

Veterans in Pain: Learning to Live With the Pain

Part1: What Is Chronic Pain?

Penney Cowan: Endo Pharmaceuticals are the ones who have provided the money for me to be here, to provide you with the food and all of the workbook. It was an educational grant for us to come out and talk with you, so I want to thank them. I also want to thank every one of you, because without you, our country wouldn't be what it is today, and I really appreciate the service that you have given to our country. It does not go unnoticed, and there's a lot of people that are very supportive of your efforts. And every time I tell someone about the program that I'm doing, they say, "It's about time." So, again, I want to thank you, and it is my honor to be here with all of you. So, thank you all very much.

[applause]

Penney: What is the American Chronic Pain Association? We've been around since 1980, to provide help and hope for people with pain. What we are not, we're not health-care providers. So, we don't provide any kind of medical treatment or advice. But we have groups all over the world for people with pain. And while we can't cure your pain and we can't provide you with any medical treatment, we can provide you with ways to improve the quality of your life. We're going to talk about a lot of that today. Our mission, and we have started this mission back in 1980 and we have never strayed from it, is to provide peer support and hope for both people with pain and their families and I'm delighted that some spouses are here today with you--but also to raise public awareness around pain. You don't hear a lot, anywhere, in any of the media, about pain and the issues that people have to deal with pain. That's something we really want to begin to change, so we've done a number of things to try to bring pain to the forefront.

Really, American Chronic Pain Association is just people helping people. When I started this back in 1980, my goal was to reach out to one other person, and that is still the mission of today. It's not about massive numbers. It's about one person, because each person is very important, because that person has to live with pain on a day-to-day basis. So, that's why we're here is because of one person, not groups. Delighted to have you all here.

We also have a website. I know that the gal who manages this and developed it is going to be here, at least, she was planning to be here. It's called vetsinpain.org. That's going to be a direct link from our web page. You can go to vetsinpain.org now, and there's a lot of really good information for veterans, a lot of resources, things that I really don't know anything about. So, she has volunteered her time to do this. This is a website specifically for veterans in pain.

What is chronic pain? It's the number one cause of disability in the country. But what's really interesting is that there's 116 million people who are living with chronic pain. Now, that's about one out of every three people in this country. Think about it. How often do you hear about it? Very rarely. Yet, it's one out of three people in this country are living with some form of pain.

The Institute of Medicine just came out with a new report. And so, now this number, right there. There we go. 116 million. That is an accurate number. That is a huge number of people who are trying to live day-to-day with their pain.

The cost? We used to say it was almost 300 billion. Well, the Institute of Medicine just came out with a new cost, between \$500 and \$600 billion a year. That's more than cancer, heart disease, and diabetes put together. That is how much pain costs in America. Only in America. Trust me, it is all over the world.

There's another part of pain, and a cost to it. People who still have jobs, that still go to work, but they don't perform up to where they should be working because they need those benefits. It's called presenteeism, where they're at work but they're not really performing their job to the fullest of their ability, because they're in pain.

And so, their coworkers have to work with them. They have to take up the slack. That's a huge expense to this country. It's over \$61 billion. Again, all of this information is on your handouts, on your slides.

What is chronic pain? It's a process that turns a person into a patient. What the American Chronic Pain Association wants to do is to change that idea of a patient back to a person. I must tell you right now, and you'll hear me referring to people with pain, because I really hate the word "chronic pain patient." It's a negative phrase. It takes the air out of you. It just deflates you.

So, you're a person with pain, and so much more. But your pain does not identify who you are. It's only a piece of you. What we really are trying to do--and you'll see everything that we have--is moving from that patient back to a person again. That's really the focus of what we're really trying to do here today.

What is chronic pain? It's any pain that lasts longer than three months or goes on beyond the normal healing process of an injury or an illness. It will affect your life. It really puts a damper on what you can do from day to day to day. But the hardest thing about pain is that second bullet point. It's never consistent. It's never 100 percent. It's never at a 10, it's never at an eight, constantly, day in and day out. Your pain goes up, and then it goes down. And you do have good days, and then it goes back up again.

And so, because it's going up and down and up and down, it's really confusing. Because you often wonder, "Is it really pain? Maybe I am imagining this." I have gotten a lot of calls in our national office from people who say, "My doctor told me it's all in my head." Well, it is partly in your head, and it's in your body. You can't separate your mind and your body. You are a package deal, and what you're going to experience in your head you're also going to experience in your body as well. So, it's the whole person. You're not imagining it.

But the hardest thing is that inconsistent up-and-down. Then people around you look at you and go, "Well, how can you do that today when yesterday you couldn't get out of bed?" or, "Look what you did yesterday, and now you can't move." It's just confusing, not only to you but to everyone around you. You question it. I know I did.

And just to let you know, I'm also a person with pain. That's why I started this organization. I went through a multidisciplinary pain-management program. It's been 32 years now. That was the hardest thing I ever did in my life because when I went into that program, I was a patient in every sense of the word. Holding a cup of coffee, for me, was almost impossible. That's how bad my pain was.

I spent seven weeks on that program. Actually, when I went there, I didn't believe anyone could help me. I went there to fail, to prove to my husband that there was no help. After six years of looking, hoping for an answer, one thing after another, hopeful that it would help, and then only it never really helped and the pain was still there. I kept getting worse and worse. He believed that this would help. That's what he believed.

So, I thought, "All right." Because I just wanted to quit, I wanted to give up. I had enough. It's hard to live with pain every day, in and out and in and out. So, I went. Seven weeks later, I came out, in every sense of the word, a person. So, everything that I'm talking about today, I've been there. I've lived it. I know exactly what it's like to live with pain on a day-to-day, and I know the controls it has on your life, and we will talk about that.

But for me, the hardest thing was, if I could just get a healthcare provider to understand my pain, to know how much it hurts, if I could just describe it in the right words, then they would get it. Because it's impossible for people to understand your pain. How do you explain it? I would spend hours on end trying to figure out the best way to describe my pain. You know what the problem was? The more I thought about my pain, the more I suffered.

I was really not doing myself a favor, because I kept increasing my sense of suffering, because I was trying to figure out how to describe my pain. You can't do that. No one is ever, ever, ever going to understand what your pain feels like. No one.

We expect miracles, right? Imagine what people can do today, what medicine can do. They can do a number of different organ transplants: hearts, lungs, livers. I mean, that's amazing. That's absolutely amazing. They just started and I think it was the third or fourth successful face transplant. So, it doesn't make sense to us that they can't fix our pain. It's not logical, right?

Our expectation is, "Just give me the right pill, or that one procedure, that one surgery, and I'll be good." Right? Never works. What happens is you get stuck in that little maze, and you just go from one dead end to another, and you're just stuck in there. The harder you try to find the one answer, the deeper you go and the more you get stuck and the more hopeless you feel. That's what it's like when you have chronic pain. And you're hopeful.

Our expectation is medicine can eliminate it, right? Doesn't that make sense? It's not that easy. Why? Because pain's invisible. What does a back pain look like? What does a headache look like? How can you see someone's nerves that feel like they're on fire? You can't. It's invisible. You can't measure it. You can't weigh it. There's absolutely no way to say, "Aha, I see it!"

You're all people sitting there with pain, and yet you look fairly normal to me. Who would know? So it's really hard. It is really hard. I kept saying, "If only they knew. If only they knew what was causing my pain, I'd be able to manage it." Problem is, once they put a name to it after six years, I thought, "OK, now you know what it is. Then fix it." Right? They know what it is, then they should be able to fix it. Didn't happen.

The sad thing for most of us is that we're willing to do just about anything if someone says, "I can fix your pain." Doesn't matter what it takes, we're willing to do it because we want to get rid of the pain. That's our goal is always get rid of the pain. Doesn't matter how we have to do it, as long as they can fix it and get rid of it.

The pain is not the problem. It's the fear of the pain, never knowing. Remember I said it's up and down and up and down? So on those good days, you think, "OK, maybe it's finally gone." But then you know, but it comes back. You never know when it's going to hit and how hard it's going to hit you. And so, you are controlled not by your pain, you're controlled by the fear of your pain, never knowing.

So that's where all the isolation comes in. You make less and less plans. You don't want to plan something and then not be able to make it, so you pull back from everything and everyone. Eventually, you find yourself very much alone and isolated, because it's that fear that's the controlling factor.

We look to our healthcare providers. They're supposed to know how to help us, right? They went to school. They had all this training. They're really smart people. Problem is, you know how much pain management they had in all of that training? Two hours. That's it. That's if they're lucky. It's not in any of the medical schools at this point. They've never been trained. They have never been trained how to help you manage your pain. They don't know.

I do a lot of lectures to health-care professionals, and it's amazing. They're willing to listen, which is even more amazing, and it's wonderful. They've never been trained and they don't really like to work with people with pain, because we don't get better. We keep coming back and saying, "OK, now what? Now what?"

So what do they tell you? "Learn to live with it." How many have been told to learn to live with it? Right. And you know how it makes you feel?

[laughter]

Penney: That's it. That's exactly how it makes us feel. Well, great. But how do you do that? How do you live with it? No one told me how to live with it. They just told me I had to, but never how. I think the most important thing for us, more than anything else, is that we want validation. We want someone to believe our pain. We want them to say, "I believe you." Because the further down--remember that maze that we were stuck in? And the deeper in we go, the more we need that someone to believe us. When they don't and they look at us, and we're thinking, "OK, maybe they don't believe how much pain I'm in," we become more and more defensive.

Most people with pain that I've met are very defensive. I was. I kept telling them how bad my pain was, and they didn't really believe me. Because the interesting thing about when you go to a healthcare provider, when you go to a doctor's appointment, how many of you have ever gone in your pajamas? No one. You know why? Because you try to look as good as you can when you go out.

So, we're always sending those mixed messages. We're trying to help them understand how bad our pain is, and yet we spend three hours getting ready so that we look good. We're sending those mixed messages.

The longer your pain goes on, the longer it is in control of your life, the more you as a person disappear. I like to use this picture because it's these two gentlemen walking down that road in the fog, and the further down they go, the harder it is for you to see them. That's exactly what

happens to a person with pain. They lose their identity, and they become the horrible chronic pain patient. I don't like that word, because you're not. You are a person, with much more than just your pain, and I will keep reminding you of that.

So, when you're told to learn to live with pain, this is what it looks like. I'd be there the rest of my life if I had to solve this. I have no idea what it is. I can't even explain it to you, other than it's something scribbled on a chalkboard. If someone said, "OK, before you can leave this room, you've got to solve it," they'd better bring a lot of stuff because I'm going to be here for forever. There's no way I can do that.

However, if I took a few classes, maybe started with some algebra, plain geometry, got into some trig and calculus and then maybe differential equations, and if I worked really, really hard, I bet I could solve that problem. But you see, when they tell you, "Learn to live with it," that's what it looks like. What we need for them to do is not make it so difficult that we don't understand what they're saying. What we need is one plus one equals two. That's what we need so that we can actually live with our pain.

The other one makes no sense, and we don't know how to do that. We do know one plus one equals two. And so, what our organization has done is really try to take all the information that you need to take an active role in the recovery process and change it from that very complex formula into a very simple one. One plus one equals two.

So, when you're told to learn to live with it, the first thing that you need is validate it. You need to know that, "OK, my pain is real." OK. You need someone else to believe that your pain is real. It's not who you are, but it is a piece of you. It's a part of who you are, and it's going to present you with challenges.

You need to know that there's hope. I think that's the one thing this organization is trying to give to all of you. There is hope. It is possible to live a life in spite of your pain. That is so important for you to remember. Don't ever lose hope.

The problem with pain for so many of us, and I hear this over and over and over again, is all the things people can't do. "I can't do this anymore, and I can't do that anymore, and I can't do that. I used to be able to do this and now it takes me five times as long. There's nothing that I can do anymore that I like to do."

We're so focused on what we can't do that we forget to maybe look at what we can still do. What are our abilities? We always look at what we can't do anymore. We're that "the glass is half-empty." We're not "the glass is half-full." But it is half-full. It's always half-full. There's always hope. We just have to look at it in a different way and start to think about what our abilities are.

You have to become part of the treatment team. And that's the difference with chronic pain, because the typical medical model-- people go to the hospital, they take care of you. They pamper you. They bring you your meals. They do everything for you. You have a very passive role, right? When you have chronic pain, you can't be passive, because you're not in the hospital.

People aren't going to take care of you. People actually get tired of you being sick and that's all they ever hear is about your pain. Instead of that passive patient, you now have to become an active participant in your care. You really have to accept some of that responsibility.

The way to explain how you are part of your medical team is your primary care is your coach. OK? Everybody needs that coach. They're the ones that really coordinate everything for you. But guess who you are. You're the quarterback. You are the quarterback. You're the one where the coach tells you what you need to do, and then you go out on the field and you talk to all of your teammates, whoever they are, whether it's your physical therapist, if it's your counselor, whoever it is.

You tell them, "OK, this is what we need to do." You're an active part of that. If the quarterback just stood out on the field, I'm afraid he'd get clobbered. And so, you need to be that active participant. You really need to be an equal part of that treatment team. Without you, nothing's going to happen. You have to be a part of that team.

What the goal of pain management is, and so many of us think, "I just want to get rid of the pain." You know what the goal of pain management is? It's to improve the quality of your life, increase your function, and reduce your sense of suffering. Nowhere in there do we say, "Get rid of the pain," because that may be impossible. That's not necessarily mean you're going to suffer the rest of your life, because we're going to help you understand how to reduce your sense of suffering.

Remember I talked about when you try to think about the best way to describe it, the more you think about your pain, the more you suffer. So, redirecting your attention onto other things you have more control over is key in reducing your sense of suffering. We'll talk about how to do that later. It's to increase your function and your quality of life. Everybody wants quality of life. So that's really what we're trying to do here.

When everything has been said and done--and I lived in Pittsburgh, which is a huge medical mecca. They have some of the best of the best. The first transplants were done there. They still couldn't help me. And when I saw the best of the best, the bottom line was there still may be some level of pain. That doesn't mean it's necessarily bad news.

So, the goal is never to get rid of the pain a 100 percent. There may always be some level of pain. It's how you deal with it. That's what matters. You can still have a full life in spite of pain. You can. I've been doing this for 31 years now. I absolutely love it, because I get to talk to people and, hopefully, give them a little bit of hope. That's my job. It's to just give you that little... All you need is a spark, just one little spark. If you get a spark today, then we've done a good job.

Part 2: Communication Tools

Penney Cowan: Let's talk about some of our resources we have. Communication is key. Remember we saw that thing up on the board, that complex formula? That's sort of how healthcare providers talk and that's probably how we sound to them because there's no translation

there. Remember I said we want to be validated more than anything else. How do we explain it? If you ask somebody to use on a 0 to 10 scale what's your pain...and I hated that answer. I hated that. When they asked me that question it was like 0 no pain to 10 the worst pain you can think of. I was a mother with two small children, I had a beautiful home, a wonderful husband. I wanted to be that perfect mom and I couldn't. 10 didn't even come close to how it was impacting my life. It was a 20.

If I had said 20 right away they would have said OK, another nutcase, here we go because it doesn't tell you anything. I could be a seven, you could be a seven. I could be out jogging and you could be home in bed and vice versa. Those numbers don't really explain the pain. We have another way of measuring and it's called the quality of life where it's going to measure function, one of our goals.

When you use this scale if you're at a zero that means you can't even get out of bed in the morning. You can't get out of bed in the morning. If you're all the way up to a 10 that means you can do whatever you want. Somewhere in between, say you're at a four, you can get up, get dressed, maybe do a few things around the house. When you tell them, when you use this scale and you tell them where you're at it's very clear. This is what it's doing to my life right there.

It's very important to have them understand the quality of your life. This is how the pain's impacting me. This scale has been used over and over again. Very important scale.

You also need to be able to prepare to go to your healthcare providers. These are very important visits and often you wait weeks or months to have one so prepare for it before you go there.

The first thing you have to ask yourself is why am I going? What is it that I'm going? If it's a checkup then you need to make a list of everything that's happened since but if there's a reason you're going make sure you write that down, whatever it is. Use one sheet of paper, you don't want to use a whole bunch. We get letters that are 20 pages long because people want to have you understand how bad their pain is.

After the first paragraph I get it. I know. I've been there and I understand every person with pain wants to feel better yesterday. Not today, not tomorrow, they want it yesterday. We want it to go away. But you still need to be able to explain your pain. When you get ready one page is all you need because they're not going to be able to read more than one. Remember, you only have about five to 10 minutes if you're lucky. Just write down the new things, the new symptoms since the last time you saw them. Don't start back at the beginning. Just the new symptoms since you last saw them.

Then bring all your medications with you. Make sure you bring them all in the bottle so they can see exactly what you're taking, but you make sure that you also bring any over the counter medications, any vitamins or herbal supplements that you're taking because all those will have some impact on the medication that they may prescribe for you. You need to have all of that. At least write it down. You may not be able to bring them but write it all down so they know exactly what you take.

It's very important that you use only one pharmacy. I don't know how the VA system works if you get your medications here or not, which would be really good. But then do you get your over the counter medications here? I'm not sure.

What you have to do is when you go to the pharmacy always ask before you purchase an over the counter. Let them know what you're taking. Make sure it's not going to interfere with it because they don't always play nice together. You need to make sure that what you're taking, over the counter, vitamins, herbal supplements, make sure your healthcare provider knows what those are.

You need to tell them what you've tried, has it helped, has it not? Laying down helped, massage helped, heat helped, cold? One or two words, that's all you need. You need to explain any changes in your mood or your appetite. I'm more depressed and the depression is not what caused the pain and people always have a hard time with that, especially when you're being told it's all in your head. They think you're just depressed.

Well, how would you feel if you had the flu for a year? You wouldn't be a happy camper. Of course you're depressed. It's taken away part of who you are, your identity, your ability. It is depressing. Don't be afraid to tell them that you're feeling depressed because they can help you with that but you have to let them know.

Questions that you have, write them down. You're not going to remember them. By the time of the appointment you've sat out there for whatever amount of time waiting, waiting to get in to see the healthcare provider. You go in and they'll say, "Do you have any questions?" No. Then you're driving home you go I forgot to ask this and this. Always write your questions down.

If at all possible take someone with you because what they say and what you hear sometimes are very different. Remember I said we get really defensive about our pain? After a while I would go in there and I would listen to what they said and the test results would come back and they'd go, "They're negative." That's not what I heard. What I heard was there's nothing wrong with you, it's all in your head. That's what I heard.

In my heart that's what I heard because I needed that validation, which it took six years to get. So I never quite heard what they were telling me. I wanted that quick fix. I wanted that immediate feel better yesterday. It didn't happen. Take someone with you.

Another way to really explain what's been going on with you, we have something called a pain log. This is a graphical tool that we've designed to help you communicate with your healthcare provider quickly and efficiently but yet still provide a huge amount of information.

The first line we have to ask they need to know on a scale of 0 to 10 what's your pain. They need to know that one so you have to measure it. Then we're going to ask you your stress, measure that, exercise, activity, your sleep, how afraid you are of the pain, taking your medications as directed, side effects, constipation, sexual activity, your appetite, your mood, how isolated you've become, how much alcohol you consume, and how worried you are about finances.

If you do that, all you have to do is circle one of those numbers, do you know how much information you're providing to your healthcare provider at a glance? We're working on phone

apps for this but that's a tricky thing but we are working on that because we've been asked over and over again so we are working on that.

This, what it does is it tells them where your pain is but it also gives them a wealth of information. Instead of trying to explain to them what's been going on since your last visit they can look at this tool and see that your pain level went up since last time but I see that you're becoming much more isolated, you're drinking maybe more than you were, and you're not exercising at all.

Right away they've identified three contributing factors of why your pain's increased or if it's gone down they can see that because you're sleeping better, you're exercising. It really begins to provide them with exactly what's going on with you and now you have a starting point to be problem solving rather than trying to explain and get that validation.

This tool we have now made interactive on our web page. When you go into our web page you don't have to sign in or anything but you do have to for this one. You have to sign in and create a password because it's going to track for day to day, week to week, or month to month, however often you want to go in and fill these out. You can go in and this is the little sign for the fear or the pain. All you have to do is click where you're at on that scale.

As you can see below them, there's a little graph and that's what's going to print out for you. Every one of those, you click the OK and go down to the next one, the side effects. It's hard to see and I know that but this is the graph that's printed out that you can take so they can actually see one month, three months, six months, all year or forever that you started this. They're going to be able to very quickly look at this and see what's going on with you. It's a wonderful tool. All you have to do is print it out.

Another problem is taking medications and complying with the way you're supposed to take them. They'll give you a prescription and the doctor will tell you, your healthcare professional will tell you how you're supposed to take it, what it's for. You go to the pharmacy and they'll tell you exactly how to take it, what to do. You go home and what happens?

We get so many calls. People call us and say, "I was just given this medication, what's it for? I don't know how to take it." If you pull out the package insert, which is now supposed to be at a fifth grade reading level, it's not. It's not. It's not. People weren't taking medications and if you don't take them as they're directed they may not work for you.

People are afraid to ask questions. We get calls all the time from people and we say go back, either ask your healthcare provider which is sometimes hard, but go back to the pharmacy and talk to the pharmacist. They're trained to help you, to provide you with that information. Talk to them. We've designed a tool to help them explain this to you, but a way that you can actually take home with you.

When are you supposed to take it? Morning or night. It's right there. All they have to do is circle that or maybe what times of the day if they have to take it every three hours. They can put 12, 3, 6, 9, and back again. They can do it that way. Then take it with food, without food, things you should avoid, possible side effects. Then we've just added in the last few years the storage, where you keep it and how to dispose of it properly. All they have to do is circle this.

We've tested this. Pharmacists absolutely love this. My dream for this one is to get it on every bag of every prescription that is given. This is a follow-up sheet and what this one does is explains to you exactly what's happened in that visit. We don't remember everything they say. It's really hard to do that and they give you all this stuff and it's like what do I do with this?

What this does is going to explain to you the tests that they have recommended whether it's a chest x-ray or any kind of x-ray, lab work, EKGs, maybe a nerve conduction test, an MRI. All they have to do is circle that. That's what they've asked you to do. Or the kinds of treatments whether it's medications, maybe it's weight management, could be physical therapy, counseling, injections. Depending on what they've asked you. All they have to do is circle that.

Then when is your next appointment? A week, two weeks, three, a month, two months, three months, or call. Then restrictions. Things that you shouldn't do and then the next line is dietary restrictions, things you shouldn't eat like spicy foods or maybe not eat sugar or you shouldn't drink alcohol. All they have to do is circle that. The last line is recommendations, things that you should do. The last line is exercise, maybe swimming or biking or maybe they want you to do bed rest. Maybe that's what the recommendation is.

That last little icon there, that's an ACPA group that we're going to talk about. Hopefully they're always going to circle that one, that they want you to go to an ACPA group because that's very helpful. This, again, I always say a picture's worth 1,000 words so it really helps to understand exactly what they told you to do.

This is another tool that we have. It's called a fibromyalgia log and this is also interactive on our web page. We have done a number of campaigns and presentations around fibromyalgia. The only difference between this and the pain log is several items on it. The second one you can see it asks you where the pain is and specific trigger points for fibromyalgia and then is it none, mild, moderate, or several and then all you have to do is check that off.

[silence]

Then I think the last line down there on that one is the morning stiffness, what's your range of motion in the morning. You can do that one. On the left side you see the fatigue during the day. The weather, weather's definitely going to have an impact, not only on fibromyalgia but a lot of other problems so you might want to use this one.

Then the one that I like on this one is the weight gain or loss. Have you gained weight, have you lost weight? So many people say I don't have an appetite and I don't eat a lot for dinner or breakfast or lunch. They just don't seem to have an appetite but yet they're gaining weight and they don't understand why.

Well, go up to the top of the next page and you can see we're asking about snacking during the day and that's really where they go, oh, maybe I do nibble here and there a little bit and that may be why you're gaining weight and that may be why you're not eating your meals appropriately.

Then the concentration. I like that one a lot too. What's your level of concentration? There's a lot of what they call fibro fog with fibromyalgia. This is also an interactive tool. It's on our web page. We have a little video that starts. I want to show you that right now to explain exactly what

fibromyalgia is and then the importance to using a tool like this. Here comes the first of the videos.

[music]

Woman 1: Fibromyalgia is a chronic condition which is characterized by widespread pain, muscle tender points, fatigue, and poor sleep.

Woman 2: The symptoms I have from fibromyalgia are a lot of burning pain like electrical shocks up and down my legs. I also have a lot of muscle tension almost like Charlie horses in my lower back. I get some headaches because I have pain in the bottom of my neck and through my shoulders. Also, I have a lot of fatigue.

Woman 1: The exact cause of fibromyalgia is not known. We are coming to understand fibromyalgia as a disorder of nerves that are hypersensitive or hypersensitivity in the central nervous system to pain.

Man 1: When I first began to have pain I was young and active. It was in my 20s and I would play basketball and things on the weekends like everybody wants to do when your young. I didn't recover was the first thing that I noticed. My pains began to spread over more parts of my body. I had more and more pain in my wrists and elbows. It wasn't just bone pain, it was muscular. As I went to rheumatologists I tried to address that with them but they just insisted I had arthritis. They didn't know about fibromyalgia so they just treated me for arthritis.

Woman 1: Patients will also report aching, also stiffness in the morning of their muscles and their joints. They will also often report fatigue, poor sleep, and sometimes depression.

Woman 2: Sleeping can be a problem for me. A lot of nights I don't get a full night's sleep. I wake up in-between and have to try to go back to sleep because of the pain.

Man 1: I had problems concentrating, especially as the pain increased. I was always sharper in the morning and as the day went on I would have problems focusing and concentrating.

Woman 1: Fibromyalgia is diagnosed by using a good history of patient's complaints and also by doing an exam. The exam consists of a manual tender point exam where various areas are pressed and the patient's pain is assessed. Fibromyalgia is very real. It's a common condition mostly seen in women but also seen in men and it is something that is often difficult to recognize but very real. [music]

Penney: When you go onto our web page you can skip that video, you don't have to watch it every time, but it really helps people. Here is, again, how you do it. We also have a help screen so if you're not quite sure how to do it you see where the little OK is. As you click on the number, say your pain level, is it a three today, you click on that, it'll automatically go on two and then you can see the graph on the bottom how it just continues to keep track. When you go in the next time you go in and say it's at a five it's going to show you what your number was the last time. Then, again, on this one, on the symptoms, you can see this one you have to track every part of the body whether it's a zero you actually have pain in that part of your body, quality

of life, and then here's the print screen. You can either print out one month, three months, six months, one year, or the all time and then just hit print.

Then this is the print out and, again, it looks like a lot and it's very small there but it's a really very useful tool for your healthcare provider. You can see your graph on each of those as you fill them out so you'll be able to see your own progress and hopefully be able to connect some of those things, whether it's fibromyalgia or any kind of pain.

Maybe when you don't exercise your pain level spikes. That tells you a huge amount about how important exercise might be. Maybe when you're really stressed your pain level always goes up. It really is very helpful to begin to see those kinds of things.

This is one of our first interactive pieces we had. We did a whole program on neuropathic pain or nerve pain because a lot of people didn't understand what nerve pain was so we designed this little nerve man. This next screen I'm going to show you is animated. It's a little slow but it'll show you how this works.

You go to symptoms and it'll bring up this guy. As you move your cursor, this is very, very slow, over to his foot a dialogue box is going to pop up and there you see how it might feel. Every time you click on one like stabbing, tingling, burning, the little flames, it's animated. Then say it's numbness so you click numbness, you go over to your leg, and you can click all those that feel like that, go all the way up through his back, his arms, shoulders, and head.

You click that and then all you have to do is go up to print, print that out so when you go in and they ask you where is most of your pain and how does it feel, voila. There it is. A picture, again, is worth 1,000 words. This has been a really, really useful tool.

This one we designed for fibromyalgia. We do what we get funding to do. We are really a non-profit so we got a funding to do the fibro symptom checker now and it's a fibro mat kind of thing, but you can use this regardless of whether or not you have fibromyalgia. On this one it's a little bit more advanced. This is the second generation. We learn as we go on.

You can choose man or woman and then you go in and now you have right side and left side. You can go up there and you can see all the different things whether it's deep aching, radiating, shooting. The deep aching there's that little icon there. When you click on that it'll put it up there where it says neck area and then you can actually measure the intensity of that pain and you can go through the whole right side, the left side, flip it in the back, the left side of the back, the right side of the back.

Again, you see the little icons, how they position themselves up there. Then you can print this out. This is the front view. It gives the healthcare provider an icon key so they know what those icons are. Now look at all of this information that you have right there. You have a front and a back view, exactly how it feels, the intensity of the pain. Again, a picture is worth 1,000 words.

This really helps you communicate with your healthcare provider because communication is key to helping you understand what your role is, for your healthcare provider understand what you've been through since the last time, and how they may begin to help you. This is like the playbook. You're going to take it to your coach and say, "OK, this is what's going on."

Based on what you give them they will be able to then give you whatever plays you need to go out and work with the rest of your team, whoever that might be. Medications. Medications, everybody thinks all I need is that one pill and it's never quite that easy.

What you have to know about medications is that every one of them have risk and benefits and if they're not prescribed for you you probably shouldn't be taking them because interaction in medication can be really bad. They're only meant as a tool. They're only one piece of the big picture that you need to manage your pain and if you ever have any questions ask.

People don't mind you asking questions. If you're concerned about something, if you have side effects, tell them, ask them. It's one of your tools but it's one that you really have to be careful with. You have to pay attention to, you have to take them as prescribed. If they say don't drink with it you probably shouldn't be drinking with it, alcohol, you shouldn't be taking it.

Talk to your healthcare provider but remember it's only one of the many tools, not all of them. It's not the answer, it's a tool. Just one. It's not going to give you 100 percent relief. It's the little med card. Remember I said always keep a list, take the list with you to your healthcare provider? They're nice and thin and you can write all of the information down about all of your prescriptions.

You may need more than one and if you do let us know and we can send you more and just slip it right in your wallet and keep it with you. It has all the information you'll ever need so this is a good way for you to be well informed and make your healthcare provider well informed as well. OK. We have another video. We have a lot of videos. I'm not going to play anything on this one, but this one actually addresses some of the questions and concerns about opioids.

Opioids are obviously one of the things that are prescribed to help people manage pain and like anything else there are risk and benefits to that and there's a lot of responsibility that come with it. Things like I'm addicted, I'm dependent, I'm building up a tolerance to them people don't really understand that. They think if they need that medication then they become addicted. They don't understand the meaning of that, they don't understand why opioids are used, they don't understand other medications.

This video is focused specifically on opioids and all of the different and it's a menu driven video. It's on our web page, it's free. You can go in and click on it and just go through the home menu and click on the different pieces. It's really important to get the information out about not sharing your medications, especially opioids. They can be lethal in the wrong hands.

Right now the FDA is looking at ways to control some of the abuse and the diversion and they're doing it through REMS which is the Risk Evaluation and Mitigation Strategies that they're looking to have put on every medication so that they can ensure, as much as possible, the safe and appropriate use of these medications.

This PSA was a 30 second spot that we did. We got some funding to do it. We wanted to explain to people and 30 seconds isn't very long and in the shortest way possible to get a very strong message out to them. We got the funding to do it. The problem is, today people Tivo or they record their shows. Very rarely do you watch the commercials that go on in-between the shows. You fast forward through it.

If we even were lucky enough to get this on television most people wouldn't see it. Radio with satellite radio and iPods people don't even listen to the regular radio anymore so we needed a way to get this out to the public, to not only people with pain. That's, I think, one of the critical pieces of really appropriately using medication. It's not just to talk to the people who have the medication but to the general population because that's where a lot of the abuse and diversion is coming from so we need to educate them and people don't understand.

We wanted to get this message out as much as we could. We decided to show it in movie theaters and we got enough funding to do one state. We did it in Kentucky and we also did it in Sacramento because I wanted to see it on the big screen, 40 foot screen. It was like, oh wow, our first video, our first little movie. We had it play in Kentucky for an entire month at every theater.

The interesting thing was, though, that it had to be a movie PG or higher. This actually had to go through rating system before it could be played in the movie so it got a PG rating so they couldn't show it in a G movie. You'll understand why. I'm going to show you the video in a minute. This is the script for it. This is a magazine that we got to put this in a magazine to say the same message.

Here's our 30 second spot.

[music]

Man 2: Every year more than 15,000 people aren't there anymore because they accidentally or knowingly misused an opioid pain medication. Gone because someone was careless. If you've been prescribed opioids please don't take chances. Follow your dosage plan exactly, keep track of your meds, store them securely, dispose of them properly, and never, ever share. Drugs can help control your pain but it's up to you to control your drugs because isn't there enough pain already?

Penney: There you have it. That's a really powerful message in a very short amount of time. It's on our web page, by the way. You can click on it. It's on, what is that, YouTube? I'm not quite sure how to get to that. I'm not a big YouTube person. What we wanted to know is all right so you sat in the movie theater and you watched it but did you really remember what you watched? We actually did an exit survey of people who came out of the movies that just played in the theaters and asked them what their recall of even seeing this and the average recall is like 73 percent to watch this kind of video. We got an 80 percent recall of people that we surveyed and they really began to think about it which tells us we need to do a lot more of that. We just need to get the funding to do it.

Public service announcements typically they're free on the airways, not so much in a movie theater. You've got to pay for it there. Actually, when I sat there and I saw the slides that they go through and then they started the preview of the movies and I'm going they're not going to do it. I was so disappointed. In-between the previews of the movies, of the coming attractions, there it was.

It was played right in there so everyone was paying attention. It was just absolutely wonderful. Very strong message. We also were fortunate enough that we were able to get the script, the voiceover. You know when you call, and I know the VA system has this wonderful, because I've

listened to a lot of those message now and contacting all the folks at the VA, but you always are on hold and you have music or something.

Kaiser in the northwest now instead when they put you on hold they play our PSA, the voice. That's another way to get our message out and we're going to work on trying to get more of that done. The VA could do that, too, if they wanted.

We're also on Facebook, just to let you know.

Part 3: Learning To Live With It

Penney Cowan: Now what we're going to talk about, remember I talked about learning to live with it, and no one, if they just told me how. So, what we're going to talk about now are some of the coping skills. This is the basic coping skills. That doesn't mean if you get these, that's all you need to know. The interesting thing about what I've been doing for the last 31 years is I continue to learn. I continue to learn things that we need to know, things that I need to know to maintain my wellness. And so, that's why we keep developing new tools. How do I help myself? How do we help other people to maintain that wellness, to stay actively engaged in the whole process of moving from that?

It's like a journey from patient to person. And, that's really what we're putting you on this new, wonderful journey. We look at it that way. We're going to pack our backpacks and off we go.

We're calling it the 10 steps from patient to person. But, what I want to tell you, it's not like the 12 step program. You do not have to do these in any given order. It depends on your needs.

Saying that, the first two you really need to do, the first one is accepting the pain, and that is the hardest thing to do. When I talk to people about accepting the pain, they look at me and they say, "Do you mean giving up?" Absolutely not. That's the last thing I want you to do. I want you to learn how to fight back.

But, the problem is, remember I said we just want...what if I knew what I had. So you keep searching for the answer. Maybe today you say, "OK, for today, I know I have this amount of pain. This is the way it is for today, who knows what tomorrow will bring."

But, I have to begin. Instead of continuing on that relentless search which not only is physically draining, but emotionally it just gets the very best of you. Every time they dangle that carrot, you say no more and then they'll say well, maybe we'll do this one more test or treatment and you get all excited again. And then, down.

So, Not only does your pain go up and down but you're emotions go up and down, your hopes go up and down. For today, accept the fact that you have pain and say, "OK, today I have pain, who knows what tomorrow is going to bring."

Now, what I'm going to do now is show you a video of some of our members and what they say about accepting pain.

Video Speaker 1: 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.

Video Speaker 2: You will get better. For as impossible as you think this experience is, there is a way through it and beyond it. I am living proof of that.

Video Speaker 3: 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.

Video Speaker 4: Educate yourself on whatever the particular pain is.

Video Speaker 5: I can't think about past today. I live this thing one day at a time.

Video Speaker 6: Don't give up. There is help out there. You're not the only person in the whole world.

Video Speaker 7: Pain is inevitable, but misery is an option.

Video Speaker 8: It's a journey that we do together. It's not about the destination. It's about the journey itself.

Video Speaker 9: 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.

Video Speaker 10: 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.

Video Speaker 11: 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.

Video Speaker 12: 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.

Video Speaker 13: 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.

Video Speaker 14: My life now is like I'm coming up out of a hole and coming into sunshine and I feel real good about it.

Video Speaker 15: Every few months, I take a deep breath and I get in the car and I drive to Cincinnati, Ohio, and then I drive to Louisville, Kentucky or Prosberg, Maryland. I don't know how I do it, but there's grandchildren at the end of the road and I can do it! [laughs]

Video Speaker 16: I've been living with pain for a total of 15 years, four years of night and 11 years of light.

Penney: In their own words. I just love that little piece of video. It's just so inspiring. These are people who thought there was no hope. I love Ruthie's comment where she said the old Ruthie,

she's dead, she's gone, but I like the new Ruthie a lot better than I did the old. What I hear, and it's hard to believe sometimes, but sometimes what I hear from people with pain is that pain really was one of the best things that ever happened to me. Not that they had pain, but because that it forced them to reexamine their lives and look at the way where they were going and how they needed, maybe they had strayed off the path they had planned. But this made them stop and really reexamine their life.

So, you never know what adventure is waiting around the corner. That's always what I say.

The second step is to get involved. And, you have to get actively involved. You cannot be that passive patient. You have to be an active participant especially when it comes to pain management. If you sit there waiting for someone to make you better, it just ain't going to happen. So, you really have to be active.

It's very helpful, and I see some spouses are here, to really have the spouse supporting you or whoever, the significant other, to support you through this effort. We'll be talking about families a little bit later.

So, this is what I like to say about people with pain is your pain takes over your life. Things that you do, just the little every day things start to go by the wayside. You don't have time. You don't have the energy. You don't have the physical ability to do them anymore.

I like to see them sitting. It's like a little pile sitting over here beside you, and every time you put something off or you don't do it, you add to that little pile over here. Before you know it, you turn around and you look at that little pile of things that you should or wanted to do, and it's like this massive mountain sitting right beside you.

It's like what do I do? There's no way that you can say, "OK, I'm going to take care of it." It's so overwhelming that you do less because you don't know what to do.

So, you need to understand how do you set your priorities. That's really important. You need a starting point. But, how do you get this whole mountain of stuff down to some manageable level so that you can actually figure out what should be your first step.

We have an idea, and I brought the little note cards. Hang on. I'll give them to you after, but I always ask people to get those little three x five note cards and I brought some in case you didn't have any as a reminder. What you do is everything that's in this mountain here that you think you should be doing or want to do, it's not all work, it's things you really want to do, too.

Everything there, when you take these little three x five index cards, and you need to get probably about 300, I don't have 300 for each of you, probably about 300. You've got a big mountain over here and every time you think about something that's in that mountain of yours, things you want to do, should do, write it down on one of your cards. Then, just set it somewhere and start stacking them up.

So, just keep thinking about what's on this mountain. All the things that you should do, wanted to do, identify them, write them down, one on each card and just save them. Once you think you've got all the stuff on that mountain identified, take all those cards. You're going to have a huge

stack. This has been going on for a long time so there's a huge stack there, and lay them all out on a big, a really big, big table or on the floor and just step back and look at them.

You were really carrying all of that stuff in here. It wasn't really sitting there. It was all inside of you. It was creating a lot of stress, a lot of sense that you had no worth because you couldn't do. I mean, all those things, you're carrying that around. OK? That's a lot to do on top of your pain. That's hard to carry around and we do it, unfortunately. We don't have erasers in our brain. I'd like to find one. I haven't found it yet. So, it's all there.

So, when you sit down and you look at all this stuff and you just read through all those cards and you ask yourself at that moment, of all the things you've just written down, what's the most important thing for you on all those cards and pick that up.

Now, you have a priority. That is your first priority. You don't have to worry about forgetting about all the rest because it's all there on cards. Then just stack them up in any order you want. Maybe you'll take the next three that you might want to work on. Hold onto them. Keep them in your pocket. The rest, put away somewhere. You're going to get to them.

You may add cards. Some you may throw away at point. But, now you have some sense of what you need to do, what you want to do. They better not all be things you have to do, work, because it's nice to have some time and have some fun, too. You need to be able to mix in recreation with work. Don't ever just do all work because you feel like you have to do it.

So, now you have your first priority. Now, you have a starting point. You have a reason to get out of bed in the morning because for so many people with pain why get out of bed in the morning, you're just going to hurt, right? Why should I get up? Now, you have a reason. You have a priority, something that's important to you identified. It's not for anyone else, it's for you.

So, once you get your priority, then you need to begin to set a realistic goal. One of the problems with people with pain is we continually set ourselves up for failure. What we do is we decide. OK, so let's say our first priority is we're going to do our goal on that we need to get out and about. So, our goal is we live 10 blocks away from Lake Michigan and you want to walk. You want to walk down to the lakefront, right? Now, say you haven't walked that far in three years. You say, "OK, I'm going to do it."

So, you get up, you go out, start walking, right? What happens? You don't quite make it. You've got to sit down and you feel like, "Oh, I knew I couldn't do it." You feel like you failed, right? Well, that's because you tried to do too much. You set yourself up for failure. You didn't narrow it down into small, manageable steps. You may need to take a few steps at a time.

So, what you do is set up OK, for the first week my goal is to walk out to the end of the block about one block down. Do that for a week. You can do it. It's not a problem, OK? Now, you've built up some stamina. Now, the second week you take the second block.

It sounds silly for most people, but for person with pain, sometimes the tiniest little things become massive obstacles. Most people don't get that, but you get it, you know how hard some of these very simple things are.

You can't set yourself up for failure. You have to make your goal something that's within your ability to make happen, not someone else. You can't say, "I'm going to be a grandmother by the end of the year." I'm sorry, you don't have that ability. It's not up to you. OK? Make them measurable, something you can actually measure. You can measure walking that block every week and then the second block and maybe the third week you can do four blocks instead of just two.

Small steps to build up both your stamina but more importantly your ability, your belief in yourself because we've lost that. All we ever say... Remember I said all we ever look at is our disabilities, what I can't do, I can't, I can't. Well, now we've got to change that.

I always tell people when they say, "I can't do it." I say, "No, you're choosing not to do it." There's a few things we really can't do, but most things we make a choice either to do or not to do. And so, you really have to start saying I choose not to do that, not I can't. I choose not to do that because that's a really important little just in your own mind thinking about who you are in your abilities. You know you can do it, you just don't want to do it. So, you make that choice.

So one of the things, when I used to do groups a long time ago, I had them fill out a goal evaluation form. It's in the patient-to-person book. Don't look at it now. We did that every week. There was this one lady who had had diabetic neuropathy, which means both her feet and her hands were like numb. She just couldn't do a lot of things that she used to do. Like the lady back there sitting there knitting, there was no way she could do anything like that, because she just didn't have the ability in her hands. So, very small tasks became huge for her.

But one of the things that she really got a lot of pleasure out of was baking for her family. She made really good cookies, and she hasn't been able to do that in several years. That's something she really, really wanted to do.

So, what she did is, she talked to the group about what she wanted to do, and so we always set a monthly goal onto what we can get done in a month. So, she talked to the group about it, and they said, you know what? We're going to help you with this. Let's start to ask, how can we help you step by step every week to do this?

Now, for most people, having a goal to make one batch of cookies for a whole month, that's pathetic, right? You can do that in a couple hours. But for someone with pain who had to let this go a long time ago, that was huge, it was massive.

So, they talked to her about it. Then they talked to her about maybe freezing the dough once she got it to a certain point. And so, every week she'd come in and tell us what she did. At the end of that month, she actually baked those cookies by herself with no help at all. She brought them into us, too, and so we made out.

You would've thought the entire group had just accomplished the hardest Olympic task in the world. They all felt so good, because not only did she accomplish her goal, but they helped her do that just by supporting her. Not saying, "That's a wimpy thing, anyone can make cookies." So it was huge.

And so, that's how you have to begin to look at this. We're not the same people that we used to be. Now, like the one woman said, "I'm not as physically capable as I used to be, but I still am stronger than I ever was." There's different kinds of strengths we have to rediscover. So, setting goals are really important. It gives you a starting point, and it's something that you can measure to see.

It's like when you think I've had pain for five years. Somebody said they've had pain for five years. I had pain five years ago, and I still have pain today. I'm no better, right? Because every day you have pain, you think, it's the same.

But we don't really know that. You know, maybe it changed and we didn't see it, because it's a very slow thing. I'd like to equate that with standing in front of the mirror. How long would it take you to stand there to watch your hair grow till you could see it? You don't, do you? You don't see your hair grow. And yet, we know it grows. You have to get it cut. That's how you measure that.

Unless you measure your success with those goals, you're really not going to know that you did it. That's why it's so important to know that you've made progress. You need that, and a support group will help you to do that. We'll talk about those later. So, setting goals are really important. You need to be able to do that.

The next one is, knowing your basic rights. When we get new facilitators and they'll say, where should I start? Get this whole workbook, and the workbook's not meant to be gone chapter by chapter, page by page either. It depends on people's needs.

But I always say, start on these. If you don't know where to start, start on your basic rights. That's what empowers people. I love the basic rights. I will flick the screen, and there they all are. No one ever told me I had any rights at all. I didn't know that. I had no idea that I had the right to be treated with dignity and respect.

I had no idea that it was OK to ask for help. To me, ask for help, that's a sign of weakness, right? No, it's not. Because we can't do everything ourselves. No one is perfect that can do absolutely everything.

I mean, try to move a piano by yourself. That ain't gonna happen. Even on wheels it won't happen. You need help. Everybody needs help from time to time. Again, I know in the Vets, in the military, you guys really do watch each others' back. They don't ask for the help, but you do it anyway. They do it because they're willing to. I bet they would be also willing to help you if you only ask.

Unless you make your needs known, they're never going to be met. We can't read someone else's mind. So you have the right to make your needs known. You have to know, you have to tell people what you need and if you need help. People can't read our minds. They don't know. We have to make our needs known.

We also have the right to stop and think before we respond. In other words, when someone asks you something, it's that pressure. Yes or no, what is it? Give me a minute to think about it. It's OK, you have that right. You don't have to make a split decision, especially when it comes to

your medical care. You can think about it. You can ask give me some literature on it. Let me take it home, look at it. I'll think about it and I will call you with my decision. You're allowed to do that.

If by chance you say, because you felt pressure, and you go, "OK, I'll do that." You go home and you start thinking about it, you go, "Oh, I'm not sure that was the right decision for me." You have the right to change your mind. No one ever told me that one, either. Because I'm always the, "Oh sure, I'll do that." Then I think about it and I go, "Why did I do that? Why did I say yes?" I always do that. You have the right to change your mind.

And, one of your other rights is you don't have to justify your behavior. You don't have to explain everything that you do and why you do it. So, the next time somebody asks you -- your wife, your husband - says, "We're going to go to my mother's for dinner." And you can just say, "No," and you don't have to explain why. You said no.

So if you don't feel well, or if you hate her, it doesn't matter. They don't know. You just say no, and you don't have to justify your answer. You're allowed to say no. I never knew that. I always thought if I said no, I had to explain why. I always liked to explain myself. I still do it, even though I know that right and I try to catch myself.

That I don't have to explain everything. Like when you take something back to a store? You say, "I want to return this." I never do that. I always have to explain what I did, why I take it back, dah, dah, dah. And the poor clerk could care less, but I feel compelled to explain, and I don't have to do it. Sometimes I really remember. I say, I'd like to return this. Then it's like, I can't say anything. I have to bite my tongue here. I don't have to justify my behavior.

You have the right to make mistakes. I love that one. No one ever told me that. That's what I built this whole organization on was my mistakes. I learned from my mistakes. As long as you learn from them, that's OK. But you have the right to make mistakes. No one's perfect. Everyone makes mistakes.

Especially my grandchildren, I watch them, and I watch the way they respond to those kinds of things, that they made a mistake. They chuckle and go, "Oops." I would be explaining and asking all this stuff. I don't have to. I can make mistakes, it's OK.

The one I like the best is you have the right to do less than humanly possible. You don't have to drive yourself crazy. You don't have to keep pushing. You have to learn to listen to your body. Remember I said the pain goes up, and goes down, and up, and down? What do you do on those good days? Everything. Everything you can, because of the guilt you feel because you haven't done what you should be doing. You're not carrying your weight, right?

On those good days, how often did you just go out and really enjoy the day? Never. What happens after you push yourself beyond your limits on that good day? The next day's not so good.

Woman one : The next three days.

Penney: Right. Well, yes, and the day and the day and the day. And so, what are you doing? You're your own worst enemy. You're setting yourself up for failure every time. You're not being realistic. You're not obviously enforcing your basic right to do less than humanly possible. And, you're not listening to your body, because the first time it says "Ouch," what do you do? "I can handle this. I'm going to do a little bit more. I'm going to push just a little bit more." And it goes "Ouch, ouch," and you go, "I can do more. I only have 10 more cords of wood to split. I can do that." Right? I used to do that all the time with one arm tied behind my back when I was young. Well, guess what? We're not so young anymore.

But you don't listen to your body, and it's telling you to stop. What's really amazing is, if you maybe stop for five minutes, you might be able to start up again. It's called pacing. Pacing is so important in managing pain. You have to pace yourself. Maybe you have to take a half-hour in between.

But you have the right to do less than humanly possible, so maybe on one of those good days you're going to go out and enjoy the day. Like I said, I was amazed. Your city is beautiful. There is so much to do. Just to walk around is just amazing. Enjoy it. You don't have to be productive every hour. I always thought I did.

Because you know what we do? We always base our self-esteem on how much we accomplish in a day, right? That's the one thing that pain took away from you, because you can't be like you used to be. And so, our self-esteem goes right down the tubes with it.

But it's OK to do less than humanly possible and enjoy the day. Because you know what? You might have a better day the next day, too, and even the day after that. But, if you don't listen to your body, it knows best. If it says "Ouch," just stop for a little bit. It's OK. I can't impress that upon you enough.

If you overstep your limits, then you've made the mistake. You have a right to make mistakes, but learn from those mistakes. Go, OK, I know what I did. Now, there's a few spouses in here, so you're also hearing this. So remind them. You didn't listen to your body, did you? That first ouch.

These are so important. Print them out. They're on our web page. They're in your book with a lot more details. Print them out, stick them on your refrigerator. Look at them every day. These are your rights. They're the same as anyone else. You all have the same right to enjoy your life. You don't have to work hard. You don't have to explain yourself. You can ask for help. You're equal to anyone else. You're just as important.

Recognize emotions. This is a really hard one, because then we think, OK, I should be able to control my emotions, right? The one thing that you have to remember is there are no wrong feelings. You can feel anything you want. You can control your actions. You can't control your feelings. It's just going to happen. You're always going to react. That's what makes you human. So, there are no wrong feelings.

I like to use this little picture. See the guy sitting there in the blue sweater? He's the one with the pain, and he's sort of, what's he doing? Sort of pulling at himself, closing up, he's not going to say anything, right? That what we do? We shut ourselves away from everyone. We're not going

to talk about it. I don't want to hear it anymore, anyway. It can't be hurting anyone if I just sit here and be quiet and suffer in silence.

Look at her. She's not so happy. Don't you think that may be affecting her a little bit? Don't you think she knows what's going on? She's seen this behavior before. We're so afraid of negative feelings. We never hide our joy, never. Negative feelings, it's another whole story.

They say, well, maybe you're depressed. Well, like I said, if you've had the flu for a whole year, who would be a happy camper? Of course, you're depressed. You have pain. It's taken over your life, it's taken over all of that future plans you wanted. But that doesn't mean it's the end. It's just a different beginning and a different road you're going to travel.

When I went to the Pain Program... Again, remember, I went there to fail. I was just so irritated I was even there. One of the first things that they did was gave me a book to read. It was called "The Angry Book." I'm thinking "All right, what is this?" I'm here because I have pain and you're giving me this book on anger. I'm not an angry person. But they said, you have to read it and I did what I was told. I always do what I was told.

So, I read the book. It's not a very big book. It's still in publication today and that was 32 years ago. It's called "The Angry Book" by Doctor Theodore Rubin. A wonderful book, it doesn't take much to read it. In every page, in every chapter was a different kind of anger. Anger is not just yelling and screaming. There's all kinds. There's silence. There's all kinds of anger. I don't even remember all the different kind of angers that there are.

What I do remember and what I took away from the book... because, by the time I got done reading the book I thought "I'm the angriest person in the world." I saw myself in every one of those chapters, every one of those. Don't worry about me. Go ahead and enjoy yourself. It's like if you dare go out that door I'll be really angry but go ahead and go. I'm not going to say anything. That is a kind of anger. I saw myself in every chapter, every time.

At the end of the book, he talked about a slush fund. That's really what I remember and took away from that book. The slush fund is all of those negative feelings that we tend to hide and avoid and ignore and won't admit to. That's where they stay. Like all that mountain over here that you're carrying around. Also, now, you have a slush fund inside of you, too.

I like to look at that slush fund like a bucket. It's an empty bucket. Every time you ignore one of your negative feelings another drop of water goes into your bucket. Now, there's a lot of feelings that are being ignored, the negative. They just keep dropping more drops in that bucket every day. You're carrying this around. It's getting pretty heavy. All of a sudden there's that last little thing. That last drop. And what happens? The bucket overflows. You dump your bucket on somebody.

It's always your safe person. For me, it's my husband. I dump buckets on him all the time, unfortunately. I still try to recognize emotions but we're all human and we make mistakes so I sometimes hold those negative feelings in and then I just dump them all on him when he says the smallest little thing. But he's my safe person. In spite of that, he knows me too well and he's listened to these talks too many times so he really does get it.

You have to begin to realize that you're carrying even though you're saying, "It's not bothering me." You're carrying them all around. You've got a whole bucket full of water drops in there. You're carrying it around day after day after day. Imagine how hard that is with a person who is 100 percent physically well and here you are with pain and you're dragging this bucket and you got this mountain on this shoulder.

There are no wrong feelings, only inappropriate reactions. So, say somebody does something and it bothers you. What are you going to do? Say, "That's fine." You're going to say "You know what? What you just said really hurt my feelings." Tell them and it's no big deal. It's not yelling and screaming. Or "When you did that it really hurt. I would prefer that you do..."

In the books that you have, we have a bunch of assertiveness training. I'm not going to talk about that today. But it's going to give you different ways to express how you're feeling in an appropriate way. Read the chapter, do the exercises. It really does help you better communicate.

Communication is what brings everything together. But, if we continually hold those negative feelings in, we're going to explode at some point in time. And people know. "Look at her." You think you're not hurting anyone but you really are. You're shutting them out.

Learn to relax. That's easy to say, right? If I could go to that wonderful, beautiful little island there and feel that soft, warm sand and lay down on a nice blanket and feel that little sand, your body contours with the sand, and you pick the sand up and it's like silk going through your fingers. The waves are breaking against the shore. You can hear the palm trees rustling overhead. If you could sit like that then you might be able to relax, right? But that's not reality. That is not reality. So how do you relax?

Remember I said, a while ago, the more tension you give your pain the more you're going to suffer. One of our goals is to reduce our sense of suffering. So, right now, I want all of you to do something for me. To yourself, in your mind, I want you to count from one to 25 and at exactly the same moment say your alphabet. You can't do it, can you? Do you know why? You have a one track mind.

You have a one track mind so while you're thinking about laying on that beautiful, warm, sunny beach listening to the waves crashing against the shores, for that instant you're not thinking "Oh my God, my back is killing me." For that instant, you have reduced your sense of suffering. It didn't mean the pain went away but you're not suffering because you're not giving it your undivided attention. Now the question is how do you do that? How do you redirect your thoughts onto something else?

I don't know if they do biofeedback here or not but when I went to the Pain Program that was another one of the things that they had me do. I had four sessions. I went into these sessions and the whole idea is to turn the whole sound off and get your hands nice and warm. I was terrible. I couldn't do them. The sound went up. I tried so hard that I stressed myself out. It didn't work.

I was really, really fortunate that the gentleman who was doing it, the biofeedback person, taped those sessions because as I was hooked up, he was reading these wonderful little relaxation exercises. He taped them. He said "When you go home, practice them."

Remember, I said I used to do what I was told. I still try to but not all the time. So, I listened to them. Twice a day, I practiced them. They were about 20 minutes each. I kept practicing and practicing. One day I realized, I didn't need those tapes anymore because I could tell my body how it is I wanted it to feel because I listened to my body. Remember, we talked about listening to what your body is telling you.

When I felt that first little ouch... There's a bunch of different kinds of relaxation exercises. My favorite one, for me, is the breath relaxation. I always think about, when I just get that little 'umph' or if I'm on a plane and it goes 'arghh.' I will take in a deep breath and I imagine how that breath looks as it begins to fill my lungs. Is it a color? Is it a substance? Then, as you exhale, has it changed consistency? Has it changed color? Is it something altogether different? Just taking in that deep breath and letting it out and thinking about that?

Another way that they did that, with the tape, was as you breathe out instead of breathing out of your mouth, you imagine the breath going down your shoulder, down your arm, and out your fingertips. You just imagine that. Again, while you're thinking about that... You only have a one track mind. You can't think about "Oh my God, this is hurting me."

If you listen to your body and you begin to learn how to do these, you might be able to regain some control not only of what you're doing but your body as well and begin to take more control. I personally love control. I would think that most of you do like control. You like to be in control.

You really can tell your body how you want it to feel but it takes a lot of practice. It's not something you're just going to try once and go "This doesn't work." Don't do that. Keep working at it and working at it. We have, I think, four different exercises available. But you can get them from all kinds of different places. Barnes & Noble have a bunch of tapes.

There's probably some online. You don't have to use ours. They're very effective but you have to practice and practice and practice. It's just like learning to ride a bike. You don't just jump on a bike and off you go. You're going to fall down and skin your knees. Don't get disappointed. Don't get discouraged. You can do it.

Now, what I'm going to do for you... This is something that's also on our web page. I'm going to play a five minute relaxation for you. If you want to lie down, if you want to kick off your shoes, you have great chairs. These chairs are really nice. Get as comfortable as you can and we're going to play this five minute relaxation for you.

Just listen and hear what it has to say. If you want to get up and stretch for a minute and then get comfortable I'll give you a minute until you get all settled.

[music]

Woman 2: 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. As you breathe out feel the tension begin to drain away. Then go back to 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 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 all over 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.

[music]

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

Penney: Telling your body how you want it to feel, paying attention to it. Just even how you hold your hand, making that tight fist. All that muscle tension is just going to increase your pain level. So, begin to learn how to tell your body how you want it to feel. The next step is exercise. This is a hard one to do. Because most people, and for me even, they kept saying, "If it hurts, don't do it." Every time I do something and tell the doctor it made it worse, "Well, then, don't do it anymore." You can imagine, after six years, where I was at. I was so de-conditioned that it didn't matter what I did. It was going to hurt because I became de-conditioned. I didn't do anything.

When I went to the pain program, and they said, "Well, you've got to start doing exercise." I was thinking "Oh." You've got weightlifting after that. Remember, I couldn't hardly hold a cup of coffee, and they wanted me to lift weights. I was at the Cleveland Clinic. Unfortunately, the Cleveland Browns worked out there, too. So, there's this wimpy lady trying to lift a five pound weight, and they're pressing 300 or 400 pound. I'm thinking "Oh."

It only intensified my inability to do what I wanted to do. The problem is that we tend to, remember we don't listen to our body? We don't hear what it's telling us. In the workbook that you have, we have a section on exercise. There's 18 very mild stretches in there that we don't tell you to do. They're there so you can take them to your healthcare provider and say, "OK, what of these can I do? What do you think is OK for me to do?"

Maybe, they'll say, "They're all OK," or "Three are OK," or "Four are OK." What I want you to do is pick out one. One that you think you want to do. For the heck of it, we're just going to say a leg lift. In the morning, before you get out of bed, what you need to do in starting an exercise program. That has to be a regular schedule, right? Where you're going to do it is work it into your daily schedule.

First day, before you get out of bed, before you get dressed, lift your leg as high as you can. Just as high as you can, don't feel any pain. Put it down, that's it. You've done your exercise for that day. You've worked within your limits. You haven't set yourself up for failure. You're not pushing beyond your limits. You can do it, right? The next morning, do the same thing.

Maybe by the end of the week, you'll actually get your leg up pretty high, and it won't hurt at all. The next week, you add another exercise. Very slowly and gradually, pacing yourself, you'll find yourself doing a lot more exercise. It didn't hurt. You can't wake up the next morning and go, "I can't believe I did all that, and I'm really hurting." Because you've stayed within your limits. You haven't set yourself up for failure. You've accomplished your goal.

A lot of people use exercise as their personal goal. You have to do it gradually. You are so de-conditioned. Every day you spend in bed, every 24 hour day you spend in bed. You know how long it takes you to get back to where you were before that first 24 hours? Two weeks! Imagine how de-conditioned some of you may be. I know I was. I was up and around, but I wasn't doing anything. No matter what, I did hurt.

For me, at the pain program, it got a lot worse before it got better. I always tell people, when they go through a pain program, it's going to get a lot worse before it gets better. I wanted to prove that this wasn't going to help. So I pushed, which wasn't the smartest thing to do. It was really interesting.

I guess the VA is like this, but the Cleveland Clinic is three or four blocks long. We had to walk. You weren't a patient. You were never even allowed to talk about your pain. We had to get up every morning, get dressed, make our bed, walk down to breakfast, walk down to lunch. We walked everywhere. We we're people walking around the hospital.

Physical therapy was two buildings over it. It was like a block and a half away. I remember walking one day, over to physical therapy, where we did stretching exercises. It wasn't passive therapy. I was an active participant. I thought, "I just can't do this today. I'm really hurting." What was amazing to me is on the way back from exercise that day, from PT, I actually felt better. This little light bulb went off. It went, "Oh, maybe this is a good thing."

To this day, I still do those stretching exercises. It's a small price for me to pay to be able to function. It's one of the many things I do. Only one of the many.

Talk to your healthcare provider. We cannot make an evaluation and tell you what you can and can't do. That's not for us to tell you. What we can do is, once you get an OK, and your healthcare professional tells you what you can do, to encourage you to continue to do it. This is something that only you can do.

No one else can exercise for you. No one else can tell you how your body should feel. No one else can hear what your body's telling you. These are all your responsibilities. That's why you have to be that active participant.

The total picture. It's not about what you can't do anymore. It's about what you can do. You really have to step back and take a look. What has the pain done to my life? How am I going to regain control of my life? When I talk to people with pain, what they tell me is, "I want my life back." That's what they always say. "I want my life back the way it was before."

Like I said, many of us are a lot older than we were when the pain started. We're never going to go back to being 20 or 30. That's something you really can't do. Not yet anyway. Who knows? But, what can you do? You really have to look at the overall. Evaluate what it is that you want. How are you going to get there? How are you going to stay within your limits?

Look at the whole picture. Look at your abilities, not at your disabilities. Ask yourself, "What did I always want to do, and never did?" It may be painting. It may be anything. Maybe some woodworking, or some whittling, or whatever. Ask yourself, what is it that you want to do now that you never could before? You have some time, do it.

Your attitude is 80 if not 90 percent of how you will do. It really is up to you. You need the support. You need the direction from healthcare professionals. You need the support of peers, your family. But, in the end, most of it lays on your plates. It's up to you.

The last one is outreach. That's really where I started. Of course, if there were a group available to me before I went to the clinic, I would not have gone. Because I'm also very stubborn. I had given up by then. I know I would not have done it. I'm amazed by every person that walks into a group room, because that really took a lot of courage.

There were several things I learned at the clinic. The first one was, for the very first time in my life, I realized I wasn't the only person in the world with pain. Before that I never knew anyone else had pain because I had become so isolated. I had no idea. I knew there were other people out there that I needed to tell, "Hey, it's not hopeless. There's hope."

I think the main reason that I did this is we were driving home from Cleveland. Because I lived in Pittsburgh. Remember the Steelers, I lived in Pittsburgh at the time. We were driving home, and I thought to myself, "You know, in that controlled environment..." It was an inpatient program, which is unheard of today.

"In that controlled environment, everything worked OK. I could do it. But, what's going to happen when I go home. I have to start taking care of the kids again, the house. I have to do all the things I have to do." It was like 10 days before Christmas. "What's going to happen if this doesn't work?" Other things had worked for a little bit. Then, they stopped working. So, what happens?

I think, more than anything, it was out of fear that I would go backwards. That I knew I had to stay actively involved and continue to apply all those things I had learned at the clinic to my daily life, moving forward. If I wanted to remain that person, rather than a patient, that's what I had to do. What better way to do it, than share what I had learned with other people?

As I said, 31 years ago, I was at the very beginning of my journey. I have learned so much as I go along that road, along that path. There's always something new to learn. It is amazing. That's why the groups are so valuable. Because, not only do you learn from them, but people can share what they know. To reach out to others. To know that you are not alone.

You are not alone. There are a lot of other people out there who get it. You're not crazy. Your pain is real, and there's a way to begin to manage it.

This is our little car. I don't know if you saw Jill bringing in the box, and I was smiling because we sent them. You're all going to get one for these. I will explain to you why we have this little car. This is how I like to explain a person with pain. They're like a car. Except, your car has four flat tires. So, you can't go anywhere, you're stuck.

Remember I talked about our expectation? Our expectation is, "All I need is that one pill. That's all I need." Even if it is the right pill, it's only going to put air in one of your tires. You still have three flat tires, you're not going anywhere. You have to ask yourself, "What else do I need? What do I need to fill up those other three tires?" It could be counseling. It could be physical therapy. It could be acupuncture. Who knows? Everyone is different.

Maybe all that medication that you got, or even the physical therapy, gave you 20 percent relief. We'll add 20 times 4, you've got 80 percent. That's pretty good, but you've got to fill up the rest of the tires. One you get all your tires filled, guess what? You have to maintain that care on a day to day basis. You can't go back every day and say, "What am I to do?"

It's your job. You don't take your new car back to the dealer and say, "Fill her up," or "Check my windshield," or "Check my oil," or whatever else you do to cars. That's your job. If something goes wrong with your car, it makes a funny noise or whatever, what do you do? You take it back. You go back to see your healthcare provider.

On the day to day, it's your job to figure out what you need to fill up those tires. Working with your healthcare provider, hopefully, your ACPA group then maintaining it on a day to day basis. The nice thing about the VA is, if it breaks down, and you need a tow, you've got a whole bunch of people who are willing to help you. Because you guys watch each others' back.

Part 4: ACPA Materials

Penney Cowan: The American Chronic Association, back in 2001, we declared September, Pain Awareness Month. We worked at that for six years. We actually got 80 other organizations to partner with us, both healthcare professional organizations, most of the nursing organizations, a lot of the American Academy of Pain Medicine, American Pain Society and a lot of other physician organizations, pharmacists. We got all of them onboard. We got a lot of the consumer organizations, disease-specific, to partner with us to declare September, Pain Awareness Month.

For six years, we drove that effort. If you talk to anyone now in the pain community, they know that September is Pain Awareness Month. I know that one of the things we ask our facilitators to do is to have some kind of special event in September. I think they're going to be doing their potluck here, and that's what the blue sheet is.

But, it's really important, so wear your buttons. We love the little buttons, "Pain management can brighten your world." It's nice, it's bright. They see the little smiley face on the world and they'll ask you, "What is that button for?" You can let them know that we really have to pay more attention to pain. This is one way to get people's attention is through a little button. You all have one. If you want more, we also have them in Spanish, believe it or not. If you'd like more, let us know.

Let's talk about some of the other tools that we have, all right. We have, and I talked about the relaxation CD's that we have. That's what they look like. That's Autogenic and General and I think there's breath relief and pain...Breath, Relaxation and Pain Relief is the other one. Those CD's are available. Then the one little video clip that I showed you, and I'm going to be showing you another one as well, is on the Pathways to Pain and these are, based on our 10 steps.

Unfortunately, we only have two done right now because that's all the funding we got so far. We're really based on getting funding money. The funding always goes into the projects we do. Like, here we are. We really have to wait until we get the funding to do this. But, these videos are excellent, and I know a lot of the groups will borrow them, show them in the group and then return them. Those are some of the things we have. Here's the workbook that you got, and that's the number of things that are on it. The introduction, "Knowing Yourself," "Learning to Live With Others," "Helping Your Body."

This is the form that I ask to fill out. If anyone did not put their name and address and their phone number and I was, before my pain began, if you could put your email there. Then I had but, obviously, we changed this. I had to write down their facilitator guide if you wanted it. But now we have a separate form for that, so don't worry about that. We'll talk about if you want to become a facilitator and we have another workbook to do that. We'll talk about that later.

That's the business reply envelope. What I do have over there on the table are evaluations for this program. If you could just fill out one of those. If you don't want to do it now, there's business reply envelopes, you just have to stick it in the envelope and stick it in the mail.

You can fill those out to let us know how we did because there may be something that I'm doing here that I didn't do enough of or things that I did too much of. We really need to hear from you how you felt about this presentation. That will help me to form the next one, shape the next one. We really do take your comments seriously.

This is another workbook that we use. It's called "Staying Well: Managing Pain." The thing about that is remember I said I'm learning as I go on. I really believe that everyone who completes a pain management program, a lot of people think, "OK. Now, I got it. It's good. I'm just going to continue on with my life like I had before." They don't pay attention to the things that they learned. They don't stay involved.

They don't keep driving their own car. They just sort of park it and just go on with life and not worry about all the things they learned. I always say people who go through any kind of pain management program, at some point they may hit the wall. It's normal. It's natural. It happens to most people. About 10 years after leaving the pain program, I hit the wall. That's what this book is all about, all the things that I really didn't think about.

The things in the first chapter is "Do I have to go back to the doctors, because the whole time I was with the pain program, it was 'don't talk about your pain. You're not a patient, blah, blah, blah.' That was drilled into me so much that I became unrealistic about what I am supposed to do. Well, I kept driving my car and keeping my tires filled, I never paid attention to the other maintenance that I needed to have done."

That was one of the chapters. There's a lot of other ones on more things like self-awareness. One of the really nice chapters in this book is on reassessing your skills. In other words, now you find yourself where you can't go back to the job that you had. How do you define, how do you begin to reassess your skills so that you may be able to get out into the workforce? What is it that you need to do?

That chapter I didn't write. It was written by one of our board members who is a Human Resource person. This is what she does is to help people redirect, change careers, get into another profession. That is one of the chapters in here. There's one on families as well, though I will talk about families in a minute. This is the family manual, and we have one specifically for family members.

This one was really hard for me to write because I don't know what it's like to live with a person with pain. I know what it's like to live with pain. I can tell you all about that. But, when it comes to the family member, I hadn't a clue. In order for me to write that book, I had to talk to them.

I actually interviewed family members for three years before I wrote this to really understand what were their issues. We knew they were having issues because we used to do retreats for our facilitators and the spouses would come. I would sit there and talk with them and think, "You know, they need help."

After talking with all of these family members for three years, one thing occurred. It was very interesting because I thought in everyone of those interviews that I was talking to a person with pain. There was only one difference between the family member and the person with pain. The family member doesn't feel the physical pain. That is the only difference. Everything else that you're experiencing, unfortunately, so are they.

They're struggling with the same things as you are. Throughout this whole manual are excerpts from those interviews that I did with people. Someone came up to me and said, everything she said is, "That's me, that's me." When people read, the family members read this workbook and all those little interviews segments, they go, "That's how I felt. That's exactly how I feel."

This really addresses the needs of family members, and that's what it's for. The nice thing about this book is that... Remember I said I went to the Cleveland Clinic and there's a bunch of pain programs around. But, for many years they kept trying different manuals and different books and

everything. They finally threw all of it out. They exclusively use our workbook from patient to patient now, but they love our family manual.

It's the only thing out there like this at all. We just sent 100 more of them to them so they really, really like our family manual. It's a very good piece for family members. We have toolkits. These toolkits, remember when we talked about the basic rights, we talked about a number of the coping skills. Groups need to know what else they can do. People need to know. Once they get done with the workbook, they think, "All right, now what do I do?"

What they need to do is go back and review it again because it's amazing how much you pick up the second time, and sometimes even the third time you read that because you are at a different frame of mind every time you read it. But, we also wanted to be able to provide them with more information, more worksheets, more hands-on. This is how you begin to understand this concept.

So right now, I think we have six of the kits done, and the last one I did was basic rights and it's 50 or 60 pages because I think there's, obviously, a lot to be said for the basic rights. There's a toolkit specifically on basic rights, about 60 pages long. They give you all kind of worksheets and exercises to really help you better understand how you can apply those to your daily life. Those are available.

This is another book. Remember I talked about not being able to understand that you're making progress. We talked to people, a lot of people, about journal writing and being able to keep a journal. But, I think before they do that, they needed to have a positive frame of mind, needed to think about their pain, about themselves differently. This book, "Reflections of You" is 366 pages and every page has new positive affirmation, having to do something with pain and pain management.

Then at the bottom, there is a place to journal. But, a lot of people don't like to write. They sort of get choked up. We started telling them, well, have different colors for different days. A red day is stop; a yellow is you were more cautious that day; green day was a good day. You don't have to write if you don't want to.

All of these positive affirmations are now on our Web page. Every day when you go in, on the bottom righthand corner of our Web page, you'll see the first couple of sayings and all you have to do is click on that and it'll take you to the full overview for that day. We've decided to put this on our Web page. It's free and you just have to go in, click on it. Every day it's going to change. It will change every day and that will be provided to you.

I think the next one, yes, is the coping calendar. This also came out of requests from our facilitators and our members on, all right, we've done everything. We don't know what to do anymore. We decided to start doing a coping calendar and every month, there is a different focus, whether it's on exercise. It could be on basic rights. It could be on Pain Awareness Month.

Every month we have a different topic in the calendar. Then throughout that month, we will have a little either... For Pain Awareness Month, we'll have links to all of the different partners. Whatever day that is, you can go in and, maybe, see what the American Academy of Pain Medicine has got as far as the research they've done or any of the different organizations. Or, if

you're looking for exercise, it will tell you, remind you what you have to do or another way to try to do exercise.

Throughout the month there's different sort of hints or reminders to stay focused on that. This calendar is also on our Web page now. It's free. You can get the print version but it's free on our Web page. You can just go in and look at it from month to month. That's available to anyone as well.

This is a book. It's the only one I don't write. This is the "Consumer Guide to Pain Medication and Treatment." Every year it is updated, so it literally...and one of our professors, one of our board members wrote it. He is a physician. He works at Stanford University. He writes this. Every year it's reviewed. We update it with the newest medications. This is also available on our Web page. It's free.

It's really text heavy though. I mean, there's a lot of writing. Even though it's for consumers, sometimes it depends on your reading level and the knowledge you have reading it. It's a little, little heavy. But, we also have it reviewed by our professional advisory board and our board of directors before it ever goes into print. Then the online version continually gets updated. As new things come up, we will update that.

We don't update the print one because it costs too much to reprint them in the middle of the year, but we do have this on our Web page. But, one of the things that we knew is, again, people I know don't read all the time. They don't like to read especially that kind of stuff. We decided the best way to get the information to you would be through a video. We now have segments of that book on our Web page in a video format: interviews with people of pain, physicians, physician assistants, nurses, pharmacists. They're all in there.

All you have to go in. It's all chapter driven. That's what it looks like there, and all you have to do is click on the piece. The ones that are not bright are the ones that are not populated yet that we didn't do the video for. Again, that depends on funding, so as we get the funding, we will continue to do more. But, again, the print version is on our Web page. It's free, if you want to print that out.

Healthcare providers love this one. It's a really good overview for them. When we go to professional meetings, this one we take. We don't take much anymore but we take a print version of this because it's really popular. They would rather have the hard copy than sitting online reading 60 or 70 pages.