

STEPS TO IMPROVING AND GAINING CONTROL OF FIBROMYALGIA AND MYOFASCIAL PAIN

by

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EACH OF THESE STEPS SHOULD BE DONE IN THE ORDER LISTED IN CONSULTATION WITH YOUR HEALTH CARE PROVIDER

1.) Look for factors in your life which are known to make pain worse.

COMMON PERPETUATING FACTORS

Poor sleep.	Anger or frustration causing muscle tension.
Continuing to do physical or daily activities despite increasing pain	Smoking/ Nicotine
Panic attacks/ Phobias/ Fears .	Hypothyroidism
Vitamin inadequacy.	Infection or other illness.
Caffeine or chocolate.	Poor eating habits, contributing to fatigue.
Sugar.	Taking some other nervous system stimulant.
Anemia	Anxiety or depression.
Rheumatoid Arthritis	Fatigue from non-restful sleeping
Folate Deficiency	B-12 Deficiency
Systemic Lupus Erythrematosus	Lyme Disease
	Hyperthyroidism

2.) Develop a plan for improving each of these factors in order to reduce discomfort and gain control of the pain.

3.) Learn to stay in control of how you feel (emotionally or physically).

4.) Avoid activities which increase your pain by pacing yourself well, every minute of every day. Discover what makes your pain (or other symptom) worse and avoid those activities. Or, take more time, take more rests, and do it in a different way. But, if it starts to hurt, stop, think, and change how or what you are doing so that you gain control of the pain. Don't wait until the pain is so bad that it controls you. Act when it starts to bother you. If you should get into trouble with pain that you cannot get rid of with a change in activity, heat, ice, or rest, you may need to rest in bed for a limited time.

5.) Sleep well each and every night. Avoid fatigue. Structure your day and rest frequently enough to not get fatigued. If you do get fatigued, rest until you are recovered. Make your daily goal to sleep long enough each and every night, so that you are well rested throughout the day. This may require you to change your sleep habits or daily schedule to allow enough time to get well rested. Most people with this problem do not get enough deep or Delta sleep and require a medication to sleep deeply. Only certain types of medications improve on this type of deep sleep. Most sleeping pills and tranquilizers do not induce Delta sleep. They can actually reduce the amount of Delta sleep and increase fatigue.

6.) Learn how to do gentle and comfortable stretches in the muscle groups that bother you. Do them frequently.

7.) Learn how to exercise the right muscle groups comfortably. If it causes an increase in your pain that seems to last, then the method of exercising is wrong, or else steps 1-6 were not done completely enough. All of the medications, therapy, devices, treatments, biofeedback etc. in some fashion improve on one or more of these steps. The trick is to find the combination of events, treatments, medications, or exercises that is suitable for the individual needs of the patient. Here are some questions that will help identify some common perpetuating factors and maybe give you some clues on how to improve them.

Please answer Yes or No to these questions about perpetuating factors. Questions which have been answered yes, are perpetuating factors that must be corrected:

Is your sleep restless, or do you still feel tired when you wake up in the morning? Do you toss and turn at night?

Do you fatigue during the day?

When the alarm goes off in the morning, does it wake you?

When an activity increases your pain, do you keep going?

When an activity increases your pain, do you have trouble getting it under control?

Do you have trouble telling which activities increase your pain?

Do you have any excessive bleeding or reason to think that you may have an ulcer?

Do you not take a vitamin every day?

Do you take in products or drinks with caffeine in them?

Do you eat much food or candy with chocolate in them?

Do you use sugar or foods that have sugar in them?

Are you angered about having this problem or about something else in your life?

Do you eat irregularly or tend to eat poorly?

Any reason to feel that you may have a chronic infection?

Do you go out in the woods a lot?

Ever had a tick bite?

Are you anxious or depressed?

When you start to feel tired, do you keep going rather than rest in bed?

When an activity causes an increase in your pain, do you tend to keep going?

Do you have trouble staying relaxed?

Do you get scared when you start to feel a new discomfort or sensation?

Do you have trouble saying no to friends and family who seem to depend on you?

Does your mind and thoughts seem to keep going while you are trying to get to sleep?

Do you have hot flashes?

Is there some habit or activity which interferes with sleeping straight through each night?
When you feel pain or discomfort, do you tend to say to yourself "no pain/no gain"?
Are there activities that you think you "just have to do"?
Does your spouse make you feel guilty when you don't perform your normal activities?
Does your spouse not understand that the pain is bad?
Do your friends not understand?

Once all of the pain enhancing or perpetuating factors have been identified, the process of improvement begins by:

- A.) Avoiding or modifying daily activities so they do not increase your pain or fatigue.
- B.) Using good sleep habits to increase the amount of sleep.
- C.) Using specific medications to allow a deeper sleep.
- D.) Using a safe pain medication such as Extra-Strength Tylenol, on a regular basis.

GOOD PACING

Good pacing is defined as the modification of daily activities to avoid increases in pain or other symptoms. **IN ORDER FOR PACING TO BE EFFECTIVE IN HELPING WITH THE PAIN, IT MUST BE DONE EVERY MINUTE OF EVERY DAY AND MUST BE GIVEN PRIORITY OVER ALL OTHER RESPONSIBILITIES AND DESIRES.** This does not mean that you are sentenced to life in bed for the rest of your life, but what it does mean is that you need to control the pain well enough to eventually be able to comfortably use exercise. Rest in bed may be one of the most important tools you have. You should not hesitate to take a rest in bed when your body feels tired or when your pain has increased. It is vital that you get control of fatigue by getting as much rest (for your muscles), during the day or night, as you need. Too much bed will cause your muscles to get weaker, but if you do not rest enough the spasm will never quiet down enough to allow strengthening exercises. One thing to keep in mind is that any weakness or deconditioning can eventually be reversed with the right exercise, so any weakness from resting you may develop can eventually be overcome. The goal of proper pacing and resting is not getting rid of all of the pain, but is to achieve enough comfort to allow the right medicine to give you a restorative night of sleep, which almost always allows a person to be fairly comfortable when they wake up in the morning. Bed rest should not be used for long periods of time, such as when trying to avoid all pain, but it can be used to quiet down a spasm (pain). As you get stronger and stronger (by exercising the right muscles) you will find that you can do more and more with less pain or fatigue. The level at which the pain will return or become worse, increases as you get stronger. But in the beginning, you have to reduce the activity level way, way down, (as far down as is needed), to control the pain and fatigue. This is very hard, because most patients with chronic pain have difficulty slowing down and changing the way they do things, even to decrease the pain. Some of this is because they are bored, frustrated, and angry with only being able to do so little. These people don't want to pay attention when their pain says stop, and their mind and desire says go. Other people simply don't know how to pace well. Some people can't figure out how to modify what they do to reduce the pain activity brings. To make matters even more difficult, some people are not aware of subtle changes in their pain that occur with changes in activity. These subtle changes are clues to the fact that they should change what they are doing. These people simply don't feel the changes in the pain, or choose to not pay attention (we are not yet sure).

RELAXATION

What many people don't know is that every day stresses will cause an increase in resting muscle tension. This means that every time you are faced with or think about something that may be stressful or cause concern, your muscles will tense up. You may not be aware of this. Some patients notice that when they get angry or upset, the pain will intensify. With some patients, the tension and pain will increase during the course of a stressful or otherwise important conversation. Some people will have a sudden increase in their symptoms when they suddenly become scared or panicked. Because this occurs in everyone (even though they might not notice) it is very important to take time to relax (mind and muscles) during the day. The most effective way to do this is to get a relaxation tape and either read about how to relax, or seek the help of a relaxation therapist or psychologist who can teach you the process of relaxation. Sometimes using the technique of biofeedback to help the patient learn how to relax. It is important to take the time to do this. Usually, it is effective when done three times per day. Late morning, late afternoon (or early evening) and before bedtime seem to be the most helpful times. People who don't take the time to really relax, don't get better.

SLEEP

Sleep is your body's way of reducing fatigue and restoring energy to the neuromuscular system. When your sleep is disturbed in some way or your sleep is not deep enough, your system is not recharged and restored the next day. If a non-restorative sleep pattern keeps up it can really cause the fatigue in your nervous system and muscles to grow. For example, if you only recharge 80 percent each night, that means you start you day only partially restored. If you use energy during the day and then only sleep 80 percent effective again, you are only 64 percent restored the next morning. If this keeps up you are always behind and never catch up until something is done to break the cycle and you begin to be restored when you wake up.

It turns out that the more active your mind and body, the more rest you need. So not only is it important to sleep well each night, but your need for sleep and rest will increase as you are more active. Athletes have known this for centuries. This means that the time you allow for sleep, must be set by what the body needs rather than any artificial schedule or by what is thought to be normal.

The process of improving a sleep disturbance involves working on ways to sleep more deeply and longer. Usually a medication is needed to deepen the sleep and counteract the effect of the pain. But, also each of us have our own set of habits which can interfere with sleep and these must be recognized and corrected.

The goal must be to get enough sleep. In my experience this is usually about 9 hours of restful nearly undisturbed sleep. This seems like a lot for many people, but the patients who have achieved it look back and can really tell the difference. One seems to be accustomed to having a certain energy level, but when the extra rest occurs he/she can really notice the change. Then when he/she gets less than the needed amount of sleep, it is felt as a loss in energy level.

Here are some things that hinder getting a good restful sleep:

Caffeine containing products--Coffee, tea, pepsi, coke, orange soda, mountain dew, chocolate, jolt, some medications. Caffeine can stay in your system for a long time. It can actually change the chemistry of your nervous system so that you are dependent on it. Caffeine increases heart activity and increases nervous system activity. This is just the opposite effect that you want when trying to relax and get to sleep or when trying to rest during the day. It can also interfere with the activity of some medications (it is a drug itself). This stimulant will increase the sensitivity of your muscles and make it easier for a muscle spasm to come on and make it more difficult to relax one. Caffeine products should be limited to a small amount in the morning at most. (One to two cups, not mugs). If you are taking in more than a small amount of caffeine and you want to cut down, you should discuss this process with your doctor, since you may be taking in enough to have to worry about withdrawal reactions, physical dependency and psychological dependency. Getting rid of all caffeine products can make a large difference towards gaining control of your pain.

You should also be aware that sugar products act as a stimulant to the body. These should be avoided in the evening. It turns out that just eating late can interfere with sleep. It is best to time your dinner to be at least 3 hours before your bed time.

Being too active before bed time can make sleep more difficult to initiate. Most people find that they can get to sleep faster, if they take some time to "wind down" after an active evening or day. Choose a set bed time and stick to it. Take an hour or so before bed time to relax. The best way to do this is to get a relaxation tape, or play some quiet music (listening with head phones). Sometimes reading a book or watching TV can be too stimulating. If this amount of relaxation is enough to let you fall asleep quickly, the relaxation tape may not be needed. The body and the mind need to be relaxed before you can fall asleep.

Having a consistent bed time and time to get up is very useful in letting your internal clock be in sync with your habits. Changing shifts or changing bed times is tough on your system.

You don't want the bed to be a torture chamber. If you find that you cannot fall asleep or you have awoken in the middle of the night, it is better to get up for awhile, read a book or, better yet, start a journal of what is going on in your mind. It may be frustration with pain or something else. It may be a million things. It helps to write down your thoughts. TV can act as a stimulant. Other techniques of distraction and relaxation are often better.

It is important to have the right environment for sleep. Any light or noise may make sleep difficult to impossible. Usually sleep is not disturbed by just one thing, but it is usually multiple factors that need to be corrected. Make a list of things around you which might disturb or delay your sleep. Then work on correcting each one: e.g., let the dog out earlier, have your spouse watch TV in the living room, have the kids go to their bedroom earlier. Each person and their situation is different.

STRESS

The relationship between stress and myofascial pain is controversial. Some clinicians make you feel like "it's all in your head". Others are more understanding. Some patients wonder if stress has any effect. Here are some thoughts:

1. It is not in your head. The pain is an actual physiologic process occurring in your muscles and nerves.
2. Few people understand and so they don't know what to think.
3. When you are stressed (normal or abnormal) often it disturbs your sleep and if you think about it, your muscles also tense up... So, what is going to happen to your pain? It will go up... remember that anything that increases fatigue or anything that increases muscle tension will increase your pain. That doesn't mean that the pain "is in your head". When you get angry frustrated or fearful your muscles also tense up. This is a normal physiologic reaction that everybody has, but only causes pain in the muscles which are tender or in spasm.
4. When you are angry, you may tend to try and ignore things like pain and tend to push yourself, rather than slow down as perhaps you should. So, what is this going to do to your pain? Increase it of course. But, the pain is not "in your head".
5. Too much anger or fear or depression can cause so much uncontrolled muscle tension that it can be a perpetuating factor. If these emotions are strong enough to be a perpetuating factor, you may need counseling, relaxation training, or removal from the stressful environment. But, the pain is not "in your head".

EXERCISE

There are generally two types of exercise, Stretching and Strengthening. Stretching will reduce the muscle spasm that is already there and strengthening will increase the amount of activity that it takes to cause the muscle spasm. Most patients do not do well with exercise until they have controlled the perpetuating factors. Very gentle stretching early on is helpful, but if the patient tends to over do it, or their muscles are too sensitive, it will do more harm than good.

Exercise should be reserved until it is likely to do more good than harm. Strengthening does not begin until after the sleep is fixed, and you begin to wake up feeling well rested and with little pain. Exercise which causes pain will never consistently challenge the muscles in a way that will result in strengthening. Also, the correct muscles have to be exercised, or the trigger points will get irritated, but not get stronger. Exercise has to be pain free and regulated by the state of your body at that moment. Not what you would like to do. Not what you think that you should do. Not what you did before. Not what your Therapist would like you do to do. But, when you start to feel an increase in your pain--you are then done for that exercise--. Pain free or not at all.

Also, this means that the first exercises are going to seem like they are at a very low level and very easy, but they do work. Exercise that causes pain does not work, because it increases spasm. But, exercise can be comfortable and increase your strength. In other words, an exercise doesn't have to hurt to work.

MEDICATION

There are pain pills, sleeping pills, antidepressants, narcotics, anti-inflammatory agents and muscle relaxants. Medication is only helpful if it helps to treat a perpetuating factor. Many medications will help temporarily, but make treatment of the sleep disorder, pacing problem or stress more difficult. Generally, true sleeping pills, tranquilizers, and narcotic pain pills are counter productive and not helpful. Here is a list of useful medications and why they are useful:

Amitriptyline - Causes Delta Sleep.	Prozac - May cause Delta Sleep
Desipramine - Causes Delta Sleep.	Zoloft - May cause Delta Sleep
Sinequan (brand) - Causes Delta Sleep	Clonidine - Causes Delta Sleep
Imipramine - Causes Delta Sleep	Flexeril - May Cause Delta Sleep
Trazodone - Causes Delta Sleep	Lithium - Causes Delta Sleep

Extra Strength Tylenol - can be taken for long periods of time and offers a constant amount of pain control in the body to assist with pain management.

Naprosyn and other NSAIA - Can offer good short term pain assistance.

Sinemet - May assist with sleep or muscle relaxation (Not much experience).

TREATMENTS

In addition to the treatments mentioned above, patients are also offered other treatments. These might include ultrasound, hot packs, cold packs, electrical stimulation, acupuncture, massage, myotherapy, rolfing, manipulation (adjustment), acupressure, myofascial release, and injection therapy. Often patients notice a temporary reduction in their pain, but then the pain comes back. Hot Packs and Ice Packs (whichever feels better) are often most helpful if used three times per day, no matter what the status of your pain. During the treatment, it is best to lie down in a position where the muscles to be treated are not being used. You must be very careful not to burn yourself with a heating pad or hot pack. Some treatments can be too aggressive. For example massage therapy for most people can be relaxing and the discomfort felt after treatment can resolve quickly, but for patients with fibromyalgia or myofascial pain, it can worsen sleep, increase fatigue, and even worsen the pain. It doesn't have to be that way. If it hurts or increases fatigue it needs to be changed or avoided. The treatment may be a great idea, but it may need to be less aggressive. You want to be sure to get the benefits without increasing your symptoms. This idea seems to hold for most treatments, exercises, or daily activities.

The best concept to use is to try and understand how each of these work to cause muscle relaxation or what is also called "inactivation" of a trigger point. The benefit is temporary if the perpetuating factors are still there (sleep, deconditioning, poor pacing). So, if you take a weak muscle that is in spasm, reduce the spasm, and then use it again (above its comfort level), the spasm gets stimulated again. These treatments also cause you to be able to do more than you should and are often counter-productive because you cannot tell what are your true physical abilities. These treatments may offer short term relief, but at the price of your long term improvement. The worse the perpetuating factor and the longer since the initial injury, the less likely the above treatments will offer long term benefit.

YOUR RIGHTS

Most clinicians do not understand fibromyalgia, myofascial pain, or chronic pain syndromes. A clinician may make you feel guilty, more frustrated, or angry by suggesting that the pain may be "in your head" or stress related. Or sometimes the clinician believes that you have a physical problem, but doesn't know how to help you. You have a right to the best care available, and you have a right to a clinician who is supportive and helpful. Clinicians work for you, not the other way around. Usually, it works best to talk straight with your clinician. Tell him/her what you want, and ask him/her if he/she can provide it. If the clinician can't give you what you need, then you should ask for suggestions on who might be able to give you what you need. One last point, some clinicians want to help, but don't know how. You might offer them some literature on these syndromes or, the name of someone who you think can help your clinician to learn how to give you what you need and what you want. You have rights. Don't let other people's preconceived ideas stop you. Don't let unrecognized prejudices about people with chronic pain stop you. Educate yourself and whoever you are using to get help (including family and friends)!

SLOW RECOVERY

Improvement or recovery from this problem takes a long time (months to years). Here is why.

1. For every one week of inactivity, it takes 3 weeks of consistent effective exercise to recover.
2. Because your pain has its good days and bad days, it is difficult to effectively exercise each day.
3. It is normal to have temporary setbacks, which slow progress.
4. There are many variables which need to be controlled to maintain the ability to exercise over a long period of time.
5. Perhaps most importantly, getting stronger takes lots of time. Athletes train for years. Anybody who has worked out with weights, knows that improvement to any degree takes weeks to months. Often patients don't achieve what they want for years (it does depend upon how well you want to be). For example, a person might exercise for four months to get well enough to be able to do a sedentary job, but they then might need to exercise an additional few months to be able to work at the medium level or to be able to comfortably go hiking. Strengthening takes lots of time. One has to be patient and persistent.

So, the process is mostly dependent on the rate of strengthening. If you push too hard you will get more spasm. You need to realize that this is a process which cannot be rushed, but is very rewarding, when done well.

SUMMARY

This problem affects every part of your life. If the above factors can be controlled (especially the sleep) then the likelihood of improvement is good. If the sleep can become restorative and the physical activity can be controlled well enough to allow comfortable strengthening, then you will improve.

SOURCES FOR FURTHER INFORMATION

Fibromyalgia Support Groups in NH 1-800-639-2113 or 603-224-9322

Fibromyalgia Support Groups in VT 802-864-4988

Books and Pamphlets:

Information can be obtained from:

From Fatigued to Fantastic

by Jacob Teitelbaum, M. D.

Deva Press

139 Old Solomons Island Road

Annapolis, Maryland 21401

(800) 333-5287

also found in bookstores

Fibromyalgia & Chronic Myofascial Pain Syndrome

A Survival Manual

Devin Starlanyl, M.D.

Mary Ellen Copeland, M.S., M.A.

New Harbinger Publications, Inc.

Fibromyalgia Network

5700 Stockdale Hwy., #100

Bakersfield, CA 93309

805-631-1950

Coping with Fibromyalgia, from:

Fibromyalgia Association of Texas, Inc.

5650 Forest Lane

Dallas, TX 75230 Cost \$7.95

The Fibromyalgia Syndrome, from:

Fibromyalgia Association of Central Ohio

P.O. Box 21988

Columbus, Ohio 43221-0988

614-457-4222

Chronic Muscle Pain Syndrome, by Paul Davidson, M.D.

Discusses how stresses can increase muscle tension.

Please order one from a book store.

"Effective Treatment of Severe Chronic Fatigue:
A Report of a Series of 64 Patients"
by Jacob Teitelbaum and Barbara Bird
in the Journal of Musculoskeletal Pain, Vol. 3(4) 1995
pp. 91-110

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Myofascial Pain and Dysfunction
The Trigger Point Manual
Vol. I and Vol. II
Janet G. Travell, M.D.
David G. Simons, M.D.

Fibromyalgia & Chronic Myofascial Pain Syndrome
A Survival Manual
Devin Starlanyl, M.D.
Mary Ellen Copeland, M.S., M.A.
New Harbinger Publications, Inc.

Journal of Musculoskeletal Pain. Published by The Haworth Medical Press