

Fibromyalgia Regional Coordinators' Consortium UK
working with local support groups throughout the UK.

Coping with Fatigue Day by Day



INTRODUCTION

People who suffer from fibromyalgia have a lot to deal with. Not only do they often have intense pain, but up to 90% of sufferers also report moderate to severe fatigue. This fatigue isn't just your run-of-the-mill sleepiness either – this fatigue can last all of the time and for months on end.

Not all people with the syndrome suffer from extreme fatigue – some people seem to escape this fibromyalgia symptom, while others find they are able to adjust to their newly reduced energy levels. But others find that this chronic fatigue really impacts on their lives in a negative way. Most disturbing is the fact that this fatigue never seems to get better, even with extended periods of rest and sleep.

Excessive fatigue seems to have a negative impact on the symptoms of fibromyalgia, particularly pain. Fatigue and pain seem to operate in a vicious cycle. Because of the severe pain many people experience, it makes sleeping difficult and sometimes impossible. This of course contributes to fatigue, which, in turn, makes the pain much harder to bear. Recent studies have shown that the amount of fatigue a fibromyalgia sufferer experiences will directly correlate with the amount of pain they have. For example, if you are feeling particularly tired one morning, you can pretty much count on having an increased amount of fibromyalgia pain during the day.

- Eating a poorly balanced diet
- In take of excessive amounts of stimulants in the diet i.e.
- Caffeine, alcohol, sugar & sugar substitutes
- Refined carbohydrates

3. *Psyio-Social Issues*

- Trying to live up to others' expectations (or one's own expectations) despite health issues
- Trying to keep up with healthy people (denial of illness) or working in spite of intense pain
- Over –committing to activities, too much stress
- Inability or unwillingness to pace oneself

4. *Side Effects of Drugs may cause Drowsiness*

- Drugs for pain, sleep
- Other drugs i.e. antihistamines etc.

Mary Rose, PsyD, a clinical psychologist and behavioural sleep specialist at Baylor College of Medicine in Houston says "anything you do to make your quality of life better -- to give you more happiness -- you can't lose. Do what brings you happiness, and chances are it will help you refocus, get your focus away from the pain."



IN CONCLUSION

People with fibromyalgia often say they feel they have "hit the wall" with their fatigue and can go no further. It definitely can be frustrating. Not knowing when the fatigue will strike is stressful and makes it difficult to plan your daily activities. It is reassuring to know that as your symptoms improve, your fatigue levels should improve as well.

Indeed, living with fibromyalgia fatigue is more than just popping a pill. A good deal is self-treatment.

Patients have to be active, not passive.

When an individual has a chronic health condition which already includes a measure of fatigue, the introduction of even commonplace variables like those listed below can cause fatigue levels to escalate and the body's burden to grow. Therefore, the more that a person can minimise, treat or eliminate these variables, the better.

Commonplace Variables:

1. Health Conditions

- Infections
- Allergies

2. Nutritional Factors

- Skipping meals

It is reasonable to hypothesize that the constant, often severe, widespread pain which is diagnostic of fibromyalgia can cause a great deal of hardship for the body which can ultimately register in the form of profound fatigue.

Next to pain and tender points, fatigue is a major complaint. Fatigue in fibromyalgia refers to a lingering tiredness that is more constant and limiting than what we would usually expect.

Some patients complain of being tired even when they should feel rested, such as when they've had enough sleep.

Some patients report the fatigue of fibromyalgia as being similar to symptoms of flu.

Some compare it to how it feels after working long hours and missing a lot of sleep.

With fibromyalgia, you may feel:

- Fatigue on getting up in the morning
- Fatigue after mild activity such as grocery shopping or cooking dinner
- Too fatigued to start a project such as folding clothes or ironing
- Too fatigued to exercise

SEROTONIN CONNECTION

- More fatigued after exercise
- Too fatigued for sex
- Too fatigued to function adequately at work

Most people with fibromyalgia have trouble sleeping and never quite feel awake. That seems like a contradiction -- if YOU ARE always tired, why can't you sleep?

A key component of the condition is serotonin deregulation -- people with fibromyalgia generally either have too little of this neurotransmitter or don't use what they have properly. Serotonin is a key component of the sleep-wake cycle.

Here's how it works in a healthy person:

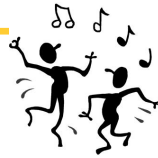
Morning sunlight falls on the eyelids; sensors in the eye signal the brain that it's about time to wake up; the brain responds by releasing serotonin; serotonin helps rouse the body from sleep, enter a state of alertness, and maintain alertness throughout the day.

The reverse process happens at night: Sensors in the eye signal the brain that it's dark and time to go to sleep; the brain responds by using serotonin to create melatonin, which creates a tired feeling and helps induce sleep. The sleeping brain then sets about producing serotonin, which it will release when the sun comes up.

USEFUL WEBSITES

Fibromyalgia Association UK:	www.fmauk.org
Fibromyalgia Focus Magazine:	www.fmauk.org head.office@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
Information from Dr Devin J. Starlanyl—what your medical team should know	www.sover.net
Irritable Bowel Syndrome Network	www.ibsnetwork
Digestive Problems	www.corecharity.org.uk
Information for Carers	www.carersuk.org www.direct.gov.uk/caringforsomeone
Myopain Society	www.myopain.org

SURVIVAL STRATEGIES



- **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.
- **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.
- **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.
- **Pace yourself.** Moderation is important if you have fibromyalgia, "when people feel good", they tend to do too much - - then pay the price later.
- **Listen to your body.** Rest before you get over-tired.
- **Volunteer work, hobbies, and a social support network** also help make it easier living with fibromyalgia. So does a sense of humour.
- **Practice "self-discipline".** You only have so much energy per day—use it wisely.
- **Work with your doctor** and investigate whether there may be any underlying conditions that may be contributing to your fatigue.
- **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.

SUGGESTIONS FOR RAISING SEROTONIN LEVELS

When you don't have enough serotonin:

You have a hard time waking up and can't be fully alert. You also can't produce enough melatonin to get that nice drifting-off-to-sleep feeling.

This doesn't explain all of the problems in these areas -- several complex processes are involved in sleeping, waking and being alert -- but some people do show some improvement when they normalise the serotonin/melatonin level.

You can influence your serotonin levels in different ways:

Food for Serotonin Deregulation

Foods aren't well researched for this, but some foods are commonly believed to contain building blocks of serotonin and therefore may raise the level of serotonin in your blood. They include:

- Carbohydrate-rich foods, especially before bed
- Complex carbohydrates, including grains and beans
- Watermelon
- Dark chocolate (which is only considered "healthy" in small amounts)

Notice that above the list it says these foods raise serotonin in the blood, where it acts as a hormone. Because

of the blood-brain barrier, it's likely that very little actually reaches your brain. Blood levels of serotonin may influence blood-flow-related symptoms and serotonin-related conditions such as irritable bowel syndrome.

Sunlight for Serotonin Deregulation

This is the most straight-forward way to raise serotonin in your brain: get more sunlight.

The reason for this is that serotonin is a crucial part of the wake-sleep cycle, which is strongly influenced by light. When light hits your eyes, especially natural sunlight, it tells your brain, "It's time to be awake," and your brain starts churning out serotonin to make you more alert.

However, it can be hard to get consistent levels of sunlight, especially when you're ill.

Fibromyalgia Fatigue

When a medical professional first sees a patient with fibromyalgia they should make sure that other causes of fatigue, like anaemia (low blood count) and thyroid problems, have been addressed.

Living With Fibromyalgia and Fatigue:

Fibromyalgia and chronic fatigue syndrome are considered separate but related disorders. They share a common symptom -- severe fatigue that greatly interferes with people's lives.

SEEK SUPPORT FROM FAMILY & FRIENDS



- It is often difficult for family members and friends to understand the degree of pain and fatigue that you are experiencing because fibromyalgia is invisible. This can create a feeling of isolation and loneliness and the belief that nobody understands. As you struggle with chronic pain and fatigue, you may have a tendency to conserve energy by further isolating yourself. By doing this you unfortunately may be cutting off the very support that you need in order to live successfully with fibromyalgia.
- Take time out to identify your support system. Identify those individuals who are helpful and those who are not.
- Identify those family members and friends who are more supportive and helpful in certain situations.
- When you are able, nurture those individuals closest to you; your support network is a valuable asset.
- Try to do things together on days when you are feeling good. Try to arrange to do things together at the time of day when you have most energy.
- Do not forget to tell family members and friends how important their love and support is to your well-being and your success in meeting the challenges of living with fibromyalgia.
- Clarify the strengths and weaknesses of your support network and begin to obtain support from those best able to help you.
- Do not be afraid to talk to family members and friends. Try to explain that you do recognise that there will be times when you will feel irritable because you are fatigued and in pain. That does not mean that you want to hurt them—you still love them.

TIPS FOR COPING WITH FATIGUE: PRIORITISE.

If you set yourself a schedule which is impossible to keep, prioritise your schedule and eliminate those things that are less important or unnecessary. Take care of the important things first. Your stress level may be reduced if you do the things that you really dislike doing first. This could considerably save you some worry time which in turn will alleviate some of the fatigue which is caused by worry!

Before you agree to do something or attend an event, seriously consider whether you have the time and interest. Do not feel guilty for saying no.

Divide your large tasks into smaller projects. Undertake the most urgent parts first and complete the whole project over a period of time, not all at once.

Make time in your daily schedule for interacting with the important people in your life.

Resist the urge to do just that one more thing. You only have so much energy per day. Think and prioritise how you will use it.

Learn to accept the things that you can control, learn to accept the things you cannot control, learn the difference between the two.

Make a daily schedule, putting the most important tasks at the top of the schedule. Always allow yourself plenty of time to complete the set tasks—be realistic.

Track your activities for one week, and then identify what activities are time wasters. Then try to eliminate or deal with each time waster.

Ask other people to help you with tasks that you find difficult. Delegating responsibilities can be difficult for many people with fibromyalgia, but there are other people who will gladly perform certain chores for you if you ask. It is best to be as independent as possible, but it is even better to allow someone else to help if it means that you will have energy for a longer portion of the day.

FIBROMYALGIA FATIGUE GENERAL FACTS

Up to 90% of people with fibromyalgia report moderate to severe fatigue.

Can be mild in some people with fibromyalgia and yet incapacitating in others.

Fatigue, after pain, can be one of the most debilitating and frustrating symptoms for people with fibromyalgia.

It can also have a great impact on a person's ability to go to work, take care of their family, or even engage in simple daily tasks.

May contribute to the memory difficulties and forgetfulness experienced by some people with fibromyalgia.

It is reassuring to know that as your symptoms improve, your fatigue levels should improve as well.

Whatever the cause of fatigue, it causes problems in our daily activities. The major negative effect of fatigue is increased pain which in turn consumes more energy and causes further fatigue.

It definitely can be frustrating. Not knowing when the fatigue will strike is stressful and makes it difficult to plan your daily activities.

Some people describe this fatigue as being similar to experiencing constant jet-lag.

The fatigue experienced by people with fibromyalgia is nothing like the fatigue most people experience at the end of a long day or following a strenuous workout. It is a pervasive, all-encompassing exhaustion that can interfere with even the most basic and simple daily activities.

TIPS FOR COPING WITH FATIGUE: PLAN.

Plan for a rest period each day. Schedule a longer period of time during the week, an afternoon or even a day if possible when you can relax and take care of yourself. This is particularly important after you have had a busy series of events.

Organise your home so things are within easy reach for you. You shouldn't have to do any unnecessary reaching for items stacked in high cabinets or spend extra time sorting through cluttered wardrobes and drawers. It may take some time to get organised but it will be worth the effort.

Plan to do an activity that you enjoy each day. We all feel less fatigued when participating in an activity we like doing.

Are you eating well-balanced meals? Lack of proper nutrition robs us of energy. Diets too rich in fat can put the body into lazy mode.

Plan activities so you have a restful or an uplifting activity after a strenuous one. Alternate these. For example, do not plan to vacuum and polish furniture in the same day. Vacuum then write those letters or pay the bills. Polish the furniture another day.

When preparing casseroles and other dishes prepare several servings at the same time, so that you can eat one serving and freeze the rest to eat on other days.

Plan to do shopping during off peak hours, this will allow you to spend less time standing in long lines and will save you energy and be less stressful.

Exercise. If you do not overdo it, it can increase your endurance and boost your energy level.

Use schedules, lists and calendars. These are also useful for coping with memory problems. You can purchase planners/calendars that will fit in a pocket or handbag or could be left by a desk. Please do not try to fit too many activities into one day. A "to do" list is great for keeping you reminded of what you need to do each day but be realistic about the number of items on your list. Cross off each "done" item and see how much you've accomplished!



TIPS FOR COPING WITH FATIGUE: PACE.

Pacing yourself is something which is hard to do, it can be a real challenge. Avoid trying to do everything during those times when you are feeling better, this can lead to you feeling exhausted from overdoing things. This can send you into a flare! Be realistic about the goals and activities you set for yourself, tomorrow is another day!

Take frequent short rest breaks during the day. Stretch, take deep breaths, or just close your eyes and listen to soothing music.

Use a relaxation tape when you are feeling most fatigued.

If you do work try to work no more than 8 hours per day, try to avoid working overtime and at weekends. If at all possible try to work flexible hours.

Try to accept that your home will not always be perfect—your family will still love you anyway!

Prepare meals that can be done quickly and do not require extensive physical labour.

Try to follow the rule of no sitting, standing or walking for prolonged periods of time, try to alternate your positions at frequent intervals.

Recognise realistically how long it takes to perform specific tasks.

Try to do your heavy or difficult tasks when you know you will have more energy.

When grocery shopping use a shopping list. Write down the items on the list in the order the aisles are arranged in your grocery store.

Listen to your body. Rest before you get overtired. Sometimes this is difficult for people with fibromyalgia; we are tired most of the time. We do not realise when we have really overdone it, until it is too late.

