

What is fibromyalgia?

What are the symptoms of fibromyalgia?

What causes fibromyalgia?

What causes the pain in fibromyalgia?

Why is sleep important to patients with fibromyalgia?

# 100 QUESTIONS & ANSWERS

# About Fibromyalgia

Sharon Ostalecki, PhD Martin S. Tamler, MD, FAAPMR

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# 100 Questions & Answers About Fibromyalgia

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# Pr EfaCE

Fibromyalgia is not technically a disease; a disease has known causes and the symptom process is understood. Fibromyalgia is a syndrome—a group of signs and symptoms that characterize a disorder. Fibromyalgia has been nicknamed "The Invisible Disease" because it is not perceptible to others. The face of fibromyalgia is every face, and unless you know what symptoms to look for, you cannot tell who has it and who does not.

Twenty years ago I spent my days searching for a reason for the pain that was taking over my life. Today I am a tenacious patient advocate working to bring awareness and education about a disorder that, although gaining recognition as a valid medical condition, is still a condition that causes physicians to close their practice to treating us because we present with a constellation of symptoms besides muscle and joint aching and pain.

Living with fibromyalgia can be difficult for not only do we live with pain, but many of us are handed a cocktail of condescension and doubts about our limitations. The crisis of confidence that follows can be contagious and soon affects every part of our being.

When I was diagnosed 20 years ago, the challenge was just that—getting a diagnosis. Today most patients see between 5 and 7 physicians to reach a diagnosis and, on average, it takes 1.9 to 2.7 years to reach a diagnosis. I was not that lucky. Before I was diagnosed I had the pleasure of meeting 37 medical practitioners and spent 12 years searching for a label to the pain that was my constant companion. At that time there was virtually no useful information that helped patients learn and understand the many faces of fibromyalgia. So, I learned by trial and error, and sadly, for the most part, our physicians had little information about a disorder they too could not understand. Chronic pain is not just about the patient but about the pain, isolation, and depression he or she suffers. Professor Harald Breivik, President of the EFIC (European Federation of International Association for the Study of Pain Chapters) states, "Chronic pain is one of the most underestimated healthcare problems in the world today, causing major consequences for the quality of life of the sufferer and a major burden on the healthcare system in the Western world. The consequences of unrelieved pain are great." What has to happen around the world to improve the treatment of those suffering with chronic pain? I believe it starts with an understanding and awareness of the condition of disorders and diseases causing chronic pain. Chronic conditions do not resolve themselves and are little noticed or understood by an unknowing public that would prefer not to think about them. With chronic illness, every facet of a once-robust life is overtaken and redefined. From the ability to find and hold jobs to the capacity to build and sustain personal relationships, the facts of a sick person's world change dramatically. Still, we go on. We double the effort and we search for answers to our questions.

For the past 10 years Dr. Tamler and I have been involved in answering these questions through a lecture series focusing on the many facets of fibromyalgia. We have lectured internationally yet the questions asked always have a familiar sound to them, for they are the same no matter what the location: "What causes fibromyalgia?" "Is there a cure?" "How do I stop the pain?" "My doctor does not understand; what should I do?" "Why does it hurt so much?"

So, when your journey with fibromyalgia starts, it is essential that you have the knowledge to navigate through the maze of medical tests and terms, the familiarity with the newest medications, and the skills to communicate with your physician. The questions presented in this book are the questions that were the chorus at our lectures and in conversation with patients, or the questions I presented to the many physicians I encountered in my quest for a diagnosis. This book also includes comments from patients living with fibromyalgia. All were ready to share. Sometimes it was difficult for them, but they are extraordinary for their courage to help others with their thoughts.

Living with fibromyalgia in the early to mid 1990s was challenging just as it is today. But today there are thousands of physicians, scientists, universities, medical institutions, corporations, professional organizations, and government agencies that are working hard to ensure a better future for us. The FDA has recently approved Lyrica and Cymbalta for the treatment of fibromyalgia, and more drugs are soon to come. We salute the pharmaceutical companies for their persistence in developing drugs that target pain, memory loss, and sleepless nights—all the companions of fibromyalgia.

The prognosis of fibromyalgia is better than ever. The efforts of individuals, support groups, organizations, and medical professionals have improved the quality of life for people with fibromyalgia. Better ways to diagnose and treat fibromyalgia are on the horizon. The symptoms of fibromyalgia can vary in severity, and they often wax and wane, but most patients do tend to improve over time. By seeking new information, talking to others who have fibromyalgia, reevaluating daily priorities, making lifestyle changes, and working hard to keep a hopeful attitude, patients can continue to live life to the fullest. And for the newly diagnosed patient, we hope this book will ease your journey and answer many of the questions most of us once asked to achieve a better quality of life despite fibromyalgia.

Sharon Ostalecki, PhD

### iNTr OduCTiON

Forty million people in the world live with fibromyalgia. Why is this number so high?

When discussing the most important aspects of treatment for fibromyalgia, four basic components are always included: the need for enhanced sleep, stress reduction, exercise, and a well balanced diet incorporating protein, which is the building block for muscle repair. These common sense requisites should be perfected by every individual in the general population. But over time, as society has become hurried, as the world becomes more rushed and industrious, as individuals try to complete more activities in a shorter period of time, the basic principles of good health get neglected. Therefore, as people continue to remain stressed and neglect the necessities of sleep, exercise, and diet, the incidence of fibromyalgia will continue to grow.

Martin S. Tamler, MD, FAAPMR

### f Or Ew Or d

Although the world is full of suffering, it is also full of the overcoming of it. —Helen Keller

I remember seeing the pleading look in her eyes. *Doctor, please help me make sense of everything that I am feeling.* How many times had I heard those words in my 8 years of private practice? Physicians referred me patients who had widespread pain, fatigue, and sleep problems. I remembered learning about fibromyalgia during my training in Physical Medicine and Rehabilitation. I struggled to provide my patients with information about this disorder—I wish I'd had this book!

Dr. Tamler and Dr. Ostalecki have created an easy-to-read, comprehensive text, organized in a question-and-answer format. They summarized recent drug trials and shared the thoughts of many fibromyalgia patients. This book contains a wealth of practical information such as: How can I avoid a flare? What should I expect at my first physical therapy visit? This manual will be a valuable resource for residents in training, medical practitioners, and patients.

Healing takes courage, and we all have courage, even if we have to dig a little to find it.

—Tori Amos

May this book give you courage to heal.

Tracy R. Johnson, MD University of Texas Health Science Center San Antonio, TX Assistant Professor Physical Medicine and Rehabilitation Residency Program Director

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To write any book involves the generosity of many people: our friends who make helpful comments, our heroes and mentors who inspire us, and those who support us in many ways.

A special thanks to my friend and mentor, Dr. Martin Tamler. You embraced my vision for this book from the beginning and your support never wavered. Thank you for joining me in writing this book to help all the patients who share my journey of living with fibromyalgia.

The following physicians and healthcare providers have contributed information, and I am extremely grateful:

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I am grateful to Jones and Bartlett Publishers for recognizing the importance of fibromyalgia education. The staff at Jones and Bartlett is a remarkable group of people to work with, open to ideas and suggestions. A special thanks to my dear friend, Ginger, who always listens to my complaints of living with pain and guided me on the path to wellness. She is a blessing to those who are fortunate enough to be part of her practice.

Most important, all the patients I have come in contact with—you are the reason this book was written.

#### Sharon Ostalecki, PhD

No book is ever the product of one person's efforts and this collaboration was certainly no different. The information in this book is the result of many hours of labor by so many people dedicated to benefiting those individuals plagued with fibromyalgia. However, this project would never have become a reality without the help and suggestions of many supportive friends and colleagues.

My biggest thanks go to Dr. Sharon Ostalecki, whose vision of this book and its benefit to the fibromyalgia community is the sole reason for its existence. Thank you for your heartfelt and tireless dedication to the fibromyalgia community. Because of your commitment, thousands will forever benefit from your advocacy.

I would also like to acknowledge the debt I owe to my first mentors and colleagues: Robert K. Silbert, MD; Myron M. LaBan, MD; Joseph R. Meerschaert, MD; and Ronald S. Taylor, MD, who shaped my career and from whom my interest in fibromyalgia grew.

And to the readers for whom the work is intended—those with fibromyalgia, their family and friends, and all the clinicians that find a curiosity as to the contents of this book—it is with great hope and anticipation that this book will prove to be useful, beneficial, enlightening, interesting, and enjoyable for all.

Martin S. Tamler, MD

# dEdiCaTiON

With a great deal of love, I dedicate this book to Matthew, Abigail, Isabella, Jacob, and "Papa," who are always there to help me in my journey with fibromyalgia. Also, to Renae, Philip, and Nick, who have learned to understand and accept that some days are not always the best when one lives with chronic pain.

#### Sharon Ostalecki, PhD

I dedicate this book to Trish, Ilyssa, Spencer, and Kendall, who unselfishly share me with the medical community and whose love, patience, and understanding have enabled me to better serve those who are truly in need. To you, those with fibromyalgia and those associated with its pain and suffering will be forever indebted.

Martin S. Tamler, MD

Par T ONE

# The Basics

What is fibromyalgia?

What are the symptoms of fibromyalgia?

How is fibromyalgia treated?

*More* . . .

#### Fibromyalgia

A chronic disorder characterized by widespread musculoskeletal pain, fatigue, and multiple tender points that occur in precise, localized areas, particularly in the neck, spine, shoulders, and hips.

#### Syndrome

A group of symptoms as reported by the patient and signs as detected in an examination that together are characteristic of a specific condition

#### Soft tissue

The ligaments, tendons, and muscles in the musculoskeletal system.

#### Wax and wane

Refers to symptoms that come and go without definitive cause. **Fibromyalgia** has dramatic effects on the body and the mind of the patient. For decades, many patients have not been able to persuade their physicians to believe in the reality of their symptoms. The term fibromyalgia has been used in a disparaging way, and many healthcare professionals generally believe that the majority of symptoms experienced by fibromyalgia patients are either imaginary or a byproduct of depression. These same physicians believe, wholeheartedly, that this group of patients is "crazy, hypochondriacs and/or drug seeking." Additionally, most healthcare professionals, including physicians, find this patient population to be one of the most time-consuming and frustrating populations that they will see in their practice.

# AN INTRODUCTION TO FIBROMYALGIA 1. What is fibromyalgia?

Fibromyalgia is a syndrome, or group of symptoms that occur together, rather than a disease. Fibromyalgia is characterized by chronic, widespread, musculoskeletal pain of at least 3 months' duration in all four quadrants of the body; stiffness; soft tissue tenderness; general fatigue; and sleep disturbances. The most common sites of pain include the neck, back, shoulders, pelvic girdle, and hands, but any body part can be affected. Fibromyalgia patients experience a range of symptoms that wax and wane over time. This condition falls into the category of muscular endurance disorders that result from exceeding the endurance capabilities of the muscle. Once this occurs, the interdigitating fibers of the muscle become mechanically locked into a position that produces pain. These pain-producing sites are known as tender points, and they can be found in virtually every muscle of the body. Any condition (i.e., infections, connective tissue disorders, trauma) that diminishes the endurance of the muscles can put an individual at increased risk of developing fibromyalgia. The use of the term fibromyalgia, however, is probably no more descriptive than using the term rash. When one thinks of the term rash, it immediately evokes the thought of a skin

disorder. However, this term alone is inadequate to reveal the etiology of that skin disorder. Similarly, fibromyalgia refers to some muscle endurance disorder but fails to disclose the underlying cause of the syndrome. When a single muscle is overused, the muscle becomes locked down or stuck in a noncontracting state and is often referred to as a "charley horse." When a group or region of muscles experiences this phenomenon, it is designated as **myofascial pain** syndrome or regional fibromyalgia. When the problem becomes widespread, involving all four quadrants of the body (i.e., the right and left sides, both above and below the waist), then it is referred to as fibromyalgia.

# 2. List the underlying conditions that cause or perpetuate the low-endurance state of the muscle in fibromyalgia.

- Sleep disorders
- Stress and tension
- Endocrine problems (i.e., **thyroid** and parathyroid disorders)
- Neurologic disorders (i.e., radiculopathy, peripheral nerve entrapment, multiple sclerosis, myasthenia gravis)
- Myopathies and muscle deficiencies
- Infectious diseases
- Connective tissue diseases (i.e., lupus, **rheumatoid** arthritis [RA])
- Nutritional deficiencies
- Chronic microtrauma (i.e., poor posture, repetitive motion)
- Macrotrauma (i.e., motor vehicle accidents, sudden impact injuries)
- Postoperative influences (i.e., immobility, spasm, muscle injury)
- Other conditions that lead to a deconditioned or debilitated state

#### Muscle

A body tissue consisting of long cells that contract when stimulated and produce motion.

#### **Tender** points

Sites where the interdigitating fibers of the muscle become mechanically locked into a position that produces pain.

#### Myofascial pain

Pain and tenderness in the muscles and adjacent fibrous tissues (fascia).

#### Thyroid

A gland located beneath the voice box (larynx) that produces thyroid hormone. The thyroid helps regulate growth and metabolism.

#### Rheumatoid arthritis (RA)

A chronic disease characterized by stiffness and inflammation of the joints, loss of mobility, weakness, and deformity.

# 3. Can you list some of the muscle dysfunctions associated with fibromyalgia?

Individuals with fibromyalgia show a number of abnormal patterns in muscle physiology, such as the following:

- High basal levels of muscle tension even at rest
- Asymmetries: higher levels of muscle tension in the same muscle on one side of the body than on the other
- Coactivations: muscles that are not designed to function during a movement are found to tense during the activity
- Failure to recover after exertion: muscles do not return to relaxation following use
- Long-term atrophy of muscle tissue with shortening of muscle fibers and increased sensitivity

Many of these abnormalities make sense in terms of the patient's body reaction to the presence of pain. When human beings experience pain, they tense. A common example of this finding is the twisting of body posture defensively around a painful site in order to splint or brace the painful region. This causes the tensed torso and musculature to lose **flexibility**. Additionally, those in severe pain tend to avoid activity in an attempt to minimize pain. This results in a muscle disuse syndrome consisting of atrophy of muscle tissue, muscle deconditioning, and loss of flexibility and strength.

# 4. Why did fibromyalgia remain invisible for so long?

One contributing factor is the fact that 80% to 95% of fibromyalgia sufferers are women. In fact, fibromyalgia is believed to be the most common cause of chronic musculoskeletal pain in women aged 20 to 50. Like other conditions predominantly acquired by women, its symptoms have often been attributed to hypochondria. In the 1950s and 1960s in the United States, fibromyalgia was often considered a "manifestation of psychogenic rheumatism," (Barrett, 2000) and patients

#### Flexibility

The ability of muscle to relax and yield to stretch forces.

were considered hysterical. Until recently, many physicians classified people who complained of the pain and fatigue as malingerers. Even with growing evidence of the physical reality of fibromyalgia, the gendered nature and virtual invisibility of this condition can result in insensitive and (at worst) nontherapeutic doctor-patient relations.

The gendered nature of fibromyalgia can also negatively impact men with the disorder. Because fibromyalgia is defined as a "women's condition," men with symptoms confront separate issues of credibility. Not only can the physical diagnosis be overlooked in men, as with breast cancer or eating disorders, but there is the added psychological impact as males face the additional burden of contending with weak, painful muscles in light of societal ideals of masculine strength and independence.

Jerry's comment:

I would like to bring up a common grievance among fibromyalgia sufferers: We are not always taken seriously because we don't look as sick as we feel—if we look sick at all. Because of that, some people don't believe that we are suffering. I know now that not looking as sick as you feel, and having some people not believe you, is not the hardest part of fibromyalgia. You must know and understand that some people either don't want to or can't understand what you're going through.

Like any difficult situation, your attitude is the key. In this case, the glass can either be half empty or half full. Although some days I felt miserable and no one could tell, on a good day I felt like a million bucks. And it was in this latter situation that not looking like the scourge of the Earth wasn't so bad.

# 5. Is awareness of fibromyalgia increasing?

Awareness of fibromyalgia is definitely growing and will continue to do so. One of the most important recent contributions to this increased awareness has been the U.S. Food and Drug Administration's (FDA) approval of Lyrica<sup>®</sup> (pregabalin) in

Even with growing evidence of the physical reality of fibromyalgia, the gendered nature and virtual invisibility of this condition can result in insensitive and (at worst) nontherapeutic doctor-patient relations.

2007 and Cymbalta<sup>®</sup> (duloxetine) in 2008. History reveals that a similar phenomenon occurred with the management and treatment of depression during the 1980s. Before the release of Prozac, depression was a disorder rarely discussed or treated by most physicians. After the release of Prozac and subsequent similar medications (**select serotonin reuptake inhibitors [SSRIs]**), a greater understanding of depression developed, and the treatment of depression became commonplace for all physicians.

Prior to the pharmaceutical companies' involvement, one of the most significant contributions to the visibility of fibromyalgia was the creation of diagnostic criteria by the American College of Rheumatology (ACR) in 1990. In 1992, a second significant contribution came when medical experts from around the globe signed an international declaration that was endorsed by the World Health Organization which stated that fibromyalgia was "indeed a true medical problem." Although the clinical diagnosis of fibromyalgia is currently based on detecting 11 of 18 tender points (regions that are painful when manually **palpated** with 4 kg of pressure), increased sensitivity to pressure in this condition extends beyond tender points and involves the entire body. While the official diagnostic criteria rest on an examination by a physician with knowledge of "tender" points throughout the body, this "classification" system is probably best reserved for sorting patients in clinical research studies. This is because the disorder is dynamic, constantly changing; in some instances a patient having a good day may only have 8 tender point locations and on a bad day 15. Does that mean the disorder was coming and going? Of course not. As a result, the diagnosis should not rest solely on the ACR criteria. Although some physicians still refuse to accept that the bundle of symptoms commonly associated with fibromyalgia actually constitutes a real disease entity, a growing number of physicians now recognize and treat fibromyalgia. With further research and education this number will continue to grow.

#### Select serotonin reuptake inhibitor (SSRI)

A type of drug that is used to treat depression.

#### World Health Organization

The directing and coordinating authority for health within the United Nations' system.

#### Palpate

To touch or feel.

# 6. How common is fibromyalgia?

Fibromyalgia is the second most common rheumatologic disorder following osteoarthritis. It is the number one cause of severe, generalized musculoskeletal pain even when back pain is included on the list. Population-based studies have demonstrated that fibromyalgia affects approximately 2% to 7% of the population, with a very similar prevalence in at least five industrialized countries. This translates into approximately 6 to 21 million Americans who suffer from fibromyalgia. However, at any one time, 10% to 12% of the general population report chronic generalized musculoskeletal pain that cannot be traced to a specific structural or inflammatory cause. Such idiopathic widespread pain most often fits the classification criteria for fibromyalgia. Women are generally affected by fibromyalgia disorder eight to ten times more than men, and the syndrome most often develops during the reproductive years. Children can also suffer from fibromyalgia; however, in this age group, boys and girls are equally affected.

#### Jenny's comment:

We think of fibromyalgia as something that happens to other people, people we don't even know. How different it seems when it happens to you. Indeed, every case of fibromyalgia is unique. The onset of this disease is unique in each patient. Nonetheless, in the stories of individual patients certain patterns emerge or at least suggest themselves. For example, the onset of fibromyalgia often follows some serious injury or illness. Some people are genetically **predisposed** to fibromyalgia so that they fall prey to it after an injury or illness. Another common theme is that, because there are so many mysterious symptoms and because the pain occurs in so many places, fibromyalgia is often misdiagnosed or regarded as "all in the patient's head." One thing is for sure: fibromyalgia always has a tremendous impact on the patient's life. Women are generally affected by fibromyalgia disorder eight to ten times more than men, and the syndrome most often develops during the reproductive years.

#### Predispose

Having factors that increase the risk of myofascial pain.

# 7. What are the symptoms of fibromyalgia?

Fibromyalgia literally means "condition of pain in the muscle fibers." The most prominent symptom of fibromyalgia is the presence of widespread muscle pain, often achy, gnawing or burning, either constant or recurrent, and varying in severity. Pain may wax and wane but is usually present all day and is made worse with increased activity, stress, and/or poor sleep. The muscle pain is often confusing to the patient and the health practitioner because the pain can fade and intensify, or even change location within the body, but this usually corresponds to the muscles that have been fatigued beyond their endurance capabilities. Muscles become tightened down into taunt fibrous bands. The stretch placed on fascia and musculotendinous fibers, as they draw inward toward the center and away from the origin and insertion of the muscle, produces the pain. The pain can begin at the site of an injury and then become systemic, spreading to all muscles of the body as accessory muscles become overused trying to compensate for other overexhausted muscles. The pain of fibromyalgia has been described as having "charley horses" scattered all over the body. As the pain worsens it can result in various combinations of numbness, tingling, and radiating pain. Over time the sensory system can develop allodynia, a painful response to a usually nonpainful stimulus. Allodynia differs from hyperalgesia, an extreme reaction to a stimulus that is normally painful. Both of these clinical features are usually present in fibromyalgia. In essence, all sensory stimuli reaching the brain's sensory processing centers is amplified or augmented to much greater levels than is normal or expected, resulting in extreme sensitivity to exertion, strain, or trauma, with many routine activities triggering intense and severe pain. Additionally, patients complain of heightened sensitivity to sounds, smells, and bright light.

The second most prominent symptom of fibromyalgia is moderate to severe fatigue. Because fibromyalgia is a muscle endurance disorder, exceeding one's endurance capability results in having no remaining energy to carry out routine functional activities.

#### Fascia

A fibrous membrane covering, supporting, and separating muscle and some organs of the body. Also known as soft tissue.

#### Allodynia

An altered sensation in which normally nonpainful events are felt as pain.

#### Hyperalgesia

An extreme reaction to a stimulus that is normally painful. Furthermore, the pain and fatigue is accompanied by a confusing variety of seemingly unrelated complaints. Some of the other associated symptoms commonly observed in fibromyalgia include stiffness and arthralgias, imitating many arthritic processes; soft tissue swelling; muscle spasms; fatigue; sleep disturbances; anxiety; depression; irritable bowel syndrome; interstitial cystitis; headaches; temporomandibular **joint** dysfunction; chest pain, abdominal pain, and perineal pain depending on the location of the tender points that develop; restless legs syndrome; impaired memory and concentration; skin sensitivities; rashes; dry eyes and mouth; ringing in the ears; dizziness; visual difficulties (i.e., eye pain, sensitivity to light, blurred vision, and fluctuating visual clarity); **Raynaud's phenomenon**; neurological symptoms; impaired coordination; and, at times, sensitivity to medications.

# 8. What causes fibromyalgia?

The cause of fibromyalgia is not known but it's likely that a number of factors contribute to its development. Researchers have a number of theories about the causes or triggers of the syndrome. Some of the theories include:

• Peripheral Sensitization (injury or trauma to either the musculoskeletal or nervous system)

This can lead to a phenomenon of peripheral sensitization of the sensory nervous system through nociceptive activation. This can be seen in such conditions as arthritic disorders; peripheral nerve damage, as in diabetic neuropathy or postherpetic neuralgia; and in sympathetic modulation as in reflex sympathetic dystrophy (complex regional pain syndrome).

#### • Central Sensitization (neurological alterations)

Many researchers agree that fibromyalgia is a disorder of central processing with neuroendocrine/**neurotransmitter** dysregulation. In other words, fibromyalgia is a pain amplification syndrome. This central sensitization theory states that people with fibromyalgia have a lower threshold for pain due to increased brain sensitivity Joint

The point of connection between two bones or elements of a skeleton (especially if the articulation allows motion).

# Raynaud's phenomenon

Discoloration of the fingers or toes due to emotion or cold in a characteristic pattern over time: white, blue, and red.

# Central sensitization

A malfunction in the brain's pain recognition centers that causes people with fibromyalgia to experience pain instead of normal sensations.

#### Neurotransmitters

Chemicals in the brain, such as acetylcholine, serotonin, and norepinephrine, that facilitate communication between nerve cells (neurons).

#### Chronic fatigue syndrome

A condition of excessive fatigue, cognitive impairment, and other varied symptoms.

#### Temporomandibular joint (TMJ)

The connecting hinge mechanism between the base of the skull (temporal bone) and the lower jaw (mandible).

Some researchers theorize that disturbed sleep patterns may be a cause rather than just a symptom of fibromyalgia. to pain signals. Researchers believe repeated nerve stimulation causes the brains of fibromyalgia patients to change. This change involves an abnormal increase in levels of certain neurotransmitters, which are chemicals in the brain that cause nerves to communicate, and is believed to result from overwhelming the "gated" protective mechanism of afferent sensory inputs into the dorsal root ganglion of the spinal column. Unfortunately, it is not known what initiates the process of central sensitization, but it is interesting to note that central sensitization is seen in other syndromes including irritable bowel syndrome (IBS), irritable bladder syndrome, chronic pelvic pain, **chronic fatigue syndrome**, tension headache, and **temporomandibular joint (TMJ)** dysfunction syndrome.

#### • Sleep Disturbances

Some researchers theorize that disturbed sleep patterns may be a cause rather than just a symptom of fibromyalgia.

#### • Changes in Muscle Metabolism

It has been suggested that deconditioned muscles and decreased blood flow to muscles may contribute to fatigue and decreased endurance. Endurance is a function of how efficient the body is at getting oxygen and nutrients to the muscle and then carting away the waste products. Therefore, anything that affects one of these variables can play a role in endurance. Metabolic alterations and abnormalities in the hormonal substance that influence nerve activity may also play a role.

#### • Infectious Agents

Some researchers theorize that a viral or bacterial infection may trigger fibromyalgia. While it is not an exhaustive list, some of the agents implicated have included hepatitis C, Epstein-Barr virus, and Lyme disease.

#### • Endocrine Disturbances

Thyroid disease is commonly associated with fibromyalgia and may play a contributing role in its cause.

#### Posttraumatic Stress

A smoothly functioning hormonal stress response system controlled by the hypothalamus-pituitary-adrenal (HPA) axis helps the body remain stable under physiological and psychological stress through the actions of three hormones. Fibromyalgia patients often show reduced function of the HPA hormone system. Some researchers also believe that in individuals with posttraumatic stress disorder (PTSD), the HPA axis response is dysregulated. Individuals with PTSD have low circulating levels of cortisol. In one study of motor vehicle accident victims, low cortisol levels immediately after the accident were associated with the development of PTSD and high cortisol levels were associated with the development of depression. Additionally, psychological trauma, resulting from childhood physical abuse or maltreatment, exerts enduring negative effects on the developing brain and induces a cascade of physiological effects, including changes in hormones and neurotransmitters in vulnerable brain regions.

#### • Abnormalities of the Autonomic (Sympathetic) Nervous System

People with fibromyalgia appear to have a problem with a vast network of nerve pathways throughout the brain, spinal cord, and body known as the **autonomic nervous system**. The autonomic nervous system may be thought of as the "automatic" nervous system that runs the life support functions typically not under conscious control. These functions include heart rate, blood vessel contraction, sweating, salivary flow, and intestinal movements.

#### • Hormonal Influence

Researchers have found little correlation with the sex hormone estrogen despite the fact that fibromyalgia is more common in women than men. Many women find that their symptoms greatly improve during pregnancy. Additionally, fibromyalgia patients produce less cortisol in response to stress than do healthy people, possibly having to do with a defect in the HPA axis. When the body Autonomic nervous system

System of the brain that controls key bodily functions not under conscious control, such as heartbeat, breathing, and sweating. is deficient in cortisol, the symptoms of fibromyalgia are mirrored. However, it is not clear how important cortisol deficiency is in the onset or course of fibromyalgia, but it is known that giving patients corticosteroid medications does not improve the condition.

#### Genetic Influence

One theory suggests a genetic predisposition to developing an autonomic or central nervous system disorder (i.e., a disorder of the brain and spinal cord) that affects the response to severe pain.

One study reports a 5% to 10% incidence of hereditary transmission and suggests that the possible gene for fibromyalgia is linked with the human leukocyte antigen system (HLA). HLA is the name of the major histocompatibility complex in humans. This group of genes, related to immune system function in humans, resides on chromosome 6, and encodes cellsurface antigen-presenting proteins and many other genes. The proteins encoded by HLAs are the proteins on the outer part of body cells that are unique to that individual. The immune system uses the HLAs to differentiate self cells and non-self cells. Any cell displaying that person's HLA type belongs to that person and will not be destroyed by the body. Another study proposed that fibromyalgia is more common in people who have a family history of alcoholism and depression. Fibromyalgia and reduced pressure pain thresholds have been shown to aggregate strongly within families. An individual is 8.5 times more likely to develop fibromyalgia if they have a family member with fibromyalgia versus a family member with rheumatoid arthritis.

# 9. Explain the autonomic nervous system and the sympathetic nervous system and its relationship to fibromyalgia pain.

The **central nervous system** is made up of the brain and spinal cord. The autonomic nervous system is a system of nerve

An individual is 8.5 times more likely to develop fibromyalgia if they have a family member with fibromyalgia versus a family member with rheumatoid arthritis.

#### Central nervous system

The brain and spinal cord. fibers in the brain, spinal cord, and throughout the body that automatically controls regulatory processes such as heart rate, blood pressure, sweating, salivary flow, intestinal movements, body temperature, and various reflexes. The autonomic nervous system has two divisions—one that works like an accelerator and one that works like a brake. These divisions, or subsystems, are called the **sympathetic nervous system** and the parasympathetic nervous system. Generally, the sympathetic nervous system serves as the accelerator, stimulating activity, and the parasympathetic nervous system serves as the brake, inhibiting or slowing activity.

When a hyperresponsive prolonged general firing of the sympathetic nervous system occurs, it is known as the "fightor-flight" response. It is the body's natural response system for dealing with dangerous situations. The response prepares humans for vigorous muscular activity to counter a perceived threat. It is usually triggered by trauma, fear, anger, or cold and prepares us to react physically and emotionally to a threatening situation. This activation is associated with specific physiological actions, both directly and indirectly, through the release of epinephrine (adrenalin) and, to a lesser extent, **norepinephrine** from the adrenal glands. These reactions include:

- Acceleration of heart and lung action
- Inhibition of stomach and intestinal action
- General effect on the sphincters of the body
- Constriction of blood vessels in many parts of the body
- Liberation of nutrients for muscular action
- Dilation of blood vessels for muscles
- Inhibition of lacrimal gland (responsible for tear production) and salivation
- Dilation of pupil
- Relaxation of bladder
- Inhibition of erection
- Auditory exclusion (loss of hearing)
- Tunnel vision (loss of peripheral vision)

#### Sympathetic nervous system

The part of the autonomic nervous system that raises blood pressure and heart rate in response to stress.

#### Norepinephrine

A neurotransmitter found mainly in areas of the brain that are involved in governing autonomic nervous system activity, especially blood pressure and heart rate. In fibromyalgia, nerve fibers become hypersensitive and more active than normal, resulting in activation of the "fight-orflight" response.

#### Acute

Condition of short duration that starts quickly and has severe symptoms.

#### Serotonin

A neurotransmitter within the central nervous system.

#### Tricyclic antidepressants

A group of drugs used to relieve symptoms of depression. These drugs may also help relieve pain. In fibromyalgia, nerve fibers found in both the central nervous system and the sympathetic division of the autonomic nervous system become hypersensitive and more active than normal, resulting in activation of the "fight-or-flight" response. As a result, any or all of the listed responses can occur. In fact, evidence suggests that the higher incidence of fibromyalgia in females is due to sex-linked differences in the responsiveness of the autonomic and central nervous system. The other major system activated in the **acute** stress response is the HPA axis.

# 10. What is the role of serotonin?

**Serotonin** is an inhibitory neurotransmitter that, along with GABA, norepinephrine, and insulin-like growth factor-1 (ILGF-1), modulates or dampens pain responses. Without adequate quantities of these substances in the central nervous system, perceived pain intensifies and the level of pain tolerance diminishes. Additionally, a deficiency of serotonin induces several biochemical abnormalities that best explain many of the signs and symptom of fibromyalgia. This was best demonstrated by administering parachlorophenylalanine, a selective enzyme inhibitor of serotonin synthesis, which produced symptoms of hyperalgesia and myalgia similar to those seen in fibromyalgia.

Serotonin not only dampens pain responses but is also believed to trigger stage 4 sleep, induce smooth muscle contraction (i.e., bowel peristalsis), and preserve the general well-being of the brain by preventing anxiety and depression. Medications that elevate serotonin, such as the SSRIs and **tricyclic antidepressants**, are commonly suggested for the treatment of fibromyalgia. Data does exist that reveals the relative power of each of the antidepressants to elevate serotonin levels. Unfortunately, these medications only allow circulating molecules of serotonin to exist in the body for longer periods of time but do not increase serotonin production. The only method known to increase the manufacturing of serotonin is exercise.

# 11. What is the role of DHEA?

When levels of serotonin are inadequate to trigger stage 4 sleep, this stage of sleep is bypassed. Consequently, dehydroepiandrosterone (**DHEA**), a vital chemical responsible for initiating the cascade of events that result in muscle tissue repair, falls to low levels in the body. It is believed that DHEA is only produced during stage 4 of sleep. When this chemical is not made, essential **protein** repair processes fail to take place. This results in gradual deterioration of basic proteins that make up the **immune system**, muscle, and enzymes necessary for digestion and cellular function. Laboratory levels of DHEA sulfate can be measured to determine whether DHEA needs to be supplemented. The normal reference range for a 25- to 50-year-old female would be 150 to 250 mcg/100ml. It has been shown that 74% of fibromyalgia patients will respond to micronized DHEA when levels are normalized.

# 12. What causes the pain in fibromyalgia?

There are mechanical reasons and chemical reasons for the pain. First, if you stretch or pull a soft tissue structure such as a tendon, **ligament**, or muscle, it will hurt proportional to the force of pull applied. For example, bend your thumb backward, and it will be painful. In fibromyalgia, the interdigitating fibers in muscle draw into center and get locked or stuck, forming the tender point. The attachment sites of the muscle found at the ends of muscle are, therefore, placed into a rigid "tug of war" stretch producing the local pain. It is observed clinically that loosening the "locked" muscle does relieve this pain.

The second cause is the process of central sensitization that develops within the central nervous system. People with fibromyalgia have a lower threshold for pain due to increased brain sensitivity to pain signals. Researchers believe repeated nerve stimulation causes the brains of fibromyalgia patients to change. This change involves an abnormal increase in levels of certain neurotransmitters, which are chemicals in the brain that cause nerves to communicate, and is believed to result from overwhelming the "gated" protective mechanism

#### DHEA

A chemical, produced only during stage 4 sleep, that initiates a cascade of events that causes proteins to repair themselves.

#### Protein

Complex molecules composed of amino acids that are essential to an organism structure and function.

#### Immune system

The body system that protects the body against invading organisms and infections.

#### Ligament

A tough band of tissue connecting the articular extremities of bones or supporting an organ in place.

#### Functional MRI (FibromyalgiaRI)

Functional MRI is based on the increase in blood flow to the local vasculature that accompanies neural activity in the brain.

One theory suggests fibromyalgia patients have a genetic predisposition to developing an autonomic or central nervous system disorder that affects the response to severe pain. of afferent sensory inputs into the dorsal root ganglion of the spinal column. A "wind-up" phenomenon-repetitive stimulation of C-fibers leading to a progressive increase in electrical charges from second order neurons in the spinal cord-results in amplification of sensory impulses in the CNS, creating greater discomfort than is seen in people without fibromyalgia. Functional MRI (FibromyalgiaRI) testing has confirmed this process of the "wind-up" phenomenon. In the following experiment, five pounds of pressure was applied to a person's thumbnail. Pain was rated on a scale of 0 to 10. FibromyalgiaRI was performed to "map" the brain during the painful stimulus. Normal subjects reported the pain at about 3/10, and their FibromyalgiaRIs revealed two activated brain areas. Fibromyalgia patients reported the pain at about 8/10, and their FibromyalgiaRIs showed much greater activation in 13 brain areas. When the normal group's thumbnail pressure was increased to 10 pounds, they reported the pain at about 8/10, and their FibromyalgiaRIs showed many more brain areas activated. Central sensitization not only causes amplification of pain but of all sensory stimuli including sounds, visual stimuli, cold, heat, odors, and tastes as well. Consequently, relatively benign stimuli will cause marked discomfort in fibromyalgia patients with central sensitization.

# 13. Are there any inherited tendencies?

One theory suggests fibromyalgia patients have a genetic predisposition to developing an autonomic or central nervous system disorder that affects the response to severe pain. Another theory developed from the parent-child relationships that are detected in fibromyalgia. One study has demonstrated an increased prevalence of fibromyalgia in first-degree relatives of patients with fibromyalgia. Another study has shown that an autosomal dominant basis exists for fibromyalgia. Dominant inheritance means an abnormal gene from one parent is capable of causing disease, even though the matching gene from the other parent is normal. The abnormal gene "dominates" the pair of genes. If just one parent has a dominant gene defect, each child has a 50% chance of inheriting the disorder. Another study reports a 5% to 10% incidence of hereditary transmission and suggests that the possible gene for fibromyalgia is linked with the HLA region. Another study proposed that fibromyalgia is more common in people who have a family history of alcoholism and depression. Fibromyalgia and reduced pressure pain thresholds have been shown to aggregate strongly within families. Yet other studies have revealed specific polymorphisms in the serotonin transporter gene and the catechol-O-methyltransferase enzyme that inactivates catecholamines.

# 14. How is fibromyalgia diagnosed?

Currently, there is no laboratory test or imaging study that establishes the diagnosis of fibromyalgia. Doctors must rely on patient histories, self-reported symptoms, a physical examination, and an accurate manual tender point examination. In 1990 the American College of Rheumatology (ACR) developed a set of criteria to diagnose and classify fibromyalgia. Included in this description was a finding of widespread pain, present for at least 3 months, located on the right and left sides of the body as well as above and below the waist. Digital palpation with an approximately force of 4 kg (enough pressure to turn the nail bed of the thumb white) applied to at least 11 of 18 established tender points must produce pain in specific areas, including the occiput, low cervical, trapezius, supraspinatus, second rib, lateral epicondyle, gluteal, greater trochanter, and knees (see Figure 1). Once fibromyalgia is diagnosed, it is imperative that any underlying condition causing or perpetuating the low endurance state of the muscle be identified. These conditions include sleep disorders, endocrine problems (i.e., thyroid and parathyroid disorders), connective tissue diseases (i.e., lupus, rheumatoid arthritis, polymyalgia rheumatica), nutritional deficiencies, neurologic disorders (i.e., radiculopathy, plexopathy), myopathies, infectious diseases, and other conditions that lead to a deconditioned or debilitated state.

Currently, there is no laboratory test or imaging study that establishes the diagnosis of fibromyalgia.

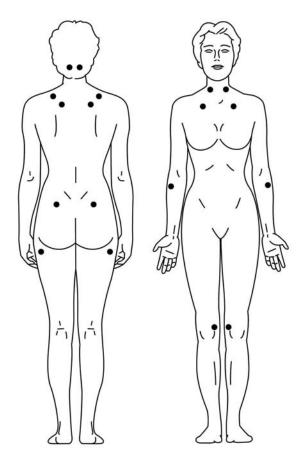


figure 1 Tender Points I ocations

#### **Trigger points**

Places on the body where muscles and adjacent fibrous tissue (fascia) are sensitive to the touch.

#### **Referred pain**

Pain from a malfunctioning or diseased area of the body that is perceived in another area, often far from the origin.

# 15. What are trigger points?

**Trigger points** are discrete, focal, hyperirritable spots located in a taut band of skeletal muscle. The spots are painful on compression and can produce **referred pain**, referred tenderness, motor dysfunction, and autonomic phenomena.

Trigger points are classified as being active or latent, depending on their clinical characteristics. An active trigger point causes pain at rest. It is tender to palpation with a referred pain pattern that is similar to the patient's pain complaint. This referred pain is felt not at the site of the trigger-point origin but remote from it. The pain is often described as spreading or radiating. Referred pain is an important characteristic of a trigger point. It differentiates a trigger point from a tender point, which is associated with pain at the site of palpation only (see **Table 1**).

A latent trigger point does not cause spontaneous pain but may restrict movement or cause muscle weakness. The patient presenting with muscle restrictions or weakness may become aware of pain originating from a latent trigger point only when pressure is applied directly over the point.

Moreover, when firm pressure is applied over the trigger point in a snapping fashion perpendicular to the muscle, a "local twitch response" is often elicited. A local twitch response is defined as a transient visible or palpable contraction or dimpling of the muscle and skin as the tense muscle fibers (taut band) of the trigger point contract when pressure is applied. This response is elicited by a sudden change of pressure on the trigger point by needle penetration into the trigger point or by transverse snapping palpation of the trigger point across the direction of the taut band of muscle fibers. Thus, a classic trigger point is defined as the presence of discrete focal tenderness located in a palpable taut band of skeletal muscle, which produces both referred regional pain (zone of reference) and a local twitch response. Trigger points help define myofascial pain syndromes.

Trigger points	Tender points
Local tenderness, taut band, local twitch response, jump sign	Local tenderness
Singular or multiple	Multiple
May occur in any skeletal muscle	Occur in specific locations that are symmetrically located
May cause a specific referred pain pattern	Do not cause referred pain, but often cause a total body increase in pain sensitivity

#### Table 1 Trigger Points vs Tender Points

Tender points, by comparison, are associated with pain at the site of palpation only, are not associated with referred pain, and occur in the insertion zone of muscles, not in taut bands in the muscle belly. Patients with fibromyalgia have tender points by definition. Concomitantly, patients may also have trigger points with myofascial pain syndrome. Thus, these two pain syndromes may overlap in symptoms and be difficult to differentiate without a thorough examination by a skilled physician.

# 16. What is a tender point exam?

Digital palpation with an approximately force of 4 kg (enough pressure to turn the nail bed of the thumb white) applied to at least 11 of 18 established tender points must produce pain in specific areas, including the occiput, low cervical, trapezius, supraspinatus, second rib, lateral epicondyle, gluteal, greater trochanter, and knees (see Question 14).

# 17. What is a trigger point injection?

Trigger point injection can effectively inactivate trigger points and provide prompt, symptomatic relief. The decision to treat trigger points by manual methods or by injection depends strongly on the training and skill of the physician as well as the nature of the trigger point itself. For trigger points in the acute stage of formation (before additional pathologic changes develop), effective treatment may be delivered through physical therapy. Furthermore, manual methods are indicated for patients who have an extreme fear of needles or when the trigger point is in the middle of a muscle belly not easily accessible by injection (i.e., psoas and iliacus muscles). The goal of manual therapy is to train the patient to effectively selfmanage the pain and dysfunction. However, manual methods are more likely to require several treatments, and the benefits may not be as fully apparent for 1 to 2 days when compared with injection.

While relatively few controlled studies on trigger point injection have been conducted, trigger point injection and dry needling of trigger points have become widely accepted. This

### Physical therapy

The treatment consisting of exercising specific parts of the body such as the legs, arms, hands, or neck in an effort to strengthen, regain range of motion, relearn movement, and/or rehabilitate the musculoskeletal system to improve function. therapeutic approach is one of the most effective treatment options available and is cited repeatedly as a way to achieve the best results. Trigger point injection is indicated for patients who have symptomatic active trigger points that produce a twitch response to pressure and create a pattern of referred pain. In comparative studies, dry needling was found to be as effective as injecting an anesthetic solution such as Novocain® (procaine) or Xylocaine® (lidocaine). However, postinjection soreness resulting from dry needling was found to be more intense and of longer duration than the soreness experienced by patients injected with lidocaine. Studies support the opinion of most researchers that the critical therapeutic factor in both dry needling and injection is mechanical disruption of the tightened muscle fibers by the needle. Because fibromyalgia is not an inflammatory state of the muscle, cortisone preparations offer no additional benefits. Trigger point injections can be repeated several times in order to facilitate an exercise program or physical therapy.

### Rob's comment:

Through my physical therapist, I found another doctor whom many of my former doctor's patients also found and migrated to. He is simply a genius in understanding fibromyalgia and the nervous system. He was so accurate with his trigger point injections that I began to get relief for months at a time. He also understood the depths of fibro and how it can eat away at every facet of your life.

# 18. If all other symptoms are present, but a patient presents with only seven or eight active tender points, which fail to meet the ACR criteria, do you not diagnose fibromyalgia?

The only thing this scenario implies is that the fibromyalgia patient is having a particularly good day. Tender points can come and go. Patients can have both active tender points and latent tender points. If the tender points are coming and going or if the patient is having a day where the muscle did not get overused, the patient is fortunate enough to experience a better day. In this instance, muscle will start to loosen up and there is less associated pain. That doesn't mean that patients cannot leave the office and later in the day tighten up from the drive home and then be back up to 12, 13, or 14 of the typical 18 tender point locations. The most important thing to remember is that ACR locations are only important for research study classification and are not critical for diagnostic purposes.

# 19. How is fibromyalgia treated?

It is important to recognize that fibromyalgia is a heterogeneous condition comprising a range of symptoms and features. Effective management must take all of these factors into account.

The successful management of fibromyalgia can be carried out utilizing a three-phased treatment approach. Any treatment used in isolation is most often doomed to fail. The initial phase should involve identification of any underlying causative factors and addressing those first (i.e., sleep, diet, connective tissue diseases, thyroid disorders, DHEA deficiency). This phase would include implementation of appropriate medication as needed to address the underlying causative factors. Another important aspect of phase one treatment is education about fibromyalgia and the causative factors. Once the particular areas of concern have been controlled or improved, phase two can begin. This phase attempts to diminish the painful tender points through the use of myofascial release, massage, physical therapy, and, when necessary, trigger point injections. The final phase attempts to improve the diminished endurance state through the use of aerobic exercise. However, if exercise is implemented too early as an intervention, before correcting those factors necessary to ensure muscle has an adequate opportunity to repair, further deterioration may ensue.

# 20. Why do some patients have more symptoms/pain than others?

The expression and response to pain is variable for all individuals. Environmental factors coupled with emotional stress,

Fibromyalgia is a heterogeneous condition comprising a range of symptoms and features.

#### Aerobic exercise

Physical exercise that increases the work of the heart and lungs; examples are running, jogging, swimming, and dancing. psychological factors (including anxiety and depression), degree of local trauma, genetic factors, and the body's own chemical alterations all impact the expression of pain. Further influences on the degree of pain expression derive from the extent of implementation of various management strategies/ techniques, medications, behavior modification, and exercise. Thus, recognizing those factors that help improve the pain and those that worsen the pain can have an enormous impact on how severe the pain will ultimately become.

# 21. Is fibromyalgia an emerging illness only in the United States?

Today it is estimated that fibromyalgia affects 7% of the world's population. Although the pain of fibromyalgia is a global experience, the approach to treatment varies greatly from country to country.

# 22. What is the prognosis?

Fibromyalgia is a disorder that causes enormous suffering. However, it is not life threatening. For most patients, the results are usually discouraging when using a single form of treatment in isolation. When phase two and phase three principles are utilized without first identifying and treating an underlying causative factor, results improve from direct symptomatic management. One study found that 47% of patients with fibromyalgia no longer fulfilled ACR criteria 2 years after diagnosis, and remission objectively occurred in 24.2%. When a phase one approach is also included, greater than 74% of patients will respond favorably. The mere fact that the pharmaceutical companies are now spending research and development monies on this disorder should provide increasing hope to the millions of fibromyalgia sufferers.

Jane's comment:

When I'm not feeling good, the first thing I do is review my sleep. Is it restorative? Do I have pain when I awake? To help maintain Although the pain of fibromyalgia is a global experience, the approach to treatment varies greatly from country to country. symptom control, I often need to rest during the day. I ask myself, "When was the last time I rested during the day?" I then rearrange my days so that I can rest. How are my pain levels? Do I need to use a Lidoderm patch to help control pain? Am I eating enough protein? Am I drinking enough water? How is my exercise going? Am I overdoing it? When was the last time my thyroid was checked? I make a point to slow down and notice that the sky is blue, and there are children playing. I remind myself how good a hot shower feels. And so on. When I slow down, I can focus again on what I need in order to be happy and to be comfortable with fibromyalgia.

I spent so many years trying to keep up with what my friends could physically do that I lost sight of the big picture: Life is to be enjoyed. I learned I had to plan a little more. I plan my days so that I can enjoy them. What things are most important to complete this week? What is most important for today? Can I hire the neighborhood teenager to help? How can my family help? Learning to ask for help and learning to say "no" can dramatically increase your enjoyment of life.

### Jerry's comment:

On the same general train of thought, recognize that no matter how well you engineer your daily life to cooperate with your body, you are going to have bad days. I feel great, and I still have bad days. That's what fibromyalgia is. The trick is to have more good days than bad days, and if you do, you're already winning. Beyond that, there's not much more you can do. There is no cleansing process. You have fibromyalgia, and chances are you always will. But take it from me, someone who was completely hopeless and cynical, fibromyalgia is manageable.

Surround yourself with positive people and positive things. Nobody wants to hear how horrible it is to have fibromyalgia, and if you're anything like me, you don't want pity anyway. Focus on positive things, find funny people, and get each other laughing.

# 23. Who can diagnose fibromyalgia?

A rheumatologist, neurologist, primary care physician, pain specialist, and/or a **physiatrist** have all generally received some form of training in diagnosing of fibromyalgia. A physiatrist is a specialist in the diagnosis and nonsurgical treatment of pain. A physiatrist usually employs a team approach to restoring a patient's abilities (rehabilitation) through various means, such as medications, physical and occupational therapies, injections, behavioral interventions, and management of other underlying medical conditions. Therefore, it is commonplace for physiatrists to include other healthcare providers and physicians from different disciplines as part of a multidisciplinary team.

# 24. What is a multidisciplinary approach to the treatment of fibromyalgia?

In the **multidisciplinary approach**, each healthcare provider (i.e., your physician, your physical therapist, your **psychologist**, your sleep physician, and so forth) treats you independently but communicates with other team members. Over time, each team member learns what the others are doing. Eventually, the team's treatments become oriented as a whole. The team is now a transdisciplinary one in which the healthcare providers' interventions overlap to fill in and reinforce the goals that characterize the team's treatment objectives.

# 25. Should I go to a pain clinic for treatment?

Fibromyalgia sufferers should go where they can get help. If the pain specialist at a pain clinic is willing to assume the role of overseeing all aspects of fibromyalgia care, then this could be a perfect fit. Additionally, other physicians who treat fibromyalgia utilizing a multidisciplinary approach might commonly request the assistance of a pain clinic in order to provide the most complete and comprehensive care. Many treatment options provided by pain clinics are available for fibromyalgia and for many other common painful conditions that can coexist with fibromyalgia.

#### Physiatrist

A physician who specializes in physical medicine and rehabilitation.

### Multidisciplinary approach

Approach that uses many experts from different disciplines working together as a team to manage and control the symptoms of fibromyalgia.

### Psychologist

A specialist who can talk with patients and their families about emotional and personal matters and can help them make decisions.

### Mark's comment:

Never give up. That would be my most important suggestion to anyone. Do your reading. Be knowledgeable. Find out what is happening with your body and relay that to your doctor. If your doctor is not willing to listen, walk away. I've walked away from a number of doctors. If they just don't understand, they're wasting your time. When you find the right doctor, you can begin healing.

### Lynn's comment:

Fibro, who? When I was first told I had fibromyalgia—actually it was written on the forms you get from the doctors as you're checking out—I never really knew what that long word meant. I thought it was just a diagnosis, and once I asked the doctor what it was, it took a while to explain it. Then you have to research it online, go to the library, learn about it, and then try to wrap your mind around it. And to modify your lifestyle to be successful, it's definitely a challenge. But a challenge that, in my opinion, you need to face head on. You can't just be totally intimidated by this work and the diagnosis. It's a challenge that you can win. It's really about wrapping your mind around fibromyalgia, getting over it, and getting on with your life.

# 26. Is the medical profession recognizing fibromyalgia as a medical condition?

Many physicians failed to receive any fibromyalgia education during their medical school training. As a result, many of these same physicians are uncomfortable with the diagnosis and treatment of this condition. Studies have shown between 16% and 71% of physicians are not at all comfortable in recognizing symptoms of fibromyalgia, and 25% to 73% are not at all confident in differentiating symptoms of fibromyalgia from other conditions. Education is the key, and as the healthcare community becomes better educated and as better treatment options become available, fibromyalgia will be acknowledged and accepted.

# 27. How do I find a physician who understands and treats fibromyalgia?

The best option is word of mouth. Ask family and friends or speak with your primary care physician to see if any fibromyalgia specialists are in your area. Check Web sites for local and national fibromyalgia organizations as these will oftentimes list physicians who treat fibromyalgia patients. Realize that while many rheumatologists, neurologists, and physiatrists are knowledgeable about fibromyalgia, not all are willing to put forth the inordinate amount of time necessary to treat this condition. Many physicians find these patients too demanding, too anxious, too depressed, or simply too difficult to treat. Find an empathetic and caring physician, one who has taken an interest in you, "the person." If you find a physician who cares about you and is willing to partner with you in your battle against pain and suffering, that's about 80% or 90% of the battle.

### Sharon's comment:

In my search for answers to the pain I did not yet understand, and which assaulted me as though I had aroused a dormant live thing inside me, I consulted many top orthopedic specialists. It did not take someone with my background in science to realize that something very real was very wrong with me: the pain was too severe to be incidental or random. As unbelievable as it may sound, one orthopedic physician told me he did not know what could be wrong with me because he could see no abnormalities on the Xrays he had ordered. This son of Hippocrates actually told me that I must have bad karma.

Having given me that "diagnosis," he referred me to his partner who confirmed that no abnormalities were visible on the X-rays—and therefore did not exist. When, 3 weeks later, I was foolish enough to return for a further consultation, this dedicated physician said, "Why are you here? I told you there was nothing wrong." Unmoved by my persistence, he gave me a prescription If you find a physician who cares about you and is willing to partner with you in your battle against pain and suffering, that's about 80% or 90% of the battle. for an anti-inflammatory before he told me, quite plainly, not to come back.

During the next 8 years, I traveled through many physicians' offices—MDs, DOs, alternative medical specialists, and even a shaman—looking for the cause of my pain. From every one, I heard the song familiar to fibromyalgia patients: You need to see a psychologist. Your hormones are out of balance. Your stress levels are high. You should learn to live with the pain. You just need more sleep, and you'll feel better in the mornings. If the verses varied, the refrain was the same: **There is nothing wrong with you**.

My persistence cost me several friends who couldn't understand that living with chronic pain has everyday effects. But I developed relationships with new acquaintances who did understand chronic pain because they too suffered from it. We spoke the same language. We could share—and compare—our reactions to treatments, physicians, **alternative medicine**, physical therapists, **massage therapy**, SSRIs, tricylic antidepressants, sleeping pills, support groups, work issues, pain clinics, trigger point injections, and cognitive difficulties. We most gratefully shared the loss of our old lives. It helped immeasurably to know others who also had to adjust to a whole new world.

My frame of mind improved, and I gained perspective. I returned to work part-time, working now through pain and exhaustion that required longer recuperation time. Finally, one physician, in an effort to dismiss me from his practice because my chronic condition was frustrating, referred me to a specialist for an EMG (a nerve conduction test). It was this specialist, a physiatrist, who began to turn my life right-side-up.

He discussed my symptoms with attention and patience. I was impressed by both the breadth of his knowledge and his openness. From the results of the EMG, he gave me a physical diagnosis; he said I had sacroiliitis. But he continued investigating my pain and, a few months later, told me there was an additional diagnosis: fibromyalgia.

#### Alternative medicine

A broad category of treatment systems such as chiropractic, herbal medicine, acupuncture, homeopathy, naturopathy, and spiritual devotions.

#### Massage therapy

Manipulation of tissues (as by rubbing, kneading, or tapping) with the hand or an instrument for therapeutic purposes. For the next few months, during my visits and in between them with phone calls, I bombarded this physician with questions. He always took the time to answer me. And while the answer might be conditional, it was never dismissive. To this day, I am grateful for the understanding, empathy, knowledge, and time this physician gave and continues to give me. Any way he could, he helped me.

### Renae's comment:

In my long and rough journey with fibromyalgia as my companion, I found nothing more important than finding professionals (including allopathic and allied healthcare practitioners) who are familiar with the disease and have an understanding temperament. I was fortunate to find an excellent physician, physical therapist, chronic pain psychologist, endocrinologist, and massage therapist. My good fortune was at least partly due to my persistence. Working with these practitioners has helped me enormously, helped me survive and even thrive along my journey in the world of chronic pain.

### Lynn's comment:

Finding a physician who listens and understands is a key component to managing your fibromyalgia. If your doctor doesn't first accept and understand that fibromyalgia is truly something that needs to be treated, if your doctor is not listening to what your complaints are, what your ailments are, you're not going to be successful at all. So, finding a doctor who validates what you're saying is crucial.

# 28. How do I go about educating my physician about fibromyalgia?

Very gently. Most physicians subconsciously don't like patients assuming the role of medical educators. Most physicians prefer to get their information from scientific journals. Therefore, the very best thing that a patient can do is print off a brief article about fibromyalgia that another physician has written. Do not provide physicians with Web sites or patient advocacy articles. Physicians should be educated by peer-reviewed scientific information, especially when there's a question about the credibility of the disease in their own mind. The last thing that physicians want to do is look at what a patient advocacy group has written about the disorder or how it should be treated. Don't take in masses of information that might consume a lot of the physician's time. A single review article highlighting some of the recent findings will result in the most effective use of the patient visit, prevent resentment or hatred of the patient, and ultimately lead to the best care for the fibromyalgia sufferer.

### 29. Is it normal to have memory loss?

Altered thought processing and memory loss, or "Fibro Fog" as it is commonly known, is one of the most common complaints voiced by fibromyalgia patients. More specifically, patients complain that they experience difficulty remembering new information or details (short-term memory loss) and feel that their mind is in a fog. Fibro Fog not only encompasses memory loss and cognitive impairment but difficulties with language and learning as well. This symptom is most likely a result of chronic sleep deprivation. During a normal 8hour night of sleep, the body will undergo the majority of its physical repair and restoration during the first 4 hours when the bulk of stage 4 sleep occurs. It's during the second half of sleep that the body repairs and restores the mind. When an individual fails to get adequate amounts of both the first and second halves of sleep (i.e., those with fibromyalgia, the elderly, and hospitalized patients, especially those in intensive care units), the result most commonly observed is altered thought processing and memory loss... or in this case, Fibro Fog.

### Mark's comment:

Fibro Fog is like opening a file cabinet to locate information, only to find the folders not in any familiar order. You attempt to organize the folders alphabetically. After checking how you've

Altered thought processing and memory loss, or "Fibro Fog" as it is commonly known, is one of the most common complaints voiced by fibromyalgia patients.

#### Fibro Fog

The cognitive dysfunction experienced by many fibromyalgia patients.

#### Sleep deprivation

A shortage of quality, undisturbed sleep that results in detrimental effects on physical and mental well-being. done, you notice the folders are still in disarray. Repeatedly you try to reorganize until you're tired of trying. If you're disgusted with yourself you may stop and leave it for another day or try to continue. When opening the folders you find that many are missing the contents. The folders that have their contents seem to be in the wrong folder. Confused, you aimlessly search through folders and begin mixing their contents with other folders in an attempt to classify the contents in their proper folder. You do this over and over, back and forth, to no avail. At some point you ask yourself, what was I looking for? No matter how hard you try, you just don't remember.

When I'm in this Fog, it's hard to communicate with others. Finding the proper words is difficult, to say the least. And forming interesting conversation is practically unattainable. What I've learned is to set daily goals. Write them down, starting with the easiest to the more challenging. The key is to keep your expectations pushing the edge just short of failure. Then, as time goes on, I build on my successes. Eventually I find my way through the Fog.

# 30. Does fibromyalgia cause depression?

Fibromyalgia doesn't necessarily cause depression, but fibromyalgia and depression can be very highly associated with one another. Common sense tells us that if a person has had chronic pain for months on end and has lost his or her ability to function in the real world, then, as a reaction to those unfortunate events, depression is not unlikely. In addition, depression and fibromyalgia share a common chemical basis—serotonin. Serotonin is a chemical that has about 18 different functions in the body. Some of the these functions include the preservation of pain inhibition, the ability to get into deep stage 4 sleep, and the ability to keep the mind on an even keel, thereby preventing anxiety and depression. Serotonin levels drop precipitously in chronic pain states like fibromyalgia. The deficiency in serotonin is, therefore, responsible in part for the anxiety, altered sleep, depression, and pain of fibromyalgia.

# 31. How will pregnancy affect my fibromyalgia?

During pregnancy, the hormonal influences seemingly have a protective effect on the mother's body in order to protect the baby's environment. Many women report that they get a reprieve from their fibromyalgia symptoms during pregnancy, and some women even resort to multiple pregnancies in order to feel better. This finding clearly suggests that there is some hormonal level or combination of hormones that improves fibromyalgia. Doctors believe this could be due to the ovarian hormone relaxin. During pregnancy, the amount of relaxin in a woman's body increases up to tenfold. Studies show that relaxin supplements help ease symptoms in many women with fibromyalgia. Unfortunately the postpartum state results in an entirely different scenario. During this time the hormonal influence is lost. The baby's needs during the night result in fractionated, poor-quality sleep for the mother. This can be a very difficult time for mothers with fibromyalgia as they can experience significant flare-ups. As the baby begins sleeping through the night, mothers with fibromyalgia typically return to their original baseline condition.

In 1997, a Norwegian study was conducted on fibromyalgia and pregnancy. The study confirmed many of the previously noted observations but found that the third trimester was by far the most challenging part of a pregnancy. Fibromyalgia symptoms increased in frequency during the third trimester. This increase in symptoms could be attributed to deterioration in sleep, as an altered body contour makes sleep difficult or nearly impossible in some instances. Most of the women in the study reported that their symptoms remained more intense than normal until about 3 months after they had delivered. They also had a greater incidence of postpartum depression. However, the babies born were all healthy, fullterm, and of a good birth weight.

Many women report that they get a reprieve from their fibromyalgia symptoms during pregnancy, and some women even resort to multiple pregnancies in order to feel better.

#### Flare-up

A period of time when symptoms reappear, becoming worse and then improving again.

### Gina's comment:

Looking back, I realize that during pregnancy I felt mostly the same as before I became pregnant, and at times I even felt better. Now I'm picking up where I left off before the pregnancy began.

I treasure the lessons I learned. I learned that if I have another child, I won't be afraid or feel helpless. I'll know that any difficulties won't be worse than I can handle; I can and will cope. My advice to anyone with fibromyalgia who wants to become pregnant—or may be already pregnant and worried—is to take control, to ask for whatever help you need, and to keep asking until someone listens. Yet, even as you look for answers from professionals, never forget that you are the primary expert on your body. Stretch, exercise, take a pregnancy yoga class, eat well, and relax. You may find, as I did, that pregnancy can actually make you feel better for the duration. Your reward for doing all those exercises and asking all those questions is your wonderful baby.

When I was pregnant with our second child, Jake, I experienced similar pains/challenges as with our first child. Throughout the pregnancy I maintained a comfort level by utilizing hot and cold therapy (ice packs and heating pads) along with stretching. My physician suggested water physical therapy, and I found it to be quite relaxing.

I had an easier and quicker recovery with this birth, and in the months that followed I adjusted to having two children and the challenges of living with fibromyalgia.

My second pregnancy, as with my first, was a constant learning experience. I have found that having fibromyalgia requires a constant and ongoing search for what can help me to feel better, and I expect that my journey has just begun.

# 32. How does acute pain turn into chronic pain?

During an acute injury an inflammatory reaction occurs in the sensory input zone of the spinal cord corresponding to that region of the body that was injured. Over time this reaction can result in permanent scarring of this sensory zone and permanent chronic pain. Even after the body part has healed, the scarred sensory input zone of the spinal cord can still generate impulses that the brain perceives as pain. Additionally, evidence suggests that patients with fibromyalgia experience abnormal pain amplification at the level of the spine, although the specific abnormalities leading to amplification have not been completely elucidated. A "wind-up" phenomenon-repetitive stimulation of C-fibers leading to a progressive increase in electrical charges from second order neurons in the spinal cord—results in amplification of sensory impulses in the CNS, and contributes to the phenomenon of central sensitization.

Rob's comment:

I never told anybody I had fibromyalgia. As a guy I still thought it wasn't cool. If anyone asked, I alluded to my car accident, some falls I'd had, scoliosis—but not fibromyalgia. The only people I could share the secret name with were two coworkers. One was my own assistant, and she had it very bad. She said I was a good boss because I understood her bad days. We laughed with dark humor at how pathetic we were when we both were having a "Fibro day." However, if I hadn't had this condition myself, as a manager, I wouldn't have had the compassion to understand my coworker's pain and dilemma.

# 33. I have constant headaches. Is this common for someone with fibromyalgia?

It is important to realize that virtually every muscle in the body can be affected by fibromyalgia. In essence, that means

Even after the body part has healed, the scarred sensory input zone of the spinal cord can still generate impulses that the brain perceives as pain. that every muscle and, for that matter, every location throughout the body can hurt. The head is no exception. Two of the 18 tender points identified in the ACR diagnostic criteria are located at the right and left occiput (back of the head). When these tender points are present, they produce pain in the back of the head. In addition, tension headaches brought about from stress may be caused by the development of widespread active trigger points found scattered throughout the muscles of the head and neck.

Par T Tw O

Sleep

Why is sleep important to patients with fibromyalgia?

How can you tell if you are getting into stage 4 sleep?

How can I improve my sleep?

More...

Sleep is a natural, periodic, and reversible behavioral state. While asleep, we are perceptually disengaged from the environment and unresponsive to it. Overwhelming evidence shows that sleep is essential to life. The defining features of sleep include minimal movement, stereotypic posture, reduced responsiveness to stimulation, and reversibility (the ability to awaken).

# FIBROMYALGIA AND SLEEP 34. Why do we sleep?

Several hypotheses exist to answer this question. First, sleep is vital to the restoration and recovery of physiological processes degraded by continued wakefulness. Second, sleep reduces metabolic rate and body temperature resulting in energy conservation. Third, a more basic biologic theory suggests that sleep reduces motor activity, thereby decreasing the likelihood of attracting predators during the hours of the day that an animal need not spend actively feeding or in pursuit of food.

Sleep is not the passive experience of withdrawing from wakefulness. It's an active progression generated by specific chemical reactions in the brain. Unlike many other neurologic functions, there is no single unique "sleep center" in the brain. Instead, sleep is a complex process that occurs in several specific regions of the brain. Three basic mechanisms coordinate and govern the processes of sleep and wakefulness: (1) autonomic nervous system balance, (2) homeostatic sleep drive, and (3) **circadian rhythms**. These mechanisms maintain sleep and wakefulness in a dynamic balance but also allow for adaptation to sudden shifts in the time and duration of sleep.

# 35. What are the stages of sleep?

There are two distinct states of sleep: **rapid eye movement** (**REM**) sleep and **non-rapid eye movement** (**NREM**) sleep. NREM is further subdivided into sleep stages 1 through 4. REM, or stage 5, is not subdivided. These stages are classified due to distinct physiologic and electroencephalographic

Sleep is vital to the restoration and recovery of physiological processes degraded by continued wakefulness.

#### Circadian rhythm

A metabolic or behavior pattern that repeats in cycles of about 24 hours.

#### Rapid eye movement (REM)

A light sleep when dreams occur and the eyes move rapidly back and forth.

#### Non-rapid eye movement (NREM)

A recurring sleep state during which rapid eye movements do not occur and dreaming does not occur; accounts for about 75% of normal sleep time. characteristics seen in each stage (see **Table 2**). Sleep stages do not occur randomly but in cycles with each stage of the cycle progressing "deeper" into NREM sleep and ending with REM sleep (see **Figure 2**).

← 100% SLEEP CYCLE				
STAGE 1	STAGE 2	STAGE 3	STAGE 4	STAGE 5
4–5% Light sleep. Muscle activity slows down. Occasional muscle twitching.	45–55% Breathing pattern and heart rate slows. Slight decrease in body temperature.	4–6% Deep sleep begins. Brain begins to generate slow data waves.	4–6% Very deep sleep. Rhythmic breathing. Limited muscle activity. Brain produces delta waves.	20-25% Rapid eye movement. Brainwaves speed up and dreaming occurs. Muscles relax and heart rate
	000		- 19 - 11	Breathing is rapid and shallow.

figure 2 Sleep Cycles

### Table 2 Nr Em vs. r Em Sleep

Nr Em	r Em	
4 Stages	1 Stage	
Usually little or no eye movement	Rapid eye movement	
Dreaming is rare	Dreaming is common	
Brain activity decreases	Brain activity increases	
Heart rate and blood pressure decreases	Heart rate and blood pressure increases and varies	
Sympathetic nerve activity decreases	Sympathetic nerve activity increases significantly	
Blood flow to the brain decreases	Blood flow to the brain increases and varies	
Respiration decreases	Respiration increases and becomes more erratic	
Muscles are not paralyzed	Muscles are paralyzed	

# Non-Rapid Eye Movement (NREM) Sleep

This stage is subdivided into several stages that distinguish the transitions from wakefulness to deeper sleep:

- Stage 1 occurs in the beginning of sleep and is the lightest stage of sleep associated with slow eye movements. People aroused from this stage often believe that they remained fully awake. During the transition into stage 1 sleep, it is common to experience muscle jerks.
- Stage 2 sleep typically accounts for 40% to 50% of sleep. It is an unconscious state from which one is easily awakened. No eye movements occur, and dreaming is very rare.
- Stage 3 is the transition stage where delta waves begin to occur, and these waves signal the start of deep sleep.
- Stage 4 is slow-wave sleep (SWS), the "deepest" stage of sleep in which there is a continuation of the delta wave. The basis for all sleep is to ultimately get into this stage of restorative sleep.

Stage 3 and stage 4 sleep are frequently combined and referred to as slow-wave sleep, accounting for about 20% of total sleep time in adults (most of which occurs in the first half of a night's sleep). The highest arousal thresholds (i.e., difficulty awakening, such as by a sound of a particular volume) are observed in stages 4 and 3, respectively. A person will typically feel more "groggy" when awoken from these stages, and indeed, cognitive tests administered after awakening from stages 3 and 4 indicate that mental performance is somewhat impaired for periods up to 30 minutes, relative to awakenings from other stages.

# Rapid Eye Movement (REM) Sleep

REM sleep is also known as paradoxical sleep during which periods of fast EEG activity occur. Although dreaming can occur during both REM and NREM sleep, REM dreams are more vivid. The function of REM sleep remains uncertain, although some data suggest an important role for REM sleep in memory consolidation.

# 36. When is the best time to awake?

The five sleep stages combine to form one sleep cycle. Sleep cycles generally last 90 to 100 minutes. Individuals generally feel rested and refreshed only when awaking at the conclusion of a sleep cycle. Therefore, most individuals will find it easiest to awaken and feel most refreshed after 3, 4.5, 6, 7.5, 9, and 10.5 hours of sleep.

# 37. Why is sleep important to patients with fibromyalgia?

Many different factors can cause a decrease in the endurance of muscle, but the most common cause is the absence of restful or restorative sleep (seen in as many as 70% to 90% of fibromyalgia patients). During the course of the day's activities, microscopic damage occurs to various parts of the body, especially muscle. Sleep is necessary to repair this damage. Failure to repair the damage results in accumulated damage. Muscle that has accumulated damage protects itself from developing large tears by tightening down into trigger points. It is during deep stage 4 sleep that a cascade of events takes place resulting in protein repair. The proteins that are manufactured or repaired include muscle, immunologic proteins (infection fighting proteins), and enzymes (chemicals necessary not only for digestion but also for various cell processes). Disturbance or absence of stage 4 sleep has been shown to induce signs and symptoms of fibromyalgia. Additionally, if the sleep disorder is allowed to persist, the symptoms of fibromyalgia generally worsen.

### Many different factors can cause a decrease in the endurance of muscle, but the most common cause is the absence of restful or restorative sleep (seen in as many as 70% to 90% of fibromyalgia patients).

### Lucy's comment:

I experienced 4 years of numerous doctor visits, months of physical therapy, along with the probing and prodding of every part of my body and brain. There were days I honestly thought I was on the verge of insanity because nothing was permanently eradicating the excruciating pain, and no one could tell me what was happening to my body. I would lie awake at night wondering if my legs would move and allow me to walk or if my shoulders would function so that I could brush my hair, let alone take care of my family and remain employed. The physical and emotional anguish was causing a major disruption in my daily lifestyle.

Then my personal miracle took place, and I discovered that I had fibromyalgia. Finally, a name had been given to the mysterious, inconsistent symptoms that had been causing my body to throb with pain and feel like it was slowly deteriorating. More importantly, I discovered the importance of quality, restorative sleep, which resulted in a "rebirth" of my life and a deterrent to the advancement of my disorder. The regenerative power of proper sleep can never be underestimated. With the use of a prescription sleep aid, I immediately began to experience restful, complete sleep. Within a matter of days, the simple act of superior sleep resulted in comprehensive physical and mental effects. I no longer experienced the daily throbbing and searing pain at my pressure points. My muscles and joints finally responded to my conscious requests. I could even dance again! My anticipation of bodily functions dissipated, which further increased the quality of my sleep. With less pain there was a decrease of pain medication. Lastly, my memory and thought process improved dramatically. I might get an occasional stiff leg or arm, especially if I have had a stressful day in the classroom, but with a warm shower, gentle stretching, and a good night's sleep, I am revitalized and ready to experience this awesome world.

Sharon's comment:

The first step in my treatment was improving my sleep with medication. I consider this the first step in my recovery because sleeping more made me feel alert during the day. I also noticed in the months to come my good days started to outnumber the bad, and that is the first step to managing fibromyalgia.

# 38. How can you tell if you are getting into stage 4 sleep?

An individual who gets into deep stage 4 sleep should feel rested, refreshed, and energetic upon awakening in the morning.

An individual who gets into deep stage 4 sleep should feel rested, refreshed, and energetic upon awakening in the morning. This is the individual who easily awakens the next morning bright and alert, ready to jump out of bed with energy to tackle the day. This is actually normal! Out of 7 days in a week, a person getting enough stage 4 sleep will feel revitalized all 7 days, not only 1 or 2 days.

# 39. What hormones are affected by the sleep—wake cycle?

Many hormones are directly influenced by the sleep–wake cycle. Growth hormone, insulin-like growth hormone-1 (ILGF-1), DHEA, prolactin, and parathyroid hormone levels all increase during sleep, with growth hormone, ILGF-1, and DHEA release occurring primarily during deep stage 4 slow-wave sleep. **Thyroid stimulating hormone (TSH)** secretion is suppressed during sleep.

There is one hormone that directly affects the sleep–wake cycle. The pineal hormone, **melatonin**, promotes sleep and contributes to the regulation of the sleep–wake rhythm. Melatonin is secreted primarily during darkness and is suppressed by light. Administration of exogenous melatonin in the early evening hours serves to advance the circadian clock (facilitates earlier sleep). Melatonin is widely available and has gained popularity as a sleep-promoting agent. Some studies suggest that melatonin may be useful in the treatment of delayed sleep phase syndrome, jet lag, work shifts, and **insomnia** in older people with low endogenous melatonin levels.

40. My physician uses the terms "sleep latency," "maintenance of sleep," "sleep architecture, and "sleep onset insomnia" in reference to insomnia. Could you explain each of these?

• Sleep latency is the time it takes for a person to fall asleep. The time period measured from "lights out," or bedtime, to the beginning of sleep.

#### Thyroid stimulating hormone (THS)

Released by the pituitary gland to increase thyroid hormone production.

#### Melatonin

Pineal hormone (a hormone secreted from the pineal gland) secreted primarily during the hours of darkness.

#### Insomnia

Inadequate quality or quantity of sleep, with difficulty initiating or maintaining sleep.

- Sleep maintenance refers to maintaining undisturbed sleep free of awakenings. Sleep maintenance can be interrupted by environmental causes such as noise, a child, or a bed partner. Internal causes can include pain, anxiety, and bathroom breaks.
- Sleep architecture refers to the NREM/REM stage and cycle infrastructure of sleep. More simply stated, sleep architecture is the five stages of sleep.
- Sleep onset insomnia refers to difficulty initiating or getting to sleep. Sleep maintenance insomnia is the inability to stay asleep after sleep was initiated and is manifest by waking up too early and not being able to fall back asleep.

# 41. What is a sleep diary?

A sleep diary is a daily written record of an individual's sleepwake pattern containing such information as time of retiring and arising, time in bed, estimated total sleep period, and sleep interruptions, characterized by number, duration, and causes. Additional information that the diary might include is naps (number and duration), stresses during the day, rating daily daytime sleepiness, rating daily irritability, and listing medication changes and effect. Sleep is a habit, and determining good and bad tendencies requires detailing all the happenings that transpire over a 2- to 4-week period of time. A detailed diary is indispensable for formulating a differential diagnosis and, ultimately, a treatment plan.

#### breathing that occurs during sleep. Usually

due to obstruction of the airway, it can also be due to inability of the brain to initiate respiration.

Sleep apnea

Cessation of

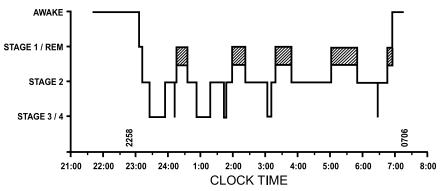
#### Polysomnogram

A technical term for a sleep study that involves recording brain waves for assessing the quality of sleep and airflow at the nose and mouth.

# 42. Is an overnight sleep study always necessary to determine a cause of insomnia?

Most causes of insomnia can be readily identified by a physician through a careful history and physical examination. However, relying on the observations of bed partners or other household members can often reveal additional causes such as obstructive **sleep apnea** or movement disorders that might otherwise be missed. An overnight sleep study, also known as a **polysomnogram** (see **Figure 3**), is generally reserved for conclusively identifying these later two conditions and for guiding their treatment. Once it is deemed appropriate to perform for the care and management of insomnia, the test involves placing electrodes over the body and scalp while an individual sleeps in order to monitor brainwave activity, respirations, and body movement. The study measures:

- Sleep cycles and stages
- Electrical activity of muscles
- Eye movement
- Breathing rate
- Blood pressure
- Blood oxygen saturation
- Heart rhythm
- Leg movements
- Body position and movement



#### NORMAL SLEEP ARCHITECTURE FOR A HEALTHY FEMALE

figure 3 Sleep Study Slide

### Dr. Tamler's comment:

It wasn't until months later that the real cause of insomnia was revealed. The patient's husband accompanied her to her office visit for the very first time. After listening to a lengthy discussion with the physician about her insomnia, he interrupted. "Has she ever explained to you why she really has insomnia? Has she ever told you about the two elderly Rottweiler dogs that sleep with her? Has she ever told you that they are incontinent each night and at least twice a night she has to get up and change the bed sheets?"

# 43. How can I improve my sleep?

There are two principle forms of treatment for insomnia: conservative therapy and pharmacologic therapy. Nonpharmacologic, conservative therapy focuses on both sleep hygiene and cognitive behavioral therapy (CBT), a set of behavioral techniques implemented by a psychologist or sleep specialist. The elements of sleep hygiene include:

- Limit use of **stimulants** before bedtime.
- Do not use alcohol as a sleep aid.
- Do not exercise 3 hours before bedtime.
- Establish a conducive sleep environment (dark, cool room).
- Use the bed only for sex and sleep. No reading or TV, which stimulate the brain to remain awake.
- Reduce or, preferably, eliminate naps.
- Go to sleep and awake at the same time each day (including weekends).

Other techniques to improve sleep include relaxation techniques, **biofeedback**, hypnosis, meditation, and yoga.

# 44. What role does stress have on sleep and fibromyalgia?

When a person is stressed, they are anxious. When a person tries to go to sleep at night with a racing mind, worried about the previous day's events and the day's events to come, the mind cannot relax, and the individual cannot get to sleep. Subconsciously, the stress continues to be disruptive throughout the entire night causing frequent awakenings. This prevents restorative stage 4 sleep from occurring, and muscles cannot repair the previous day's damage. Moreover, the stress

There are two principle forms of treatment for insomnia: conservative therapy and pharmacologic therapy.

#### Stimulants

Drugs that increase the activity of the sympathetic nervous system and produce a sense of euphoria or awakeness.

#### Biofeedback

The use of electronic instruments to measure muscle tension in any muscle group. continues to have an impact throughout the next day. When a caricature is drawn of an individual who is stressed or anxious, the individual is portrayed with little squiggle lines by the shoulder, signifying some kind of vibration taking place in that region and suggesting that the muscles are tight and tensed with some quivering taking place. In essence, this is what really occurs. Furthermore, if the postural muscles around the head and neck are maintained in a very tight and rigid fashion, the body can't tell whether those muscles are contracting due to heavy exertion, such as carrying bales of lumber, or if the body is just keeping its muscles tight from stress. The net result is overuse of those muscles, and it has a wear-and-tear effect, ultimately producing the same painful response as vigorous labor.

# 45. What over-the-counter pharmacologic interventions are available for treating insomnia, and do they work?

Despite the fact that pharmacologic therapy has become increasingly available, many patients resort to using over-thecounter medications or alcohol in a desperate attempt to get sleep. Commonly used nonprescription medications include antihistamines, cough syrups, aspirin, and several unregulated dietary **supplements**. There is no evidence to support the use of such agents in the treatment of insomnia. Many of these medications, including antihistamines, are used for their drowsiness side effect but do nothing to maintain sleep or promote deep sleep. Likewise, some physicians treat insomnia with sedating prescription antidepressants and other medications that sedate as a side effect, but these fail for the same reasons. Furthermore, alcohol actually disrupts sleep, suggesting that the use of alcohol may exacerbate, rather than alleviate, insomnia.

#### Supplements

The addition of vitamins and minerals, in a pill form, to a person's diet.

# 46. What is the best class or type of drugs to use for insomnia?

Currently physicians use both prescription drugs not indicated for insomnia (i.e., sedating antidepressants, sedating antipsychotics) and prescription drugs indicated for insomnia (i.e., benzodiazepines, nonbenzodiazepines receptor agonists, melatonin receptor agonists). Of all these available choices, nonbenzodiazepines receptor agonists provide the best option for successful treatment. Because sleep is a habit, it is likely that the drug chosen will need to be used for an extended period of time until a good sleep habit is developed. Two drugs in this category, Ambien CR® and Lunesta®, have been found in double-blind, placebo-controlled clinical trials to be relatively safe for chronic use. Additionally, they maintain normal sleep architecture, suggesting that patients using them can get into stage 4 sleep. Conversely, benzodiazepines (i.e., Valium<sup>®</sup>, Xanax<sup>®</sup>, Ativan<sup>®</sup>, Restoril<sup>®</sup>, Halcion®) actually prevent stage 4 sleep and are addictive when used chronically. Rozerem® is FDA approved for patients with sleep onset insomnia. Rozerem is a melatonin receptor agonist promoting sleep induction but does nothing for sleep maintenance. It, however, has been used when necessary in combination with the nonbenzodiazepines receptor agonists. Another agent seeking FDA approval for treating fibromyalgia-associated insomnia is Xyrem®. Xyrem is a metabolite of GABA (Gamma-aminobutyric acid) and its precise mechanism of action is unknown.

### Elaine's comment:

Although I knew as a healthcare professional that sleep was very important for the mind and the body, I had no idea how much sleep impacted my fibromyalgia. I also was very unaware that I was not getting restorative sleep.

I can see now very clearly that interrupted sleep, or not enough sleep, directly causes my pain levels to rise, and I am also aware

that my mind/brain does not function as well when I don't get enough sleep or quality sleep. My physiatrist explained about the impact sleep has on the symptoms of fibromyalgia and prescribed medications to assist me in obtaining quality sleep and sufficient length of sleep. I noticed that this made significant differences not only in improving my pain symptoms but also my mental outlook and cognitive abilities. I find proper dosing of medication(s) essential. I also find that regular and consistent exercise, both aerobic and nonaerobic, has great positive bearing on the length and the quality of my sleep. If I do not get "the sleep that I need," I experience both physical and mental/cognitive symptoms that negatively impact my daily functioning.

Recent articles demonstrate that lack of sleep or interrupted sleep (poor sleep) causes persons to have higher anxiety levels and less ability to think and problem solve. While these articles were not specifically addressing fibromyalgia patients, they were very helpful for me because as a fibromyalgia patient I do know that anxiety causes me to physically hold tension in my muscles. When this happens, it only makes sense that my pain levels will increase.

In the past I was not consciously aware of how much holding I did. I also wasn't aware of the effects that sleep played in this whole picture. As a result of visits to my **psychiatrist**, my physical therapy, and my psychological treatment, I learned to become attuned to my muscle tension, and what to do and how to release this. Now, I check my body frequently for muscle tension throughout the day. Noticing this provides me with much more choice because I can engage in breathing exercises and thought changing that can discharge muscle tension. There is no question to me that sleep plays a major and significant role in fibromyalgia.

# 47. What is restless leg syndrome?

Restless leg syndrome is characterized by an unpleasant, uncomfortable creeping, crawling, tingling, pulling, twitching, tearing, aching, throbbing, prickling, or grabbing sensation in the legs that produces an uncontrollable urge to relieve these

### Psychiatrist

A medical doctor who specializes in the treatment and prevention of mental and emotional disorders. Studies show that symptoms of restless leg syndrome and leg cramps are significantly more prevalent in patients with fibromyalgia and in those with rheumatoid arthritis. sensations by moving the legs frequently. This symptom typically occurs at rest or before sleep and is alleviated by activity. Studies show that symptoms of restless leg syndrome and leg cramps are significantly more prevalent in patients with fibromyalgia and in those with rheumatoid arthritis.

# 48. What is a sleep specialist?

A sleep specialist is a physician certified in the subspecialty of sleep medicine who specializes in the clinical assessment, physiologic testing, diagnosis, management, and prevention of sleep and circadian rhythm disorders. Sleep specialists treat patients of any age and use multidisciplinary approaches. Disorders managed by sleep specialists include, but are not limited to, sleep-related breathing disorders, insomnia, hypersomnia, circadian rhythm sleep disorders, parasomnias, and sleep-related movement disorders.

# 49. Is it safe to use herbal products for insomnia?

Many patients experiment with or use herbal products such as valerian root, ginkgo biloba, skull cap, and passion flower. Herbal products have a tranquilizing and sedating effect, but may also cause daytime sedation. These products pose several potential problems including drug interactions with other herbals or with prescription products. Predicting drug interactions with herbal products is problematic for two reasons. First, herbal products aren't regulated by the Food and Drug Administration. Second, there is no quality control in the manufacturing process, so every ingredient in the herbal products isn't always known and listed on the label. Therefore, the amounts of the substances present in each tablet can vary widely from batch to batch. For these reasons, always check with your pharmacist or physician before using prescription and herbal medications together. Par T Thr EE

Associated Pain Conditions

What causes facial pain?

Is there a connection between interstitial cystitis and fibromyalgia?

What is irritable bowel syndrome (IBS)?

More...

Fibromyalgia patients most often have associated fatigue, sleep disorders, irritable bowel syndrome, migraine headaches, immune system or endocrine system disorders, tension headaches, periodic limb movement disorder, restless leg syndrome, temporomandibular pain syndrome, interstitial cystitis, and vulvodynia.

# 50. What causes facial pain?

Temporomandibular dysfunction (TMD) causes pain and dysfunction in the head, neck, face, and jaw. These symptoms are often multiple and varied. TMD is a musculoskeletal disorder, which means that it affects muscles and bones. Sometimes people refer to TMD as TMJ. The correct term, as recommended by the American Dental Association, is TMD, or temporomandibular disorders. Both TMD and fibromyalgia affect the muscles of the face, jaw, head, neck, shoulders, and back. Unfortunately, both TMD and fibromyalgia often go undiagnosed. Eighty-five percent of people who suffer from fibromyalgia also suffer from TMD. We see the disorder most frequently in women between the ages of 20 and 50. Emotion and stress play an important role in TMD. TMD may be a sign that the patient is under stress. Anything that relieves stress is helpful, such as reading, exercising, listening to music, and the like. If the stress is getting to be a bit much, counseling may help you learn how to manage it. It is almost impossible to get relief from TMD if the underlying emotional issues are not addressed. Biofeedback is often used to gradually learn how to reduce muscle contractions.

# 51. Who should I see for facial pain—my physician or a dentist?

Keep in mind that, for most people, discomfort from TMD eventually goes away whether treated or not. Simple self-care practices are often effective in easing the symptoms. If you need more treatment, seek the advice of a dentist and aim for treatment that is conservative and reversible. If possible, avoid treatments that make permanent changes in the bite or jaw.

#### Temporomandibular disfunction (TMD)

Conditions characterized by facial pain and restricted ability to open/move the jaw.

Both TMD and fibromyalgia affect the muscles of the face, jaw, head, neck, shoulders, and back. Here are some tips:

- Avoid chewing gum and clenching your teeth.
- Eat soft foods.
- Eat small bites of food and control yawns to avoid opening your mouth wide.
- Maintain good posture and eat nutritious foods to promote joint and muscle healing.
- Hold the telephone, instead of cradling it against your shoulder.
- Eliminate spasms and pain by using mouth guards, moist heat, and medicines.
- Get counseling, stress reduction, or biofeedback/relaxation training.
- Have misalignment of your teeth corrected and, in severe cases, consider surgery.

If irreversible treatments are recommended, be sure to get a reliable second opinion. Many practitioners, especially dentists, are familiar with the conservative treatment of TMD. Because TMD is usually painful, pain clinics in hospitals and universities are also a good source of advice and second opinions. Specially trained facial-pain experts can often be helpful in diagnosing and treating TMD.

# 52. What is interstitial cystitis (IC)?

Interstitial cystitis/painful bladder syndrome (IC/PBS) defined by the International Continence Society (ICS) as "complaint of suprapubic pain, related to bladder filling, accompanied by other symptoms such as increased daytime and nighttime frequency, in the absence of proven urinary infection or other obvious pathology." Despite a century of study, the etiology of IC has been elusive. IC is a syndrome of urinary urgency, frequency, and pelvic pain but is often associated with other chronic conditions such as irritable bowel syndrome, chronic fatigue, fibromyalgia, migraine headaches, and pelvic floor dysfunction. It is unclear if the bladder is a primary pain generator or an "innocent bystander" in a more

diffuse process. More research is needed to characterize patients with symptoms of IC to determine who would benefit from different treatment targets.

# 53. Is there a connection between interstitial cystitis and fibromyalgia?

Many patients diagnosed with IC/PBS also have symptoms consistent with fibromyalgia. In 2008, a survey performed by Dr. Kenneth Peters, Chief of Urology at William Beaumont Hospital in Royal Oak, Michigan, demonstrated that 21% of the IC population at the hospital had symptoms of fibromyalgia. More research is needed to understand this association, including what percentage of those with IC have fibromyalgia.

Renae comments:

There are many similarities between fibromyalgia and IC. I have found that just like fibromyalgia, IC is not well recognized within the medical community or the general public. Not many people know what the condition is and look quite perplexed when I state the name of the condition. I have to admit it is a cumbersome word to just pronounce! And, like fibromyalgia, IC often goes undiagnosed or misdiagnosed, and it takes a diligent patient to search out physicians who understand and are able to run the appropriate tests to make the diagnoses. Once again, it is important to note that, just like fibromyalgia, IC is not a psychosomatic disorder nor is it caused by stress. Another point is that diet is very important to help control the symptoms but does not cause the conditions.

### Vulvodynia

According to the International Society for the Study of Vulvovaginal Disease (ISSVD), vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable neurologic disorder.

# 54. What causes pelvic pain (vulvodynia)?

The exact cause of **vulvodynia** is not known. Vulvar vestibulitis syndrome (now called vestibulodynia) has been reported in 11% of women with IC in surveyed populations. Vestibulodynia is characterized as severe pain upon touch of the vulvar vestibule which is located posterior to the glans clitoris, between the labia minora, containing the urethral and vaginal openings and Bartholin's ducts.

Many patients diagnosed with IC/PBS also have symptoms consistent with fibromyalgia. Vestibulodynia is often considered a subtype of vulvodynia; however, in vulvodynia the pain is present even without sensory stimulation, and the location of pain may include the vulva, perineum, and inner thighs in addition to the vestibulum. The International Society for the Study of Vulvovaginal Disease (ISSVD) defines vulvodynia as "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable neurologic disorder." The cause is unknown. It is diagnosed by touching the area with a cotton swab and noting any pain (mild, moderate, or severe, or score from 0 to 10 on the visual analog scale [VAS]). This "burning" pain is suggestive of a neuropathic pain response. There may be pain fiber proliferation, erythema of the tissues, and hypertonicity of the levator muscles.

The vulvar pain must be present for at least 3 months and infections, dermatologic, neoplastic, and neurologic conditions ruled out. Clinically, there is not a more widely used standardized test than the cotton swab (Q-Tip) test for vulvodynia and its subtypes at this time. Vulvodynia was found to be the fourth most common IC-associated symptom affecting 25% of women with IC. Extrapolations based on three studies examining the prevalence of vulvodynia in the United States suggest that more than 2.4 million women have vulvodynia.

# 55. Is vulvodynia related to fibromyalgia?

There is strong evidence of interrelated pain disorders including vulvodynia, fibromyalgia, interstitial cystitis, and irritable bowel syndrome. The exact cause is not known yet. There are a variety of medications and therapies used to treat both IC and vulvodynia. Antihistamines, antidepressants, anti-inflammatories, and physical therapy have been used to minimize symptoms of both. In addition, other therapies used for IC such as transcutaneous electrical nerve stimulation (TENS) and InterStim should be explored for their effect on vulvodynia as well as their urinary symptoms. Other useful therapies for vulvodynia include topical agents (lidocaine There is strong evidence of interrelated pain disorders including vulvodynia, fibromyalgia, interstitial cystitis, and irritable bowel syndrome. or compounded medications such as baclofen, gabapentin, and amitriptyline), oral medications (gabapentin, pregabalin, and calcium citrate), complementary therapies (yoga, guided imagery, and cognitive behavioral therapy) or a low-oxalate diet. Surgery for vulvodynia may be helpful in the recalcitrant cases but is utilized as a last resort since symptoms may be transient in many women.

# 56. What is Raynaud's phenomenon? Is this part of fibromyalgia?

Raynaud's disorder causes painful coldness and color changes in the fingers and toes. Many people with fibromyalgia also suffer from Raynaud's attacks.

Fibromyalgia patients suffer from chronic excessive sympathetic activation. One effect is cold hands and feet due to constriction of blood vessels in the fingers and toes. Research shows that this constriction is greater in females than in males. This suggests that the sympathetic fight-or-flight response has a greater effect in females and explains the higher rate of fibromyalgia in females.

### 57. What is irritable bowel syndrome (IBS)?

**Irritable bowel syndrome (IBS)** is a gastrointestinal disorder present in 33% to 77% of individuals with fibromyalgia. This prevalence rate is far higher than the 10% to 15% rate of IBS in the general population. IBS is one of several "functional" gastrointestinal disorders. A functional disorder is one in which no structural abnormality can be found, but function is disturbed.

The diagnosis of IBS is based on a specific cluster of bowel symptoms, primarily recurrent or persistent abdominal pain associated with diarrhea, constipation, or both. Secondary symptoms, such as bloating or the sudden urge to defecate, are also associated with the disorder.

#### Irritable bowel syndrome (IBS)

A chronic functional gastrointestinal disorder primarily characterized by abdominal pain and disturbed bowel functioning (diarrhea and/or constipation). It is present in 33% to 77% of individuals with fibromyalgia. Scientific study of IBS now examines its **overlapping conditions** with other medical conditions. Researchers have discovered that IBS not only co-occurs at high rates with some other digestive tract disorders, such as functional dyspepsia (stomach distress and indigestion), but also co-occurs at much higher rates than expected with four chronic health problems that have little to do with the intestinal tract: fibromyalgia, chronic fatigue syndrome, temporomandibular joint disorder (TMJ or TMD), and chronic pelvic pain.

# 58. Do fibromyalgia patients have signs and symptoms that overlap with hypothyroidism and adrenal insufficiency?

There is a significant controversy in the fibromyalgia literature as to whether fibromyalgia is caused by unrecognized **hypothyroidism**. Patients with fibromyalgia have clinical signs and symptoms that overlap with both hypothyroidism and adrenal insufficiency. It is therefore imperative to rule out these two endocrine disorders.

To treat a fibromyalgia patient with hypothyroidism, I prescribe a branded, synthetic T4 and adjust the dosage to attain a TSH level of 0.5–2.0 mU/L. My experience with patients who have both fibromyalgia and hypothyroidism is that attaining this goal often fails to produce a normal sense of well-being. This may be due to the overlap of symptoms between the two diseases or to unrealistic expectations of the treatment's benefits.

There is also significant controversy in fibromyalgia literature as to whether fibromyalgia is caused by unrecognized adrenal insufficiency. One hypothesis is that fibromyalgia patients have altered brain function that alters pain processing by the hypothalamic–pituitary–adrenal axis and the autonomic nervous system. The fatigue, sleep disturbances, myalgias, gastrointestinal complaints, and impaired cognitive function may be due to misalignment of the internal biological clock with abnormal sleep–wake cycles.

#### Overlapping conditions

A secondary illness that accompanies the primary illness affecting an individual. Patients with fibromyalgia are often affected by one or more overlapping illnesses, such as restless leg, interstitial cystitis, or tension headaches.

#### Hypothyroidism

Underactivity of the thyroid gland, causing tiredness, cramps, a slowed heart rate, and possibly weight gain.

There is significant controversy in fibromyalgia literature as to whether fibromyalgia is caused by unrecognized adrenal insufficiency. Hypoglycemia

An abnormally low level of glucose in the blood.

Clinical studies of fibromyalgia patients show normal circadian rhythms and normal diurnal cortisol and melatonin levels during the day and night. In addition, the hypothalamicpituitary-adrenal axis of fibromyalgia patients has been tested by inducing hypoglycemia through insulin injection. Hypoglycemia creates severe physiological stress, which activates the axis. Fibromyalgia patients respond with slightly lower ACTH levels than others do, but their cortisol response to stress is normal. Treating fibromyalgia requires a combination of pharmacologic and nonpharmacologic therapies. Although eliminating all the pain isn't possible in most fibromyalgia patients, partial relief can provide significant improvement in psychological distress, cognitive ability, sleep, and physical ability. The most effective treatment plan should not rely on pain medication exclusively but combine the use of exercise, physical therapy, psychological support, and patient education.

#### Renae's comment:

Hypothyroidism, manifested by profound fatigue, muscle weakness, and generalized malaise, closely resembles fibromyalgia. A few years after being diagnosed with fibromyalgia, I was diagnosed with Hashimoto's Thyroiditis — an autoimmune disease in which the immune system attacks the thyroid gland. I was now hypothyroid, for which the standard treatment is Synthroid®, a synthetic replacement for thyroid hormones T3 and T4 that restores normal levels of them in the body. The medication ordinarily works like a charm, but did not for me.

I was eager to start treatment, but after six weeks, the medication did not seem to be helping. My endocrinologist suggested I try Nature Thyroid®, a natural thyroid medication made from a pig's thyroid. (Unlike Armour®, another medication made by harvesting pig thyroid, Nature Thyroid has no inert ingredients added to it.) After 6 weeks it did help with my fatigue levels. By no means was it the answer to the pain and fatigue I live with, but there was an improvement. I feel very fortunate because my physician was willing to work with the natural medication. In fact, now when his fibromyalgia patients report sensitivities to medications or hormones, he will even suggest the use of a natural replacement.

We, as patients, need to feel comfortable discussing the need to try alternate types of medications, and hopefully your physician is willing to "think outside the box" and find whatever it takes to help control your pain and fatigue.

ParTfOur

Pharmacologic Management

What medications are prescribed for the treatment of fibromyalgia?

Which drugs are currently FDA approved for the treatment of fibromyalgia?

Why are fibromyalgia patients so sensitive to medications?

More...

# 59. What medications are prescribed for the treatment of fibromyalgia?

Drug therapy clearly plays a role in the treatment of pain. However, no single drug or class of drugs has proven to be the best choice for fibromyalgia pain. Therefore, the physician is left to sort out which of the many options may offer the greatest benefit to his or her patients. Only by taking the medications as prescribed and not skipping or omitting doses can a reliable and optimal result be attained. This is because some medications must be taken on a regular schedule, whereas others may be taken as needed to achieve the desired effect.

Medications that have been tried, with varying degrees of success, in fibromyalgia include:

- Nonnarcotic analgesics (i.e., Tylenol, tramadol)
- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Muscle relaxants
- Tricyclic antidepressants
- Select serotonin reuptake inhibitors (SSRIs)
- Serotonin and norepinephrine reuptake inhibitors (SNRIs)
- Anticonvulsants
- Stimulants
- Hypnotics/sleep aids
- Dehydroepiandrosterone (DHEA)

# 60. Do NSAIDs help in the treatment of fibromyalgia?

While NSAIDs are commonly used in the treatment of fibromyalgia, most patients find little benefit or effectiveness when these medications are used alone. However, this class of drugs may be useful analgesia adjuncts when combined with antidepressants. Furthermore, fibromyalgia patients may have other conditions that do respond to NSAIDs, such as acute and chronic inflammatory musculoskeletal disorders, headache, and fever.

#### Analgesic

A medication or agent that reduces pain.

#### Tramadol

A centrally acting analgesic for the treatment of pain in fibromyalgia. Also know as Ultram.

#### Nonsteroidal anti-inflammatory drugs (NSAIDs)

Drugs that act against inflammation, reduce fever, relieve muscle pain, and prevent blood clots.

#### Serotonin and norepinephrine reuptake inhibitors (SNRIs)

A type of antidepressant medication that increases the levels of both serotonin and norepinephrine by inhibiting their reabsorption into cells in the brain.

#### Anticonvulsants

Drugs given to prevent seizures.

### 61. What are SSRIs?

Select Serotonin Reuptake Inhibitors (SSRIs) are a class of antidepressants that selectively block the reabsorption (breakdown) of serotonin, a neurotransmitter that dampens pain responses and triggers stage 4 sleep. Therefore, despite their typical use to treat mood disorders such as depression and anxiety, SSRIs have also been proven to be beneficial in relieving pain and fatigue as well as improving the sleep disorders of fibromyalgia. Medications in this group include Prozac<sup>®</sup> (fluoxetine), Zoloft® (sertraline), Paxil® (paroxetine), Celexa® (citalopram), and Lexapro® (escitalopram). The best studied SSRI, Prozac, was found to decrease pain and fatigue while improving ability to function. There is some evidence to also indicate that other SSRIs may be just as helpful in treating fibromyalgia. Treatment with SSRIs is not always successful and even when the treatment does work, some people may find the side effects of these medicines unacceptable.

Side effects of SSRIs include:

- GI complaints including nausea, loss of appetite, diarrhea
- Mood complaints including irritability, anxiety, or dulled sensorium
- Sleep complaints including insomnia or drowsiness
- Sex complaints including loss of libido, sexual desire, or ability
- Constitutional complaints including weight gain, headaches, orthostatic hypotension, or dizziness

Many of these side effects generally improved after a few days of continuous use.

Other considerations:

• Using an antidepressant medicine to treat fibromyalgia does not mean that the condition is "all in your head."

Using an antidepressant medicine to treat fibromyalgia does not mean that the condition is "all in your head."

- The dose of an SSRI used to treat fibromyalgia is usually the same as that needed to treat depression.
- Studies suggest that using an SSRI and a tricyclic antidepressant together may be more successful at breaking the cycle of pain and sleep problems caused by fibromyalgia than using either of these medications alone.
- Studies have found that daily use of SSRIs may increase the risk of bone fracture in adults over the age of 50.
- SSRIs may cause drug interactions because they inhibit enzyme systems in the liver that break down other medications. These medications accumulate faster than the body can dispose of them. This can lead to higher drug concentrations and potentially increased pharmacological effects as well as increased adverse side effects. SSRI drug interactions have been reported with Xanax (alprazolam), tricyclic antidepressants, Coumadin<sup>®</sup> (warfarin), MAO inhibitors, Dilantin<sup>®</sup> (phenytoin), Tegretol<sup>®</sup> (carbamazepine), and theophylline.
- While unlikely, taking SSRIs and triptans (a class of medicines used to treat migraine headaches) together can cause a very rare but serious condition called **sero-tonin syndrome**.

### 62. How do the SSRIs raise serotonin levels?

SSRIs actually block the degradation or breakdown of serotonin. This maintains the serotonin in the brain for a longer period of time increasing the serotonin effect. The best analogy to use to demonstrate how this works is a bathtub. If water is flowing from the faucet into the bathtub but the drain is wide open, then the water empties right down the drain and nothing accumulates. An SSRI is equivalent to a drain plug. As soon as a drain plug is fitted into place, the level of water starts to accumulate in the bathtub. Now the water levels rise and water is available for a bath.

### 63. What are SNRIs?

Another group of antidepressants are the selective serotonin/ norepinephrine reuptake inhibitors (SNRIs). They selectively

### Serotonin syndrome

A hyperserotonergic state that is a very dangerous and potentially fatal side effect of serotonergic enhancing drugs; it can have multiple psychiatric and nonpsychiatric symptoms. block the reabsorption of both serotonin and norepinephrine. Thus, they are also known as dual reuptake inhibitors. Medications in this group include Cymbalta (duloxetine), Effexor® (venlafaxine), and Savella<sup>™</sup> (milnacipran). Two small studies found that patients who completed 8 weeks of Effexor (venlafaxine) therapy experienced at least a 50% reduction in fibromyalgia symptoms including significantly improved pain, less fatigue, better sleep, less morning stiffness, less depression and anxiety, and improvements in the disability caused by fibromyalgia. Cymbalta and Savella demonstrated efficacy in a number of outcome variables independent of its effect on mood in two high-quality multicenter studies conducted over a 3-month period of time.

Side effects of SNRIs include:

- GI complaints including nausea, indigestion, constipation, or loss of appetite
- Mood complaints including irritability, depression, or dulled sensorium
- Sleep complaints including insomnia, lethargy, or drowsiness
- Sex complaints including loss of libido, sexual desire, or ability
- Constitutional complaints including weight gain, dry mouth, headaches, elevated blood pressure, sweating, hot flashes, loss of balance, orthostatic hypotension, or dizziness

Other considerations:

- Cymbalta (duloxetine) is FDA approved for the treatment of fibromyalgia.
- Savella (milnacipran) is FDA approved for the treatment of fibromyalgia.
- SNRIs are sometimes prescribed instead of tricyclic antidepressants because they tend to work faster and cause fewer side effects.

Cymbalta (duloxetine) is FDA approved for the treatment of fibromyalgia.

Savella (milnacipran) is FDA approved for the treatment of fibromyalgia.

- SNRIs are not recommended for people with heart conditions because of the norepinephrine effect.
- Similar to SSRIs, taking SNRIs and triptans together can cause a very rare but serious condition called sero-tonin syndrome.

### 64. What are anticonvulsants?

Anticonvulsants are a class of drugs designed to prevent seizure activity. They are also useful in neuropathic pain (pain that originates within nerves). Medications in this group include Neurontin® (gabapentin), Lyrica (pregabalin), Topamax<sup>®</sup> (topiramate), and Keppra<sup>®</sup> (levetiracetam). Both Neurontin and Lyrica reduce the calcium-dependent release of several neurotransmitters, resulting in a diminished number of electrical signals passing between nerves in the central nervous system. Neurontin is the best studied and best tolerated anticonvulsant for treatment of neuropathic pain associated with diabetic neuropathy, postherpetic neuralgia, mixed neuropathic pain syndromes, phantom limb pain, Guillain-Barré syndrome, and the acute and chronic pain from spinal cord injuries. In a 12-week study, researchers found that fibromyalgia participants who were treated with Neurontin displayed significantly less pain, better sleep, and less fatigue compared with participants who received a placebo. Multiple studies, lasting as long as 1 year, have been carried out using Lyrica. These studies reveal that patients with fibromyalgia experience not only a significant reduction in pain, but also improvements in the areas of sleep quality, fatigue, global function, and quality of life.

Side effects of anticonvulsants include:

- GI complaints including nausea, constipation, or upset stomach
- Cognitive complaints including depression, amnesia, decreased thought processing, or dulled sensorium

- Sleep complaints including sedation, somnolence, fatigue, lethargy, or drowsiness
- Neurologic complaints including double vision, blurred vision, involuntary eye movements, tremor, or ataxia
- Constitutional complaints including weight gain, dry mouth, lower extremity swelling, or dizziness

Other considerations:

- Lyrica (pregabalin) is FDA approved for the treatment of fibromyalgia.
- There are no significant drug interactions with Neurontin.
- Added sedation may occur when using anticonvulsants with other medications that depress the central nervous system.
- Antacids given concurrently with Neurontin reduce its absorption by 20%. If antacids are taken, Neurontin should be taken 2 hours later.

### 65. What are tricyclic antidepressants, and are they still used for the treatment of fibromyalgia?

Tricyclic antidepressants are yet another class of antidepressant medications used in the treatment of fibromyalgia. This class includes the first available antidepressant medications and, logically, the first studied for fibromyalgia. Tricyclic antidepressants generally function as norepinephrine reuptake inhibitors; however, two (Elavil® and Tofranil®) also have weak serotonin reuptake inhibition. Researchers believe that this gives tricyclic antidepressants their analgesic effect. Medications in this group include Elavil (amitriptyline), Sinequan® (doxepin), Pamelor® (nortriptyline), Tofranil (imipramine), and Flexeril® (cyclobenzaprine). Randomized, controlled trials show that 10 to 50 mg of amitriptyline at bedtime is effective. Flexeril is marketed as a muscle relaxant, but structurally it is a tricyclic. In randomized, controlled trials lasting 6 to 12 weeks, patients given 10 to 40 mg per day also found it effective. Lyrica (pregabalin) is FDA approved for the treatment of fibromyalgia. Side effects of tricyclic antidepressants include:

- GI complaints including constipation
- Sleep complaints including sedation, somnolence, fatigue, lethargy, or drowsiness
- Neurologic complaints including blurred vision, impaired balance, impaired gait, or impaired attention levels
- Constitutional complaints including weight gain or dry mouth
- Additional complaints including skin rashes, jaundice, sexual dysfunction, decreased tear flow, urinary retention, arrhythmias, or abnormalities that prevent the muscle cells of the heart from contracting in an efficient, synchronized pattern

There are other considerations:

- Doses recommended for fibromyalgia are much smaller than the doses used to treat depression.
- For patients who need to be slowly titrated on the medication, doxepin (10 mg/ml) is available as a liquid.
- Tricyclics depress activity in the brain and spinal cord. Accumulative depressant effects may occur if they are taken along with other medications that depress the central nervous system, such as antihistamines, tranquilizers, sleep medications, narcotics, muscle relaxants, and alcohol.
- Expect to wait 1 to 3 weeks for maximum sleep modification and analgesic effect.

### 66. I use Elavil for sleep. Is this an effective drug?

Elavil and Desyrel<sup>®</sup> (trazodone), two first generation drugs, have significant anticholinergic side effects including dry mouth, heart problems, and sedation. It is because of their sedative side effect that these medications were typically chosen to treat fibromyalgia. However, if a patient is put to sleep with Elavil but then is kept up all night with a dry cotton-mouth, the medication is a poor choice due to the disruptive nature to deep stage 4 sleep. Until 1992, tricyclic antidepressants were all that were available and thus the best choice at the time. They were also viewed as ideal medications because of their antidepressant properties (it was believed that all fibromyalgia patients were depressed). However, studies now show that the doses that are used for sleep in fibromyalgia are incapable of providing antidepressant characteristics. In addition, while strong evidence exists to demonstrate Elavil's effectiveness in helping sleep and overall well-being, better medications have been developed as alternatives with less concerning side effects and better targeting of specific neurotransmitters.

#### Jane's comment:

I did not like the Elavil. Though it helped me sleep, I awoke feeling drugged. In addition, I started craving sugar. Never in my life had I wanted straight sugar on a spoon. Needless to say, I started to gain weight. I took the Elavil for a while and started feeling a little better, but I gained 25 pounds. So I stopped the Elavil and lost 20 pounds. Then the pain and fatigue increased, so I went back on the Elavil. This started a vicious cycle.

### 67. Why is it sometimes necessary to try many different drugs to treat my symptom?

The World Health Organization recommends a stepped approach to managing pain. During initial treatment, the lowest dose of a single agent is used. The dose is titrated to determine the effectiveness of the medication. If a single medication doesn't control the pain, then an additional medication from another class is added. This method incorporates all the different types of medications to maximize pain control. During each step, the patient is assessed to determine his or her response to the treatment. Fibromyalgia patients present with different symptoms and severity of symptoms. As a result, it is common for physicians to try different drugs in various combinations.

The World Health Organization recommends a stepped approach to managing pain

### 68. Which drugs are currently FDA approved for the treatment of fibromyalgia?

There are three medications currently approved by the U.S. Food and Drug Administration (FDA) for the treatment of fibromyalgia. Lyrica (pregabalin), manufactured by Pfizer, was the first to receive approval in June 2007; Cymbalta (duloxetine), manufactured by Eli Lilly, received approval in June 2008; and Savella (milnacipran), manufactured by Cypress Bioscience, Inc., received approval in January 2009.

Lyrica was found to be effective in treating fibromyalgia in an 8-week randomized, double-blind placebo-controlled trial. The study compared various doses of pregabalin in 529 patients. The study reported that Lyrica at 450 mg/day significantly reduced the average severity of pain in the study compared with placebo (-0.93 on a 0 to 10 scale;  $P \le 0.001$ ), and significantly more patients in this group had  $\geq$  50% improvement in pain at the end point (29%, versus 13% in the placebo group; P = 0.003). Lyrica at 300 and 450 mg/day was associated with significant improvements in sleep quality, fatigue, and global measures of change. Lyrica, at 450 mg/day, improved several domains of health-related quality of life. Dizziness and somnolence were the most frequent adverse events. Rates of discontinuation due to adverse events were similar across all four treatment groups. The authors concluded that Lyrica at 450 mg/day was efficacious for the treatment of fibromyalgia, reducing symptoms of pain, disturbed sleep, and fatigue compared with placebo. Lyrica was well tolerated and improved global measures and health-related quality of life.

**Cymbalta** was found to be effective in treating fibromyalgia in a 12-week randomized, double-blind placebo-controlled trial. The study compared a 60-mg dose of Cymbalta to a placebo in 207 patients. The study reported that Cymbaltatreated subjects improved significantly more (P = 0.027) on the **Fibromyalgia Impact Questionnaire (FIQ)** total score, with a treatment difference of -5.53 (95% confidence interval -10.43, -0.63), but not significantly more on the FIQ pain

#### Fibromyalgia Impact Questionnaire (FIQ)

The FIQ is an assessment and evaluation instrument developed to measure fibromyalgia patient status, progress, and outcomes. It has been designed to measure the components of health status that are believed to be most affected by fibromyalgia.

Cymbalta was found to be effective in treating fibromyalgia in a 12-week randomized, double-blind placebocontrolled trial. score (P = 0.130). Compared with placebo-treated subjects, Cymbalta-treated subjects had significantly greater reductions in Brief Pain Inventory average pain severity score (P = 0.008), Brief Pain Inventory average interference from pain score (P = 0.004), number of tender points (P = 0.002), and FIQ stiffness score (P = 0.048), and had significantly greater improvement in mean tender point pain threshold (P = 0.002), CGI-Severity (P = 0.048), PGI-Improvement (P = 0.033), and several quality-of-life measures. Cymbalta treatment improved fibromyalgia symptoms and pain severity regardless of baseline status of major depressive disorder. The authors concluded that Cymbalta was an effective and safe treatment for many of the symptoms associated with fibromyalgia in subjects with or without major depressive disorder.

Savella was found to be effective in treating fibromyalgia in a 12-week randomized, double-blind, placebo-controlled, flexible dose escalation monotherapy trial. The study compared milnacipran twice daily, milnacipran once daily, and placebo in 125 patients. Eighty-four percent of all milnacipran patients escalated to the target dose of 200 mg with no tolerability issues. Of the milnacipran-treated patients, 37% reported at least a 50% reduction in the intensity of their pain, compared to just 14% of placebo patients (P = 0.0395). Milnacipran twice daily was also statistically superior to placebo treatment on the FIQ, the McGill pain questionnaire, and a 24-hour recall visual analogue pain scale. Furthermore, milnacipran patients reported significant improvement in fatigue on the FIQ fatigue scale and 75% of all milnacipran-treated patients reported overall global improvement, compared to 38% in the placebo group (P = 0.004). The results of the study revealed that both the once- and twice-daily groups showed statistically significant improvements in pain, as well as improvements in global well being and fatigue, and the drug was generally well tolerated.

Another drug actively seeking FDA approval is Xyrem (sodium oxybate), a GABA agonist and neuroprotective nutrient that is classified as an orphan drug. In one study, Xyrem effectively

reduced the symptoms of pain and fatigue in patients with fibromyalgia and dramatically reduced the sleep abnormalities (alpha intrusion and decreased slow-wave sleep) associated with the nonrestorative sleep characteristic of this disorder.

### 69. Should I be concerned with the side effects of the medications I am taking?

All medications have side effects, including Tylenol (**acet-aminophen**), and all have the potential to make an individual feel worse. Manufactures are required to list all potential side effects, although this does not mean that every patient will experience all of these reactions. In fact, the FDA requires the manufacturers to list all patient complaints experienced while taking a medication during the drug's FDA-approval process. Therefore, antidepressants will have depression listed as a side effect and hypnotics will have drowsiness listed. True side effects of a medication are the ones that occur at a frequency significantly different than those experienced while taking a placebo. If a concern develops about a medication's side effect, the prescribing physician should be notified as soon as possible to determine the best course of action.

If you have a complaint about a product regulated by the FDA, they would like to hear about it. Two reporting systems are available:

- Consumer Complaint Coordinators (CCC): Located in FDA offices throughout the United States and Puerto Rico, they will listen, document your complaint about an FDA-regulated product, and follow up as necessary. Consumers should report problems to the CCC for their geographic region. (http://www.fda.gov/opacom/ backgrounders/complain.html)
- 2. **MedWatch**: Used for reporting any adverse events (unexpected side effects) that occur while using human healthcare products and FDA-regulated products such as medicines, over-the-counter products, supplements,

#### Acetaminophen

The generic name for Tylenol.

#### MedWatch

The Food and Drug Administration's reporting system for adverse events. cosmetics, and medical equipment. (https://www.access data.fda.gov/scripts/medwatch)

# 70. What is the role of a compounding pharmacy?

For patients with fibromyalgia, compounding pharmacies play a completely different role than conventional pharmacies. They offer medications in different forms and different dosages than those available and supplied by commercial pharmaceutical manufacturers. They also offer unique medications and combinations not produced for nationwide distribution. Compound pharmacists typically have more training, equipment, and knowledge in the area of compounding than traditional pharmacists. A compound pharmacy has thousands of dollars invested in special equipment such as capsule-making machines, sensitive scales to measure accurate doses, ventilating hoods for safety, mills to reduce particle size, and various mixing devices. As a result of this equipment and their expertise, compound pharmacists will typically prepare unique dosage forms of capsules, creams, suppositories, and liquids on a daily basis.

Examples of medications that can be obtained through a compounding pharmacy are:

- Liquid forms of medications supplied in various concentrations
- Transdermal gels
- Capsules (in both immediate- and sustained-release versions)
- Suppositories
- Oral troches

There are different reasons for using each delivery method and each one effectively dispenses the correct dose of medication to the patient. For patients with fibromyalgia, compounding pharmacies play a completely different role than conventional pharmacies.

#### Compounding pharmacy

A facility that both makes and sells prescription drugs. A compounding pharmacy can often prepare drug formulas that are specially tailored to patients.

### 71. Are there any concerns with the use of herbs and supplements?

The use of herbs and supplements can pose several problems. First, these products aren't regulated by the FDA. Therefore, they can make unsubstantiated claims of safety and effectiveness. Realizing that fibromyalgia patients will do almost anything to relieve pain, fatigue, and suffering, many of these unregulated companies prey on fibromyalgia patients, attempting to convince them that a particular herb or supplement is necessary to resolve the syndrome. Second, there is no quality control or accountability during the manufacturing process. Therefore, every ingredient in the herbal products is not always identified or listed on the label. Additionally, the relative amounts of the substances contained in each pill can vary widely from batch to batch. Finally, there can be very serious drug interactions with these over-the-counter products and traditionally prescribed medications. Thus, it is imperative that fibromyalgia patients always check with their pharmacist or physician before using prescription and herbal medications together.

### Dr. Tamler's comment:

I noticed some extra containers in the bagful of medications brought in by the patient. They happened to be the nonprescribed supplements that she was taking. Her son living out West was an herbalist and had told her he wanted her to take these products. Of course he had his mother's best interest in mind. One of the herbs was Arnica Montana, used in liniment and ointment preparations for strains, sprains, and bruises. Arnica preparations used topically have been demonstrated to have anti-inflammatory properties and assist normal healing processes. However, if ingested internally, this herb not only produces severe gastroenteritis and internal bleeding of the digestive tract, but **heart muscle paralysis** as well. After I had voiced my concerns, the patient later found out that her son neglected to tell her that the product was suppose to be used topically. She stopped using herbs and supplements altogether.

# 72. What are some of the visual side effects that occur with medications used to treat fibromyalgia?

There are several visual complications that can occur with prescription and over-the-counter medications, although most of them are temporary and reversible. These side effects include:

- Dry eye disease (DED): A condition in which the clear front surface of the eye, the cornea, no longer remains moist
- Accommodative spasms: Cause blurred vision, which is the second most common visual complaint of patients with fibromyalgia
- Binocular dysfunction

### 73. Why are fibromyalgia patients so sensitive to medications?

With fibromyalgia, it is as if someone has turned up an amplifier within the body. Every response is amplified: sounds, smells, sensitivity to touch and pain. All of these are overly exaggerated due to an overly sensitive central nervous system. As a result, all body systems have the potential to overrespond to any stimulus presented to the body, such as medications, chemical additives, perfumes, etc.

### 74. Does one drug work better than the others?

There currently is no single drug to cure fibromyalgia, and no drug is clearly superior to another. The best regimen is usually established through closely coordinated care with a physician interested in treating fibromyalgia and its associated conditions. Oftentimes by simply listening to the patient, the most effective medication regimen can be instituted. Dry eye disease (DED)

Decreased tear production or increased tear film evaporation.

There currently is no single drug to cure fibromyalgia, and no drug is clearly superior to another.

ParTfivE

Complementary Āpproach

How can I avoid a flare up?

What are self-management skills?

What nutritional therapy/recommendations would you suggest for fibromyalgia?

More...

Fibromyalgia treatment involves the positive blending of both mainstream medicine and alternative treatments. The patient most likely to "succeed" is open-minded. Implementing self-management strategies can have rich rewards—symptom relief and the resulting ability to function at a higher level so you enjoy improved quality of life.

Because fibromyalgia is a disorder with multiple presentations, its management must take multiple approaches. There is no single "tried-and-true" recipe for treatment. Management varies according to the severity of symptoms in each patient.

The key to effective management is collaboration between knowledgeable healthcare providers and a patient's selfmanagement techniques. Among the patient skills that matter most is a positive attitude.

### 75. What is cognitive behavioral therapy, and how is it helpful to those with fibromyalgia?

**Cognitive behavioral therapy (CBT)** is a blend of two types of psychotherapeutic techniques. The cognitive part focuses on the individual's mental environment. The therapist helps the individual identify maladaptive beliefs about their illness and reduce expectations for failure to solve problems in a more adaptive fashion. Cognitive therapy focuses on the use of rational thinking to help a person gain an accurate understanding of the nature of their condition so that the condition can be managed more effectively. The behavioral component focuses on the way the person's symptoms are affected by various factors so that the individual can develop better strategies for managing their symptoms via modifications in their behavior.

For example, patients with fibromyalgia tend to try to ignore their pain levels while performing activities for as long as they can. This strategy is commonly employed by most people without fibromyalgia while performing their activities of daily

#### Cognitive behavioral therapy (CBT)

A type of psychotherapy in which the therapist teaches the patient to restructure his or her cognitive beliefs (thought patterns) and hence, behavior. living as a way of completing tasks in spite of mild discomfort or fatigue. When individual with fibromyalgia tries to ignore and push through the pain, the pain increases to very high levels and they are often unable to complete the task or, in more severe cases, end up in bed for days on end. Individuals with fibromyalgia need to learn to identify when their pain levels are increasing so they can take breaks and employ relaxation techniques to keep the pain from escalating. For example, a female executive with fibromyalgia had to walk very long distances in her job and would often miss work on Thursday or Friday because her pain and fatigue levels would build over the course of the workweek. By taking a few minutes and sitting down on benches when the pain and fatigue levels from increasing to intolerable levels and was able to stop missing work.

# 76. What is involved in cognitive behavioral therapy, and who should I see for this therapy?

Cognitive behavioral therapy is generally conducted by psychologists who have been trained in these techniques. Cognitive behavioral therapy is conducted in three phases. The first phase involves education concerning the nature of fibromyalgia, self-monitoring of symptoms, and goal setting. The second phase involves acquiring the skills to accurately predict which methods (taking breaks, slowing down, reprioritizing, altering activity order, practicing relaxation, taking medication, sleep hygiene, aerobic exercise) provide the best outcome. The third phase involves employing the techniques in real life. Most CBT practitioners are psychologists, although CBT can be conducted by other types of practitioners who are trained to perform the techniques.

Jane's comment:

My pain management psychologist helped me learn the difference between good pain and bad pain. He helped me learn to structure my days and not overdo. He taught me that if I have five units Cognitive behavioral therapy is conducted in three phases.

of energy for the day, why waste four units walking the grocery store? I should use a scooter to get my groceries. By not walking, I saved that energy to spend quality time with my husband. I learned not to struggle with pain just to do the dishes. I'd fill the sink with water and dishes, then lie down. After 10 minutes, I'd wash the dishes, fill the sink again, and lie down again. I followed this process until I had the strength to wash all the dishes. My pain management psychologist also taught me how to recognize my fatigue signals. I had ignored them for so long that I had to relearn them. One of the most crucial elements of this healing process was recognizing the anger I had because I was sick. I felt that I had no control over my life and that my body had betrayed me. My pain management psychologist's help was very important. Through biofeedback I learned to recognize that I was contracting muscles I wasn't using. Doing so adds to muscle pain and fatigue. I learned how to relax those muscles. I learned that I put way too much stress on myself. Because I felt tired and unable to do things like clean or see friends, I would obsess over not having vacuumed or dwell on the thought that going out to dinner and dancing with friends was too much and life was so unfair. Over time I learned a new outlook: Do I really need to vacuum? Will it make that much difference if I don't do it until Saturday? Why don't I meet friends for dinner and then come home? They are my friends; they will understand or they should.

#### Jenny's comment:

The doctors at the pain clinic soon referred me to a chronic pain psychologist who works with fibromyalgia patients and specializes in treating people living in chronic pain. It was wonderful to talk to someone who had studied fibromyalgia. He could finish my sentences about the pain. His face showed not only that he was listening, but that he really cared. He helped me manage the pain and find ways to relax. Equally important, he taught me ways to say "No." All my life, I've tried to do everything for everyone all the time. It has been hard for me to accept that I can no longer do that, and it's been hard for others to understand. I see this wonderful psychologist regularly.

# 77. What are behavioral pain management techniques?

Certain activities can reduce sympathetic and central nervous system activation. Play quiet, calming music; avoid noisy environments; wear ear plugs; dress warmly in cold temperatures; shop when stores aren't crowded; avoid loud people; soak in a hot tub or whirlpool; use heating pads; and so forth.

Slow down. Hurrying activates the sympathetic nervous system. It causes your muscles to contract more. Understand that slowing down is hard to do. Initially, your psyche will rebel, because it associates hurrying with goal achievement. The faster I go, the more tasks I can complete per unit time. When I slow down, I feel like I'm not getting anything done. Slowing down is hard because it reduces short-term feelings of accomplishment. This can arouse feelings of inadequacy, laziness, and guilt.

Learn to conserve. If you have moderate to severe fibromyalgia and you want to attend a wedding on Saturday, get plenty of rest on Thursday and Friday. Get your clothing ready several days in advance. On the day of the wedding, get some rest after the ceremony and before the reception. Make sure you have a comfortable chair (bring a pillow if necessary). Try to find a comfortable seating position, and take breaks in the lounge or sit in your car when you need to. Don't plan much for the next day, so you can give your body a chance to recover.

Prioritize. If you want to give your child the quality time he or she needs, don't try to keep an immaculate house. Your children aren't going to remember that the house was clean. But they may remember that you preferred to do housework rather than spend time playing with them. The same goes for your partner. When your partner returns from work, he or she may be more pleased if the house is a little messy but you are feeling good, are in a good mood, and can be up and around. Figure out how to move/position your body without increasing the pain. This may sound easy, but it can be difficult. Severe pain is so traumatizing to the psyche that, once it subsides, the psyche tries to forget how bad it was. Therefore, it's hard to remember what movements you should avoid. In addition, patterns of body movement are overlearned habits that we do automatically. For years, a fellow with severe lower back pain bent at the waist to brush his two dogs every day. One day he tried sitting on a footstool and was amazed at how much less pain he experienced when he brushed his dogs in this new position.

### 78. What is catastrophizing?

**Catastrophizing** occurs when a person ruminates about all the terrible things that are probably going to happen. It is an ineffective cognitive method of coping. When you are faced with a threat, such as being in pain for a long period of time, focusing on all the terrible things that could happen generates increased anxiety, dread, and hopelessness about the future. In addition, research using function **magnetic resonance imaging (MRI)** indicates that catastrophizing is associated with increased activation of brain regions involved in cognitive and emotional activation. Finally, catastrophizing is also associated with increased pain sensitivity in fibromyalgia patients.

### 79. What is mindfulness, and how is it used to counteract the tendency to catastrophize?

**Mindfulness** is a form of deep relaxation that involves focusing on being "in the moment." This involves learning how to stop the "mental chatter" that mirrors everyday concerns, past hurts inflicted by others, reasons why one is angry, etc. Coupled with learning how to stop the mental chatter is learning to focus internal bodily sensations that occur during deep relaxation and enhanced experiences of various sensory phenomena.

Practice mindfulness. Try to enjoy your surroundings (air, plants, people, music, etc.) to their fullest. This requires mental discipline and a refocus on the quality of your experiences as

#### Catastrophizing

Occurs when a person ruminates about all the terrible things that are probably going to happen.

#### Magnetic resonance imaging (MRI)

A noninvasive, non-X-ray diagnostic technique based on the magnetic fields of hydrogen atoms in the body. MRI provides computergenerated images of the body's internal tissues and organs.

#### Mindfulness

A form of deep relaxation that involves focusing on being "in the moment." opposed to the quantity of them. What we really desire is contentment with what we have, which requires that we stop focusing on what we don't have. It is human nature to take what we have for granted, and it is important to work on not doing so. In addition, practice deep relaxation techniques. Biofeedback training can also help you in this situation, so that you can learn how to relax muscles and reduce nervous system activation.

Relaxation skills can moderate fibromyalgia pain and often moderate other features of the disorder, such as sleep disorder, tender point sensitivity, and overall feelings of well-being. Relaxation, assisted by biofeedback training, raises the trainee's sense of self-efficacy—the confidence that he or she can do something to improve his or her condition.

### 80. What is biofeedback?

Biofeedback involves using various sensors to record bodily functions and simultaneously present visual and auditory information in order to allow a person to gain voluntary control over functions that are normally involuntary.

### Mark's comment:

Biofeedback made me aware of how much stress has to do with your condition. There were many types of stress I was undergoing at the time, and through biofeedback you can actually look at a monitor as it shows you how tense your muscles actually are and that you have the ability to actually lower some of the tension in your body.

### 81. How is biofeedback used in the treatment of fibromyalgia?

The greatest controlled research support for biofeedback in the treatment of fibromyalgia is surface **electromyogram** (sEMG) **biofeedback**. In sEMG biofeedback of fibromyalgia, the therapist attaches sensors that record the electrical activity of muscles. Research has shown that fibromyalgia patients tend to have resting sEMG levels an average of 4 to 5

Biofeedback involves using various sensors to record bodily functions and simultaneously present visual and auditory information in order to allow a person to gain voluntary control over functions that are normally involuntary.

#### Electromyogram (sEMG) biofeedback

Surface EMG biofeedback allows therapists to record the electrical activity of muscles through sensors attached to the skin. times the resting activity of normal control subjects. The therapist guides the patient through the process of learning how to develop voluntary control over these resting muscle contractions. It is important for the therapist to be familiar with common pitfalls that interfere with learning deep muscle relaxation such as trying too hard, becoming competitive with the devices, focusing excessive attention on the feedback signals, not repositioning often enough, etc.

# 82. What other forms of biofeedback are being used in treating fibromyalgia?

Some therapists are performing EEG (brain rhythm) biofeedback to try to reduce the central sensitization that characterizes fibromyalgia. Some therapist are also using heart rate and respiration biofeedback to train a deep relaxation response. Finger temperature biofeedback has a long research record of being effective in treating the Raynaud's Phenomenon (cold hand attacks) that is experienced by many fibromyalgia patients.

# 83. What other behavioral techniques are being used in treating fibromyalgia?

Hypnosis is sometimes helpful in pain management. In addition, some therapists are reporting some symptom reduction using audiovisual entrainment, a treatment that consists of flashing lights and rhythmic auditory sounds that are designed to alter brain rhythms.

### 84. How can I find a biofeedback therapist in my area?

Biofeedback therapists obtain certification from the Biofeedback Certification Institute of America (BCIA). In addition to written and oral exams, they must undergo supervised internship training and, after being certified, are required to obtain 20 hours of continuing education credit per year.

# 85. Do fibromyalgia patients experience the stages of grieving?

Yes, allow yourself to grieve your reduced functional capacities. Each activity you're no longer able to engage in causes a grief reaction. Grief is the feeling of loss, such as in the loss of a loved one. Mourning a loss is a process with five stages:

- 1. Denial
- 2. Anger
- 3. Bargaining with God (when applicable)
- 4. Sadness/depression
- 5. Acceptance

When you become unable to engage in activities that give you a sense of accomplishment, you lose the joy those activities brought you. So, it is important to find new activities that restore that sense of accomplishment without increasing the pain.

Think outside the box. Try container vegetable or herb gardening, talking to support group comembers, listening to books on tape, cooking for scout groups, volunteering, and so on. If the sadness becomes overwhelming and you feel hopeless, talk to someone you trust (such as a minister or health professional) about what you should do. Reaching acceptance means that you aren't denying your limitations, and you feel less sad and angry.

### Mark's comment:

Probably my biggest hurdle was to accept the fact that I had something that I couldn't control. I lived most of my working and private life being a leader by example, the person who could overcome and adapt to any situation, the man who could get the job done, and being the provider, supporter, and role model to my family. I then found myself in a position where I didn't have control over the way I felt anymore and it just devastated me—literally devastated me.

# 86. How does physical therapy help patients with fibromyalgia syndrome?

Physical therapy utilizes four types of interventions that benefit fibromyalgia patients:

- Exercise: includes stretching, strengthening, aerobics, coordination exercises, and balance training
- Therapeutic modalities: **ultrasound**, electrical stimulation, low-level light therapy, heat, and cold
- Manual therapy: includes soft tissue mobilization, massage, myofascial release (type of massage), spray/stretch, manual stretching, joint mobilization, and proprioceptive neuromuscular facilitation
- Patient education: consisting of instruction in proper posture, body mechanics, ergonomics, and self care

All four of these interventions help the two main problems associated with fibromyalgia—central nervous system hypersensitivity and muscle dysfunction.

Exercise improves flexibility, coordination, and muscle strength. It increases endurance and tolerance to activity. Stretching stimulates circulation to the muscles—relaxing them and facilitating the removal of waste products (lactic acid). Aerobic exercise, along with the well known benefits to the circulatory system, increases the release of **endorphins** (hormones) that decrease pain signals in the brain. Exercise is movement, and most fibromyalgia patients are afraid of moving because it is painful. If we do not move we "rust." Our muscles stiffen and weaken leading to pain and discouragement.

Fibromyalgia patients have trouble with balance for several reasons. They frequently have pain in the legs and the lower back areas that help send feedback to the brain (**proprioception**) to tell us where our body is in space, which is important in balancing. Pain disrupts the proprioceptive feedback to the brain, leading to loss of balance and coordination. Tightness and

### Ultrasound

An electrical modality that transmits a sound wave through an applicator into the skin to the soft tissue in order to heat the local area; for relaxing the injured tissue and/or dispersing edema.

Exercise improves flexibility, coordination, and muscle strength.

#### Endorphins

Any of a group of proteins with potent analgesic properties that occur naturally in the brain.

#### Proprioception

The ability to sense the location, position, orientation, and movement of the body and its parts. weakness in the legs and trunk further contribute to poor balance. Standing on one leg, within easy reach of something to hold onto to steady yourself (kitchen sink), for a goal of 2 minutes is the most helpful exercise to regain your sense of balance.

Therapeutic modalities such as ultrasound, electrical stimulation, light therapy, heat, and cold block pain signals from the muscles to the brain, breaking the pain cycle associated with central nervous system hypersensitivity. These modalities help by increasing blood flow, which helps to heal tight and damaged muscles. Ultrasound and electrical stimulation vibrate muscle tissue, breaking up the "knots" frequently found in tight fibromyalgic muscles.

Manual therapy, especially massage, is frequently the only treatment that can loosen the tightness in fibromyalgic muscles. Skilled hands can feel how much pressure to apply and in what direction to get the muscles to relax and the tissue restrictions to release. Manual therapy gives instant feedback to the patient and practitioner to whether the muscles are relaxing. Manual stretching by the physical therapist teaches the patient what proper stretching should feel like and what muscles are most problematic. PNF (proprioceptive neuromuscular facilitation) is hands-on treatment that involves manual techniques to facilitate stretching or retrain (strengthen) weak muscles.

Instructing the patient in how to take care for themselves with proper posture and body mechanics is crucial to maintain the benefits received in physical therapy treatment. The patient going home and sitting awkwardly at his computer for several hours just negates all the positive effects of treatment.

### Sharon's comment:

Physical therapy was also suggested to help control my pain. But finding a physical therapist who understood fibromyalgia was as challenging as finding an understanding physician had been. For The patient going home and sitting awkwardly at his computer for several hours just negates all the positive effects of treatment. one thing, I found most physical therapy sites too eager to start exercises that included free weights and machines, which always made me worse. For another, I found few places where patients were given time to talk to a therapist before starting treatment. I never felt comfortable putting my questions to the aides who actually performed the therapy, so I was constantly changing sites, searching for a center that offered the all-around therapy situation I felt I needed. Finally, one of my new friends recommended a therapist at a center near my home. Eighteen years later, this therapist continues to treat me.

The problem with physical therapy, as with other fibromyalgia treatments, is that it isn't designed specifically for treating fibromyalgia. Therefore, some ways of administering it can make fibromyalgia worse. That's why it's crucial to find a therapist who understands fibromyalgia. My experience taught me that, when considering a therapy site, that's the time to ask the therapist whether they've worked with the disorder and what success he or she's had.

Jane's comment:

On the medical side, I had a lot of physical therapy, some of it in water. Finally, I started getting better. I started walking on my treadmill 1 minute a day. After a week, I moved up to 2 minutes. Although I could have walked longer, I knew when to stop so that I didn't overdo. So I started slow and listened to my body for signals. As I got better, I was taken off Zoloft. I also cut back, then eliminated, the Vicodin, then the Ultram. It is amazing to think that at one time I was taking eight Vicodin and eight Ultram a day and still having pain.

### 87. Why do many patients feel worse with physical therapy treatment?

Many physical therapists do not understand the underlying problems with fibromyalgia, in particular central nervous system hypersensitivity. Fibromyalgia patients' brains have a lower threshold to pain so they do not tolerate the same stretching and strengthening exercises normally given to other patients. They also have tight and knotted muscles, further lowering their pain threshold. Interrupting the pain cycle must be done before attempting exercise.

There is a three-step protocol to treating fibromyalgia patients:

- Phase one consists of relaxing the muscles utilizing modalities such as heat and ultrasound. Manual therapy of massage and soft tissue mobilization breaks up restrictions in the muscles, decreasing muscle guarding and tightness. This leads to less pain and prepares the muscles for stretching and strengthening exercises. Phase one lasts about 1 to 2 weeks with a frequency of three treatments per week.
- Phase two involves the same treatments, but stretching and low-intensity aerobic exercise is begun. Patient education in proper postures, body mechanics, and ergonomics is done throughout all the phases. During these first two phases the brain begins to learn not to overreact to the pain, and the muscles begin to repair themselves. The patient is able to relax, which helps break up the pain cycle. Now that the patient is feeling better and his or her muscles have more flexibility, he or she can begin to tolerate strengthening exercises. At home, heat is used to relax the muscles and block pain. Gentle stretching exercises are also done.
- Phase three begins with strengthening exercises as well as other exercises that target the patient's unique and specific problems, such as loss of balance or coordination. Muscles that were found weak in the initial evaluation are targeted.

Most patients even in a moderate amount of pain are able to tolerate 4 to 5 minutes each on an exercise bicycle, walking on a treadmill, and an upper body bicycle. By using several different machines, one area of the body is not overworked. Movement is the most important aspect of the treatment. Throughout the course of treatment, aerobic exercise is increased by a couple minutes until 30 minutes of steady exercise is achieved at a low intensity. Movement is the most important aspect of the treatment. It increases circulation as well as gets the body moving, which has a positive psychological effect on patients when they realize they are able to move without pain. Movement also modulates (decreases) pain by blocking pain signals.

Key points to remember with physical therapy treatment are:

- Soft tissue mobilization (massage) is done gently, slowly working deeper as muscles relax and loosen. Massaging perpendicular to the muscle fibers is better tolerated and should be done first. Pushing directly down onto trigger points (tender areas of muscle restriction) usually aggravates fibromyalgia patients' pain.
- Manual therapy is applied to only a few areas of the body per treatment to lessen posttherapy soreness. Since fibromyalgic muscles are tighter and have more knots, extra muscle waste products (lactic acid) are released with massage. Most fibromyalgia patients do not tolerate a 1-hour full body massage because of this.
- Stretching is done slowly, gently, and to just the muscles that are the tightest and, whenever possible, should be done after warming up with hot packs or low intensity aerobic exercise.
- Strengthening is tolerated best with low weight and 20 to 30 repetitions maximum. Weight is only increased when 30 repetitions are done easily and without pain. Distribute strengthening exercises to several different muscle groups usually focusing on the postural muscles.

### 88. How can I avoid a flare-up?

Fibromyalgia patients have less strength, less endurance, and more tightness, so flare-ups are somewhat inevitable. There are many things you can do to decrease the pain intensity and

Fibromyalgia patients have less strength, less endurance, and more tightness, so flare-ups are somewhat inevitable. frequency. Using ice, heat, and balms to block pain signals gives short-term relief. Getting regular massages helps lessen the accumulation of restrictions in muscles. It is important to stretch the tightest muscles daily to maintain flexibility and prevent knots from returning. A physical therapist can show you the best stretches for your problem areas. Regular aerobic exercise (three to four times a week) helps maintain and increase endurance while benefiting the cardiovascular system. Aerobic exercise improves endorphin release, which mellows the nervous system and blocks pain. Movement of the body involved in aerobic exercise helps coordination and balance and lubricates your joints. Most patients have trouble when they stop doing their home program and become sedentary, stiff, and weak, leading to a return to a cycle of pain. Practicing good ergonomics and body mechanics prevents injury and aggravation of hypersensitive muscles.

### 89. What should I expect at my first physical therapy visit?

A physical therapist does an initial evaluation on the first visit. The evaluation consists of taking a medical history, including a history of your current problem, and getting to know what makes your pain worse and better. Also noted on the first visit is what other medical conditions you have and how they might influence how your fibromyalgia manifests itself. Next, the therapist does an objective exam that consists of testing your flexibility and strength, as well as feeling and palpating the muscles for trigger points or tightness. Physical therapists experienced in treating fibromyalgia can usually tell the difference between patients with fibromyalgia and how their muscles feel compared to those who do not have it. Fibromyalgic muscles tend to be tighter, feel "gunky," and have more knots and trigger points. After the initial evaluation, the therapist will make a list of your problems and come up with a plan of care that targets your specific areas of pain and dysfunction. There is usually time to answer your questions and give you an idea of what to expect with treatment.

Sometimes you will get treatment such as heat and electrical stimulation that can help begin to relax your muscles and block pain. You may also have a short massage. The initial visit usually lasts about 90 minutes.

# 90. How do I find a physical therapist who understands fibromyalgia?

The American Physical Therapy Association (www.apta.org) has a list of physical therapists in your area. You want to pick a therapist who specializes in orthopedic and manual therapy. Call the clinic and find out if they schedule enough time for patients (two patients per hour) and whether they do hands-on treatment. Ideally and most importantly, you should ask them what fibromyalgia is. They should be able to answer that it is a central nervous system hypersensitivity syndrome as well as a muscle dysfunction problem. Many healthcare professionals, including physical therapists, do not yet understand these important aspects of fibromyalgia. Some schools still teach that fibromyalgia is mostly a psychological problem.

# 91. Does yoga help relieve the pain and discomfort of fibromyalgia?

Leading medical authorities now recognize fibromyalgia pain as involving central sensitization, a malfunction of the painprocessing centers in the brain and spinal cord. Unfortunately, this not only causes pain, but also limits the brain from having normal sensations.

Repetitive movements and exercise in poor alignment cause pain, which leads to exercise-related flares (sudden worsening of fibromyalgia symptoms). So we become afraid to move and exercise. Then we ache, because the tissues are deprived of oxygen by low muscle tone and immobility. All this pain makes us afraid to use our bodies. We become tense and anxious, so we move clumsily and reinjure ourselves. We curl up in a protective fetal position to sleep or support ourselves with numerous pillows, never lying flat to fully open the chest. Doing this contributes to shallow breathing, which in turn contributes to **hypoxic** muscle pain and aching. All this leads to poor circulation, which causes tossing and turning to get blood to all areas. This unconscious shifting deprives us of deep sleep. Fatigue contributes to pain, clumsiness, and brain fog, which contribute to more injuries and even more pain—a vicious cycle.

Yoga can help with all these problems. Breathing practices increase the oxygen supply to the tissues, reducing aching. Increased oxygen to the brain can help clear brain fog. An exercise done slowly with meticulous attention to posture and alignment, yoga postures allow us to exercise without microinjuries, thus reducing the chances of exercise-related flares. By constantly varying your yoga practice (which is easy to do because there are many yoga poses), you avoid the hyperpathic pain triggered by repetitive motions. By learning new postures and movements, you provide new sensory input to the brain, thus bypassing the learned pain patterns of allodynia and learning new ways to feel your body. By learning deep relaxation skills, you improve your sleep. Also, by exercising regularly, you improve your muscle tone and circulation, providing adequate blood supply to all your muscles so you can sleep better.

# 92. How does acupuncture help those with chronic pain?

Pain is one of the great remaining mysteries of medical science. But we are getting ever closer to answers. We do know that many sets of nerve-cell fibers are involved, each secreting their own neurotransmitter to communicate with the nerve cells they connect to. Some of these neurotransmitters make it easier for the pain-sensing nerve fibers to fire, which increases our sensitivity to pain. Other neurotransmitters make it harder for the nerve fibers to fire, thus decreasing our sensitivity to pain. In other words, some act as an accelerator, and others act as a brake. Morphine, for example, is of the latter type. It kills pain because it is a neurotransmitter that inhibits Fatigue contributes to pain, clumsiness, and brain fog, which contribute to more injuries and even more pain—a vicious cycle.

#### Нурохіс

Deficient in oxygen.

#### Yoga

A system of exercises that help your control of the body and mind. It also improves your breathing and focuses the alignment of your body. the transmission of pain stimuli. The brain naturally produces it when we are in pain—though not in the massive amounts that a physician can prescribe. Normally, the brain increases production of opiates and other pain-killing neurotransmitters to desensitize us to pain that doesn't go away.

Chronic pain represents a hyperactive state of the central (brain and spinal cord) and peripheral (outside the brain and spinal cord) nervous systems in which both systems become sensitized to pain. Over time, the nervous systems begin to overrespond to pain stimuli. This means that it takes less stimulation to cause pain and that pain is felt for a much longer period of time following the stimulus.

Moreover, in chronic pain, the sympathetic nervous system is often in a heightened state of arousal. The sympathetic nervous system is a massive network of nerves throughout the brain, spinal cord, and body that causes the familiar "fight-or-flight" response, in which the body is almost instantly prepared for a dangerous emergency. Heart rate increases, breathing rate increases, blood pressure rises, emotions flare, adrenalin flows. Needless to say, it's unhealthy to be in this aroused state more or less permanently. It leads to high blood pressure, irritable bowel symptoms, anxiety, and despair.

Acupuncture acts on pain-sensing nerve-fiber transmission in two ways. One way is by increasing the strength of inhibitory (pain-blocking) circuits in the brainstem. The brainstem circuits at the top of the spinal cord act as pain gates that are closed by acupuncture. The other way is by reducing the excitability of pain circuits in the spinal cord and brain. These acupuncture-induced alterations reduce the hypersensitivity of the nervous system that develops in chronic pain. It also works by calming the chronically hyperaroused sympathetic nervous system, which reduces the muscle contractions present in fibromyalgia.

#### Acupuncture

The practice of piercing specific sites on the body, called pathways or meridians, with thin needles in an attempt to relieve pain associated with some chronic disorders.

Acupunctureinduced alterations reduce the hypersensitivity of the nervous system that develops in chronic pain. In all these systems, the treatment improves circulation of **Qi**, blood, and fluids. Treatment also helps the body's mechanisms for maintaining a steady state, thus moving you toward better balance and better health.

# 93. How does massage benefit those with fibromyalgia?

Fibromyalgia patients experience an abnormal level of muscle tension caused by shortened and tight muscles tissue. Chronic muscle tension of a lasting nature gradually increases in intensity and pain. The effectiveness of massage therapy is that it directly affects the muscles, fascia, and circulatory system. When deep pressure is applied to this tightened muscle tissue and then released, it releases the blood and lymph flow to make its way into the tissue, providing it with nourishment (oxygen). This increased flow will also carry waste products, such as lactic acid, out of the muscle and fascia and into the bloodstream. Deep pressure massage also elongates muscles and tendons and softens fascia, allowing circulation and relief from tension.

The fascia in the body plays an important part in the pain of fibromyalgia patients; myofascial release helps dampen the pain. Its focus is the package that we're wrapped in, the connective tissue and every muscle and muscle fiber. The fascia gets restrictions in it; it tightens down and sticks to itself. It has an elastic quality, so as you work with it, you warm it up and it starts smoothing with you, independent of the muscle and the tissue (the skin).

As with all types of body work, it is essential that the therapist has experience working with fibromyalgia patients and understands the disorder. When patients follow a maintenance program once a week or bimonthly, massage has been found to work better than other therapies in providing relief. Qi

Energy flow.

#### Mark's comment:

Deep myofascial release is very important. When my muscles become stuck I experience overall muscle pain, muscle spasms, restless legs, head and neck pain, muscle stiffness, limited motion, muscle loss and constant aching pain in those muscles in addition to other muscles groups. Left untreated, trigger points develop and spread, causing more stuck muscles, more pain, more sleepless nights, more anxiety, more dysfunction, and the feeling your body is a toxic. Having deep myofascial release in conjunction with trigger point injection gave me relief from pain, a greater range of motion, offered more freedom of motion, and allowed more blood flow, which promoted more healing to happen. Deep myofascial release helps sleeping. Proper sleep reduces pain and stiffness in the muscles and helps clear the mind. When you're in constant pain your body and mind actually forget what it's like not to feel pain and tends to remain guarded. I stretch every morning in a hot tub, and as needed, which increases range of motion and releases toxins from the stuck muscles. It also prepares my muscles for activity and reduces the incidents of injury. I learned to balance my activity with rest, being aware not to overwork my muscles. This is still the most difficult to do because of my nature to be productive and never give up.

#### Denise's comment:

Massage has been a lifesaver for me. I was diagnosed with fibromyalgia in 1983 and have tried many different remedies for the pain over the years. Massage has been the most beneficial in my experience. Discovered to be helpful during early physical therapy sessions, massage has relaxed my muscles and eased my pain and stress like nothing else. A wonderful massage therapist works on me for an hour a week and I would see her more often if I could! She is not a luxury in my life—she is a necessity. I also use a shiatsu massager first thing every morning to loosen my muscles in order to function during the day. This is the only thing that keeps me going! I find it very difficult to exercise, and I feel with massage at least my tissues are being moved regularly. And it feels fantastic, too.

# 94. What can patients do at home to reduce symptoms?

One very common treatment is to use items that are soft and round, such as a tennis ball or some other kind of firm ball, in order to apply acupressure (a direct pressure to the painful area or tender point for 20 to 60 minutes in order to break up the tightened, restricted fibers). The rationale for this form of treatment comes from the following analogy: When an individual suddenly develops a charley horse in the middle of the night, the natural inclination is to grab at the muscle, start to massage it, and then stretch it out. This is a reflexive, instinctive action. On the other hand, when a partial area of muscle tightens producing the same painful phenomenon, the body has no reflex to address the problem. Despite this fact, when the same treatment technique is used-massaging out the muscle knot, stretching out the fibers, and then bringing them back to their normal resting length-the exact same results can be achieved. The result is successful pain relief!

# 95. What are self-management skills?

There is no known cure for fibromyalgia, but the symptoms can be managed. This is a process that involves making wise choices and changes that will positively affect your overall health. The optimum treatment of fibromyalgia is, therefore, a classic blend of the efforts of the patient and the doctor. **Selfmanagement skills** are vital to avoiding flare-ups and living without pain. Whether the issue is pain, fatigue, or cognitive difficulties, patients must listen to their body and adjust daily activities depending on what each day is like.

How you manage fibromyalgia varies, depending largely on how severe your symptoms are. They can range from very mild and occasional to severe and persistent, so there's considerable variance in the appropriate level of management. Self-management requires not only self-awareness, but also diligence—active participation on the patient's part. The optimum treatment of fibromyalgia is a classic blend of the efforts of the patient and the doctor.

# Self-management skills

A process that involves making wise choices and changes that will positively affect your overall health. With a positive attitude, self-awareness, and diligence, the resulting decrease of pain and tenderness, plus the increase of strength and energy, markedly improve our lives.

The saying "knowledge is power" applies strongly to fibromyalgia. Educating ourselves about the disorder is the first step to wellness. It's enormously empowering to know what we're dealing with. With fibromyalgia, we must have faith in the body's ability to heal and be proactive about our treatment. The first step to feeling better is to feel capable of taking control of our healing. Understanding the battlefield is often half the battle. As we who have fibromyalgia develop a better understanding of our condition, it becomes far easier to recognize both our limitations and our capabilities. As we empower ourselves with knowledge, our journey becomes much easier to travel.

Pacing and moving is essential to all of us because it allows the blood to move freely. In most individuals, movement is pleasurable; stretching feels wonderful, and moderate exercise makes us feel stronger and free of pain. The person with fibromyalgia feels little of this.

Everyone—from doctors to chiropractors to physical therapists—encourages patients to stretch. Few tell their patients how tricky it can be to find the right stretching program because it is not their area of expertise. So doctors send patients to a gym where someone puts a pair of weights in their hands and says "Your muscles are weak. You will feel better if you lift weights, and you will get stronger over time." This works in theory only and is the worst thing you could do.

When the skin under the skin (fascia) is too tight and full of knots, it can't strengthen. It will just rip more and hurt more. I always use the analogy of the clothesline. If your clothesline of muscles is ripped, old, and shrunk, it may be able to handle a blouse, but it can't sustain the weight of a winter coat. Trainers who ask you to lift weights but don't provide you with an alternative have little experience with individuals with chronic pain. Ask your physical therapist (or doctor) about gentle strengthening exercises to make your muscles more resilient.

**Journaling** can be a key to discovering triggers. This doesn't have to be a time-consuming process; jotting down what occurs to you is all that's necessary. The more informal you are, the more likely you are to be honest about your feelings. Journaling is also a useful tool for recording any changes in your medications or dosages, or keeping track of dietary changes and their effect.

Journaling also helps us communicate more productively with our physician. No one can recall accurately specific reactions to medications, dates new symptoms started, and so on. Referring to our daily notes makes any doctor's visit more productive.

One of the most important techniques for managing fibromyalgia is to prioritize activities. Most patients find their energy levels highest in the morning and lowest in the afternoon. So it stands to reason that we should try, whenever possible, to accomplish our most important, energy-consuming tasks in the morning. "First things first" is one of the most useful axioms anyone ever came up with.

Overexertion always exacts a price. When tempted, remind yourself that this is one of the bad things about fibromyalgia you can control. Whenever we think it's safe to increase our activities, the only responsible way is to take baby steps in that direction. If we don't, chances are we'll end up taking a giant step backwards. By going forward at a strictly measured pace, we can avoid a flare-up of symptoms.

#### Renae's comment:

It is important for patients to understand their limitations are different from other fibromyalgia patients. We must learn not to overstress with things we cannot change. My journey is ongoing;

#### Journaling

The process of recording information about your daily life.

One of the most important techniques for managing fibromyalgia is to prioritize activities. I realize what will make me feel worse and what will assist me in feeling better.

#### Margo's comment:

Once I accepted this, that it wasn't going away, and I learned to move slower, then I could do more things. If I tried to move fast and do everything I could do before, I wasn't going to get anything done because I would be hurting so badly that I would end up lying on the couch the rest of the day. But if I would just do a little bit, lie down and take a break, then feel better, get up and do a little bit more, eventually I would get more things done.

## 96. Does stress increase my pain levels?

The number one cause of flare– ups is stress. The number one cause of flare-ups is stress. We sometimes forget that stress is a natural, normal force that's part of everyone's life. However, it affects people differently, and the range of effects even on the healthiest folks is very broad. For anyone with fibromyalgia, stress is always a serious issue. The only way to manage our condition effectively is to find and keep a balance between work, rest, and play.

Although stress is a normal part of life, for us it is likely to arise from the simplest daily routines. Merely living with chronic pain is in itself a constant source of stress.

It's also natural for anyone with a chronic condition to have some negative thoughts. And these thoughts bring additional stress. Because negative thinking increases pain, we need to replace any negative thoughts with pleasant, positive affirmations.

Sometimes, changes in environmental factors (such as noise, temperature, and weather exposure) can cause stress and exacerbate the symptoms of fibromyalgia, and these factors need to be modified. Many patients report that sticking to a schedule is beneficial—that is one reason why vacations are difficult for many of us—making it all the more urgent to develop everyday tools for dealing with ongoing stress. Probably the best tool is taking time out of each day to let go of the demands of that day. There are numerous ways to do this: biofeedback, yoga, meditation, tai chi, and reading are all techniques that may help you relax.

# 97. What nutritional therapy/recommendations would you suggest for fibromyalgia?

There is no single food that can cure fibromyalgia, but there is no question that what we eat can ease the symptoms of this challenging condition. I have seen patients experience improved energy and concentration and endure less Fibro Fog and fatigue by following **nutritional therapy/recommendations** and improving their nutritional intake.

Most fibromyalgia patients have what are known as **perpetuating factors**. These are biochemical imbalances that make muscles more vulnerable to trigger points and render some therapies less effective or lasting. (These imbalances are one reason why many patients don't respond to physical therapy.) A major example of a perpetuating factor is a diet with nutritional inadequacies. Think of these inadequacies as potholes that pose a continual threat to the machine that is your body.

Fibromyalgia patients typically eat diets high in **carbohydrates** and extremely low in protein. The basic components of muscle are proteins and minerals. Yet the typical fibromyalgia patient's diet is low in protein, so he or she lacks the material to repair and maintain healthy muscle. When protein is supplied to the body in an insufficient amount, protein synthesis can be inadequate or fail to take place. For this reason high levels of protein in the diet are required.

Typically, a 40-30-30 diet, in which 40% of the diet is made up of carbohydrates, 30% protein, and 30% fat, is adequate to supply the protein requirements, providing kidney function is not compromised. The higher levels of protein provide an intermediate fuel source that can control the hypoglycemia often seen in fibromyalgia patients.

#### Nutritional therapy/ recommendations

Using food and supplements to encourage the body's natural healing. **Complementary approach** 

There is no single food that can cure fibromyalgia, but there is no question that what we eat can ease the symptoms of this challenging condition.

#### Perpetuating factors

Factors that interfere with healing or enhance the progression of myofascial pain.

#### Carbohydrates

One of the three main classes of food and a source of energy. Carbohydrates are the sugars and starches found in breads, cereals, fruits, and vegetables.

#### Renae's comment:

#### Nutrition

The process by which an individual takes in and utilizes food material. Nutrition plays a very important role. My doctor always reminds me I need to eat better. Because of fibromyalgia we suffer from fatigue and depression and eating comfort foods helps lift our spirits. And eating nutritiously is a daily goal. It's a challenge I am working on with a nutritionist.

#### Mark's comment:

Nutrition is a real important part of my program. Because my muscles don't tolerate the level of exercise I should be getting, other factors become involved, like being overweight, low endurance, lack of energy, diabetes, high cholesterol, excessive yeast in the blood, shallow breathing, slow heart rate, and lack of mental sharpness. I have learned that I need to eat to live, not live to eat. It was easy to use food as a source of comfort as to how I was feeling. What I eat is as important as how much. In order to get back the energy I was lacking and reduce more pain, I eliminated processed foods and refined carbohydrates from my diet. My body did not process them very well and they made me feel lethargic. I select what type of protein I eat and monitor the types of fat. I eat fruits and vegetables that are low in sugar, dark leafy greens, legumes, beans, whole grains, almonds, and walnuts. If I can't make it I don't eat it. In addition, I drink lots of water and take dietary supplements that give me more energy and boost my immune system. Getting nutrients to your cells seems to be the key to vitality and healing.

And they're all things you need to work at on a daily basis, so it's a very hard challenge from day to day.

# 98. How do I find a support group in my area?

The National Fibromyalgia Association has a network of support groups across the United States and encourages participation within the fibromyalgia community. Participation in support groups can provide an opportunity to reach out to others who have had similar challenges and foster an improved understanding of lifestyle management.

Perhaps one of the most important benefits of participating in a support group is a decreased sense of isolation so many people feel when they are experiencing chronic pain. In a support group environment, feelings of anger, depression, guilt, and anxiety can be expressed, validated by others, and accepted as a normal response to living with chronic pain. Having the freedom to express negative feelings and to identify with one another helps participants to realize they are not alone in their struggle. They can experience a sense of emotional relief from the support of others.

Keep in mind that if one group doesn't work for you, it's worth going a little out of your way to find another. In the long run, participating in a fibromyalgia group that works well can be enormously helpful and therapeutic. Also, you will have an opportunity to share what your own experience has taught you, and helping others is among the best therapies there is.

#### Rob's comment:

It's funny in an odd way that I could tell one friend that another friend has cancer but cannot talk about fibromyalgia. Why, after all this time? Maybe because few people realize how bad it can be and don't care or understand the disease and its devastating tentacles into your life. Or maybe because it isn't mainstream enough to be acceptable and good lunch talk? When I finally made the decision to attend a fibromyalgia support group, it was a sense of relief to see other men in the auditorium. Men tend to be very stoic, but as our comfort levels increased I found I was not the only "man" trying to present a macho image but suffering with pain under my mask. The group is now a part of my life as are my physical therapy, physicians', and psychologist appointments. Perhaps one of the most important benefits of participating in a support group is a decreased sense of isolation.

# 99. How can I help to bring about fibromyalgia awareness?

Participating in awareness day activities and advocacy efforts have paid off. Doctors are beginning to recognize that fibromyalgia is real and more physician education programs on the condition are readily available.

In 1993, not a single project on fibromyalgia was funded by the National Institutes of Health (NIH), the branch of the US government that oversees awards for biomedical research. The number of studies funded on fibromyalgia has slowly increased. Today, an estimated \$10 million is spent on fibromyalgia by the NIH each year. Many of the fibromyalgia projects funded by the NIH are making a true difference in determining the physiological mechanisms responsible for the many symptoms of this condition, but not all of them are patient-relevant. For a current list of projects being funded through your tax dollars, visit the government's "Estimates of Funding for Various Diseases, Conditions, Research Areas" at www.nih.gov/news/fundingresearchareas.htm.

Inroads have been made, but there is still a great deal of work to be done. While you may think you are just one person and your voice is too small to be heard, this is just not the case. In fact, it is essential that you write to your elected officials and to the NIH. That's how grassroots lobbying exerts its impact. The greater number of people who write (snail mail and e-mail) and call, the more impact we have. First, you should be aware of many important facts about fibromyalgia. There are a multitude of people, associations, and agencies dedicated to helping people, including the American Pain Foundation and the National Fibromyalgia Partnership. It's not necessary to make a trip to Washington, DC, to become an advocate for fibromyalgia awareness. Writing letters to your local elected officials is a start and a way for you as a patient and citizen to make your voice heard!

Today, an estimated \$10 million is spent on fibromyalgia by the NIH each year.

# 100. Where can I find information about fibromyalgia?

Educating oneself about fibromyalgia, or any other disease, is synonymous with empowerment. Fibromyalgia is not only an enigma to patients and families, but also to the medical community. As patients we must be open to discussing questions and concerns with our healthcare providers. We have included a list of fibromyalgia-related and other professional Web sites that patients have found very helpful (see Appendix). Google Scholar is another valuable resource for journal articles published by medical journals.

# aPPENdix

Appendix

# Web sites

#### American Academy of Craniofacial Pain 520 West Pipeline Road Hurst, TX 76053 www.aacfp.org

#### American Academy of Medical Acupuncture

4929 Wilshire Boulevard, Suite 428 Los Angeles, CA 90010 (323) 937-5514 www.medicalacupuncture.org

#### American Academy of Neurology

www.aan.com

#### American Academy of Pain Medicine

13947 Mono Way #A Sonora, CA 95370 (209) 533-9744 www.painmed.org

#### American Academy of Physical Medicine and Rehabilitation

One IBM Plaza, Suite 2500 Chicago, IL 60611 (312) 464-9700 www.aapmr.org

#### American Academy of Sleep Medicine

One Westbrook Corporate Center, Suite 920 Westchester, IL 60154 (708) 492-0930 www.aasmnet.org

#### American Chronic Pain Association

P.O. Box 850 Rocklin, CA 95677 (800) 533-3231 www.theacpa.org

#### American College of Rheumatology

1800 Century Place, Suite 250 Atlanta, GA 30345-4300 (404) 633-3777 www.rheumatology.org

#### American Fibromyalgia Syndrome Association

P.O. Box 32698 Tucson, AZ 85715 (520) 733-1570 www.afsafund.org

#### American Massage Therapy Association

500 Davis Street, Suite 900 Evanston, IL 60201 (847) 864-0123 www.amtamassage.org

#### **American Pain Foundation**

201 N. Charles Street, Suite 710 Baltimore, MD 21201-4111 www.painfoundation.org

#### American Pain Society

4700 W. Lake Avenue Glenview, IL 60025 (847) 375-4715 www.ampainsoc.org

#### American Physical Therapy Association

1111 N. Fairfax Street Alexandria, VA 22314 (800) 999-2782 www.apta.org

#### Arthritis Foundation

P.O. Box 7669 Atlanta, GA 30357-0669 (800) 687-2277 www.arthritis.org

#### Association for Applied Psychophysiology and Biofeedback

10200 W. 44th Avenue, Suite 304 Wheat Ridge, CO 80033-2840 (303) 422-8436 www.aapb.org

#### **Centers for Disease Control and Prevention**

1600 Clifton Road Atlanta, GA 30333 (800) 232-4636 www.cdc.gov

#### **Chronic Pain and Fatigue Research Center**

www.med.umich.edu/painresearch

#### Division of Rheumatology at the University of Michigan

www.med.umich.edu/intmed/rheumatology

#### **CO-Cure**

A fibromyalgia/chronic fatigue database with resources, articles, and clinical updates www.co-cure.org

#### **Fibromyalgia Network**

P.O. Box 31750 Tucson, AZ 85715 (800) 853-2929 www.fmnetnews.com

#### FM-CFS

Support groups throughout Canada http://www.fm-cfs.ca

# Food and Drug Administration

www.fda.gov

#### HealthFinder

A gateway consumer health Web site with access to innumerable publications and other resources www.healthfinder.gov

#### Helping Our Pain and Exhaustion

23915 Forest Park Novi, MI 48374 (248) 344-0896 www.hffcf.org

#### House and US Representatives

House of Representatives: www.house.gov United States Senate: www.senate.gov

#### **Immune Support and ProHealth**

Web site with medical articles, advice from leading physicians, a support community, and up-to-date news on nutrition and wellness www.immunesupport.com www.prohealth.com

#### Interstitial Cystitis Association

www.ichelp.org

#### **International Academy for Compounding Pharmacists**

www.iacprx.org

#### International Association for Chronic Fatigue Syndrome

27 N. Wacker Drive, Suite 416 Chicago, IL 60606 www.iacfsme.org

Job Accommodation Network www.jan.wvu.edu

Lupus Foundation www.lupus.org

#### Massage Finder Information

www.massagetherapy.com/home/index.php

#### **Medline Plus**

www.nlm.nih.gov/medlineplus/fibromyalgia.html

#### Medline Plus Drug Information Website

www.nlm.nih.gov/medlineplus/druginformation.html

Men with Fibromyalgia www.menwithfibro.com/home.html

#### National Center for Complementary and Alternative Medicine

NCCAM Clearinghouse P.O. Box 7923 Gaithersburg, MD 20898 (888) 644-6226 www.nccam.nih.gov

#### National Fibromyalgia Partnership

www.fmpartnership.org

# National Fibromyalgia Research Association

www.nfra.net

#### National Headache Foundation

820 N. Orleans, Suite 217 Chicago, IL 60610 (888) NHF-5552 www.headaches.org

#### National Library of Medicine

Represents every significant library program, from medical history to biotechnology www.nlm.nih.gov

#### National Women's Health Resource Center

157 Broad Street, Suite 106 Red Bank, NJ 07701 (877) 986-9742 www.healthywomen.org

#### NIH Office of Dietary Supplements

ods.od.nih.gov

#### Partnership for Prescription Assistance

www.pparx.org

#### PubMed

The US National Library of Medicine's huge online medical database www.ncbi.nlm.nih.gov/pubmed/

#### **Restless Legs Syndrome Foundation**

1610 14th Street, Suite 300 Rochester, MN 55901 (507) 287-6465 www.rls.org

#### The TMJ Association

P.O. Box 27660 Milwaukee, WI 53226 (262) 432-0350 www.tmj.org

#### **Vulvar Pain Foundation**

203 N. Main Street, Suite 203 Graham, NC 27253 (336) 226-0704 www.vulvarpainfoundation.org

#### Womenshealth.gov

(800) 994-9662 www.4woman.gov

# Books

Fibromyalgia and Chronic Myofascial Pain Syndrome: A Survival Manual. Starlanyl, D., Copeland, M. E. Oakland: New Harbinger Publications, 1996.

*Myofascial Pain and Dysfunction: The Trigger Point Manual.* 2nd ed. Simons, D. C., Travell, J. C., Simons, L. S. Baltimore: Lippincott Williams & Wilkins, 1999.

*Orthopaedic Physical Therapy Secrets.* 2nd ed. Placzek, J. D., Boyce, D. A. Philadelphia, PA: Hanley & Belfus, Inc., 2001. Fibromyalgia: The Complete Guide From Medical Experts and Patients Ostalecki, S. Sudbury, MA: Jones & Bartlett Publishers, 2008.

# Papers

The American College of Rheumatology 1990 criteria for the classification of fibromyalgia: report of the multicenter criteria committee.Wolfe, F., Smythe, H. A., Yunus, M. B., et al. *Arthritis Rheum* 1990;33:106–172.

Fibromyalgia: An "Invisible" Disability Barrett, D. A. www.quackwatch.org/03HealthPromotion/fibromyalgia/fms03.html. Accessed February 14, 2000.

# Documentary

Fibromyalgia: Fitting the Pieces Together www.hffcf.org www.mccicorp.com 248-358-4700

# Magazines

Massage Magazine www.massagemag.com

Yoga Journal www.yogajournal.com

Journals American Family Physician www.aafp.org/online/en/home/publications/journals/afp.html

American Journal of Physical Medicine and Rehabilitation www.amjphysmedrehab.com

Archives of Physical Medicine and Rehabilitation www.archives-pmr.org

Johns Hopkins White Papers www.johnshopkinshealthalerts.com/bookstore/index.html

Journal of Arthritis & Rheumatism www.rheumatology.org/publications/ar/index.asp

Journal of Chronic Fatigue Syndrome www.cfs-news.org/jcfs.htm

Journal of Rheumatology www.jrheum.com

Journal of Musculoskeletal Pain www.haworthpress.com/journals

Journal of the American Medical Association jama.ama-assn.org

*Physical Medicine and Rehabilitation Clinics of North America* www.pmr.theclinics.com

Rheumatology International www.springer.com/medicine/rheumatology/journal/296

# gl OSSar y

Glossary

## A

**Acetaminophen:** The generic name for Tylenol.

Acupuncture: The practice of piercing specific sites on the body, called pathways or meridians, with thin needles in an attempt to relieve pain associated with some chronic disorders.

**Acute:** Condition of short duration that starts quickly and has severe symptoms.

**Adjuvant:** Drugs that augment the effects of analgesics. They include anti-depressants and anticonvulsants.

Aerobic exercise: Physical exercise that increases the work of the heart and lungs; examples are running, jogging, swimming, and dancing.

**Allodynia:** An altered sensation in which normally nonpainful events are felt as pain.

Alternative medicine: A broad category of treatment systems such as chiropractic, herbal medicine, acupuncture, homeopathy, naturopathy, and spiritual devotions. Alternative medicine is also referred to as "complementary medicine." The designation "alternative medicine" is not equivalent to holistic medicine, which is a narrower term. **Analgesic:** A medication or agent that reduces pain.

Anticonvulsants: Drugs given to prevent seizures.

Autonomic nervous system: System of the brain that controls key bodily functions not under conscious control, such as heartbeat, breathing, and sweating. The autonomic nervous system has two divisions: the sympathetic nervous system and the parasympathetic nervous system. The sympathetic nervous system accelerates heart rate, constricts blood vessels, and raises blood pressure. The parasympathetic nervous system slows heart rate, increases intestinal and gland activity, and relaxes sphincter muscles.

## B

**Biofeedback:** The use of electronic instruments to measure muscle tension in any muscle group.

#### С

**Carbohydrates:** One of the three main classes of food and a source of energy. Carbohydrates are the sugars and starches found in breads, cereals, fruits, and vegetables. During digestion, carbohydrates are changed into a simple sugar called glucose. **Catastrophizing:** Occurs when a person ruminates about all the terrible things that are probably going to happen.

**Central nervous system:** The brain and spinal cord.

**Central sensitization:** A malfunction in the brain's pain recognition centers that causes people with fibromyalgia to experience pain instead of normal sensations.

**Chronic disease:** A disease showing little changes or of slow progression; the opposite of acute.

**Chronic fatigue syndrome:** A condition of excessive fatigue, cognitive impairment, and other varied symptoms. Classified by the World Health Organization (WHO) as a disease of the nervous system, it is of unknown etiology and could last months or years, causing severe disability.

**Circadian rhythm:** A metabolic or behavior pattern that repeats in cycles of about 24 hours.

Cognitive behavioral therapy (CBT):

A type of psychotherapy in which the therapist teaches the patient to restructure his or her cognitive beliefs (thought patterns) and hence, behavior.

**Complementary approach:** A group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of conventional medicine.

**Compounding pharmacy:** A facility that both makes and sells prescription drugs. A compounding pharmacy can

often prepare drug formulas that are specially tailored to patients; for example, a compounding pharmacy could create liquid versions of medications normally available only in pill form for patients who cannot swallow pills.

**Craniosacral therapy:** A gentle form of manipulation. Craniosacral therapists manipulate the craniosacral system, which includes the soft tissue and bones of the head (cranium), the spine down to its tail end (the sacral area), and the pelvis. This manipulation also works with the membranes that surround these bones and the cerebrospinal fluid that bathes the brain and spinal cord.

# D

**Degenerative joint disease:** Osteoar-thritis or rheumatoid arthritis.

**DHEA:** A chemical, produced only during stage 4 sleep, that initiates a cascade of events that causes proteins to repair themselves.

**Dolorimeter:** A device for quantifying the threshold of pain.

**Dry eye disease (DED):** Decreased tear production or increased tear film evaporation.

## E

Electromyogram (sEMG)

**biofeedback:** Surface EMG biofeedback allows therapists to record the electrical activity of muscles through sensors attached to the skin.

**Endorphins:** Any of a group of proteins with potent analgesic properties that occur naturally in the brain.

# F

Fascia: A fibrous membrane covering, supporting, and separating muscle and some organs of the body. Also known as soft tissue.

**Fibro Fog:** The cognitive dysfunction experienced by many fibromyalgia patients.

Fibromyalgia: A chronic disorder characterized by widespread musculoskeletal pain, fatigue, and multiple tender points that occur in precise, localized areas, particularly in the neck, spine, shoulders, and hips. It also may cause sleep disturbances, morning stiffness, irritable bowel syndrome, anxiety, and other symptoms.

#### Fibromyalgia Impact Questionnaire

(FIQ): The FIQ is an assessment and evaluation instrument developed to measure fibromyalgia patient status, progress, and outcomes. It has been designed to measure the components of health status that are believed to be most affected by fibromyalgia.

**Flare-up:** A period of time when symptoms reappear, becoming worse and then improving again.

**Flexibility:** The ability of muscle to relax and yield to stretch forces.

**Food and Drug Administration:** The FDA is responsible for protecting the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation.

Functional MRI (FibromyalgiaRI):

Functional MRI is based on the increase in blood flow to the local vasculature that accompanies neural activity in the brain.

#### Η

**Hyperalgesia:** An extreme reaction to a stimulus that is normally painful.

Hypermobile: Abnormally flexible.

**Hyperpathia:** Abnormally severe pain from a stimulus that normally is slightly painful.

**Hyperthyroid:** Excessive functionality of the thyroid gland marked by increased metabolic rate, enlargement of the thyroid gland, rapid heart rate, high blood pressure, and various secondary symptoms.

**Hypoglycemia:** An abnormally low level of glucose in the blood.

**Hypothyroidism:** Underactivity of the thyroid gland, causing tiredness, cramps, a slowed heart rate, and possibly weight gain.

Hypoxic: Deficient in oxygen.

#### I

**Immune system:** The body system that protects the body against invading organisms and infections.

**Initiating factors:** Factors that cause the onset of myofascial pain.

**Insomnia:** Inadequate quality or quantity of sleep, with difficulty initiating or maintaining sleep.

Irritable bowel syndrome (IBS): A chronic functional gastrointestinal disorder primarily characterized by

abdominal pain and disturbed bowel functioning (diarrhea and/or constipation). It is present in 33% to 77% of individuals with fibromyalgia.

**Ischemia:** Lack of blood flow to a body part, often caused by constriction or obstruction of a blood vessel.

# J

**Joint:** The point of connection between two bones or elements of a skeleton (especially if the articulation allows motion).

**Journaling:** The process of recording information about your daily life.

# L

**Ligament:** A tough band of tissue connecting the articular extremities of bones or supporting an organ in place.

## Μ

#### Magnetic resonance imaging (MRI):

A noninvasive, non-X-ray diagnostic technique based on the magnetic fields of hydrogen atoms in the body. MRI provides computer-generated images of the body's internal tissues and organs.

**Massage therapy:** Manipulation of tissues (as by rubbing, kneading, or tapping) with the hand or an instrument for therapeutic purposes.

**MedWatch:** The Food and Drug Administration's reporting system for adverse events.

**Melatonin:** Pineal hormone (a hormone secreted from the pineal gland) secreted primarily during the hours of darkness. **Mindfulness:** A form of deep relaxation that involves focusing on being "in the moment."

#### Multidisciplinary approach:

Approach that uses many experts from different disciplines working together as a team to manage and control the symptoms of fibromyalgia.

**Muscle:** A body tissue consisting of long cells that contract when stimulated and produce motion.

**Myofascial pain:** Pain and tenderness in the muscles and adjacent fibrous tissues (fascia).

## Ν

**Neurotransmitters:** Chemicals in the brain, such as acetylcholine, serotonin, and norepinephrine, that facilitate communication between nerve cells (neurons).

**Non-rapid eye movement (NREM):** A recurring sleep state during which rapid eye movements do not occur and dreaming does not occur; accounts for about 75% of normal sleep time.

Nonsteroidal anti-inflammatory drugs (NSAIDs): Drugs that act against inflammation, reduce fever, relieve muscle pain, and prevent blood clots.

Norepinephrine: A neurotransmitter found mainly in areas of the brain that are involved in governing autonomic nervous system activity, especially blood pressure and heart rate.

**Nutrition:** The process by which an individual takes in and utilizes food material.

# Nutritional therapy/recommenda-

**tions:** Using food and supplements to encourage the body's natural healing.

# 0

**Overlapping conditions:** A secondary illness that accompanies the primary illness affecting an individual. Patients with fibromyalgia are often affected by one or more overlapping illnesses, such as restless leg, interstitial cystitis, or tension headaches.

#### Р

Palpate: To touch or feel.

**Perpetuating factors:** Factors that interfere with healing or enhance the progression of myofascial pain.

**Physiatrist:** A physician who specializes in physical medicine and rehabilitation.

**Physical therapy:** The treatment consisting of exercising specific parts of the body such as the legs, arms, hands, or neck in an effort to strengthen, regain range of motion, relearn movement, and/or rehabilitate the musculoskeletal system to improve function.

**Polysomnogram:** A technical term for a sleep study that involves recording brain waves for assessing the quality of sleep and airflow at the nose and mouth.

**Predispose:** Having factors that increase the risk of myofascial pain.

**Proprioception:** The ability to sense the location, position, orientation, and movement of the body and its parts.

**Protein:** Complex molecules composed of amino acids that are essential

to an organism structure and function. Meats, eggs, and dairy products are significant sources of protein. You can also get protein from a variety of grains, legumes, nuts, and seeds. Proteins are the "building blocks" of the human body.

**Psychiatrist:** A medical doctor who specializes in the treatment and prevention of mental and emotional disorders.

**Psychologist:** A specialist who can talk with patients and their families about emotional and personal matters and can help them make decisions.

# Q

Qi: Energy flow.

## R

**Rapid eye movement (REM):** A light sleep when dreams occur and the eyes move rapidly back and forth.

**Raynaud's phenomenon:** Discoloration of the fingers or toes due to emotion or cold in a characteristic pattern over time: white, blue, and red.

**Referred pain:** Pain from a malfunctioning or diseased area of the body that is perceived in another area, often far from the origin.

Rheumatoid arthritis (RA): A chronic disease characterized by stiffness and inflammation of the joints, loss of mobility, weakness, and deformity.

**ROM:** Range of motion. The amount of movement at one joint or multiple joints of the body.

#### S

#### Select serotonin reuptake inhibitor

(SSRI): A type of drug that is used to treat depression. SSRIs slow the process by which serotonin (a substance that nerves use to send messages to one another) is reused by nerve cells that make it. This increases the amount of serotonin available for stimulating other nerves.

**Self-management skills:** A process that involves making wise choices and changes that will positively affect your overall health.

**Serotonin:** A neurotransmitter within the central nervous system.

Serotonin and norepinephrine reuptake inhibitors (SNRIs): A type

of antidepressant medication that increases the levels of both serotonin and norepinephrine by inhibiting their reabsorption into cells in the brain.

Serotonin syndrome: A hyperserotonergic state that is a very dangerous and potentially fatal side effect of serotonergic enhancing drugs; it can have multiple psychiatric and nonpsychiatric symptoms.

**Sleep apnea:** Cessation of breathing that occurs during sleep. Usually due to obstruction of the airway, it can also be due to inability of the brain to initiate respiration.

**Sleep deprivation:** A shortage of quality, undisturbed sleep that results in detrimental effects on physical and mental well-being.

**Soft tissue:** The ligaments, tendons, and muscles in the musculoskeletal system.

**Somatic:** Pertaining to the body.

**Stimulants:** Drugs that increase the activity of the sympathetic nervous system and produce a sense of euphoria or awakeness.

**Substance P:** A protein substance that stimulates nerve endings at an injury site and within the spinal cord, increasing pain messages.

**Supplements:** The addition of vitamins and minerals, in a pill form, to a person's diet.

**Sympathetic nervous system:** The part of the autonomic nervous system that raises blood pressure and heart rate in response to stress.

**Syndrome:** A group of symptoms as reported by the patient and signs as detected in an examination that together are characteristic of a specific condition.

#### T

**Temporomandibular disfunction** (**TMD**): Conditions characterized by facial pain and restricted ability to open/move the jaw.

#### Temporomandibular joint (TMJ):

The connecting hinge mechanism between the base of the skull (temporal bone) and the lower jaw (mandible).

**Tender points:** Sites where the interdigitating fibers of the muscle become mechanically locked into a position that produces pain.

**Thyroid:** A gland located beneath the voice box (larynx) that produces

thyroid hormone. The thyroid helps regulate growth and metabolism.

#### Thyroid stimulating hormone

**(THS):** Released by the pituitary gland to increase thyroid hormone production.

**Tramadol:** A centrally acting analgesic for the treatment of pain in fibromyalgia. Also know as Ultram.

**Tricyclic antidepressants:** A group of drugs used to relieve symptoms of depression. These drugs may also help relieve pain.

**Trigger points:** Places on the body where muscles and adjacent fibrous tissue (fascia) are sensitive to the touch. These areas are generally in the upper and lower back muscles, but they may occur elsewhere. Also, an area of low neurological activity that when stimulated or stressed transforms into an area of high neurological activity with referred sensations to other parts of the body.

# U

**Ultram (tramadol):** A (synthetic) analgesic (pain reliever).

**Ultrasound:** An electrical modality that transmits a sound wave through an applicator into the skin to the soft tissue in order to heat the local area; for relaxing the injured tissue and/or dispersing edema.

# V

Vulvodynia: According to the International Society for the Study of Vulvovaginal Disease (ISSVD), vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable neurologic disorder.

# W

Wax and wane: Refers to symptoms that come and go without definitive cause.

World Health Organization: The directing and coordinating authority for health within the United Nations' system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing health trends.

# Y

**Yoga:** A system of exercises that help your control of the body and mind. It also improves your breathing and focuses the alignment of your body.

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