

Fibromyalgia/Myofascial Pain Syndrome Handout # 1
Devin Starlanyl, M.D.

Pain is often the most prominent symptom of FM, but there are many others, especially when MPS gets in the picture. Trigger points (TPs) cause muscle spasticity (tightness), which disrupts the flow of liquids in the body. Your eyes may often be dry, yet at times they water. Your thermal regulatory system is out of whack. This is noticeable when you get out of bed (often, due to bladder irritability) during the night. You then wait for your temperature to regulate after getting back in bed, before you cover up again. Spasticity can constrict your peripheral blood vessels--those close to the skin. Then, in the winter, certain areas of your body-- most often the buttocks and thighs--feel like cold slabs of meat.

Perhaps you have "vasomotor rhinitis"--a chronic runny nose, which starts a "domino effect". It's "mechanical"--not caused by a virus or bacterium. As you sleep, stuffiness in your nose moves from side to side as you roll. Post-nasal drip hits the back of your throat. Throat and neck TPs--especially in the sternocleidomastoid (SCM)-- develop satellite TPs. You get TPs down your arm, and loss of motion in your neck and shoulders. The constant drip into ever-more restricted vessels can result in a sinus infection, because viruses and bacteria take advantage of the situation.

Dr. Janet Travell, in her autobiography, "Office Hours Day and Night" noted that dizziness, ringing of the ears, loss of balance, and other symptoms can all be caused by SCM TPs. Dr. Travell was White House physician to John F. Kennedy. She and her partner, David Simons, wrote the definitive texts on MPS. The tight SCM complex transmits nerve impulses that inform the brain of the position of the head and body in the surrounding space. It doesn't match the input from your eyes. When head movement changes the SCM message--when you turn, or look up from changing the kitty litter, you get dizzy. This, coupled with poor equilibrium, can make it seem that the walls are tilting. When we take corners while driving, we get the impression that we're "banking" the turn at a steep angle, as if we're on a motorcycle. Cold drafts can bring on neck TPs. Be careful how you move in bed. When you turn, roll with your head flat, and use your arms to help. Don't lift your head and "lead with it" as you roll. That puts a great strain on the neck area and "loads" TPs, just as climbing steps or walking uphill "loads" the muscles of the thighs. A common symptom of SCM TPs is a "drunken" walk, as we bump into doorways and walls.

Muscle weakness causes much FM grief. This is often due to "latent" TPs. They aren't "active"--they don't cause pain unless we press them. But if we stress them, they "give out". You try to take a drink from a glass, and end up wearing your drink. As you twist your wrist to bring the drink to your mouth, a latent TP-stressed muscle is asked to support the drink. Your body couldn't tell where the drink was in relation to your mouth, or how heavy it was. Learn to use two hands to carry things, not to carry heavy things, and be prepared for lots of spills. When our muscles frustrate us, don't dwell on it. Move on. Don't berate yourself for something you can't help. Our worst enemy isn't pain, and it isn't muscle weakness, it's negativity. Cultivate a sense of humor. Wear printed fabrics. Use straws.

Another distressing facet of TP-inspired muscle weakness is the so-called "weak-ankle, weak-knee". You're walking across level ground and bam! You're down. Or you "catch yourself" and avoid the fall, meanwhile stressing muscles even more. Be cautious on steps. Be especially careful on uneven surfaces.

Vary your tasks--use different muscle groups. Slow your working pace. Listen to your body. Rest often. Cultivate a rhythm of movement. Play music while you work, if you can. Don't fight your body; work with it. If at all possible, lie down for a few minutes at times during the day. Muscles are constantly working to hold your head up. Don't sit too long in any one position. When you drive, pull off the road every hour and walk around the car. Stretch. At home, use a rocker to prevent the muscles from building up electrical activity. When you must lift, keep the load close to your body, and look up just before you lift. That tightens the long spinal muscles and prepares your back to lift.

Added stress to the body will cause FM to flare up. Any infection, or yeast overload, is also stress. Disrupted carbohydrate metabolism of FM patients causes intense craving for sweets, which feed yeast. In a "Scientific American" article in the January '89 issue, the Wurtmans discuss the relationship of sleep-deprivation, melatonin, serotonin, (neurotransmitters), and carbohydrate craving. Carbohydrate-cravers

snack not because they're hungry, but because eating is used to combat tension, anxiety, or mental fatigue--especially in the late afternoon and early evening.

The alpha-delta sleep anomaly of FM makes it just about impossible to get rest. When morning comes, you're stiff, achy, and your muscles are unresponsive. Your body/mind hasn't received the proper quality or quantity of sleep it needs. You feel as though you've had a run-in with a truck the day before, and the truck won. Level 1 sleep (alpha stage), is the lightest sleep we get. Delta is the deepest. In delta, immune chemicals and rebuilding chemicals are created, and the body/mind is repaired. When an FM patient enters delta stage, sleep is interrupted by alpha wave intrusion. We never get the deep, refreshing sleep others enjoy. This is a major handicap. Medications, such as amitriptyline, may increase the quantity of our sleep, but they do nothing for the quality. FM patients can also get bruxism (teeth clenching and grinding), muscle spasms in the arms and legs, (myoclonus), sleep apnea and shallow breathing (check out those chest TPs). We also feel sleepy at "inappropriate" times. If we push ourselves "over the hump", we slide into wakefulness/ insomnia pattern. It's important for us to eat regularly (and not too close to bedtime), avoid stimulants, avoid alcohol, and develop regular sleep patterns. Some of us need waterbeds, and almost all of us need cervical pillows.

Fibromyalgia Handout #2 Social Security Disability
Devin Starlanyl, M.D.

The most frequently asked question was covered in an article titled "Helping Fibromyalgia Patients Obtain Social Security Benefits", by Joshua W. Potter, Esq. (attorney), in the September 1992 edition of "The Journal of Musculoskeletal Medicine". The Social Security Administration (SSA) defines disability as "An inability to perform any substantial gainful activity because of a medically determinable physical or mental impairment...for a continuous period of not less than 12 months." Claims are made at the local SSA District Office in person or by telephone (800-772-1213). They will ask you the nature of FM, your physician(s), and job background. The SSA will then investigate your: medical history-- initial description of condition, including capacity for lifting, walking, standing, & sitting; job history--date last worked, description of past work; and proof of citizenship and insurance status. A response from this may take 6 to 8 months. The physician-reviewer who is part of the reviewing team is usually not a practicing physician and probably knows little or nothing about FM. Initial applications for disability are routinely denied. Be prepared.

An appeal must be made to the SSA within 60 days of its mailing. The SSA will not have a legal basis to hear your appeal if it's late. This appeal is called a "request for reconsideration". This appeal may be made at the SSA District Office or through an attorney who deals with these cases. The attorney will charge 25% back benefits from the time when you are unable to work. This request triggers an in depth investigation of your problem and abilities, including your medical charts. You may have to be examined by a physician working for the Disability Determination Service. To quote from the article, "Frequently, waits are long, examinations are brief, and medical records are not available for review by the SSA physician, who is paid approximately \$88 for the examination and report." Again, it is usual that the request is denied. There is no time limit to this determination, and can take 6 months or more. The denial usually will have suggestions for alternative work, which usually has no relation to your work history. You don't have to act on these alternatives.

At this time, you must file a "request for hearing" within 60 days. This will result in a trial by a judge, usually within 4 months. At this time, "experts in forensic medicine and trial advocacy are needed." You will testify, as well as your physician. If the judge rules that you are not disabled, you may appeal to the Appeals Council within 60 days. Their decision, usually within 7 months, almost always agrees with the judge. This may be appealed by filing suit in the US District Court. An attorney for this must have a special license. Usually, if anything, the District Court will return the matter for a new hearing (a remand). This is based on the initial application. Now you understand why they call us "patients"!

The key is a comprehensive medical chart and report. Your physician must be familiar with the SSA "Listing of Impairments". This is contained in "Disability Evaluation Under Social Security," available

from the Office of Medical Evaluation of the Office of Disability, SSA, 6401 Security Blvd., Baltimore, MD 21235.

Of course, there is no specific listing for FM. Sometimes people have to utilize other headings, since we often have many of the criteria for psychiatric or other disability. Your doctor must have a detailed medical record for you. Not only your medical signs and symptoms but adaptive reactions, physical limits and dysfunctions. "Every patient visit should result in entries concerning physical capacities (verified with measured weights); time durations for sitting, standing, and walking (by history); the nature, location, and intensity of pain (by history); psychosocial and adaptive behavior, including the ability to interact appropriately with others, follow instructions, and adhere to a regular schedule; and the complex of depressive symptoms."

You must be incapable of performing ANY work, although there is some flexibility in this rule if you are over age 50. Most work requires regular attendance, the ability to concentrate and follow instructions, etc. "A claimant's case is greatly furthered by a report that reads: 'Patient's past work required sitting all day, analysis of complex data, and lifting to 10lb. Now the patient can sit a maximum of 20 minutes, cannot concentrate because of medications and pain, and is always exhausted because of lack of sleep. Patient is irritable, argumentative and misses appointments. Measured lifting is now to 3 lb. Cannot and should not work....'" If the medical notes on your chart are vague, forget benefits. You are orchestrating your medical team. Make sure your key player, your physician, is caring, careful and understanding. He should specify your pain, and list those things that make it worse. A complete report, if supported by a good medical record, need only be two to three pages long. The fact that FM isn't on the "List of Impairments" is a real minus for us. We have to educate ourselves and others. This includes writing congressmen, etc.

SSA disability benefits range from \$350 to \$1000 a month, with Medicare starting 24 months after onset of FM. Disability benefits are payable as of one year before application. Supplemental Security Income is payable from the application date.

Remember, the cards are even more stacked against you to get an positive settlement on an insurance case. The Fibromyalgia Network had a good article on this in the July 90 edition. Alan T. Radnor, attorney, pointed out that many doctors don't believe that there is such a disease as FM, and the symptoms are psychosomatic. You often have to see several physicians before obtaining a diagnosis of FM. You say you are in pain, but where's the proof? Your tests are normal. Paul O. Scott, attorney, points out in that issue that studies indicate patients are predisposed to get FM. Both attorneys state flatly that orthopedic surgeons don't believe in FM. Clearly, education is needed.

Fibromyalgia/Myofascial Pain Syndrome Handout # 3
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A GUIDE FOR RELATIVES AND COMPANIONS

What exactly is fibromyalgia? (FM)

FM is a "chronic invisible illnesses". It isn't just a form of muscular rheumatism. It's actually a type of neurotransmitter dysfunction. (Neurotransmitters are what the brain uses to tell the body what to do.) We think 4% or more of all people have FM.

One symptom is a type of dysfunctional sleep called the alpha-delta sleep anomaly. As soon as people with FM reach the deep level sleep, alpha brain waves intrude and jolt them back to shallow sleep. Not only are they denied refreshing sleep, but delta level is when the body does its repair work and chemical replenishment. If people with FM are immobile at any time, such as during travel, or sitting in a meeting, their muscles get rigid and painful. Morning stiffness can be severe. Since neurotransmitters affect every part of the body, symptoms can show up all over, and yet the usual medical tests comeback negative. FM symptoms fluctuate from hour to hour and day to day, and often worsen with changes in barometric pressure. It's no wonder that FM is one of the most misdiagnosed illness. Doctors often refer FM patients to psychologists or psychiatrists, and yet recent studies show that psychologically, FM patients have about

the same amount of abnormal psychology as Rheumatoid Arthritis patients. An editorial in the Journal of the American Medical Association in 1987 stated that FM, "...a disease which may have occupied five minutes of time in medical school really exists and is a major cause of morbidity and disability." People with FM have a history of being misunderstood and doubted.

Research is showing that people with FM have defects in the neuroregulatory system, especially neurotransmitters. They have low growth hormone, which is involved with muscle repair. Some researchers think that the key problem is a CNS abnormality upstream of the spinal cord. The FM body is an engine idling at 35% power, rather than a normal 5%. Most FM patients have memory and cognitive impairments.

In FM there is an abnormal production of neurotransmitters such as serotonin, melatonin, norepinephrine, dopamine, and other chemicals which help control pain, mood, sleep and the immune system. It looks like there is a genetic predisposition. Often there has been a trigger event, such as accident. An American College of Rheumatology study in 1992 found that the impact of FM on your life is as bad, or worse, than Rheumatoid Arthritis. They listed one major factor in this as "clinician bias". FM patients don't look sick, so they are often victimized by clinicians, family, and friends, leaving them with self-doubt, guilt, and loss of self-esteem.

FM patients have 3 times the normal amount of substance P in their spinal fluid. Substance P tells the body how much pain it feels. They also have more pain receptors. They are hypersensitive to everything--sort of like the "Princess and the Pea" in nursery stories. Little things that others take for granted, like wringing out a wash cloth, or writing a letter, become pain endurance sessions.

A comparative analysis in the "Journal of Rheumatology" this year found that the quality of life for women with FM is worse than for those who have Rheumatoid Arthritis, osteoarthritis, chronic obstructive pulmonary disease, or insulin-dependent diabetes.

How can someone know if they have FM?

Suspect it if you have a history of widespread pain, and wake up every morning feeling like you've been run over by a truck. You may have headaches and loss of balance. Looking both ways when going into traffic can cause dizziness. You can't always find your car in a parking lot. On your best days you feel like you have the flu. You usually develop esophageal reflux. You put on weight. Some objective signs are ridges on the fingernails, goosebumps behind the upper arms and thighs, and mottling of the skin. Sometimes you get muscle twitches. You are electro-magnetically sensitive. Technically, you will have 11 of 18 specific "tender points". If these spots are pressed, you will have pain. Fibro-myalgia patients just about always have myofascial pain syndrome. That's a related dysfunction that has "Trigger Points". These TPs are incredibly painful areas that often feel like knots or hard lumps in the muscles. Taut bands of fibers form in the muscles. The TPs refer pain to other areas. They can trigger gastritis, irritable bowel syndrome, grinding of teeth at night, pain when you put your hands in cold water, dizziness, chronic inversion sprains of the ankle, weak knees, weak ankles, pelvic pain, dysmenorrhea and painful intercourse in women, impotence in men, etc. The tightened and spasming of the muscles can entrap nerves, blood vessels, and ducts. You can have blurring of the eyes or double vision. Leg cramps, hypoglycemic-like symptoms, problems swallowing, immune dysfunction, allergies and sensitivities, sciatica, hives and rashes, numbness or tingling, mood swings, confusional states, loss of balance--the list goes on and on.

What can we do for someone who has FM?

There is no cure for FM/MPS. Many researchers working on it. There are medications that help some of the symptoms. Trigger points can be relieved by some types of physical therapy. It takes a commitment on the part of the patient to practice good nutrition, a program of gentle stretching and moderate exercise, and a recognition of both the patient and her/his companions in life that there are real limitations for people with fibromyalgia. It isn't easy to find the right balance to optimize the quality of life. Be kind. Be patient. Be compassionate. Listen. And ask if there isn't something you can help.

Handout #4 Fibromyalgia/Myofascial Pain Syndrome
Devin Starlanyl, M.D.

Synapse: the functional membrane to membrane contact between one nerve cell and another nerve cell, receptor, or other cell. In most cases, impulses are carried across the synapse by a chemical transmitter "bridge".

Neurotransmitter: any specific chemical agent released by a presynaptic cell when activated, that causes the synapse to stimulate or inhibit the postsynaptic cell.

Serotonin: a vasoconstrictor (constricts blood vessels) liberated by blood platelets, that inhibits gastric secretions and stimulates smooth muscle. It is present in large amounts in some areas of the Central Nervous System.

Myofascia: the thin layer of connective tissue that covers, supports and connects the muscles. It is the support network that gives the body its shape, and determines its flexibility.

It does seem that almost all of the patients have vasomotor rhinitis. I think a cascade of symptoms is on-going here, too. With muscle tightening, normal fluid passages are constricted. Fluid backs up in the sinuses. They have a constant postnasal drip, although their nares may be dry. Patients complain of unilateral sinus blockage, which changes from side to side as patients switch sides that they sleep on during the night. The side they sleep on most has the worst pattern of symptoms from postnasal drip. The SCM TrPs are sore on that side, and the scaleni, with a sore throat and digastric TrPs. Sometimes this cascade can be avoided by using warm saltwater as nose drops before bed, cleaning off the nasopharynx area. Some FMS patients say their symptoms started after a severe cold or flu. Some feel that whiplash or other neck trauma triggered the problem. Both of these conditions have a commonality in neck congestion.

In FMS, among other things, there's a dysregulation of the limbic system. A trigger event activates cytokines, causing a cascade of symptoms. Right now there are a lot of fingers pointing at Interleukin-1 beta. It increases secretion of growth hormone, corticotropin releasing hormone, serotonin, beta-endorphins and catecholamines, so it aids memory, reduces anxiety, increases body temp and causes weight loss. If this theory is right, we have to find the IL-1b antagonist sparking FMS and find a way to block it. But that's only one of the problems in fibromyalgia. Also implicated are a hyperactive autonomic nervous system and dysfunctioning hypothalamic-pituitary adrenal axis. Plus FM patients have 3x the normal amount of substance P in their spinal fluid, and 2x normal number of pain receptors in their body. These people hurt. There are also significant abnormalities in the metabolism of tryptophan, and a deficiency of cortisol. To complicate matters, FM consists of several subsets, just as there are many forms of arthritis. There seems to be a genetic predisposition. Many FMS patients have multiple environmental sensitivities.

To understand FMS/MPS complex, look at the big picture. Neuro-transmitter activity determines the plasticity of the tissues. Most of the body's processes rely on the appropriate movement of fluids through the system. In FMS/MPS, connective tissues become stiffened, shortened and tightened.

We know growth hormone has a powerful effect on the connective tissue. It directly stimulates the production of fibroblasts and mast cells, ground substance and collagen fibers. It's significant in wound healing, where rapid production of collagen fibers by many fibroblasts is necessary for repair. But growth hormone is released during delta-level sleep. People with FM have the alpha-delta sleep anomaly. The patient with fibromyalgia never enjoys delta level sleep. As soon as it's reached, alpha waves intrude and jolt your patient back to shallow sleep. FM patients have very low levels of growth hormone. The body can't repair itself. Connective tissue is the major repair mechanism of body. Its chemistry monitor inflammatory response, and its fluids deliver antibodies and wbc to fight infection. All of these are disrupted in FMS. Immune killer cells are present in the normal amounts, but most are dormant. MRIs show that about 78% of FMS patients have an alteration in their subcortical white matter. Tryptophan does not cross blood-brain barrier in FMS. And there's more.

So much of the psychological and physical sense of continuity and security depends upon our ability to repeat appropriate and predictable actions. Spindle reflex arcs keep muscles constantly informed as to what

they're doing, so that the action can be modified. In FM, most of the required muscle tension of the body is improperly controlled by the higher brain centers. You might think nothing of picking up a glass of water, and bringing it to your lips. You know just how much contractile effort and speed it will take to do this smoothly. They have muscular incompetence in the absence of proper sensory feedback. The thumb grasps with too little pressure. The wrist muscle lets go when flexed. The economy of effort is not there. To sit, walk, and stand, the entire musculature must feel its own activity.

FMS patients, at best, function at 60% capacity. They're usually burdened with a long history of undiagnosed illness. They suffer from loss of self-esteem. Their condition is invisible, so friends and family don't believe them when they say they hurt. Fibromyalgia seems to trigger Myofascial Pain Syndrome. Janet Travell, JFK's White House physician, wrote the definitive medical text on MPS with her partner, David Simons, over 30 years ago. It went virtually ignored by medical schools. Now the demand for it is so great a new version will be out next year. A lot can be done to relieve MPS, and lighten your patient's pain load. Acute pain from FM creates a reflex neuromuscular contractile response which reverses the desired process of softening and lengthening. Congestion can impair circulation and neural transmission through the area. This affects not only the muscles, but the surrounding organs. A muscle in a state of sustained tension is working; thus its need for nutrition is high. At the same time, the sustained contraction reduces circulation in the area by squeezing the small arteries and capillaries which service the working cells with glucose and oxygen. Chronic muscle tension and contracture creates an area of heightened metabolism and is chemic and buildup of toxic waste--a TriggerPoint. Fluid circulation in and around the nerve cells is curtailed, and the capillaries which supply the nutrition and carry off waste products are squeezed tightly as well. The contracting muscles are producing increased waste products and demanding increased nutrients from capillaries that are less and less able to handle them. This causes more contraction.

FM/MPS Handout # 5 Devin Starlanyl, M.D.

FM tender points hurt where they are. MPS trigger points refer pain elsewhere. Latent TPs don't hurt unless you press them, they just restrict motion. Just because you don't hurt doesn't mean you aren't in trouble. The muscles are still working and constricted around them. The TPs are there, and can be activated. Active TPs hurt when you move them. When severe, they can hurt all the time. Older or more sedentary people tend to have more latents. Bodywork will activate latent TPs, and cause flu-like symptoms, and you will feel worse at first. But you are on the road to recovery.

[info on Dr. St. Amand is only his theory, and trial tests using Guaifenesin on patients is ongoing as we speak. MRL]

FM/MPS seems to at least partially stem from a phosphate metabolism problems--practically all neurotransmitters in the brain are metabolized with the aid of pyridoxal phosphate (B6, pyridoxine). Deterioration of behavior and mental function is seen in experimental pyridoxine deficiency.

Dr. R. Paul St. Amand data. Guaifenesin. Explain mitochondria? Phosphate metabolism problems--practically all neurotransmitters in the brain are metabolized with the aid of pyridoxal phosphate (B6, pyridoxine). Any ? on this. Any changes noted? During each stage of regression, the body/mind needs to find its new balance. Adjust meds. May find don't need niacin. Explain why some people say it is toxic. Listen to your body. Help it as much as possible. Detox, rest, water. Good food, but not too much. Body is clogged with toxins and constricted. Mitochondrial factories, smokestack, not operating with energy efficiency. Free flow of energy is disrupted, and turned back. Mind your posture. Lay down for 5 minutes a few times a day if possible--with a cold pack on your neck. Use visualization. Soothing music. Reaching, stretching, massage, meditate. 15-20 min. warm baths, not hot. Going through a "little death", but this time it is the death of FM and MPS. Baby yourself. A little bit about guaifenesin. It is an expectorant which reduces viscosity of respiratory fluid secretions and loosens phlegm and bronchial secretions. Plasma 1/2 life, 1 hr. Increases renal clearance for urate and lowers serum uric acid levels. No studies in pregnancy or nursing mothers. Others, no serious side effects. Other type of cough meds repress cough reflex. This doesn't. (The excess phosphates will be excreted through the urine)

Note of hope: Remember, we didn't notice the symptoms until they became obvious. They crept up, in most cases. They will lessen long before all deposits disappear. Anybody who goes to CMC are welcome to take data. According to Cornell U Med Center (Daniel Wagner M.D.) it takes 4 to 6 weeks of getting enough sleep to fully recover from prolonged sleep deprivation.

The nature of the reversal misery depends on the nature of the deposits: how many, how dense they are, how much tissue is displaced and the type of tissue and placement; how good your body is at detox; on electrolytic balance--the body needs a good one for maintenance, and calcium phosphate release will be disruptive. For the latter, a good mineral supplement will help. Niacin might enable guaifenesin to get to the peripheral areas more easily and detox them first. Then you will no longer need the niacin. This reversal is not easy, but neither is FM. Right now, there's no way out but through. No RDA for beta-carotene, but U of California Berkeley Wellness Letter recommends 5 to 6 mg daily. Good sources: carrots, cantaloupe, sweet potatoes and spinach.

Remember, serotonin isn't the only neurotransmitter, nor even the most important, that the body uses. There are many others: acetylcholine, histamine, dopamine, norepinephrine, melatonin.... Everyone is different, and FM/MPS will be different in each one of us, which is one of the reasons why it is so difficult to deal with. We react to medications differently. There's no easy fix.

Support Group. Look around. Find people who live close by, and/or have similar experiences. Exchange phone numbers. Support each other. Find someone who really talks your language. Just please, ask them what is the best time to call. Avoid late night or early morning calls. Irritability is one of the symptoms, remember. The person you call at 8 AM may have only gotten to sleep at 5.

Migraine TP locations--SCM, upper trapezius, posterior cervical, splenius, temporalis. Migraine seems to come from serotonin disruption. Article Any luck?

Active TPs on upper rim of pubes producing urinary frequency, retention and groin pain. Also lower internal oblique muscle and possibly lower rectus abdominis. Rectus abdominis TPs cause distended, lax abd. Contracting of abd is inhibited by TPs. Any luck?

Eye-exercises--anyone have any comments? Go over procedure. Photo of eyeball. Splenius cervicis--blurring of near vision.

SCM sternal portion deep ear pain. Deep masseter may cause tinnitus, low-roaring. Superficial masseter, tooth pain, sensitive to pressure, percussion, heat or cold. Medial pterygoid--deep ear pain and stuffiness in ear.

When you are stretching one way, stretch the other. Beware of reactive cramping from over-stretching one side. You may need to cut labels out of clothes before they cut you. Can cut yourself with fingernails.

Anyone having luck reducing jaw grinding by tiring jaws--eating apples or carrots before bed? Bagels?

Exercise creates serotonin.

If you have a problem eating breakfast, especially with nausea, try eating non-breakfast nutritious foods you like. Keep your metabolism as balanced as possible.

Grain-filled pillows covered with flannel--heat in microwave and it will stay warm for hours. Chill it in the freezer, and it will make a good "icepack".

If you're getting the chills, put on a warm hat--even in the house. It helps.

Stitch in side--serratus anterior TP usually

Nausea, vomiting usually upper rectus abdominis TPs Coming up--little deaths. Spouse relinquishment ex. cranio-sacral release. If we go through life looking for "fair" we'll miss out on life entirely. We have to create "fair".

Book in Brat library, "Why Doesn't My Funny Bone Make Me Laugh!" by Alan Xenakis, M.D.

Belch: anxiety and excitement increase amt air we swallow. Also chewing gum. Stomach air-belch. Intestinal air, flatulence. bloating: takes 3 L liquid before bloating becomes obvious. 2/3 fluid we drink passes into intracellular fluid. W/o presence of excess liquids, passes 1/3 L water away back into body.

Ventilated rubs will cause the body to let off heat, which produces evap and cools. Aspirin will get rid of pain and lower temp, also serve as anti-inflammatory. Tylenol will only get rid of pain and lower temp. epsom salts can reduce irritation caused by excess fluid or swelling. Some excess water will pass out of body as the solutions try to work toward equilibrium. Less pressure causes less irritation on tissues.

Craving for chocolate stems from a lack of neurotransmitter serotonin, which can leave you agitated and distressed. Also craving carbohydrates. Craving salty things also means fluctuating hormones. chocolate causes the brain to produce more insulin, which produces more serotonin production.

Crying: one basic ingredient of tears is cellulose, which is why we get deposits in eyes. Emotional tears are stimulated by the hypothalamus and pituitary (axis problems FM) as well as limbic system.

Double vision: in order for vision to be clear, the two eyes must take basically the same picture at the same time. Misalignment of eyes by muscle fatigue, irregular contraction (MPS), or alcohol.

Feeling hot or cold: hypothalamus at base of brain is thermostat. Sends messages to blood to contract or dilate blood vessels, via neurotransmitters.

Artificial light has an effect on our energy level. Moderate lights in house an hour before sleep.

Migraine: constricted blood vessels inside the skull which suddenly expand. Strong correlation to food sensitivities, and neurotransmitter imbalances. Serotonin regulates the constriction and dilation of blood vessels. Prodrome aura of visual disturbances that can include zigzag lines and flashes of light. the trigeminal nerve pathway involved runs close to our reticular formation in the eyes. the constant stimulation of both decreased blood flow and increased nerve involvement causes optical effects.

reflux: back pressure opens a muscular valve, called the cardiac sphincter, between the bottom of our esophagus and top of stomach. Bending over or lying down often adds just enough pressure to grav to cause reflux. Also hiatal hernia

Hunger: blood sugar low, brain receives signal from hypothalamus that causes muscles in stomach wall to contract. For some people, hunger pangs caused by desire to chew.

Itches: sensory itch, allergic itch. Merkel's discs in skin, pressure plate receptors in outer skin layer. Unfamiliar pressures translated as itch. Cold numbs the receptors. Dryness creates an enhanced pressure reception.

Laughter: triggers electrical impulses in brain, which sets off chemical reactions. Secretions of natural tranquilizers and painkillers.

FMHO #7 Cranio-Sacral Release Technique; FM/MPS in other cultures Devin Starlanyl, M.D.

CSR is a therapy technique which releases tightened, constricted tissue. Studies in Israel indicate that fascia serves as an electrical conduction system. Body fascia is a slightly mobile, body-wide laminated sheath of connective tissue. All living beings are batteries, generators and capacitors. People with fibromyalgia and myofascial pain syndrome suffer from sensory overload. CSR releases the bottled up tension in the

fascia, and balances the system. Our skin holds in our electricity and protects us from environmental electricity which could interfere with our functions. CSR is a method of restoring electromagnetic balance. Myofascia is connective tissue that holds organ systems and musculature together, and gives the body its shape. Through this interconnecting myofascial system, any injury or illness which results in contracture or swelling can affect the whole body. Areas of clinically significant change can produce fascial rigidity. Any kind of scarring or adhesion can create long-standing problems in the elasticity of myofascia. Postural dysfunction, athletic stresses, injuries and biochemical or electromagnetic imbalance will disrupt the myofascial balance.

There is material in fascia called ground substance, which changes from solid to liquid, and fascia has the ability to contract or relax. The practitioner must be relaxed and comfortable, or his or her tensions will not allow the release to occur.

CSR is based on the premise that the inherent energy that causes motion is present in the unhealthy tissue, but it is fighting against restriction. Restrictions can result from adhesions, inflammation, infection, dysfunction, or neuroreflexes. When the restriction is loosened, it is called a release. Often the body can't discharge accumulated stress because there is insufficient opportunity. We tend to accumulate more energy from stressful situations than is dissipated. Any joint is a potential cross-restriction to the free movement of the fascia. There are even three membranes around the brain which are capable of independent motion. They allow the spine to rotate and bend without stressing the spinal cord. Tennis ball compression of spinal cord is actually a form of cranio-sacral release.

The Japanese practitioners feel that the center of the FM/MPS problem is "hara". Hara is the center of body strength--the abdominal area, between the rib cage and the pelvic bone. "Hara guroi" is a sneaky, dishonest person. "Hara o tateru" is an angry or upset person. "Hara ga aru", to have hara, describes a brave person with energy and spirit. "Hara kiri" means to cut off the hara. When a Japanese person is angry, he squeezes his hara to express fury and relieve it. The Kai energy comes from the hara.

They use shiatsu and acupuncture, and herbal remedies, as well as moxibustion and electrostimulation of trigger points. Shiatsu of hara is called ampuku. Kenbiki (pushing and pulling) therapy is also recommended.

Dene Native Americans treat people with FM/MPS with great respect. They are considered people with a special link to the spirit world, and they are consulted on many matters of importance. Illness is not a state of being but a process of transformation. You must surrender--there is no way out but through. Accommodate, and optimize life within your limitations. Use your "down time" wisely. You will eventually be restored to harmony. Your passage will give you a greater understanding of life, and a great deal of wisdom. They feel you should concentrate on the discomfort instead of ignoring it, and it will fade faster. The body is trying to teach you something. It will try until you learn. They emphasize creative dreaming and visualization. If you visualize a situation you usually don't handle well, figure out how you could do better and visualize yourself doing it.

The Chinese see FM/MPS as a disturbance of Chi. They use herbs, acupuncture, acupressure, and equalization and balance of energies to unblock the flow of Chi. Tai Chi is recommended. Also walking backward, which strengthens abdominal and back muscles, quadriceps and hamstrings. They work in teams, one walking forward while another walks backward. A strong circle of friends and family is very important. A study at the U. of Texas School of Medicine agrees that moral support triggers the brain to release chemicals that promote healing and reduce blood pressure.

The Kahunas of Hawaii pay more attention to emotions with respect to health. FM/MPS is the self talking to self. The mind is not the brain, but the whole body, enlivening energy and correlating functions. They use herbs to aid the process of understanding. They believe taste and smell are the most easily conditioned senses, and often work through these for healing. Grief is seen as positive and healthy, and separated from depression, which is negative and unhealthy. Laughter is important in healing, as it not only provides a psychological boost but reduces stress, lowers heart rate and enhances circulation.

All of these healers expect disruption of normal body processes while healing takes place. Long-standing toxins are liberated from trigger points throughout the body. The liver enzymes rise as the body detoxifies. These TPs are not only in the muscles, but in other tissues as well. They affect every part of your body. Eating natural foods and vitamins aren't enough when your body is clogged with toxic products.

These healers have much advice in common. They tell their patients to avoid unnecessary changes in their lives, and simplify things as much as possible. Inventory what is important to you, and streamline your life. They all ask their patients to learn "responsible selfishness". Take time to meet your own needs, and do the things you find most rewarding and fulfilling.

FMHO #8 FIBROMYALGIA/MYOFASCIAL PAIN SYNDROME MEDICATIONS Devin Starlanyl, M.D.

Medications which affect CNS are appropriate--target patient symptoms of sleep lack, muscle rigidity, pain and fatigue. They have 3x the amount of Substance P in their CNS fluid, and 2x the pain receptors. They hurt. Mild analgesics such as darvocet are recommended for use prn. Steroids and narcotics contraindicated.

Psycho-active drugs influence neurotransmitters. Reassure your patient that these "anti-anxiety" medications are not an indication that symptoms are "all in the mind". Tricyclic anti-depressants prolong the effect of serotonin at the nerve junctions, inhibiting the re-uptake of serotonin and norepinephrine. These medications don't stop the alpha-wave intrusion on sleep, but they can extend the quantity of sleep and ease daytime symptom "flares".

Amitriptyline (Elavil): This tricyclic antidepressant (TCA) is cheap and useful. FM patients react oddly to drugs due to skewed metabolism. Most patients will adapt to this med after a few weeks. Maximum benefits by 2 weeks.

Carisoprodol (Soma): A CNS "muffler"--should be tried as a half- pill, alone or in conjunction with low-dose Elavil. It mitigates erratic neurotransmitter cascade. Approximates meditative state.

Cyclobenzaprine (Flexeril): A muscle relaxant.

Doxepin (Sinequan): TCA and anti-histamine. Can produce marked sedation. This may work synergistically with Klonopin.

Fluoxetine (Prozac): Anti-depressant, increases the availability of serotonin. Its side-effects might limit or exclude usage.

Alprazolam (Xanax): A benzodiazepine useful if anxiety contributes to symptoms. Benzodiazepines work on neurotransmitter receptors. May be potentiated by ibuprofen.

Nortriptyline (Pamelor): A good choice for daytime, it increases serotonin while stimulating rather than sedating.

Clonazepam (Klonopin): Another benzodiazepine, not only anti-anxiety, but also an anti-convulsive/anti-spasmodic. This is helpful with muscle twitching and bruxism.

Fluconazole (Diflucan): anti-fungal which can penetrate all of the body's tissues, even the CNS. This is expensive. Only a few may be enough to reduce cranial swelling. Very short term use can be considered if cognitive problems and depression is present. Yeast may be at the root of irritable bowel, sleep dysfunction (muramyl dipeptides from bowel bacteria induces sleep), etc. Restricted diet may help maintain low yeast loads. Yeast die-off phenomenon: flu-like stage while body deals with dead and dying yeast cells.

Buspirone (Buspar): Partially activates serotonin receptor site #1A, aiding memory, anxiety, appetite, and temperature regulation. Sertraline (Zoloft): Serotonin re-uptake inhibitor.

Tagamet, Zantac: Histamine receptor #2 antagonists alter immune function and modify reflux. Tagamet may increase stage 4 sleep.

Paxil: Most potent SSRI so far--it may also produce an analgesic effect. Does not potentiate other CNS drugs. Don't use with other meds that markedly increase brain serotonin.

Effexor? wait for data

Niacin: Time-release niacin, 250 mg/day, enhances peripheral circulation and reduces swollen feeling.

Guiafenesin: Seems to reverse FM by ridding the body of inappropriate phosphate deposits. Suggested starting dosage 300 to 600 mg bid/tid, with dosage adjusted as patient tolerates. A flu-like fatigue for about a week will often occur, signalling the body repair work, followed by symptom pattern reversal. Patients need to be encouraged through this period. Deposits and toxins are released and the liver will be working to detoxify the body. The amount of misery the regression entails will vary with the patient, due to the amount, placing and nature of the deposits, the length of time and severity of the FM/MPS, how efficient the liver is at detox, and how much bodywork has already been done to release deposits. Calcium phosphate is being released in quantity. Ensure multimineral supplementation to balance the body electrolytes. A gentle form of accupressure massage may be soothing at this time, and encourage the release of the deposits. As the deposits dwindle, medications may need adjusting. One of the first of these may be niacin, which clears the peripheral area and allows guiafenesin to dissolve these deposits first, after which, supplemental niacin may no longer be needed.

Tx: Heat for muscle pain and tightness, ice for nerve entrapment and muscle tightness. Cervical pillow use, stretching, shiatsu (accupressure) massage, good posture, cranio-sacral release and myofascial release techniques, "stretch and spray" and sine-wave ultrasound with electrostim for trigger points, good nutrition, relaxation tapes, and meditation. Teach your patients to optimize their quality of life, recognize and avoid precipitating factors, and educate their companions. Encourage good nutrition and a healthy life-style. Yeast-free vitamins, especially high B complex and beta-carotene, may boost patient energy levels. Bodywork and release of trigger point waste products may cause flu-like symptoms or exhaustion, as the body deals with the toxins.

A Fibromyalgia Reading List

"Sick & Tired of Feeling Sick & Tired: Living With Chronic Invisible Illness" by Paul J Donoghue & Mary E. Siegel

"Myotherapy" and "Pain Erasure" by Bonnie Prudden

"Stretching" by Bob Anderson

"We Are Not Alone: Learning to Live with Chronic Illness" by Sefra Kobrin Pitzele

"Office Hours Day and Night" by Janet Travell, M.D.

"Myofascial Pain and Dysfunction: Trigger Point Manual Volumes I & II" by Janet G. Travell, M.D. and David G. Simons, M.D.

"Streamlining Your Life" by Stephanie Culp

"Feeling Good", by David D. Burns, M.D.

"Prescription for Anger", by Gary Hankins, Ph.D. and Carol Hankins

"Living With Chronic Illness--Days of Patience and Passion" by Cheri

Register

"Mastering Pain" by Dr. Richard A. Sternbach

"When Muscle Pain Won't Go Away" by Gayle Backstrom and Bernard R. Rubin,
D.O. Taylor Pub 1993

"Job's Body" by Deane Juhan

"Nasty People: How to Stop Being Hurt by Them Without Becoming One of Them",
by Jay Carter

Resources:

Fibromyalgia Network, 5700 Stockdale Hwy, Suite 100, Bakersfield, CA 93309
805-631-1950 owner/publisher: Kristin Thorson, newsletter

The Well Spouse Foundation, PO Box 28876, San Diego, CA 92198. 619-
673-9043. Exec. Dir. Peggy Meisel, support groups, newsletter

Brattleboro Fibromyalgia Support Group Brattleboro Memorial Hospital 4th
Wednesday of month 6:30 PM Brew Barry Conf Room
Devin Starlanyl, 603-256-8630

Cheshire Fibromyalgia Support Group Cheshire Medical Center
2nd Tuesday of month 6:30 PM Auditorium A
Lois Kitz 603-352-4111

Greenfield Fibromyalgia Support Group, Franklin Medical Center Sanderson
Street Building, last Thursday of the month 7:00 PM
Nancy Mooney 413-773-8797

FIBROMYALGIA

History of widespread pain in all quadrants of the body. Pain in 11 of 18 tender point sites on digital palpitation.

Occiput: Bilateral, at the sub-occipital muscle insertions. Low Cervical: Bilateral, anterior aspects C5-C7. Trapezius: Bilateral, midpoint upper border. Supraspinatus: Bilateral, above scapula, near medial border. Second rib: Bilateral, second costochondral junctions. Lateral epicondyle: Bilateral, 2cm distal to epicondyles. Gluteal: Bilateral, upper outer quadrants, anterior muscle fold. Greater trochanter: Bilateral, posterior of prominence. Knee: Bilateral, medial fat pad proximal to joint line.

Look for some or all of these: Widespread pain, stiffness (especially morning), myofascial pain syndrome, reflux, fatigue, non-restorative sleep, reduced coordination, cold intolerance, decreased endurance, dizziness, paresthesias, cognitive and memory dysfunction, headaches, Sicca syndrome, dysmenorrhea, irritable bladder and bowel, fingernail ridges, mottling of skin, Raynauds, mitral valve prolapse, myoclonus, nocturnal calf cramps.

Recommend: Education, stretching, massage, support, medicate for symptomatic relief, visualization, meditation, relaxation tapes, cold/heat, streamlining, pacing yourself.

Avoid: repetitive exercise, swimming crawl or breast stroke (especially in cool water), immobility, yoga, weight training, narcotics, steroids, stairs or uphill climbing. Some Possible Symptoms and Signs of the FM/MPS Complex Fibromyalgia is a neurotransmitter disease, and neurotransmitters basically tell the body how to work. Depending on which transmitters and sites are involved, symptoms and signs vary, especially

if the patient also has Myofascial Pain Syndrome. Nerves, blood vessels and other channels for body fluids can be constricted by the rigid muscles, and this leads to the strange pain patterns. The FM/MPS patient can present with: sleep dysfunction (alpha-delta sleep anomaly and/or fragmented sleep, and sleep more easily disturbed by noise), pain, stiffness, weakness, fatigue, dyspnea, electromagnetic sensitivity, headache, hypoglycemic-like syndrome, dysphagia, vasomotor rhinitis, mold and yeast sensitivity, reflux esophagitis, menstrual problems, pelvic pain, nail ridges and/or beads, immune dysfunction, deficits in cognitive thought processes, speech and language difficulties, difficulties with sequential problems, directional disorientation and visual perception problems, memory impairment, weight gain, sensitivity to odors and foods, motor coordination problems, PMS, eye or ear pain or dysfunction, toothache, pseudoangina, disrupted fat metabolism, conjunctivitis, nausea, cramps, carbohydrate craving, sensitivity to cold, bloating, chest pain, photophobia, bruising, tender lymph nodes, anxiety, confusional states, hair loss, non-IgE allergy, sleep apnea, environmental sensitivity, sore throat, Reynaud's, hives, weak ankles, leg cramps, groin pain, sciatica, impotence, mottled skin on inner arms and thighs, painful intercourse, tinnitus, bruising, muscle twitching, numbness and tingling sensations, tearing and red eyes, diffuse swelling, itching and rashes, tennis elbow, high or low temperature, lack of endurance, mouth sores, swollen glands, hyper-sensitive nipples, dermatographia, breast pain, buckling knee, problems climbing stairs, inversion sprain of ankle, sore throat, photophobia, anxiety, mood swings, irritability, trouble concentrating, panic attacks, chronic cough. Mitral valve prolapse is common in FM patients. Diagnostic hint: If a Diagnosis of FM and Myofascial Pain Syndrome (TPs) is suspected, check for taut bands behind the neck, "goosebumps"--pilomotor activity--on the back of upper arms and thighs, mottling on the forearms, and for nail ridges. These signs are common with FM/MPS. Turn your patient's head and feel for TPs in the SCM. If present, they will be quite painful, so be gentle. It isn't necessary to press--usually you can feel them if you just rest your hand gently on the area. The same is true for the digastric TPs, which often mimic swollen glands. There may also be taut bands in the arms and legs. There isn't a lot to be done for FM except for symptom relief, but there are things you can do for the Myofascial Pain Syndrome, and that will reduce the patient's pain load.