



FaMily Magazine

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FIBROMYALGIA MYTHS: THE TRUTH ABOUT 9 COMMON MYTHS

Get the facts about these nine common fibromyalgia myths. Learning all you can about fibromyalgia is the first step toward gaining control of your symptoms.

Fibromyalgia is a widely misunderstood condition that causes widespread pain and fatigue. If you've been diagnosed with fibromyalgia and are trying to learn all you can about the condition, you may come across some of the many common myths and misconceptions about fibromyalgia. Don't let these myths confuse you or discourage you from seeking help for your fibromyalgia symptoms. Here's a look at nine common myths about fibromyalgia and why each is wrong.

Myth: Most doctors don't believe fibromyalgia is a real condition.

Truth: This myth may come from a misunderstanding. Since fibromyalgia is defined by a list of symptoms, claiming that fibromyalgia isn't real is essentially saying that your symptoms aren't real. That doesn't make sense. Most doctors believe your symptoms are real.

The controversy comes when deciding whether fibromyalgia is a disease process that can be reversed or cured. Most doctors believe fibromyalgia is a set of symptoms that aren't caused by an underlying disease. Most doctors believe that fibromyalgia symptoms can be managed, but there is no underlying disease to "cure."

In some cases, a doctor may not be familiar with fibromyalgia. He or she can refer you to someone who knows more about the condition.

Finding a compassionate doctor can be a frustrating part of living with fibromyalgia. But don't give up if you haven't found the perfect doctor. Focus on finding a doctor who is willing to listen to you and take you seriously.

Finding a doctor who's an expert on fibromyalgia may not be practical, for instance, if there aren't many specialists in your area. But a doctor who's willing to learn more about fibromyalgia and listen to your concerns can be an invaluable ally.

In this issue: Jury Orders Punitive Damage Of \$14 million, "The Fibromyalgia Coach" by Life Coach Pam Wright is a self-help book with a difference!, FM Research Review, Christine's Recipe, Family Phone Friends



Myth: Fibromyalgia damages your joints.

Truth: Though fibromyalgia pain can be severe at times, it doesn't damage your bones, joints or muscles. Some people worry that when pain worsens, it means that fibromyalgia is progressing. But that isn't the case. While increasing fibromyalgia pain can make it difficult to go about your daily activities, it isn't damaging your body.

Myth: You look fine, so there's nothing wrong with you.

Truth: You know this is a myth, but friends, family and co-workers who don't understand fibromyalgia may sometimes hold this belief. It can cause tension when others wonder if you're faking your pain because they think you don't look sick. Resist the urge to get angry and withdraw rather than explain how you're feeling.

Open and honest communication can help others better understand fibromyalgia. Be honest about how you feel and let others know that if they have questions, you're willing to listen and explain.

Absolutely Everything you need to know about Fibromyalgia

FIBROMYALGIA MYTHS: THE TRUTH ABOUT 9 COMMON MYTHS

Myth: You were diagnosed with fibromyalgia because your doctor couldn't find anything wrong with you.

Truth: Fibromyalgia is a specific diagnosis based on your symptoms, not a diagnosis you're given when there's nothing wrong with you. The American College of Rheumatology developed a set of criteria to help doctors diagnose fibromyalgia.

Diagnosing fibromyalgia often takes time. Since there's no single test that can confirm you have fibromyalgia, your doctor will often run tests and procedures to rule out other conditions. Enduring repeated tests can be frustrating, but it's an important part of determining whether your symptoms are caused by fibromyalgia or something else. The results will guide your treatment.

Myth: Fibromyalgia causes pain. Those other symptoms you're experiencing must be caused by something else.

Truth: Fibromyalgia can cause symptoms in addition to pain. Many people with fibromyalgia also experience fatigue and difficulty sleeping. Other fibromyalgia symptoms may include headaches, sensitivity to light, dizziness, memory problems, and numbness and tingling in your arms and legs. A number of other conditions commonly accompany fibromyalgia, including irritable bowel syndrome, bladder control problems and mood disorders, such as depression and anxiety.



Truth: Overdoing it on the good days may catch up with you. You may feel exhausted the next day and your fibromyalgia symptoms could worsen. But that doesn't mean you should keep your activity to a minimum. Doing very little could weaken your muscles and increase your pain.

Cope with the good days and the not-so-good days by finding a balance. Pace yourself. Set goals for each day. Your goals should be reasonable. And they should include daily exercise and time for yourself, such as time to relax or listen to music.

Myth: Fibromyalgia is a life-threatening disease.

Truth: Fibromyalgia isn't fatal and it doesn't damage your body. Fibromyalgia symptoms fluctuate over time, sometimes getting worse and sometimes becoming milder. Fibromyalgia pain rarely disappears completely, but you can learn to gain some control over it.

Myth: You can't have a productive life with fibromyalgia.

Truth: Learning to control your fibromyalgia pain takes time. It's likely that the pain will never completely go away and you'll have to accept that your life might never be the same. But that doesn't mean your life can't be satisfying and productive.

Work with your doctor to adapt your daily activities so that you can have time and energy for what's important to you. Your strategy may include a number of approaches, such as setting goals, for instance, making time for relaxation exercises every day, or making lifestyle changes, such as walking most days of the week.



Myth: No treatments for fibromyalgia exist, so it's no use going to the doctor.

Truth: There's no standard treatment for fibromyalgia, and the Food and Drug Administration has approved just one drug for treating fibromyalgia. But you have many options for controlling fibromyalgia pain, including medications, lifestyle changes, and complementary and alternative treatments. Often you'll need to try a few treatments in different combinations to determine what works best.

Myth: On days when you're feeling good, you should try to do as much as you can since you may be unable to accomplish everything you want on other days.

JURY ORDERS PUNITIVE DAMAGES OF \$14 MILLION

By Elizabeth Fitzsimons and Ray Huard

While the jury deliberated this week inside the courthouse in El Cajon, plaintiff Darla Johnson laid down on a bench, her head on a pillow and went to sleep.

Johnson, 49, who suffers from chronic fatigue, lupus, fibromyalgia and an immune system disorder, spent much of the six-week trial with her head down on the table between her attorneys. Sometimes she rested on the floor, overcome by pain and exhaustion.

The Chula Vista woman was in court because her insurance company didn't believe she was sick. But a jury did.

On Thursday, the jury ordered Prudential Insurance Co. to pay \$14 million in punitive damages on top of \$1.5 million it awarded Johnson last week in compensatory damages to cover benefits the company had refused to pay.



"I feel vindicated, like a huge weight has been lifted," said Johnson, earlier this week. "I know there's a long road ahead still."

Prudential spokesman Bob DeFillippo said the company would ask Superior Court Judge Eddie Sturgeon to set aside the verdict, and if the judge doesn't, it plans to appeal.

"We think the verdict against Prudential is wrong," DeFillippo said.

"We believe that the award of punitive damages was excessive and exceeds the amount allowable under the law."

Johnson's lawyer, Sean Simpson, disagreed, saying the award did not exceed the legal limit.

Harris Steinberg, a San Diego trial attorney who specializes in insurance law, said the nearly \$15 million awarded Johnson "is on the high end" of what juries have historically awarded in such cases involving individual plaintiffs. Typically, punitive damage awards range from \$1 million to \$7 million, Steinberg said.

After hearing the jury's verdict, Johnson said she hoped Prudential has learned a lesson. "I want them to stop this," she said. "They're just bullies."

Simpson said he hoped the verdict would lead Prudential and other insurance companies to reconsider the way the evaluate disability claims.

Steinberg, however, doubted the verdict would change company practices.

"A lot of these folks who are handling these claims view it as a game," Steinberg said. He said companies sometimes feel it is cheaper to deny valid claims than pay them, thinking that most people won't fight back.

Johnson was the project manager in the construction department at the University of California San Francisco, when she was diagnosed with lupus, fibromyalgia, chronic fatigue and antiphospholipid antibody syndrome, a disorder of the immune system.

She would come home from work to her husband and 4-year-old daughter and drop from exhaustion. "I was always in pajamas and I was always in the chair. That's what my daughter remembers from our time in San Francisco," she said.

In 1995, Johnson left her job and went on disability.

For five years, Prudential paid Johnson \$3,130 per month, half her previous income. Johnson's family moved to San Bernardino County in 2000, where they bought a house. Prudential assured the lender of her future disability income.

Six months later, her benefits were terminated. The doctor Prudential had sent her to for an independent medical exam had filed a report saying Johnson wasn't disabled.

"He performed a perfunctory exam, he filed a perfunctory report," said Charles Moore, one of Johnson's lawyers. "He was paid to find she wasn't disabled."

Johnson filed two appeals with the insurance company, then turned to the courts, suing in August 2003.

The case went to trial in January of this year, and Johnson's lawyers argued that Prudential had targeted her because her chronic fatigue and fibromyalgia syndromes have no definitive cause. When the company realized it would be paying disability benefits until Johnson was 65, it terminated the benefits, Johnson's attorneys argued.

Prudential's lawyers, Robert Young and Stan Calvert, said that Johnson had not provided the insurance company with sufficient evidence of her disability.

An expert in insurance claims who testified for the defense said that in late 1999 or early 2000, Prudential began requiring more stringent objective evidence to support disability claims, such as X-rays and blood tests.

The \$1.5 million Johnson was awarded in compensatory damages covers past and future benefits as well as general damages for the grief and inconvenience she suffered when Prudential refused to pay her claims.

The company also must pay attorneys' fees, which is likely to be more than \$500,000.

Simpson said it could take three years for Johnson to receive any money.

Elizabeth Fitzsimons: (619) 542-4577; elizabeth.fitzsimons@uniontrib.com

Find this article at: www.signonsandiego.com/news/metro/20070310-9999-1m10prudent.html

“THE FIBROMYALGIA COACH” BY LIFE COACH PAM WRIGHT IS A SELF-HELP BOOK WITH A DIFFERENCE!

Fibromyalgia awareness continues to grow, which is great, but have you noticed that there is still a large gap between recognising the condition and helping people deal with the life-changing issues that come as a result of having an invisible disability?

When I decided to become a Life Balance and Health Coach, Life Coaching in the UK was a new and unproven profession. Coaching appealed to me because of its positive nature. The idea was simple: start from where you are now, and work towards where you want to be, in such a way that matches what really matters to you at a pace you can manage. For over a year, as part of my extensive training, I worked on my own change and development. Lying in my bed with all the worst symptoms of Fibromyalgia, I recognised that the positive small steps holistic coaching approach was the most empowering way to move forward. Whenever I took back control of even the smallest event or personal decision, I felt my spirits lift. And so I began to turn my full attention on to my health and life issues and seriously regarded myself as my own ‘special project’. I was doing something practical and useful with my days (even if that included doing nothing in particular!) instead of just bemoaning my fate and fearing the future. It worked, and I got my life back. A different life, but one in which I am using all my old skills in a new and interesting way as well as adding some new ones to the list!

It’s not surprising then that I am passionate about coaching and its beneficial effects on self-esteem, confidence and small steps action planning which can be applied to all aspects of life, including illness management. I believe everyone should have the opportunity to work on their health and life issues in a practical yet holistic mind, body, spirit way that helps them move forward according to their own needs. It is alarming that there are still millions of people across the world all trying to find their way through the ‘try-this-try-that’ options available to them without any plan or reference to their most basic needs – their character, spirit and personal circumstances. Doctors have little time to empower patients to be a partner in their own health management, and many patients feel lost and unsupported as they deal with their enforced changes alone. “The Fibromyalgia Coach” addresses these issues in a simple, clear way which can be easily implemented.

This book provides you with self-coaching skills that will help you to successfully manage life changing situations as well as your health issues. It also enables you to plan your

personal positive way forward. Life coaching is a practical process that works on moving you forward from where you are now, to where you want and need to be in order to live life to the full, even with managing Fibromyalgia. It enables you to become more positively self-aware and to exercise choice, control and freedom in a way that is right for you.

Most of my coaching clients, who come from all parts of the UK, have worked with me by phone. Some have visited me at home in Whitstable, Kent. They have all made significant positive changes within their own circumstances, and many of them are happy to share their experiences with you in “The Fibromyalgia Coach” book.

How is “The Fibromyalgia Coach” different?

It is the first self-help coaching book on Fibromyalgia written by a professional life coach who is herself, successfully managing life with FM.

“The Fibromyalgia Coach” has been written in a way that enables you to feel, as much as possible, the support and empathy that comes from working alongside a life coach who understands from personal experience the issues involved in living with a debilitating invisible disability.

“The Fibromyalgia Coach” is also a ‘self-help book with a difference’ because it is not medical, nor is it a ‘do-this-do-that-and-you’ll-be-well’ type of book. It doesn’t get bogged down with reams of factual information, but instead enables you to focus on your unique circumstances, and encourages you to adapt the ideas to your own reality. Based on a small-steps positive approach to change “The Fibromyalgia Coach” is an easy read with simple yet effective drawings, charts and purposely chosen bigger-than-average print.

What’s inside “The Fibromyalgia Coach”?

“The Fibromyalgia Coach” is a self-coaching toolkit for your successful journey through the issues of FM. It’s an addition to your bookshelf that you will want to return to again and again.

There are 12 chapters. Some of the headings included are
Acknowledging the Past

The Fibromyalgia Reality Check

Getting your Motivation Right

Choosing the Right Way Forward for You

Pacing Yourself

10 Success Skills (which include Zapping Your Gremlins and Saying No without Guilt), are added gradually with real-life examples of how they can be used. 20 Action Points include photocopiable charts, questions to ask yourself, and practical small-steps ways to make and carry out your plans. Featured in every chapter are stories of real people who have used the ideas and methods to help themselves move forward, feel better and get on with their lives. At all times, there is a supportive, caring commentary from your coach Pam Wright, and rather unusually, you are often encouraged to put the book down and have a rest!

Within its 200 pages, you are helped to identify your practical, emotional and spiritual needs and then to match your ideas and practical plans to your life values. You can learn how to banish your self-doubt, improve your self-esteem, cultivate your self-reliance and self-image, prioritise your action, discover what motivates you and make that movement forward by taking action at a pace that is exactly right for you and your circumstances.

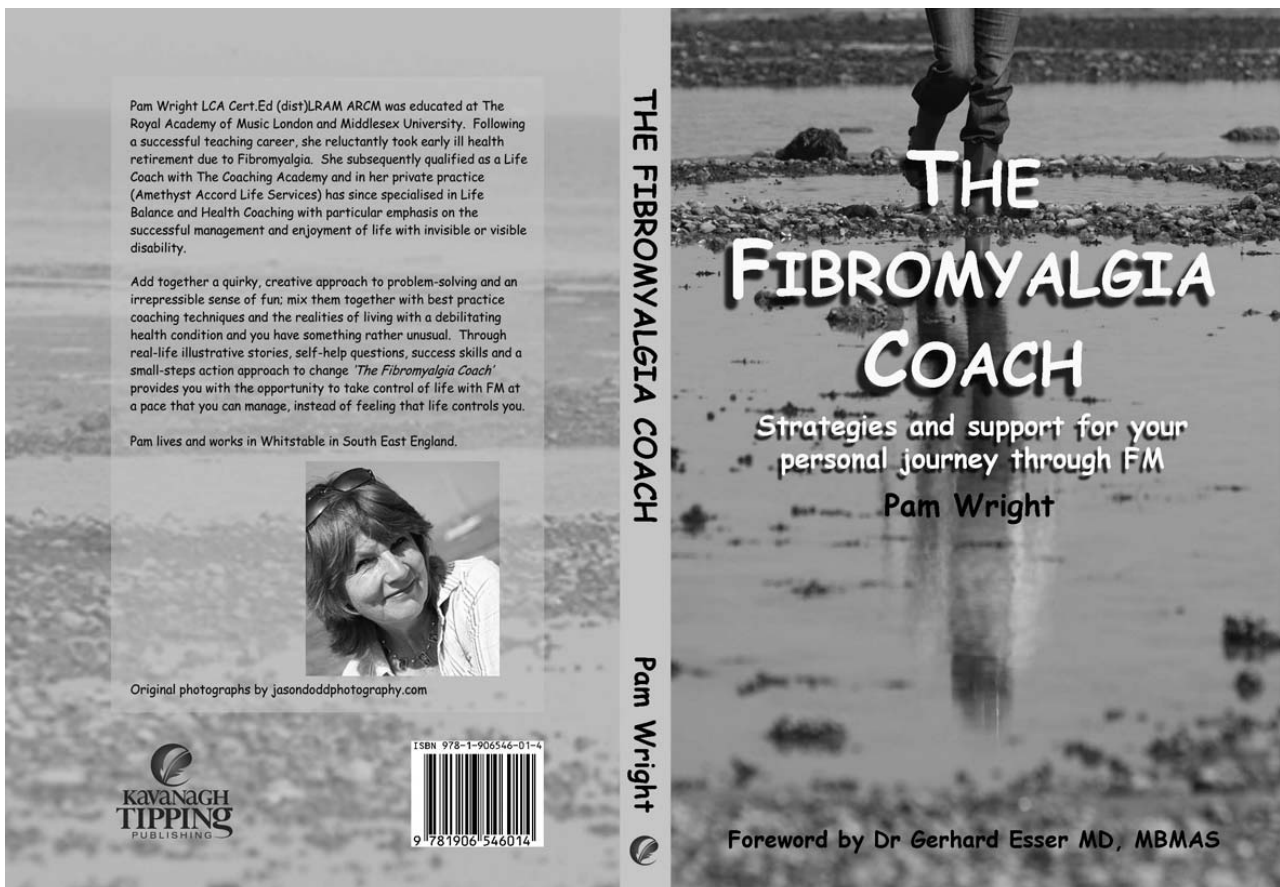
As well as real-life positive stories from people who have FM, there is a mixture of problem-solving suggestions, challenges and success skills, self-help questions, and coaching techniques which enables you to feel in control and to move forward at your own pace with confidence.

With a foreword from GP Dr. Gerhard Esser MD MBMAS "The Fibromyalgia Coach" will be of interest and use to anyone involved with the ongoing successful management of Fibromyalgia as well as similar and associated conditions.

This book gives you the tools to personally empower yourself (and to empower others) within the difficult situation of dealing with an invisible disability. The coaching methods in its pages are tried and tested. What's more they really work!

Published by Kavanagh/Tipping Publishing at £14.99 (plus £2.50 postage & packing) "The Fibromyalgia Coach" is available NOW from www.amethystaccordlifeservices.com using secure Paypal facilities.

Alternatively please order by sending your details and a cheque for £17.49 payable to Amethyst Accord Life Services to: 44 St.Mary's Grove, Seasalter, Whitstable Kent CT5 4AF



Pam Wright LCA Cert.Ed (dist)LRAM ARCM was educated at The Royal Academy of Music London and Middlesex University. Following a successful teaching career, she reluctantly took early ill health retirement due to Fibromyalgia. She subsequently qualified as a Life Coach with The Coaching Academy and in her private practice (Amethyst Accord Life Services) has since specialised in Life Balance and Health Coaching with particular emphasis on the successful management and enjoyment of life with invisible or visible disability.

Add together a quirky, creative approach to problem-solving and an irrepressible sense of fun: mix them together with best practice coaching techniques and the realities of living with a debilitating health condition and you have something rather unusual. Through real-life illustrative stories, self-help questions, success skills and a small-steps action approach to change 'The Fibromyalgia Coach' provides you with the opportunity to take control of life with FM at a pace that you can manage, instead of feeling that life controls you.

Pam lives and works in Whitstable in South East England.



Original photographs by jasondoddphotography.com



THE FIBROMYALGIA COACH

Pam Wright

Foreword by Dr Gerhard Esser MD, MBMAS

"The Fibromyalgia Coach" by Life Coach Pam Wright is a self-help book with a difference!



HOT TOPICS FROM THE FORUM

by Jeanne Hambleton

BLOOD TESTS

Latest news on the forum is an announcement about a blood test that is said to "detects anti-polymer antibodies in the blood of the majority of fibromyalgia patients and that the titers (amounts) of these antibodies correlate with the severity of a variety of the patients' fibromyalgia symptoms, including headache, stiffness, anxiety and depression."

Wow! I am sure, you too, have been embarrassed when told by your GP that your blood test results showed no markers. Have you heard that the scan or x-ray of the place that hurt so much, showed no inflammation? Well in theory this new test should put an end to all that – but will it?

One member called Min, posting on the ukfibromyalgia.com/forums printed an extract from the Autoimmune Technologies US website and suddenly there is so much excitement and hope. (see The UKFM Lounge - Fibro blood test developed). The news is described by Velvet as "Probably the best news I have heard for a long time. This is something we can point to and say, 'There is where I am broken. That is the bit not working. I am not making this up. I don't want attention just for the sake of attention. I am not mad'".

Cat123 suggests, "Boy oh boy what fantastic news!!!! Anyone with a doctor who thinks it is in their heads should show them this news. Things are looking brighter for us. I am sure they will find a cure one day. At least we know it is being researched in Canada and the USA..... So the fight goes on to make the government sit up and take notice."

But are you ready for the bad news! Remember please do not shoot the messenger – I am only telling it like it is.

This news was announced on 19 August 2004. Corgenix in Colorado, working with Autoimmune Technologies, announced APA Assay Fibromyalgia test kits were available.

Corgenix with the exclusive rights to manufacture the kit, which detects anti-polymer antibodies (APA), serves as the first serum-based assay specific for fibromyalgia, a common pain and fatigue disorder.

Corgenix and Autoimmune are collaborating on distribution of the product, and expected to launch the patented APA ELISA test kit in September 2004 in Europe through Corgenix' international distribution network. International distribution will be coordinated by Corgenix' subsidiary in the UK. The product will subsequently be available in the US if the FDA grants regulatory clearance. The press release adds, "Current data suggests that APA-positive fibromyalgia patients comprise the majority of fibromyalgia patients," said Luis Lopez, MD, Chairman and CEO of Corgenix.

"This test is intended for use as an aid in the diagnosis of patients presenting with the symptoms and signs of fibromyalgia syndrome, as an aid in differentiating fibromyalgia patients from patients with other autoimmune diseases, and as an aid in determining which fibromyalgia patients have an immune response that is associated with their symptoms."

"The APA Assay is the first specific clinical laboratory test for objectively identifying fibromyalgia patients," said Russell B. Wilson, PhD, President and Chief Science Officer of Autoimmune Technologies.

"The APA ELISA test detects IgG anti-polymer antibodies in human serum. Research has shown that not only are these antibodies detected in the majority of fibromyalgia patients tested, but antibody titers also correlate with the severity of symptoms in these patients."

Between 2% and 5% of adult women in the US are believed to have received a diagnosis of fibromyalgia, but the total number of FMS sufferers might be far greater. Researchers have found that, although half of US women have none of the 18 possible fibromyalgia tender points, approximately 20% of US women may have 6 or more of these tender points. Other research has determined that the direct medical costs of fibromyalgia, which include patient visits to multiple physicians to obtain a diagnosis, may exceed more than \$15 billion per year in the US alone.

Likewise this total waste of the precious NHS budget must surely be a big point to make to your MPs. All we hear is how starved of cash the NHS is.

In discussing the potential market for the APA ELISA test kit in the context of these figures, Doug Simpson, President of Corgenix, said "Although other laboratory markers exist, this is the only serum-based lab test that specifically picks up fibromyalgia patients. Research findings to date strongly suggest that fibromyalgia in APA positive patients is associated with an abnormal immune system response. As a result, we expect the APA ELISA test to be useful not only in helping physicians make an initial diagnosis of fibromyalgia but also in indicating to them which of their fibromyalgia patients might benefit from one or more of the many existing drugs or therapies that modulate the immune system."

Michael D. Charbonnet, CEO of Autoimmune said, "Not since the discovery of rheumatoid factors in the 1940s has a laboratory test had the potential to so dramatically change the perception of a medical disorder. Rheumatoid factors provided the earliest laboratory evidence that rheumatoid arthritis was a 'real disease' and led to dramatic advances in treatment for it. We believe that the APA Assay has the ability to do the same thing for fibromyalgia, formally establishing fibromyalgia as a separate and distinct physical disease and leading to greatly improved patient outcomes."

Corgenix now claim the APA kit uptake by UK doctors has been practically non-existent. The test is available through a Newmarket laboratory. This costs £89.00 per test + sample transport costs. It requires a single blood sample to be sent to the lab. Those taking the test should consult their doctor/GP. It is not currently available on the NHS. For information contact NPTECH Services Ltd. Wellington House, Wellington Street, Newmarket, Suffolk, CB8 8SX. UK. Tel: 01638 665350; email: info@nptech.co.uk; website: www.nptech.co.uk

Talk soon Jeanne



Published by UKfibromyalgia.com,
7 Ashbourne Road,
Bournemouth, Dorset BH5 2JS
www.ukfibromyalgia.com

Tel: 01202 259155

Fax: +44 (0)870 169 3701

E-mail: family@ukfibromyalgia.com

Managing Editor: Martin Westby

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Ashbourne Road, Bournemouth,
Dorset. BH5 2JS
Fax: 0870 169 3701

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FIBROMYALGIA ASSOCIATION UK



Welcome to the FMA UK section.

This month MAB member, Dr Kim Lawson, gives his comments to the government's response to the e-petition for better education for doctors on fibromyalgia and myofascial pain syndrome. Check out pages 4-5.

In the Spotlight we have Anne Mills, who tells her story about living with FM and the booklets she has written to help others find the help and advice they need.

Also, a new group has started up in Winchester, to find out more contact Jennifer Bennett on 0845 345 2678 or jen62ben@hotmail.com

April's free draw winner is: Ruth Alderton. Congratulations!

Best wishes,
Kathy Longley (FMA UK Editor)

Fibromyalgia Association UK
PO Box 206
Stourbridge
West Midlands
DY9 8YL
0845 345 2322 helpline
01384 895002 office
fmaukoffice@aol.com
fmauk@hotmail.com
www.fmauk.org
Registered Charity No. 1042582

Benefit Helpline: 0845 345 2343
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International Awareness Day 12th May 2008

Can you get the word fibromyalgia on the radio?

Many radio stations have request programmes, so there must be one you like to listen to. Be ready to get their number down and put in a request on International Awareness Day for everyone who knows the pain fibromyalgia can cause, so they know you are thinking about them and to educate all those who have never heard of it. You might have to teach them how to pronounce it, and can explain what it means in the process:

Fibro - fibrous tissues, my - muscles,

algia - pain. Just think how many people you might reach with just one phone call.

I hope you have remembered to post the postcards included with last month's magazine. The more your MP and MEP get, the more likely they are to attend these events and find out more about fibromyalgia.

If you have any other ideas about raising awareness, please let us know so we can pass it on. Contact the FMA UK office at: PO Box 206, Stourbridge, West Midlands, DY9 8YL, 01384 895002, fmaukoffice@aol.com

It's a Scream! Stephen Roach runs and runs.....

Stephen Roach is a seasoned runner who has taken part in 73 marathons. His wife, Olive, has fibromyalgia and is in constant pain needing to use a wheelchair to cope. So Steve has now decided to use his talents to raise awareness and money for fibromyalgia. At the start line for the



Blackpool half marathon he certainly stood out in his Scream costume, a very apt outfit to represent fibromyalgia! As he ran he gave out numerous information flyers on fibromyalgia and overall he raised £340 in sponsorship. Great going Stephen! As if running a marathon wasn't taxing enough, Stephen is now planning to run up and down Snowdon on



26th July, this time as Superman. Once again, he will be handing out information leaflets and is collecting sponsorship. Well done Stephen for turning your passion into such a positive awareness raising initiative. We wish you well for your next run. To sponsor Stephen go to: www.justgiving.com/StephenRoach



South Bucks FM Support Group

We meet in Seer Green, near Beaconsfield, Buckinghamshire, (near Junction 2 on M40). Members come from Amersham, Chesham, Aylesbury, Slough, Rickmansworth, Bourne End, High Wycombe, Princes Risborough and Hemel Hempstead.

Our group aims to support people with fibromyalgia and their carers. We meet every two months, usually on the 3rd Monday, to share our ideas and concerns of how to cope with the syndrome and generally to provide support to each other. We try and keep up to date with the latest and tested treatments, so we don't waste our money on inappropriate treatments (currently, two of our members have just been to the conference on FM & ME/CFS in Southampton). At our meetings, we sometimes have a speaker, or a specific topic discussion. From time to time we also have social meetings in a pub over lunch. Recent examples of speakers are Dr Robert Lister who has done research into fibromyalgia and Dr Dee Burrows from the Amersham Hospital Pain Management Programme, who spoke to us about coping with chronic pain.

We maintain a library of relevant books that our members can borrow as well as some equipment that can be lent out - allowing members to try before they buy. We produce a newsletter six times a year - in between each of the support meetings. This is particularly important for members who are unable to attend meetings.

We know it is not easy living with constant pain and fatigue, especially as we often don't look unwell and family, friends and doctors sometimes have very little sympathy for us. For more information on our group please contact Linda Horncastle on: Tel: 0845 345 2416 or e-mail: Linda.ch@btinternet.com

Easter Bonnets in the Black Country



Black Country Support Group Members in Easter Bonnets.

The Black Country Fibromyalgia Support Group's March meeting had an Easter Theme, with group members encouraged to come along wearing their Easter Bonnets. Lisa Rochell came as the Easter Bunny with ears and tail! The activity for the meeting was making Easter Cards and we also enjoyed a buffet. Samantha Everiss, one of our newest members, surprised us with a wonderfully decorated Easter Cake, for which we thank her. We also held our monthly raffle with prizes of



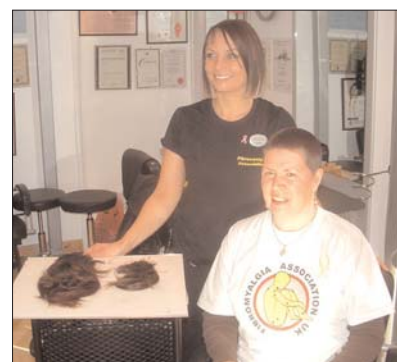
Samantha Everiss and her Easter cake.

donated Easter Eggs which raised £36, half of which will be donated to Russell's Hall Hospital Pain Ward.

A Hair Raising Event

Back in February, Barbara Parker organised a rather unusual event: a hair raising day! She wanted to raise money for fibromyalgia and breast cancer and so far has raised £172.21 for fibromyalgia and £786.28 for cancer research, with still more to come. It was a lovely day and went well, with intrepid participants taking to the chair and smiling bravely as their hair fell to the floor around them. Barbara would like to start a support group in Swindon, so look out for this new group. If you would like to donate go to:

www.justgiving.com/barbaraparker2



Success Through the Combination Approach

By Jacqueline Turner,

a member of the Nottingham and East Midlands Fibromyalgia Support Group

I have had fibromyalgia for about 12 years and like the rest of you I was brain washed into thinking it was something I had to come to terms with and that there was no solution to beating this debilitating condition.

I had tried my best to keep it under control with exercise until this became extremely difficult. The only exercise I could manage was to go walking. I did manage to keep my job, but had to reduce it to 3 days a week.

I read many articles on the internet, in FaMily magazine, and the local Nottingham magazine, a lot of which I noticed pointed to diet having an impact on pain levels. I decided to embark on an eating regime which included not eating anything from the nightshade food group and, along with fellow colleagues from the newly formed Newark Group, I had food intolerance tests to see what foods might be triggering various problems. We were all amazed that we had similar intolerances, just as suggested on many fibromyalgia websites. As a result of changing our diet many of us saw our pain levels decrease and we all had some mild general improvement.

I then went to one of our meetings in Nottingham after reading in our newsletter about how our Chairperson, Christine Brown, had had some dramatic improvements in her health. I was amazed to see this woman, whom I had seen a year ago on the verge of being confined to a wheelchair, now walking and smiling seemingly in perfect health. Christine shared with the group how she had visited Norah Wickerson and started doing the combination approach involving changes in her diet. I checked out Norah's website, which I had actually visited before a while ago. Previously I had been very sceptical about the statements that were being made and thought it was someone offering false hope again.

Anyway, armed with new enthusiasm, I emailed my medical history as requested on the website and got a reply from Norah. She had had fibromyalgia for 20 years and had dramatically improved her health with diet, exercise, changing her mind set and teaching herself new life coaching skills. She learned how to be positive and to deal with the psychological problems she had developed from many years of negative teaching from the medical profession.

I spoke with Norah and arranged my first appointment. She explained that you have to be 100% committed to the programme for her to take you on board and for the programme to work. I won't promise you that it is an easy programme, but if you are committed and follow Norah's advice you will see an improvement. After my first appointment and following the first part of the programme, I started to see small improvements, then by the second appointment some 3 months later I started to see much bigger improvements. By my third appointment the fibromyalgia had completely gone from my legs and lower body, the only place left to work on was the neck, shoulders and upper arms. The fatigue and the pain was the last thing to disappear.

I now have my exercises to do to improve my core muscles and I have to make sure I eat a little something every 2 hours to maintain my blood sugar levels and breathing exercises to improve the action of my diaphragm, which I didn't realise had been tightened and reduced due to the fibromyalgia.

I am now almost totally pain free, can enjoy many more activities and for the first time in 12 years am able to sleep all the way through the night without waking up every time I change position. Although this has only happened in the last 6 weeks, I can actually stay awake for the whole day, something I hadn't been able to do for 12 years. My memory is also back to how it used to be, which my family all thinks is marvellous.

I will probably have one or two more sessions with Norah and then that's it for me, and yes, I will continue to stay on this programme for the rest of my life. I admit there are many big life style changes and there are a lot of things I cannot enjoy food wise, but if enjoyment means pain, fatigue and the return of fibromyalgia symptoms, then to me how can that be enjoyment.

Please be reassured that there is treatment for fibromyalgia. I and many others are testimony to that; the treatment is out there if you really want it.

You can find out more about the programme on her website: www.tacklingfibro.co.uk

Contact Jacqueline Turner on jallsop1@sky.com



The Government's Response to Petition:

"We the undersigned petition the Prime Minister to ensure that doctors are educated about fibromyalgia and myofascial pain."

With comments by MAB member Dr Kim Lawson

Details of Petition:

"Research shows that between 5-8% of the population suffer from fibromyalgia and chronic myofascial pain, yet most sufferers are not diagnosed until they have suffered for at least 2 years. We need awareness to be increased so that patients will be diagnosed earlier on and be able to start treatment sooner. Patients should not have to wait for more than 2 years for a diagnosis of a condition that is so common! Most medical degrees include only 1 or 2 lectures about fibromyalgia and myofascial pain, despite the fact that more than 1 in 20 people suffer from these painful conditions! Doctors need to learn more about fibromyalgia."

The Government's Response

The Government recognises fibromyalgia as a serious condition and appreciates the effect it has on the lives of those with the condition. There is currently no cure for fibromyalgia, so treatment aims to ease the symptoms as much as possible and to improve the patient's quality of life. Fibromyalgia can be successfully managed within the primary care setting. However, in cases where there is some difficulty with the diagnosis, or there are complicating factors, the patient will normally be referred to a rheumatologist or neurologist.

Nevertheless, the Government is committed to ensuring better services for people with fibromyalgia. In October 2006, it launched the Musculoskeletal Services Framework, which sets out new guidance to provide high quality and integrated services for people with musculoskeletal conditions, including fibromyalgia. The framework has been developed in consultation with patients themselves, and with organisations representing them.

The framework aims to improve assessment, diagnosis and treatment for fibromyalgia and other musculoskeletal conditions. It will encourage more support for people to manage their own conditions and get access to better information and advice. It will also provide a clearer focus on the needs of children and their families, and sets an 18-week target for referrals from GPs to the start of hospital treatment.

Diagnosing fibromyalgia can be difficult as there is no specific diagnostic test that can be used, and the symptoms can vary from person to person. A diagnosis is usually made by taking a medical history, checking the symptoms and carrying out a physical examination.

Blood tests, X-rays and other scans may be used to rule out medical conditions with similar symptoms to fibromyalgia.

In August 2003, the Chief Medical Officer (CMO) issued a newsletter which was sent to all doctors in England, specifically addressing the problem of fibromyalgia information dissemination. The CMO acknowledges the condition and the extent to which it affects the population. He raised awareness of a leaflet about fibromyalgia, which has now been made available to all GP surgeries throughout the UK. The leaflet offers guidance on the main symptoms, diagnosis and treatment of fibromyalgia together with a brief summary of the current ideas for the underlying pathogenesis.

The Medical Advisory Board of the Fibromyalgia Association UK produced the leaflet, Fibromyalgia Syndrome, which preceded a more comprehensive medical pack on the management of fibromyalgia for the multi-disciplinary team, which can also be requested on the website. Both these documents are available from the association's website at: www.fibromyalgia-associationuk.org (click on the 'Fibromyalgia' option, then on 'Doctor's Medical Pack').

Information on the care of people with fibromyalgia, specifically for use by health professionals, is now included in the musculoskeletal specialist library of the National Library for Health. This document, Standards of Care - Regional Musculoskeletal Pain, was produced by the Arthritis and Musculoskeletal Alliance, and is available from the National Library for Health website (enter the document's title in the search bar).

A patient information leaflet on fibromyalgia, suitable for use by health professionals and those newly diagnosed with this condition, is also available from the Clinical Knowledge Summaries website (enter 'fibromyalgia' in the search bar).

Turning to concerns about the training GPs receive in dealing with fibromyalgia and myofascial pain, the Department of Health is not responsible for setting curricula for health professional training. Each university determines its own curriculum in the light of recommendations from employers and the regulatory bodies. However, the Department of Health shares a



commitment with statutory and professional bodies that all health professionals are trained to have the skills and knowledge to deliver a high quality health service to all groups of the population with whom they deal, whatever their condition.

In addition to this, the General Medical Council (GMC), which is independent of Government, sets the standards and outcomes for basic education in the UK. This covers undergraduate education and the first year of training after graduation.

Education and training for both health and social care workers are, and always have been, priorities for the Department of Health. However, we do accept that there is room for improvement. Lord Darzi's interim report *Our NHS Our future: NHS next stage review*, published in October 2007, sets out a ten year vision for the NHS, reflecting on feedback from patients, staff and the public. It looks at how the NHS can become fairer, more personalised, effective and safe, acknowledging progress made so far and setting out immediate and longer term priorities in these areas.

The report recognises that our approach to education and training needs an overhaul. As a result, we intend to look at the content of curricula in undergraduate and postgraduate training for both health and social care. Fibromyalgia diagnosis and care will be considered as part of the wider context of this work. Relatively little is currently known about the causes of fibromyalgia. Despite a great deal of commitment on the part of professionals and voluntary organisations, there are still considerable gaps in our knowledge about the diagnosis and treatment of this condition.

The Department of Health supports research and development of relevance to the NHS in hospitals, general practice and other healthcare settings. It also funds the NHS Research and Development Programme, which is managed on its behalf by the Medical Research Council (MRC). The MRC is the main Government agency for research, and receives its funding through the Department for Innovation, Universities and Skills.

Currently, the MRC has no specific research on fibromyalgia, although the basic research that the MRC supports in areas of pain and neurobiology is relevant to developing our understanding of the condition. There is now a Medical Advisory Board attached to the Fibromyalgia All Party Parliamentary Group, and one of its tasks will be to look into research on fibromyalgia.

The MRC does not directly commission research

projects or earmark funds for particular research areas. Funds are allocated by a process that requires investigators to submit proposals for rigorous peer review. The MRC always welcomes high quality applications for support into any aspect of human health and these are judged in open competition with other demands on funding. The key factor in deciding whether a proposal is funded or not is quality of the science and its potential contribution to human health. In addition, the MRC identifies priorities for medical research in a number of ways, including strategic reviews of specific areas of science and by responding to Department of Health priorities.

Comments by MAB member Dr Kim Lawson:

I have read the Government response to the petition related to fibromyalgia and I have a number of concerns for which I would appreciate clarification. Within the first paragraph there is the statement "Fibromyalgia can be successfully managed within the primary care setting". How is success determined in this setting? If the condition can be managed, is there evidence of whether it is managed and what level of success is achieved?

In paragraph 5 there is the statement "...a leaflet about fibromyalgia, which has now been made available to all GP surgeries...". As a member of the Medical Advisory Board of the Fibromyalgia Association UK and co-author of this document, I know that it has not been available to a number of GP surgeries, including my local surgery. Can you please clarify what is meant by "...all GP surgeries..?"

Regarding training of clinicians (paragraph 9), while there are, as correctly highlighted, constraints on the content of undergraduate courses, what CPD provision is available with an emphasis towards fibromyalgia rather than general pain management?

In paragraph 15 there is the statement "There is now a Medical Advisory Board attached to the Fibromyalgia APPG, and one of its tasks will be to look into research on fibromyalgia." As a member of this Medical Advisory Board I am not aware of such a task or an intention of such a task. Can you provide further details of this situation, please?

I believe that the points that I have highlighted are somewhat misleading and may not represent the reality of awareness and management of fibromyalgia in the UK. I therefore look forward to your comments regarding the issues that I have raised.

Dr Kim Lawson, BTech(Hons), PhD.
Sheffield Hallam University



In the Spotlight with Anne Mills



Anne used to be a successful businesswoman, creative, capable & confident, until she developed the symptoms of CFS & fibromyalgia at the beginning of 1998. In her struggle to get to grips with the life changing effects of fibromyalgia and her desire to help other people with the condition she has put together a series of booklets dedicated to various aspects of living with fibromyalgia. Here she tells her story and what inspired her to write her series of eBooks.

What was your experience of developing fibromyalgia?

Horrible! My husband and I can now laugh about some of the really silly things I said or did, but the pain and devastation are not forgotten.

Like many others I was not initially diagnosed with fibromyalgia. A bite from some nasty little bug carrying the bacteria, Rickettsia, caused a blood infection which is thought to have been my trigger. We were initially overjoyed to have some explanation for the state I was in and there was hope that I would return to good health quickly. I had been feeling distinctly 'off' for some months and we really did think that a few weeks of treatment would see me back to my old self again (that was May 1998). We didn't have a clue about what was to come.

Referred to a medical practitioner who was using antibiotics to treat patients with similar types of infections, I was prescribed simultaneous doses of two different antibiotics over several months. In addition, I received painkillers, anti-depressants and sleep medication. Not surprisingly, I deteriorated - my general health noticeably worsened, and I rapidly became a complete zombie. This was when I hit the depths of my fibromyalgia experience: I was in unrelenting pain, unable to reason, incapable of holding a conversation and becoming increasingly depressed. While I know it happened to me, I sometimes think this happened to someone else, I have significant patches of time that I simply cannot remember. Without my partner rescuing me and taking me to see a naturopath (who was also a medical practitioner, herbalist and iridologist) I just cannot imagine what may have become of me.

What effect did this have on your personal life and work?

Although the symptoms arrived in a very gradual way, I was struggling for quite a time before finally reaching the point where I had to walk away from the business my partner and I had built up over 15 years. This was extremely distressing for me, but I always contend that it was so much more difficult for my partner, who had to take on an additional role as my carer.

Not only was I physically limited, I felt during the next year or two that I was fading away, as I had lost my personality and interest in life. Knowing nothing about the illness, and unable to take in any information, meant I didn't know what was happening or likely to happen. The overwhelming fatigue made it seem impossible to fight back physically or mentally. I felt totally useless as I was unable to do the simplest tasks or give my partner any meaningful support. The worst, though, was my sense of humour totally deserted me! Predictably, our business eventually failed. With little understanding or support from my family, which I have since discovered is rather too common, we faced a very uncertain future for a time virtually alone. However, as I had been diagnosed with CFS and a little later with fibromyalgia, it did mean we could start rebuilding our life very slowly!

How did you start putting your life back together?

The very first step towards recovery for me was nutrition - both what I ate and nutritional supplements. A hair analysis, a particularly helpful (and painless!) procedure, provided my naturopath with a starting point and a plan to build up my deficiencies. A traditional Chinese medicine practitioner was significantly helpful in reducing my pain, overcoming my sleep difficulties and improving my digestion. The mud-like taste and texture of the Chinese herbs cooked up into a warm 'tea' to sip provided a whole new challenge until I started to feel a little improved! Then a friend, who was a qualified massage therapist, had done research into fibromyalgia so she was able to administer the tender point test and to massage me in a manner that provided me with relief, although not entirely comfortably due to the fibromyalgia. However, the most important member of my little 'team' has been my partner, who was incredibly patient in the face of my maddening mindlessness and always encouraging. Having supportive people around you that take the time to understand what it is that you are experiencing can, I believe, make an enormous positive difference.

Over the years I have tried many, many treatments and therapies but nutrition has remained the most powerful for me. With improvements in my cognitive abilities



and a little more energy, I felt brave enough to undertake a diploma in clinical nutrition as I wanted to better understand what I could do to improve my own health. Correspondence learning was necessary, as any sufferer will know, because it is impossible to know which day your brain may be full of fog or at what hour of the day your body decides to close down. I still follow the nutritional guidelines in my book *Create Energy!*, which was the direct result of my studies in nutrition as well as other natural therapies.

What inspired you to put these booklets together?

I have this belief that things in life happen for a reason and it is best to find something positive within them. As I had gathered together bits and pieces of information in my mission to beat my illness, I believed that someone else may find the knowledge helpful. My well-known quote is, *"These are the things I wish someone had shared with me!"*

It is the day to day living with fibromyalgia that seems to be missing in many of the books and much of the information available. We do need the more formal information, but we are also desperately seeking ways of managing. I found this practical information the most difficult to find. Others who do not have the energy or access to ideas and suggestions may benefit from what I have collected and studied.

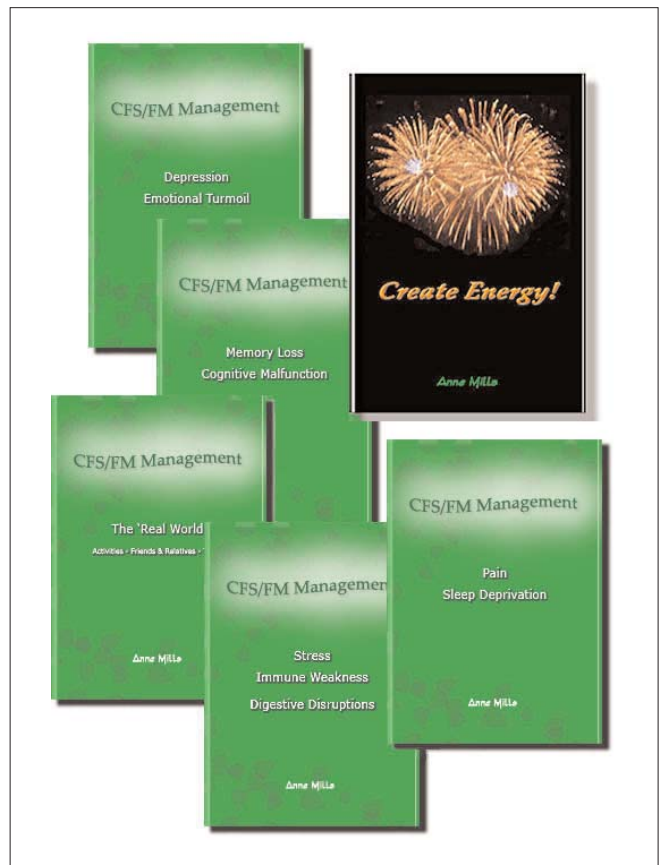
With a diploma in clinical nutrition I am able to offer unique advice as a fellow sufferer of CFS and fibromyalgia that has beaten the illness into some submission! Motivation comes from a simple desire to help - I know how terrible this illness can be and how even the smallest degree of relief in one symptom can really lift the spirits and provide some energy to tackle the next. So, I started writing...

What topics do you cover?

Chronic Fatigue Syndrome and Fibromyalgia Management is offered as six separate books so people can choose the ones that best meets their needs. They all contain practical strategies, a range of therapies and other suggestions - and lots of them, as what works for one of us may not work for another. This is an approach that is quite different to many other books as there is not just one single treatment or regime promoted.

The six books are entitled:

- Create Energy! - Nutrition, Supplements & Exercise
- Depression - Emotional Turmoil
- Memory Loss - Cognitive Malfunction
- Pain - Sleep Deprivation



Stress - Immune Weakness - Digestive Disruptions
The 'Real World'- Activities, Friends & Relatives, Travel

There are also three free articles available from the website. Each is written to help explain to family, friends or others about what a sufferer and their carer/s may face:

- * A Description of Fibromyalgia
- * A Description of Chronic Fatigue Syndrome
- * The Cruelty of CFS/FM

How can people access these booklets?

The books and articles are available at:
<http://fmauk.cfsfm.hop.clickbank.net>

There are excerpts from all the books on the website so you can read a little from each and also access some free suggestions. They are eBooks which means that as soon as you make an online purchase you can download your own copy and put it to work for you today!

A generous percentage of each book's price goes to FMA UK to provide further support for fibromyalgia sufferers in the UK.





Pregnancy and Beyond-

From Preconception Care to Postnatal Success

With Midwife Denyse Moore

Pain Relief During Labour- Part 1

Okay, now this is a tricky article to write. The thing is, we are all so different and therefore all have different reactions to the pain of labour and how we perceive and cope with it. Some women need minimal or no pain relief at all while others want everything going! Both options are absolutely fine, midwives will be guided by your needs and will tell you what your options are at the time, as these will vary according to what stage of labour you are in and what medications you are currently using. In my experience, women with FM seem to tolerate pain for longer than women without FM. This is probably due to having built up a certain amount of tolerance to pain through daily living with FM. This month I am going to discuss the drug free methods of pain relief that are available.

Breathing

Okay, okay, I know we all have to breathe! I am talking about structured, controlled breathing in this instance. Let me explain... As your contraction begins to build you can inhale slowly and deeply through your nose. Concentrate on how your breath feels as it passes over your throat area. Then gently plug your ears with the respective index fingers and close your eyes. Exhale slowly producing a long and continuous humming sound, and repeat as often as required. This technique serves to distract you from the pain, but also has the added benefit of getting a good flow of oxygen to your hard working muscles. I have also seen women try the following various techniques:

- * Visualisation (you are ambling along a sandy beach, in a meadow etc)
- * Affirmation (My body is strong, is working well for me, knows what it is doing etc)
- * Conscious relaxation of tense muscles
- * Non-focussed awareness (notice what you see, hear, feel, smell and then forget about it, move onto the next sensation)
- * Vocalising (moaning, making single sounds like 'oh, oh', groaning)
- * Singing or prayer

Mobility

Moving around during labour is often a great help to

women. For those of us with FM, changing position and the ability to wander around to some extent during labour is almost vital if you want to avoid the pain associated with stiff muscles from staying in one position too long. Even if you only change your position from sitting to standing to kneeling on all fours, it can help to ease your baby deeper into your pelvic outlet, the start of your birth canal. Walking up and down stairs or stepping on and off a step in a sideways movement is thought to also help shift your baby deeper into your pelvic outlet. Some women find that kneeling on all fours or sitting on a birthing stool can help them push more effectively. A bean bag or large ball such as one used for abdominal exercising can be very comfortable to sit on while in labour and will encourage you to sit in a good position too.

TENS

This is a hand held, battery powered device that sends electrical impulses through your lower back via four electrodes. You control the intensity of the stimulus and are able to boost it during a contraction. The theory behind this is that it blocks some of the pain signals from passing through the 'pain gate' thus restricting the amount of pain your brain has to process. In my opinion you will either love or hate this method, if it works for you it will work well and vice versa. The majority of women I cared for with FM found this very helpful in helping them to feel in control of their labour pain. Unlike most of the other pain relief methods, this can not be used in conjunction with hydrotherapy and you will need to rent one before going into labour as most hospitals do not have a large enough supply.

Hydrotherapy

Anyone with FM will have been advised to try warm/hot water for pain relief, so you will have the distinct advantage of knowing whether this works for you already. The labour/birthing pools used in maternity care are much deeper than a normal household bath, about the depth of a Jacuzzi tub. I would advise women with FM to consider this as one of their methods of pain relief. It is completely reversible, if you do not like it you can get out and try something else. You can use alternative pain relief methods in conjunction with this such as gas and air,



breathing and massage, and the added buoyancy of the water makes it much easier for you to change positions as well.

Hypnosis

Hypnosis is just a fancy term for being really relaxed, and for clearly focussing in on just one thing, while everything else fades into the background. Hypnosis for birth is proving increasingly popular, and research shows that it really makes a difference to birth outcome and maternal satisfaction. Hypnosis is all about the mind's ability to affect the body's reactions and self-hypnosis is a state of deep relaxation, where the mum remains fully alert and fully in control throughout. To find out more about HypnoBirthing classes near you, go to www.hypnobirthing.co.uk. For more information and birth stories, go to the US website at www.hypnobirthing.com.

Massage

Massage is a good technique to use during labour. It can be especially beneficial for women with FM who are unable to change positions easily, say for example, if they have opted to have an epidural. In these cases massage may help prevent muscles stiffening up and the discomfort associated with this. It is advisable for you and your partner to experiment with massage

during your pregnancy to find what pressure you can tolerate and which parts of your body you prefer to have massaged. Some women with FM find even gentle massage too uncomfortable and labour is not the right time to discover this! However, if, like me you are one of those people who find massage too uncomfortable, don't despair. Here are some similar techniques which may work in much the same way for you: hot compresses such as a flannel or hot water bottle placed on your back or wherever else you hurt, or ice packs used in the same way; a warm blanket over your entire body or a lengthy warm shower, take the shower head off the wall and direct the spray to precisely the area you need it most. One other technique you may wish to consider is acupuncture however I am not able to advise you on this and suggest that you seek out the advice of a qualified practitioner during your pregnancy.

Next month in part 2, I will discuss the different types of medical pain relief and the pros and cons of each in relation to use in labour by women with FM. Until then, I would like to wish you the best possible health and maximum enjoyment of your quality of life.


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What is 'EPA' and how can it help me?

It is important to adopt a proactive approach to managing our health, and a good diet may make all the difference in helping your body cope with the symptoms of fibromyalgia; consider the following advice as a 'nutritional', rather than a 'pharmaceutical' intervention into your condition.

There are nutritional 'strategies', which involve adapting what you eat to offer biological reinforcement to different areas of the body. Changing your dietary intake may help to alleviate symptoms, albeit through indirect means, by providing additional support for your immune system, and naturally stimulating the generation of anti-inflammatory prostaglandins within your body, which provide pain-relief to the muscles.

Fibromyalgia is a rheumatic disorder classified primarily by chronic pain throughout the muscles, tendons and ligaments. Individuals may also suffer from headaches, have poor concentration or lack of memory and they may even feel irritable or depressed. By monitoring their nutritional intake of the polyunsaturated fatty acid eicosapentaenoic acid (EPA), sufferers can help manage their symptoms. Whilst our bodies are naturally equipped to generate EPA by a series of conversions of the foods which we eat, the rate of conversion is very often insufficient to meet requirements.

Within the body, EPA is converted into powerful 'hormone-like' substances called 'eicosanoids', which play a major role in the cardiovascular system. These lower blood pressure, increase circulation and reduce triglyceride and cholesterol concentrations. They are known to exhibit anti-inflammatory actions, and play a

major role in immune system function, which explains their utility for managing the symptoms which characterise fibromyalgia, such as severe muscular pain.

During an immune response, signalling compounds, known as cytokines, are produced, which allow cells to communicate with one another. When the immune system is fighting pathogens, cytokines are released, which signal to the relevant immune cells to travel to the site of infection. Cytokines 'activate' those cells, stimulating them to generate additional cytokines.

Cytokine production falls into two categories: inflammatory and anti-inflammatory. There is increasing evidence that inflammatory cytokines register in increased numbers in fibromyalgia patients, and explain many of the associated symptoms such as fatigue, fever, lack of sleep, pain, and aching. An EPA supplement, such as the Vegepa preparation, is designed specifically for managing the symptoms of conditions such as these.

Vegepa is a patented and unique formulation containing ultra-pure EPA from marine fish oil, and GLA from organic virgin evening primrose oil. Vegepa provides a highly concentrated source of omega-3 & omega-6 long-chain fatty acids and is distinctive as a supplement because the other oily fish long chain fatty acid, docosahexaenoic acid (DHA), is removed. This is because EPA and DHA actually compete within the body to be taken up by our body cells.

Vegepa is available from www.vegepa.com and costs £11.95 for 60 x 500mg capsules.

Meet our February prizewinner, Mrs Lamb

I am retired and have suffered with the symptoms of fibromyalgia for many years, despite only being diagnosed last year. I was born in a Yorkshire village, but have lived in Nottinghamshire for the last 40 years. I enjoy reading the FaMily magazine and find the readers' letters helpful and sometimes amusing. Thank you for my prize of £10.



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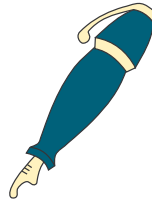
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Letters



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Or email to info@ukfibromyalgia.com

I am a new subscriber to FaMily Magazine I think its great also I have been to two meetings with the Sheffield Support Group of which I am a new member, at long last I don't feel alone and isolated.

After 18 months of my own research I reached the conclusion I had FM I also realised that I could have had it for a good part of my life blaming it on arthritis. On my next visit to my doctor I asked to be referred to a Rheumatologist. I saw a lovely man he confirmed that I was right, I could have kissed his feet with relief at last I finally had someone to believe me and confirm also I wasn't an hypochondriac, I came out of his room in tears of joy.

It is not so much the FM that is the problem but Food Intolerance, I am intolerant to a few things but at top of the list is Maize (corn) its not life threatening like wheat but all the same it is just as difficult. What I'd like to know are there any readers with the same problem and would like to share this with me, if there are if you would like to contact me I'm sure we could be of help to each other I'd love to hear from you.

Mrs Veronica Clixby 66 years of age
v.clixby@btinternet.com

Support Group North Cornwall

Are you interested in having a ME/CFS/Fibromyalgia support group in North Cornwall?
If yes please contact Sasha on 0785 400 1543 or email supportmeinnorthcornwall@hotmail.co.uk

Dear FaMily

We are starting a clinical study on TDLBI (trans dermal laser blood irradiation), a treatment form used for many years several countries in Europe.

Our study (mono-therapy-study) will include:
ME/CFS, Fibromyalgia, Post Viral Fatigue

We are looking for ME/CFS/fibromyalgia sufferers who want to take part in this study, which includes

- a) initial consultation/tests
- b) 6-10 treatments
- c) final consultation/tests

consultations/tests/treatments will be free of charge

(patients should live in the London area, because 3-4 treatments are necessary per week)

Dr. Peter Gruenewald, MD., Head of the Laser Clinic London and Bristol

Dirk Budka, Study Director, M.Sc, M.Sc., B.Sc, Dip Dok Immune Biology, Environmental Science, Microbiology and Nutrition.

Our websites: www.immunecliniclondon.com

Hope to hear from you soon, kind regards

Dirk Budka M.Sc, M.Sc, B.Sc, Dip Dok

STEROIDS AND FM

I would be interested in hearing about anyone's experiences with steroids in relation to fibro. Thank you.

Mr V Bright
Rugby, Warks

POEM Here's a little poem I wrote for you all to understand.

I wish someone would help me and take me by the hand
The one thing that I want in life
Is just to be free of pain
and maybe just for once I could be my old self again
I want to walk just by myself
and run through all the trees
To play with the grandchildren and paint with them on my knees
I try so hard to understand,
what is happening to me
I pretend to each and all of you
that yes I can cope ,
"I am fine"

Take care and gentle hugs **Julie Bull** - julie.bull@sky.com

Cortisol and Fibromyalgia

Data study suggests cortisol could alleviate for chronic fatigue syndrome and fibromyalgia

Chronic fatigue syndrome (CFS) and fibromyalgia (FM) are two serious and debilitating diseases with no confirmed cause and limited treatment options. However, results of a new comprehensive literature study propose a simplified treatment process that could help alleviate symptoms for patients suffering from these diseases.

Kent Holtorf, M.D., medical director of the Holtorf Medical Group Centre for Endocrine, Neurological and Infection related illness Torrance, Calif., is advising a simplified treatment process that may help alleviate CFS and FM symptoms. From an extensive review of more than 50 published studies that assessed adrenal function in CFS and FM patients, Dr. Holtorf found that the majority of CFS and FM patients displayed abnormal adrenal function due to hypothalamic-pituitary dysfunction. The comprehensive review also showed that the majority of patients could be treated for this adrenal dysfunction. Dr. Holtorf's analysis, recently published in the Journal of Chronic Fatigue Syndrome, demonstrated that patients that were given cortisol as part of a multi-system treatment experienced significant improvement in their symptoms.

'My review of existing studies suggests that a treatment protocol of early administration of cortisol may help improve and reduce the symptoms of chronic fatigue syndrome and fibromyalgia,' said Dr. Holtorf. 'This research provides a new understanding that treating the known causes of illness in CFS and FM can improve the symptoms and quality-of-life of patients who suffer from these conditions.'



CFS and FM primarily affect women in their 30s and 40s. According to the Centers for Disease Control and Prevention (CDC) more than one million Americans suffer from CFS while it is estimate that FM affects about 2 percent of the U.S. population. Unfortunately, both of these diseases are poorly understood by many physicians and there is no

generally accepted test to accurately detect them. In addition, many CFS and FM patients express frustration because there is no clear treatment path for their conditions.

Dr. Holtorf's research was further confirmed in an observational study following the conditions of 500 patients from his clinic, where of the patients given cortisol as part of their treatment protocol:

- * 94 percent showed improvement by the fourth visit;
- * 75 percent noted significant improvement;
- * 62 percent reported substantial improvement; and
- * Energy levels and a general sense of well-being for patients doubled by the fourth visit.

The effectiveness of this multi-system treatment was further confirmed through the analysis of the cumulative findings of over 40 independent physicians and over 5,000 patients.

As shown in the Journal of Chronic Fatigue Syndrome study, cortisol doses of 5-to-15mg a day have been shown to be safe, with little or no associated risk while having the potential for significant benefit for CFS and FM patients.

'Cortisol treatment carries significantly less risk and a greater potential for benefit than treatments considered to be the standard of care for both conditions,' Dr. Holtorf .

Kent Holtorf, M.D. is an expert in the treatment of chronic fatigue syndrome, fibromyalgia, complex endocrine dysfunction and chronic infections (including EBV, HHV6 and Lyme disease). Dr. Holtorf received his doctorate of medicine from St. Louis University with residency training at UCLA. He has personally trained numerous physicians across the country to effectively treat chronic fatigue syndrome, fibromyalgia and chronic infectious diseases. Additionally, Dr. Holtorf was the founding medical director and developed the protocols for Fibromyalgia and Fatigue Centres and other centres across the country.

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FIBROMYALGIA RESEARCH REVIEW

JOANNA RAWLING



MAY 12TH

INTERNATIONAL FIBROMYALGIA AWARENESS DAY

The celebrated English nurse and pioneer of the International Red Cross movement, Florence Nightingale, was thought to have suffered from fibromyalgia/chronic fatigue syndrome, possibly caused by a chronic bacterial infection. Her birthday, May 12th, now marks international chronic fatigue syndrome and fibromyalgia awareness day, which promotes further research and public knowledge of these syndromes. But who was Florence Nightingale, did she really suffer from fibromyalgia/chronic fatigue syndrome, and how did she cope with the illness she battled for most of her adult life?

NIGHTINGALE IN SCUTARI: HER LEGACY RE-EXAMINED

Florence Nightingale trained as a nurse in Germany in 1851, believing that this was God's calling for her. In contrast, Nightingale's nursing training was strictly against her parents' wishes, who viewed such a profession as inappropriate for someone of her class. Just three years later in November 1854, Nightingale would find herself leading a team of 38 volunteer nurses at the front lines of the Crimean War (1854-56). Nightingale was sent to Turkey by war minister Sidney Herbert to manage care of troops at the British army hospital in Scutari (Istanbul). On her arrival, Nightingale is famously quoted as saying "the strongest will be wanted at the wash tub" after witnessing the appalling sanitation and crowding in the hospital wards. In fact, conditions at the barracks hospital were so grave, that infections contracted while at the hospital killed far more soldiers than bullet wounds.

Although she had no concept of the microbial transmission of disease, Nightingale understood the strong connection between the filthy conditions in the hospital and the spread of infection. The extreme crowding on the wards would have been the perfect breeding ground for the spread of typhus, typhoid fever, dysentery and respiratory infections. Nightingale introduced a number of revolutionary procedures to improve hygiene standards, which included the regular washing of soldiers and their linen, improved nutrition, and even the installation of new windows capable of opening to ventilate the pestilent stench of the wards. Many of the current health care practices that should be carried out to reduce hospital infections nowadays actually date from those introduced by Nightingale in Scutari. Although resented by the army surgeons, she earned the adoration of the soldiers by preferentially caring for patients with infectious diseases (at her own risk), who had been deemed beyond help by the army doctors. Nightingale was said to have been at her happiest while she was with her patients, and her nightly tours of the 6.4 km-long Barracks Hospital wards inspired the

popular image of Nightingale with an open flame lantern and her nickname "The Lady with the Lamp". As one soldier's ballad reads "The wounded they lover [love her] as it has been seen, She's the soldier's preserver, they call her the Queen. May heaven give her strength and her heart never fail. One of Heaven's best gifts is Miss Nightingale."

Gill, C. J. & Gill, G. C. (2005). "Nightingale in Scutari: her legacy re-examined." *Clin Infect Dis* 40, 1799-1805.

Center for International Health, Department of International Health, Boston University School of Public Health, 85 E. Concord St., Boston, MA 02118, USA.

FLORENCE NIGHTINGALE'S FEVER

Unfortunately, Nightingale had her own grave health problems to face. In early May 1855, Nightingale left Scutari to inspect hospitals some 300 miles away in Balaclava. Although she arrived safely on May 5th, she was taken ill on May 12th (her birthday), just a week after her arrival. Doctor Anderson, Chief Medical Officer at the General Hospital in Balaclava, diagnosed Nightingale with Crimean fever, remarking that she was suffering from "as bad an attack of fever as I have ever seen". Symptoms of Crimean fever (also known as Malta or Mediterranean fever), included feverous, nervous irritability and delirium, accompanied by sweats, weakness, aches and pains. The bacterium responsible for causing Crimean fever was isolated from the spleen of a soldier in 1887 by David Bruce, who thus named the bacteria *Brucella*. Although animals are the natural carriers of the *Brucella* bacteria, humans can contract this disease by contact with animals or animal products. The original name of remittent fever derives from the temporary remission from symptoms that sufferers would experience, only to succumb once more to a fresh wave of fever. In most cases the infection is cleared within a few weeks to several months, however *Brucella* may persist in a proportion of patients, leading to a condition termed chronic brucellosis.

Nightingale appeared to recover from the initial bout of *Brucella* infection, and returned to Scutari to resume her nursing in August 1855. However she appeared painfully thin and exhausted (see picture), reportedly suffering from depression and nausea at the site of food. Between her return to the UK in August 1857 and the end of 1861, Nightingale endured five further attacks of fever, which were accompanied by a range of symptoms, including palpitations, delusions, weakness and indigestion. By the end of 1861 she was bedridden, and remained so for the next 6 years, suffering so severely from spinal pain that she was said to have been unable to change position for some 48 hours at a time. Her doctors diagnosed her with "congestion of the spine, which leads straight to paralysis", although Nightingale may in fact have been suffering from *Brucella* spondylitis, a complication of chronic brucellosis, caused by bacterial infection of the spine.



Nightingale experienced no further attacks, and by the 1870s most of the specific symptoms of brucellosis disappeared. However she continued to be plagued by severe headache, insomnia and depression. Nightingale experienced feelings of worthlessness and failure, in spite of the incredible achievements in revolutionising nursing and healthcare that she had continued to accomplish throughout her illness. The work of the Nightingale School of Nursing, which dates from the first ever school of nursing opened by Nightingale at St. Thomas' hospital in 1860, still continues today. The legacy of Nightingale's work also lives on in the International Red Cross organisation, which is responsible for organising international relief for the victims of war and humanitarian crises.

Florence Nightingale suffered from chronic pain and fatigue for a large part of her life, and her battle with illness, combined with her incredible list of achievements, continue to inspire all sufferers of chronic illnesses. Interestingly, medical opinion shortly after her death favoured the idea that Nightingale had been suffering from a weakened nervous system; a condition termed "neurasthenia". Neurasthenia was discovered in 1880 by the US neurologist Beard, who described a condition prevalent among young women with a remarkable resemblance to the syndrome we now refer to as "fibromyalgia". The symptoms of neurasthenia consisted of widespread pain, fatigue, dizziness, palpitations and psychological disturbances. Accordingly, Beard termed this disease nervous exhaustion or "neurasthenia", attributing symptoms to the "enfeeblement of the nervous force". In contrast nowadays, neurasthenia patients receive a variety of diagnoses, including chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS), postural orthostatic tachycardia syndrome (POTS), or fibromyalgia syndrome (FMS). Indeed, the wide range of symptoms experienced by Florence Nightingale (pain, fatigue, weakness, headaches, laryngitis, insomnia, anorexia, palpitations, nervousness and depression), has led to the suggestion that she was suffering from fibromyalgia, chronic fatigue syndrome, or even post traumatic stress disorder. Others dispute this view, claiming that Nightingale was suffering from non-specific symptoms of the chronic bacterial infection brucellosis. Although we will never be able to diagnose her condition with certainty, it is of interest that research suggests that bacterial or viral infections are risk factors for FMS and CFS. Moreover, recent findings suggest that chronic bacterial (mycoplasma) infection may in fact cause FMS/CFS.

Young, D. A. (1995). "Florence Nightingale's fever." *BMJ* 311, 1697-1700.

Wellcome Foundation, 23 Hillcrest, Downham Market, Norfolk PE38 9ND.

MYCOPLASMA INFECTIONS AND CHRONIC ILLNESS

Mycoplasmas are the smallest form of free-living bacteria. In humans, mycoplasmas are found in the mucous surfaces, i.e. of the respiratory and urogenital tracts. While some species of mycoplasma are non-pathogenic, others are able to infect major organs, leading to acute or chronic illness (i.e. *Mycoplasma pneumoniae*). They are resistant to many types of antibiotics, including penicillin, and are able to evade the immune response by "hiding" within human cells. Although definitive proof is lacking, mycoplasma infection has been implicated in disorders as diverse as rheumatoid arthritis, chronic asthma and Crohn's disease. A number of research groups have also detected the presence of mycoplasma in the blood of fibromyalgia syndrome (FMS), chronic fatigue syndrome (CFS), and Gulf War illness (GWI) sufferers. Averaging the results from several studies, mycoplasma DNA was detected in about 50% of FMS, CFS and GWI patients, compared to only 10% of healthy controls (see table). Furthermore, FMS/CFS sufferers infected with more than one mycoplasma species experienced greater symptoms than patients infected with a single species. The species most often encountered in patients with FMS, CFS or GWI were *Mycoplasma pneumoniae* and *Mycoplasma fermentans*. While it is not known whether these infections are the cause of FMS/CFS, or simply the result of a weakened immune system, it is worth noting that long-term antibiotic therapy has been reported to offer some relief from symptoms in a proportion of FMS, CFS and GWI patients. It is hoped that the experience of Florence Nightingale and many others will inspire researchers to determine whether FMS and related disorders do indeed result from chronic bacterial or viral infection, as suggested by sufferers and scientists alike.

Endresen, G. K. M. (2003). "Mycoplasma blood infection in chronic fatigue and fibromyalgia syndromes." *Rheumatol. Int.* 23, 211-215.

Department of Rheumatology, The National Hospital, University of Oslo, Forskningsvn. 2-Block B, 0027, Oslo, Norway.

Diagnosis	N patients	Percentage of patients positive for mycoplasma	N healthy controls	Percentage of controls positive for mycoplasma
CFS	100	52.0	100	15.0
CFS	100	52.0	50	14.0
CFS	100	52.0	160	2.0
FMS	40	54.0	-	-
GWI	60	55.0	-	-
GWI	30	46.6	21	0.0
GWI	170	44.7	41	4.9
CFS and/or FMS	132	62.9	32	9.3
CFS and/or FMS	91	59.3	32	2.0
CFS and/or FMS	565	53.1	71	9.9
CFS	261	68.6	36	5.6

The results of several studies on the prevalence of mycoplasma infections among fibromyalgia syndrome (FMS), chronic fatigue syndrome (CFS), and Gulf War illness (GWI) patients are summarised in the table. N refers to the number of patients.



FaMily Phone Friends- Make a new friend-Phone Today!

We receive a lot of requests from FaMily readers who do not have access to the internet (or a local support group) to have telephone numbers of fellow FM sufferers, so that people can chat to people who understand what having FM entails. We have launched this FREE service for paid up FaMily subscribers where you can add your details for people to get in contact.

To appear on this page we need your Name, Town, County, Telephone number and convenient contact times.

Send to:
7 Ashbourne Rd, Bournemouth, BH5 2JS
Tel 01202 259155 Fax 0870 1693701
Email: family@UKFibromyalgia.com

Alison Smith Ramsbury, Wilts 01672 521278 Mon-Fri 10am-2pm	Manju Laroya Maidenhead, Berks 01628 625081	Mrs Jo Fisher Fibromyalgia support group for Surrey and Sussex Helpline Monday to Friday 10am until 4pm 01403 255450
Sandy McFall Bristol 0117 960 3228 After 10am	Jennifer Carter East Sussex 01323 848590 7 days a week	Linda Allen Stoke on Trent Weekdays 10am-2pm 01782 208462
Ms Gill Galyer 5 Winston Drive Elston Newark NG23 5NX 01636 526160	Miss Bede Miles West London 020 8840 7759 Not mornings	Mrs Carolyn Mapleson Rayleigh Essex 01268 780133 During the day between 10am and 4pm
Maureen Schofield Stoke on Trent 01782 264071 7 days a week	Mary Grice (widow) Oxford 01865 515032 Anytime (retired)	Mrs Linda Pedder Heysham Lancs. 01524 859068 Anytime
Mrs Julia Barns Littleover, Derby 01332 521605 9am - 3pm	Julie Bull Leeds 01132 721071 12-3pm or email julie.bull@sky.com	Shirley Taylor Worcs. 01584 811615 Friday to Tuesday 10am to 1.00pm & 5.00 to 7.00pm shirleytaylor24@yahoo.co.uk
Mrs Coral Duvall Blackburn, Lancs 01254 609576 Mon-Fri after 10am	Margaret Evans Cardiff 01132 721071 12noon-6pm weekdays	



THE SOAPBOX

by Jeanne Hambleton

We are on count down to May 12 and encouraging folk to do something special for this annual International Fibromyalgia Awareness Day but some people had other reasons to remember this date.

You might be surprised just how many well known Taurians have been born on this day, the important people who have died on May 12, and some of the major events.

May 12 is not just the International Fibromyalgia Awareness Day it is shared with the CFS/ME organisations, and is also listed as the International Nurses Day. This celebrates the date of Florence Nightingale's birth in 1820 in Florence, Italy, to a wealthy English couple who found she was a quick-witted and an independent 'wild child'.

In 1854 when the Crimean War broke out Florence Nightingale took 36 nurses to British military hospital in Constantinople. This was the first time female nurses had served in military hospitals under war conditions. She became known as 'The Lady of the Lamp' due to her continuous nursing of British soldiers during the Crimean War where she persuaded army officials to change terrible conditions in the hospitals.

The website Answers.com says every year in London in Westminster Abbey on May 12 there is a service when a symbolic lamp is carried from the Nurses' Chapel into the Abbey. This is passed from one nurse to another before the Dean of Westminster Abbey places it on the High Altar. It is said this is symbolic of passing the knowledge of nursing from one to another.

In East Wellow, in Hampshire, UK, at St Margaret's Church, where Florence Nightingale was buried in 1910, a service is held on the Sunday after May 12. There is a significant memorial in the graveyard.

Wikipedia, the free Internet encyclopedia, provides a long list of important events which happened on May 12 including the Coronation of King George VI in 1937, the Queen's father. In 1942 on this fateful day 1,500 Jews were sent to the gas chambers in Auschwitz; and on a brighter note on May 12 1965 the Soviet spacecraft Luna 5 crashed on the Moon.

The May 12 action day was the inspiration of Tom Hennessy, an American with Chronic Immunological and Neurological Diseases. His inspiration galvanised the CIND community to pressurise governments to respond to these devastating illnesses. According to the R.E.S.C.I.N.D. website (www.geocities.com/CapitolHill/4277/event.html) symptoms of the Chronic Immunological and Neurological diseases included cognitive problems, chronic muscle and joint pain, extremely poor stamina, and numerous other symptoms. Those suffering with these problems increased dramatically. In the 1980s, and patients were often dismissed by the medical profession as suffering from psychosomatic illness. (Sounds familiar! How little has changed!)

As the illnesses became more widespread many people were so weak that they could not care for themselves. The mystery aches, pains and fatigue continued to spread unchecked with little response from government. (There is something that reminds me of 2008 in that comment!) To raise awareness of the seriousness of the situation, the response was the May 12 International Awareness Day. It all began in 1992 during a train journey in New York taken by Tom Hennessy. The idea became a huge success with patients, families and friends demanding that the government responded to these devastating illnesses. Tom who is bedridden, still receives emails from all over the world about his May 12 action day, but is too sick to answer all of them.

In her 30s (late 1850s) Florence Nightingale, whose work led to the creation of the International Red Cross, suffered a paralyzing FM/CFS/ME-like illness and spent the last years of her life virtually bedridden. In spite of her fibromyalgia sickness, she founded the first School of Nursing.

It is fitting that the determination of this lady of the late 19th century became an inspiration to victims of CIND - FMS/CFS/ME/PVFS/MCS (fibromyalgia, chronic fatigue, myalgic encephalopathy, post viral fatigue syndrome, multiple chemical sensitivity) and other long-term chronic pain illnesses in the late 20th century. Thank heavens for multi-functional women.

Christine's Cookbook

Have you ever tried cooking with cannellini beans? Well maybe you should give them a try – they're high in fibre, low in fat and help keep you feeling fuller for longer. This small, white, kidney-shaped bean can be purchased dried or tinned borlotti beans make a good replacement if you can't find them. Cannellini beans are good for using in salads and casseroles. The dried variety needs to be soaked in cold water before cooking.

Tuna & Cannellini Bean Pasta Serves 4

1 tsp olive oil · 1/2 medium red onion, finely sliced
75g (3oz) courgette, finely sliced
50g (2oz) button mushrooms, sliced
1 x 300g tin cannellini beans
2 tsp green pesto
1 small tin tuna (in spring water), drained
1 chicken/vegetable stock cube
150g (6oz) fusilli pasta – small spirals

Heat the oil in a large pan and fry the onion, courgette and mushrooms for a couple of minutes. Add the cannellini beans, pesto and tuna and combine together. Crumble a stock cube into the pan, add the pasta and stir all the ingredients together. Add sufficient water to just cover the ingredients and simmer for 7-8 minutes, stirring occasionally, until pasta is cooked. (The liquid will thicken to a sauce as the pasta cooks). Serve.

Cannellini Bean and Red Onion Risotto - Serves 6

1 tbsp olive oil · 1 large red onion, finely chopped
2 cloves garlic, finely chopped
4 sprigs thyme
500 g risotto rice · 200 ml dry white wine
1 litre hot vegetable stock
800g canned cannellini beans, drained and rinsed
2 tbsp freshly grated parmesan cheese
1 pinch freshly ground black pepper

Heat the oil in a large pan and gently cook the onion, garlic and thyme for 5 minutes until softened. Add the rice, stir for a few seconds then pour in the wine. Bubble rapidly until the wine evaporates, then slowly add the stock in batches, letting the rice absorb the liquid each time before adding more. Add the beans about halfway through – keep the heat fairly high and the whole process should take about 20 minutes.

Season with pepper. Once all the liquid has been absorbed and the grains are soft and creamy, divide the risotto between bowls. Top each serving with a sprinkling of parmesan and a good grinding of black pepper and serve swiftly.

Cannellini bean dip Serves 4

2 tbsp olive oil · 1 garlic clove, finely chopped
1 tsp fresh rosemary, finely chopped
250g/9oz tinned cannellini beans, rinsed and drained
salt and freshly ground black pepper
1/2 tsp sesame oil · dash Tabasco sauce
1 tsp white wine vinegar

Heat the oil in a pan; add the garlic and rosemary and saute for 1-2 minutes. Pour into a food processor and add the beans, salt and freshly ground black pepper, to taste, sesame oil, Tabasco sauce and vinegar.

Blend together to form a smooth paste, adding extra olive oil, if necessary. Transfer the mixture to a serving bowl and serve the toasted breads alongside.

Christine Craggs-Hinton is the author of 'Living with Fibromyalgia', 'The Fibromyalgia Healing Diet', 'The Chronic Fatigue Healing Diet', 'How to Beat Pain' from Sheldon Press. They are available from the www.ukfibromyalgia.com website and from all good book shops.

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