise for chronic pain.

In the afternoon, delegates heard from four speakers about current measures aiming at improving the lives of those living with chronic pain: The Health Foundation's Cocreating Health Initiative, Pain UK, the British Pain Society (BPS) Pain Patient Pathway Mapping Guidelines, and the role of the Royal College of General Practitioners (RCGP) Clinical Champion for Pain.

After brief reports of the workshops, Dr Beverly Collett, Chair of the Pain Summit Steering Group, spoke about next steps for the Pain Summit, before the day was concluded with remarks from former Chief Medical Officer, Professor Sir Liam Donaldson.

Above is intro text from the Report - The full report has been attached to emailed newsletters and a copy is available from our library for other members to read.

JANUARY'S CLASSIC "FIBROFOGGIE"

Yesterday my friend asked me if my orthopaedic appointment today was at Sevenoaks and I said 'No, Maidstone'. This is a bit of a clue to what happened today. Steven said 'which hospital are we going to, Sevenoaks?' I replied 'No, Maidstone' ... you've already guessed haven't you? We set off a little later than planned, but still with enough time for Steven to get me to Maidstone hospital and leave me at the main entrance in a wheelchair, while he parked the car and then returned to trundle me along to the orthopaedic check-in.

As we were cruising down the M20 I decided to look at the appointment letter to find which clinic it was.... 'Oh heck' says I to Steven, 'it **is** Sevenoaks!' Fortunately we hadn't yet reached the Snodland exit, so Steven turned off there, changed direction and calmly headed back to Sevenoaks.

Then out of the blue, I became uncertain whether I would need the newer outpatients & physio building or the old hospital where the X-ray and minor injury departments are. Silly really, but I was becoming less logical by the minute – as sometimes happens - so along the way I phoned the number on my appointment letter to find out which building I needed.... that number took me to somewhere deep in the heart of Maidstone & Tunbridge Wells Trust where they had no idea which building I needed.... They couldn't even find the number for Sevenoaks hospital for some time! Eventually they produced it, so I phoned Sevenoaks myself and found it was the newer building after all. All rather stressful, causing my fibro-mind to become increasingly blurry. We arrived with time to spare and no-one else waiting. It was calm and quiet. I was called after a few minutes and saw a very pleasant, unhurried doctor.

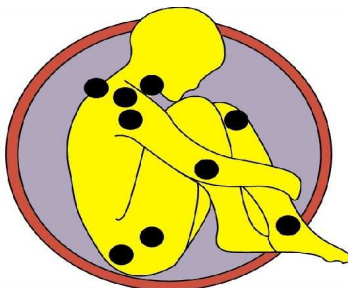
So, we headed home but when we got here I discovered I hadn't got my hand bag! I phoned the hospital who found I'd left it next to the examination couch, and I sent my long suffering hubby back to the hospital where he found himself saying to the male receptionist "I think you've got a handbag for me!" Thank goodness it **was** calm, quiet Sevenoaks and not the chaos that is usually found at Maidstone!

It could happen to anyone, couldn't it? **Been there – got the t-shirt!**

If any members have stories to share, about fibrofog, your personal journey through the illness, or anything else related to living with fibro, please let me know. I can do the writing, if you will tell me your tale.



The inclusion of articles and features in this newsletter 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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