

TAP FM News

Another Busy Month for TAP FM

One again, the committee s of TAP FM have had another busy month.

A Quiz Night on 4th June (story on page7) and the Thrift Shop in Lochee—Story to Follow next month—which has stretch out volunteers to the limit.

Although most of them will tell you they enjoyed running the shop, this is a very time consuming and demanding “fundraiser” Items were collected from various households throughout the area and every item had to be sorted and displayed before the shop even opened. Once the shop is open, it had to be manned for up to eight hours every day.

TAP FM members owe a debt of gratitude to the volunteers in the Thrift Shop! Well Done!!

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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 Doggart
Janet McFarlane



Fibromyalgia Logo

Fundraising Committee:

Catherine Bennett
Joyce Peggie
Isobel Wynne
Morag Kelly
Colette Boland

Dates for your Diary

7th July—Monthly Meeting

Ian Darling—Arthritis Care

11th August—Monthly Meeting

Karen Shepherd & Laura McDermott

15th August—Quiz Night—Lennon's

1st September—Monthly Meeting

8th—15th September—Awareness Week UK

15th September 2007

Scottish Fibromyalgia Conference

Ninewells Hospital & Medical University

Lecture Theatre

10 am—4 pm

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

Fibromyalgia Myth Busting

For many years Fibromyalgia has been considered something of a mystery, confounding the doctors who are trying to treat it and the patients who have to live with it. Only recently has new technology begun to unravel the truths about this mysterious disorder. As a result of the previous lack of scientific evidence, several myths about Fibromyalgia have developed that, unfortunately, are still being repeated today. It's time to dispel the myths and clarify the facts.

Myth 1: Fibromyalgia is a form of arthritis.

Fact: Fibromyalgia is a neurologic disease.

Although it was once thought that Fibromyalgia might be a form of arthritis, research over the past 10+ years has proven that to be false. Arthritis is defined as an inflammation of the joints, but there is no inflammation with FM, nor is there any damage to the joints. A Fibromyalgia patient may have a type of arthritis (like osteoarthritis or rheumatoid arthritis) in addition to FM, but it is a completely separate disorder. On the FM research front, new brain-imaging techniques and scientific studies are revealing that Fibromyalgia is better defined as a central nervous system disorder that results in abnormal pain processing.

Myth 2: Fibromyalgia affects the muscles, joints and connective tissue.

Fact: There is no damage to the muscles, joints or connective tissue of people with Fibromyalgia.

For many years Fibromyalgia was described as a musculoskeletal disorder because much of the pain people experience with FM feels like it is coming from the muscles, joints and connective tissues. However, years of testing failed to reveal any actual damage to the musculoskeletal system. What research has discovered is that a malfunction in the central nervous system of FM patients causes disordered sensory processing which leads to pain amplification. In other words, a stimulus that would not even be noticed by most people can be extremely painful to someone with Fibromyalgia.

"It's time to dispel the myths and clarify the facts."

Fibromyalgia Myth Busting — cont/

Myth 3: Fibromyalgia is an autoimmune disease.

Fact: Fibromyalgia is NOT an autoimmune disease.

Autoimmune disease is the result of a body's overactive immune response. In a sense, the body's immune system begins to attack its own cells and tissues. There is no evidence that Fibromyalgia is an autoimmune disease. In fact, years of research have not turned up any virus, bacteria or immune disorder.

It's not unusual, however, for someone with FM to also have one or more autoimmune diseases, such as: celiac disease, Crohn's disease, lupus, multiple sclerosis, rheumatoid arthritis, Sjögren's syndrome, or some types of thyroid disease. Other illnesses that are suspected to have an autoimmune link and may occur with FM include: Chronic Fatigue Syndrome, endometriosis, interstitial cystitis, and Lyme disease.

Myth 4: Fibromyalgia is a middle-aged woman's disease.

Fact: Fibromyalgia affects men, women and children.

To date, a larger percentage of adult women have been diagnosed with Fibromyalgia than men or children. However, it does affect all ages and both sexes. In fact, it may turn out that more men and children have FM than previously thought. Doctors are finding that men may have fewer than the traditional 11 tender points, yet still meet all the other criteria for FM. Thus, there may be considerably more men with FM than previously thought. And what was once thought to be "growing pains" in children may actually turn out to be a form of Fibromyalgia. But because most pediatricians are not very familiar with FM, they are unlikely to diagnosis it. Although FM will likely continue to be diagnosed more often in women, we may eventually discover it affects significantly more men and children than once thought.

"it does affect
all ages and both
sexes"

Fibromyalgia Myth Busting — cont/

Myth 5: Fibromyalgia is a psychological problem.

Fact: Fibromyalgia is a physical disorder with real, measurable biological abnormalities.

This myth probably causes the most frustration to Fibromyalgia patients. After years of being told "It's all in your head," patients finally have proof that Fibromyalgia is a very real, physical illness. Research studies have revealed a number of biological abnormalities, including:

- Decreased blood flow to specific areas of the brain, particularly the thalamus region, which may help explain the pain sensitivity and cognitive functioning problems experienced by Fibromyalgia patients.
- High levels of "substance P," a central nervous system neurotransmitter involved in pain processing.
- Low levels of nerve growth factor.
- Low levels of somatomedin C, a hormone that promotes bone and muscle growth.
- Low levels of several neurochemicals: serotonin, norepinephrine, dopamine and cortisol.
- Low levels of phosphocreatine and adenosine, muscle-cell chemicals.

Despite the scientific evidence, some medical professionals continue to dismiss Fibromyalgia as a psychological problem, insisting that the symptoms are caused by depression. The fact is that the percentage of FM patients who suffer with depression is no higher than for any other chronic illness. Unfortunately, since it takes an average of 17 years for new research to become part of mainstream medicine, we're probably going to be fighting this myth for several more years.

"After years of being told "It's all in your head," patients finally have proof that Fibromyalgia is a very real, physical illness. ."

Quiz Night—Monday 4th June

The Quiz Night held on Monday 4th June in the Fort Bar was a great success with a number of teams joining the fun. Thanks must be expressed to the fundraising team and everyone who donated prizes for the Raffle raising over £200 for the Group Funds

One of the teams is to represent TAP FM in the Winners Quiz Night at the Fort Bar on Monday 2nd July. They are Isobel Wynne, Margaret Halliday, Catherine Bennett and Joyce Peggie. Good Luck to them!!!!



Joyce Peggie & Catherine Bennett



Isobel Wynne & Margaret Halliday

"Thanks to everyone who helped make the evening a success"



Marvellous selection of Raffle Prizes

HEALTH QUESTION & ANSWER SESSION

Q: I've heard that cardiovascular exercise can prolong life; is this true?

A: Your heart is only good for so many beats, and that's it... don't waste them on exercise. Everything wears out eventually. Speeding up your heart will not make you live longer; that's like saying you can extend the life of your car by driving it faster. Want to live longer? Take a nap.

Q: Should I cut down on meat and eat more fruits and vegetables?

A: You must grasp logistical efficiencies. What does a cow eat? Hay and corn. And what are these? Vegetables. So a steak is nothing more than an efficient mechanism of delivering vegetables to your system. Need grain? Eat chicken. Beef is also a good source of field grass (green leafy vegetable). And a pork chop can give you 100% of your recommended daily allowance of vegetable products.

Q: Should I reduce my alcohol intake?

A: No, not at all. Wine is made from fruit. Brandy is distilled wine, that means they take the water out of the fruity bit so you get even more of the goodness that way. Beer is also made out of grain. Bottoms up!

Q: How can I calculate my body/fat ratio?

A: Well, if you have a body and you have fat, your ratio is one to one. If you have two bodies, your ratio is two to one, etc.

Q: What are some of the advantages of participating in a regular exercise program?

A: Can't think of a single one, sorry. My philosophy is: No Pain...Good!

HEALTH QUESTION & ANSWER SESSION—cont/

Q: Aren't fried foods bad for you?

A: YOU'RE NOT LISTENING!!! ... Foods are fried these days in vegetable oil. In fact, they're permeated in it. How could getting more vegetables be bad for you?

Q: Will sit-ups help prevent me from getting a little soft around the middle?

A: Definitely not! When you exercise a muscle, it gets bigger!!!!!! You should only be doing sit-ups if you want a bigger stomach.

Q: Is chocolate bad for me?

A: Are you crazy? HELLO Cocoa beans! Another vegetable!!! It's the best feel-good food around!

Q: Is swimming good for your figure?

A: If swimming is good for your figure, explain whales to me.

Q: Is getting in-shape important for my lifestyle?

A: Hey! 'Round' is a shape!

Well, I hope this has cleared up any misconceptions you may have had about food and diets.

And remember: "Life should NOT be a journey to the grave with the intention of arriving safely in an attractive and well preserved body, but rather to skid in sideways - Chardonnay in one hand - chocolate in the other - body thoroughly used up, totally worn out and screaming "WOO HOO, What a Ride!"



Reader's Letters

Dear Ed,

I love the newsletter, I look forward to it falling through the letter box. I find the Fibro Fog first then the letters before I read the rest. I feel alive now thanks to TAP FM.

Dear Ed,

I would like to thank TAP FM for all their help and support and the much needed information. It is so good to know that I am not the only one with Fibromyalgia. I was surprised to find your meetings so much fun, I was expecting it to be all doom and gloom with lots of "Poor Me"

I am looking forward now instead of looking back at what I had lost.

Thank you!

Thoughts on the Weather.

Sometimes foggy days are cleared by the sunshine breaking through. Perhaps this can be true for Fibro Fog too. When it clears you can see the good in your life again. At really stormy times, nature lets the rain fall. Perhaps those effected by FMS should too - sometimes a good cry can off-load some of the burden and let you glimpse the sunnier parts of your FMS life. (At times a strong, sympathetic shoulder is desirable, but sometimes peace and solitude in which to weep and get it out of your system can work too).



Fibro Fog!

I started making Bolognese for tomorrows tea and left it to simmer for a while. My Husband switched it off at 5.30 am in the morning. It was tender!!
A.F.

"Mum, that Chocolate Milk Shake tastes horrible!" my son said. I had used Coffee instead of Chocolate!
A.F.

Took my washing off the line to put it in the tumble dryer. I got really upset when I couldn't find it and I thought someone had stolen it. We all laughed when my daughter opened the fridge door and the washing fell out
A.F.

I turn the house up side down trying to find my phone book " It has to be here" i kept telling my self
We were having a Charity Event on Friday Night and my daughter went to check the freezer to see if there was enough ice - You've guessed - there beside the frozen food was my phone book
I cannot remember putting it there Still we had a good laugh!
M.K.

Book Review

Women Living with Fibromyalgia by Mairi Skelly *(available from the TAP FM Library)*

This book was written by a female author who suffers from Fibromyalgia Syndrome (FMS) herself. Each chapter contains contributions from other female sufferers, together with text written by the author.

The book opens with an introduction by the FMS expert Devin Starlanyl, followed by an overview of the condition. The rest of the thirteen chapters cover just about every aspect of how FMS affects women's bodies, minds and lives, and offers suggestions and practical solutions for the everyday problems women face when living with FMS. The subjects included range from those typically found in other FMS books - e.g. dealing with doctors, finding solutions and the implications of being diagnosed with FMS – to less commonly discussed topics. Where this book is different from most FMS books are the inclusion of these less common subjects, dealing with how FMS affects the more private and personal areas of a woman's life, including menopause, sexual intimacy, emotional health and family relationships. There is a chapter dealing with the financial implications of being less able to support yourself after diagnosis, which is aimed at the American reader, but is still useful to British readers – just ignore the detailed references to the American Social Security system. The principles are the same wherever you live. The book concludes with a look at ongoing developments in both conventional and complementary treatments. The drug names are American, but can be 'translated' using the Internet if you want to find out more about any particular drug.

This is a useful and informative book for both women sufferers and their partners. It has an easy-to-read format, with clear chapter headings and sub-headings, and is suited to being read either from start to finish or by picking through the sections that interest you most. The author's text is informative and clear, and it is easy to locate specific information. A glossary of terms is also included, giving clear, concise explanations of many of the terms and treatments mentioned not only in this book, but also in many others on FMS.

The numerous contributions from other real-life sufferers are sometimes depressing and sometimes uplifting, but I feel sure that every reader will find some entries that express their own emotions or problems. This book can also help the reader to feel that they aren't alone in getting particular symptoms or feelings – this may give more confidence to those who are hesitant to discuss problems with partners or doctors.

Try to get your partner or family to read it too!

Susan Cumming



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

.. My name is Fibromyalgia,

And I'm an Invisible Chronic Illness. I am now velcroed to you for life. Others around you can't see me or hear me, but YOUR body feels me. I can attack you anywhere and anyhow I please. I can cause severe pain or, If I'm in a good mood, I can just cause you to ache all over.

Remember when you and energy ran around together and had fun? I took Energy from you and gave you Exhaustion. Try to have fun now! I also took Good Sleep from you and, in it's place, gave you Brain fog. I can make you tremble internally or make you feel cold or hot when everyone else feels normal. Oh yeah, I can make you feel anxious or depressed too. If you have something planned , or are looking forward to a great say, I can take that away too.

You didn't ask for me. I chose you for various reasons: That virus you had that you never recovered from, or that car accident or maybe it was the years of abuse and trauma. Well, anyway, I'm here to stay!

I hear you're going to see a doctor who can get rid of me. I'm rolling on the floor, Laughing. Just try. You will have to go to many many doctors until you find on who can help you effectively. You will be put on pain pills, sleeping pills, energy pills, told you are suffering from anxiety or depression, given a TENs unit, GET massaged told if you just sleep and exercise properly I will go away, told to think positively, poked, prodded and MOST OF ALL, not taken as seriously as you feel when you cry to the doctor how debilitating life is every day.

Your Family , Friends and fellow workers will all listen to you until they just get tired of hearing about how I make you feel, and that I'm a debilitating disease. Some of them will say things like:

"oh, your just having a bad day" or " Well remember, you can't do the things you used to do 20 YEARS ago", not hearing that you said 20 SAYS ago. Some will just start talking behind your back, while you slowly feel that you are losing your dignity trying to make them understand, especially when you are in the middle of a conversation with a "NORMAL" person , and can't remember what your going to say next!

In closing, (I was hoping that I kept this part a secret) but I guess you already found out... The ONLY place you will get any support and understanding in dealing with me is with other people with Fibromyalgia.

Advice Surgery

WELFARE RIGHTS
PERTH - TEL: 01738 476700
ANGUS - TEL: 01307 461460

**Money Advice
Support Team**
Dundee - Tel: 01382 432452
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 dvce 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: 0871 750 1710

email: tapfm@btopenworld.com

We're on the Web

www.btinternet.com/~fibromyalgia

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

Trolley Coin Key Ring - £1

7 Day Pill Dispenser - £1
a helpful reminder if you've taken
your pills or not!