

About Health TV with Jeanne Blake
Chronic Pain
www.abouthhealth.com

JEANNE BLAKE: Welcome to *About Health TV*. I'm Jeanne Blake. Nearly 50 million Americans live with chronic pain, and another 25 million Americans every year suffer from acute pain due to injury or surgery. On this edition of *About Health TV* we'll talk about pain and what you or someone you love who is living with pain can do about it. We're joined for our discussion by Sue Gold. Sue, thanks for coming back; you were with us on a previous occasion for an interview.

SUE: It's good to be here, thank you.

JEANNE BLAKE: So you live with chronic pain, which by the way, technically, is pain that one lives with for over a month. Tell us how you experience pain and how it's related to your rheumatoid arthritis.

SUE: I first started experiencing pain about 11 years ago. It became so severe that I could barely get out of bed in the morning. Both my knees swelled up, I couldn't turn my hands, the pain consumed me at some point. I was able to work, but that's all I could do.

JEANNE BLAKE: Now, how soon after the onset of the pain did you get it diagnosed as rheumatoid arthritis?

SUE: A year and a half.

JEANNE BLAKE: It took that long?

SUE: Almost two years.

JEANNE BLAKE: I'm so surprised. I can't believe that a doctor wouldn't recognize what it was.

SUE: My doctor told me that I was getting older. I was 40 and I complained about pain in my shoulder, and he said he had difficulty when he went to play ball with his boys. He had pain in his shoulder after that too. What he didn't realize and -- probably to be fair I didn't tell him -- was that I wouldn't even be able to get to the ball field at that point. I don't want to disparage my doctor, because

he was a good doctor, he is a good doctor, but a lot of doctors are not schooled in chronic pain, and patients aren't schooled in how to convey chronic pain.

JEANNE BLAKE: Help me be clear about this rheumatoid arthritis part of this. I mean, once rheumatoid arthritis is treated with medicine, doesn't that diminish some of that pain? I guess I don't know a lot about rheumatoid arthritis.

SUE: In many cases, that is true, and that has happened to me, fortunately. There are medications that can help keep the swell or inflammation under control. Unfortunately for me, by the time I was diagnosed the disease had destroyed most of the cartilage in many of my joints, and I did have to have a shoulder replacement, and I'll probably have knee replacements at some point.

JEANNE BLAKE: Pain impacts every part of one's life. How would you describe what it's like to live every day of your life with pain, for those of us who can't even begin to imagine.

SUE: It's like having an elephant in the living room. You try to push it away, you try to ignore it, but it's always there. For some people with chronic pain, they have pain constantly, 24 hours a day. For me, I have it off and on, so I do have some good days. But when I realized how much it overcame my life, when I finally had medication and I was feeling better, I was able to go outside at night to go to a function with my husband and I looked up and I saw the stars and I realized I had not seen the stars for nine months because I was not able to go any place for nine months outside of my bed.

JEANNE BLAKE: It's hard to imagine, because you can't tell by looking at someone. Certainly if I didn't know you were in pain, there is absolutely no indication that you have anything that you're dealing with at all. I read a survey that one out of three people who live in Maryland have reported living with pain. Well, that's a huge number of people. If you extrapolate from that on a national level, there is a whole lot of pain going on here.

SUE: Yes.

JEANNE BLAKE: And that's one of the myths, too, is that you look fine so you must be fine.

SUE: That is. Many people in my support group would really like to have a big "P" stamped on their forehead for pain so that people know they're in pain.

JEANNE BLAKE: Why?

SUE: Because people don't understand. It's similar to a little boy who's big for his age and people expect him to behave as an older child. When you're in pain, there's certain things you can't do. You can't make commitments to go someplace, because you might not be able to even get out of bed that particular day. You might not be able to take on another assignment at work. You might not be able to vacuum the house. But if you look fine, people think you're a malingerer or they blame you for not doing these extra things that you can't do because of pain.

JEANNE BLAKE: So the physical part of it is just half of it. The emotional aspect of living with pain sounds overwhelming.

SUE: It can be, especially if you don't have anyone who knows what it's like to be in pain. As much as family members and friends want to understand, if they haven't had chronic pain, they really can't understand. I certainly didn't before I experienced it myself.

JEANNE BLAKE: That must be the value ... I will say, and I've spoken about this before on this program ... a little over a year ago I suffered from acute lower back pain and it lasted about two weeks, and I remember thinking every day – and the pain medication didn't work, nothing worked – and I remember thinking at the time of people who live with pain every day and wondering how they managed to do it. It was the closest that I've ever come to having pain, and it was 24 hours a day and I couldn't sleep. I remember stopping about a block from the TV station one day and the tears just rolled down my face. I couldn't keep walking. I had to sit down on the ground. So I've had that tiny little experience and I have enormous respect for people like you, Sue, who live with such dignity with such an overwhelming challenge. I think it's incredible. The support group is something you decided to start because of needing support and someone to talk to yourself, or was it by then you had found out the value of being able to talk with people and that you wanted to share that?

SUE: Actually, it was much more selfish. I very much needed to have people understand. I was finding that I was becoming very angry because people didn't understand. One example was, a friend stopped and asked me how I was doing, and she seemed genuinely concerned, so I did explain to her about my condition and that I had chronic pain. And then later that week she called and said she had some extra tickets for downhill skiing and asked if I'd like to go. And I had just finished talking with her about not being able to even get out of bed because my knees were so painful.

JEANNE BLAKE: Why do you think that is?

SUE: I think people like to deny it, and they think if someone looks healthy and lives a healthy lifestyle, that if they can be in chronic pain, then that person could be in chronic pain too and they don't want to acknowledge that. And so I think that part of it's fear, is that if they think ... another example is when I told another friend, she asked if I had rheumatoid arthritis because I didn't exercise enough. She felt, I think, that if she exercised then she wouldn't get it.

JEANNE BLAKE: Do you think the woman with the ski tickets was thinking it was an emotional issue for you and that maybe if she could get you out skiing it would go away?

SUE: Maybe, maybe, that's a possibility. I don't know.

JEANNE BLAKE: Have you made a decision to not share the information about being in pain with as many people because of how people react to it?

SUE: Oh yes, yes. And at first I tried to force it on friends, because I had to have somebody to talk with, and that's why I decided to get the pain group started. Now that I have all the wonderful network of people who very much understand, I rarely talk about chronic pain with my friends outside of the group, and that's fine. I can do friend stuff with them and it makes it much more pleasant.

JEANNE BLAKE: How did you get the support group going?

SUE: I started it in my church. They provided the space. I sent out press releases. I sent notices to doctors' offices and different healthcare professionals I thought might be interested in referring people, and word of mouth, and put up some flyers in grocery stores and pharmacies.

JEANNE BLAKE: And what was the response? Huge response? Were you surprised by the response?

SUE: It was slow at first. But it's been steady and at almost every meeting – we meet twice a month – and at almost every meeting we have someone new. We have people come and go as they need the group. And inevitably when they come, they're amazed at how many people are there. It's a very mixed group. We have rich and poor, we have older and younger, we've had people in their early 20s and we've had people in their late 70s.

JEANNE BLAKE: And you all certainly share a common bond.

SUE: We certainly do. Men and women too.

JEANNE BLAKE: What do you think the benefit – maybe you can share an example of what somebody has said – that the group has provided for them?

SUE: Well, it's helped them to change their attitude about their life. We really stress acceptance. Chronic pain is not going to go away in most cases. Many people are going to have to live with it for the rest of their lives. There are treatments that you can seek that may help alleviate it, but if they can accept it then they can deal with it. And I've had people ... I had one young woman come who had RSD, which is reflex sympathetic dystrophy, it affects the nerves, and it's called the suicide disease because it's so painful, it's constant burning, searing pain. This young woman came to us and was in total denial. She said she was not going to be in pain for the rest of her life. She was not going to live like that. And through the group she was able to finally begin to accept that she was going to have to be in pain, but she didn't have to be a victim of pain. And she eventually went to a pain management program in Washington state, and today she holds a full-time job with the American Cancer Society. She is a fantastic advocate and just a wonderful friend.

JEANNE BLAKE: What does that mean, that you may live with pain but you don't have to be a victim to it? Give me an example of how someone becomes a victim to their pain.

SUE: Well, I have a couple of people who are kind of stuck and haven't been able to accept pain. They constantly spend their time looking, waiting for a cure, and not dealing with life as it goes by. In fact, I just wrote an article about the fact that you can live a good life without good health. You can still do many things. We have many of our people who can't work, but they volunteer, and they do it on the basis that they come on days when they feel well or feel better and are able to cope. But there are other people who aren't willing to accept that they're going to be in pain, so they spend their entire time looking for a cure and waiting until they get that cure.

JEANNE BLAKE: To live.

SUE: And so they're postponing their life. And this is the only life that I know that we have right now.

JEANNE BLAKE: I understand what you're saying. Having someone that you are in partnership with, whether it's a spouse or a partner or a good friend, is incredibly important, and it is in essence ... pain becomes a family disease, because everyone around you becomes affected by it or impacted by it. You have a husband. Tell me, how does he do?

SUE: He's fabulous. I'm very fortunate. When I first developed these symptoms, I managed to go to work but I couldn't do anything else, and eventually I had to move my office to my house, because there were days when I couldn't open my office door. But I was able to continue working because he did everything else. He did all the housework, he supervised our teenage sons, he walked the dog, he did the home repair, he did everything. And it was very difficult. It's always difficult if you have to do everything. And we had some negotiation, especially as I went through treatment, we had to do some negotiation as I got a little better. I could take on things, but he wasn't quite ready to let me do that. So we had to really improve our communication.

JEANNE BLAKE: I would imagine so. It would really test and put right under a microscope every little flaw in a relationship wouldn't it?

SUE: It does. It's very difficult, and several of our members in our pain group have gone through divorce because the relationship couldn't handle the chronic pain.

JEANNE BLAKE: Your website has got a lot of information on it. I just want to talk a little bit about what's available there for folks who would want to access that, and I'll remind you of that at the end of the program. But you have a newsletter that you have available online. It's called Connections. But you also will mail it out to somebody who isn't Internet savvy.

SUE: We can put you on our mailing list.

JEANNE BLAKE: And what kinds of topics do you cover in the Connections newsletter?

SUE: It's somewhat for our group members to let them know what our schedule is, but I also talk about things like living a good life when you have poor health, learning how to help your loved ones cope with the disease. We've dealt with how to communicate with your doctor, being an advocate for yourself.

JEANNE BLAKE: How challenging is it to find the right topic? I mean, that's something we talk about on this program regardless of what the issue is, but I imagine that if pain is something that can't be tested or measured, I can just imagine how challenging that would be to find someone who one, believed you, and two, would continue to work with you, because a physician wants to see progress. He wants to know that he or she is making you better.

SUE: And we don't necessarily get better. We cope with things better. We encourage people to talk with their doctors. We encourage people to keep a record of their pain and try to put down as many words to describe their pain as possible: searing, burning, whatever metaphors they can use to describe it. Cover a whole day – I got up in the morning and my pain was at a number 10. We tell them to rate it from 1 to 10. I took three aspirin, or whatever, and it was down to number 6.

JEANNE BLAKE: And that does what to the doctor?

SUE: It gives it a little more validity and it gives him a little more guideline of what you're doing and how you're dealing with it and what the magnitude of the pain is. We've had some progress. JCAHO, which is the organization that accredits hospitals and other healthcare facilities, has just included pain as one of the vital signs. So when you go to a hospital now, they have to check on your level of pain. So that is giving it more status and helps give professionals more information.

JEANNE BLAKE: On your website you list the ten chronic pain myths and reality checks ... aren't they on your website?

SUE: I will put them on.

JEANNE BLAKE: Okay, I think you should. But you sent these to me and I was grateful for that. I thought maybe, just in the remaining moments that we have, we would just go through them and you can address each one of them. Some of these I think that we've actually gone through. Myth #1 is, you're looking wonderful, you must be feeling fine now.

SUE: For many of us, we look best when we're feeling worst, because we try to make ourselves look better so we'll try to feel a little bit better. I learned long ago that I try not to respond to people who can't be aware of my pain, so I just say thanks and move on.

JEANNE BLAKE: Well, that's smart. That's actually a very good idea, because you can't convince them or help them understand, and I would think it would just lead to frustration. And then you go to your support group and talk about these people.

SUE: I do.

JEANNE BLAKE: I can only imagine.

SUE: Fodder for our conversations.

JEANNE BLAKE: Myth #2 is one that I brought up. You're depressed, so just talk yourself out of it.

SUE: Chronic pain is less stress or depression. It changes the brain chemistry and almost everybody who has chronic pain at some point will have some kind of depression. That needs to be treated. It's not something you can talk yourself out of. You need to have medical care.

JEANNE BLAKE: Okay. The third myth, Sue. You were able to do that yesterday, why can't you do it today?

SUE: That one's a very difficult one, especially for family members, because you might do something with your friends one day and they'll see you being very active, and the next day you say you can't wash the dishes. It's not necessarily a dodge. You have to make choices on how you spend your time, because every day is not going to be a good day.

JEANNE BLAKE: Myth #4, it's all in your head – just put mind over matter and you'll be fine. After you punch them in their face, you say what?

SUE: Well, mind over matter. Attitude does mean a lot. We do have a saying. It says pain is inevitable, misery is optional. And you can adjust your attitude, but in many cases you can't relieve your pain. You just don't have the ability to do that. You need to seek medical treatment to get as much relief as you can.

JEANNE BLAKE: Myth #5. This is one that your alleged friend said. You don't exercise enough and that's why you're in pain. Is that something that people hear a lot?

SUE: I think so. It is part of the “blame the victim” mentality, I think. As I mentioned before, I think people are fearful that if their friend got this then maybe they could get it too, and so they want to have some reason for your pain. Exercise is certainly very valuable for people with chronic pain, but you have to modify it to suit you. They used to say No pain, no gain. Well, that’s not true for people with chronic pain. You want to do it so it doesn’t give you more pain.

JEANNE BLAKE: Oh brother, this one. When my friend Liz had metastatic cancer, she used to have people come knocking on her door bringing her deer antler powder, she never had deer antler powder – that would have been snake venom and all kinds of treatments – and it really was frustrating for someone living with cancer, and so I can imagine it’s really no different for someone living with chronic pain when someone says, Just take this and you’ll be fine.

SUE: I sure get things from my aunt and from other people. I know they’re coming from a place where they care about me, so I try to use that when I respond to them. I say thank you for caring about me, but I’m an expert on this disease, I’ve had this disease for 10 years now, my doctor’s an expert at it, and if there’s going to be some help for me, it’s going to come through that route. I certainly use and encourage people to look into alternative treatments like massage and other things like that, but I always tell them they need to clear it with their doctor first.

JEANNE BLAKE: That’s good advice. Myth #8, you don’t look handicapped.

SUE: We’ve had people with handicapped plates in our group who have actually been yelled at by healthy people who tell them they shouldn’t be parking in that space because someone else might need it more. We have one woman who has a problem with her neck and her arm and she can’t carry anything. She can walk fine, so when she gets out of the car she looks okay, but she has to use a handicapped plate because she can’t carry anything for very long. People need to understand that you don’t always know someone’s story.

JEANNE BLAKE: This whole conversation is annoying. On top of living with pain, you have to be incredibly patient.

SUE: You do. Maybe that “P” on your forehead would be for patience as well as for pain.

JEANNE BLAKE: I think that’s right, Sue. I think that’s right. Myth #9, you don’t need all that pain medication, just be tough.

SUE: You know, the bias against narcotics runs throughout our society. And even some people who are in pain don't take the medication they need because they're fearful of getting addicted. Fewer than 1% of people with chronic pain ever have any kind of addictive behavior, and it can help many people to alleviate their pain and let them live a good quality of life. There are other medications as well, not just narcotics.

JEANNE BLAKE: And that feeds right into Myth #10, you must be addicted to pain medication. And I guess the answer is the same.

SUE: Yes. We do advise people not to share with other people who are taking narcotics, because there has been such bad publicity about them, especially OxyContin is one, but there are others too. We don't keep our pain medication in our medicine cabinets. We do have to take care.

JEANNE BLAKE: Well, Sue Gold, you're doing, as some people would say, God's work, and I'm sure that the people that have benefited from your support group are glad you started it. And we can share more through your website, which we'll link on ours, as I said. Thank you for coming in and talking to us.

SUE: Thank you. I've certainly gained more than I thought I would from my group.

JEANNE BLAKE: Well, good. I'm glad. We want to thank you for joining us on this edition of *About Health TV*. I'm Jeanne Blake and I'll see you next time.

About Health TV is sponsored in part by
Harvard Pilgrim Health Care Foundation.
Improving health through medical education,
clinical research and community service.