

## Understanding Fibromyalgia Presentation Transcript

*(Pittsburgh, PA event)*

October 17, 2009

**Penney Cowan:** My name is Penney Cowan; I'm with the American Chronic Pain Association. Actually, the American Chronic Pain Association has been around for 30 years now. Our focus is to provide peer support and teach coping skills to people with pain. We had this wonderful opportunity to come out and talk to you about fibromyalgia, and it is a sponsorship with the support of Pfizer. So we want to thank them for allowing us to do this; to provide the lunch, and to make these talks available.

What we're going to be talking about today is fibromyalgia. What I'd like to do first is talk a little bit about chronic pain. What is chronic pain? It's a pain that continues a month or more past the usual healing period, and it usually lasts from three to six months. If pain goes on that long, it's chronic pain. The point I want to make here is, it's not always the same consistent level, and I think that's where chronic pain becomes so very confusing. You're not always at the same, exact level of pain. It goes up and it goes down; you have good days and you have bad days. So people get the wrong impression thinking you look good today, you know, why are you not being able to do something that you could do yesterday. So it's never that consistent level.

Let's talk about fibromyalgia, and who gets fibromyalgia. More than five million people are dealing with fibromyalgia in America today. About 80% to 90% of them are women; but that doesn't mean that men don't get fibromyalgia.

You can get it at any age, but usually it's between the ages of 20 and 50 when you first begin to see the symptoms of it. I think one of the most problematic things is that it can take up to three years—and I know from myself, and I'm actually a person that also has fibromyalgia—I've had it for 36 years now, and that's why we're doing all of this. But it can take three to five years to get a diagnosis, and I think that's what is one of the most difficult things about having fibromyalgia is just getting that answer. It is the most common, widespread muscle pain condition in the United States.

How do you diagnose fibromyalgia? If you look at the chart up there, you can see that there's little red dots? Those are called trigger points, and if you have 11 of the 18 trigger points, then there's a good chance that you have fibromyalgia. You have to have that pain for more than three months, which falls into the category of chronic pain. The symptoms include aching, radiating, shooting, burning, exhausting, nagging, pain. It's a little murky. It's a little unclear exactly what it is, and I think again that lends to how confusing it is to treat fibromyalgia.

So you may experience achy muscles that feel tender to the touch. I know for me, probably a few years into it, it hurt to wear clothes. I was wearing my husband's clothes; the looser the better, because it just hurt to even touch my skin sometimes, it was that bad.

Morning stiffness; you wake up and you feel just as bad as you did before you went to bed the night before, so you're very stiff, and I always sort of looked at myself like the Tin Man, you know, and I needed that oil in the morning. The Wizard of Oz, the Tin

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Man, and he had those really creaky joints; that's what I felt like a lot especially in this kind of weather. Dull aching pain, or a deep, intense pain; or just flu-like symptoms. You may experience widespread pain all over your body.

I have trouble with memory; it's called fibro-fog; concentration, being able to keep focused on things all the time; that is another symptom. Poor sleep; fatigue when you wake up. You can sleep many hours and you still don't feel rested in the morning, and that's a real problem.

Some of the myths about fibromyalgia: That it isn't a real medical condition. It is. It is. I want you all to know it is definitely a real medical condition, and it's something that we all need to take very seriously. Part of why we're doing this is to really increase awareness and knowledge, and hopefully you'll be able to take this information to your healthcare professionals and share some with them. That it's rare; more than 5 million people in this country, I don't think it's rare, and that's only the ones we know about. That's not all the people who have not yet been diagnosed. Like I said before, that it only affects women; it doesn't, it can also affect men. There's actually an online support group for fibromyalgia just for men.

So you may wonder, I mean this is where many of us are right now. Is the pain real? Is it really pain? Or am I just depressed? We always hear that, you know, maybe it's just because you're depressed, and that's really very hard for us to understand, because we think, we didn't do this to ourselves. It's not because we're depressed that we're hurting. How did I get it? Was there a beginning? Was there something I could put my finger on and say, ah-ha! That's when it started.

For some people it is, because sometimes it is a result of an injury, but a lot of times there's no definitive, you know, this is exactly when I did it. Am I just imagining it? Will I ever get my life back? That was the one thing that I kept asking myself, and I really thought it was over. In fact, I felt so bad at one point that I wanted my husband to take the kids and just leave. I didn't have the energy to do it, but I had so much guilt around not being able to fulfill and get my life back; fulfill all my duties that I wanted to do, that I thought, am I ever going to get my life back? Is it fatal? I think sometimes, especially before you know what's going on; you think it might be a blessing. Unfortunately that's part of how I felt, and I was in my early 30's when all this took place.

Look at what modern medicine can do today. They can give you a new heart, new lungs, new livers; they can do all these amazing things. So what do we expect? What is our expectation? That they can take away our pain, right? That's our expectation. They should be able to do that. But what happens with people with fibromyalgia, and I like to use the maze. We get stuck in there. We sort of get dropped in there when our pain starts, and we just keep going from one dead end to another. I mean I did that for six years, and that's how it feels; that's exactly what happens. It's so confusing.

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Your pain, let me ask you this, how does a headache look? Can you see it? A backache? How does it look? Our pain is invisible; you can't measure it, you can't x-ray it; you can't an MRI of it; there is no way for them to say, oh, you have a 5 level of pain today. Or oh, this is a 10, that's pretty bad. There is no way to measure pain, and that's part of the problem.

I always kept telling myself if I only knew what was causing my pain, than I would be able to live with it. So it took them six years to figure it out and give me a diagnosis, and then I felt, well if you know what it is, than you should be able to fix it. So it didn't help at all, because then my expectations were, okay, now fix it, because remember we think modern medicine can perform miracles.

But what's really interesting about pain, and it's not even the pain as much as it is the fear of the pain; never knowing. Never knowing the next time it's going to hit. Not knowing if you can make the plan tomorrow—I mean I know coming here today, I bet there are some people who made reservations and just couldn't make it, and we understand that, because you never know, and so you don't make plans from one day to the next, you're never sure. Or, unfortunately, sometimes people will anticipate that their pain may get out of hand, so if they go out they may take a little more medication than they need because they don't want to have to go home. The fear is the controlling factor of your pain.

We look to our healthcare professionals to give us the answers. The problem is in all of the medical education that they get, some of them 8, 10, 12, 20 years, they get two hours of pain management, that's it. So how are they supposed to help us? They don't know, and so when you go to your healthcare professional and you ask them, and they give you this look, sometimes it's because they just don't know what to do. They don't know what to do. They have been trained to cure and to heal, and we keep coming back and saying it's no better, or I am worse, and it's really frustrating for them. Unfortunately they don't know how to say, I don't know. A lot of them just don't know how to. I was fortunate enough, finally someone said, I don't know, we need to send you here, and it was because a lot of people go through procedures that they may not need to have.

Interdisciplinary pain management, we're going to talk about that later. We're going to really look at the first part we're talking about fibromyalgia, but the second part is really how do you live with it? Interdisciplinary pain management is something that you really need to have if you're going to live with fibromyalgia, or any other kind of chronic pain problem. But they are very expensive, and unfortunately they're very hard to find these days.

What happens to people with pain? What do they always hear? Learn to live with it. When they do that, this is what happens. That's exactly how we feel. Its like, how am I supposed to do that? Many times they told me, learn to live with it, and I thought to myself, you know, if I could do that, I would have figured it out by now. You know, I'm

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very inventive, sort of creative, and thought I really didn't want to be in this patient role. I would have figured it out. No one ever told me how though, that was the problem.

What we want more than anything else is validation. We want someone to believe our pain. We want them to believe that yes, we do have pain, I understand. I think that's what one of the things the American Chronic Pain Association does. We validate your pain, because we don't ask you are you sure? You know, are you sure maybe you're not feeling that? We don't put you on the defense, and that's what so many people with pain feel like all the time, they feel very defensive. They're always trying to defend their pain. We're there to have them help us, so we become very defensive when all we want is someone to validate our pain, to say yep, I believe you. Because then we can start to get to work.

The problem is, and I love this picture because that's how it happens. We just sort of let our pain take over who we are, and we go further and further. The further down we go, the less we see of ourselves. We walk into this big, foggy cloud and we just disappear after a while, and we are defined by our pain. The one thing that really bothers me is when people call, and they'll say I'm a chronic pain patient. I'm thinking, okay, we have to talk because you are a person with pain, but there is so much more to you than just the pain, and that's something as we continue, you'll see a lot of the things that we do, it all talks about going from patient to person. That's really the key here. We don't want to get lost in our pain. We don't want it to take over who we are. We are a person with pain, but we have so much more than just our pain, and that's really where we have to begin to focus.

How do you explain it to your healthcare provider right? Remember all the things we just talked about; how confusing, you know, it may be aching, it may be a deep, intense pain. You may just hurt all over, you're tired, and how do you explain all that to your healthcare provider? Because what we want is for them to understand exactly how we feel. I don't know how many people have said to me, if my doctor could just feel my pain for just five seconds, than they'd know. But they're never going to do that.

The problem that I had was I kept thinking about what's the best way to describe my pain? How can I tell them this? So I spent many, many hours thinking about it. What is the best way, so they'll really get it? The problem was, instead of focusing on other things, all I did was focus on my pain and how it felt. So what I did was I increased my sense of suffering, because all I did was think about my pain. The more we think about our pain, the more we're going to suffer. So that was one of my big problems. I kept wondering how am I going to explain this. No one is—you're never going to be able to do it. If we could take our pain out of our body, and hold it in our hand and say, here, now you get it; but we can't do that.

One of the things amidst—this is on your table, we have created a new fibro log, and this is specifically for people with fibromyalgia. It's designed to help you track all the different areas of pain. First of all—and we have to ask what your pain level is from a 0

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to 10. They need to know, where are you at? But then the next like we talk about where the pain is. Different areas of your body—is there no pain? Is it mild? Is it moderate? Or is it severe pain? All you have to do is check, it makes it really easy.

What about your quality of life? Is it very good? Or is it dwindling away? How about exercise activity? Are you very active? Or do you stay in bed all day? I mean it goes from one extreme to the other.

How about your interference with sleep? How much does your pain interfere with your sleep? Then your range of motion; your morning stiffness. How stiff are you when you get out bed? Can you get up move all over the place? Or are you at the other end of the scale where you can't move at all and don't want to get out of bed.

Then exhaustion; how much energy do you lose during the day? How fatigued are you during the day? That's something that we all struggle with that have fibromyalgia, because it makes us very tired some times.

The change in weather; I was just talking to someone before about the weather here in Pittsburgh. I used to live in Pittsburgh for most of my life, and so I understand the weather changes here. How does that affect you? Does it not affect you or does it affect you in a great way?

Your stress level, that's also a key. How about your mood? That's another thing that we need to measure, and then how isolated you've become. I know for myself, that I would just pull away and I didn't want to get involved; I didn't want to be with other people, because what do they tell you? They tell you oh, you look so good; I don't understand why you're in so much pain.

One of the things that we always do is we give mixed messages. I want to ask you, when was the last time you guys went to your doctor in your pajamas? You don't do you? No, we make the most effort to look as good as we can, and then we want them to figure out that we're really feeling bad. I don't want you to go to the doctors in your pajamas, but think about it. I mean people look at us and they see what we want them to see. So instead we start to pull away and become very isolated. So we really need to look at that.

How about weight gain or loss? It's another thing. Your appetite, is it good? Or is it decreased? How about snacking during the day? That's certainly going to have an affect on your pain. Inactivity is also very important.

How about alcohol? Do you drink a lot? Do you drink a little? Ability to concentrate is also very important. The fear of the pain—we measured that—and then your exercise. What this scale does, these are all graphical. All you have to do is circle. You don't have to write out long journals. You just circle this, you take it into your doctor, and in a matter of two minutes, and he can look at all of this and see what's going on. Because think about it, you have what, maybe five or ten minutes at the most at your doctor's

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office. Do you know how long it would take you to talk about all of this? We want that validation; we want them to understand what we're going through, but we spend so much time.

So by using this fibromyalgia log, you'll be able to take it to your doctor and say—when they ask you how you're doing, there it is; very easy, understand, this is how it's affecting—because every one of these things that I just talked about has an impact on that very top level of how much pain you're in. It's all connected, and we'll talk about that later. So this is a really good, graphical tool to help you better communicate with your healthcare provider. This is on our web page. You can go on the web page and download it as many times as you want; print it out. Let your doctor know that they can use it; it's there for everyone to use.

Another one; and this is one I've always had a real problem with. When the doctor would ask me, on a scale of 0 to 10, what's your pain? Right? Now, I was in my late 20's when it started. It was hard for me at the very end, before I went to a pain management program, and I'll be talking to you about that later, to even hold a cup of coffee. I couldn't take care of my children; I couldn't take care of my house; I couldn't be the wife I wanted to be. And so when they asked me, on a scale of 0 to 10, 10 being the worse, what's my pain? I wanted to say 20. And right away they think, okay, nut case, there you are. Because I wanted them to understand how much this is impacting my life. How much control it had over my life.

So 0 to 10, what does a 5 mean? I could be standing up here in a 5 and you could be home in bed. Or, I could be up here with an 8 or in bed with an 8 and someone else could be out playing tennis. There's no real numbers; we don't know what those mean. It's different for everyone else.

However, if we can measure the quality of life; your level of functioning, that really begins to communicate with your healthcare provider how your pain has impacted your life; your quality of life, what's it doing?

So this is another scale, this has been used widely. We've been using this for a long time; it's on our web page as well. So if you're at a 0 you stay in bed all day, you can't function. All the way up to 10 where you go on with your normal, everyday life. It can be anything in between, say you're at a 4 and you get up, maybe do a few things around the house, but that's about it. Then they get it. They get this is how this pain is impacting my life. It's another good communication tool.

Preparing to go to your doctors, and this is something we really need to do, and we think a lot about it, but we really need to be prepared. Again, because our visits are so short. We don't have that much time. So let's prepare; let's break down only the new things that have happened since the last time you saw them; not start at the beginning. They understand, they know, they have it in your chart. Just write down anything—any new symptoms that have occurred. Include all the medications that you're taking, list them

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all. But when you do that, make sure that you also include any over the counter's your taking, vitamins, and herbal supplements, because they all have an impact on those prescription medications. That is so important, don't forget to do that.

Things that you've tried. The heat, did it help, did it not? Ice, just in very—take one sheet of paper, bullet points, write these things down, very short, very concise. Again, we want to make the most of our visits. We're there for answers. We're not there to discuss all of these things in a very lengthy amount of time. We want to let them know what we're doing so that they can give us some resolve for those issues.

Change in your daily function. Is it better? Is it worse since the last time that they saw you? What about your mood, your sleep, your appetite? Has that changed at all? Again, the fibro log is going to help you with a lot of these things. Questions that you have, and that is so important; you really need to write those down because we never remember them. I always think to myself, I have to remember to ask this. Then on the way home I go, I forgot again. I've given this talk and I talk about writing them down so many times, and I must admit sometimes I forget to do that myself. But I'm really angry at myself because I wanted to know, and if you try to call back, you can't get them. So you really need to write it down and be prepared.

One of the most important things is to take someone with you. We don't always hear what they say. Office visits are very emotionally charged, and we're there with so many high expectations hoping that this is the one; this is the time that they're going to give me the answer I'm looking for and take away my pain. So unless we take someone with us, we may not hear what they're saying.

How do you manage pain? The problem is, when you don't manage it, it's like if you've ever been caught in one of those big waves that goes ashore, and you just sort of tumble around. You don't know what's up; you don't know what's down. That's how it feels when you have a chronic pain problem, especially fibromyalgia. You're just not sure where you're going. It's total control of your life. So if you think you have fibromyalgia we encourage you to take all of these materials that we've given you today and talk to your healthcare provider about it. It's really important.

When you have pain, you feel hopeless and depressed; and your depression did not cause your pain. Think about it, if you had the flu for an entire year, would you be happy? No. You'd be depressed, that's just the way it is. Depression is part of a long-term chronic pain problem. You'd be angry. I was angry because I felt like it took my whole life away. I had a great deal of anger. I was confused because one time they'd say this; another time they'd say that, and I was just like on an up and down rollercoaster.

The other problem is though; remember I said pain is never consistent at the same level? So I was confused by my own—today—oh maybe it's gone, maybe it just disappeared. Plus then I went out and did more than I should and realized, no, it's not gone yet. But

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we get very confused. People around us get confused. They see you doing something one day, and then you're in bed for the next three days, it's really hard.

Guilty? I mean I felt so guilty. Like I said I wanted my husband to take the kids and leave. I couldn't handle the guilt of not being able to fulfill my role. It was really hard for me; and by the way he didn't. Because I always say that, and people said, well did he do it? No, he didn't, we're still together.

Out of control; I felt totally out of control, I had no control of my life whatsoever. But what's really interesting about all of this. A few years back we started getting calls from family members, because they were looking for some kind of help and understanding. So while I know what it's like to live with pain, I don't know what it's like to live with someone who has pain.

So I had to actually interview family members, and I did it for three years. Over those three years it was amazing the things I heard. So after that we do have a family manual now, for people with pain. Or for family members who live with a person with pain. There was only one difference in all the conversations I've had, there was only one difference. I would have thought I was talking to a person with pain. The one difference between a person with pain and a family member, the family member does not feel the pain. All this other stuff up there, they're right there; they experience the same thing. It has total control over their life; it takes over their identity. It really does and I don't think that we think about that very often. But they really have to be part of all of this.

The family members experience the same thing; they really have to be part of this, we have to involve them. We have to talk to them. We have the family manual, but we also in some of the groups—we have family support groups where they can go and talk too, because it's very critical to have them as part of your support system. But we can't forget that they're struggling as well.

Medication, and this is something we're all looking for. We think all I need is the right pill, right? You get an infection; they give you an antibiotic, you're good to go. You get a headache, you take an aspirin; you're good to go. If we just found that right pill, than we'd be okay. That's our expectation. The problem is, what we don't realize is that medication is only one of the many, many tools that you need. It's not the whole thing. The pill is unfortunately, not going to solve anything. It's a tool and it's an important and valuable tool. Every medication has risk and benefits. That's why it is critical that you talk to your healthcare provider and make sure that they all know what medications that you're taking.

We have a little card on our web page that is a card that you can fill out with all your different medications and keep it in your wallet. I don't know if there's any lying out there, but it's very important to do that. Medications can reduce your pain; they may reduce some of your pain. It may not take it totally away; it's not the silver bullet. But again, you have to talk to your healthcare provider.

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We have recently put a new piece on our web page called the consumer guide to pain medication and treatment. It's in a video format, and we don't have it all populated; we don't have all the sections done yet, but it really talks to you about all of the different kinds of medications, and it's healthcare providers; consumers really addressing all of these issues. It's just right on our web page, you can click on it, and you can see it. It's a very helpful tool.

One of the tools that we have designed, and we like graphical tools because we think they're very easy for people to use, is on taking medication. Because a lot of people will get a prescription, but they may not follow or take it as directed, and so that's a key for how well medication's going to work. If you don't take it as prescribed, it may not do you any good.

So what we have here is a card. We call it the care card, and you either take it at the morning or at night; little circle, daytime/nighttime. Or, if it's specific hours of the day, all the pharmacist has to do is draw little hands on those clocks. Take it on a full stomach or an empty stomach, which one? Things to avoid and possible side effects, and it's all right there. So that way you know what's going on. We've actually added—this is also on our web page—and we've added storage and disposal of these medications. Because that's critical to the safety of not only you, but your whole family and people that come in; it's to appropriately store medication and then to dispose of it. Different medications need to be disposed of in different ways. Again, there's these little cards out there, you can pick those up and then again, they're on the web page for your healthcare provider if you'd like to tell them to use it.

So when we look at talking about fibromyalgia with your healthcare provider, I think the one thing, and I was thinking about this this morning, and I thought, no, it's sort of like—and I wish I had a different picture here, it's sort of like a football team, and our healthcare provider's our coach; they're going to throw us all the plays. But we are the quarterback. We are a critical part of that team. Then we have all the other players out there, our little tools, our coping skills, everything else that we need, whatever it is. But we have to be a critical part of the treatment team. This is not passive. That's another reason I don't like people calling themselves chronic pain patients, or a patient. A patient is a passive role, and especially with fibromyalgia you cannot be passive. It's really something that you have to participate in. But you need to know how and that's what we're going to talk about.

The goal of living with a chronic pain problem, with fibromyalgia is to reduce your sense of suffering, and improve the quality of your life. That's really what the goal is. There may always, in everything—and I'll tell you, I lived in Pittsburgh at the time, and I saw the best of the best, and I expected them to make it go away. You may see the best of the best, listen to everyone, and at the end of the day, there may still be a certain level of pain. But the key—and you see the word that you need to learn to live with it—not

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existing with it. That's the big problem. I think too many of us exist with it, we give up, and we just don't participate. There may be some pain, but you can live with it.

I like to use this example, I have no idea what that is on the black of the board. It's very confusing, it could be solved; maybe not, I don't know, and if someone asked me to solve that, I would be here the rest of my life. I have no idea. I don't know what it is. That's how it is when they ask you to live with your pain; that's what it looks like. You don't know; have no clue. However, I might be able to take a couple classes, algebra, geometry, calculus, differential equations. If I really worked hard, I bet I could solve that problem, or say, oh well this is what it is, and this is what it means. That's how pain is, we don't know. We have to be taught the skills. This is what it looks like, and we're going to try to erase that board and give you a clean slate today.

The coping skills that the American Chronic Pain Association features, and the coping skills that many pain programs teach, and they're universal; there's a number of them. But it depends on what you need as an individual. So what we're going to do today is to give you a tool box full of different kinds of tools. Some you may use, and some you may not, and just to know we're only scratching the surface. We're only scratching the surface of all that is involved in pain management. We're giving you the basic steps.

What I'd like to do now is to have you listen to some of our members. Some of the people in the American Chronic Pain Association, and what they have to say about how pain affected their life.

[VIDEO PLAYED]

### **Is There Life With Pain?**

**Narrator:** Your pain will be a factor in your life but it will not be who you are. By taking stock of your strengths and limitations, and reminding yourself of the things that are important to you, you'll begin to find ways to move forward in spite of your pain.

**Member 1:** You will get better. For as impossible as you think this experience is there is a way through it and beyond it, and I am living proof of that.

**Member 2:** Put your faith in someone that you trust, a physician that you know is going to help you through this process and give it a chance.

**Member 3:** Educate yourself on whatever the particular pain is.

**Member 4:** I can't think about passed today I live this thing one day at a time.

**Member 5:** Don't give up there is help out there. You're not the only person in the whole world.

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**Member 6:** Pain is inevitable, but misery is an option.

**Member 7:** It's a journey that we do together it's not about the destination. It's about the journey itself.

**Narrator:** You didn't invite pain into your life and you don't have to let it take over. You can reclaim the life that belongs to you.

**Member 5:** I'm a different person now the old Ruthie is gone, she's dead. I don't think she'll ever come back, but truthfully, I like the new Ruthie better than I did the old Ruthie.

**Member 1:** And where I am now is I have more power than I ever had, even though I'm less physically capable than I used to be.

**Member 2:** And I don't do all the things that I once did, but I still have that joy. Music is a great joy to me and fills my heart with a lot of happiness.

**Member 4:** Helping my daughter plan her wedding and just doing all that fun stuff and showers and actually being at the reception and dancing, that was great boy that was one of the best days of my life.

**Member 8:** My life now is like I'm coming up out of a hole and coming into sunshine and I feel good about it.

**Member 9:** Every few months I take a deep breath and I get into the car and drive to Cincinnati, OH and then I drive to Louisville, KY or Frostburg, MD. I don't know how I do but there are grandchildren at the end of the road and I can do it!

**Member 6:** I've been living with pain for a total of fifteen years; four years of night and eleven years of light.

**Penney Cowan:** What I would like to talk to you about is our ten steps from patient to person, and we don't really—it's not like a ten-step program that you have to go step one, step two, step three. This is just sort of a beginning of a roadmap for you to really understand what are some of the main components in learning how to live with your pain. That being said, the first two steps you really need to do in order. You need to do step one, and that is accepting the pain. That is so hard for so many people to do, because we think if we're going to accept this pain is just giving up and quitting, and it's not that at all. It means that for today I'm going to accept what I have. I'm going to make the most of today. Today I'm accepting it. Who knows what tomorrow's going to bring. We believe anything is possible, and there is hope for tomorrow.

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So many people spend so much time looking, and looking, and looking, thinking there's an answer out there. Unfortunately sometimes there is no answer, but you have to accept it for today.

The next step is to actually get involved in the recovery process; to take an active role, and I've talked to you about this before. We can no longer be a passive patient, because this is your life. It's involving every moment of your life, so you really need to be more active; you have to take a part. Ask questions, let your healthcare provider know up front that you know what, I want to know, and I want to be well informed. I need to be able to make good decisions, but I—you have to talk to me, so that's why we have all those communication tools to really help you have that good conversation in a very short amount of time.

The next one is priority. This is something that I think so many people struggle with, because as your pain takes over your life, your ability to function sort of decreases. What happens is you put something off. You say you're going to put it off; you're going to set it over here in a pile. Then you put something else off because you're not feeling well, and before you know it, you've got a mountain standing next to you, and you look at it and it is just completely and totally overwhelming. There is no way that you're going to even know where to begin with this, it's just overwhelming, and that's what happens to so many of us, because we keep thinking I'll wait for a good day and that day never really comes.

What you need to do, the first thing is to understand where is your starting point? You need to have a starting point; where do you begin? How do you get that mountain down? So one of the things that we like to tell our group members to do is to get a number of those index cards—those little 3 x 5 cards, probably about 300; you've got a big mountain, 300. Then, keep about 10 or 15 of them with you all the time, and a pen, and every time you think about something that's in that stack over there, write it down. One card, one thing. Okay? So each time you think of something you write it down on that card. It may take you a week, it may take you two weeks, it may take you three months, until you think you have everything on that pile identified. Once you do, what I want you to do is take those cards and get a really big table, because you'll probably have a lot of them, or on the floor. Lay them all out, and just step back and look at how much you've been carrying around. I mean every time you think, it's over there, it's not bothering me, you're carrying that all around on your shoulders because it's still inside and you're thinking about them; all those things.

Then, ask yourself, of all those things laying out there, everything that's on those cards, right at that moment, what is the most important thing for you? What is the most important thing? It may not be something—work? It may not be some housekeeping, it may just be something else, and you pick that card up, and now you have your first priority. Then you take that and you pick up the other cards in some order. I'd say probably pick up the next 20 that you think are really important to you, that you think you need to do now. They're all on individual cards because you have to pick a priority,

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right? You have to be able to move them around; nothing is set in stone. But it really gives you a good sense, and you may add cards, you can start throwing them away, but now you actually have identified it. You feel like you have some control. I personally love control. I need to have that control, and it really begins to take away some of that sense of being so overwhelmed. Because that's exactly what the pain does.

Once you have your first priority, what do you do? You need to find a place to start. A lot of times our priorities of what we want to do are kind of big; they're big things. So we have to know how to narrow them down to where we can manage it. Think about this; remember I said we have good days and bad days? When you have a good day, what do you do? You do as much as you possibly can, right? The guilt of all not being able to do it, we get out there and we really work hard, and what happens? The next day you can't move. You can't move, and you tell yourself, I knew I couldn't do that. I couldn't do that because look what happened. Well, maybe you couldn't work 10 hours a day, but I bet you could have probably worked a half an hour.

We tend to set ourselves up for failure. That's part of what we do, we're overachievers. I'm not one of those, but there's a lot of people out there that are overachievers, and so we tend to think, okay, if I'm good today I have to get all of this done. We have to narrow it down so that we don't set ourselves up for failure. It's within our limits to make it happen, and sometimes it just needs to be fun. We need to have some fun, and so hopefully always one of your goals is to have a little fun. Whether it's going to the movies, out to dinner, coloring with your grandchild; I don't know, but those have to be part of your goals, but we have to narrow them down.

I used to do support groups a long time ago, and I had one lady in our group and she had diabetic neuropathy, so her fingers and her feet were always numb. One of the joys in her life was cooking for her family; baking. Her goal that month was to make chocolate chip cookies by herself. Now for anyone who doesn't have pain, they think that's silly, you can do that in an afternoon. It doesn't take me a month to make cookies, right? However, for her that was a big deal, because she did very, very little. So every week she'd come into group to tell us what she did, and she had to freeze the dough, and by the end of the month, and it took her a month, she made the cookies by herself without any help, and she brought them in and shared them with the group, and I found it very interesting because the whole group felt like we did this. They all shared it because they all helped her, we talked about it in the group, how to really begin to do this.

So what we have to do is narrow those things down; not set ourselves up for failure. Say you've been shut in the house for a while, it's hard to get off the recliner, and you want to walk to the park, but the park is three blocks away. Do you just get up and walk to the park? On a good day, probably. Probably that's what you'd do and then realize that you'd never do that again. How about let's narrow that down. On the first day, the first week, just get up and walk to the front door and then back. The second day, the second week, walk to the mailbox and then back. You can handle that, right? It's slowly building up there and doing it. We become very, very de-conditioned because of pain.

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Then the next day maybe the end of the block, and the next week, and then you add week after week you add a little more and you build it up. Don't set yourself up for failure. Anything is possible, you just have to work within your limits, and I think that's where we have a hard time. Just focusing on what we need to do.

Knowing your basic rights. Sometimes people go; well what's that have to do with pain? This is my favorite one, and when I talk to people, usually support group leaders, I always tell them; because we have a workbook, and all of these coping skills are actually in our workbook. We have a sample of them out there. If you want to look at any of the manuals I've talked about, we have them laying out there for you after the event. But I always say, start on the basic rights. This is what really empowers people. I love the basic rights. A couple favorite ones; one is the right to make mistakes. No one ever told me I could make mistakes and it was okay. As long as you learn from it, it's okay to make mistakes. You have the right to do less than humanly possible. It means you don't have to kill yourself. If you have the support team, you don't have to get up on a good day and do everything. You have the right to do less than humanly possible. On a good day, enjoy it; actually enjoy it, and guess what, you may have a better day the next day too. It's amazing.

You have the right to be treated—and here they all are. They're on our web page. You can download them and I tell people to print these out and stick them on their refrigerator, because they're all very critical to us:

We have the right to ask why. We have the right to ask for help. We don't have to do everything ourselves; it's not a sign of weakness. I always get reminded of that when I watch my grandchildren, and they're trying to do something and if it's too much, they don't even hesitate to say, help. I need help. But do we do that? No. We're going to do this ourselves; we're going to prove that we can do this, right? We have the right to ask for help.

You have the right to say no, and not feel guilty. It's okay, other people say no, do you hold it against them? No, you let them do it, it's okay, but sometime we beat ourselves up on that one. You have the right to change your mind. This is really an important one, because maybe in the emotion of the whole appointment with your healthcare professional, you say, okay I'll try that. You go home and you read what they gave you, and you go, oh, I'm not so sure. Call them up and say, you know what, I've changed my mind; or I need more information, but you have that right. Just because you said yes once doesn't make it that you have to continue sayin it.

You don't have to justify your behavior, and this is really important. Because what we don't want are people to always use their pain as their excuse, that this is why they don't want to do something. You can just simply say no, and not feel guilty, and you don't have to justify your behavior. You don't have to explain it. Just say, I don't think so. No, or—instead—and I did this, I mean after a while it was like; you know I'm not going to feel good, or I don't feel good, I can't go. We don't have to justify our behavior. So

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the next time that your spouse or your friend asks you to go visit their mother for dinner, you can say no, you don't feel guilty about it; you don't have to justify your behavior. It doesn't matter if you don't really like her, or if you just don't want to go, or if you don't feel good. None of that matters. We haven't put ourselves into that patient role. That's what we do when we keep justifying our behavior. We throw ourselves back into that patient role. That becomes our identity, and we don't want to get lost in the fog. These are critical points.

Recognizing emotion, and this is a really hard one, and this is where the whole mind/body thing comes in, and it's been actually 30 years, because I just went up to the Cleveland Clinic; that's where I went through a pain program 30 years ago, and they just celebrated their 30th anniversary. I remember, we searched, we searched, we searched, and someone, a doctor here in Pittsburgh said, go there, see if they can help you. They had pretty much given up on me. Somebody said, you know, there's a new doctor and he said he could help people live with the pain, and I thought, yeah right. There's no one who can help me live with this. If I could have, I would have already figured it out. It was the first time in six years that someone said, I can help. My husband was so excited, he thought finally, yes. Okay? And I thought to myself, no you can't, and my husband wouldn't let me quit. He kept telling me that I was stronger than that, I could keep going, keep going, and so I agreed to go to the pain program to fail. I didn't tell them that, but I thought, I'll show you that there's no hope for me. I still came out, but I was there for seven weeks, so I held the record.

One of the things that they did—the first thing they did when I got there, was they gave me a book, the book was about anger. I thought to myself why are they giving me this book because I'm not an angry person, but by the time I was done reading the book I saw myself that I was the angriest person in the world.

The thing I took away from the book more than anything else, we talked about a slush fund. So I imagined it as a bucket. Every time we don't deal with a negative emotion, put it in your slush fund—or bucket, another drop of water in your bucket, right? So time goes on, another drop, another drop, another drop. What happens? At some point, it's gonna be one too many drops, and what's going to happen? The bucket is going to overflow, and that's what happens when we continually hold in those negative feelings like that. The wrong person, wrong time, just that one little tiny thing, and you took their head off, and you're wondering where did this come from? They don't realize you just dumped your whole bucket right on them. They have no idea where it came from.

Imagine carrying a bucket of water around with you all the time. That's exhausting. It takes a lot of energy to keep all that in, it really does. It's sort of like all that your mountain there. It's not really there, but it's all in here. So are all those negative feelings, and you keep carrying them around because we want to be nice people, right? We don't want to make a fuss. So we don't do that, we don't express our negative feelings. If you did them as they occurred, they would be tiny, little things instead of that

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huge, massive explosion. So it's really important, and you have to understand there's no wrong feelings; no wrong feelings. Only inappropriate actions. Remember that.

Now I like to use this picture, and this is a little story I have. This man here is the one who has the pain. See his wife back there? Now he's sort of repressing one of those feelings and holding it all in, and she's sitting back there and she's not a very happy camper. She's wondering what the heck is going on. Is he hurting? Did I say something? They're both unhappy. It impacts them both, it's not just about him, and it's about them. We do—people read us, I mean that's part of who we are, and our family, and interacting. They pick up on that. If he had just explained to her. Now maybe she gave him the wrong vegetable for dinner or whatever, who knows, but we can't hold in our feelings. We have to be able to express them, because holding them in is only going to increase your stress, and that's going to make you feel even worse. Because it takes a lot of energy to do that, and it increases your stress, and tight muscles are going to hurt more. It's a wonderful lead into the next coping skill, which is relaxation.

I'm going to tell you to relax, alright? Just relax. How do you do that? How do you just relax? I mean if we could go to this wonderful island, lay on that nice, warm sand. You can hear the waves almost breaking away. You know, you pick up that sand and it's like that warm silk running through your fingers, and the birds are sort of over head and the palm trees are rustling. If we could just go there when we're stressed, that'd be okay. But reality is we're here, and we can't do that. So how do you relax?

What I want you to do right now for me, in you mind, I want each of you to count from 1 to 25 and at exactly the same instant, say your alphabet. You can't do it can you? You know why? You have a one-track mind. You have a one-track mind, so while you're thinking about being on this gorgeous island, listening to those waves break against the shore, feeling that warm, soft sand beneath you, for those few seconds you're not thinking about; oh my God we're back to [INDISCERNIBLE]. So in that instant, what you have done is reduced your sense of suffering—one of our goals, right? You've reduced your sense of suffering; probably also relaxed your muscles a little bit and maybe decreased your pain. But at least you've reduced the sense of suffering.

This is a learned skill, to try to tell your body how you want it to feel, and we have to pay attention to what our body's telling us. It goes back to that over achiever and being realistic about setting our goals. When your body's going out, stop. Give yourself five minutes. Don't say, but I only have 10 more things to do, and then by the time you're done it's screaming at you. Listen to what your body's telling you. Because if you took five minutes out, you might actually feel okay and can finish the next time; and maybe finish five more, and take another five minutes and finish five more. It's called pacing. That's something that took me a long time to learn and I'm still actually learning it.

So you have to do it but it's a learned skill; learning how to relax. When I was in the program, when I was in the pain unit, I took these biofeedback tests. I don't know how many of you have ever had biofeedback? But I had biofeedback, and they had me

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hooked up to the monitor for you forehead and your fingers, and it measured the temperature of your fingers and the stress on your forehead. The whole idea was as they read this wonderful relaxation; you were supposed to be able to turn the sound down. But I tried a little too hard, and always the sound went back up; it never worked. The one thing that the gentleman did for me when I was taking biofeedback was he recorded those sessions, and he said when you go home, listen to them, practice them, and I did, and I practiced them twice a day, and it was amazing because at some point in time, I found myself during the day listening to my body go ehh—and I would just start. I like breath relaxation the best, and I would start doing that and it was amazing. I told my body how I wanted it to feel, but it took a lot of practice. It's like you just can't jump on a two wheeler and start driving down the street. You have to learn, you're going to fall a little bit. It takes a lot of practice. It is something that is really worth it. It's one of the most important coping skills for pain. Listening to your body and telling it how you want it to feel.

Now what I'm going to do now is I'm going to play a five minute relaxation for you. This is something that is also on our web page. You can go on any time on the home page; click on the five minute relaxation and listen to this. So I'm going to play this, if you want to kick off your shoes, relax, you can take five minutes and just listen to it.

[VIDEO PLAYED]

***Narrator:*** Close your eyes gently, settle down comfortably. Begin by breathing out first; then breathe in easily just as much as you need. Now breathe out slowly with a slight sigh, and as you breathe out feel the tension begin to drain away. Then go back to your ordinary breathing; even, quiet and steady. Now direct your thoughts to each part of your body; to your muscles and joints. Think first about your left foot. Your toes are relaxed and still. Your foot is resting easily on the floor. Now your right foot, toes, ankles.

Now, think about your legs. Your thighs roll outward when they are relaxed so let them go. Your back muscles will relax when you hold yourself upright and your spine is supported by the back of the chair. Let your abdominal muscles become soft and relaxed. There is no need to hold your tummy in tightly. It rises and falls as you breathe quietly.

Think about the fingers on your left hand; they are curved, limp, quiet and still. Now the fingers on your right hand; relaxed, soft and still. This feeling of relaxation spreads up your arms to your shoulders. Let your shoulders relax, let them drop easily. Your neck muscles will relax if your head is held upright; resting easily balanced on the top of your spine.

Let your face relax. Let the expression come off it. Make sure that your teeth are not held tightly together and let your jaw rest in its relaxed position. Your cheeks are soft because there is no need to keep up an expression. Your lips are soft and

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hardly touching. Relax your forehead so it feels a little wider and a little higher than before.

Now, instead of thinking of yourself in parts, become aware of the overall sensation of letting go, of quiet and rest. When your muscles are relaxed you begin to feel peaceful, rested and quiet.

Stay like this listening to your breathing for a moment.

Now wiggle your hands and legs a little and open your eyes and sit quietly for a moment.

**Penney Cowan:** That gives you just a little sense of what it's like to go into relaxation. It's really helpful, but again you have to practice it. One of the things that you might want to do when you're just out, or doing anything, or even sitting at home, ask yourself, your hands do you have them clenched tight in a fist? Be aware of your body. Are you clenching your teeth? Are you relaxed? Are your lips all sort of tight? How about your forehead? All of those things are really good keys to give you an indication that maybe you're starting to get a little bit tense. You can just begin these relaxation exercises and really begin to help yourself. It will help you reduce sometimes the pain. It's a very important tool.

Exercise is another one, and one of the problems I had over the six years, was every time I did something and it made the pain worse, the doctor would say, than don't do it. After six years, I wasn't doing anything. Like I said, it was hard to even hold a cup of coffee because I had become so de-conditioned.

So again, we talk about pacing and you think, okay, I'm going to start an exercise program and exercise is very good for fibromyalgia. The problem is that sometimes we jump into it really fast. In our workbook we have 18 mild stretching exercises, and they're illustrated to help people. We did that so they could take it to their healthcare provider and say, which of these are good for me? Because we have no idea what you can and can't do. That's something you have to talk to your healthcare provider about. A lot of times people say, well I can do whatever, and we have people that go home and they'll try to do all 18 of them and do ten repetitions of each, and they'll come back and say, there's no way I can do this. It's just too much, because they set themselves up for failure. They jumped in with both feet instead of maybe narrowing it down to a manageable level.

So what we suggest, say one of the exercises that they said you could do was a leg lift, okay? Before you get out of bed in the morning, you get up and you don't get up. You just lift your leg as high as you can without feeling any pain and put it down. You've exercised for the day. The next morning, the same thing; it's not going to hurt, you're not going to get discouraged. It's pretty easy to do. Next week you add another leg lift. Over a period of time, you build up and continually add them. In the mean time, you're

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toning those muscles. You haven't set yourself up for failure, and you're actually strengthening muscles; putting the tone back in and restoring the circulation. But we have to pace ourselves; we have to do it a little bit at a time. We can't just jump in with both feet.

It's interesting because I use this picture on all the talks and I go all over the country, but because I'm from Pittsburgh originally, I always talk about Pittsburgh on this picture. Because January first, there's a bunch of very crazy people that stand on the river's edge, and you know how cold it is here in January, and they jump in, because it's the thing to do. They call themselves the Polar Bear Club. That's crazy, and it's like doing exercises. If you're going to go out and do them all at once, when you haven't done any, you're going to get a real shock. So don't be a polar bear when you start an exercise program. Work within your limits. It's very important. Exercise is really critical; motion is important in pain management.

Now when we sort of step back, we have to look at the whole picture. It's about you, it's about all of you, and the problem with so many of us is that we always focus on what we can no longer do; on our disabilities. Well I can't do this anymore; I can't do that. How about thinking about what you still can do? Maybe discovering things that you never knew you could do? Opening up new doors instead of, again, it's like is the glass half full? Or is it half empty?

What are your abilities? We all have disabilities, but we all have abilities, and that's really where we need to focus, because in the end, pain management, I would say 80% at least 80%, maybe even 90% of it is our attitude.

Remember I told you I went to the clinic to fail? However, I did everything they told me to do, and I realized deep, deep, very deep down inside there was a tiny spark. Just one little speck of hope and that's all I needed to keep me going. Every one of you sitting here today has that same little speck of hope, or you would not be sitting here today. I just wanted to let you know that. You're all very helpful, and you all are willing to make that journey from patient to person.

Now what I want you to listen to is some of the people talking about going to one of our support groups and what it did for them.

[VIDEO PLAYED]

**Penney Cowan:** The significant part of being involved in your recovery is being involved with your peers.

**Member 1:** Once I joined the ACPA – the support groups, the knowledge just flowed.

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**Member 2:** Somebody's always bringing something in to you know say I found this book – I read this book and you know we pass it around.

**Member 3:** Everybody who has pain can give something to somebody else. It could be just “oh, I took that and it had side effects so keep an eye out” or “oh I tried doing this and that and it worked out real well.”

**Member 4:** When I first started going through the program I just fought it. I said you know, no way it's not gonna help, it's not gonna work. And then after a couple weeks I started seeing the benefits of it.

**Member 3:** It s lonely when you have chronic pain.

**Member 1:** The first time I walked into a room with people who had chronic pain what a validation that was for me. It was like Mary Ann you're not the only person in the world that lives with this.

**Member 5:** No matter how supportive your husband is or anything and how...

**Member 6:** To tell you the truth I never would have survived all this without my pain group.

**Member 7:** It's just this kind of reinforcement that you're not alone; that there are other people out there going through the same thing.

**Member 2:** It's been my lifeline at the ACPA members and having the support group.

**Member 3:** You need them.

**Penney Cowan:** So the last step that we look at is the outreach, and I think that's where I started—when I started the organization back in 1980; because when I left the pain program a couple things occurred to me. First of all, I realized I wasn't the only person in the world who had a chronic pain problem. There were other people; they were in the unit with me. What I had learned was just too good to keep to myself, because if it had actually helped me, maybe it could help someone else.

But I think the main thing was, I was scared to death. Because I had tried so many things before, and they worked for a little bit, and then they stopped, and I thought alright, is this another fluke? Is it going to last? Is it going to continue? Am I still going to be that person that I've worked for seven weeks to become? So I knew I needed some kind of positive reinforcement to maintain my wellness, and that's really the biggest part of this. So that's how the American Chronic Pain Association was born, and it was right here in Pittsburgh.

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This is how I like to explain a person with pain. We actually have our little car here. This is a car, except the person with pain; a person with fibromyalgia, their car has four flat tires and there's no way they're gonna go anywhere. We always think it's that one thing, if we can just find the right thing, we'll be able to go; we'll be able to continue our lives. The problem is, that one thing only puts air in one of your tires. You still have three flat tires, where are you going? So you have to ask yourself, what else is it that you need?

So many people I talk to, they'll try something, it doesn't work, so they stop, let the air out of their tire, so they keep filling up the same tire, back and forth, but they never look at the other three. It depends on—like we talked about medication before—it may reduce some of your pain, so let's keep the air in that tire. Maybe you start an exercise program, maybe it is helping a little bit, so you put air in another tire. But you have to do them altogether, that's why we talk about so many different areas of pain management. You really have to put air in all four of your tires. It could be a biofeedback session, it could be acupuncture, and it could be taking a vacation. I don't know what you need; everyone's tires are different. Once you get those four tires filled, you need to maintain your car. It's your responsibility to maintain your wellness.

If something goes wrong with your car, you take it into the mechanic. If it needs gas, you're going to fill it up. If something's wrong you're going to take it to a mechanic, so you have to go for the usual check ups; you have to go—and if something goes wrong, you're going to talk to your healthcare professional. But on a day-to-day basis, it's your job to make sure your car is running. You have to keep checking the air in those tires. It's just a good way to think about pain management. It's not just one thing, and so many of us look for that.

We have support group here in Pittsburgh; we have a couple in the outlying areas; we have them all over the world actually. We have groups; we have workbooks to help people start support groups if they're interested in it. If you're from a distance you can call our office. It really helps to talk to other people.

You heard Maryanne in the one video. What a validation that was to know that she wasn't the only person. I heard someone when they walked in here today, they said, wow, it's not just me; there's other people. Fibromyalgia is so confusing. You really do need some positive reinforcement. We need to know that we're not alone, and that is so critical.

Here are some good references: The Fibro Center, and I know that this video—there are videos that will be on the Fibro Center, and it will all be on our web page as well, and some other resources for you. If you have any questions at all, all you have to do is call our office; there's our number. It's on the handouts we have. We are in California; that's where I live now, but you have to call during regular business hours in California.