

Fibromyalgia 101

I would like to welcome you to Fibromyalgia 101, a presentation by the American Chronic Pain Association that was supported through a grant from Forest Laboratories.

In the next few minutes we're going to look at what fibromyalgia is, the causes and how are you going to live a full life in spite of the pain.

There are two kinds of pain; there's acute pain and chronic pain. Chronic pain is a pain that continues for a month or more beyond the usual recovery period of an injury or an illness. It can go on for a very long time. The interesting thing about chronic pain is that you have good days and bad days. It's never consistent, the same level of pain every day and I think that has to be the most confusing part of chronic pain.

And when we're talking about Fibromyalgia it is a type chronic pain. Fibromyalgia is a condition in which a person has long-term, body-wide pain and tenderness in the joints, muscles, tendons and other soft tissues. Fibromyalgia has also been linked to fatigue, sleep problems, headaches, depression, and anxiety.

It's estimated that about five million Americans are dealing with fibromyalgia. While fibromyalgia is most common in women between 20 and 50 men can also have fibromyalgia.

Fibromyalgia is very difficult to be diagnosed and it can take years to get a definite diagnosis of fibromyalgia. The cause of fibromyalgia is unknown, but there are some possible causes or triggers that include: physical or emotional trauma; an abnormal pain response – meaning that their brain functions differently than other people and so they may feel pain more intensely than other individuals; sleep disturbance; an infection such as a virus - although there's none that have really been identified to link it directly to fibromyalgia.

Pain is the main symptom of fibromyalgia and it may be either mild or severe. Painful areas are called tender points. Tender points are found in the soft tissue on the back of the neck, shoulders, chest, lower back, hips, shins, elbows, and knees. The pain then spreads out from these areas.

The pain may feel like a deep ache, or a shooting, or burning pain. While the joints are not affected, pain may feel like it is coming directly from your joints.

Everybody experiences fibromyalgia in different ways, some have difficulty concentrating, memory loss called Fibro Fog, sensitive to loud noises or bright lights, they may experience a lack of energy, poor sleep, morning stiffness and fatigue – when they sleep at night they wake up feeling more exhausted than when they went to bed the night before.

People with fibromyalgia tend to wake up with body aches and stiffness. For some people, pain may improve during the day, but gets worse at night. Others have pain all day. In addition, pain may get worse with activity, cold or damp weather, anxiety, and stress. Fatigue, depressed mood, and sleep problems are seen in almost everyone with fibromyalgia.

If you have fibromyalgia fear may be the most controlling factor – never knowing when the pain is going to strike, how well you’re going to feel and it’s difficult to make plans in advance even in a day, a month or a year.

Our expectation today is that modern medicine can eliminate pain when in fact, for many people, especially with fibromyalgia, they may be able to reduce it, but it will never go away. So we look to our health care providers to help us manage our pain. The problem is they’ve never been trained and so what we hear too often is “Learn to live with it.”

When you hear “learn to live with it” it can often look just like that formula on the blackboard impossible to solve. What the American Chronic Pain Association tries to do is take that impossible formula into a simple solution of $1 + 1 = 2$.

One of the most important components of living a full life with fibromyalgia is to have a good relationship with your healthcare provider and that means good communication.

There are two things that are very important in working with your healthcare provider; the first is that they validate your pain - that they believe you have pain; the second one is good communication. The American Chronic Pain Association has designed several communication tools to share with your healthcare provider – one of them is called the Fibro Person. When you go to our webpage theacpa.org you’ll see our Fibro Person. There you’ll be able to click on a map of an individual -- man or woman, and in the front and the back you’ll be able to point to where on your body your pain is, how it feels and the intensity. Once you’ve completed that you can hit print, take it out and you can see the map that you can take to your healthcare provider, to explain exactly how your pain feels, where it’s at and the intensity.

Having a good relationship with your healthcare professional means using the time to the best of your ability. Tools that help you communicate exactly how you feel and in the impact it has on your life allows you that time to begin to problem solve with your healthcare provider so that you can live more fully in spite of the pain. If you have fibromyalgia you need to know that there is hope for a better tomorrow. One thing that we need to be able to help you to do is to help you focus on your abilities rather than your disabilities.

A key to living well with fibromyalgia is to become a part of the treatment team. It is important that you’re no longer that passive patient, but an active participant in your treatment and you work with your healthcare professionals as part of the team.

It’s important that you understand the goal and your goal is to reduce your sense of suffering, improve the quality of your life, and increase function. There may always be some level of pain, but that doesn’t mean you can’t live a full life in spite of the pain. The question is “how do you do that”?

The American Chronic Pain Association has developed “Ten Steps from Patient to Person.” This is the beginning of making that journey from that disabled patient, back to a functional person. They don’t need to be done in any order. They’re important depending on what your needs are. You will pick and

choose where you want to start. Saying that, the first step, which is accepting the pain is important. For many people accepting the pain means giving up, when in fact what it means is educating yourself, understanding the pain, knowing that today you may have a certain level of pain, but that doesn't mean tomorrow it will be the same. There's always hope for a better tomorrow.

The second one is to get involved and this means again not to be that passive patient, but an active participant and ask your healthcare professional "what is it that I can do to help reduce my sense of suffering, improve the quality of my life and increase my function?"

A good starting point is understanding your priorities. If you're someone who has fibromyalgia you may understand that as the pain gets worse, your ability to function is reduced. So many of the things you did on a day to day basis are let go. It's important that you begin to identify what is the most important thing for you – what is your priority for today? It's important to look beyond the pain and to things that are important in your life. That means setting priorities, but how do you do that? We need to have a starting point each day. One way to help you do that is to think about all the things that have gone by the wayside since your pain began, things that you are no longer able to do, get index cards – little 3 x 5 index cards, carry them around with you and every time you think about something that you didn't do or that you should do, or that you wanted to do – write it down on one of those cards. After you think that you have all of that written down, what you need to do is take all of those cards, lay them out and just step back and take a look at all of the things that you've been carrying around with you. All the things you've felt guilty about that you couldn't do. Then ask yourself – of all of those things lying out there – what is the most important one for you right now? When you find it, pick up that card and you've just identified your number one priority. Then you can pick them up in any order that you want and you can shift them around as your needs change. You now have a starting point.

Another step is setting realistic goals. At the beginning of this remember we said that people with pain have good days and bad days. On good days with fibromyalgia because we feel so guilty, we try to get as much as we possibly can done in that day. Typically what happens is that we overstep our limits and the next day we can't even move and instead of realizing that we eliminate that activity – knowing that it's going to create more pain. What we have to be able to do is to narrow down what we want to do in small manageable steps setting realistic goals. When you decide what you want to do today, ask yourself, is this within my limits? Can I actually do this today? Do I understand what it means to stop, listen to my body and when it says ouch, stop there take five minutes to relax and then go back to the activity. Don't set yourself up for failure – make your goals measurable and one day at a time you will make progress.

It's important that a person with fibromyalgia feels empowered. One way to do that is understand your basic rights. You have the right to be treated with dignity and respect. You have the right to make mistakes. You have the right to do less than what is humanly possible. You have the right to ask for what you want. You have the right to stop and think before you respond. You have the right to say "no" and not feel guilty. You have the right to ask for help, or to disagree, or to ask why. These rights are going to give you a sense of empowerment.

Another tool in moving from that patient back to a person again is to recognize your emotions. For many people with fibromyalgia they may have heard “it’s just because you’re depressed.” Your emotions do have an effect on your level of pain. We can’t separate our mind and our body. What we feel physically is going to affect us emotionally, and what we feel emotionally is going to affect us physically. It’s important that you begin to recognize your emotions, both the positive ones, but also the negative emotions. As we begin to avoid our feelings, we keep them buried deep inside of us and those create more stress – it’s like carrying them around. It’s important that you recognize your emotions, both the positive and the negative emotions. As you deal with them as they occur, it’s not going to increase your stress level. Increased stress is going to increase your pain levels.

People often hear that you just need to relax – not worry about it. That’s an easy thing to do, but it’s a hard thing for us to understand. It’s important that you listen to what your body is telling you and when you begin to feel the first increase in pain – that maybe you just need to take five minutes and just relax. How do you do that? How do you tell your body how you want it to feel? How do you redirect your attention off of your pain and on to something else? It is a learned skill and it takes practice. One example of how this works is, right now in your mind to yourself I want you to count from 1 to 25 and at exactly the same time say your alphabet. It’s impossible because we have a one track mind. So while we’re telling ourselves that we’re laying on this white sandy beach listening to the waves crash against the shore, the sea gulls overhead – while we’re thinking that- for that moment we’re not thinking about how much the pain is affecting our bodies. So when you think about yourself lying on the beach in the nice warm sand, listening to the waves crash against the shore, hearing the seagulls overhead – for that instant you’re not thinking about how much your pain is affecting you, therefore you’ve reduced your sense of suffering. That’s one of our goals in managing fibromyalgia pain. Relaxation exercises help you reduce stress which help you better manage your pain.

Exercise is a key component in managing the pain from fibromyalgia, but for you it may mean more pain. Fibromyalgia begins to take over your life – your activities are decreased because every time you do something it tends to increase your pain levels. When people tell you to exercise all you can think about is more pain. It’s important to talk to your healthcare professional about where your limits are. Once they have approved the fact that you can actually exercise, think about the goals we talked about earlier and don’t set yourself up for failure. When you start an exercise program do it within your limits. That may mean doing one leg lift each morning before you get out of bed the first week, adding a second one the next week, and slowly and gradually increasing your level of exercise - any movement is exercise. The key is you have to keep moving to keep those muscles in tone. That is important when you’re living with fibromyalgia.

We’ve talked a lot about living with pain, but what we need to look at is the total picture and for so many with fibromyalgia we often hear them say “ I can’t do this anymore, I can’t do that anymore,” rarely do we hear someone say “this is what I can do” and a key component to living well with fibromyalgia is to look at the total picture – not just your disabilities, but begin to focus on your abilities. Think about the things that you can still do, how you can do them, how you can incorporate them into your life. It’s important to have a positive attitude when you’re living with fibromyalgia.

Learning to live well with fibromyalgia is not just a solo exercise. It means that you need to talk to other people – support groups are a wonderful way to begin to understand not only what you need to do, but how other people learn how to better manage their pain. The American Chronic Pain Association has a number of peer led support groups throughout the country. It is helpful for us to be, not only to learn from other people, but to share what we have learned about managing and living well with fibromyalgia.

Sometimes it is difficult for a person to understand all of the components of pain management that we've just talked about. We use the example of a car – a person with fibromyalgia is like a car, but their car has four flat tires. Expectation is that if you give me the right medication that's all I need, but it's only going to put air in one of your tires. You still have three flat tires. So the question is what else do you need? And for each person it's different. For some it may be physical therapy, maybe biofeedback, it may be acupuncture, counseling – it's up to you to discover what you need. Once you get all four tires filled, it's important that you maintain that car on a day to day basis. If something goes wrong, then you need to go back to your healthcare professional and talk with them. Have that good relationship. It is possible to live a full life, reduce your sense of suffering, improve the quality of your life and increase your function in spite of fibromyalgia. You can live a full life.

For more information you can go to the American Chronic Pain Associations website at www.theacpa.org or call us at 1-800-533-3231.