

Fibromyalgia: the invisible illness by Lorna Vanderhaeghe, B.Sc.

Lorna Vanderhaeghe, BSc., is co-author of *The Immune System Cure*, (Cicco Books, UK) published in six countries and four languages. She is also author of *Healthy Immunity, Scientifically Proven Natural Treatments for Conditions from A-Z*, Kensington Books, USA.

Called the invisible illness because it is difficult to diagnose, fibromyalgia (FM) is a common rheumatic syndrome affecting close to sixteen million North Americans. This multi-syndrome disorder is characterized by musculoskeletal pain, stiffness and chronic aches and pains; the most common symptom is widespread muscle pain. FM comes from the Latin fibro meaning supportive tissue, myo for muscle and algia for pain. It currently accounts for 1 out of 8 of all visits to rheumatologists in the UK. Like rheumatoid arthritis, it is more common in women and affects those between the ages of 30 and 60.

Fibromyalgia is characterized by musculoskeletal pain, stiffness and chronic aches and pains; the most common symptom is widespread muscle pain.

The pain of FM is thought to be caused by a tightening and thickening of the thin film of tissue, which holds muscles together. In order to diagnose FM physicians apply pressure to certain trigger points including the neck, rib cage, hips, knees and shoulder area to see if tenderness and pain are present. Eleven of 18 specific locations must feel tender in order for your doctor to confirm FM.

Diagnosis is difficult

Symptoms of FM are varied and may include allergies, anxiety, mental confusion, fatigue, carpal tunnel syndrome, depression, dizziness, heart palpitations, dysmenorrhea, fingernail ridges, stiffness, inability to exercise, gastrointestinal disturbances, headaches, irritability to light, sound and smells, mood swings, sleep disturbances, skin tender to the touch, total body pain, aching and joint swelling. FM patients describe a feeling of extreme muscle fatigue as if they had been shovelling snow for days. The pain is so intense that it feels like the muscles are being stretched and torn.

Symptoms are unique to each person, making FM difficult to diagnose.

Many diagnostic tests - blood, urine, x-ray, CAT scan, magnetic resonance imaging and more - may be performed with no conclusive evidence of anything wrong. FM sufferers are often referred to psychiatrists for their symptoms. Their lives become unbearable, especially when no one takes their pain seriously. It is often difficult for family and friends to understand this shadowy disease.

in this issue

Page 1
Fibromyalgia: the invisible
illness by Lorna
Vanderhaeghe.

Page 4
News, Announcements and
Research

Page 5
Fibromyalgia and the Leaky
Gut Syndrome

Page 6
Exercise and Fibromyalgia

Page 10
Fibromyalgia in Men

Page 11
The muscle in Fibromyalgia

Page 14
Postcard Awareness
Campaign

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

Incorporating the
Fibromyalgia Association
UK Journal - July, October,
January, April
Tel: 01384 820052

Tel: +44 (0)1202 259155
Fax/Voicemail: 0870 169 3701
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family@ukfibromyalgia.com

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Causes

No one cause can be pinpointed but it is believed multiple stressors - a traumatic emotional event, stress and depressive episodes - contribute to the disorder. Nutritional deficiencies and heavy metal and chemical toxicity are also major factors. There is also thought to be a connection between chronic fatigue syndrome and FM, as often those who acquire FM have a history of relentless fatigue. Repressed emotions or a traumatic emotional or physical event and serious illness are also linked to the disorder. Physicians must peel away the causal layers of each symptom and treat each one individually in order to eliminate the disorder.

Treatments for fibromyalgia

A healthy diet rich in organic fruits, vegetables, nuts and seeds is of paramount importance. Total body detoxification is also important. Several methods of detoxification combined work best. Saunas help excrete toxins via the skin; internal cleansers that combine herbs and fibre will aid the removal of waste products from the colon and support the kidneys and liver. Dry brushing the skin with a soft body brush will increase circulation to the skin and enhance the lymphatic system. As well, the removal of mercury amalgam dental fillings may be required for optimal healing. The elimination of allergy-causing foods and substances should be adopted and the following nutritional supplements should be added to your treatment program.

Many of the symptoms of FM overlap with those of chronic fatigue syndrome (CFS). The main symptom difference between the two is fatigue in CFS and muscle pain in FM. Treatments for CFS focus on the elimination of viruses that may be causing the fatigue, whereas FM treatments look at reducing the inflammatory factors that cause the pain and swelling of joints and muscles. Due to the many symptoms of FM and CFS a combination of therapies may be required to get the conditions under control.

Sleep, laughter and exercise

Let's look at how we can support the body while it is undergoing the healing process. Focus on repairing disrupted sleep patterns with the addition of valerian extract or melatonin before retiring at night to induce a restful sleep. Gentle exercise should be performed during the day to keep muscles from wasting. Exercise may include anything from just walking from the front door to the sidewalk or no-impact water walking at your local pool, to sitting in a chair lifting your legs and arms. To get more from your gentle exercise routine strap on velcro weights which you can purchase in 1/2lb - 3lb sizes.

Laughter has a soporific action; rent comedies and spend time around funny people. Laughter and exercise both increase brain serotonin levels, known for reducing pain. Sleep and gentle exercise not only help produce a good sleep state, they also enhance the functioning of the immune system. Poor sleep quality and pain go hand in hand with fibromyalgia. When one improves so does the other. Take melatonin beginning with .5 mg and increase it gradually until deep sleep is obtained without a groggy feeling the next morning (Melatonin is available only on prescription in the UK-Editor) Each person's dose is different but on average around 3 mg works effectively. Valerian also

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induces a relaxed, sleepy state. It is available in tablet, tincture and tea form. Choose the form you wish and take as recommended on the label.

5-HTP and St. John's wort

5-HTP and St. John's wort are effective at increasing serotonin levels in the brain. Many clinical trials have shown their effectiveness at relieving depression, and one double-blind study involving 50 fibromyalgia patients showed that 5-HTP in a dose of 100 mg three times per day improved symptoms of anxiety, muscle pain, sleep patterns and early morning stiffness. 5HTP increases serotonin levels, improving sleep and mood. St. John's wort has been proven to be a very effective herb for the treatment of depression. It also increases serotonin levels. A dose of 100 mg three times per day is effective at reducing certain symptoms of FM.



Magnesium and malic acid

Magnesium, a potent immune nutrient, is especially important for FM persons. Magnesium levels are low in most people with chronic illnesses. In healthy individuals it is found in high concentration in muscle cells, as it is required for production of ATP, the energy substance. Magnesium should be supplemented in a dose of 100 mg three times per day. Magnesium glycinate is our choice as it is very well absorbed. Studies have shown that the combination of 300 to 600 mg of magnesium per day, along with malic acid, reduce FM symptoms.

Malic acid should be added in a dose of 1200 to 2000 mg per day. It is a powerful detoxifier of aluminum and has been shown in clinical studies to reduce the pain associated with FM. Also include coenzyme Q10, 300 mg per day, and L-carnitine, 500 mg per day, as both are important in the Krebs's cycle for energy production; reducing the fatigue associated with FM.

Sterols and sterolins and FM

Chronic viral and bacterial infections are also common in persons with FM, due to the poor

state of their immune systems. The plant nutrients, sterols and sterolins are very effective at modulating the immune system and reducing inflammatory responses and autoantibody reactions. Sterols and sterolins should be the basis for your FM recovery program because it will shut off the inflammatory immune factor

Interleukin-6 (IL-6) that is responsible for causing pain and inflammation. Sterols and sterolins will also increase your mother hormone, DHEA, as they are precursors to pregnenolone, from which the body then makes DHEA. Many FM sufferers have found that none of the supplements they try work. There is a good reason for this. FM is made worse by the release of IL-6 and unless we turn off this powerful inflammatory immune factor everything we take is ineffective. But once

we turn off IL-6 with sterols and sterolins all the other nutrients do their job. Take two capsules of Moducare three times per day on an empty stomach for six weeks. Then for maintenance take one capsule three times per day thereafter. Within weeks, many FM patients report a decrease in pain and general improvement in well-being. Combined with the other nutrients recommended above, an excellent diet, and detoxification therapies, FM will soon be only a bad memory.

Professor Bouic, Ph.D, coauthor of The Immune System Cure, Cicco Books, UK believes that FM is a curable condition. "It requires a person to take responsibility for their own healing, seek the right professional help and therapies, and transform their attitude towards the illness from a curse to an incredible opportunity for growth and self-transformation". No small task, but that is what you require to heal. He says that since there are multiple causes to this illness, there are multiple cures. "What works for one person may not work for another due to biochemical individuality. Do not give up; the most important gift is the power of faith. Faith in the healing process and faith in oneself to heal."

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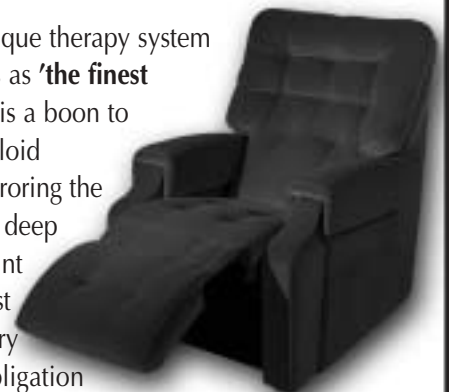
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News and Announcements

I received a phone call from a Jessica Hendry in Edinburgh who is carrying out research for a pilot study on behalf of Dr David Johnston, a Consultant Paediatric Neuro-psychologist to try and find out if we know of any children of members who exhibit symptoms of ME/CFS/FMS and have been exposed to pesticides. I told her that without circulating our members it would be difficult to say. Because of confidentiality we could not give out names of either children or parents but if the parents wanted to make contact then that would be OK. She stated that at this early stage all they wanted was an idea of numbers if any.

Regards,
John Dunwoody.
jdunwoody@nireland.com

Doctors Directory

We still need you to write in if you feel you can recommend your Doctor for other sufferers.

The following people are looking for a sympathetic doctor in their area;

Eleanor Knoesen in Rickmansworth, Hertfordshire.
Eleanor.Knoesen@plc.cwplc.com

Chesterfield, Derbyshire.
eddas1@skynow.net

Laura Jordan in London (living in NW6 and working in EC2)

laura@lateral.net

Fund Raising Success

F.M.A. UK is very grateful for the efforts of Jackie Brown in the London Marathon this year. As a result of her sponsored marathon, she raised £1,337 for FMA UK.

Jackie is a member of Reading Road Runners, and whilst she has participated in numerous half marathons, in such locations as Las Vegas, Brisbane & Barbados, this was her first full marathon. Jackie said she found the race tough, but the thought of the money she was raising for FMA UK kept her going. She completed the race in a very respectable 5 hours 10 minutes.

F.M.A. UK would also like to express its thanks to all those volunteers who distributed sponsor forms and donated hard earned cash. Without contributions like this, FMA UK would not be able to function.

It would be good to have more sponsored runners in next year's marathon –any volunteers out there!

Gerry Crossley
Trustee, FMA UK

Research News

Discrimination of FM patients from normal controls using levels of cerebrospinal chemicals

In this thought-provoking study, researchers from San Antonio, Texas, set out to predict which neuro-chemicals from the cerebrospinal fluid (CSF) could discriminate FM patients from healthy normal controls. Drawing on a large bank of CSF samples from medication-free FM patient and healthy normal controls, they selected a sample of demographically matched FM patients (28) for their study. The three neuro-chemicals which they found best discriminated fibromyalgia from healthy normal controls were: Substance P (SP), nerve growth factor (NGF), and 5-hydroxyindole acetic acid (5HIAA). The researchers determined that the best formula for these three neuro-chemicals was: $\text{Log } [y/1-y] = -.156 + 0.359 (\text{SP}) + 0.051 [\text{NGF}] - 0.067 [\text{HIAA}]$.

This formula distinguished FM patients from healthy controls with 90.6% accuracy, an accuracy comparable to that of the ACR's 1990 criteria.

The Texas research group noted that the new formula not only provided a new study tool for fibromyalgia research but also served as additional evidence of FM as a clinical disorder with objective neurochemical abnormalities.

(MYOPAIN Abstracts by T.S. Kuan, Z. Vukimirovic, Y.M. Xiao, R.A. Lawrence, and I.J.Russell)
Fibromyalgia Frontiers, Vol. 9, # 4, the official publication of the National Fibromyalgia Partnership.
Check it out: <http://fmpartnership.org/FMPartnership.htm>

Fibromyalgia and the Leaky Gut Syndrome

The natural treatment of FMS requires an understanding and amelioration of the leaky gut syndrome phenomenon. The basic lesion in leaky gut syndrome is an intestinal lining that is more permeable than normal. In simple terms, this means that larger-than-optimal spaces are present between the cells of the gut wall, allowing the entrance of bacteria, fungi, parasites, toxins, undigested protein, fat, and waste material into the bloodstream. Substances that are normally not absorbed in the healthy state pass through a damaged, hyper-permeable, or “leaky” gut.

The leaky gut syndrome is basically caused by inflammation of the gut lining. Inflammation causes the spaces between the cells to enlarge, allowing the absorption of large protein molecules. These are usually broken down into much smaller pieces before being absorbed through the normally small spaces between the gut-lining cells.

The immune system starts making antibodies against the larger molecules because it perceives them as foreign, invading substances. Antibodies are produced against the “invading” proteins and previously well-tolerated foods. The antibodies can get into various tissues and trigger an inflammatory reaction when the corresponding food is consumed. This occurs because body tissues have antigenic sites very similar to those on the foods, bacteria, parasites, candida, or fungi. Auto-antibodies are thus created and inflammation can become chronic. If this inflammation occurs in a joint, autoimmune arthritis develops. If it occurs in the blood vessels, vasculitis (inflammation of the blood vessels) is the resulting autoimmune problem. If it occurs in the muscles and multiple organ systems, the result may very well be FMS or ME/CFS.

The inflammation that causes leaky gut syndrome also damages the protective coating of antibodies of the IgA family. These are normally present in a healthy gut. As a result, the individual becomes less resistant to viruses, bacteria, parasites, and Candida. These microbes

are then able to invade the bloodstream and colonize almost any tissue or organ. The microbes and their toxins — if present in large enough amounts — can overwhelm the liver’s ability to detoxify. Resulting symptoms may include confusion, memory loss, brain fog, or facial swelling when the individual is exposed to a perfume or cigarette smoke, for example. He or she may have had no adverse reactions to these odors prior to the development of leaky gut phenomenon.

Leaky gut syndrome also creates a long list of mineral deficiencies. The inflammation process damages the various carrier proteins present in the gastrointestinal tract, needed to transport minerals from the intestine to the blood. For example, magnesium deficiency is quite common in conditions such as FMS, despite a high magnesium intake through diet or supplementation. If the carrier protein for magnesium is damaged, magnesium deficiency develops as a result of malabsorption. Muscle pain and spasms can occur as a result.

Similarly, zinc deficiency due to malabsorption can result in hair loss or baldness as occurs in alopecia areata, another autoimmune disease. Inflammation involves edema and the presence of many noxious chemicals, all of which can block the absorption of vitamins and essential amino acids.

A leaky gut does not absorb nutrients properly. Bloating, gas, alternating diarrhea with constipation, and cramps occur, leading to irritable bowel syndrome. Eventually, systemic complaints such as fatigue, headaches, memory loss, poor concentration, or irritability develop.

Exercise and Fibromyalgia A review of the research

Martin Westby (Editor)

With the July 27th 2002 issue of the British Medical Journal featuring as it's cover story "Prescribing Exercise for Fibromyalgia" it seemed appropriate to review the recent history of the topic.

A review of recent research

In 1999 Gowans (1) suggested that short-term exercise and educational programs could produce immediate and sustained benefits for patients with fibromyalgia. However the benefits may have been due to exercise or education since both interventions were given.

In 2000 Meiworm (2) conducted research with twelve sedentary FM patients (11 female, 1 male) They performed only aerobic exercise - 12 weeks of jogging, walking, cycling or swimming and found "a positive effect of aerobic endurance exercise on fitness and well-being in patients with FM."

Nielens (3) in 2000 found that FMS patients over score their perception of exertion. The report felt this may be due to a greater overlap of peripheral pain and perceived exertion perceptions during exercise. However 2 years later Valim (4) discovered that FM patient's anaerobic thresholds and peak oxygen uptake were significantly reduced. Maximum heartbeat rate was significantly lower in FM, indicating sub maximum effort. These results confirmed the hypothesis of lower physical fitness in patients with FM.

A Finish 2001-study by Hakkinen(5) concentrated on strength training. Groups carried out progressive strength training twice a week for 21 weeks. The major outcome measures were muscle strength and electromyographic (EMG) recordings. Secondary outcome measures were pain, sleep, fatigue, and physical function capacity.

It concluded by saying that the strength training data indicate comparable trainability of the neuromuscular system of women with FM and healthy women. "Progressive strength training can safely be used in the treatment of FM to decrease the impact of the syndrome on the neuromuscular system, perceived symptoms, and functional capacity. These results confirm the opinion that FM syndrome has a central rather than a peripheral or muscular basis".

The American Physiological Society (6) in April 2002 produced research saying exercise did not worsen FM symptoms. Fifteen women with fibromyalgia and 15 healthy women were individually matched with respect to age, smoking and frequency of physical activity. All subjects had at least a half-time job. One physician

performed a standardized and detailed physical examination, and blood tests for rheumatic and thyroid diseases were taken. Subjects with coexisting diseases were excluded, and so were controls on sick leave because of musculo- skeletal disorders during the last three months. Anti-depressive medication was abandoned three weeks before the experiment, and all other medication was abandoned one week before.

The test subjects' ages ranged from 21 to 45 years, and the difference in each matched pair was below six years. Five subjects in each group smoked, and five in each group trained at least once a week. A slightly higher body mass index (BMI) was observed in the FM group compared to the control group, but no differences were found in height and weight.

All subjects answered a pain questionnaire; pain; fatigue and morning tiredness were registered on 100 mm visual analogue scales (VAS). The end points for pain were 'no pain' and 'worst possible pain', for fatigue 'no fatigue' and 'completely exhausted' and for morning tiredness the end points were 'waking up completely refreshed' and 'waking up completely exhausted'.

The FM patients reported widespread and intense pain. Thirteen out of 14 patients reported daily pain and continuous pain. The control group reported no pain and minimal fatigue and sleeping problems. Blood samples were taken three times at rest; during exercise, blood samples were taken at every workload twice after exhaustion. At each workload the expired air was collected to determine the oxygen uptake. The peak oxygen uptake in the FM patients in this study was markedly reduced compared to the control subjects, even though they were matched on self-reported activity level. The hormonal and metabolic responses were comparable in the two groups, indicating normal muscle physiology and normal responses from the sympathetic nervous system during dynamic exercise and a patient group. Neither the control subjects nor the FM patients reported augmented pain in the post-exercise days. The report concluded, "Many FM patients experience continuous pain both at work and at home, and if this condition is linked to altered physiological processes, one should organize their occupational work and tasks at home accordingly. However, the results from this research indicate that no adverse responses to exercise in FM patients was noted, suggesting that physical tasks by themselves do not create possible the responses that would exacerbate the disorder.

When it comes to research into the types of exercise which are most beneficial to FM sufferers Mannerkorp (7) in 2000 investigated pool exercise - the results

Exercise and Fibromyalgia A review of the research

Martin Westby (Editor)

suggested that a 6 month program of exercises in a temperate pool combined with education will improve the consequences of FM. This was later endorsed by Jentoft(8) in 2001

Strength training was studied again in 2002 by Rooks (9) Fifteen women with confirmed FMS were monitored for injury and exercise compliance, and assessed for muscle strength (1-repetition maximum technique), cardiovascular endurance (6-minute walk test), and functional status (Fibromyalgia Impact Questionnaire [FIQ] before and after a 20-week exercise intervention. It concluded that a program of progressive strength training and cardiovascular exercise can be safe, well tolerated, and effective at improving muscle strength, cardiovascular endurance and functional status in women with FMS without exacerbating symptoms. This program may also contribute to a reduction in the severity of several symptoms.

Jones (10) in 2002 looked at the effectiveness of a muscle strengthening program compared to a stretching program and concluded Patients with FM can engage in a specially tailored muscle strengthening program and experience an improvement in overall disease activity, without a significant exercise induced flare in pain. Flexibility training alone also results in overall improvements, albeit of a lesser degree.

Which brings us to the latest research in the B.M.J –Prescribed exercise in people with fibromyalgia-Selwyn Richards and David Scott.

It concluded that prescribed *graded* aerobic exercise is an effective treatment that leads to improvements in self reported health status and suggested that personal trainers previously inexperienced in the management of people with ill health could prescribe the exercise.

Graded Exercise and Pacing

One area that is more controversial is how any exercise is prescribed to FM sufferers.

'Graded' Exercise means that patients cannot reduce or stop activity when they feel ill, while gentle exercise and pacing are more flexible.

In January 2002 the Department of Health released a

report from the working party for Chronic Fatigue and ME. Which discussed graded exercise versus pacing.

Whilst these conditions are different from fibromyalgia there are a number of similarities in symptoms.

As a general principle, the Working Group agreed that both activity and rest could be harmful when overdone and yet be beneficial when carried out with the appropriate degree of balance. Graded exercise is a form of structured and supervised activity management that aims for gradual but progressive increases in aerobic activities such as walking or swimming. It is based on a principle - contested by some - that a principal factor maintaining the illness is inactivity, subsequent

physical deconditioning, and its physiological consequences, which graded and supervised increases in exercise can help to reverse. In addition, it may act as a rehabilitative behavioural therapy by gradually exposing the patient to an activity (exercise) that has been avoided. Gradual, supervised exposure within the individual's limits is thought also to help improve confidence in physical ability.

One key controversy that exists over graded exercise rests on whether the nature of the treatment is appropriate for the nature of the disease, at least in some individuals. Existing concerns from voluntary organisations and some clinicians

include the view that patients have a primary disease process that is not responsive to or could progress with graded exercise, and that some individuals are already functioning at or very near maximum levels of activity.

Research findings - The York review found promising results for graded exercise: all three randomised controlled trials so far found varying degrees of improvement in fatigue and disability with differing graded exercise regimens compared with no treatment and two control treatments. These trials all scored highly in the validity assessment, although, as with most clinical trials, the findings encompass only the range of patients able to meet the entry criteria. The York review found that people who were unable to attend outpatient clinics were excluded from these and other trials of treatment effectiveness.

In the trials, very few participants reported feeling worse with graded exercise, although the dropout rate



Exercise and Fibromyalgia A review of the research

Martin Westby (Editor)

was just under a third in one of the trials - thought to be related to demands of the programme.

No randomised, controlled trials of graded exercise have been conducted in patients unable to attend outpatient clinics or in children. Several open studies suggest that graded exercise can be helpful to improve disability in more severely affected patients, so long as the treatment is carefully planned, regularly reviewed, and mutually agreed with the patient: however these studies lack the rigour needed to make/allow definitive comment on the role of this approach in severely affected patients as pointed out in the York review.

Patient reports - Voluntary organisations, as well as the Sounding Board events, note that graded exercise therapy can be effective in some individuals, but substantial concerns exist regarding the potential for harm, particularly when such therapy is applied inflexibly or without mutual agreement with the patient. The non random survey of people who were severely affected found that out of 1214 who had tried graded exercise, 417 believed it was "helpful", 187 reported "no change", and 610 believed it had made their condition "worse" Similar adverse comments were also reported in patient group survey results from less severely affected patients, and no other treatment - pharmacological or non-pharmacological - received such negative feedback in patient surveys.

The Working Group did agree that whenever graded exercise is being undertaken, activity levels should be initially based on current physical capacity. The programme should be mutually agreed between patient and therapist, it should be regularly adapted according to the clinical response, and patients should be carefully monitored to ensure that exertion does not exceed target levels.

A successful outcome probably depends on the therapy being initially based on current physical capacity, mutually agreed between the therapist and patient, and adapted according to the clinical response. Appropriate education regarding the rationale and cautions of this therapy needs to be given to potential candidates for graded exercise. Patients who drop out of therapy need to be followed up swiftly to review the reasons and reassess their management plan.

The place of this therapy for more severely affected patients is currently uncertain, but a suitably modified (initially low intensity) exercise or activity programme may reverse the adverse consequences of pervasive inactivity, if this is perceived to be a key factor in an individuals illness.

respondents found pacing helpful, 201 reported no change, and 30 stated they were made worse.

These results indicate that pacing is a highly acceptable and effective approach to activity management in CFS/ME."

The logical assumption must be that pacing of exercise is also the ideal method for FM sufferers.

(1) Gowans SE, deHueck A, Voss S, Richardson M Department of Rehabilitation Services, Toronto Hospital, Ontario, Canada.

(2) Clinical Rheumatology vol 19/4 (2000) pp 253-257 L. Meiworm (1), E. Jakob (2), U. A. Walker (1), H. H. Peter (1), J. Keul Division of Rheumatology and Clinical Immunology, Division of Rehabilitative and Preventive Sports Medicine, Department of Medicine, University Hospitals, Freiburg, Germany

(3) Nielens H, Boisset V, Masquelier E Physical Medicine and Rehabilitation Department, Cliniques Universitaires Saint-Luc, Brussels, Belgium.
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(4) VALÉRIA VALIM, LEDA M. OLIVEIRA, ALINA L. SUDA, LUCIANA E. SILVA, MÁRIO FARO, TURÍBIO L. BARROS NETO, DANIEL FELDMAN, and JAMIL NATOUR

(5) Hakkinen A, Hakkinen K, Hannonen P, Alen M Department of Physical Medicine and Rehabilitation, Central Finland Health Care District, Jyväskylä, Finland.

(6) American Physiological Society April 22, 2002

(7) Mannerkorpi K, Nyberg B, Ahlmen M, Ekdahl C Department of Physical Therapy, Sahlgrenska University Hospital, Goteborg, Sweden.

(8) Jentoft ES, Kvalvik AG, Mengshoel AM. Haugesund Sanitetsforening Rheumatism Hospital, Norway.

(9) Rooks DS, Silverman CB, Kantrowitz FG. New England Baptist Bone and Joint Institute, New England Baptist Hospital, Beth Israel Deaconess Medical Center, and Harvard Medical School, Boston, MA.

(10) KIM DUPREE JONES, CAROL S. BURCKHARDT, SHARON R. CLARK, ROBERT M. BENNETT, and KATHLEEN M. POTEPA From the Schools of Nursing and Medicine at The Oregon Health and Science University, Portland, Oregon, USA.

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Fibromyalgia in Men

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The relationship between Fibromyalgia (FM) and gender has been a source of confusion and controversy among researchers and patients alike. Although FM is clearly more prevalent among women, the illness does afflict men as well.

Little research has been conducted that measures the prevalence of fibromyalgia, and estimates vary widely as to the proportion of male versus female patients. A 1999 epidemiology study conducted in London found a female to male ratio of roughly three to one. However, a 2001 review of the research literature in *Current Rheumatology Reports* stated the ratio was nine to one.

The gender gap goes beyond the numbers. Research has shown that FM symptoms differ between men and women. A recent study in the *Journal of Rheumatology* found that men with fibromyalgia seem to have fewer and milder symptoms than female patients, including number/severity of tender points, fatigue, and irritable bowel. However, an Israeli study that compared 40 men and 40 women with FM, matched by age and educational status, found that men reported more severe symptoms than women, in addition to decreased physical function and lower quality of life.

It's clear that more study is needed before the true nature and prevalence of fibromyalgia in men will be known. But what's a guy with this illness to do in the meantime? It seems obvious that a man's experience with this disease would be quite different from that of a woman, if only because of the sheer numbers. One man with FM writes, "at times I do feel isolated being the only male in most support groups. I try to keep my sense of humour."

It's A Man's World?

A common debate within FM discussion forums and support groups is whether male sufferers have it better or worse than their female counterparts. On the one hand, men may have a more difficult time getting diagnosis or treatment since FM is generally perceived as a "woman's disease." Balancing this, perhaps, is the widely publicized gender bias in physician's attitudes toward their patients. A 1999 study in the *New England Journal of Medicine* found that women complaining of chest pain are less likely than men to receive important cardiac testing. Research has also shown that doctors perceive female patients as more likely to make excessive demands on their time, which may be due to women's real tendency to voice more complaints and ask more questions than men do during a typical visit. The same study also found that women's complaints were judged more likely to be influenced by emotional factors.

Still, while the loss of function and quality of life imposed by FM is devastating to both men and women, males with this illness may face some additional burdens. Though gender roles are gradually changing somewhat, men have long been expected to "feed and protect the family." Societal roles and expectations strongly influence perceptions of success and self-worth. Many men may base their self-worth on their ability to work, their income potential, or their employment position. Once afflicted with fibromyalgia, men often can't meet these expectations and must suffer even greater feelings of failure.

Furthermore, males are socialized from a young age not to reveal or express their feelings and fears. The well-known fact that men are less likely to seek counselling or attend support groups suggests that men may experience even greater isolation. One young man with fibromyalgia explains, "I think it is important for people to know how hard it is for men with FM. Growing up you are taught to be tough, have a job, support a wife and two kids which is very hard to try to achieve. It is much more difficult for a man to maintain a relationship or explain his condition to friends."

Reaching Out Across Gender Lines

There is support out there for men and women alike. Online support venues may help in bridging the gender gap, because the relative anonymity of online communication means that an individual's gender is not so readily apparent. In addition, men can more easily connect with other men like them, since they have access to the global community rather than just their local support group, where encountering another male may be less likely.

Most men seem to find that even though online support networks may consist predominantly of women, these groups are extremely welcoming to members of both genders. Says one male patient, "All the women online readily accept me and are amazed that I am 'brave' enough to openly speak with them and not be intimidated by being the only male."

The society we live in tends to associate self-worth with an individual's ability to be "productive." As FM sufferers, our old expectations simply become unrealistic. Continuing to judge our lives and ourselves by unrealistic standards can only lead to discouragement and hopelessness. As with any major life challenge, we need to find new measures of meaning and unique definitions of success. Managing our own and others' expectations is a challenge that everyone, with or without fibromyalgia, must face.

Tips for Men (and women, too)

For all individuals who suffer from fibromyalgia, but especially males, the following guidelines are helpful in managing the impact of chronic illness:

1. Do not attempt to push yourself beyond your present physical capacities. Accept and work within your present realm of abilities.
2. Set immediate, realistic, and obtainable short-term goals which can be achieved on a daily basis.
3. Talk, talk, talk. Express your feelings and fears—allow others to assist you in seeing yourself from a more realistic perspective.
4. Attend area support group meetings. Try to connect with other individuals that share your background or unique concerns.
5. Throw out "old lessons" about expectations that one must meet in order to be of value. Write "new lessons" for your life.
6. Realize that change does not necessarily produce negative results or consequences. Look for the gains, which can be achieved by and through the changes.
7. Accept that you may not be as powerless as you feel or fear. While you may not have power over your own physical abilities now, or how others may perceive you, you always have absolute power and control over how you view yourself.

Adapted from material compiled by Dr. Dennis G. Cowan, M.D.

The muscle in fibromyalgia

A. Bengtsson, Rheumatology Unit, University Hospital, 581 85 Linköping, Sweden

The main symptoms in fibromyalgia are muscle pain, stiffness and muscle fatigue. In 1981, when we started our fibromyalgia studies, we had a lot of patients with such symptoms at our clinic. None of them had arthritis or laboratory signs of inflammation, which is the key that opens the door to the Rheumatology unit. Fibromyalgia patients in our own studies were all diagnosed according to the Yunus criteria from 1981 to 1990 and according to the ACR criteria since 1990 [1, 2].

The first questions that should be asked are these: When do we feel pain in the muscles? What kind of changes in the muscle tissue produce pain?

Is there any evidence that such changes exist in the muscle in fibromyalgia?

Muscle fibres are not provided with nociceptors [for reviews see 3–5].

Chronic degenerative muscle disorders are not painful. Inflammation can cause sensitization of pain receptors, but on the other hand polymyositis can exist without pain. Hypoxia in combination with muscle work causes pain as well as energy depletion.

In the late 1980s we carried out several studies to find out if there was any peripheral contribution to the pain of fibromyalgia. An epidural catheter was inserted in the patients. According to the method introduced by Cherry et al. [6], the patients were given physiological saline twice followed by an opioid, given naloxone intravenously, and finally a local anaesthetic (lidocaine) [6]. The nine patients were placed on a bicycle ergometer and were asked to exercise to an intensity of 40 and 80% of their maximal oxygen uptake [7]. These studies showed that the patients did not respond to placebo, they were able to work without any increase in pain during administration of the opioid, and when they were given the local anaesthetic they were all free of pain. The conclusion was that there probably is a peripheral component in fibromyalgia.

Because the main symptoms in fibromyalgia (pain, stiffness and fatigue) are located in the muscles—at least according to the patients—muscle biopsies, mostly from the trapezius muscle, have been studied [8].

Biopsies have also been taken from the deltoid, the brachioradial, anterior tibial and quadriceps muscles. Light microscope, histochemical and electron microscope studies have been done, as well as specific analyses of, for example, the content of substance P in muscle biopsies, which is increased in fibromyalgia muscle. Serotonin has been measured by the use of microdialysis in the masseter muscle and found to be higher in patients with fibromyalgia than in controls.

Muscle biopsy studies have been made by our group as well as by Yunus et al. [9], Bartels and Danneskiold-Samsoe [10], Kalyan Raman et al. [11], Pongratz and

Spath [12] and Drewes et al. [13]. Drewes et al. studied the quadriceps muscle by electron microscopy, and in most cases they found empty sleeves of basement membrane, cellular damage manifested as lipofuchsin inclusions, and mitochondria with irregular patterns of cristae. Electron microscope studies have also been done by Kalyan Raman et al. [11], Fassbender and Wegner [14], Yunus et al. [15] and Lindman et al. [16, 17], and these studies have shown minor mitochondrial abnormalities.

In general, there has been no sign of degeneration or regeneration or inflammation. Atrophy of type 2 fibres has been reported in several studies. The frequencies of type 1 and type 2 fibres have been determined in patients and controls, as has mean cross-sectional area of the fibres, and no differences have been found. Most of the studies have been made in the upper part of the trapezius muscle. Studies of the normal trapezius indicate a relatively poor supply of capillaries as well as low mitochondrial volume density compared with limb muscles [17]. In the normal trapezius there are some differences between men and women, females having smaller cross-sectional areas of both type-1 and type-2 fibres. As the mitochondrial volume density of a muscle is directly related to its endurance capacity, our results might indicate a relatively low oxidative capacity of the muscle fibres and thus little ability for endurance work.

The presence of moth-eaten and ragged-red fibres indicates uneven distribution and proliferation of mitochondria. Accumulation of mitochondria is seen in Gomori trichrome staining, and this gives the ragged appearance. Mitochondrial proliferation may be a compensatory phenomenon in disorders or pathophysiological states affecting oxidative metabolism. Ragged red fibres appear to be related to insufficient blood supply, as shown by Heffner and Barron in 1978 [18].

Ragged red and moth-eaten fibres are not specific to fibromyalgia, but are often seen in chronic neuromuscular disorders. They have also been found in controls. Ragged red fibres are also found in localized chronic shoulder pain, predominantly on the painful side and if the patient has been exposed to static loading. They can also be found in polymyalgia rheumatica, mitochondrial diseases and experimental ischaemia.

Muscle microcirculation can be measured in different ways. Lund et al. [19] used an oxygen multipoint electrode on the muscle surface in 10 patients and eight controls. The trapezius and brachioradial muscles were studied. A pathological distribution of tissue oxygen pressure values was found in all patients but in only one of the controls. These results indicate abnormal capillary microcirculation, at least in the tender point area. Blood flow in the tender point area has also been examined using an intramuscular needle electrode, and lower values were found in the patients.

The muscle in fibromyalgia

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Capillary density was examined in the trapezius muscle in 10 patients and nine controls, and no differences were found between the two groups [8].

Lindh et al. [20] examined the vastus lateralis muscle and found a lower density of capillaries (numbers of capillaries per fibre and per mm²) in fibromyalgia patients. Lindman et al. [21] found a greater thickness of the endothelium of the capillaries of fibromyalgia patients. Similar changes had been observed by Fassbender and Wegner in 1973 [14]. These changes are either caused by or are the cause of localized hypoxia. These findings are similar to those of Gidlöf et al. [22], who observed derangement of limb muscle capillaries after tourniquet-induced ischaemia. The endothelial changes were also found in controls, but they were more frequent in fibromyalgia. Muscle blood flow has also been examined by Bennett et al. [23] using xenon 133 clearance, and lower values were found in fibromyalgia.

The microcirculation in the muscle is controlled by locally produced metabolites, the sympathetic nervous system and humoral factors. When eight patients received a stellate ganglion blockade with the local anaesthetic bupivacaine, patients with total sympathetic blockade were free from pain and tender points in the arm. Sham blockade did not have this effect [24]. Larsson et al. [25] studied blood flow with a laser Doppler technique in the trapezius muscle in patients with shoulder pain on only one side. On the pain-free side there was an increase in blood flow as the load increased. On the painful side, however, blood flow did not increase on increasing the load. This also indicates disturbed local regulation of the microcirculation.

Levels of ATP and phosphocreatine were analysed in muscle biopsies from the trapezius [26] and the tibialis anterior muscle in patients with fibromyalgia and in the trapezius muscle of healthy controls, and lower values were found in the patients than in the controls.

Studies using magnetic resonance spectroscopy (MRS) have produced results different from studies of muscle biopsies. The MRS studies were all carried out under different circumstances and in different muscles.

At our clinic, fibromyalgia patients and controls were studied during rest and under different workloads. At rest and under submaximal loading there were no differences between the two groups, but under maximal load the patients produced only half as much work as the controls (A. Bengtsson et al., submitted for publication). The pH reduction was the same in controls and patients, as, for example, Vestergaard-Poulsen et al. have also found [27]. The patients thus reached the level of pH reduction at which pain and fatigue inhibit work after a much shorter time and under a lesser workload compared with the controls. Park et al. found lower ATP values at rest in patients with fibromyalgia [28].

Oxidative enzymes were studied by Lindh et al. [20], who found that 3-hydroxy CoA dehydrogenase and citrate synthase were lower in patients than in controls.

Maximal voluntary contraction has been examined in fibromyalgia in several studies, and all of these found a reduction in muscle strength, but when the muscle was stimulated electrically normal values were found. Jacobsen et al. [29] found a significant reduction in isometric and isokinetic strength in the quadriceps muscle. Mengshoel et al. [30] tested grip strength in the dominant hand and found a significant reduction in muscle endurance, tested by repeated maximal grip pressure, dynamic endurance work and static endurance work.

Bäckman et al. [31] presented evidence that the reduced strength was due to an impaired central activation of motor units. In one study by Elert et al. [32], patients and controls were asked to do 100 repeated shoulder flexions. EMG was controlled simultaneously. Pain and perception of effort were not recorded. However, this study showed that patients with fibromyalgia had EMG activity between muscle contractions. One hypothesis is that this was due to the prolonged relaxation time recorded in fibromyalgia [31]. When the muscle is not relaxed between contractions, the microcirculation of the muscle might be affected.

When the microcirculation and metabolism of the muscle are affected, muscle pain can arise in work, but fibromyalgia patients have pain at rest as well as widespread pain and allodynia that cannot be explained by the results of muscle biopsies. Pain cannot be explained by the findings of muscle biopsies if a state of central sensitization does not exist [33].

Pharmacological analyses of pain in fibromyalgia showed that patients were all pain-free after epidural blockade [7]. Resting pain disappeared, as did the tender points.

The effects of intravenous infusion of morphine, lidocaine, ketamine and placebo were analysed in 18 patients. Only two patients responded to placebo [34]. Thirteen responded to one or several drugs but not to placebo. Only three patients did not respond to any drug or to placebo. Thirteen patients responded to ketamine, which blocks NMDA (N-methyl-D-aspartate) receptors. This points to central sensitization as an important factor in fibromyalgia and the likelihood that different fibromyalgia patients probably have different pain mechanisms [35].

Sörensen et al. [33] studied experimentally induced muscle pain by infusion of hypertonic saline and showed that hyperalgesia in fibromyalgia is present in fibromyalgia muscle without pain. In the cerebral fluid, the concentration of substance P is higher in fibromyalgia patients than in controls, and these findings have been confirmed by Russell [36].

The muscle in fibromyalgia

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The muscle biopsy studies show that there are no specific changes conclusively for fibromyalgia. However, moth-eaten fibres, ragged red fibres and type 2 fibre atrophy indicate that the muscles are involved in the pathogenesis of fibromyalgia. The studies mentioned above indicate that the regulation of the microcirculation is disturbed in fibromyalgia in a way that might lead to sensitization of the intramuscular nociceptors. My conclusion from the studies on muscle metabolism in fibromyalgia is that there is a defect that is not seen at rest and when the patient is working at a submaximal load, but is seen under maximal loading and under static contraction.

The mechanisms of pain are not the same in all patients with fibromyalgia. It may be that this confuses us all because different fibromyalgia patients are seen according to whether we work in a rheumatology unit, a general practice or a psychiatric clinic.

However, in the majority of patients there is a state of central sensitization. In these patients, changes in the muscles, such as mitochondrial changes, a change in the microcirculation and/or a change in muscle metabolism, might sensitize muscle nociceptors and thereby cause pain, fatigue and muscle weakness.

It is important for us to understand the influences of other chronic pain mechanisms, such as pain-inhibitory and pain-facilitating pathways, and the cortical and subcortical processes involved in the establishment of chronic pain. Studies of both peripheral and central factors will be necessary before we achieve a full understanding of pain in fibromyalgia.

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Dear

I have had Fibromyalgia Syndrome for _____
Please advise me what plans the Primary Care Trust have for providing and improving treatment of my illness. I would also like to know how you intend to educate medical personnel to diagnose and understand Fibromyalgia within this area.

Signed _____
Name _____
Address _____

Post Code _____

UK NATIONAL FIBROMYALGIA
AWARENESS WEEK
14TH TO 21ST SEPTEMBER 2002



Working with
FIBROMYALGIA
ASSOCIATION UK

To Local Primary Care Trust

Dear

I have had Fibromyalgia Syndrome for _____
You may/may not be aware of the formation of an All Party Parliamentary Group for Fibromyalgia in 2001. As a voter residing in your Constituency I request that you support this APPG in any way you can.

Signed _____
Name _____
Address _____

Post Code _____

UK NATIONAL FIBROMYALGIA
AWARENESS WEEK
14TH TO 21ST SEPTEMBER 2002



Working with
FIBROMYALGIA
ASSOCIATION UK

To Local Member of Parliament

Dear

I have had Fibromyalgia Syndrome for _____
As a patient residing within your area, I am requesting you to promote education of personnel within the National Health Service to recognise, diagnose and treat my condition.

Signed _____
Name _____
Address _____

Post Code _____

UK NATIONAL FIBROMYALGIA
AWARENESS WEEK
14TH TO 21ST SEPTEMBER 2002



Working with
FIBROMYALGIA
ASSOCIATION UK

To Local Area Health Authority

Dear

I have had Fibromyalgia Syndrome for _____
As your patient I request that you promote and support education about this condition within the local Health Authority & Primary Care Trust to enable medical personnel to recognise, diagnose and treat Fibromyalgia.

Signed _____
Name _____
Address _____

Post Code _____

UK NATIONAL FIBROMYALGIA
AWARENESS WEEK
14TH TO 21ST SEPTEMBER 2002



Working with
FIBROMYALGIA
ASSOCIATION UK

To GP

NATIONAL UK FIBROMYALGIA AWARENESS WEEK

14TH TO 21ST SEPTEMBER 2002

JOIN IN THE FIBROMYALGIA ASSOCIATION UK'S POST CARD AWARENESS CAMPAIGN

Dear Group Members,

On the reverse are suggestions that can be hand written by Fibromyalgia sufferers, either on one side of a local picture post card, or split into two halves on the front and reverse of a plain post card. You will note that the recipients are those that can have a great effect on how the Fibromyalgia Cause moves forward within your area. Obviously, should you have already received support from any of the recipients, it is important to alter the wording to thank them for this and request they continue. If you are unsure about who is supportive, please check with your Group Leader/Help Line Co-ordinator.

**USE THIS OPPORTUNITY TO STAND UP AND BE COUNTED BY
SENDING YOUR POST CARDS IN THIS YEAR'S FM AWARENESS WEEK**

GO ON - JUST DO IT!

Heather Butterick – Nene Valley Fibromyalgia Support Group – Working with Fibromyalgia Association UK