

FIBROMYALGIA

General Introduction

Fibromyalgia (FM for short) is not a life threatening illness but is often life changing.

It does **not necessarily affect everyone in the same way**

It is a condition that is **often invisible to others**, however **research supports that FM is a distinct clinical condition.**

FM is **recognised by the Department of Health** and is listed on the **NHS Direct website.**

The **more you know** about the illness, **the easier it is to cope with.**

Possible feelings after Diagnosis:

relieved that you have been given a positive diagnosis **that something “real” is wrong with you.**

in “no man’s land” because you do not really know what your next step should be, or indeed **where to go to get information and help.**

What does the Word Fibromyalgia Mean?

Fibromyalgia is possibly a word that you have never heard of before. What does it mean?

Fibro = Fibrous Tissues (tendons & ligaments)

My = Muscle

Algia = Pain

What is Fibromyalgia?

Fibromyalgia is a condition of:

- **chronic widespread pain / chronic pain amplification**
- **fatigue**

The **pain** involves mainly:

muscles

tendons **tendons** hold muscles to bones.

ligaments **ligaments** hold bones together.

bursa a **bursa** is a fluid filled sac that decreases the friction over joints.

The muscle pain fluctuates and is often aggravated by:

- **various physical factors**
- **environmental factors**
- **emotional factors.**

In addition to widespread pain and fatigue, fibromyalgia syndrome can be associated with:

- **irritable bowel syndrome**
- **fluctuating stiffness**
- **numbness**
- **a feeling of weakness**
- **cold intolerance**
- **poor sleep**
- **headaches**
- **chest pain**
- **cognitive difficulties**
- **sensitivity to light, smells, temperature and sound**
- **dizziness (balance problems)**
- **anxiety/panic attacks**
- **as well as other symptoms**

It can be called a “Head to Toe” condition.

Fibromyalgia is NOT:

Fibromyalgia can cause symptoms that resemble arthritis or neurological disorders, but it is different from these disorders.

Unlike arthritis, **it does not cause the joints to swell or become deformed**, even though it may cause pain in the tissues or a feeling of swelling around a joint.

It does not cause paralysis or progressive neurological problems

It is not crippling

It is not a ruptured disc

It is not a pinched nerve, even though the symptoms may resemble those caused by a pinched nerve

It is not a tumour

It is not life threatening—despite what the pain may be telling you

It is not all in your head

It is not a mental health problem

It is not a “new” disease or some recent “medical” fad

It does not turn into one of the above mentioned conditions

However:

People with fibromyalgia may look okay on the outside, but are definitely hurting on the inside.

What are the Characteristics of Fibromyalgia?

- Seen in about 2% of the population, affects men, women, and children of all ages, races and economic levels, according to Government statistics 14,000 people are diagnosed annually.
- Onset of symptoms can be at any age, but mainly from 20-60 years of age.
- Mild to incapacitating, no two people are the same
- Variable chronic symptoms
- Pain changes location
- Affects women more than men in the ratio: 9 to 1

How Common is Fibromyalgia?

Fibromyalgia is a **common illness**. In fact, it is **as common as rheumatoid arthritis** and **can be more painful**.

People with mild to moderate cases of fibromyalgia are **usually able to live a near normal life**, given the appropriate treatment.

If a person's symptoms are **more severe** they may find that they

- **have to greatly modify their typical day,**
- **or find themselves not being able to hold on to a job**
- **or enjoy much of a social life**

What Causes Fibromyalgia?

Some **possible triggers** of FMS are:

- some sort of **trauma** such as a **fall or car accident**
- a **viral infection**
- **hormonal problems**
- **an operation**
- **muscle physiology problems—decreased oxygen supply to muscles may account for some of the pain mechanism**
- **or it begins without any obvious trigger.**

It is a **complicated condition**:

- which often has **more than one factor** involved
- **may even stem from a genetic predisposition**
- **triggers may be recognised, but the exact mechanism of how fibromyalgia**

- syndrome develops from any trigger is not fully known
- it is an “end point” condition with multiple paths leading to it.

Latest research has identified:

- a deficiency in Serotonin in the central nervous system and a resulting imbalance of Substance P (a transmitter substance that sends pain messages to the brain).

The effect of this is:

- disordered Sensory Processing (the brain registers pain, which is amplified, when others might experience a slight ache or stiffness).

Research now strongly indicates

- that a central nervous system dysfunction is primarily responsible for the increased pain sensitivity of FMS.

With these advances come the hope that a cause may be found and hence a cure, or at least more effective treatment.

Will the Pain Worsen?

People with fibromyalgia have physical abnormalities that result in pain amplification, causing pain to be perceived even when they are exposed to sensations that would not normally cause pain i.e. wearing certain items of clothing, a touch on the arm or even a bright light can cause extreme pain & fatigue.

- the pain usually consists of **generalised aching**, it can be described as **stabbing, burning, or even cramping**—a sense of “I hurt all over”
- certain parts of the body may be particularly painful
- the pain may move around and be accompanied by muscle spasm
- the pain can fluctuate from day to day, even hour to hour
- everyone with fibromyalgia syndrome will experience worsening of their pain from time to time; that is part of the illness
- usually the worsening is temporary, and is known as a flare-up, we can’t stop this from happening, some people have frequent flare-ups others don’t
- usually we can identify the cause of the increased pain, if not, we call the flare-up spontaneous
- sometimes flare-ups happen even when we have taken care to handle everything we do correctly
- we simply have to deal with them as they occur and try to accept that these intrusions are part of the condition

When you don’t feel well how do you know if it is because of Fibromyalgia or something else?

The impact of fibromyalgia differs in type and severity from person to person.

FM does not preclude the possibilities of you suffering from other medical conditions.

You should never assume that everything that you are experiencing or feeling is because of fibromyalgia.

Because FM is associated with:

- **widespread pain in all parts of the body**
- **including the chest and abdomen**
- **as well as severe fatigue**

it is **often difficult to know** whether symptoms are **related to FM or caused by another medical condition.**

Acute pains, shortness of breath, and high fevers are your body's warning signs which you should not ignore.

If you are experiencing any new symptoms:

“The GOLDEN RULE” must be to check them out with your own MEDICAL PROFESSIONALS.

Similarly if you feel that:

- the treatments
- medications

that you are receiving are not helping you manage your condition you will need to discuss this with your own **medical professionals.**

Fibromyalgia : It's Not All In Your Head

Source of information: [Food & Fitness Advisor, May, 2007](#)

Study undertaken by Dr. Daniel Clauw, a rheumatologist and Professor of Medicine at the University of Michigan, - Director of the Chronic Pain and Fatigue Research Center:

- **used functional MRI scans** to provide the first objective proof that fibromyalgia pain is real.

Clauw's study used the same number of patients with and without Fibromyalgia.

The study:

- applied a small amount of pressure to their left thumbs.
- **in the fibromyalgia patients, blood rushed to areas of the brain involved in pain perception.**
- the healthy volunteers might just as well have been getting a manicure. Clauw had to double the pressure on them to elicit the same pain response that he saw in the afflicted group.

Dr. Daniel Clauw believes:

- **in fibromyalgia, sensory messages to the brain are intensified**
- **countervailing messages from the brain are too weak to shut off the pain response**
- **the combined effect is to "turn up the volume on pain,"**

Women with fibromyalgia appear to have a lower pain threshold, stemming (in part) from overactive pain signal processing by the central nervous system caused by abnormalities in central brain structures.

Supporting evidence of a pain processing problem

- **is the fact that fibromyalgia responds to antidepressants called tricyclics, which dampen nerve pain, as well as to anticonvulsants.**

*The Arthritis Research Campaign also say:
Fibromyalgia is 'linked to abnormalities in blood flow to brain'*

The statement is based on new research by scientists from France using imaging techniques which has revealed, that symptoms of the disease are related to the areas of the brain where pain is processed.

Looking to the Future

- European Declaration on Fibromyalgia

The European Parliament is calling through this declaration, for the European Commission and the Council to:

- **help raise awareness of the condition and**
- **facilitate access to information for health professionals and patients, by supporting European and national awareness campaigns; to encourage Member States to improve access to diagnosis and treatment;**
- **facilitate research on fibromyalgia through the work programmes of the EU 7th Framework Programme for Research and future research programmes;**
- **facilitate the development of programmes for collecting data on fibromyalgia.**

Use of a Multidisciplinary Approach to Treat People with Fibromyalgia—

Educating healthcare professionals, patients and the public to promote better understanding and management of Fibromyalgia will benefit patients, healthcare providers and the society.

Recommendation

General

- **Full understanding of fibromyalgia** requires comprehensive assessment of pain, function, and psychosocial context. Fibromyalgia should be recognized as a complex and heterogeneous condition where there is abnormal pain processing and other secondary features.
- **Optimal treatment requires a multidisciplinary approach** with a combination of non-pharmacological and pharmacological treatment modalities **tailored according to pain intensity, function, associated features such as depression, fatigue and sleep disturbance in discussion with the patient.**

Non-Pharmacological Management

- **Heated pool treatment** with or without exercise is effective in fibromyalgia.
- **Individually tailored exercise programmes** including aerobic exercise and strength training can be beneficial to some patients with fibromyalgia.
- **Cognitive behavioural therapy** may be of benefit to some patients with fibromyalgia.
- Other therapies such as **relaxation, rehabilitation, physiotherapy and psychological support** may be used depending on the needs of the individual patient.

Suggestions for Survival Strategies for dealing with Fatigue

1. Try not to nap. Make sure your sleep time follows a regular schedule The chronic lack of sleep affects the overall health of a person with fibromyalgia as well as their pain. Improving sleep is an important part of easing fibromyalgia fatigue

2. Try to Reduce stress. Anything that reduces stress -- Yoga, Pilates, Meditation --

will help you It will also help normalise heart rate and blood pressure, so you feel better. Psychological therapy, relaxation exercises, visualisation, meditation, and biofeedback can help ease anxiety, tension, and stress which cause fatigue.

3. Start stretching. Several times a day, it's important to give tight muscles a good stretch. Before you get out of bed in the morning, start with stretching: move your head and neck, and your shoulders up and down. Make stretching a ritual. A warm bath can make the stretch more comfortable.

4. Practice “self –discipline”.

You only have so much energy per day—use it wisely.

5. Pace yourself. Moderation is important if you have fibromyalgia, “when people feel good”, they tend to do too much -- then pay the price later.

6. Work with your doctor and investigate whether there may be any underlying conditions that may be contributing to your fatigue.

7. Listen to your body. Rest before you get over-tired.

8. Strive to keep a sense of hope and well-being through understanding and knowledge. Take ownership of your fibromyalgia, do not let it take ownership of you.

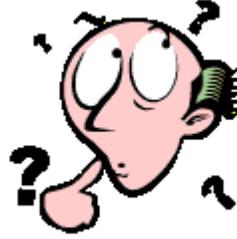
9. Volunteer work, hobbies and a social support network also make it easier living with fibromyalgia. So does a sense of humour.

10. Do what brings you happiness, and chances are it will help you refocus, get your focus away from the pain.

Websites for further information:

Fibromyalgia Association UK:	www.fmauk.org
NHS Direct:	www.nhsdirect.nhs.uk
Stress Management	www.patient.co.uk
Fibromyalgia & Sleep	www.prohealth.com www.fibromyalgiasupport.com
Fibromyalgia Support Diet & Nutrition	www.fibromyalgiasupport.com www.prohealth.com
General FM information, letter to relatives explaining how people with fibromyalgia feels	www.fibrohugs.com

Memory Problems:



CRS-Can't Remember Stuff!

Reference: Taking Charge of Fibromyalgia Julie Kelly, M.S.,R.N.
Rosalie Devonshire, M.S.W.

Many individuals with fibromyalgia experience cognitive problems. Trying to remember a name, putting the wrong word in a sentence, forgetting what your boss just told you to do 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 also 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 get better 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. Check it every day.

Make a list of important phone numbers for each phone in your house. Tape it to the wall or inside your cabinet so it doesn't "walk away," preferably right next to the phone.

Keep a pad of paper next to your favourite chair with a pen to jot down notes to yourself.

Buy a pocket recording message tape player that you can speak into and leave audio messages to yourself. Don't forget where you keep it!

Talk to your doctor about your memory problems. He or she can determine if you need medication and/or if depression is contributing to your memory problems.

Consider seeing an 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; you may find your memory problems decrease. Do crossword puzzles; try to read interesting articles or books.

Try to avoid taking oral directions when travelling by car. Keep a notepad handy on which to write directions and any other important information you need to remember.

Speak to your family 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 the Human Resources Department. Explain the specific difficulties that you're having with your memory and ability to concentrate. Often it's 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.

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 spot in your house. For example, on a desk or table in the kitchen or another room you frequently inhabit, such as the family room. Some individuals find that Post-It notes are helpful.

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. Plus it will save you a lot of time and frustration. If you misplace something, you will ultimately find it. Don't be too hard on yourself. Simply recognise that this is part of fibromyalgia.

Being generally forgetful is part of fibromyalgia. Some people can do well with memory tricks such as trying to associate a person's name or an object with a familiar

object or something important. Writing things down forces you to focus on things you want to remember. You should give yourself “permission” to forget. Experiment to find out what your best memory technique is and use it. Fibromyalgia will certainly give you many opportunities to do this.

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 anything you might have forgotten.

Try to go through files, drawers, and wardrobes 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 on our driving with fewer distractions.

Suggestions for Survival Strategies to help with Sleep

1. Try not to nap.

- If you **must take a nap** during the day **do not sleep for more than 30 minutes.**
- **Rest periods of 10 minutes without falling asleep** may help restore your energy level when you become tired during the day.
- Make sure your sleep time follows a regular schedule, this will help reset your biological clock.
- The chronic lack of sleep affects the overall health of a person with fibromyalgia as well as their pain.
- **Improving sleep is an important part of easing fibromyalgia fatigue**

2. Make your sleep environment as quiet, dark, and comfortable as possible.

- People with fibromyalgia are **very sensitive to light; blackout curtains or blinds may help** reduce the outside light.
- Keep your room **calm**, decorate your bedroom to make it a **relaxing place.**

- Do not paint the walls with bright colours or jam the room full of furniture and clutter.
- Hide your bedroom **clock** from your view
- Ban ticking clocks, shrill alarms could make you “jump” or make you feel tense.

3. Minimise the cold chills

- **Keep your limbs covered with long sleeves and long-legged clothing, and wear cotton socks to bed.**
- Athletic socks work well and keep your feet warm. The higher the socks, the warmer the legs.
- Put on mittens if your hands are cold. This warms the extremities and has something to do with blood vessel dilation, body temperature and increased blood flow through the body.
- **When you are warm it is easier to get to sleep.**
- **Don't wear uncomfortable nightclothes, make sure that they are not too tight or too restrictive, being uncomfortable will keep you awake.**

4. Make sure your bedroom is not too hot or too cold.

- **Try to avoid extreme temperatures.**
- Ensure your room is **well ventilated**,
- If possible have your window slightly open (make sure you are safe and can relax, being on guard will have an adverse affect on your sleep).

5. Protect your room from external noises and bright lights.

- Disconnect the telephone if it is likely to disturb your sleep.
- Wear ear plugs and/or sleep mask (eyeshades) if necessary.

6. Make sure you go to the bathroom right before you get into bed.

- This is important so that you hopefully won't have to get up in the middle of the night.

7. Don't work in your bedroom.

- Use your bedroom **only for sleeping and being physically close to your partner.**

8. Evaluate your sleep area:

- Check bed for comfort, firmness.
- Choose pillows to support neck & body.
- Consider an electric blanket or pad.
- Adjust room temperature (Ideal 72F).

9. If you cannot fall asleep after 20 minutes, get out of bed and do something besides trying to fall asleep.

- Concentrate on the pleasant feeling of relaxing.
- Do not expose yourself to bright lights whilst you are up because this will wake you up instead of helping you to go to sleep.

10. At bedtime keep your mind off worries or things that upset you:

- Avoid discussing emotional issues in bed.
- When in bed avoid watching stressful programmes on T.V.

Websites for further information:

Fibromyalgia Association UK:	www.fmauk.org
Breaking Through the Fibromyalgia Sleep Problem:	www.health.com
Sleep Disorders:	www.webmd.com
NHS Direct:	www.nhsdirect.nhs.uk
Stress Management:	www.patient.co.uk
Fibromyalgia & Sleep:	www.prohealth.com www.fibromyalgiasupport.com
Support & Comfort for Sleep-Challenged People:	www.nvo.com/isleepless
General FM information, letter to relatives explaining how people with fibromyalgia feels:	www.fibrohugs.com
Information from Dr Devin J. Starlanyl—what your medical team should know:	www.sover.net
National Fibromyalgia Association. An overview of fibromyalgia for newly diagnosed patients by Dr Robert Bennett:	http://fmaware.org/fminfo/overviewFP.htm

Fibromyalgia Sleep Hygiene:	www.med.ufl.edu
National Sleep Foundation:	www.sleepfoundation.org
Information for Carers:	www.carersuk.org www.direct.gov.uk/caringforsomeone
Myopain Society:	www.myopain.org

Notes about Pain - Ways to take Control

1. Know your enemy! Keep a pain diary

- When we experience pain, most of us try to ignore it.
- Keeping a pain diary can be very useful however, so that you and your doctor and other healthcare professionals know what they are dealing with - and what steps are needed.

There are many different forms of diary that you can keep, they can be as simple or complex as you like. Choose the type that you feel able to cope with.

Keeping a pain diary is useful for both you and the medical professionals you talk to. It will help you describe your pain more clearly, and help your doctor better understand what can be done to help. So when you next have an appointment, you will be able to tell your doctor about:

Where pain occurs

Where in your body is your pain being felt - such as your spine, hands, legs and so on?

Draw an outline of the human body and then working from head to toe write by the side of the appropriate part of the body all of the symptoms that you are experiencing i.e. if you experience headaches on the diagram draw a line from the head to the side of the page and write the word “headaches”

Type of pain

Describe the pain as best you can. For example, is it a shooting, throbbing, or aching

sensation? Other words people use to describe pain are numbing, stabbing, pins and needles, burning, constant, coming and going, deep, unbearable and so on.

- What words would you use to describe your pain ?

Examples are:

Dull ache	Tingling	Crushing
Nagging	Shooting	Pulsing
Stabbing	Sharp	Gnawing
Burning	Stinging	Cramping
<p>These words might help explain the kind of pain a person with fibromyalgia may experience</p> <p>They may help a person's medical professionals when they are choosing the best treatment for them.</p>		

When it occurs

Is there anything that triggers your pain?

For example does a certain activity, or time of day, or a feeling of anxiety worsen your pain?

QUESTIONS ABOUT YOUR PAIN

Think about how your pain makes you feel,

- Does the pain disturb your sleep?
- How is your appetite?
- What other problems are troubling you?
(e.g. nausea, constipation)
- When do you have pain?

- (e.g.: at rest or just when you move)
- What does your pain feel like?
(e.g. sharp, aching, numb)
 - What does your pain stop you from doing?
 - Why do you think you have the pain?
 - What makes your pain worse?

Severity

How bad is your pain? Rate your pain on a scale of 1-10, where 1 is no pain at all, and 10 is severe pain.

Duration

How long have you experienced this pain? Weeks or months, or years? And if it comes and goes, how long does an episode last? This could be a few minutes, or hours, for example.

What helps?

Certain medications you have been prescribed, or activities such as having a massage may help you feel better.

2 . Think positively

- Coping with pain can make it difficult to keep positive.
- Simple techniques like a morning reminder to think positively can make a huge difference.
- Making time for fun and laughter,
- Express your feelings can also help to switch negative thoughts to positive ones.

3.Focusing your mind away from pain

Taking your attention away from your pain can reduce its intensity. There are a variety of techniques people find helpful:

Pay attention to your breathing.

Whenever you feel discomfort, block it out by concentrating on your breathing pattern. This can help block pain and other distracting thoughts.

Relaxation is important.

Stress and anxiety may increase the pain you feel. Try to have a 20-minute relaxation session each day, to let your tensions go and help you keep positive. Relaxation exercises on tapes or CDs can help. Listen to some on www.calming.org

The Alexander Technique.

This teaches you how to perfect your posture so that you can stand, sit, and use a chair comfortably, to help your body move with greater ease. You learn how to get rid of harmful tension in your body. Many chronic pain sufferers have benefited from this technique, and your local college may run a course.

Massage.

A soothing massage can help you unwind and be a natural painkiller. Massage has also been shown to boost your immune system.

4. Plan for flare-ups

- Don't try to beat your pain by competing with it.
- Take control; try hot and cold packs on your painful area for a maximum of 3 x 3-minute periods.

5. Attend a Pain Management Clinic

- Talk to your GP about attending one of these clinics, as there may be one near your home.

6. Try to Get out of your pain cycle

- Do little and often. For example, rather than mowing all the lawn or doing all the ironing in one go, break it into smaller sessions throughout the week.
- Mix and match jobs that you do in any one day to avoid over-stressing one particular muscle group.
- Allow your body to stretch and move different muscles.
- Be sure to take short breaks between jobs.

7. Exercise daily

- Regular exercise is essential to help reduce pain.

- Ask your GP for more information about moderate exercise to keep pain at bay.

8 Maintain a healthy weight

- Losing weight will lessen the stress on your joints, and may make you feel better about yourself too.

9 Don't suffer in silence

- Nobody knows your pain better than you.
- If your medication is not helping you, talk to your doctor as there may well be a treatment that will help you more effectively.
- It is important not to stop taking a treatment without first discussing it with your doctor.

10. Consider complementary therapies

- **Keep your doctor informed about any therapies you wish to try before you undertake them.**
- **Many people find complementary therapies of benefit.**
- **Always make sure that the therapist that is going to give you the treatment is fully qualified and has knowledge of fibromyalgia.**

Don't forget to laugh

- Remaining positive in stressful situations doesn't mean that you are in denial.
- Laughter is a helpful mechanism and is thought to have all kinds of positive health effects.
- If you can't find humour in your situation, make time for things you do find funny, like your favourite TV comedy, a book, or just getting together with friends

Exercise – Why Do It?

You may not want to exercise because you are 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 must learn to listen to your body and let it tell you what it can handle. 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.**

1. Stretching can be your main form of exercise and should always be done before and after low-impact and aerobic forms of exercise (avoid activities involving sustained repetitive motion as they can aggravate fibromyalgia pain).

As a form of exercise, stretching should be done several minutes every day

2. Breathing and relaxation exercises are excellent complements to a stretching programme

3. Make sure that you warm up before starting any exercise by stretching or massaging your muscles. **Also, cool down afterwards to lessen muscle soreness.**

4. Remember, all kinds of physical activity can be considered exercise. Walking your dog, strolling through your local shopping centre, playing with children or walking up and down your staircase several times a day can all keep you physically active. **Remember to just keep moving!**

5. Avoid cold water and cold or damp air when exercising. Hydrotherapy (exercise in warm –water) exercise that takes place in a pool with a water temperature of 90⁰ allows your muscles to relax and gives you the opportunity to move in a gravity- free environment that is less taxing on your joints and muscles

6. Work with caregivers to choose an exercise program that stretches your muscles and also increases your endurance over time. Endurance is the ability to exercise longer than you used to be able to. **Together decide on the type and amount of exercise best for you. Choose low-impact exercise** such as walking, riding a stationary bike, and swimming. **This kind of exercise helps the painful muscles but will also make you**

feel and sleep better.

7. Break your exercise into tolerable sessions (four 5-minute walks rather than one 20-minute walk). Slowly start to do more each day. Rest when you feel it is needed.

8. Stand and walk using good posture by keeping your head and shoulders up. Also, hold your abdominal (belly) muscles in.

9. Protect your neck and shoulders from strain

10. When walking heel to toe make sure that your shoulders are back and that you are standing straight.

11. Set yourself exercise targets for the week and reward yourself if you achieve your goals—rewards could be having a massage, taking extra time to do something you enjoy doing i.e. reading.

12. You should think about exercising with a friend or maybe consider joining a low impact exercise class such as dancing, this will help eliminate your feeling of isolation and increase your social interaction with other people.

Working with Your Doctor

Tips based on information by Jenny Fransen, R.N.

Within the working relationship between you and your medical professionals you have responsibilities that need to be recognised in order for the partnership to work and for you to receive health care that meets your needs.

Prepare for the visit ahead of time to make the best use of your short time together:

- Provide concise, accurate information (e.g. if seeing a medical professional for the first time -medical history, current symptoms, sleep quality, current and past medications)
- Accurately report adverse fibromyalgia symptoms and any side effects of

medication. Use the information below to help record details that needs to be reported to your medical care team.

- Become educated about your condition – this will enable you to ask the appropriate questions
- **Be an active participant in your treatment.** (Listen, ask questions, give feedback, and follow through with treatment to the best of your ability.)
- **Be honest in expressing feelings and concerns.**

Be sensitive to your own symptoms and concerns and give some thought to the questions that you might ask your doctor.

Keep a list handy to jot questions down between visits to the surgery.

Consider other resources for information, such as your pharmacist for medication questions.

As there is no magic bullet for fibromyalgia, great patience is required to find a combination of therapies and medication to bring about improvement.

Recognise that there will be inherent frustrations for patients and doctors when treating a condition that continues to hold many mysteries for the researchers.

Realise much of your treatment is up to you: exercise, relaxation, stress management, pain management, pursuing additional therapies and treatments such as stretching and massage.

Learn as much as you can about your own illness, since you are the one who will manage the day-to-day problems that occur.

Actively manage fibromyalgia -related problems, such as pain, sleep problems, etc.

During surgery visits be prepared to ask for what you need to manage your fibromyalgia. Be as specific and as concise as possible. Don't ramble.

Work with your doctor to develop a plan of action should you have a flare-up so you can initiate treatment on your own. Can you increase your sleep medication or take ibuprofen for pain? What else can you do during a flare-up to reduce symptoms and feel better?

If you are having symptoms of depression, inform your doctor. Depression can

further disrupt sleep cycles and will need treatment.

Reinforce and thank the doctor for specific behaviours and techniques you find helpful "I appreciate that you really listen to me, Dr. Jones."

Learn to ask for what you need from your doctor. "Would you explain to me what could be done to help me sleep better?"

Develop a good relationship with the doctor's nurse and receptionist. Identify rules of the surgery: doctor's day off and when the best time is to call and leave a message. Know the nurse's name and ask for him/her when you call. Be patient if they are unable to call back immediately

Avoid angry or defensive communication.

If your physician has told you to return in three months, you can make an appointment earlier to discuss your questions or concerns if necessary.

If a problem arises with medication or treatment, ask if you can call for an answer rather than make another appointment.

Be assertive and take responsibility for your own treatment.

Remember you are in charge of your own treatment programme.

Tips for Travel

Travel while offering a break from everyday life, may also be the occasion of a flare in symptoms. What can you do to tip the balance in the direction of enjoyment and away from relapse?

1) Extra Rest: Before, During and After:

Travel requires more energy than everyday life, shrinking your available energy. If you don't adjust your activity level to match the lesser energy, you risk a flare up of symptoms. **The most common travel strategy is to take extra rest: before, during and after a trip.** Store up extra energy by taking extra rest before a trip (twice normal is often used); limit symptoms during a trip by taking extra rest while away; and take whatever extra rest is needed after to bring you back to normal.

2) Plan in Detail: Plan trips in great detail. Use books and the Internet to decide what you want to see, then set your itinerary based on how much activity you could do. Planning also involves packing ahead of time and, for some people, making arrangements to use wheelchairs or motorized carts in airports. Having a detailed itinerary set ahead of time can help you to resist the temptation to do too much when away from home.

3) Talk with Companions about Your Limits: People report having more enjoyable trips when they **talk to their travel companions ahead of time about their limits** and make a joint plan. Decide what you can do, then discuss your limits with others and decide on a plan. If you discuss your limits with others ahead of time, you can reduce the chances that they will be surprised or disappointed, and the chance they will pressure you to do more than you can handle.

4) Adjust Your Expectations: For some people, making mental adjustments is crucial. **Trying to do everything you used to do on a trip can lead to repeated crashes, you have to adjust your expectations to fit your body's new limits.** For example, plan to stay in one place for a while, taking time to recover from travel before beginning sightseeing. Keep schedules flexible to accommodate unforeseen events or higher than expected symptoms. Focus on what you *can* do, rather than what you cannot..

5) Pace Yourself: Alternate periods of activity with times for rest time, prioritise the activities you want to do. **Take a rest day between active days** or have a flexible schedule that allows more rest, if needed.

6) Opt Out of Some Activities: If your travel companions would like to do more than you, you can agree to do some things together and let them do other things on their own while you rest, but you can still meet later for dinner.

7) Use Creature Comforts: Ask what you need to be comfortable while travelling. Always carry a "Fibro Rescue Kit," a bag that contains medications, water for drinking and water to mist your face, snacks and Thermal-Care heat pads.

8) Use Mobility Aids: Use a motorised cart or wheelchair in airports. If flying, ask for assistance when you book your flight. There is no charge for this, you just have to ask. If you have a scooter you may wish to take it with you, if it can be stored in the boot of your car or checked as baggage.

9) Remember to Stop and Stretch:

Travel can be less taxing and less painful if it's interrupted. Stop and stretch periodically to keep supple and to avoid pain. Stop for a few minutes every half / to an hour, at least every two hours or so.

10) Become an Armchair Traveller or a Day Tripper: If long trips or plane rides are not possible, you can **seek out alternatives to travel. Become an armchair traveller** or take short trips near home. You could read books and magazines, and watch TV programs on places you are interested in. You can find interesting shows on the travel channel and even the food channel. They can take you to Europe and throughout the US, without the fatigue.

How to be a Fibromyalgia Survivor

Educate Yourself / Learn about the condition

Accept that you have fibromyalgia and it is **not life threatening, nor deforming, nor paralysing**

Understand that at this present time there is no cure for FMS, but **you can do a lot to help yourself**

Make contact with a **Local Support Group**

Work with your **Medical Professionals** to actively discover what works best for you

Learn to self manage your illness

Try to eat a balanced diet and eat at least 3 regular meals per day

Increase your fluid intake to 6-8 eight ounce glasses per day

Try to laugh, it is therapeutic. Don't be afraid to use humour to help manage your

FMS.

Do not be afraid to say NO when you cannot do something

Focus on your strengths

Learn relaxation techniques

Learn about correct posture and breathing exercises

Try to find a chair that supports good posture and a bed which is comfortable

With the help of medical professionals develop your own home exercise programme

Consider **stretching** as a form of exercise. Expect **some discomfort when beginning exercise, start at a very low level and make sure you build up very, very slowly**

Consider varying your exercise programme

Consider undertaking your exercise programme with a friend

Talk to your **family and friends**

Learn to **ask for help** and to **delegate tasks**

Try to **reduce stress, have fun!**

Participate in **activities that you find enjoyable**

Try to make sure that you have some exposure to outdoor light each day.

Try to **remain positive** at all times and eliminate negative thoughts

Learn to **pace and prioritise** your activities

Divide tasks into smaller projects

Try to **resist the urge to do “just one more thing”**

Expect to have a good quality of life in spite of having FMS.

Do not give up