

SOLUTIONS TO THE SUFFERING OF FIBROMYALGIA AND RESULTING SLEEP LOSS

Pain must have started when Adam was put out of the Garden. Trouble sleeping must have come at the same time, for trouble sleeping and pain are bed-mates, and he can't have had an easy conscience after biting into that forbidden fruit.

Ask someone who doesn't know, "What's this Fibromyalgia Syndrome all about?" and they'll tell you, "Pain!"

Ask someone who suffers from the Fibromyalgia Syndrome and they'll tell you the same, "Pain!!" But then they'll add, "If only I could sleep, I might feel better."

What's in a Name?

Pain may be as old as Adam, and the word we use comes from the goddess of restitution and justice, Nemesis, whose attendant, Poena, was sent to earth to punish mankind. But the word *Fibromyalgia* is only thirty years old, and although those who coined it undoubtedly meant well, their choice of words has caused endless confusion, for the only part of the word that should be there is in its tail – *algia* – meaning pain. The *fibro*, meaning fibrous tissue, and the *myo* meaning muscle, have no place at all, and have taken attention away from what does matter – the pain, and the difficulty in getting restorative sleep that might reduce the pain.

The philosophical, political, and religious meanings of pain defined the suffering of individuals for much of human history. Pain is the central metaphor of Judeo-Christian thought, as illustrated in the test of faith in the story of Job and the sacrificial redemption of the crucifixion. For millennia, pain was equated with just retribution and suffering was a punishment for known or unknown sins. "We have left undone those things which we ought to have done; and we have done those things which we ought not to have done; and there is no health in us." Therapy was limited to penance, hacksaw, and opium; if we're honest with ourselves, we haven't gotten much further.

Neurasthenia

George Beard, an 1866 Columbia University medical graduate, became an electrotherapist and seems to have been the originator of this word, *neurasthenia*. Beard built the concept on many similar current terms in American and European medical practice, all of which implied some failure or weakness of the central nervous system, and all of those weaknesses open to improvement with electrical treatment. The symptoms covered were whatever could be imagined, both mental and physical, but primarily of a sensory nature, and so they were labeled "hyperesthesia," or feeling everything too much. Neurasthenia became the catch-all disease and a specialty in itself, although the cynics designated it as a diagnostic wastebasket and a "mob of incoherent symptoms borrowed from the most diverse disorders." These



symptoms were characterized by a mix of exhaustion and insomnia; "the longer they stay in bed, the tireder they feel," so "fatigue neurosis" was suggested as an alternative name to neurasthenia. All body symptoms were regarded as a "real disease" instead of manifested in a patient's head; however, the diagnosis became so convenient, so all embracing, that it was eventually valueless and the field moved out of the hands of the neurologists, the "nerve doctors," and into the field of psychoanalysis. In reading the reports of the distressing symptoms that became classified as neurasthenia, it is easy to think of the legitimate diagnoses we would give now, but not to the persons who, after a course of electric shocks, were restored from prostration to a full and active life. Although the effect of the mind on the body was clearly known to the earliest practitioners of the healing and spiritual arts, the coining of the word *psychosomatic* dates to 1818, at the time when Mesmer was holding sway with animal magnetism.

Fibrositis - Early Reports

In fibromyalgia, we are now trying to come to grips with invisible pain, essentially invisible by definition. If a cause can be seen, heard, or felt, then the diagnosis must be rethought, for it can't be fibromyalgia. Gowers in 1904 coined the term *fibrositis* while writing about back pain. and Graham in Toronto in 1940 made use of the term fibrositis when he wrote about "tension rheumatism." The issue became clouded in wartime by ill soldiers, and perhaps by soldiers who wished to be thought of as ill, when Hutchison in 1942 reported 69% of military rheumatology referrals were for fibrositis and Ellman, also in 1942 used fibrositis as a definition for all forms of soft tissue pains, including what was known as "psychogenic rheumatism," and reported at the time that 24% of military referrals for fibrositis had concomitant issues in their psychological profiles

But Why Fibromyalgia?

In 1977 in Toronto, Hugh Smythe (son of the Maple Leaf Hockey Conn Smythe) and Harvey Moldofsky, showed in brain wave tracings (electroencephalograph) there were changes in their fibrositis patients akin to those found in experimentally sleep deprived persons. They devised the term, non-restorative sleep syndrome, which they associated with "tender points." With a list of symptoms to include poor sleep and fatigue, and with the help of colleagues, they went on to devise a set of criteria for clinical diagnosis, formalized in the American College of Rheumatology's 1990 statement, to be termed Fibromyalgia. In 1992 The World Health Organization accepted Fibromyalgia as a medical condition, just as much as rheumatoid arthritis, or any other established and internationally accepted diagnosis.

What Are The Diagnostic Criteria?

The criteria set up by the 1990 Committee are considered by many to be inadequate or not to meet the more up-to-date understanding of the condition. However, they are used as legal judgement issues, comprising a specified length of time for the pain to have persisted unremittingly, the requirement it should be present in all limbs and the torso, and that a



specified number of points in the body should be reported as tender to pressure, even though it is recognized there is no specific abnormal feature at those points. Some specialists are reported to have abandoned the "tender point" requirement, and to make the diagnosis on the history of chronic pain and non-restorative sleep.

Who Has Fibromyalgia?

The diagnosis of fibromyalgia depends on a doctor to make it. It's not like a broken leg or a migraine which you don't need a doctor to tell you what know you've got. In fact it's reported by many persons they've seen as many as twenty doctors before one makes this diagnosis. And then once the diagnosis is made, they have in effect fibromyalgia for life since although therapy may alleviate the symptoms of fibromyalgia, there is to date no cure.

Understanding the difficulty of making a diagnosis, it is therefore uncertain how many persons would be diagnosed with fibromyalgia if everyone who had the condition was seen by a doctor who was "tuned in" to the condition. It is, however, generally thought that in the USA and Canada two percent of the population have been diagnosed with the condition and estimated at the extreme as ten percent might in fact suffer it. That's a lot of people! And then when you consider the sufferers are 90% women, and most are likely to have a mother, a husband and one or more children, then that's an awful lot of people who are affected by fibromyalgia!

What Treatment Is There For Fibromyalgia? Setting up a treatment program

It must first be understood that treatment is directed at restoration of function – directed at keeping the fibromyalgia patient functioning in her family, her community, and if possible, her employment. Experience has shown it is most likely to meet success in these goals if the patient is part of an organized programme, directed by experts in fibromyalgia and conducted by a team of therapists.

Yes, suppression of symptoms is intended. Measures to relieve pain will be practised, taught, and continued. Measures to relieve difficulties with <u>sleep</u> will be an important part of the programme. But concentration is directed at maintaining function in the broadest sense of that word.

The whole person

The word "holistic" has been very popular in recent decades and confuses many since it should be written "wholeistic," but it would lose its pseudo-magic if it became understood. It means no more than treating the whole person, body and mind, and since Socrates' axiom was, "The part can never be well unless the whole is well," it's an oversell to claim "holistic" is a new idea. But, new or old, the patient in the fibromyalgia program will have all issues addressed – pain, sleeplessness, difficulties with work and family – they must all be addressed.



Psychosocial Issues

Many persons in this world have skeletons in their cupboard, perhaps those suffering with fibromyalgia have worse skeletons or more skeletons or are more affected by the ones they have than are the remaining 90% of the population. Whatever the reason, it may help the patient to be interviewed by and to open up freely to an understanding counselor, psychologist, or if appropriate psychiatrist. Even without skeletons preceding the onset of the condition, social issues are almost certain to follow its onset and family counseling might well be beneficial.

Stress, Tobacco, Diet

The counselor will assist in minimizing the effects of stress which are unquestionably liable to enhance pain and to interfere with sleep; these may be obvious in origin such as actual or threatened loss of employment and marital difficulties; they might be less obvious with problems with children and associates, threat of foreclosure and countless other problems that beset the chronically ill.

Tobacco must be given up. There is no specific ill effect, but there is a general attitudinal issue in turning the patient towards a healthy life, and the effects of tobacco on the lungs and liability to cancer do not need to be dwelt on here.

There is no specific diet to be followed, but the patient's dietary habits should be discussed with a knowledgeable person. The chances are in a patient suffering from chronic pain and chronic sleeplessness that they are not eating properly. In a normal diet supplements of vitamins and minerals are not generally required, but if the diet is not normal these might need to be considered. It may be that weight has been gained during a period of inactivity.

Therapists, active and passive treatment

An exercise program should be part of the overall treatment plan. This will be a "Jane Fonda" stretch and movement program, definitely not a "Hulk Hogan" to build large muscles. Sometimes, if available, a warm pool makes movements easier to perform and more comfortable. It should be enjoyable and usually when performed in a group in an atmosphere of mutual encouragement, it is more pleasant and more effective. If it is possible for the patient to sleep better after a period of exercise, then that will be an additional benefit.

There is a role for passive treatment by massage which eases discomfort. Whether the use of machines, TENS, acupuncture, lamps etc., should be employed will be a decision made by the therapists, but in general it is believed what the patient does for herself with encouragement (active therapy) is far more effective than what is done to her (passive therapy).



Medication for pain and depression

Some medication for pain is usually required, but most patients will wish to keep this to a minimum. The question of using morphine or its derivatives is frequently raised, with the spurious argument, if it's used for cancer, why not fibromyalgia? The answer, which some find difficult to accept, is that in fibromyalgia morphine simply doesn't work. The nervous system is equipped with what are termed "morphine receptors" on which the drug works but fibromyalgia patients are found to be deficient in them and the otherwise extremely valuable drug is therefore ineffective.

There are three specific medications on the market approved by the strict regulations of the US Food and Drug Authority (FDA), and the equivalent Canadian body. They were originally marketed for the relief of what is called *neuropathic pain*, a type of very severe pain believed to originate in a confused functioning of the central nervous system, and found in diabetics, amputees and paraplegics. It is considered that patients with fibromyalgia suffer from the same *central pain* which explains the absence of clinical findings.

Anti-depressants are often ordered for persons in chronic pain, for two reasons. Firstly, chronic pain causes depression and they have value in relieving that. Second, there is a close pharmacologic action in the relief of the two symptoms and mild anti-depressants are often all that is needed.

Sleep hygiene

Sleep is in itself a period of active rehabilitation, not an empty gap between periods of activity. Most persons with fibromyalgia are distressed by inefficient or insufficient sleep, such that *non-restorative sleep* has become a hallmark of the condition.

The physician (preferably a <u>sleep</u> specialist) should take some considerable trouble with such patients to enquire into their sleeping habits. These should include the nature of the mattress (latex, memory foam and fully adjustable beds are good choices), the persons with whom their accommodation is shared, the hours of going to bed and getting up, ventilation, noise environment, and whether coffee, alcohol etc., are taken before going to bed. The patient should keep a <u>sleep</u> diary which would include not merely the sleep at night, but also any dozing during the day.

From these enquiries can be determined what need there is for any medication, which will always be kept to a minimum, will be given for short periods only, and will not become part of an habitual routine. The patient will learn to adjust her life so that she <u>sleeps</u>s in comfort, naturally, and is not drugged.