What is fibromyalgia?
Fibromyalgia is characterized by chronic widespread pain, fatigue (overall physical exhaustion and lack of energy), and multiple tender points. If you have fibromyalgia, the pain and fatigue can affect many areas of your life, making it harder to work and do daily activities. It may result in less ability to enjoy hobbies, take care of your family, and do the things you love to do. Currently, there is no known cure for fibromyalgia, but its symptoms may be managed.

Because each person is unique, he or she may experience the symptoms of fibromyalgia differently than someone else with the disorder. That’s why it’s very important for you and your healthcare provider to put together a fibromyalgia self-care plan that is right for you. You can use the resources offered in the FibroGuide program as part of a plan that meets your specific needs.

What are the symptoms of fibromyalgia?
If you have fibromyalgia, you may be experiencing symptoms such as:

- **Chronic widespread pain lasting more than 3 months**—Head-to-toe aching that may be worse on some days than it is on others
- **Fatigue**—Deep physical and mental exhaustion that may make it hard to do daily activities
- **Body stiffness**, especially in the morning
- **Problems with memory, concentration, or disorganized thinking** [sometimes called “fibro fog”]
- **Emotional changes**, such as depression or anxiety
- **Sleep problems**—waking up frequently and having difficulty falling back to sleep

If you’re like many people with fibromyalgia, you may also experience other health problems, such as headaches, restless leg syndrome, irritable bowel syndrome, or irritable bladder. Be sure to talk with your healthcare provider about all of your health conditions and symptoms. Only your healthcare provider can diagnose you with fibromyalgia.

When you live with a lot of fibromyalgia pain and not much energy each day, it may be harder to enjoy life. The FibroGuide program shows you nondrug ways that may help you manage your fibromyalgia symptoms and live with less pain so you may be able to do more of the things you need, want, and love to do.

A word about fibromyalgia and arthritis
Sometimes fibromyalgia is confused with arthritis because of the pain and tenderness it causes. But fibromyalgia is not the same as arthritis. Arthritis causes painful swelling in the joints. Fibromyalgia does not cause physical changes or physical damage to the joints, skin, or tissue. Instead, pain usually occurs in the soft tissues around the joints and in the muscles and skin throughout the body. But because there are similarities, many patients with fibromyalgia are treated by rheumatologists—doctors who specialize in arthritis and other joint conditions. The Arthritis Foundation also offers information about fibromyalgia.
What causes fibromyalgia?
The exact cause of fibromyalgia is not known. Sometimes the onset of fibromyalgia is associated with physical and psychological stressors, including:

- Physically stressful or traumatic events, such as a car accident
- An infection, such as a viral illness, or autoimmune disease, such as lupus
- Emotional distress, such as a divorce

Also, once a person has fibromyalgia, continued exposure to stressors may keep the disorder active. These stressors may be the same as or different from the original ones.

A balancing act
The exact cause of fibromyalgia is not known. Fibromyalgia may be linked to abnormal levels of naturally occurring substances (such as substance P, serotonin, norepinephrine, and dopamine) in the brain, spinal cord, and body that let you know when you are experiencing pain. Abnormal levels of these substances may increase the sensitivity of your nervous system so that normally nonpainful stimuli become painful.

Some researchers believe that the imbalance of these substances may also increase sensitivity to other sensations, such as heat, noise, odors, and bright lights. It’s as if the “volume control” for pain and other sensations were set too high. That is why a person may feel pain and other sensations more intensely than people who don’t have fibromyalgia.

Why fibromyalgia hurts
Some researchers believe that several factors may contribute to fibromyalgia pain, but the exact causes are still not fully understood. According to some current theories, fibromyalgia patients may have:

- **Too much substance P**, a substance in the spinal fluid that sends pain signals to the brain when the body feels pain. Too much substance P may lead to too many signals being sent, which can lead to more pain
- **Too little serotonin and/or norepinephrine** may affect the body’s ability to dampen pain signals reaching the brain. Too little serotonin and/or norepinephrine has been found in some people with fibromyalgia
- **Too little dopamine**. Having low levels of this substance may make it easier to perceive pain
- **Changes in the hypothalamic-pituitary-adrenal (HPA) axis**, which helps the brain and glands work together to regulate body chemistry. These changes can lead to abnormal levels of substance and hormones, which may cause someone to feel pain differently than someone without fibromyalgia

Fibromyalgia pain is real
Because your pain symptoms may not be physically apparent or obvious, others may not fully understand or believe what you are going through. But research has shown that pain in fibromyalgia patients is real. Increased pain sensitivity to pressure has been shown in experiments comparing people with and without fibromyalgia. In one study, participants were asked to rate pain intensity when pressure was applied to their thumbnail. Scans were taken to record brain activity as the pressure was applied. The people with fibromyalgia reported feeling pain at lower levels of pressure than did the people who did not have fibromyalgia. Brain scans from the study also showed that sensitivity to pain in a person with fibromyalgia was higher than normal.
How do you know if it is fibromyalgia?
Currently there are no diagnostic tests, such as x-rays or blood tests, to detect fibromyalgia. The symptoms of fibromyalgia may overlap with the symptoms of some other conditions. This is why fibromyalgia is sometimes difficult to diagnose.

Your doctor may use certain guidelines to help determine if you have fibromyalgia. According to the American College of Rheumatology, a person may have fibromyalgia if he or she:

- **Has chronic widespread pain for more than 3 months.** Widespread pain affects the right and left sides of the body above and below the waist
- **Feels pain in at least 11 of 18 possible tender points** (9 on one side of the body, 9 on the other) when pressure is applied

Only your doctor can determine if you have fibromyalgia. He or she may use the guidelines listed above, or other methods, to find out if you have the condition.

When discussing your pain with your doctor, you can do the following to help him or her make a diagnosis:

- Talk about all of the symptoms with your healthcare provider. Openly discuss how you are feeling and how the symptoms are affecting you
- Work together to create a plan that meets your individual needs
- Complete the **Working With Your Healthcare Provider Work Sheet** to help you prepare for your appointment

Teaming up with your healthcare providers
If you have received a diagnosis of fibromyalgia, you should not have to manage your fibromyalgia alone. There may be several healthcare providers with different areas of expertise to help with your care. Depending on your symptoms, your healthcare provider may refer you to a:

- **Primary care or family physician**—treats a variety of general health needs
- **Rheumatologist**—specializes in diagnosing and treating arthritis and fibromyalgia
- **Pain management specialist**—diagnoses and treats pain associated with various conditions
- **Psychiatrist**—specializes in diagnosing and treating mental and emotional disorders
- **Physical therapist**—helps patients increase their mobility, restore physical function, and alleviate pain
- **Psychologist or social worker**—helps patients work through emotional issues

You may also want to talk with your pharmacist. He or she may be able to answer questions you have about your medicines.

You are the most important member of your healthcare team. You can help yourself the most by taking an active role in your care. Try to talk as openly as you can with the members of your healthcare team about how things are going. Are you having a hard time following their suggestions for managing your symptoms? If you are, it may help to talk honestly about your concerns and work together to solve any problems. Your healthcare team’s goal is to help you feel better.
Tips for talking with your healthcare providers
It helps to stay in close touch with your healthcare team. You don’t have to wait until you are not feeling well to go see a healthcare provider. Regularly scheduled visits may help you and your healthcare team manage your symptoms over time and keep track of your progress.

Before you go to see your healthcare provider, try to choose 2 or 3 issues you want to discuss. For instance, you might focus on:

- Symptoms that bother you the most and how they affect your life
- What you believe is causing these symptoms
- Stressors that may be making your symptoms worse

Don’t worry about trying to discuss everything at one visit. By seeing your healthcare provider on a regular basis—not just when you have a pressing need—you may be able to talk about different issues at each visit.

The Working With Your Healthcare Provider Work Sheet can help you plan your conversations with your healthcare provider.

Where do I go from here?
It is important for you and your healthcare team to develop a fibromyalgia self-care plan that is based on your individual symptoms and lifestyle. Your healthcare provider can help you create a realistic plan that you can commit to and put into action. Your plan may include:

- **Education** to help you learn more about fibromyalgia and how to manage the symptoms that you are experiencing
- **Physical activity** based on your needs and abilities. Exercise may be an important part of managing your fibromyalgia. *Be sure to talk with your healthcare provider before starting or changing any exercise program*
- **Multiple medicines**, both nonprescription and prescription, depending on your symptoms. For example, your healthcare provider may prescribe medicines to help with pain, sleep problems, or emotional symptoms. There are also medicines approved by the FDA specifically for the management of fibromyalgia
- **Support** from family, friends, and support groups, or one-on-one therapy

The FibroGuide program can help you and your healthcare provider create your own plan based on what you can do right now. You can learn about ways to relax, read about the benefits of good communication and exercise, or track your progress with helpful work sheets. And with FibroGuide, you can customize and change your plan as your needs and abilities change over time by taking the Steps for Me assessment.

Your healthcare team is there to support you. There are also a number of organizations and support groups that can help you learn more about fibromyalgia and how to manage it. You can find a listing of these groups in the Support Organizations link located in Added Features in the lower right corner.

To learn more about managing fibromyalgia symptoms, watch Steps to Living With Fibromyalgia, featuring Daniel Clauw, MD, a leading fibromyalgia expert.
A note for family and friends

Fibromyalgia has changed my life, too
If someone you care about has fibromyalgia, you may know how challenging the pain and fatigue of fibromyalgia can be. You understand that the disorder doesn’t just change the life of the person who has it; it may change your life, too. Fibromyalgia may limit the things you are able to do together. If you take over chores and errands, more demands are made on your time and energy. Learning and understanding all you can about fibromyalgia may help you be a strong source of comfort and support for the person who lives each day with the challenges of the condition. The FibroGuide program offers valuable information and useful tips that may benefit both of you.