

TAP FM News

OCTOBER NEWSLETTER

Hello Members

Janet has asked me if I will do the newsletter again as she is trying to come to terms with things that have been happening to her lately.

Can't believe it's time to put the clocks back again, it seems just a few weeks ago we were putting our clocks forward. It's Halloween again and children love to get dressed up and go guising at the neighbour's for Trick or Treat, so keep some loose change and sweets or fruit to give them.

We have a few new articles that I hope will be of interest to you and would like some feedback from the members regarding starting a problem page next year, so please can we have your comments about this as it is for you, the members (see inside)

The *Christmas Bring and Buy* will be at the next group meeting and we are looking for items you can sell. (No Books Please)

There will also be a preview of the latest exercise DVD for FMS which will be available for hire after Christmas. Please remember and bring any library books you still have as we are doing a Library Audit, so there will be no books etc. for lending from the library until next meeting in 2008. Only another couple of months till Xmas, hope you are all trying to make things easier by doing your shopping early and starting to write your Xmas Cards to post early.

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The New Committee

Chairman	Richard Stevenson Tel: 01382 509566
Vice Chairperson	Mary Stevenson Tel: 01382 509566
Treasurer	Margaret Scott Tel: 01382 805391
Secretary	Lynne Gavin

"It is good when
new people come on
board"
"they bring with
them renewed
vigour and fresh
ideas"

Committee Members

Maureen Crighton
David Payne
Pam Shaw
Margaret Halliday
Heather Gavin
Duncan Haggart
Patricia Payne
Lynne Daggart
Janet McFarlane



Fibromyalgia Logo

Fundraising Committee:

Catherine Bennett
Joyce Peggie
Isobel Wynne
Morag Kelly
Colette Boland

Dates for your Diary

3rd November—Monthly Meeting
Christmas Bring and Buy
Fibromyalgia DVD's Demonstration

1st December—Monthly Meeting
Members Christmas Lunch

Keep up to date
write the dates
in your diary lest
you forget

Please Note

**THERE IS NO MONTHLY MEETING
JANUARY 2008**

Please Note:

Saturday 2nd February 2008

This will be the First Monthly Meeting
of the year 2008

WOMEN'S EXPERIENCES OF BEING DIAGNOSED WITH FIBROMYALGIA

By Linda Noble (BSc Hons, Health Psychology)

This is a shortened version of Linda Noble's Report

I interviewed eight women living in Scotland aged between 39 and 60, from a variety of backgrounds. The average length of time since diagnosis was six and a half years, although several of the women had experienced symptoms for a number of years prior to diagnosis. Only two of the women were currently in employment and of the remaining six, four were unable to work due to the disabling effects of FMS. Interestingly, half of the participants were from 'caring' professions—three former nurses and one care assistant. Five of the interviewees were recruited from FMA UK support groups and the other three were personal acquaintances.

Analysis of the interview data resulted in the emergence of four major themes: The Need to Be Believed: was a powerful theme, with most of the participants feeling that they were not taken seriously by the medical profession while they were seeking a diagnosis, or feeling rejected, dismissed or a lack of support. This drove some of the participants to seek out a more sympathetic doctor, with the result that seven out of eight women expressed satisfaction with their current GP. The interviewees also had a strong sense of being judged by others who, due to a lack of understanding of FMS, concluded that because they looked healthy, they must have been exaggerating the service of their symptoms.

The second theme, Coping with Uncertainty, relates to them feeling uncertain before and after diagnosis. The lengthy diagnostic process had a detrimental effect on the emotional well-being of several of the participants, who described having to cope with constant pain and worry while waiting for a diagnosis. They were anxious that they might have had a serious medical condition, possibly even cancer. However, even after the diagnosis, the uncertainty continued for some participants, who were doubtful as to whether all their symptoms could be accounted for by FMS. Lack of knowledge about their condition contributed to the uncertainty and affected how they felt about their diagnosis.

Women and Fibromyalgia (cont.)

The Third Theme, Ambivalence Towards Diagnosis:- expanded on this, with the women describing how, on the one hand, they felt validated and relieved to at last be able to put a name to their pain, while on the other hand, they felt confused and uncertain about what FMS would mean for their future. This uncertainty was compounded by the lack of accurate information given at the time of diagnosis.

The final theme was entitled Learning to Adapt:- and describes how participants had adapted to life after a diagnosis of FMS, with most of the women finding ways of coping with their physical limitations through acceptance, learning to 'pace' themselves, maintaining a positive attitude and finding and finding new activities that they enjoyed. In addition, interviewees talked about coming to terms with a change of identity, particularly in terms of their self-esteem which they felt was affected by two main factors—the inability to work and weight gain (often a side-effect of an enforced reduction in physical activity).

The results of my study largely confirm those found in previous research. However, the positive attitude of the majority of my participants was at odds with much research into FMS, which usually tends to concentrate on negative factors such as, depression or pain levels. Also, the adverse psychological effects of coping with uncertainty during the process of diagnosis is a subject which previous research has not adequately addressed and which deserves further attention. Finally, issues of weight gain and the inability to work in relation to self-identity and self-esteem came through strongly in my study, yet there is little or no literature dealing with these topics. Therefore, I feel that these would be interesting topics for future research.

I would like to take this opportunity to say a heartfelt "Thank You" to all of my participants, without whom this piece of research would not have been possible and also to Janet McFarlane, who gave permission on behalf of FMA UK for me to enlist the assistance of local support groups. I would also like to thank my dissertation supervisor, Dr Joanne Fox, for her valued support and guidance during this project. If you would like to read my research project in its entirety, or if you have any questions, please email me at noble_35@hotmail.com

(To view the full report email Linda Noble)

SOME LIGHT HUMOUR

I wanted to become a doctor but I didn't have the patience.
I wanted to become a surgeon but I didn't have the guts.
I wanted to become an optician but I was the only pupil.
I wanted to be a bin man but the job was rubbish.

David S Payne

NEW IDEAS FOR TAP FM

We are always looking for new ideas and interests for TAP FM Support Group and we have received a suggestion from one of our Members saying why not have a Problem Page in the monthly newsletter. This might be a good idea!!

The Editor or Committee cannot offer answers or comments.

Members would send in their health concerns and questions.

Other members can then write in or e-mail TAP FM with their answers and comments to the various points raised.

The Editor/Committee cannot offer answers/comments,

Perhaps a beneficial forum in the newsletter may be formed for constructive discussion among the members.

Such a discussion could also be the basis for one of our meetings when there is no speaker available.

Please send your comments and ideas to the Editor or you can bring them along to the meeting due to the problems with Royal Mail, and they can be edited in the next newsletter.

The Group is yours and we want to know what ideas you have to make it even better for the members.

(Please note: Medication cannot be discussed in the newsletter!)

MEDICAL STUDENTS

On Saturday 6th October Group meeting, two medical students were invited to the meeting to give us a talk about things they do and what they actually learn at the University. Both second year students, Ryan Paterson and Wen Ling Choong spoke to us about their medical course and of their limited exposure to Fibromyalgia.

Ryan and Ling are getting ready for their exams later this year and both were delighted at being invited along to speak to the members.

Ling spoke about the medical course being split into 3 modules over 5 years, the blocks start from Basic Anatomy then move on to shadowing doctors on rounds to wards and clinics. Ryan explained more detailed information about what he is currently learning on the course. Ryan first started on the campus at Perth Road and has now moved to the University at Ninewells Hospital.


Courses start with Anatomy, Dermatology and Basic Life Support and continue on to Cardiology. Anatomy is taught within the first years. Clinical Skills sessions are attended every week to keep up the Basic Life Support.

Ryan told the group that not many students know about Fibromyalgia, but he has tried to find out more by reading up on notes about the syndrome, and found there is still no diagnosis as to what causes FMS and how it also overlaps with Chronic Fatigue Syndrome. He also said that there is no cure been found for FMS or Chronic Fatigue and doctors can only give out pills and advice to sufferers. And sometimes refer them for Physiotherapy. Ryan also mentioned that he had read that Auto-Immune diseases can come with FMS and someone with an Auto-Immune condition can have symptoms of FMS but might not actually have the syndrome. Most doctors recommend a healthy diet, moderate exercise and medication which can help with the symptoms of Fibromyalgia but nothing is definitive.

It was a very successful meeting and there was an excellent discussion between Ryan, Ricky and the members about many aspects of Fibromyalgia which kept people talking until well after the meeting was closed.

It is intended to ask other students, at various stages in their courses, to come to our meetings and promote lively discussions from which a lot could be learnt and from which much can be gained.

Ryan and Ling learned a lot about Fibromyalgia from the members and are looking forward to coming back next year if invited along to the meeting again. *I am sure they will be asked again!!!*



Polymyalgia Group Meeting
Speaker - Dianne Stevenson (Physiotherapist)
Talking on Arthritic Conditions & Exercise

Some of the TAP FM members were invited to go along to the above group meeting. There was a good turnout to hear Dianne the physio-therapist from Kings Cross Hospital, on her subject of Exercise and Arthritis.

She explained that Polymyalgia has a sudden onset and muscles that are affected, are mainly in the areas of the Shoulders, Back, Legs and Neck. This can be found in more women than men, and can start around the ages of 60 to 70. Like Fibromyalgia, pain and stiffness can sometimes feel like flu symptoms, but treatment is different, as the pain from Polymyalgia is treated with steroids.

Polymyalgia is diagnosed from blood tests or electric therapy where pulses are introduced into the muscles. A correct diagnosis is very important as steroids are the main course of action and can have serious side effects if taken over a long period of time.

Exercise can help flexibility and movement, which can help lessen the pain. If the patient does not exercise, muscles weaken, joints stiffen and are less supported, more strain is put on the joints.

As exercise cannot be stored in the body, little and often is the best course of treatment and it can also give you confidence in yourself. Medications will help lessen the pain, but does not help the stiffness of joints, will not strengthen muscles, or help with cardiovascular health. Sometimes doing too much exercise at once, is a bad thing, therefore, it cannot be stressed enough by both doctors and physiotherapist that exercise should be little and often.

Flexing muscles properly every day can help. Rheumatic flare-ups and stiffness is usually due to a lack of flexibility exercises, A heat pack is also best for stiffness, but if inflammation is the problem, then an ice pack is probably the best.

In warm environments, people tend to relax more and are usually not as sore as when they are in a cold environment.

It can be a bad thing doing too much exercise at once.

Exercise little but often!!

Always check with your GP first

(continued) Physiotherapist Talk

Walking is a good exercise for people with osteoporosis, and although swimming is good for your heart it does not help your Osteoporosis. Walking is a weight bearing exercise and will help with your posture. Hoovering, shopping, gardening and dancing are all great examples of weight bearing exercise. Posture is very important, sitting up correctly and not slouching will help with back pain, using a lumbar support or a small rolled up towel, can help arch your back. Try sitting for no more than an hour, get up and walk around if you feel sore and instead of using the remote, walk over and change the channel on the TV. While waiting for the kettle to boil, try standing with your heels against the skirting board and press your back against the wall, your body will be able to stretch and you will be standing straight, try to push your shoulders against the wall and try reaching out and up with your arms. Try sitting on a gym ball while watching TV as this may help your leg muscles and posture. Be careful not to fall off and hurt yourself. If you are fearful of falling over when you walk outside, use a walking stick, as this also helps your posture as you tend to stand straight and not look downwards, this also helps your neck and shoulders. If you are trying to get down to floor level for exercising etc. use a chair to hold on to as this will help, when getting down bend one knee and then the other, do not try to go down on both knees at the same time, the same goes for getting up again. When cleaning your house do one room at a time. When after doing exercise or cleaning don't worry if your muscles are sore for about 20/30 minutes, but if you are sore for much longer then you have probably done too much in the one time. A massage can be good for people with Fibromyalgia /Polymyalgia and can be very relaxing, especially in the soft tissues of your back, neck and shoulders and is also helpful if feeling stressed. A heavy massage will only cause tissue and muscle pain.

Pace yourself, try walking on alternative days and swimming on the odd days!



Reader's Letters

Do you get pestered with telesales calls especially when you have settled down to have your evening meal? You can call TPS and register your phone number not to receive unsolicited calls and marketing telephone calls. When you register your number it will take 28 days to become effective.

For more information about Telephone Preference Service log on to www.tpsonline.org.uk Tel. 08450700707

Dear Ed

Here is a warning which should be passed on to the members especially as Xmas is fast approaching It has been confirmed by Royal Mail, The Trading Standards Office are making people aware of the following : - A card is posted through your door from a company called PDS (Parcel Delivery Service) suggesting that they were unable to deliver a parcel and that you need to contact them on 0906 6611911 (a premium rate no.) **DO NOT CALL THIS NUMBER**, as this is a mail scam originating from Belize. If you call the number and you start to hear a recorded message you will already have been billed £15 for the call. If you do receive a card with these details, please contact

Royal Mail Fraud- 02072396655 or ICSTIS (the premium rate service regulator)

Here are some details for the Pain Association Meetings at Dundee/Angus/ Perth

DUNDEE - Conference Centre, Kings Cross Hospital,

Monday 19th November 2pm - 4pm

Monday 17th December 2pm - 4pm

ARBROATH - Boardroom, Admin Building, Royal Infirmary

Monday 26th November 2pm - 4pm

PERTH - Seminar Room 4 (beside Steel Memorial Room) Royal Infirmary

Tuesday 6th November 2pm - 4pm

Tuesday 4th December 2pm - 4pm

www.chronicpaininfo.org



Fibro Fog!

My friend and I were on holiday and we were doing some Sight seeing, when she decided to take my photograph.

"Move back a bit " she said "just stand beside that penguin."

I moved back, but I couldn't see any penguins.

My friend was getting agitated with me and shouted to me

"Will you just stand beside that penguin so I can take a photograph,

"Stand beside the penguin" I asked, "what *penguin*, there's no *penguin*"

By this time my friend was very agitated,

"That penguin over there!" she said

When I looked over to see where she was pointing all I could see was

A Pigeon there, "That's not a *penguin*, that's a *pigeon*"

"Yes! that's what I meant" she said,

Needless to say, we both ended up in fits of *laughter*-----



I was in a bit of a rush trying to make the tea when I got home,
 And decided that fish cakes would be a quick way to have a meal,
 I put the fishcakes in the oven and got everything ready.
 When I noticed a funny burning smell coming from the kitchen
 I opened the oven to find that in my haste to have a meal ready quickly, I
 had put the fish cakes on a plastic tray in the oven
 and it was melting all over the fish cakes!!!!!!!!!!
 The family had to end up with a carry out from the chippie!!!

Library Book Audit

PLEASE RETURN ANY LIBRARY BOOKS

AT THE

NOVEMBER GROUP

MEETING

THANK YOU!!

An audit of the library will take place within the next month, all library books are to be handed back into the library by the November meeting.

If you are unable to come to the meeting please call

Margaret Scott Tel: 01382-805391

Mary Stevenson Tel: 01382-509566

to make arrangements for either pick up or posting of the book, (pick up's only within Dundee Area)

Please do not leave books for TAP FM Library at Reception Desk - Ninewells Hospital

as they will not be passed on to us, and books have previously went missing.

**Ninewells
Hospital will not
take any books
to hand over to
TAP.FM**



Library Rules

The library is for the enjoyment of everyone and to ensure we know who has borrowed a book there are a few simple rules.

- Your membership card must be used to take out a book
- A reminder postcard will be sent with your newsletter
- There will be a 50p charge per month
- If you miss a month—you need to pay an extra 50p

**“No Card
-No Book
One Card
-One Book”**

Book Review

If you have found a book or information sheet helpful or useful then we would like to know. Tell us what you think good or bad.

Sometimes it is a bit overwhelming with so many books to choose from to know where to start.

Your recommendation could help someone find the right book and help them cope a bit better. Don't be shy!!



Returning your Library Book!

If you are unable to attend a meeting but you would like to return your library book. Please do not send to Ninewells Hosp or leave it with receptions because they do not pass them on.

If you need to post anything please send to

TAP FM Support Group
PO Box 10183
Dundee DD4 8WT

Paul Reilly is TAP FM's new Webmaster who is now in charge of the website. The Guestbook is up and running again and Paul will monitor it to make sure there are no nuisance messages.

If you have internet access, why not visit the website and sign the Guestbook.- type in the address www.tapfm.co.uk

How to sign in: Click the link Sign Our Guestbook

Click on post entry, enter your details. when you are asked to verify, type in the same code which is highlighted, then type your message and then

If anyone has any problems signing the guestbook please

Telephone or e-mail Paul or

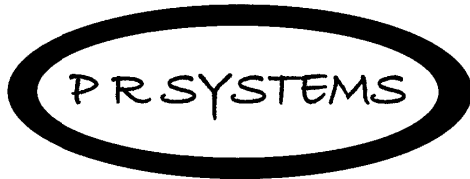
Email: tapfm@btopenworld.com

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Advice Surgery

WELFARE RIGHTS
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ANGUS - TEL: 01307 461460

**Money Advice
Support Team**
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Fife - Tel: 01592 416379
Angus - Tel: 01575 575800

Citizen's Advice Bureau

Dundee Tel: 01382 227171
Forfar Tel: 01307 467097
Perth Tel: 01738 624301
Montrose Tel: 01674 673263
Arbroath Tel: 01241 870661
Cupar Tel: 01334 412485
Call for an appointment

Princess Trust

For help and advice with benefit forms etc.

Call for an appointment

Benefits Agency

Dundee Area
Tel: 01382 313419
Angus Area
Tel: 01241 446099
Montrose Area
Tel 01674 6776605
Perth Area
Tel: 01738 412000

Dundee North Law Centre

Tel: 01382 432458

If you have any legal problems or worries and would like to obtain a dvice or assistance - we can help!

Call for an appointment!

D.I.S.I.P.

Disability Information Service in Perthshire

Tel: 01738 440099 / Fax 01738 687546

Email: disip@disip.org.uk

Website: www.disip.org.uk

Contact Us

TAP FM Support Group

PO Box 10183

Dundee

DD4 8WT

Tel: 01382-509566

email: tapfm@btopenworld.com

We're on the Web

www.tapfm.co.uk

The items below are available for the benefit of our members, at the same time generate a small income to T.A.P. FM Support Group.

You can purchase them from the information desk at the meeting or they can be sent for an additional cost to cover postage.

Items For Sale

Help TAP FM

TAP FM Pens - 50p

Logo Badges - £1.50

Ribbons 50p

Car Stickers - 75p

*** Buy all 4 - £3 ***

Buy your Pens, Badges and Ribbons
and help support TAP FM

and promote

Fibromyalgia Awareness

Help for Yourself!

Plug Mates - 65p each

to help pull out your electrical plugs

Walking Stick "Frog" - £1.99

To hang it on the Table

Walking Stick Loops -£1.99

To hang on the Wrist

Trolley Coin Key Ring - £1

7 Day Pill Dispenser - £1

a helpful reminder if you've taken
your pills or not!