

FIBRO NEWS



North Somerset Fibromyalgia Support Group

Oct 2008

Issue 79

Chair

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2008 DIARY DATES

Date	Topic	Speaker
October 29th	Herbalist	Sue Hinchley
November 26th	Craft Session	
December 17th	Christmas Party	

Meetings are held the last Wednesday of each month

10.30 – 12.30 at the Folk Hall, Portishead

£1.50 per session

Group Charges

Group membership is £10 per annum. Each member receives a monthly newsletter by post. When attending meetings a fee of £1.50 is made to cover refreshments, a raffle and hall hire. Books can be borrowed for a returnable deposit of £1.

Happy Birthday

to all of you, who are celebrating this month

Our **September meeting** was based around pain and ways to cope with it using methods like Cognitive Behavioural Therapy (CBT), gentle exercise, hypnotherapy and other means.

More about this later in the newsletter. Betty was away with Norman attending a conference in London and so the meeting was led by Julia, the groups treasurer and GDB (General Dogs Body!!) Other members sending apologies included Averil, Carol (Clague) Nuala, Richard and Nickie. Nickie is recovering slowly from a double operation and has had several other health issues arising at the same time including a dental abscess! Get well soon Nickie.)

We also welcomed three new friends, Diane from Kingswood plus Shirley and Lucy from Staple Hill.

It is great to know that people are finding us from such a large area, several members of our group travel quite a way to our meetings. And don't forget the informal invite that's open to everyone to go to the Windmill Pub for lunch afterwards - if you don't know, just ask! It's good to know that the word is spreading about our friendly group - it must be the smiles on our faces that does that, but more likely, the leaflets posted at doctors surgeries etc!!

We received a laminated certificate from FMAUK to show our fundraising efforts towards the children's leaflets were successful to the tune of £250. Well done all!! And to continue the fundraising efforts, we've just heard about another Lions fundraiser from our friend Wendy Szymak. We are taking a stall on **Saturday December 6th** at **Weston Super Mare** again (indoor venue this time thank goodness - or we'd be very cold!!) and we would welcome all the help you can give to make this as successful as the last!

Don't forget the Christmas shoppers will be out in force so bear that in mind if you can donate or make gifts to sell at the stall. We would really, REALLY appreciate people to help man the stall - there's going to be seats or bring your own! Lets make it another good day out - it's fun!! All contributions in by **November meeting latest PLEASE!!**

Okay, back to the meeting..... There was a discussion about making the best of holidays and getting a good and comfortable nights sleep. Julia spoke about how on her recent holiday she took her Tempur topper mattress and suggested to the B&B owner about maybe offering this type of mattress to fibromites in her adverts. "Fibro what?" was the reply but later in the same holiday, Julia discovered another holidaymaker staying in the same small four bed B&B was also a fibromyalgia sufferer - that was a 50% ratio of their clientele!!!! Seems like it would be a good thing to get a whole new bunch of clients but after speaking to Betty, it seems that FMAUK have already spoken to a leading chain of hotels about this with not much interest, but you never know, maybe something to try again in the future?

Jennifer Brown has some useful information regarding caravan holidays, if this could be your ultimate getaway, ask Jen next time you're at a meeting.

Following on from last months request by Betty regarding future speakers and other comments, several items came up and were discussed at the meeting. One item was asking for help with home safety, and we discovered that not only can we ask the police for advice but also the fire service and Neighbourhood Watch. Another request was for an Occupational Therapist (OT) to come along and demonstrate home and personal aids that are available to help our daily needs and finally we spoke about support within our support group.

We can help each other so easily as we understand exactly how the pain feels! There is a group buddy list available and if anyone needs a copy please ask Betty and don't forget to add your name if you'd like to be a part of it too. Remember to greet yourself each day with a smile - that first glance in the mirror each morning could be the transformation of your day! We all love to see people smiling and it's possible to do that even, surprisingly, when you're in pain, practice until you're an A Level standard!! There will be gold stars if you're really good!! It was suggested that people might like to swap their usual seating position at the meetings and it was agreed that it could certainly help us all to meet other members and might help new members etc to feel more 'settled' in? What do you think?

Julia then read a short paragraph from an article on the web entitled "**Pain, pain go away**"

(by PsychologyToday.com) suggesting that you can outsmart persistent pain using **CBT (Cognitive-behavioural therapy)** It can be extremely effective in helping lower the experience of pain (Julia herself uses this kind of method) and quoting the article "Changing the way a person thinks about and interprets pain can alter the experience of pain" It continues "What surprised me (Benson Hoffman of Duke Univ. Medical Centre, USA) was that the greatest impact was on pain intensity.

These treatments don't just help you deal with the physical discomfort, they actually reduce it. The use of psychological treatments reflect a shift away from the medical model of pain, which construes pain narrowly- as a sensory event directly arising from disease or tissue damage." Benson also explains that pain is "also an emotional experience, one shaped by our thoughts and beliefs about the causes and consequences of the pain, as well as by our reactions to stress and our social world. Emotional arousal can influence pain directly by increasing muscle tension and altering levels of hormones and neurotransmitters associated with pain. It may also have an indirect impact.

Fear of re-injury or more pain, for example, can lead us to limit or avoid activities, which then decreases muscle strength and causes loss of function and more pain and disability. Those in pain often feel angry, frightened, helpless, resentful, depressed or guilty about being a burden and they may try to bottle it up to ease others discomfort. But suffering is a social experience. Partners and loved ones also experience intense feelings - they have to watch someone they care about in distress - and they too tend to hold in their feelings of sadness, anxiety or inadequacy.

When the patient, the partner, or, especially both shy from emotional expression, the silence can make the pain worse." Researchers are working to pinpoint which patients would benefit from a particular intervention or combination of approaches but say that CBT and other methods are designed to bring about the same endpoint; helping a person self-manage their own condition, taking an active

role rather than play the fatalistic victim.

One lady, Penny Cowan, a fibromyalgia sufferer, experienced so much pain prior to entering a residential pain management programme that she had tried to convince her husband to leave home and take their two children with him. "I didn't have any hope" she says and wanted to "show the doctor that nothing would work. But I left home as a patient and came back as a person". She was so inspired that she founded the American Chronic Pain Association to help others learn and maintain the skills that helped her finally manage her pain.

Julia says that her journey to a more positive attitude to her health and life was through similar courses including the six week pain management courses that run in this country - attending two of these - and has also learnt self hypnosis and relaxation and has reduced her pain killing medications significantly. If you would like to read the article there will be a copy in the group library. Other group members also gave details of the help they have received through hypnosis and other methods like Emotional Freedom technique.

Jackie Fisher who was the Hypnotherapist and Neuro Linguistic Programming therapist who visited our group a few months ago has since treated three of our members and all have reported great success from her sessions.

After our coffee break we teamed up in pairs to work on a quiz that Julia had prepared for us. It's title was Recognising Skills and we decided between each team who would be asking and who would be answering the questions! It was quite thought provoking and the first question asked 'Name something that you are good at, something you have achieved or something you enjoy doing?' so it really put us on the spot!

The questions were then aimed at asking why we DID it, why DO we do it, then describe what it was we did, when we did it and where we did it!!!! Not too easy then and for most fibro mites, the scratching of heads in thought and faces screwed up thinking why, what and how was quite funny to any onlookers!

In the end only two finished questionnaires were handed in, the others went home or in the bin(!) but they were very interesting and everybody got involved and thinking, a good exercise in itself!

To round off the meeting we watched one of our library exercise video's and we gently relaxed and moved with the guidance of the teacher for about 15 minutes making it a very relaxing end to our meeting.

Report on FMA UK experience at the Nursing in Practice Conference

London 22-24 September. 2008.

Jean, Betty, and Norman attended the conference. Setting up was done on 22nd and Keith the courier delivered the goods bang on time.

Speaking to the organiser we learned that 1900 delegates were registered over the two days. As per previous experiences there were numerous visitors to the stand and information and booklets were given out. The greatest interest was for our professional guidance pack and Devin Starlanyl's work. We were a bit short on freebies and apart from a small handful of pens, we were thankful to have the bookmarks. The samples and material from the other stands was substantial and a number of the delegates chose to take only the bookmark with our details for ease of carrying and for later contact. One practice nurse had been given the bookmark by a colleague and came to the stand to get more information.

The majority of those who visited the stand were practice nurses from London and SE England (but one visitor from the Highlands and Islands). There were a number of nurses working in nursing homes and in elderly care.

Other visitors to the stand included district nurses, health visitors, community psychiatric nurses, a few hospital staff nurses, student nurses, occupational health staff, school nurses, nursing lecturers, and other exhibitors.

A nurse practitioner in army barracks indicated that some female soldiers had presented with fibromyalgia symptoms after trauma, while another army nurse said that a soldier's wife has the condition. A delegate pointed out that she runs a self-referral integrated rehabilitation service in Epsom. There were a small number of nurses who were convinced they had FM although not yet diagnosed. The degree of knowledge was very patchy; some were quite familiar with fibromyalgia while others were not aware of the condition.

We had an interesting position next to the Slimfast stand who gave away drinks and snacks. It was always busy which helped us.

We made contact with MedicAlert and there may be the prospect of reduced fees for their bracelets. Another useful contact was one of the lecturers who happened to be from the West Midlands. He is a trainer for health professionals and offered to talk about his work to FMA UK. Jean and Betty thought he may be relevant for a future group leaders meeting.

Various comments by delegates were recorded e.g.: "a very nasty condition", "FM is crippling", "do not know anything about it", "heard about the charity on Kent radio and came to see the stand", "my 30 year old son has just been diagnosed", "delighted to get the information, well done", "you guys are doing a wonderful job".