

## Chapter 1

# Yes, Fibromyalgia Is Real

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### *In This Chapter*

- ▶ Considering symptoms, causes, and the pain aspect
  - ▶ Knowing who gets fibromyalgia
  - ▶ Looking at medical problems confused with fibromyalgia
  - ▶ Finding a good doctor
  - ▶ Exploring over-the-counter and prescribed medications and alternative remedies
  - ▶ Considering how fibromyalgia affects work and family
  - ▶ Improving sleep, decreasing stress, and dealing with emotional effects
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**K**nowing that fibromyalgia syndrome (FMS) is a real medical problem that needs to be dealt with is an important first step toward mastering your fibromyalgia — and moving toward that place where you can start to feel like you're making progress. Sure, you can try to ignore the problem. But mostly, it won't let you.

Fibromyalgia has many aspects to consider. In this chapter, I line up the major issues for you and refer you to chapters later in this book where I discuss how fibromyalgia affects you individually and what treatments and medications may work best for you.

## *Dumping Your Doubts about Whether FMS Is Real*

Many people spend months or years questioning their fibromyalgia symptoms, sometimes wondering if they're imagining how bad the symptoms are. After all, if you feel terrible one day and then significantly better or almost normal the next day, you may start to think that maybe you were exaggerating the pain and fatigue of the previous day.

The thing is, most people can't remember pain well. They can remember that they *had* pain, but they can't remember what it actually felt like. (This is

generally a good thing!) As a result, people experiencing the ups and downs of pain and other symptoms that accompany fibromyalgia worry sometimes that perhaps the problem isn't that big of a deal and could even be all in their heads. Consequently, they may try to ignore the problem and hope that it'll go far, far away — preferably today.

But if you have fibromyalgia (and I recommend that you take my self-test later in this chapter to see whether you could be a possible candidate), simply ignoring the problem doesn't work. The sooner you acknowledge that fibromyalgia is a real and long-term problem, the sooner you can work toward reclaiming your life.

You can gain enormous control over the symptoms that stem from your fibromyalgia, but only rarely can you eradicate them altogether. Most people have plenty of room for improvement, however.

## *Examining the Symptoms, Causes, and Pain Problems Associated with Fibromyalgia*

Fibromyalgia isn't a one-size-fits-all kind of medical problem, but I can make some descriptive generalizations about it regarding symptoms, causes, and pain.

### *Sizing up the symptoms*

Many people with fibromyalgia report that the following statements are true about their fibromyalgia symptoms. In fact, most people with fibromyalgia say that they have at least several, if not all, of these symptoms (which I cover in much more detail in Chapter 2):

- ✓ Flu-like pain that can be severe
- ✓ A constant feeling of extreme fatigue
- ✓ Several tender body areas that hurt
- ✓ Overall body aches
- ✓ Depression and/or anger
- ✓ Feeling very anxious
- ✓ Muscle stiffness and pain
- ✓ Chronic back pain

- ✓ Insomnia
- ✓ Worsening of pain after physical activity
- ✓ Mental malaise and confusion, often referred to as *fibro fog*

Many people with FMS have other pain-based medical problems as well, which I also cover in more depth in Chapter 2. Some examples of the array of medical conditions that people with fibromyalgia may experience, on top of the fibromyalgia that they already have (as if FMS isn't enough), include

- ✓ Restless legs
- ✓ Irritable bowel syndrome
- ✓ Interstitial cystitis (a chronic, painful bladder condition that may feel like a constant bladder infection)
- ✓ Tension headaches or migraine headaches
- ✓ Benign joint hypermobility syndrome (BJHS; an often painful form of hereditary joint hyperextension)
- ✓ Attention deficit hyperactivity disorder (ADHD)
- ✓ Chronic fatigue syndrome

## *Considering causes*

No one knows for sure what causes fibromyalgia, but physicians and other experts have many fascinating theories to explain what may induce the onset of FMS. The cause could be hormones or an autoimmune problem or biochemicals gone awry, chronic stress, or it may be related to a previous trauma, such as an injury that you incurred in a car crash or in another serious accident. Individuals who have been abused as children or adults are more likely to develop fibromyalgia than others.

The cause could also be a combination of different factors coming together at just the right time (or the wrong time when you think about it) for you to develop FMS. For example, maybe you got the flu, and then were involved in a serious accident. Or some other awful combination may have occurred.

As researchers (like me) continue to study this medical problem, they move closer to the truth. Speculating about causes can be fascinating, and Chapter 3 offers some common theories for what causes fibromyalgia.

## *Pondering pain*

Thinking about pain is certainly no fun, and yet pain is part of what makes us alive and human. But when pain runs rampant in our bodies, extracting

particular pain in certain parts of it, it becomes a major problem, and fibromyalgia pain can be very intense. I talk about the purpose of pain and how and why it needs to be managed in Chapter 4. It may sound like a chapter to avoid, but hold on! You need to read it because it includes some important and useful ideas.

And by the way, I'm not just *saying* that I believe that the pain and symptoms of fibromyalgia are real because I'm a nice guy who doesn't want to hurt your delicate feelings. I think that I *am* here to help you, but even more important, I'm a physician who's a clinical researcher, and I've proven in my studies on the pain of people with fibromyalgia that their pain (and yours) is real.

My studies, as well as the studies that have been done by other researchers, have shown that the pain sensations experienced by people with fibromyalgia (especially women) are actually more intense, and the pain lasts longer than does the pain of people who don't have fibromyalgia. Read Chapter 4 for further information on the ins and outs of fibromyalgia pain.

## *Considering Who Gets Fibromyalgia*

Just about anyone of any age can develop fibromyalgia, but most research so far indicates that the majority of people with FMS are of the female persuasion, partly because women are more sensitive to pain than men. This is a time where a little equal opportunity of pain would be preferable (if you're a woman). But who gets fibromyalgia isn't about fairness.

Although women are the primary sufferers of fibromyalgia, many men have been diagnosed with FMS, too, and some men with fibromyalgia go undiagnosed for years. For more information about some of the major patterns that have been identified so far among people who develop fibromyalgia, which you may share with these fellow sufferers, be sure to read Chapter 5.

What about children and adolescents? Do they have fibromyalgia? Sadly, yes. If your child or teenager has FMS, he may have a difficult time because most physicians, as well as the general public, still don't realize that kids can experience chronic pain from FMS. Instead, they think kids are faking it when they say that they're too sick to go to school. Maybe they *are*, but then again, maybe they're not. Skip ahead to Chapter 20 for some advice on how to tell the difference.

## *Looking at Related Medical Problems*

Sometimes, people strongly suspect (or are *sure*) that they have fibromyalgia. Instead, however, they may have arthritis, Lyme disease, lupus, thyroid

dysfunction, Raynaud's phenomenon, or a variety of other common and not-so-common medical problems. And sometimes people have both fibromyalgia *and* other serious medical problems. Having fibromyalgia doesn't exempt you from getting sick with other illnesses (even though it seems like it would be only fair that it should).

With the existing array of possible medical problems and their often-overlapping symptoms, even doctors can become confused sometimes about which is which when they're working on a diagnosis. A good doctor is up to this task, of course, as long as you don't expect instant results on your first visit.

For example, suppose that one of your primary symptoms is extreme fatigue, possibly to the point of total exhaustion — even though you haven't been doing anything more strenuous than using the remote control to change channels. This action may use up one calorie or less, but you feel like you've climbed Mount Everest. Maybe your problem is fibromyalgia, but maybe not.

Extreme tiredness is one of the possible symptoms of many medical problems, including hypothyroidism, anemia, chronic fatigue syndrome, Lyme disease, arthritis, and — oh, yes — fibromyalgia, too. No wonder sorting it all out can be so hard sometimes! To find out more about illnesses often confused with FMS, and how doctors sort them out, read Chapter 6.

## *Do You Have Fibromyalgia? A Self-Test*

Only your physician can diagnose you with fibromyalgia and then treat you. Reading this book is a very good idea, but it still doesn't really cut it when it comes to making an actual diagnosis in your own individual case. What I can give you is a simple self-test to use to help you determine if you *may* have fibromyalgia syndrome.

Grab a scratch piece of paper and jot down your answers to the following “yes” or “no” questions. Then, read my analysis at the end of the list. If you think that you may be a possible candidate for fibromyalgia, make an appointment with your physician and find out for sure.

- 1. Do you have a lot of pain in certain specific areas of your body? If so, do these areas lack any obvious damage (such as bruising or swelling)?**
- 2. Is your overall body pain sometimes severe?**
- 3. Do you have trouble sleeping on three or more nights per week?**
- 4. Do you feel exhausted about half the time or more?**
- 5. Do people often say that you look sick?**

6. Do you turn down social invitations rather than risk having to go out feeling achy and tired?
7. Do you find yourself wondering whether your aches and pains will ever go away or if you'll feel like this forever?
8. Are you always losing things and forgetting things? Do you have so much mental confusion that you sometimes wonder if it could be an early onset of Alzheimer's disease?
9. Are you having trouble finding any real pattern to your pain — because some days it's bad and some days it's not?
10. Have you started to feel “down” about your pain and fatigue? Are you wondering whether depression could be the underlying problem?

If you answered “yes” to as many as three or more of these questions, you may have fibromyalgia, although every person's case is different. That's why even if you only answered “yes” to one or two of the questions, but you think that you may have fibromyalgia, a consultation with your physician is a good idea.

Now, here's some explanation of what may be happening to you, depending on your answers to Questions 1 through 10. Keep in mind, though, that only your doctor can actually diagnose you with fibromyalgia.

- ✔ **Question 1:** If you're experiencing pain in specific parts of your body, but you're not seeing bruises or any apparent evidence of tissue damage (and neither is your doctor), these painful areas may be the muscle pains characteristic of fibromyalgia. Read Chapter 8 for more information on tender points.
- ✔ **Question 2:** If you said that your pain is sometimes very severe, this is another indicator that you may have fibromyalgia. Be sure to consult a physician to find out.
- ✔ **Question 3:** If you have trouble sleeping three or more nights per week, this is serious. The problem may or may not be connected with fibromyalgia (although nearly everyone with FMS has sleep problems), but it's important to resolve your serious sleep deficit. If you're a walking zombie because you're not getting enough sleep, you can't perform well at work or home, nor will you be a happy person.  
  
Also, if you're prone to developing fibromyalgia, this continuing bad pattern of a lack of sleep every night will make your other symptoms, such as your pain and fatigue, much worse.
- ✔ **Question 4:** Severe fatigue is a chronic problem among nearly everyone who has fibromyalgia. Often, it's linked to a lack of sleep. But it may also be an element of FMS as a medical problem. You may also have chronic fatigue syndrome or thyroid disease, and your doctor will need to help you sort it out.

- ✔ **Question 5:** If you agreed that those you care about, or maybe even strangers around you, are commenting that you look sick, something about you probably doesn't look right. You may be displaying your chronic pain and associated depression on your face without even knowing it.

On the other hand, other people tell individuals with fibromyalgia that they look "fine" and "great," and the pain and symptoms are *not* reflected in the face or body language of the fibro sufferer. If this has happened to you, you're definitely not alone.

- ✔ **Question 6:** If you're turning down invitations that you would have accepted in the past, have a serious talk with yourself to find out why. Is it because of pain and fatigue? Or could you be having a problem with depression or anxiety — both very common problems for people with and without fibromyalgia?

- ✔ **Question 7:** When your pain is constant and chronic, asking yourself if it's ever going to end is only natural. But what you need to do is consult with a physician. You may have fibromyalgia, or you may have another problem altogether. Don't wait for the pain to magically disappear. Take action.

- ✔ **Question 8:** If you constantly lose things or forget things, you may have the "fibro fog" that often stems from fibromyalgia. You may also have attention deficit hyperactivity disorder (ADHD). Another possibility is that you may have neither of these but you're simply trying to do too many things at once, and you need to take some things off your plate.

How do you know which it is? You make a stab at analyzing what you're forgetting and when. If you can't even begin to do that, and you're also experiencing chronic pain, fatigue, and sleep problems, you may have fibromyalgia. But see your doctor to find out for sure.

- ✔ **Question 9:** If your pain is severe on some days and then far less of a problem on other days, and you think there doesn't seem to be any pattern to it at all, you may be experiencing the chronic ups and downs of fibromyalgia.

Pain that can appear in one part of your body one day and migrate elsewhere on another day is a common symptom of FMS, as are days when you feel really bad and other days when you feel only mildly bad.

- ✔ **Question 10:** If you don't seem to enjoy anything anymore and maybe are sort of overwhelmed by your many aches and pains, you may have depression. Many people with fibromyalgia have both depression and FMS. You could also have a problem with an anxiety disorder, such as generalized anxiety disorder (GAD), where you are overwhelmed with extreme worry.

But before rushing off to the nearest psychiatrist to ask for the latest antidepressant or anti-anxiety medication approved by the Food and Drug Administration (FDA), as a first step, consider talking to your regular doctor or to a pain specialist. Why? Your primary problem may actually be fibromyalgia, and if your medical problem is treated and then your symptoms subsequently improve, so may your sad mood. Many doctors prescribe antidepressant medications to treat pain *and* FMS. Get more details on this in Chapter 10.



This test is just a starting point. If you're really concerned that you may have FMS and/or another chronic illness, make an appointment with your doctor.

## ***Finding a Doctor Who's a "True Believer" in Fibromyalgia***

Although I believe that most well-educated physicians are at least *aware* of the existence of fibromyalgia and its basic symptoms, and also know that it's a valid problem that needs to be treated, I also know that a few doctors out there still haven't gotten the word yet. If your doctor isn't helping you with your FMS symptoms, you need to help him understand it. Taking this book to your appointment and showing him what you're reading is a good start.

A good doctor will consider your symptoms as valid, take a complete medical history, and perform a physical examination. Read Chapters 7 and 8 for more details.

Sometimes, no matter what you do, a particular physician isn't working out for you. Maybe the two of you have a personality conflict, or maybe he thinks that you should just tough out your fibromyalgia. Or maybe the problem stems from something else altogether. Whatever it is, sometimes, you just need to find a new doctor. (I've devoted a significant part of Chapter 7 to help you find a new doc, if that's what you need to do.)

After you find a good doctor who's interested in working with you, she can formulate a plan for you to follow — one that's doable in your life. Usually, such a plan involves medications to take (over-the-counter and/or prescribed drugs and, sometimes, supplements or alternative remedies, too), as well as advice on basic lifestyle changes that you can make to improve your health. Some of these lifestyle changes may involve foods to eat or avoid (for example, foods high in caffeine may make you feel worse), exercises to perform, and other therapies that may improve your symptoms.



## *Treating the Problem*

When you have fibromyalgia, at least some of the time you may want to take some medications, whether they're over-the-counter drugs; prescribed medications, such as muscle relaxants or painkillers; or other medications such as prescribed or over-the-counter topical ointments that can help to ease your pain and symptoms. I cover these topics thoroughly in Chapters 9 and 10. You can also often gain benefit from hands-on therapy, including heat, ice, and massage therapy, all covered in Chapter 11.

And don't forget about the promise of alternative remedies! People with fibromyalgia have some very intriguing choices to consider, including acupuncture, acupressure, biofeedback, herbal or homeopathic remedies, and neurofeedback. Read more details about all these different choices in Chapter 12.

## *Making Lifestyle Changes: Pulling Yourself into a Non-Fibro World*

As you work to pull yourself farther back into the non-fibromyalgia world, you may sometimes feel like a person loaded down with 50 pounds of extra weight, trying to slog your way through the swamp. During your struggle you watch others on dry land with no heavy packs dart by you, maybe waving at you and telling you that they'll see you later.

If you want to improve your quality of life and be able to reduce your backpack of troublesome symptoms, consider the following basic ideas:

- ✓ **De-stress yourself.** Stress is a normal part of life, but if you have fibromyalgia on top of the usual daily stresses, or maybe with some extra stress thrown in once in a while, you're in a bad situation. Stress can greatly worsen the chronic pain, fatigue, and other symptoms of the person with fibromyalgia. Be sure to read Chapter 13 for my suggestions on relaxation therapy, hypnosis, meditation, and other methods to "de-stress" yourself. They work!
- ✓ **Improve your sleep to decrease your pain.** Don't kid yourself. Five or even six hours of sleep each night aren't enough. So, if insufficient sleep is a problem for you, as it is for many people with fibromyalgia, face up to it. You may need medication (such as a sleep aid or an antidepressant or anti-anxiety medicine), an alternative remedy (such as valerian or melatonin), or another form of treatment to solve this no- or low-sleep problem that you're going through. Read Chapter 14 for some ideas on how to resolve sleep problems and help yourself feel better.



- ✓ **Exercise.** Unless you're an exercise-aholic, you probably don't much like the idea of exercising (most people don't), and the mere thought of it may be nearly migraine inducing for some readers. But the fact is, aerobic exercise will usually help you to limber up and lose weight, making you more mobile and also helping you to feel better. So consider "getting physical." Read Chapter 15 to find out more about the benefits of exercises and for some specific, FMS-friendly exercises you can try.

Exercise shouldn't hurt a lot, nor should it be really unpleasant and something to dread. If you hate swimming or bicycling, don't use those activities as your exercises. Maybe walking would suit you better, or maybe dancing or some other form of aerobic exercise with your partner or a friend. You can exercise in many different ways: Be creative and find the best ways for you.

- ✓ **Pay attention to your emotions.** Stress isn't the only problem that people with fibromyalgia often face. Depression and anxiety are also very common, and they may be problems that you face. These problems are treatable and, in Chapter 16, I talk about how to know if you may have a problem, and how to identify a good therapist to help you, if you need one.

## *Coping with Fibromyalgia at Home and on the Job*

Unfortunately, fibromyalgia doesn't end at 6 p.m. or whenever you arrive home from work, nor does it go away when you wake up in the morning, struggling to get ready for another day at work or at home. When you have FMS, it's always there on the sidelines, waiting to jump on you yet again with its aggravating symptoms.

You also need to keep in mind that other people you interact with on a daily basis (your partner, children, friends, co-workers, and other family members) are directly affected by your fibromyalgia, even if they don't have FMS themselves.

Virtually anyone you interact with on a regular basis needs some understanding of what you need from them, whether you tell them that you have fibromyalgia or not. (Some people with fibromyalgia tell everyone that they have "arthritis" because they think that it sounds better.)



Even as you become more aware of your symptoms and how best to resolve them, you still have to deal with the “non-fibro” world, comprised of your family members who don’t have fibromyalgia, your fellow workers, and many others you interact with. You need to develop workable strategies to cope with these varying situations and come up with a winning game plan for your life. I cover these topics in Chapters 17 and 18.

## *Working with fibromyalgia at work*

Many people with fibromyalgia continue to work full-time or part-time, despite their pain and fatigue. They struggle with what to do when their symptoms make it hard to continue to work.

Many people worry about whether they should tell others at work about their FMS, whom they should tell, what they should say, and so much more. In Chapter 17, I provide a thorough overview of these issues and how they’ve affected real people. I also include advice from an attorney expert in getting people with FMS approved for Social Security disability.

## *Handling fibromyalgia with family and friends*

Even the most loving family members and friends usually don’t really understand fibromyalgia if they don’t have it themselves. And even if they do have FMS, too, their symptoms may be very different from what you experience, and the intensity of their symptoms may be better or worse than the way your symptoms grab hold of you.

As nice as it would be if this were true, the reality is that fibromyalgia isn’t a quickie one-time explanation. For people to understand what your problem is, especially the people with whom you share your home and your life, helping them get a clue about what you’re going through and what you need takes a lot of work.

You have to be candid, and you also need to know how to respond to the dumb things that people often say to people who have fibromyalgia. Read Chapter 18 for more information on how (and also how not) to explain fibromyalgia to your children of all ages, your partner, and other family members and friends, so that they can better understand what’s really going on here.

Don't miss the information that I provide on sex and fibromyalgia for readers who are sensing that their partners are maybe feeling a teensy bit deprived in this area of life. (Thinking about sex when you hurt is a hard thing to do, but it's not hard for your non-FMS partner to think about it. Finding common ground is a good idea.)

### *Sorting it out when you don't have fibromyalgia*

Maybe you don't have fibromyalgia, but you live with someone who does, and you really want to understand the problem and to help as much as possible. But where do you begin? Not to worry, I've provided a chapter just for you — Chapter 19.

This chapter describes techniques to assist you in helping your friend or loved one deal with FMS, and it also tells you some things you should *not* do or say because they drive most people with fibromyalgia wild. (People who do have fibromyalgia may enjoy reading Chapter 19, too, and sharing it with their friends and family members who don't have FMS.)