FMA UK

Patient Information Pack

Isle of Wight Fibromyalgia/CFS Support Group

Working with the Fibromyalgia Action UK

Isle of Wight Fibromyalgia/CFS Support Group working with Fibromyalgia Action UK
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Isle of Wight Fibromyalgia/CFS Support Group
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Isle of Wight Clinical Commissioning Group CCG

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Welcome...

I have put together this pack to contain all the information that I wish someone had handed to me when I was first diagnosed with Fibromyalgia. It is quite comprehensive and there is a lot to take in, but to ‘manage’ your FMS you need to read as much information as you can.

I have sourced the information from several places, but mostly through our Fibromyalgia Association UK. Where authors are known they are credited.

I hope this information pack will help you understand and manage your symptoms, and save you from complete bewilderment!

Yours in friendship,

Karen Smith,

Isle of Wight Fibromyalgia Support Group

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FMA UK

To Whom It May Concern…

Fibromyalgia is a chronic condition of widespread pain, fatigue and loss of restorative sleep. Other symptoms can include Irritable Bowel Syndrome (IBS), short term memory lapses, confusion, headaches, skin sensations/sensitivity, eye and jaw problems, and loss of balance. Many sufferers have the symptoms for months and even years, before being correctly diagnosed.

Fibromyalgia Syndrome was recognised by the World Health Organisation during a consensus conference in Copenhagen between 17th and 20th August 1992. Guidelines for diagnosis included the presence of chronic, widespread pain for at least 3 months, the exclusion by clinical tests of other chronic conditions (e.g. Rheumatoid Arthritis, Systemic Lupus) and by painful reaction to pressure being applied to 11 out of 18 recognised tender point sites throughout the body (9 on each side).

Fibromyalgia Syndrome was recognised by the WHO during the 1992 consensus conference in Copenhagen

It is now thought that Fibromyalgia is primarily a problem with an imbalance in the central nervous system, which leads to disordered sensory processing. There also appears to be a problem with blood flow to some parts of the brain and perhaps through muscle capillaries. FMS sufferers do not respond well to sustained activity, particularly repetitive tasks and in most cases regular employment cannot be maintained.

Treatments are aimed at reducing the effects of symptoms and it is often a matter of finding a combination of medications and therapies that suit anyone individual. An improved quality of life depends on the ability to understand the condition and to "manage" it. Exercise, whilst important, must be very gentle, and any build up in an exercise programme has to be very gradual.

It is now thought that Fibromyalgia is primarily a problem with an imbalance in the central nervous system

FMS is recognised by the various benefits agencies and there have been successful instances of sufferers claiming long-term medical insurance payments and pensions.

Fibromyalgia Association UK, a registered charity administered by Trustees, offers information and support to sufferers and carers, as well as co-ordinating 100 local groups throughout the UK, including Northern Ireland and Guernsey. FMAUK hosts a website, and operates two help-lines: one for general enquires; the other for benefits advice. Medical information is also available to healthcare professionals.
The Association is a member of the International Fibromyalgia Exchange (IFME) and the European Network of Fibromyalgia Associations.

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Background and History

Fibromyalgia has been around for a long time, even though it has only recently begun to be better understood and more and more people are being diagnosed with the condition.
Fibromyalgia was first thought to be inflamed areas in fibrous tissue or fascia that surrounds muscles and bind them together. The fascia is like a glove covering a hand. The hand is the muscle, and the glove is the fascia.

Subsequently, sophisticated microscopic studies were performed, and they reported that there was no actual inflammation with the muscles or connective tissue. If we were to look at your muscles under a microscope, we would not see evidence of muscle disease; in fact, the muscles themselves function normally, or have normal strength. But your muscles are painful, and this pain has certain characteristics, which make up a specific syndrome, the Fibromyalgia Syndrome.

The cause of Fibromyalgia is unknown, but recent medical research has provided some clues about the factors that may contribute to this syndrome. We use the word 'syndrome' instead of disease because, unlike a ruptured disc, which can cause a pinched nerve, or arthritis, which is a disease of the joints, Fibromyalgia is not paralysing or deforming

Because this syndrome can cause symptoms resembling a pinched nerve or arthritis, those with Fibromyalgia often mistake it for a more serious disease. Even though Fibromyalgia is not a destructive disease, it causes painful symptoms that can vary from mildly annoying to severely incapacitating. And though there is no true inflammation, as recent medical research shows, the pain is very real, and definite characteristics can be identified with Fibromyalgia.

American College of Rheumatology develops criteria to make diagnosis

In the past 30 years, there has been a renewed interest in studying this condition. In 1981, Dr.Yunus developed criteria, which were used as a standard to objectively diagnose Fibromyalgia. A virtual explosion of research has occurred in the past decades, mainly in America. In 1989, investigators world-wide convened in Minneapolis, MN for the first international myofascial pain and Fibromyalgia symposium to present research and share knowledge. In 1990 the American College of Rheumatology devised updated Fibromyalgia criteria based on a multi-regional study. These criteria include:

- History of Widespread pain lasting over three months.
- Pain in 11 of 18 distinct tender point sites on palpation or pressure with a finger.

Other muscles and soft tissue areas may be tender in addition to these 18 areas described in the criteria. The criteria attempts to establish strict findings for diagnosing generalised Fibromyalgia in those who have muscle pain. In 1992, the Second International Myofascial Pain and Fibromyalgia Symposium was held in Copenhagen, Denmark attracting over 500 medical professionals throughout the world interested in Fibromyalgia. As a result of this symposium a document called the "Copenhagen Agreement" was formulated. Sufferers have used it to provide documentary evidence when applying for state benefits and to show unsympathetic GP's that Fibromyalgia does exist and is not "all in the sufferer's head".

Fibromyalgia has been termed "the invisible condition"

Fibromyalgia is now recognised as a distinct medical condition with characteristic findings. The Department of Health has produced a two-page document all about FMS; this is something to which all GP's should have access. In 1995, a third Symposium was held in San Antonio, Texas, and a Fourth Symposium was scheduled in 1998 in Italy.

We are all aware that even at this present time there is still a lot of controversy about Fibromyalgia, why is this? This is because the original theory that an inflammation existed was incorrect; many doctors falsely concluded that Fibromyalgia was not a legitimate condition. These doctors suggested that the symptoms were "all in the head." In fact, many physicians use the term "psychogenic rheumatism" to describe Fibromyalgia.

Routine laboratory studies and x-rays will all be normal with this condition. No disease is found in the bones or nerves. Because routine tests are normal does not mean that Fibromyalgia does not exist, or that all of the tests will be normal. Sleep studies, electron microscopy studies, muscle oxygenation tests, and other sophisticated studies have been shown to be abnormal in persons with Fibromyalgia. These tests are mostly carried out in America, where their health scheme is very different to our NHS. These special tests are very expensive. Therefore, they are are not considered part of the routine testing for individuals with muscle pain, even though they would be abnormal if the person had Fibromyalgia.

Just because there are no routine lab abnormalities, and the only readily observable indicators of Fibromyalgia are "tender points," does not mean that there are no problems. Tender points and normal lab results are exactly what we expect to find with Fibromyalgia. To an experienced examiner, tender points are still the "signature" findings of Fibromyalgia.

Fibromyalgia has been termed "the invisible condition," because the muscles appear normal and no obvious abnormalities are evident when looking at an individual with this syndrome. Fibromyalgia muscles may look good on the outside, but they are definitely hurting on the inside.

Characteristics of Fibromyalgia

Anyone can get Fibromyalgia. Worldwide, up to 2 or more of the population has this condition, so it is very common, and it affects millions and millions of people. Currently it is diagnosed about 9 times more in women than men. Children can also have Fibromyalgia, although the condition usually first causes symptoms between ages20 and 45.

Normally, the symptoms have been present for years even though the diagnosis may not have been made until after ages 50-65. A rheumatologist or "Fibro Friendly G.P" can make an actual diagnosis of Fibromyalgia. Many people have Fibromyalgia who have yet to see a medical professional and be diagnosed.

Fibromyalgia pain is usually described as a chronic, generalised aching, with certain areas that may feel like tingling, or sharp, stabbing sensations. The pain may radiate or travel to different locations. For example, areas of discomfort in the upper back may cause numbness and tenderness in the arm, even though there is no problem per se, in the arm.

A person with Fibromyalgia can often point to the exact area or areas of discomfort and note that a particular area is very tender to touch. The pain may "wander" to different sites. The pain can also flare up suddenly for no apparent reason. The muscles are not the only sore areas. Other soft tissues such as ligaments, tendons, and bursa can be sore.

Since different locations and sites can be painful with Fibromyalgia, it is important to always be certain that the cause of the pain or discomfort is in fact Fibromyalgia and not another medical condition.

For example, a common area of pain in Fibromyalgia is in the sternum or breastplate where the ribs attach. This is called costochondritis. It can mimic heart pain, but there is nothing wrong with the heart. It is always a priority to get the more urgent possible medical problems checked out first, by medical professionals.

Be safe. Do not assume symptoms are from Fibromyalgia unless a physician has properly diagnosed you. The golden rule has got to be if you are experiencing any new symptoms, please get them checked out by a medical professional. If you are not happy with what your GP has to say, you are perfectly within your rights to ask for a second opinion.

Chronic Generalised Pain

Fibromyalgia is classified as a syndrome. The chief complaint of Fibromyalgia is pain. The pain can cause functional limitations varying from mild to incapacitating. This pain is in the muscles, tendons, ligaments, bursa and sometimes feels as if it is in the joints.

This is mostly related to pain at the muscle and tendon insertions into the joint area and is not a reflection of actual joint pathology or inflammation. The pain may be described as a constant ache or throbbing.

Typical pain locations include the head, neck, shoulders (especially between shoulder blades), and lower back and hip muscles. Chest pain can be a problem especially for larger busted women. Certain areas may cause sharp stabbing pain, and these areas are sensitive to touch. The body's process of monitoring pain, recording pain, and expressing pain is an energy consuming process that involves nerves, neurotransmitters and other various enzymes and hormones.

Most of the time, there is no clear reason why the pain occurs; that is, there has been no specific illness or trauma. In one third or more of Fibromyalgia cases, some type of event either an injury like whiplash, or sometimes a viral illness such as flu like illness, precipitated the Fibromyalgia condition.

Usually the pain begins in one location, such as the shoulder, but over time, it begins to involve more and more other areas until it is no longer localised, but rather generalised throughout the body.

A person in constant pain will use up more energy and have less stored energy

Pain may wander to different sites; the lower back may be sore one day, and then the next day the neck hurts! These wandering symptoms may lead you to think you are losing your mind, Fibromyalgia, indeed, causes wandering pain.

A person in constant pain will use up more energy and have less stored energy, than a person without constant pain. Studies have shown that muscles in people with Fibromyalgia do not use oxygen as well as normal muscles. Lack of oxygen usually sends a signal of pain.

Morning Stiffness

Most people with fibromyalgia report morning stiffness, usually lasting a few hours.

They feel somewhat ‘looser’ and better during the late morning to early evening, and then have more pain again in the evening. Most would say the worst time o f the day is in the morning. Instead of waking up refreshed and pain-free, we wake up tired, stiff and sore!

Once we get going, our muscles loosen up within a few hours, and we are fairly mobile, until later in the day. The morning stiffness may be particularly bad the day after doing strenuous or unusual activities, or the weather changes to a cold damp morning

Fatigue & Poor Sleep

Fatigue is a major complaint with those who have fibromyalgia. Poor sleep certainly contributes to this problem, but persons with fibromyalgia will often indicate they have no energy whatsoever, cannot get motivated to do various projects, and would rather lie down and go to sleep.

Poor sleep is a hallmark in nearly everyone with fibromyalgia. Many people report that the quality of their sleep is poor even though they may sleep for eight hours, and when they awaken in the morning, they do not feel well rested. Sleep may be characterized by frequent awakening especially in the early morning hours and lack of deep, sound sleep. This disturbed and non-restorative sleep pattern is typical of people with fibromyalgia.

Sleep studies using monitors measuring brain waves of sleeping individuals have found that there is an abnormality in the deep sleep stage. This lack of deep sleep accounts for the feeling that our sleep is non-restorative, or that our battery did not "get recharged “during the night.

There are doctors who consider fibromyalgia and chronic fatigue syndrome as the same thing. Some doctors treat both the same way. Fatigue is more of a major factor in chronic fatigue syndrome.

Poor sleep is a hallmark in nearly everyone with fibromyalgia

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Numbness

There may be tingling, numbness, or feelings of heat or cold with Fibromyalgia. These abnormal sensations are called paraesthesia and may radiate or travel to different locations. For example, painful muscle areas in the upper back may cause arms to become painful and tingling even though no problem in the arm is present. The skin is also described as extremely sensitive and painful in many people with Fibromyalgia.

Weakness

Fibromyalgia causes the muscles to be tight, stringy, and to have inconsistent localized spasms. Fibromyalgia muscles do not use oxygen well and have decreased energy compounds, fatigue is a major problem. The muscles, therefore, are painful, tight, and easily fatigued. When we attempt to exercise, muscles often respond by increasing pain.

Negative painful experiences may lead to decreased motivation and decreased activity or exercise phobias. A cycle of increased muscle tightness, spasms, and increased pain starts over again, which can lead you to sink deeper and deeper into a painful condition state.

A person in constant pain will use up more energy and have less stored energy than a person without constant pain. This causes fatigue. The body usually signals pain when there is a lack of oxygen, and, as mentioned, Fibromyalgia muscles do not use oxygen well.

Also, muscles have less access to oxygen because they are always contracted and therefore have limited blood supply. Some weakness can be attributed to the muscles being so tight.

One of the most important things for a person with Fibromyalgia to do is to stretch. Since Fibromyalgia muscles are so tight, they are more vulnerable to strains, so it is especially important to counteract this tightness mechanism by stretching,

One of the most important things a person with Fibromyalgia can do is stretch

BUT it is important to remember to warm up the muscles before you begin your stretching routine. Taking a warm bath, standing under a hot shower or by gently marching on the spot, can do this. An excellent routine to follow is the one compiled by Dr Sharon Clark, which is especially for people with FMS. Stretching increases muscle flexibility which in turn leads to decreased pain and decreased vulnerability to injuries or strains.

Passive stretching exercises can involve different body parts; head, neck, trunk, upper body, lower back, hips, and legs. Most people with Fibromyalgia can learn self-passive stretching exercises to help the feeling of weakness, pain, and stiffness and swelling in their muscles.

The muscles, especially in the arms, can feel weak when doing isometric type activities. For Example, when holding the arms up to change a light bulb, the energy will feel like it is being drained from the arms and this will cause a sensation of weakness. This is due to the sustained contractions and the increased demand for oxygen that is needed by isometric activity.

Swelling

Weather changes can also cause Fibromyalgia symptoms to increase, especially if it is cold or damp. It appears that muscles act like weather barometers. When it is cold and damp, perhaps our muscles absorb more moisture or are more swollen or sensitive which may cause the increased pain. Whatever the reason, the majority of people with Fibromyalgia do better in warm, dry regions or during warmer, drier seasons. There are of course those who cannot tolerate heat and prefer cooler conditions. A woman with Fibromyalgia may notice increased swelling before her menstrual cycle. Fibromyalgia symptoms often do flare-up, just before menstruation. This may be related to increased muscle swelling during the fluid-retentive state of their menstrual cycle. In fact, the common pre-menstrual syndrome (PMS) is often more severe in women with fibromyalgia.

Joint Pain

Joint pain and stiffness are usually found in those with Fibromyalgia. This is mostly related to pain at the muscle and tendon insertions into the joint area and is not a reflection of actual joint pathology or inflammation.

Cold Intolerance

People with Fibromyalgia are very sensitive to weather changes especially cold, damp conditions and cold draughts. One major enemy is cold air conditioner draughts, which can exacerbate neck and shoulder pain.

Even if we are completely relaxed and enjoying ourselves, a cold draught on exposed skin overlying tender muscle areas can cause an automatic reflexive reaction, sending a signal to the muscles and causing muscle pain. In people with Fibromyalgia, the skin is very sensitive especially to cold air.

Likewise, cold water is a difficulty; problems arise in pools where the water temperature is lower than skin temperature. Swimming pool water temperatures should be at least 85° F (30° C).

Headaches

Anyone suffering with persistent or severe headaches should consult their doctor or GP immediately

Tension/migraine headaches: These are suffered by the majority of people with fibromyalgia. Also called muscle contraction headaches, they usually begin at the base of the neck and extend upward to the temples, forming a band-like squeezing headache. Migraine headaches are vascular in origin. Some events trigger blood vessels to the brain to constrict and then dilate, leading to severe headaches. Nausea, vomiting, eye pain, and other symptoms may also be associated with headaches.

Temporomandibular Joint or TMJ dysfunction (sometimes called TMD) causes jaw pain, dizziness, and 'head' or 'face' pain, a common associated condition of fibromyalgia.

Post-concussive syndrome: This occurs after a concussion, often part of post-traumatic fibromyalgia and severe whiplash injury. PCS can cause residual headaches, neck pain, and/or difficulty concentrating

Allergy flare-ups, with congestion or cold symptoms. In the USA some of the medical professionals believe that allergies are more common in people with fibromyalgia. This is not the case with the UK medical professionals; they believe that there is insufficient evidence to substantiate this claim.

Other causes can include:

- Referred pain from tender/trigger points in neck and shoulder areas.
- Side effects from medications used to treat fibromyalgia, for example; tricyclic antidepressants, beta-blockers, migraine headache medications, and muscle relaxants.
- Hormonal changes in women (women with fibromyalgia commonly experience headaches as part of the pre-menstrual syndrome (PMS) or menopause).
- Dry eye syndrome (common in fibromyalgia); may cause eye irritation and headaches; seen in one-third of those with fibromyalgia).
- Eye strain, (fibromyalgia pain and fatigue in eye muscles, causes headaches).

Sleep Disturbance in Fibromyalgia

How is it possible for sufferers to wake up in the morning feeling more tired than when they went to bed the night before? Some sufferers do not realise that this problem is recognised as one of the major symptoms of Fibromyalgia.

Many people with FMS do not progress through the five stages of sleep. They may go to sleep easily, but wake up early in the morning (3 to 5am) unable to go back to sleep, or to go back into deep sleep. Others may have difficulty getting to sleep and then have interruptions during the night.

Some even sleep through the night unaware of any difficulties, but may not be experiencing a deep restorative sleep. Other similar sleep scenarios are experienced by many people with Fibromyalgia.

Alpha-Delta Sleep Anomaly

This sleep disturbance in Fibromyalgia occurs in stage 4 of the sleep cycle. A disturbance in the brains' electrical activity occurs, resulting in arousal, preventing the normal progression through the sleep cycle.

The sleep disturbance is referred to by researchers as the Alpha-Delta sleep anomaly, a condition in which brief periods of awake-like brainwaves (alpha waves) interfere with deep level (delta wave) sleep. It can be described as a state of partial wakefulness within sleep itself.

When this disruption occurs in stage 4 of the sleep cycle the body is not restored during sleep, this non restorative sleep is believed to be associated with the pain, fatigue and other symptoms of Fibromyalgia.

While the Alpha-Delta Sleep Anomaly is the most common sleep disorder found in Fibromyalgia patients, it is not the only one. John Russell MD. Studied 44 Fibromyalgia patient and discovered the following sleep disorders: Alpha- Delta sleep anomaly (43%), Sleep Apnea (25%), Sleep Myoclonus (16%)(involuntary arm and leg jerking during the night) and Teeth Grinding (14%).

The Link Between Serotonin, Sleep and FMS

Serotonin is a major neurotransmitter (a chemical that helps nerves transmit their messages) which is essential for the induction of deep level, slow wave sleep. An important component of the sleep disturbance in Fibromyalgia involves serotonin.

People with Fibromyalgia have been found to have low levels of serotonin in their blood and spinal fluid. At this time doctors are prescribing medications that increase the availability of serotonin in the body, with the ultimate goal being an improvement in the patient's quality of sleep (more time in delta sleep) and reduced pain sensitivity.

More research must be done on the relationship between prescribed medications and the alpha-delta sleep anomaly. While these medications do influence the availability of serotonin the exact mechanism by which they operate is still not understood. There are still many questions to be answered.

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How To Improve The Quality Of Your Sleep

- Consult with your Doctor about the necessity of taking a medication to improve your sleep quality
- If you are experiencing morning grogginess while taking a medication to improve sleep quality, take the medication as early as 6 pm
- Allow time to wind down before bed
- Follow a bedtime ritual (i.e. a warm bath, relaxing music, reading)
- Eliminate caffeine after 12 noon
- Reduce or eliminate fluid intake after 6pm. if you have a need to urinate during the night. Medications such as diuretics and blood pressure medications that get rid of excess fluid should be taken earlier in the day, whenever possible (you will need to consult with your doctor first)
- Use relaxation tapes
- Develop a programme of gentle aerobic exercise, but avoid exercising in the evening
- Actively deal with problems that interfere with sleep (e.g. pain and discomfort, crying baby, uncomfortable mattress or pillow, snoring spouse, concern about issues etc)
- Seek treatment for depression, anxiety and/or stress if you are experiencing these
- Avoid taking a nap late in the day as it may be more difficult for you to go to sleep at your normal time, or you may sleep for a few hours, then find yourself awake and be unable to get back to sleep
- Don’t work in your bedroom
- A glass of milk before bed may be helpful

To Sleep Or Not To Sleep?!

Establish a routine. Go through the same routine each night and have a consistent bedtime regime. Prepare for bedtime by reducing your activity level several hours before bedtime, and by having ‘going-to-bed’ rituals, that you do consistently at the same time every night.

Things like a warm drink, brushing your teeth, taking your meds, and maybe a bit of light reading every night can help you wind down and get ready psychologically for sleep.

- Use your bed only as a place to sleep (Ahhem!.. erm there is one exception !) do not use your bed for other things….. such as eating, reading, paying bills or watching television. Avoid caffeine and alcohol within 6 hrs. of bedtime. Both can interfere with sleep.
- Get up and go into another room to read or do something else relaxing when you cannot sleep. Tossing and turning all night keeps the muscles tensed and active. This may also contribute to you waking in pain and feeling tired.
- When you begin to feel sleepy go to bed and try again, you may need to repeat this pattern several times during the night.
- Try to get some regular exercise during the day or early evening, to help you feel physically tired. This will help you sleep better, but be sure to finish exercising several hours before bedtime (Ahhem…erm there is one exception).
- Have a comfortable environment, try to provide yourself with a good mattress or mattress topper, and control light, noise and temperature (note: Noise, Ahhem….this includes snoring by your partner!).
- Limit daytime napping, unless this doesn’t disturb your sleep at night, in which case you may need more rest.
- Unwind and cleanse the mind, taking all your problems off to bed with you heightens anxiety and makes it difficult to relax, try writing down any issues and put them in a box, put the lid on and leave them till tomorrow.
- Set up a sleep schedule, based on the number of hours sleep you need per night (no less than 7 hrs a night) incorporate your bed-time rituals, and what time you need to get up. It makes it easier to work out when you should start your bedtime regime.
- Use relaxation or distraction techniques to fall asleep, such as concentrating on your breathing, peaceful calming background music.

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- Get up at the same time, setting an alarm so that you keep a routine by getting out of bed at the same time every day, can help you to adjust back to more normal hours

Tips To Help You Manage Your Pain

Not only is pain the main symptom of Fibromyalgia, it is a symptom that can be treated in a variety of ways. People with Fibromyalgia have different types of pain, so it is important to work with your Medical Professional to find out what treatment is best suited to your needs.

Sometimes multiple treatments are used at the same time, because they may have a better chance of reducing the pain more quickly. Fibromyalgic pain may not be the only pain that people with Fibromyalgia are experiencing- they may suffer with other types of pain too.

- Understand that medication is not the only tool for treating pain. There are many non-medical treatments that can be used to help ease fibromyalgic pain i.e. hot or cold treatments. Self-help measures can be used to help cope with symptoms i.e. self-supervised gentle exercise programme (start with gentle stretching) and eating a balanced diet.

- Set pain management goals and follow through on them. Pick your greatest pain problems and set goals to focus on each one.

- Check your progress, use a chart or log to mark your progress as you meet each goal, keep a list of what does (and doesn't !) work for you

- Plan each day, use a 'to do list 'or a schedule for exercise or other activities, but don't overdo it.

- Seek and accept support, from friends, family, support group members or carers, they can help keep you on track, and help on difficult days

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- Prepare for difficult situations, make a list of trouble areas with your pain, and create a plan. Being prepared can help to decrease anxiety and lessen stress. Try putting a remedy box together.
- Reward yourself, treat yourself to something nice when you reach a goal or complete a pain strategy. This will strengthen your positive attitude and your successes.
- Review treatment strategies from time to time. Discuss with your medical professionals what you have found works for you, and share it with support group members! If you are contemplating trying complementary therapies, discuss this with medical professionals before you begin treatments. Never just stop taking prescribed medication.
- Don’t be too hard on yourself, be patient and try to understand and accept that Fibromyalgia is not life threatening, and though it can be life changing, maintaining a positive attitude means this can sometimes be for the better.

Memory Problems and CRS (Can’t Remember Stuff!)

Many individuals with Fibromyalgia experience cognitive problems. Trying to remember a name, putting the wrong word in a sentence, forgetting what you have just been told five minutes ago, misplacing things, an inability to concentrate on reading, or studying are common complaints by many FMS patients.

Sometimes these problems in cognitive functioning are referred to as ‘fibro-fog’. When Fibromyalgia symptoms are flared, often memory and concentration problems will be more severe. It is not fully understood why this occurs, because the brain’s processing system is very complex.

It is known however that poor sleep quality exacerbates cognitive problems. As you recover from a flare, difficulties with memory and concentration should improve.

If cognitive problems are really extreme, sufferers should discuss these symptoms with their GP.

Tips For Coping With Memory Problems

- Use a desk calendar large enough to write in the activities you need to do each day. Or put reminders on your phone to alert you to appointments. Check it every day!
- Make a list of important phone numbers for each phone in the house. Tape it preferably next to the phone, so it won't 'walk away'.
- Keep a pad of paper next to your favourite chair, with a pen to jot down notes to yourself.
- Buy a pocket recording message player, that you can speak into and leave audio messages to yourself, but don't forget where you keep it!
- Talk to your Doctor about your memory problems, he/ she can determine if you need medication and/or if your depression is contributing to your memory problems
- Consider seeing your occupational therapist, these health professionals will often suggest excellent memory compensation techniques to use until your memory and concentration improve
- Exercise your mind. The more you do to use your mind, the more you may find your memory problems decrease. Do crossword puzzles, and try to read interesting articles or books
- Try to avoid taking verbal directions when travelling, keep a notepad handy on which to write directions and any other important information you need to remember
- Speak to your family and friends about your memory problems; it will save you some worry!
- Don't feel bad when you ask someone to repeat something they just said, tell them you have CRS (Can't Remember Stuff)!
- If your memory is interfering significantly with work, you may need to talk to your supervisor or someone in Human Resources Department. Explain the specific difficulties that you're having with your memory and ability to concentrate. Often it is better to get things out in the open. Allow yourself more time for projects at work, or make the decision to do some extra work at home
- Avoid stressful situations when you can, they often make memory problems worse

- Leave tasks that require concentrated effort for those times of the day and/or week when you feel better able
- Divide tasks into smaller portions. Do a little at a time and they will seem more manageable
- Keep Lists! Try to keep your lists in a planner or at a specific place in your home, for example on a desk or table in the kitchen or another room that you frequently inhabit. Some people find Post-it notes or coloured dot stickers as a memory joggers are helpful, or storing lists/reminders on a mobile phone.

You need to train yourself to follow a routine with easily misplaced items, strive for consistency. Once you have trained yourself, it will become automatic for you, and it will save you a lot of time and frustration. If you misplace something, you will ultimately find it so don’t be too hard on yourself, simply recognise that this is part of Fibromyalgia.

Being generally forgetful is part of FMS. Some people can do well with memory tricks, such as trying to associate a person’s name or something important, with a familiar object. Writing things down forces you to focus on things you want to remember. Experiment to find out what your best memory technique is and use it, Fibromyalgia will give you plenty of opportunities to do this! You should also give yourself ‘permission’ to forget!!

If you misplace something you will ultimately find it so don’t be too hard on yourself

You can train yourself to stop and review what you have to do, and where you have to go before leaving the house. That way you sometimes can remember things you may have forgotten

Try to go through files, drawers, wardrobes, cupboards etc. regularly, to get rid of unneeded clutter that just frustrates you, with the goal of keeping everything simple and pared down to essentials

At times you may need to decrease your sensory input (noise, lights, and interruptions) and give your body/mind a chance to restore communication links. Sometimes decreasing sensory input helps, that’s one of the reasons we often need to turn off the radio in the car, it’s easier to concentrate with fewer distractions.

Coping Day To Day

Do you ever feel that this is just a test life? If it were a real life, surely you would have been issued a lifetime-guaranteed working body and instructions on how to use it!

At times every day may seem to you to be an obstacle course; a perverse game you play where the rules keep changing, and no one can tell you what they are.

One of your first tasks is learning how to cope on a day to day basis, is to accept the fact that you have FMS.

This is a Major Loss. Life as you knew it is over, but a new one is beginning. In many ways you can mould that life to be just as good as or even better than the one you had.

Rather than dwell on what has been lost, focus on optimising the quality of your life. Learn to live in the present. Sir William Osler, one of my favourite quotable doctors in history, said that the best way to live to a healthy old age, is to get a chronic disease and take care of it. Well you've already done the first part, so let's get to work and tackle the second.

Some days the constant grind of chronic pain will really get you down; you can take some small comfort in knowing you are not alone. When you feel so low you could walk under a duck, be assured that there are many other people with FMS right down there with you. When times are tough, be gentle with yourself.

Accept that whatever you can accomplish is deserving of recognition and praise. Those of us who have already run the first stages of the obstacle course are here to help you. This section will supply you with some tools to help remove some of the obstacles, minimize some of the others, and help you over the rest.

Coping With Mornings

Like most people with FMS, you probably have problems with mornings. ‘Fibrofog’ envelops you. You cannot remember things. Items you think you have a firm grip on, go flying across the room. You may always have been a ‘morning person’, but now your body and mind seem to be feuding, and every day you need to negotiate a truce before you can begin to function.

Some Simple Steps To Take The Night Before

You can make things easier for yourself in the mornings, by taking a few simple steps:

- Start your morning the night before, try to make a list of those things you want to accomplish the next day. Then even if you’re ‘foggy’ in the morning, you can usually start on something, and give your mind a chance to catch up.
- Some days the best thing to do is first to go through the list and figure out what you can put off until another day!
- Set out your medication and vitamins for the next day. Put them in separate little containers, morning, noon, and night. That way you’ll never have to try to scramble under the bed for dropped pills, and you’ll only have to deal with one set of pills in the morning.
- Set out your clothes the night before. That saves a lot of time because it’s one less decision to make in the morning, you might want to also put out an alternative set, in case you swell a size or two overnight, or spill something on the first set!
- Prepare as much as possible for the next day so you can live that day as well as possible.

Morning Stiffness

Many individuals with Fibromyalgia experience stiffness in the morning when they get out of bed. Muscle stiffness can also recur throughout the day, especially after being in one position for an extended period of time.

- Choose easy-care clothing and hairstyles, dress for comfort
- Simplify your morning routine as much as possible
- Always allow extra time to get ready in the morning, Avoid rushing when you are stiff and in pain
- When you get out of bed take a hot bath or shower to relieve pain and loosen up muscles and joints, then stretch gently, do a range of motion stretching exercises
- Hot paraffin wax may help relieve stiffness in your hands and fingers
- Take medication on awakening to reduce pain, you may even want to set an alarm early to take your medication, and then go back to sleep
- Whenever possible adjust your routine to accommodate morning stiffness, you may need to schedule early morning activities later in your day
- Isotone gloves (turned inside out) have been found to help reduce swelling in the hands when worn at night
- Cushioned resting splints worn at night help to reduce swelling, pain and stiffness in the morning
- Upon waking slip on shoes with cushioning, like aerobic or walking shoes. They provide support and cushioning to stiff painful feet
- Use adaptive equipment with easy grip handles, building them up with adhesive foam, foam curlers or pipe insulation. Consider building up toothbrushes, hairbrushes, steering wheel etc.
- Report how long you are stiff in the morning to your Doctor, this information is important to know in planning your care
- Ask for help from family members, let them zip up back zips, assist with breakfast and help with other morning tasks

Starting The Day

As your day begins, survey what lies before you. Think of all the good things that can happen. Then do everything in your power to make them happen. Plan on eating breakfast, and keep it simple, it's hard enough to move in the morning, preparing a meal first thing may be more than you can handle and it could start the day off on a bad note. Collect easy, one-dish recipes.

Helping Yourself Through The Day

You'll encounter numerous obstacles during a normal day. Here are some of the things you can do about them.

- If you're feeling irritable, tackle a small task, or a portion of a task that can be accomplished easily. Reaching the goal will cheer you up
- Time or your sense of it, is often one of your biggest stressors. Your hours are precious, but you may forget to use them as treasures. There will be days when you feel like someone is behind you cracking a whip, too often the culprit is you, so scale down your expectations
- Live in the present. The past is gone. You don't know what the future holds. Arrange priorities, simplify, delegate, delete. Allow time for 'being', rather than 'doing'. Don't live for today; just live today
- Call a friend you haven't seen for a while, find a reason to laugh together
- Schedule blocks of rest time for you. Acknowledge your limits. If at all possible lie down at intervals throughout the day. Your muscles are constantly working to hold your head up, they deserve a rest. Take a soothing bath
- At the end of the day review what you have accomplished. Resting, physical therapy, and exercise are noteworthy accomplishments

Information gathered from extracts taken from;' Fibromyalgia & Chronic Myofascial Pain Syndrome' A survival manual by Devin Starlanyl MD & Mary Ellen Copeland MS MA & ' Taking Charge of Fibromyalgia' by Julie Kelly MS. RN. & Rosalie Devonshire

Flare Management

What is meant by an FMS Flare?

When you are experiencing an FMS flare for the first time, your whole body may feel as if it's screaming for your attention. You may experience new symptoms, as well as all of the old ones, and they may be amplified.

A flare is a time of high intensity pain, in your trigger and tender points that can either creep up on you or hit you suddenly. Flare, like a flash fire, is all consuming.

What causes a flare?

Flares are usually triggered by one or more activities or stressors. It may be something very small, such as a virus or a yeast infection, or something large, such as a traffic accident.

The stressor could be as complex as a divorce, or as simple as playing a game of football, a menstrual period, a dip in a swimming pool that is too cold, a draught or sudden change in temperature, or the onset of an allergy, i.e. hay-fever; any one of these , alone, or working together can cause a major flare.

It is possible for a person with Fibromyalgia (FMS)/ Myofascial Pain Syndrome (MPS)* complex, to suffer a severe flare, after an upper respiratory infection or an allergy attack. Some Fibromites have an unusual amount of histamine, which may be a factor in setting off a flare

A flare is a time of high intensity pain. Like a flash fire, a flare is all consuming

Myofascial Pain Syndrome is a neuromuscular condition, which happens because of mechanical failures. It is a painful musculoskeletal condition, a common cause of musculoskeletal pain.

MPS is characterised by the development of Myofascial trigger points (TrPs) that are locally tender when active, and refer pain through specific patterns to other areas of the body. A trigger point or a sensitive painful area of the muscle or the junction of the muscle and fascia (hence Myofascial pain) develops due to any number of causes.

Trigger points are usually associated with a taut band, a ropey thickening of the muscle tissue. Typically a trigger point, when pressed upon, will cause the pain to be felt elsewhere. This is what is considered "referred pain".

*Many people suffer with both Fibromyalgia and Myofascial pain dysfunction syndrome (termed FMS/MPS Complex). Dr Janet Travell, believes that in some sufferers Fibromyalgia seems to trigger Myofascial Pain Syndrome.

What Are The Signs Of An Approaching Flare?

Flare has a way of creeping up on you, when you aren't expecting it, but in time, when you are completely 'au fait' with FMS, your body will give you clues as to when you are once again on the verge of a major flare.

Jerks and spasms of the body often indicate that the muscles aren't getting enough oxygen, and these symptoms increase before a flare. In addition you may experience one or more of the following symptoms:

- Your muscle strength may become unreliable, and you may drop things more often than usual. You may also be aware of weakness during certain movements, such as pouring liquids, turning a doorknob, opening jars and cans. This occurs because the muscle involved has learned to limit the force of its contraction to below the pain threshold, as a result it starts compensating and restricting certain movements.
- An involved extremity, may feel cold compared with the other one, due to constriction of the blood vessels.
- You may feel frequent dizziness when you change your posture, this could be restricted to when you get up from lying down, or it could happen every time you move your head. Some people can't walk without feeling that they are falling forward.
- Spatial disorientation is another symptom. You can no longer tell where you are in relation to the world around you. You bump into walls, fall over kerbs. You may find it necessary to restrict yourself to one floor level. Along with this or instead of this, you may have distorted weight perception; it may be hard for you to judge the weight of objects you pick up. This can result in apparently throwing objects around.
- It may be increasingly difficult for you to feed yourself without spilling food; you may need to use straws to drink.
- Fibrofog and the inability to think clearly may become extreme. The fog may creep up and get so thick that you are unaware that you are in a flare
- Depression due to chronic pain may worsen, as may the pain itself.

When you are in a flare, your judgement can be seriously impaired

Preventing Flare

You can use the time between flares to take action that will improve your chances of avoiding flare in the future. You can draw up a management plan for future flare. By doing this it may help you to identify actions or processes which previously sent you into a flare. The following suggestions may help prevent or minimise flares before they appear.

- Avoid any unnecessary changes in your life
- Improve the quality of life by practicing healthy living
- Make contact with your care team, family and supporters; explain to them how they can help a when flare strikes, this is important because flare can often creep in undetected and because of the growing fibrofog, you may find yourself in deep flare before you know it. It is important to educate your family so that they can help you when you may not recognise the symptoms of a flare yourself.
- Try to arrange for extra appointments with your healthcare team, doctor, physiotherapist, complimentary therapist etc. when you really need their help.
- Allow yourself extra time to do things
- Keep a quantity of extra food and other essentials in the house for when you feel that going out is too much for you. On good days, when you cook, make extra portions and freeze the surplus for times when you are unable to cook.
- Try to break down any problems into manageable units, and handle one unit at a time.
- Work on changing habits or strategies to those which make you feel better, but remember to make changes gradually.
- If your sleep has been disturbed by impending flare, try to rectify this, restorative sleep is essential. If you are exhausted give in to it, take a bath or hot shower, and try to take a nap. Read a good book, listen to soothing music, but remember, make sure that what you do is of a positive nature.
- Do not overdo anything if you feel that a flare is coming on. Spend your time having fun, this can sometimes help to avoid flare.
- Try to avoid any exposure to things that can be toxic to your body , i.e. stay away from people who smoke.

- Prepare for any potential problem, If you live alone, arrange to pay your bills by direct debit, this will eliminate the worry of forgetting to pay one and possibly having your utilities cut off!

Preparing For A Flare

Sometimes no matter how careful you are, things happen which create a flare. The best way of riding out a flare is to follow the plan that you have made to suit your own individual lifestyle and circumstances.

Make sure that your care team know what you will need if the flare becomes severe, and a plan of action to take on your behalf .Check that your plan includes information about:

- Healthcare Professionals who can be contacted.
- Treatments/extra medications to be used if flare/fibrofog becomes so severe that you can't make decisions for yourself
- If your condition needs to be closely monitored, make a list of any hospital facilities that you know might be appropriate.

Working Through Your Flare

Use the following suggestions to help you through it:

- Keep a positive outlook, keep telling yourself you will get out of it soon as you are in control
- Try to avoid doing anything at all strenuous, but at the same time do not become immobile
- Save your energy for what really must be done
- Be prepared to ask for help
- The key point is that you must be prepared to take ownership of your own flare management. If a flare comes in spite of your best efforts, be sure you have a plan in place to deal with it, always try to remain positive, and take good care of yourself.
- Remember you will get out of it and live to fight another day!

Exactly What Happens To The Body That Is Experiencing FMS/MPS Complex?

The FMS/MPS Connection: Some theories – extract taken from Fibromyalgia & Chronic Myofascial Pain Syndrome, A Survival Manual, by Devin Starlanyl MD & Mary Ellen Copeland MS. MA – chapter 5

To understand the FMS/MPS complex, we need to look at the big picture. Most of the body's processes rely on the unobstructed movement of fluids through the system:

- Blood circulates, carrying food, fuel, oxygen and other materials, it also carries away wastes.
- Lymph circulates, carrying fats, salts, proteins, white blood cells and other substances.
- On a microscopic level, every cell in the body depends on the motion of liquids from outside to inside the cell, and back. In one 'Star Trek' episode, an alien, called human beings "bags of dirty water". The description while quite unsavoury is quite correct. Your body depends on the motion of this dirty water, in and out of its cells.

Neurotransmitters activity determines the elasticity of the tissues, but in FMS/MPS, connective tissues become stiffened, shortened and tightened. That means that the fluid exchange is disrupted as well. This often starts with simple FMS.

In FMS, muscles in the area of the tender points that characterise FMS 'guard' the painful area. The myofascia forms a sort of splint, trying to minimise the pain. The body reacts to pain immediately because pain signifies damage, so the body goes into a self-protective stress mode.

The muscles around the tender points are in a state of sustained tension and they become tight and hard. This means they are working all the time, even when you are resting. When muscles are working their need for nutrition is greater, than when they are at rest, and they produce more wastes. But in FMS the sustained contraction hampers the delivery of fuel and oxygen and the removal of waste. In a relatively short space of time, the tender point can become a toxic waste dump- what we call a Myofascial trigger point.

FMS perpetuates MPS and the reverse is also true. This is a true 'catch 22' situation, you can't get rid of the MPS, until you successfully treat the FMS, and you can't successfully treat the FMS until you get rid of the MPS. They perpetuate each other. Then, too, chronic pain, all by itself, causes stress, which can create TrPs.

That’s another reason why so many cases of FMS are accompanied by MPS. The spiral of pain/contraction/pain/contraction continues until it is interrupted by an outside force, or by relief in some form. Don’t despair, a lot can be done to relieve MPS and lighten the pain load, and there are many things that work for FMS as well.

Fibromyalgia & Exercise, Why Do It?

You may feel unable to exercise, or afraid that it will make your pain worse. but the discomfort of exercise usually goes away within 30 minutes.

Exercise strengthens your muscles, lessens fatigue and helps lessen pain over time.

Fibromyalgia pain causes muscles to shorten and tighten. A daily programme of stretching helps warm the muscles by increasing blood flow and lengthening them, protecting you from the chance of injury.

You need to listen to your body, and let it tell you what it can handle and remember each individual reacts differently to different types of exercise. Lack of exercise can cause tight, painful muscles; can reduce functioning capacity of your cardiovascular system, and can cause weight gain.

Remember to choose activities that do not intensify your Fibromyalgia symptoms.

- Stretching can be your main form of exercise and should always be done before and after low impact and aerobic exercise (avoid exercises involving sustained repetitive motion as they can aggravate pain). As form of exercise, stretching should be done for several minutes each day.
- Breathing and relaxation exercises are excellent complements to a stretching programme
- Make sure that you warm up before starting any exercise by stretching or massaging your muscles, also to cool down afterwards to lessen soreness.
- Remember, all kinds of physical activities can be considered as exercise. Walking the dog, strolling to local shops, playing with children, walking up and down stairs several times a day, (and, Ahem…. while you are up there) can all keep you physically active, remember to just keep moving.
- Avoid cold water and cold or damp air when exercising. Hydrotherapy in a pool with a water temperature of 90 degrees allows your muscles to relax giving you the opportunity to move in a gravity-free environment, which is less taxing on joints and muscles.
- Break your exercise regime into tolerable sessions (four-5min walks rather that one 20 min walk) slowly increase each day, but remember to rest when you feel it's needed.

- Try to maintain good posture, keeping your head and shoulders up, protect your neck and shoulders from pain, and practice pulling your abdominal muscles in. When walking heel to toe, try to make sure that your shoulders are back.
- Set yourself exercise targets for the week; reward yourself when you achieve your goals. Consider exercising with a friend or joining a class for low impact exercise such as dancing, this will help increase your social interaction with other people.

Working With Medical Professionals

One of the most important members of your healthcare team is your Doctor.

His/Her job is to provide you with advice, treatment and hope. Your job is to help health care providers to help you. This shouldn’t be a one sided relationship, you cannot expect your doctor to wave a magic wand.

Recognise that will be inherent frustrations for patients and doctors when treating a condition that continues to hold mysteries for the researchers. There are constructive ways that you can help.

- Prepare for your appointment ahead of time to make the best use of the time with your doctor. Be sensitive to your own symptoms and concerns and give some thought to the questions you might ask.
- Take time to write down your questions and symptom complaints in an organised format, i.e. what the symptom is, how often you experience it, how it is affecting your life; if you have previously been prescribed medication, is it helping you cope with the symptom.
- If you are experiencing pain, keep a diary and record the level, on a scale of 1-10, duration, and location of the pain (use a body outline, and shade the areas).
- During surgery appts. be prepared to ask for what you need to manage your Fibromyalgia. Try to be concise (easier said than done I know!) and (even harder) not ramble.
- Remember that sharing information is important, but listening is just as important, ask your doctor to repeat or clarify information that is unclear and write things down. It is helpful to summarise your understanding of what the doctor has just told you.
- You can’t expect your Doctor to be your friend, but you can expect them to treat you with respect, and listen to your concerns and requests.
- As there is no magic bullet for Fibromyalgia, great patience is required to find a combination of therapies and medication to bring about improvement. Work with your doctor to develop a plan of action should you have a flare up, so you can initiate treatment on your own, i.e. can you increase your sleep medication or can you have a standby medication that works for you, with your existing

combination. What else can you do during a flare-up to reduce your symptoms? Consider other resources such as your pharmacist.

- Realise that much of your treatment is up to you; exercise, relaxation, stress management, pain management, and pursuing additional complimentary or holistic therapies such as massage.
- Your doctor can’t guarantee that a particular medication will work for you, but you can ask why he/she has recommended it and what they hope to accomplish by prescribing the drug.
- Consult your doctor if you feel that your symptoms require investigation, do not be tempted to put everything down to Fibromyalgia.
- Learn as much as you can about your illness, since you are the one who will manage the day to day problems that occur. Remember that you are in charge of your own treatment plan
- Don’t forget that even Non-prescription treatments (herbs, vitamins, supplements) can interact with prescription medications. It is better to be safe than sorry and let your doctor know about everything you are taking.
- Be respectful of the time constraints.

Why Join A Support Group?

When you suffer from an invisible illness (one where you don't look sick), it can be comforting to have the understanding and support of others who share the same challenges that you have to face. Finding support and becoming open to new adventures can make your journey through life easier.

Joining a Support Group can help you move on with your life. Instead of getting a blank stare when you explain your symptoms, others who have Fibromyalgia, will react with understanding because they have lived through similar experiences.

Most people with Fibromyalgia want reassurance that what they are experiencing is 'normal'. Reassurance can be a powerful therapeutic tool, and most find joining a support group to be an empowering experience.

A support group not only offers the opportunity to gather together with people who share similar situations, problems and symptoms, but also provides an opportunity to talk about your fears; you may find that many of them are unrealistic.

A support group provides education as well as providing emotional support. It allows participants to validate their common experiences through sharing information, whilst getting feedback and support.

The activities of the group are usually determined by the needs of the members, most can provide resources such as a group library, and help to find solutions to issues at hand. Joining a support group is a positive step, and can help you learn to deal with your illness in a positive way-rather than focusing on the negative issues.

A support group can provide education as well as emotional support

A support group promotes problem solving and encourages members to help one another. It is an excellent way to develop new relationships, and it is a wonderful place to make new and understanding friends, it also provides a place where personal information can be discussed in the confidence that the interaction is strictly confidential.

The element of social interaction encourages you to get out of the house and become less isolated. Volunteering to help with the running of the group is a great way to help you stop thinking about your own problems and feel good about helping others deal with theirs. It feels good to feel useful again, and helps to boost self-esteem.

The role of a Support group doesn't stop there; it can provide support and education for carers, family, friends and co-workers, helping them to understand the condition and therefore enabling them to provide support, and encouragement for the person with Fibromyalgia, as well as receiving support themselves from fellow carers.

No two groups are the same; some are informal, which involve a group sharing situation, where the general atmosphere is one of mutual trust. Others are more formal and consist of a co-ordinator and guest lecturers. Some others may fit in between the two, but generally whichever type you choose, the experience and focus should be a positive one.

Love Letter To Normals

By Claudia Marek

Here is my letter written to explain to family and friends what it's like to have fibromyalgia. It won't work miracles: it's hard to understand our illness from the outside looking in. But it is a start and can open the door to important dialogues. You are all welcome to use it, either as is, or as a basis for writing your own. Remember that you have a responsibility to tell those close to you what is wrong and communicate as clearly as you can how you feel and what you need. The best time to do that is when you are not upset!

Fibromyalgia isn't all in my head, and it isn't contagious. It doesn't turn into anything serious and nobody ever died from fibromyalgia (thought they might have wished they could on really awful days!!) If you want to read articles or books about fibromyalgia I can show you some that I think are good. If you just want to learn as we go along, that's fine too.

This is definitely going to be a process. The first step is for you to believe that there is an illness called fibromyalgia and that I have it. This may sound simple, but when you hear about my symptoms I don't want you to think I'm making this all up as I go along.

Fibromyalgia is a high maintenance condition with lots and lots of different kinds of symptoms. There's no way to just take a pill to make it go away, even for a little while. Sometimes a certain medication can make some of my symptoms more bearable. That's about the best I can hope for. Other times I may take a lot of medication and still won't feel any better. That's just the way it goes. I can't control how often I feel good or when I'm going to feel terrible.

Lots of people have been cutting new drugs advertisements out of magazines for me and I appreciate the thought, but I've seen them too. Look at the list of side effects and the few symptoms they help in return. Even in the best studies those expensive compounds didn't help over half the people who tried them. No matter how happy the people in the pictures look, there's still no miracle drug available.

There's no cure for fibromyalgia and it won't go away. If I am functioning normally, I am having a good day. This doesn't mean I'm getting better -- I suffer from chronic pain and fatigue for which there is no cure. I can have good days, several good weeks or even months. But a good morning can suddenly turn into a terrible afternoon. I get a feeling like someone has pulled out a plug and all my energy has just run out of my body. I might get more irritable before these flares, and suddenly get more sensitive to noise or just collapse from deadening fatigue. Weather changes can have a big effect on how I feel.

Other times there may be no warning, I may just suddenly feel awful. I can't warn you when this is likely to happen because there isn't any way for me to know.

Sometimes this is a real spoiler and I'm sorry. The sadness I feel for what my illness does to those around me is more than I can easily describe. You may remember me as a light-hearted fun loving person -- and it hurts me that I am no longer what I was.

Fibromyalgics have a different kind of pain that is hard to treat It is not caused by inflammation like an injury. It is not a constant ache in one place like a broken bone. It moves around my body daily and hourly and changes in severity and type. Sometimes it is dull and sometimes it is cramping or prickly. Sometimes it’s stabbing and excruciating.

If Eskimos have a hundred words for snow, fibromyalgics should have a hundred words for pain. Sometimes I just hurt all over like I've been beaten up or run over by a truck. Sometimes I feel too tired to lift up my arm.

Besides pain, I have muscle stiffness which is worse in the morning and evenings. Sometimes when I get up out of a chair I feel like I am ninety years old. I may have to ask you to help me up. I'm creaky and I'm klutzy. I trip over things no one can see, and I bump into the person I am walking with and I drop things and spill things because my fingers are stiff and my coordination is off. I just don't seem to connect the way I should. Hand-eye, foot- eye coordination, it's all off. I walk slowly up and down stairs because I'm stiff and I'm afraid I might fall. When there's no railing to hold on to, it's terrifying.

Because I feel bad most of the time, I am always pushing myself, and sometimes I just push myself too hard. When I do this, I pay the price. Sometimes I can summon the strength to do something special, but I will usually have to rest for a few days afterwards because my body can only make so much energy. I pay a big price for overdoing it, but sometimes I have to. I know it's hard for you to understand why I can do one thing and not another. It's important for you to believe me, and trust me about this. My limitations, like my pain and my other symptoms are invisible, but they are real.

Another problem I have is my memory and concentration which is called fibrofog. Short-term memory is the worst! I am constantly looking for things. I have no idea where I put down my purse, and I walk into rooms and have no idea why. Casualties are my keys which are always lost, my list of errands, which I write up and leave on the counter when I go out.

Even if I put notes around to remind myself of important things, I'm still liable to forget them. Don't worry, this is normal for fibromyalgics. Most of us are frightened that we are getting Alzheimer's. New kinds of brain scans have actually documented differences in our brains.

I mentioned my sensitivities earlier and I need to talk about them again, it’s more like I have an intolerance to everything! Noise, especially certain noises like the television or shrill noises can make me jittery and anxious. Smells like fish or some chemicals, or fragrances or perfume can give me headaches and nausea.

I also have a problem with heat and cold. It sounds like I'm never happy but that isn't it. These things make me physically ill. They stress me out and make my pain worse and I get exhausted. Sometimes I just need to get away from something, I just don't know how else to say it. I know sometimes this means I will have to go outside, or out to the car, or go home to sit alone and that's really all right.

I don't want or need you to give up doing what's important to you. That would only make me feel worse. Sometimes when I feel lousy I just want to be by myself. When I'm like this there's nothing you can do to make me feel better, so it's just better to let me be.

I have problems sleeping. Sometimes I get really restless and wake up and can't get back to sleep. Other times I fall into bed and sleep for fourteen hours and still be tired. Some nights I'll toss and turn and not be able to sleep at all. Every little thing will keep me awake. I'm sure that's confusing to be around, and I know there are times when my tossing and turning and getting up and down to go to the bathroom disturbs you. We can talk about solutions to this.

All these symptoms and the chemical changes in my brain from pain and fatigue can make me depressed as you'd imagine. I get angry and frustrated and I have mood swings. Sometimes I know I'm being unreasonable but I can't admit it. Sometimes I just want to pull the covers over my head and stay in bed. These emotions are all very strong and powerful.

I know this is a very hard thing about being with me. Every time you put up with me when I'm in one of my moods, secretly I'm grateful. I can't always admit it at the time, but I'm admitting it now. One thing I can tell you is it won't help to tell me I'm irrational. I know I am, but I can't help it when it's happening.

I have other symptoms like irritable bowel, muscle spasms and pelvic pain that will take their toll on our intimacies. Some of these symptoms are embarrassing and hard to talk about but I promise to try. I hope that you will have the patience to see me through these things. It's very hard for me too because I love you and I want to be with you, and it makes everything worse when you are upset and tired of dealing with all my problems.

I have made a promise to myself and now I am making it to you: I will set aside time for us to be close. During that time we will not talk about my illness. We both need time to get away from its demands. Though I may not always show it I love you a million times more for standing by me. Having to slow down physically and having to get rid of unnecessary stresses will make our relationship stronger.

CFS & FMS Symptom Comparison Table

Compiled by Melissa Kaplan 1999

Not everyone who has been diagnosed with CFS or FM - or both - will have every symptom listed below, nor will they have every symptom they do have all the time. That is the variable nature of this disorder. Symptoms may also wax and wane, getting worse or better, more prominent or maintaining a sort of constant background "noise" that goes on for so long that one begins accommodating it without thinking about it.

However, constantly having to deal with many of these symptoms puts a tremendous strain overall on the body, creating a state of constant stress on the immune system, organ function, and musculoskeletal system, making even the most minor and seemingly inconsequential activities of daily living (like getting up in the morning) so, difficult if not-or impossible- for so many for so long.

Treatment modalities directed towards mitigating specific symptoms or symptom clusters (such as improving the quality of sleep) should be looked at by everyone, regardless of whether they have been diagnosed with CFS or FM. While not everything works for everyone, and modalities that work for a time may cease working after a while, to ignore something because it doesn't bear the diagnostic label you were tagged with may result in your missing out on something that may help alleviate some significant symptoms and improve your quality of life.

You	CFS	FM	Symptom
	√		Activity level reduced to less than 50 of pre-onset level
	√		Allergies (nasal, other; increased or worsening)
	√		Blood pressure, low (below *110/70)*
	√	√	Bruxism (grinding/clenching teeth)
	√		Canker sores (frequent)
	√		Cardiac abnormalities (mitral valve prolapse; tachycardia; palpitations; dysrhythmia)
	√		Carpal tunnel syndrome
	√		Cold hands and feet
	√		Cough
	√		Dyspnea (out of breath) or shortness of breath (air hunger) after minimal or no exertion
	√		Flu-like symptoms, on-going or recurrent after initial gradual or acute onset; includes mild fever (99.5-101.5 F /37.5-38.6 C), chills, extreme fatigue after minimal exertion
	√		Endometriosis
	√	√	Fatigue, prolonged, disabling, made worse by exertion or stress
	√		Hair-loss (alopecia)
	√		Herpes simplex or shingles rash
	√		Hoarseness

	√		Impotence
	√		Low-grade fevers
	√		Lymph nodes painful, swollen (in neck; under arms)
	√	√	Morning stiffness
	√	√	Multiple chemical sensitivities (including perfumes, drugs, etc.)
		√	Night sweats(not
		√	Periodontal disease
		√	Sighing, frequent,
	√		Sore throat
	√		Symptoms worsened by extremes of temperature (hot, cold), stress, and/or air travel
	√		Temperature irregularities; often feeling hot or cold irrespective of actual ambient temperature and body temperature or low body temperature (below 97.6 F /36.4 C)
	√		Thirst, increased
	√		Thyroid inflammation (acute thyroiditis; hypothyroidism; Hashimoto's thyroiditis)
	√		Urination (frequent; uncomfortable); painful prostate
	√		Weight changes (usually

CENTRAL NERVOUS SYSTEM (CNS) SYMPTOMS

	√		Alcohol
	√	√	"Brainfog"; inability to think clearly
		√	Difficulty moving tongue to speak
	√	√	Fainting or blackouts; feeling like you might faint
	√	√	Headaches (severe, recurring)
	√		Libido (decreased)
	√	√	Migraine headaches
	√	√	Muscle twitching
	√		Severe muscle weakness
	√		Nightmares (frequent, extremely vivid)
	√	√	Numbness and tingling in face and extremities
	√		Paralysis or severe weakness of limb
	√	√	Photosensitivity
	√	√	Ringing in ears (tinnitus)
	√		Seizures; seizure-like episodes
		√	Sensory alterations (hyper- or hyposensitivity) - smell, taste, hearing (noise intolerance)
	√		Tremors, trembling
	√	√	Vision - frequent acuity changes (prescription changes frequently

EQUILIBRIUM/PERCEPTION

	√	√	Distances (difficulty judging when driving or when putting ‘things down on surfaces)
	√	√	Dizziness or vertigo
	√	√	Dropping things frequently
	√	√	Disequilibrium (balance problems)
	√	√	Impaired coordination

	√	√	Perception (not quite seeing what you are looking at)
	√	√	Staggering gait (clumsy walking; bumping into things)
PAIN SYMPTOMS			
	√	√	Abdominal pain
	√	√	Chest pain
	√	√	Generalized pain
	√	√	Joint pain, without redness or swelling
	√	√	Muscle pain, stiffness, weakness
	√	√	Temporomandibular Joint (TMJ/D) or Myofascial Pain Syndrome (MPS)
	√	√	Tender or trigger point pain or tenderness ("FM" stipulates 11 out of 18
			tender points)
PSYCHOLOGICAL SYMPTOMS/MOOD/EMOTIONS			
	√	√	Abrupt/Unpredictable mood swings
	√	√	Anxiety or fear for unknown reasons
	√	√	Appetite increase/decrease
	√	√	Depression or depressed mood
	√	√	Personality changes (labile, irritable, anxious, confused, forgetful)
	√	√	Decreased self-esteem
	√	√	Frequent crying for no reason
	√	√	Helpless/Hopeless feelings
	√	√	Irritability; overeaction; rage attacks for no reason
	√	√	New phobias/irrational fears
	√	√	Suicidal thoughts or suicide attempts
SLEEP SYMPTOMS			
	√	√	Abnormal brain activity in stage 4 sleep
	√	√	Altered sleep/wake patterns
	√	√	Difficulty falling or staying asleep
	√	√	Hypersomnia (excessive sleeping)
	√	√	Myclonus ("restless leg syndrome")
	√	√	Unrefreshing/Non-restorative sleep

Additional Symptoms You Have:

Common Fibromyalgia Symptoms

Physiological Problems

- Recurrent flu-like symptoms
- Recurrent sore throats/red infected
- Painful lymph nodes under arms and neck
- Muscle and joint aches with tender and trigger points-up to 18 of them
- Night sweats and fever
- Severe nasal (and other) allergies
- Irritable bowel symptoms (IBS)
- Weight change-usually gain
- Heart palpitations
- Mitral valve prolapse
- Severe PMS
- Yeast infections
- Rashes and itching
- Uncomfortable or frequent urination
- Interstitial bladder –cystitis
- Chest pains- non cardiac –costochondritis
- Temporomandibular joint dysfunction (TMD or TMJ)
- Hair loss
- Carpal Tunnel Syndrome
- Cold hand and feet
- Dry eyes and mouth
- Severe and debilitating fatigue
- Widespread pain
- Other chronic illness (es) usually present (like diabetes, hypoglycaemia, asthma, lupus, ME etc).
- Numbness in limbs
- Painful swelling in the hands, legs, feet and neck
- G.E.R.Ds (gastro-oesophageal reflux disorder)
- Growing pains that started in childhood, and often continued into teens or adulthood
- Widespread pain during/after physical exertion

PLEASE DO NOT SELF DIAGNOSE - ALWAYS CONSULT YOUR DOCTOR

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Cognitive Function Problems

- Attention deficit disorder
- Spatial disorientation
- Calculation difficulties
- Memory disturbance
- Communication difficulties (problems speaking, confusing words)

Psychological Problems

- Depression
- Anxiety and panic attacks
- Personality changes
- Emotional lability (mood swings)

Other Nervous System Problems

- Sleep disturbances (stage 4 sleep deprivation) sleep paralysis
- Headaches
- Changes in visual acuity
- Numb, tingling, or burning sensations
- Light headedness or dizzy spells
- Feeling ‘spaced out’
- Disequilibrium
- Frequent unusual nightmares and disturbing dreams
- Tinnitus (ringing in the ears)
- Difficulty moving tongue to speak
- Severe muscle weakness
- Susceptibility to muscle, tendon or ligament injury
- Intolerance to bright lights
- Intolerance to alcohol
- Intolerance to sound
- Intolerance to smell
- Alteration of taste smell and hearing
- Insomnia
- Morning stiffness in muscles and joints
- Restless leg Syndrome
- Muscle spasms, twitching and jerking
- Muscle tremor and shivering during/after activity or exercise

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Useful Contacts/Resources & Information

Below is a selection of useful web based resources covering UK, US and Europe. They are in no particular order, nor are they specific recommendations. Often there are links to treatments and medication which may offer to improve or indeed cure Fibromyalgia, but may have limited value to individual sufferers.

- http://www.fmauk.org The national charity for Fibromyalgia which provides information of national and international awareness events and latest trends in treatments across the world. Most of the UK support groups work with this organisation which operates through various regions controlled by an RC (regional co-ordinator) to whom enquires should be made for details of groups in their area. New support groups are encouraged to be set up.
- http://www.fibromyalgia-support.net The authors own web site which provides a wide range of useful information about Fibromyalgia as well as an interactive map of UK support groups. A useful section also explains how to set up a local support group and promote it.
- http://www.ukfibromyalgia.com is a commercial web site which has a wide range of up-to-date knowledge and information about Fibromyalgia as well as an online forum which is widely used. It also publishes in printed version the monthly magazine Family – specifically for Fibromyalgia sufferers and support groups. Back copies and free down loads are available. There is an up-to-date list of UK support groups by region.
- http://www.fibromyalgiasyndrome.co.uk The Fibromyalgia Syndrome website is designed and written to help support people with fibromyalgia, and their families, friends and colleagues. It provides an approachable and easy-to-read introduction to fibromyalgia syndrome, and gives no-nonsense information about living with this potentially long-term disorder.
- http://www.painsupport.co.uk Founded by Jan Sadler. Pain Support provides a wide range of advice and techniques about controlling pain generally, not just for Fibromyalgia sufferers. An online forum provides a wide range of experiences. http://www.controlpain-livelife.com Offers a free booklet "Control Pain Love Life" via download of a useful read for general pain.
- http://www.paintoolkit.org The Pain Toolkit is an excellent read for anyone with persistent pain. Besides the web resource you can download the Pain Toolkit from the site for later reference. Also available in French, German and Italian. There are an excellent range of links to other useful related pain control web sites.
- http://www.en.wikipedia.org/wiki/Fibromyalgia Wiki on Fibromyalgia. A Wiki is a series of linked web pages on a variety of subjects which people can contribute

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new and changed facts to. The Wiki community monitors pages so this link providessome useful and up-to-date information as well as providing links to Wiki pages on other related illness or treatments.

- http://www.afsafund.org The American Fibromyalgia Syndrome Association (AFSA) is a non-profit organization dedicated to research, education and patient advocacy for FMS (Fibromyalgia) and CFS (chronic fatigue syndrome).
- http://www.fibrocoalition.org Founded by Yvonne Keeny this is a US inspirational site about many people who have recovered or are much improved from Fibromyalgia, including the founder. Many useful newsletters packed with practical tips available at small cost
- http://www.fms-help.com Founded by Dominie Bush a Fibromyalgia survivor this US site lists 100 symptoms and 100 tips for coping with Fibromyalgia plus useful links and a free newsletter.
- http://enfa-europe.eu The European Network of Fibromyalgia Associations comprising members who provide a wide range of support services to sufferers within their individual country. Countries not represented may have a developing but potentially fragmented support network and may join ENFA later in their development.
- http://www.fmpartnership.org The National Fibromyalgia Partnership offers medically accurate information on the symptoms, diagnosis, treatment, and research of fibromyalgia.
- http://www.livingwithfm.com DVD documentary recounting the experience of 7 sufferers lives. An inspiring and educational journey. Many local support groups have a copy in their lending library.
- http://www.nfra.net The US National Fibromyalgia Research Association is a source for what's new in fibromyalgia.
- http://www.rheumatology.org The American College of Rheumatology mission is one of research, treatments and knowledge improvement which includes Fibromyalgia.
- http://www.who.int The World Health Organisation looks at Fibromyalgia and other illnesses and treatments worldwide.
- http://www.secretstorecovery.com looks at differences between CFS, ME and FMS, and offers a free e-book on the subject, although commercially based is of interest to those seeking a better understanding of the possible links.
- http://www.afme.org.uk Action for M.E - Improving the lives of people with M.E. M.E. is also known as Chronic Fatigue Syndrome (CFS). It is sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS).

- http://www.meassociation.org.uk provides information, support and practical advice for people who are affected by ME/ CFS/PVFS (Myalgic Encephalopathy/Chronic Fatigue Syndrome/Post Viral Fatigue Syndrome), their families and carers. They also fund and support research, and offer education and training

Home Based Business

If you are considering starting a home based business as an enforced alternative to traditional paid employment these organisations may provide useful help and advice.

- http://www.smallbusiness.co.uk a useful arrangement of news, and advice links for new business starters.
- http://www.businesslink.gov.uk The Governments' advice service for small business with sections for England, Northern Ireland, Scotland and Wales.
- http://www.thisismoney.co.uk/small-business A wide range of free financial advice including how to start a new business.
- http://www.freshbusinessthinking.com A useful service stimulating new ideas for business. Your local bank may offer free banking services for an initial period as well as access to advice and support. Open a separate business account and talk your ideas through with them.

Mobility Support And Aids

- http://www.mobilise.info Disabled motoring UK - help and advice for anyone who drives and who has a mobility problem including the Blue Badge parking scheme.
- http://www.boots.com Online catalogue of over 700 mobility aids to help people with reduced mobility problems.
- http://www.halfords.com Offers a range of mobility aids including mobility scooters, mobility wheelchairs and walking aids. Order for delivery or reserve and collect in store.
- http://www.benefitsnowshop.co.uk For aids to daily living, has over 16,000 products including mobility aids, bathroom aids, exercise products, kitchen and dining aids and many more. Separate site gives advice on claiming financial benefits.
- http://www.waysandmeans.co.uk Disability aids for daily living

Benefits And Finance Support

- http://www.benefitsnow.co.uk A comprehensive online resource for mobility benefits. Find out what is available via an online checker. Helps you understand the application process and dealing with appeals.
- http://www.turn2us.org.uk The charity Turn2us exists to help people access the money available to them - through benefits, grants and other financial help. Their free, accessible website has been designed to help people find appropriate sources of financial support, quickly and easily, based on their particular needs and circumstances.
- http://www.entitledto.co.uk People across the UK are missing out on benefits and tax credits worth more than £5 billion a year. 'Entitled to' can help make sure you get what is yours. Just use this simple calculator to work out how much you could claim.

These resource links above are provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnosis and treatment of any medical or health condition. The inclusion of any links or reference to a resource is not an endorsement or personal recommendation by the author or the publishers. Readers should take suitable advice and exercise good judgement when making decisions which may affect their health or finances.

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