

AgrAbility: Growing Well With Pain

This talk was developed by the American Chronic Pain Association and presented to groups of agricultural workers across the United States in cooperation with the AgrAbility Project.

The AgrAbility Project – The AgrAbility Project assists people with disabilities employed in agriculture. The project links the Cooperative Extension Service at a land-grant university with a private nonprofit disability service organization to provide practical education and assistance that promotes independence in agricultural production and rural living.

To learn more about AgrAbility, visit its web site at www.agrabilityproject.org.

About Agrability

Penney Cowan, Founder & Executive Director American Chronic Pain Association: What I'd like to do is talk about why I'm here. And for the last twenty-eight years I have been involved with people, helping them to move from that patient to a person. But one of the groups that I had never heard about in all of the time I've been working with people with pain is the farmers and ranchers. And I was just amazed-- I mean it. No one ever said this is a group that is completely under served and we're not paying enough attention to their needs. And so I found out about Agra-Ability about a year and a half ago and I thought "I need to be able to get out and talk to folks." So I wrote a grant, and it was funded by the Medtronic Foundation. That is why I'm here, because I really think that you need to --I mean you don't get days off, you don't get vacations, you don't get sick days. You have to work twenty-four-seven regardless. It is one of the hardest most dangerous jobs we have and I think that we have underserved your population so that's one of the reasons I'm here.

So hopefully today you're going to learn a little bit about how do you manage that pain --at the end of the day during your work, what do you do? So let's hope we can cover that for you.

We have been around since 1980. The one thing that we are not is a health care provider. We don't provide any kind of medical treatment for advice to work in addition to what your healthcare provider is telling you. We don't offer a cure we offer an education and in support to help you through your journey from patient to person.

There's our mission again is to facilitate support groups to help both the person with pain and their family and also to generate awareness about the whole issue of pain.

What is Chronic Pain?

Penney Cowan: Pain is the number one health care condition in the world, in the US. More than anything else, it is the one that causes disability. Let's see, it's one out of every three people have some form of chronic pain, one out of every three people. The cost-- one hundred and fifty billion dollars a year; that costs more than cancer and heart disease put together.

When was the last time you heard anything about chronic pain? You don't. You hear about heart disease all the time, you hear it about cancer, but why not pain? I feel we have done a disservice to all those people with pain and so we really do need to move forward and generate a lot more attention so that our needs will be met.

Also, it leaves a lot of people without healthcare insurance because health care insurance is so expensive. And I know for a fact that a lot of ranchers and farmers don't have health care insurance. Their parents and their parents before them did not have health care insurance. So this puts you at great risk. Chronic pain turns a functional person into a disabled patient. What the American Chronic Pain hopes to do is to take that patient and help them become a functional person again. And what I want to do right now is let you listen to-as she said I went to a pain management program at the Cleveland clinic the director was Dr. Edward Covington, and he is going to explain what is chronic pain.

Narrator: Most pain is temporary and manageable but chronic pain is different, and because it is different we need to think about it in very different ways.

Edward Covington, M.D.: In the overwhelming majority of cases acute pain can be linked to some specific occurrence-- there's an inflamed appendix, there's an inflamed joint, there's a broken bone. With chronic pain there may be no apparent physical injury or illness to explain it. The physician and patient are accustomed to deal with acute pain and both naturally expect that some cause will be found, and when it's found it can be fixed, and at that point the pain will go away.

Part of the problem with chronic pain is that when we start looking for an explanation, it's not so much that we are looking in the wrong place, but we may be looking in the wrong time. And what I mean by that is that the presence of a severe pain problem which exists for some period of time can actually change the nervous system so that the peripheral nerves are changed, after a period of time the spinal cord changes, after period of time there are even changes in the various levels of the brain, so that to explain a person's pain one day it may be necessary to look at an illness that actually went away a few years earlier.

Narrator: We don't know everything that there is to know about chronic pain, but here is what we do know. Chronic pain is any pain that continues beyond the expected period of healing for and illness or injury. You could experience pain even if you are no longer ill or if your injuries have healed. In fact, many persons experience pain even in the absence of an apparent cause. What chronic pain has a physiological or neurological basis even when we don't know what it is. Chronic pain is real.

Penney Cowan: Ok so that gives you a good overview of what chronic pain is. You may not know what the cause is; you may not even have a name for it. What I want to focus on here is that pain is very confusing and one of the reasons is that you never have the same level of pain day in and day out. It goes up, it goes down. You have good days you have bad days, and that creates a lot of problems both for us and everyone around us because they see our level of functioning going up and down and that becomes very confusing. We will talk about that a little bit later. What you have to realize is it's not always at the same intensity day in and day out. So our level of function and our abilities are going to have to go along with our level of pain. Ok, because a lot of people will look at you and say if you did it

today why can't you do it tomorrow? It doesn't make sense. So we wonder how did I get this? And for things some things just happen and our expectation is that medicine can eliminate anything, right? They can give you new hearts, new lungs, new liver, they can do so much. Why can't they get rid of the pain in your back, foot, head, or neck? It doesn't make sense, that's our expectation.

So what we do is we start in this unfortunate maze, that's what it's like when you're in pain. You go into this medical maze and you start going from one place to the other, but guess what you keep getting these little blocks don't you and you keep going around because you really want to believe there's gotta be an answer for what is wrong with you. That makes sense right? Problem is pain is invisible you can't see it. You can't see it you can't measure it there is absolutely no way to say "Ah-ha!" I see you're at a 10 today, you're at a 3, you're at a 5 and it's really hard to put your finger on and we always tell ourselves if only I knew what was causing my pain then I would be able to deal with it and I know for 6 years I said that and I kept thinking if they could tell me what was causing this then I could deal with it.

The problem is once they told me what it was I thought then we'll fix it. I mean if they know what it is they should be able to fix it. But the bigger problem with pain is it's not necessarily the pain that's the controlling factor because it takes total control of your life. It's the fear of the pain. It's afraid what's going to happen if I do this, what's going to happen if I do this to get stuck there and the pain peaks, and it's that fear that controls us. Last time you did something it really made your pain worse, "I'm not going to do that again." So we start pulling away more and more from first our family then friends then we become very isolated, that fear is a really big controlling factor.

We looked to our healthcare providers, but they are not trained in pain, in all of the medical education that they get they get two hours of pain management, that's it. So somebody like a surgeon can go for twenty years sometimes by the time he is done and ready to start practice, two hours that's all they get so they really don't know how. So when we look to them, they don't know how. Pain management is not a simple thing, it's very complex and we will start talking about all of that. So what do physicians do? They tell you to live with it. How do you do that? Learn to live with it. I heard that a lot, this is what happens to somebody. What we want more than anything else is someone to say I believe your pain, that's the first thing we want that validation. We want somebody to at least acknowledge that even though I may not know what is causing it I believe you have pain. That is so important it's that validation as we walk down that road as we get stuck in the maze it's like walking down this foggy road and the further down you travel looking for those answers and that validation the more you as a person disappear and all of a sudden this chronic pain patient loses who they are and their pain becomes their identity. And that is so dangerous because think about it you are a lot more than your pain, you're a person with pain, you're a person with blue eyes, you're a person with so many talents, why does the pain have to override all of that? That's a big problem with Chronic Pain.

Our life experiences are going to impact how we are going to deal with our pain, and especially in your community. I mean your parents and the parents before them they continued, it didn't matter if they got hurt, they had to do it --the animals needed taken care of, the crops needed to be harvested, it just didn't stop, it was expected of you. And so that's what you're thinking and we'll talk about pacing and that in a minute. The different thing about being a person with pain and being another kind of -- the

typical medical model is that expectation of when you get sick -- cold, flu and even surgery -- people take care of you. They take care of you and you are the passive patient. The problem with chronic pain is you can't be passive because you can't just sit there and wait for somebody to help you because it's not going to work. You have to take an active role in your recovery process. You have to step up and we're going to talk about what that means what are some of the things that you can do to make that transition from a patient back to a person. And the bigger thing is - it's not as much, it's so important for us to know what caused our pain, and for some of us we may not have an answer, but that doesn't mean it's not real. But the more important thing is not what caused your pain, but how are you going to deal with it?

How are you going to deal with this pain that completely and totally taking over your life? And it's not just your life, it's your family. And it's all like you all got stuck in this big wave and it's just turning you round and round. We know what the force of water can do, it's so powerful, and you can't resist it. And it just keeps spinning you around. You don't know what's up you don't know what's down.

People's pain, they feel very helpless and hopeless when the health care providers keep going "I don't know", that doesn't feel real good because we expect them to give us answers. Or, they'll say well maybe it's because you're depressed. Think about this, if you had the flu for a year would you be a happy camper? Of course it's depressing, but it doesn't mean that the pain was caused by depression. If you're really happy that you have pain then we do have a problem, but I don't know if that's going to be the case. All I ever hear from people when they call is "I want my life back," that's what we all want, we want our life back. We're angry. I mean, why did this happen to me? How did it happen? We're confused. Why can't health care providers take care of this? There should be a reason. We feel guilty and that's a big one, because we can't fulfill our role. And the way we evaluate our worth, for so many of us, is by how much we can accomplish in a day. And if we can't accomplish what were suppose to in a day then we're worthless -- right? -- not right, but that's the way we think. And we're also out of control. We don't know what to do. Where do you turn?

What's really interesting, your family experiences those same emotions. There's only one difference. And we have a manual now for family members. And for three years -- I don't know what it's like to live with someone with pain; I only know what it's like to live with the pain. And for three years I had to interview family members and talk to them to get an understanding of what they were going through and what were their needs and some of the struggles that they had. And in all that time, I would have thought I was just talking to people with pain because there's only one difference -- between the family member and the person with pain. And that is that the family member does not feel the pain, all this they have, same thing they're feeling it too. We don't realize that, but it's true, but they do, and the children as well.

Talking With Your Doctor about Pain

Penney Cowan: So let's talk about how we start taking that active role. The first thing is when you go to your doctor's you need to be prepared. You know times have changed especially in the medical community, and you may get five --if you get ten minutes you are doing good, but maybe five minutes, I

think the average is like seven minutes with your doctor. So that is a valuable piece of time, so we should be prepared before we go to our doctors.

So what you need to do is get out one sheet of paper no more than that, just one sheet. And the first thing you want to write down –and it's just going to be bullet points, brief words, what you want to do is write down what has happened, what is new since the last time you saw them. And you can start putting these in a binder so you can always refer back to them. The current medications you are on and we do have back there little medication cards that you can fill out and carry it with you. But when you are listing those current medications make sure that you include over-the-counter and vitamins and herbal supplements that is all critical. What I always kept thinking was “If you just look at me you are going to know.” But they cannot read our minds so unless we tell our health care provider they're not going to know. Blood test won't show, we have to be on a team, we have to be able to communicate with them.

Changes in your mood, your appetite, your level of activity and methods that you have tried--did heat help, did cold help-- and again short words so that you can make most of that time. Any questions that you have write them down. Every time I go to the doctor I say I'm going to ask this, this and this, but I sometimes don't write them down and on the way home. I think “why didn't I ask that question?”

And most importantly, what you want to do is take someone with you if you can. Because we don't always hear what they say and we are processing it through not only how we are feeling physically, but also emotionally we are processing what we are hearing. And I know for me they would run another test trying to figure out this is what it is – I was going to get the answer the next time-- my expectations was this is the one that will explain what's wrong with me. The problem is I would go in and they would say that the test is negative and “I don't know where to go from here” or “You're just going to have to live with it.” But what I heard is “there is nothing wrong with you”, “it's all in your head, you're crazy” because that's what I was feeling. It must be my fault. Our expectation is that we somehow failed our health care provider.

This is one of the tools that we have right now, it's designed to help you communicate with your health care provider, and so they always ask you your pain score. What is your pain level, your stress level, your activity, your exercise, and sleep and on the back is appetite, mood, how isolated you have become, how much alcohol you consume and how worried you are about finances. Now we encourage health care providers to keep this out at the front desk - when you sign in, circle those. Just look at it, it doesn't take much time—you don't have to write anything out. Just look at them, circle them and you go in and give it to them and this is a wonderful communication tool. Because you're telling them “this is what's going on with me at a glance.”

Remember we want validation and to make them understand our pain which is never going to fully happen. One of the things that I was constantly trying to do was explaining how I felt to my health care provider. How can I make them understand how bad this pain is, the more I thought about it the more I suffered. I gave all of my attention to my pain and that's not always a good thing. So here is a way to

evaluate pain so you can use the precious 5 to 10 minutes with your doctor effectively, rather than what is the problem?

If you go to our website it's on the back of your handouts you'll see there's a section on it takes nerve. When you click that nerve man is going to come up and you are going to go down and click go to symptoms. When you run the cursor over his body it shows symptoms running up the entire body. You can print this and take it into your doctor and say this is where it hurts and this is how it feels. Again this tool is making the most out of the visit to your health care provider. This is on our website, it's free, you can just go in and do it anytime you want.

This is another tool that we have—what I really used to hate is when they would ask me to rate my pain on a scale of 1 to 10. Well I was in my late 20's early 30's and had two children and I was no longer able to take care of them, my husband, my house or anything and so if 10 was the worst pain in the world mine was a 20, but if you told them it was a 20 they would think you are nuts, right? So what we did is we decided that you needed really to measure your function, not your pain, because that's really where it's at. So if you have a 0 that means that you do not function at all, nothing -- you can't even get out of bed all the way up to a 10- where you can get out of bed, get dressed --do all normal activities, you can go plow the fields, milk the cows, whatever you need to do--fix the tractor that day -- you can do anything. And there is all of these in between, so when they ask you what's your pain level, and you use this scale, you can demonstrate what your pain level is because it shows what you are capable of doing. It's about our quality of life.

Medications. And this is something we all think this is what we need, just find the right pill. You get a headache; you take Tylenol, Advil or aspirin any of those things. You get an infection; they give you an antibiotic. There are all of these wonderful miracle drugs, so they should just be able to give you that pill, right? The problem is its only one of the tools, and even if you do have the right one, and again our expectations is if it's the right one you'll feel like you did before the pain. That's our expectation. However, if it's the right one it may reduce your pain a little bit, it may allow you to sleep at night, but it may not take it away 100% because it's only one of the many tools – it's not the whole ball of wax. I think that's what we expect. And every medication has its benefits and risk. And on the back table we have something we called the *Medication Supplement* that we put out every year and it talks about all of the medications because you really do need to know what they are and used for. We are currently turning that into a video format so you can hear people talk about questions they may have about medications and have experts answer them.

As I said before you have to make sure --people think that if it's over the counter it's safe, it's not, look, ask your pharmacist. You know, go to the same pharmacist for everything that way they're going to have a record, they're going to know of interactions --vitamins all of those, there can be issues. When we go to the doctor they give you a prescription and they tell you why they are giving it to you, what it's for, how to take it, and you say "thank you very much," and you don't want to ask questions because you don't want to look stupid. Now if you where that smart you would be the doctor, think about it.

Then you go to the pharmacy and the pharmacist may come out and tell you, you know this is a new prescription this is how you are supposed to take it. And you say thank you very much-there's a whole line of people there and it's like "I don't want them to hear this" "I don't want them to know what I'm taking," so you just sort of nod your head, say "yes, yes" and then you go home. And then you look at this bottle of pills and say "Now what did they tell me?", "How am I supposed to take this again?" I mean because they can only get so much information on that tiny little label.

So we designed this [*Pharmacist CARE Program form*] to better explain how to take their medications. Take it in the morning or take it at night, or what time of the day should you take it? Should you take it on a full or empty stomach? Possible things to avoid -- driving, alcohol, sun, dairy products and vitamins. And then, possible side effects -- drowsiness, blurred vision, dry mouth, or constipation. But this is something that if you pull it out you say "Ok I am supposed to take this in the morning on an empty stomach;" it's right there it's in a picture. On the back of the form are resources that are very helpful.

This is another program that we did called "In Case of an Emergency," our expectations if we go to the emergency department. We did a survey and work with the American college of emergency physicians and we did this whole survey about people with pain and their expectations about going to the emergency room and how that worked out for them. All of that information is on our web page. But we also designed this little booklet. And this one helps you to really understand what happens in a emergency department. And remember not all physicians want to treat people with pain and we found out there are a lot of people that call their health care provider and they are told to go to the emergency department. So you find yourself there. So you really do need to be prepared. You need to know what kind of questions to ask and how to give them the history that they need.

So here is a little form that can be found on our web page [*Just in Case form*]. And on the front side you want to list all of your basic information – insurance information, again list all of the medications that you're on. Keep this with your car keys. And then on the back when you get there, if you want you can begin to locate where the pains is, and draw that for them. So once you get in to see the ER people you can show them what happened and where it hurts. This gives you more time to think about it and be prepared, and what are your expectations and remember this is a one-time thing; this isn't your health care provider. A lot of people go in there thinking they are going to do more tests, x-rays and I will get an answer and that's usually what's not going to happen.

To live with pain you got to become part of the treatment plan. You can't be that passive patient because it's just not going to work. You have to take an active role in the process; you have to work with your doctor and set goals. More than anything else your goal is to reduce sense of suffering and improve quality of life. It may not be getting rid of the pain, but that doesn't mean you can't live with a certain level of pain.

Learning to Live with It

Penney Cowan: When all is said and done, or when they have done absolutely everything they can do for you, and you may still have some level of pain. That is hard for us to accept, but that may be the reality at that moment. When you are told to live with pain this is what I think it looks like [image displayed with large mathematical equation written on a chalkboard], and I have no idea what that is on the board, I am absolutely clueless. And if someone asked me to solve this before I could leave this room, I might as well just go to bed and realize I am going to be here the rest of my life. I could not do it, I don't even know where to begin and that's what it feels like when someone says learn to live with it. Who knows? However, if I took a few classes in algebra, geometry, trig, some differential equations and really worked at it-- I bet I could solve that problem. I have to take an active role and figure out how to do that. I need experts to tell me how to do algebra or whatever --and it's the same way with pain. Many coping skills for pain are universal regardless of the type of pain. These tool can apply to anything whether you have fibromyalgia, whether you have low back pain, whether you have postherpetic neuralgia—all of those; the coping skills are good for all of those. It depends on what your needs are, what tools you are going to pull out. So we are going to try to give you the beginning of the toolbox; for you to begin to look at--and it will just depend on what your needs are and where you begin.

Section 4: Step 1 Accept the Pain & Step 2 Get Involved

Penney Cowan: And we're going to talk about our ten steps from patient to person. And these were designed not like the typical twelve step programs; you don't need to do step one, step two, step three in that order. What you need to do though – the first two I think are really important. Because the first one is accepting the pain and that is by far the hardest thing. Because you know when I tell people the first step is accepting the pain they think we're saying "roads closed, you're done, it's all over." When in fact it's just a detour in your life, it's just a detour; it's not the end of the world. We just have to figure out how to get down that road. It means to educate yourself, to begin to understand it and for today— for today, this is the way that it is. That doesn't mean tomorrow is not going to be better or there is not going to be an answer for you tomorrow, but if we keep waiting and sitting there doing nothing then we're only going to get worse and worse and worse.

Now I have a little short video here of some of our members talking about accepting the pain...

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

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

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

Member 3 (in video): Educate yourself on whatever the particular pain is.

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

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

Member 6 (in video): Pain is inevitable, but misery is an option.

Member 7 (in video): It's a journey that we do together it's not about the destination. It's about the journey itself.

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

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

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

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

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

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

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

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

Penney Cowan: Getting involved, and we've been talking about that – being an active participant, doing what you can asking your doctor what can I do – “what else can I do?” Do a little more research, find out things. Go on the internet. Our website has a lot of links to useful sites. I mean there's a lot of stuff on the internet that's not good so be very careful about what you look at. If you don't have the internet and you want to get some information, call our office because we'll actually go through it and print out stuff for you and send it to you. Because information is critical for you --for you to understand -- remember it's the fear that is the controlling factor. So the more we educate ourselves and understand the process and our expectations then it may take away some of that stress that we are feeling about managing the pain.

Section 4: Step 3 Learn to Set Priorities

Penney Cowan: Setting priorities, that's a good coping skill for pain. And why is that good? Because the pain takes over our life we begin to put things off. We can't do this today, we can't do this today. So we start to build this little pile over here. And we put things over here that we can't get done; for the day, week, month and this little pile becomes bigger and bigger until we've got this mountain looking at us. And every time you stop to look or think about this stuff you become completely overwhelmed so what do you do, nothing. You don't know where to start it just too much and being able to recognize a priority gives you a starting point, but how do you do that? Here is a good way to begin to understand and recognize your priorities.

On the way home I want you to get about 300 of those little index cards and every time—carry about twenty of them or so with you at any time. And every time that you think about something that you put over here --that you put off, whether it is work related or even something that you enjoy doing and you didn't do it because you didn't feel good, everything that's on that pile write it down. It may take you a week, 3 weeks, or 3 months, but once you believe you have all of the items identified you want to get a really big table, you may even have to use the floor lay them all down face-up and just take a look at all of the stuff you have on those cards. My God how hard is that to carry all that around because it really has been on our shoulders the entire time. The mountain wasn't sitting there, it was sitting right here. That is just a huge amount to carry around and it keeps nagging at us. And then as you look at all this stuff and each card closely you ask yourself of all of this stuff right here right at this moment what is the most important thing to me? You pick up that card and you've now got your first priority.

And say maybe you know the next ten or fifteen things that might be important, you pick those up and you take them with you. The rest you all just stack. And they aren't going anywhere; you know what you have to do and it's all right there. And the reason they are on separate cards is so you can shift them, it is never etched in stone. You can shuffle priorities. You don't always have to worry that I have to get this done before I get this done, they are flexible. It's a wonderful way to help focus and narrow down your priorities to work within your limits.

Section 4 Step 4 Set Realistic Goals

Penney Cowan: Once you have your priorities you really need to start setting realistic goals for yourself. Remember I said that we tend to value ourselves by how much we accomplish in a day. People with pain tend to be overachievers, not me--most people. And so we push ourselves beyond our limits because we have to get all these things done. But let's be realistic you are setting yourself up for failure.

Remember we talked about the pain on good days, bad days and up and down? What do you do on a really good day when you are feeling ok? You go out and try to catch up on everything you possibly can in that one day, right? And then the next day what happens--you can't move-- or the day after that, because you have way overstepped your limits. You weren't realistic. You weren't staying within your limits. You weren't pacing yourself. You were trying to prove yourself and that's a problem. I know I can still do this, I know this, I have done it before.

So you have to be realistic about your goals you really need to narrow them down. So many of us think if you have a good day you can start running again. What you need to realize is that you need to start walking again, one step at a time. And what's wrong with setting one of your goals around something enjoyable? The next time you have a good day do something fun, you don't always have to be productive every second of the day. Or you can narrow those down until they are small manageable steps.

We had a woman in our groups, she had diabetic neuropathy so her fingers and feet were numb. It was hard for her to do some very basic stuff like buttoning your clothes, because when your hands are numb that's a problem. One of the things that she enjoyed more than anything else was baking for her family which was something she could no longer do because it took too much time on her feet, too much coordination with her hands that she couldn't do it. So her goal was to bake cookies. That whole month—that was it. Now for most people that don't have pain they would say that's silly, that shouldn't even be a goal. But every day she would try to do this and so she decided that would be her goal for this month. And so every week she would do something else, she would come back to the group and we would talk about it and see how she could possibly move forward. At one point she froze the dough, and by the end of the month she had baked those cookies by herself with no help from anyone. You would have thought that she climbed Mt. Everest—it was the best thing. And the whole group actually felt good about it because we helped her all the way by walking through with her, giving her that support and encouragement she needed. So think about it you must take it one step at a time and if you think you have a goal that's realistic you should then say "How can I break this one down?" Make it into small steps and be good to yourself. Don't be your own worst enemy.

Step 5: Know Your Basic Rights

Penney Cowan: Your basic rights, this is my favorite one. No one ever told me I had rights. No one ever told me that I have the right to make mistakes. The whole organization was built on mistakes and I can make mistakes. I can also do less than humanly possible imagine that. I don't have to be that --100% working all the time, I don't have to do that. I can do less than humanly possible and that's ok.

You have the right to ask for help.

You have the right to change your mind.

Just because you said you were going to do it doesn't mean you have to, you can change your mind you don't have to justify your behavior. So you don't have to explain why you did this or didn't do this. And what happens when we try to justify our behavior is we put ourselves back into that patient role because our pain becomes the excuse. But you can just say no and you don't have to justify your behavior and you're also allowed to say no and not feel guilty, other people do it, they say no and you are allowed to change your mind. You have the right to stop and think before you respond. Now in this fast paced world everyone wants answers now, but I say let me think about it and I will get back to you. That is really powerful. You have the right to be treated with dignity and respect and that also means by

your healthcare providers and if they aren't meeting your needs you can change your mind. Maybe think about getting someone else, even if they have been with your family forever, if they aren't meeting your needs you can change. Ask yourself who is paying who? You wouldn't take your car to a mechanic let him screw it all up and say thank you very much and go back there the next time—not saying your healthcare provider is messing it up—but if you aren't happy with the service you don't do it. You have the right to change your mind. You have the right to be treated with dignity and respect. All of these rights are on our website; print them out and look at them every day. They are very empowering and they really do help you feel like you're equal because we do start to feel like second class, third class citizens because of our pain – like we failed not only ourselves but the whole world.

Step6: Recognize Emotion

This is a hard one, so many people tell you it's all in your head, or you're just depressed. So it's pretty hard when it come to emotions and pain, it gets a little touchy. We get a little touchy about it. And I know when I went to the pain program, and I will tell you this right now, that for six years we looked, and looked and looked for an answer and there was no answer. And I just kept hearing “learn to live with it.” And I went to the Cleveland clinic and someone said to me I can teach you how to live with it, and my husband was just so happy. And I thought uh uh, I want to quit. After six years I don't want to do this anymore, I've done it and I am tired. But he wouldn't let me quit. I was so mad and I thought, ok I'm going to go and I will show you it isn't going to work.

So I went to the pain program not because I believed it was going to help me, but because I thought I was going to fail. I was going to prove it doesn't work. So all of this stuff I'm telling you I didn't believe any of it either because I was going to prove to him nothing is going to help me—I'm done, I'm a lost cause. Obviously that didn't happen –29 years later I'm here functioning as a person.

One of the things they did first when I went on to the program was they gave me this book called The Angry Book. It's still available today, The Angry Book by Theodore Rubin. And they said you have to read this book. And I'm thinking, alright I am here because I'm in pain and you are making me read a book about anger when I am not angry? I thought why would you ask me to read this book and what does it have to do with my pain? But I always did what I was told, so I read the book. It's a very easy book to read. I got it done that night – what else was there for me to do? And I'm reading this book, and as I read each chapter I realized “Oh my god that's me.” By the time I finished that book I felt horrible, I felt so bad that there was one thing that I remember from that book. At the end of the book he talked about your “slush fund” and I imagined that as a bucket. And every time you do not deal with an emotion you but a drop of water in your bucket. Anger is not all yelling and screaming, there are a lot of forms of anger. Every time you suppress a negative emotion you put it in the bucket and at some point what is going to happen? That last drop is going to overflow and that is what happens with our anger we keep putting it aside that those feeling become so strong we explode. Then we usually dump our bucket onto someone who is safe. And they are standing there going I just said one thing then they exploded on me, because they are dumping their bucket on you from how long? They have been carrying that bucket around for so long and think of how heavy that is; holding all of those emotions in. Do you know how much that takes? Have you ever carried a bucket of water around for a week? A full bucket? Try it it will

make you very tired and you do that when you carry your emotions. And you probably have never carried a positive emotion, only the negative ones; why do we do that? Feelings, we can't control them you are allowed to feel however you want; the only control you have is on your actions there are no wrong feelings. And so if you begin to tell people say you hurt my feelings go and express that, but somehow we wait until it gets this big and then express and that's inappropriate and that makes us look a little nuts because it's just going on and on.

I like to use this picture here. This man here suffers from pain and that's his wife. He is the type that has pain, but doesn't want help. He's just going to hold it all in, it's affecting her. If they would have just communicated or if he had just said this is really bothering me or this is how I am feeling, they could be a couple and work together and there wouldn't be this massive wall in between the two of them. The problem is if you don't start communicating and recognizing feelings that gap gets bigger and bigger so your feelings play a very important role. They say it's all in your head but it's in my body too and you can't separate them, your mind and the body are connected they come as a packaged deal. What we feel emotionally has effect on us physically, and what we feel physically has an effect on us emotionally. It is a packaged deal, depression is part of pain.

Step 7: Learn to Relax

Penney Cowan: Learn to Relax. Just relax right? Now if we could go to this wonderful south sea island somewhere or we could go lay on the nice warm sandy beach listen to those waves crash against the shore here the rustle of wind through the palm trees, we might feel a little bit better right? But that is not possible.

What I want everyone to do right now is count from one to twenty-five and at exactly the same time say your alphabet. You can't do it can you? You know why; because you have a one track mind. So say you are lying on this little sandy beach. Imagine to yourself the warm and silky sand going through your fingers, curl your toes in hear the birds above. While you are thinking about that for a few moments you aren't thinking "Oh my back is killing me." Doesn't mean the pain is not there, but what it means is you've reduced your sense of suffering. When I was at the pain program I took sessions called bio-feedback and they hook you up to a monitor and read some text to you and your supposed to turn the pain off. I really wanted to do that and I tried so hard. There's a wonderful voice reading this relaxation text and the more he read the more tense I got because I was trying so hard to relax. So it went up more. I failed terribly. However what he did for me was record the sessions and he gave me the tapes. He said when you go home practice them and so I did. And I listened to them and there was a point several months or years ago, but I no longer needed the tapes anymore. So when you are out there working and your body goes ouch! What do you do? You keep pushing on, I can do one more. We don't listen to what our body is telling us, we don't listen until it screams. If we would just listen to our body when it says "Ouch" and take a couple minutes doing some form of a relaxation skill, get it under control it will not go to the next level. We are pushers, over-achievers, we our own worst enemy. So listen to what it is telling you, so when it says ouch slow down and give it five minutes. What I am going to do

now is play a little video on our web site, it's a 5 minute relaxation text. This is going to give you an example of what some of our relaxation tapes are like. So what I want from you is to get comfortable and relax. Ready, here we go.

Narrator (in video): Close your eyes gently, settle down comfortably. Begin by breathing out first; then breathe in easily just as much as you need. Now breathe out slowly with a slight sigh, and as you breathe out feel the tension begin to drain away. Then go back to your ordinary breathing; even, quiet and steady.

Now direct your thoughts to each part of your body; to your muscles and joints. Think first about your left foot. Your toes are relaxed and still. Your foot is resting easily on the floor. Now your right foot, toes, ankles.

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

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

Let your face relax. Let the expression come off it. Make sure that your teeth are not held tightly together and let your jaw rest in its relaxed position. Your cheeks are soft because there is no need to keep up an expression. Your lips are soft and hardly touching. Relax your forehead so it feels a little wider and a little higher than before.

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

Stay like this listening to your breathing for a moment.

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

Penney Cowan: That gives you a little idea of what it is like to go through a relaxation test/ exercise. What it does is make you aware of your body, the different parts the little signals. Ask yourself are you holding your hands together real tight? Are you clenching your teeth? These are signs or pretty good indications that you are stressed and what happens when you are stressed? Muscles are going to hurt more, remember pain is not always just in the body it's in the head too. So when you are stressed it is going to increase your pain levels. You have to tell your body how you want to feel but we have to pay attention to what our body is telling us, we can't push day in day out. So if you are out there working what is wrong with taking a couple minutes and collecting yourself they say. I personally like the breathe relaxation ones, those are the ones that I can do best. Imagining my breath as a substance and as you

breathe in that air what color is it, what does it look like? And as it goes down into your lungs how does it look as it fills up your lungs, does it change color or texture? Hold it there and you can feel how tense your lungs get and then as you breathe out you know, is it a different color or is it a substance. Just things like that but then again this is a learned skill which means you have to practice this and you may practice and find yourself getting a little tense at first but it's because we tried too hard. But with time you can begin to listen to your body and then tell it how you want it to feel. No matter what you are doing, even out there in the fields, in the barn, you can still take a couple minutes listen to your body and tell it how you want to feel.

Step 8: Exercise

Penney Cowan: Exercise. That is really a hard one. When I would exercise, it would really hurt. So I eventually got to the point where I didn't do anything for six years. I hurt so bad that holding a cup of coffee was difficult for me. That is how de-conditioned I became. I was completely nonfunctional, which is not me at all. But when we do something and it hurts, we think that our body is telling us that we should not do that anymore, right? Well that is not necessarily true. And so what you need to do is talk with your health care provider. See what your limits are because sometimes it is like sitting around all winter long. The snow and the cold, the first time you go out there and really become physical it really hurts doesn't it? So imagine someone with pain who eliminates all of the physical activities, and soon you aren't doing much. Then you have one of those good days and you go out there and you do everything. What happens? You are going to hurt. You are going to hurt because you over achieved, but you are also going to hurt because your body was not used to it, it had become de-conditioned.

A really sad fact is that for every day that you spend in bed, 24 hours, it is going to take you two weeks to get back where you were. That is really depressing. Two weeks is a long time to get back one day. So the more inactive we are, the more likely it is when we do become active again that our pain is going to start hurting.

Another problem is that it doesn't seem like we are making progress, because we did this or that and it hurt. And day after day we are in constant pain. Often we do not realize that actually we can do something more than we could before. But we do not see that, because as long as the pain is still there, we figure that we still have not made any progress. This is why it is so important to journal. And this is a good thing to journal on; your exercise and your activity level. You can use those pain logs. We have them in a 31 page spiral bound binder that you can easily journal every day on to know exactly how you are doing. It is sort of like trying to watch your hair grow. We know it grows because we have to get it cut, and yet if we stand in front of mirror and watched it, we would be there for a long time; for a very long time. And we wouldn't see anything happen, would we? Because it is so slow. And that is how it is for people with pain. We may take five steps forward and then fall back three so we think "that's it" and "I can't do it," and so we are done. And we become so de-conditioned, it becomes hard for us. So I went to the clinic again and they were like "ah, you have to exercise." So they sent me to physical therapy, but it was not your typical physical therapy. I had to do stretching exercises, and then go to sports medicine and lift weights. I mean, I could not even hold a cup of coffee, just think about it. And my pain got a whole lot worse before it got better. And there was a point about three and a half weeks

into the program that I was walking up to physical therapy, and if you know anything about the Cleveland clinic it is about three blocks large and so when you walk from one place to another it is a long walk, and I kept thinking to myself that I could not do it. It was a bad day for me, and I did what I had to do, going through all of my stretches and then I realized that I felt better. I actually felt better because I stretched. It was an amazing thing for me. And to this day I do not like to exercise, I will be the first one to admit it, but it is a very small price to pay for being able to function. Like I said though, we are overachievers. And mine was an isolated situation because I was at a clinic. I decided to do what I was told, and so when I was told to do them all, I did them all.

When people are told to do an exercise program they are overachievers. We have illustrated exercise positions in our work book, but we always say to get your doctor approval first. We have no idea what your abilities are. So once you get your doctors approval and he approves three of the eighteen exercises we'll say, and we go home and decide since we can do three we can do them all. So we do them all and the next day when we get up, we hurt so we no longer want to do them. You say to yourself "I couldn't do that, I knew it!"

Remember when we talked about goals and narrowing it down to manageable steps. That is what we need to do. Let's say that one of the exercises that the doctors approved for you was a leg lift, so what you are going to do is say "okay, let's do some leg lifts." So before you get out of bed in the morning when you wake up, you do one leg lift. You do not have to lift it up real high, just till you feel it. That's it, you have exercised for the day. Go ahead and get up. You haven't hurt yourself and you certainly have not overstepped your limits. The next morning you are going to do the same thing. You are going to lift it up, that is it. Get out of bed... The next week, you do two and the next week you do three. It sounds silly, but it is one small step at a time.

I think that we all want to start out running. We want our lives back. We want to be like we were before the pain. Well I am 30 years older than I was; I am never going to be exactly like I was before the pain. We are older and we change. But by pacing yourself and doing it very slowly and very gradually, pretty soon you are at another exercise and you are doing a whole series of exercises. But again, our expectation of ourselves is that "if they say I can do it, then I should be able to do it," right? We do not know how to pace ourselves. I was actually born and raised in Pittsburgh Pennsylvania, and I live in California now. And on New Year's Day, when it was very cold in Pennsylvania, people would go to the river's edge and they would jump in. That water was so cold. They just jumped right in without thinking about anything else. They are called the Polar Bears. That is exactly what I do not want you to be when you start and exercise program. You cannot just jump in and freeze. No, you have to put your little toe in first. Be realistic. Pace yourself. Do not try to do everything all at once. Don't be a Polar Bear. And think about it this way. Any movement at all is exercise; any body motion. Sitting still and doing nothing at all is the problem, and that is what we do because of the fear.

Step 9: See the Total Picture

Penney Cowan: Total picture. It is not about one thing. It is about all of those things that we just talked about. It is about encompassing everything that involves your family, your friends, your whole life. But

more importantly, all we think about when we have a pain problem and the pain takes over our lives is what we can't do anymore. We can't do it anymore, and so we focus on "I can't". There is another side of that. We have these abilities that we forget about. You heard those folks talking about how they had more power than they ever did even though they were less able. Maybe attitude has a lot to do with how we manage our pain. Is the glass half empty or is the glass half full? Can we really do this? I believe that we can.

I believe that there is a way that you can move from patient back to person again and to redefine yourself. But we have to begin to focus on, what we still have, not what we don't. That is depressing. Let's focus on what we can still do; on our abilities. I am going to show you another little video with our members again talking about just this.

Speaker 1 (in video): The significant part of being involved in your recovery is being involved with your peers.

Speaker 2 (in video): Once I joined the ACPA and the support groups the knowledge just flowed.

Speaker 3 (in video): Someone is always bringing something in to say "I found this book" or "I read this book", and we pass it around.

Speaker 4 (in video): Everybody who has pain can give something to somebody else. It could be just, "Oh I took that and it had side effects to keep an eye out," or "I tried doing this and that and it worked out real well".

Speaker 5 (in video): When I first started going through the program I just thought, "no way, this isn't going to help, this isn't going work." And then after a couple weeks, I started seeing the benefits of it.

Speaker 4 (in video): It is lonely when you have chronic pain.

Speaker 3 (in video): The first time I walked into a room with other people who lived with chronic pain... what a validation that was for me. I realized that I was not the only person in the world that lives with this.

Speaker 4 (in video): To tell you the truth, I never would have survived all this without my pain group.

Speaker 6 (in video): It is just this kind of reinforcement that you are not alone, that there are other people out there who have been through the same thing.

Speaker 2 (in video): The support group and the ACPA members have been my lifeline.

Speaker 4 (in video): You need them!

Step 10: Reach Out

Penney Cowan: Now we get to our tenth step and that's really where I started was the outreach-- to reach out to other people. Remember I said I went to the pain program, what amazed me is the whole six years I was going through all of my pain programs I really thought I was the only person in the world that had this problem and no one understood it. But then I went to the Cleveland Clinic in the pain program and there were other people there that had pain. I wasn't the only one and that totally amazed me and I needed to let other people know "you're not alone, there's someone else out there who gets it and I get it."

Also what they had taught me there was too good to keep to myself. I thought you know this is just really good because I was able to make that transition from that patient back to a functional person again. This was really good and I knew I wasn't alone because there were some other people – there had to be someone else out there. But most importantly I was scared to death when I left the program because I thought in this controlled environment – I mean I was there it was an in-patient program which is unheard of today, but 29 years ago they were available -- and for the very first time in my life I focused on me. I had never done that in my life. And so in that controlled environment without having to take care of the kids and do all of the other stuff that you do, I could live with this pain. But what was going to happen when I got home? And it's what I learned here that lasts, because how many times did you do something and it worked for a little bit but then it didn't work anymore. So I was scared to death that maybe this wasn't going to work. So I knew I needed to keep up and do what I had learned at the clinic; all of these things that I had learned about and a lot of things I have learned since. So the best way to do that is to talk about it with other people, but I needed to talk about it with my peers – people who got it. And that's how the ACPA was born because it was really partly out of my fear of me trying to maintain my wellness and keep well.

Section 5: Getting Started

Penney Cowan: This is how I like to explain a person with pain. Now a functioning person is a car, and it has all the tires and off it goes. However, if you are a person with pain, you have four flat tires. You're not going anywhere, that's what it feels like, you are just stuck right there. And so say you get the right medication, it's going to fill up one of your tires. But you still have three flat tires. It's not that one single thing... it's not. It depends on what else you need to fill up those tires. What do you need? And for everyone on of us it is different. Things that I have talked about, things that I haven't even talked about yet, it depends. Talk to your health care provider and find out what is available to you and see if you can fill up all four of your tires. It may be something like physical therapy. It may be acupuncture, it may be some kind of injection, it may be a vacation, who knows? You need to find out what you need. And then when you get all four of your tires filled you can go, but remember you still have to maintain that car. You are responsible for keeping it running. You take your car back to the mechanic to get an oil change or whatever it needs, but on a day to day basis you are the one responsible to keep it safe and running.

These are some of the manuals that I was talking about. This is the family manual. And the nice thing about this is throughout the manual there is actual text from the interviews I did with the family members and I know when people read it they are thinking "I could have said that, that's just exactly how I felt." Patient to person first steps and then staying well, which is an advanced pain management skill. Support groups can be really helpful, they really can. Knowing that you are not alone... The interesting thing about our mission is that we are here to help people with pain make that transition from patient to person. But the whole idea of this organization wasn't to go and literally be all over the world. It was to find someone that I knew was out there, that I knew was sitting there, that was so isolated and so alone that they believed that there was not going to be a tomorrow, or didn't want tomorrow to come. I know how that feels; I know how overwhelming pain can be. And I knew that if I could just touch them, and just talk to them that first of all just let them know that they are not alone.

That is why these groups are so important. You need to know that you are not alone and that someone else gets it. And you can, with their support, and effort on your part begin to make that transition. So we have support groups, all you have to do is call our office. I know we have a number of them here in Pennsylvania. We do answer our phones. Call our office. The phone will be at the end. We have a facilitator guy that talks people through step by step how to start a group. So if there is not one where you live, we will actually work with you. We have a facilitator coordinator named Tiffany. She even writes special newsletters for our facilitators to help them start groups, to provide new information, to talk about issues that may come up in groups.

We have been doing it all for 29 years now. All of those manuals that I have talked about except for the "staying well" are also available in French and Spanish as well. Our webpage is www.theacpa.org. You will find relaxation techniques, exercises and also what to do in case of emergency. There is also another section there now for fibromyalgia. We started a new campaign, and there is a lot of information back on table about that. Our website is pretty active. We get usually on a slow month 700,000 hits. On busier months we get over 2,000,000 hits. People stay on the site for an average of 13 minutes. There is so much information on there. If you do not have access to the internet, call us. Because we can get some of that information for you. We will print it off and we will send it to you. The ACPA is just about people helping people. That is it. We do not have all the answers, we do not have a cure. There is no magic. It is about helping you take an active role in moving from that patient back to a person again. The number to contact us is 1-800-533-3231. Feel free to call it. Like I said we really do answer our phone. Keep in mind that we are in California, and if you call at about 9:00 in the morning, it is only 6:00 A.M. there. People will sometimes call us and will get a little cranky because we are not answering the phone. We don't answer at 6:00 A.M. but we do return phone calls. So if you call and we are not there, leave a message and we will call you back.

Question's & Answer's

Penney Cowan: And now I think we will have some time for some questions, anyone have a question?

Audience Member 1: I'm asking how you finance and how we can help you with the finances.

Penney Cowan: We've always worked on donations for many many years we didn't have a real office, but we have done a lot of work. Right now we do a lot educational campaigns like the ones I talked about It takes nerves, the emergency room department all of those programs we do get funding from pharmaceutical companies that's who we get a lot of it because people with pain don't have a lot of money if we look to them for support because a lot of our materials we donate I mean it's not about how you can afford it's about the commitment you making to yourself so donations are absolutely welcome anyone can do it but it's actually never been about money, many of us work really cheap.

Audience Member 2: The question was how do you find a support group?

Penney Cowan: How do you find a support group in your area and the answer is call our office, if there's not one available--what part of that country do you live in? That would be around the Pittsburgh area right? We have a regional director there, yes we have groups. Call the office, we always list them on our Web page it will say - find a group, when you click on that, put in your state and it will list all of them because all of our facilitators are people with pain. We don't put their address phone number or anything on there, call our office at the eight hundred number and we'll give you their contact information, but we don't list how to contact on the website. We are very protective, people with pain are so desperate that they will do anything and that's why she said the non branding campaigns we don't endorse or advertise anything because that's between you and your healthcare provider. You know what's best for you. We can't possibly know.

Audience Member 3: I had a question about complimentary therapies and what kinds of information you have on the Web Slater what kind of information can provide about complimentary therapies.

Penney Cowan: There is there's actually we will cover that in our newsletters we have a lot of different articles we have it to called basic *ACPA Chronicle*, it's actually online now so we will talk about those weather it's a focus on acupuncture or a massage therapy, but we do talk about those in part of what we doing on are Medicaid. *Consumer's Guide to Pain Medication and Treatment*, we changed the name on it so I'm always stumbling on it. We are going to address some of those different kinds of therapies as well, but again, you know what you need now is you have to talk to your health care provider what might be best for you. For some people acupuncture is very helpful others don't. Any kinds of supplements, herbals I think you really need to talk to your Dr. before you try any of those.

Audience Member 4: The other question I had is the aging in place are you doing anything with? That is the aging in place movement.

Penney Cowan: We don't do a lot of that right now we did do it two years ago the International Association for the Study of pain their focus was on the older adult, so we did a whole toolkit for older adults with pain which is on our Web site and it talks about all of that. We are really involved in another a number of other committees that are really beginning to look at that I know that there is a book that someone just asked me to point out were actually in its association for the study of pain about older adults in pain. I know there's information in that and we will be putting all of that information on our Web site.

Audience Member 5: Why were you diagnosed with so much pain?

Penney Cowan: You know things happen it was after I had my second child then I will tell you I have fibromyalgia and they didn't even know what that was then. Then six years down the road they said ahah --fibrositis. But what's really interesting is that children also have a lot of pain problems we have a whole program called growing pains and that's for kids with pain. If you think about it, remember I talk about we give the wrong messages get up shake it off a more telling that a lot of our children are more and more are active in sports and athletic events and they're getting injured but they're not paying attention to their body and an expectation as to not shake it off keep going well you know we need to help these kids understand how to manage their pain to their issues are so different you know because they have peer pressure they have to do with parents and siblings so we have a whole interactive module that were waiting to get funding on for kids in pain.

Audience Member 6: I think one of the most on frustrating things is when you're in pain and your kind of being treated like hypochondriac I had migrating joint pain and it went on for seven weeks and I was to the point where I was ready to give up until I start coughing blood and they found out that I had a very serious heart condition and I would've died but for those seven weeks it was like "Oh I'm not going back to the doctor again I just can't even."

Penney Cowan: You know that sort of like, and I can remember saying this is that the last one I can and do it anymore but if they dangle that carrot in front of you and think OK maybe there's another task, then you are willing to do it or see another doctor again desperation it really is about desperation and not every physician, medicines become so specialized know that that because you're going to this position doesn't mean they know about all the other things down the road so that's why they do make those referrals but it is emotionally draining for us to go from that one to the other there really is but if you if you have pain it's real all you have a right to have it treated and don't give up don't give up. Believe your pain it's not it is in your head that it's in your body and it's going affect you so you continue to look and get good medical care.