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Proem 00:53

A word for 2020: narcissist. Not the way you think. Pain is the ultimate narcissist. When below the pain threshold, I can think and function. Above threshold, pain rules all, jealous. Perhaps podcasting about chronic pain helps me keep pain below threshold. Perhaps examining pain intimately helps me stay mindful and grateful that my body speaks to me. Can you imagine if it didn't speak – no sensation? We are in control together – spirit and body. Perhaps exploring other people's experiences helps me stay connected to friends and strangers and the wonder of their tools to manage pain that could be in my toolbox or yours. What a gift!

Introducing Penney Cowan 01:47

My guest, Penney Cowan, knows and shares more pain management tools than anyone I know. Penney Cowan is the founder and chief executive officer of the American Chronic Pain Association (ACPA). She is a person with chronic pain and established the ACPA in 1980 to help others living with the condition. The ACPA provides peer support and education in pain management skills to people with pain and their families. The ACPA also builds awareness about chronic pain among professionals, decision-makers, and the general public. If you have chronic pain, your life will improve if you check out the ACPA website.

Health Hats: Penney Cowen. Thank you so much for joining me. I appreciate it. We just met, but I've been a fan of yours for years. Really, not so much you, because I didn't know who the master behind the

scenes was, but I discovered your site a couple of years after I got diagnosed, perhaps ten years ago, when I was trying to manage my way. I thought, 'Oh my goodness, this is so cool.' When Ting Pun introduced us virtually, I was so excited. Anyway, I'll stop fawning, and we can get on with this.

Penney Cowan: Thank you. It's nice to hear that it was that helpful. So, thank you very much.

Health Hats: How do you introduce yourself in a social situation?

Penney Cowan: I'm Penney.

Health Hats: That's it? And if somebody wants to know a little bit about what you do? Hi Penney, nice to meet you. My name's Danny, what do you do?

Penney Cowan: That's a hard one to answer because I see myself as just Penney. I don't see myself as CEO of this international organization and all of that. I just say I'm Penney. But if they ask me what I do, then I focused on pain management and education and teaching people how to manage their pain better. That's what I do. It depends on what they ask me next. It depends on whether they're a person in pain or have a family member who might have questions about it. A lot of times, people go, 'Oh, that's fine.' Often, I get jokes, 'Oh, I live with a chronic pain.' And I let it go. Okay. Fine.

[Starting the American Chronic Pain Association 04:38](#)

Health Hats: So, you've been doing this a while. So how did you get to the point of starting something like this? Describe the beginning.

Penney Cowan: Actually, I've been doing this for 40 years now. It started after I left the pain management program. For the first six years of my pain, I tried to do absolutely everything to eliminate the pain. I saw the best of the best. I lived in Pittsburgh, Pennsylvania, at the time. So, we had a good medical center, and I kept going from one doctor to another, the same story that so many people living with pain hear. I kept hearing, 'in the end, you're just going to have to learn to live with it.' Finally, after all that time, they gave me a diagnosis and sent me to the Cleveland Clinic. I saw a rheumatologist there, and he did a bunch more tests and said, 'you're just going to have to learn to live with it.' But he had this afterthought that a new physician said he could help people manage pain. And I thought 'no way in heck are you ever going to help me live with this pain. I've tried everything, and nothing works.' So, I agreed to go to the pain program to satisfy my husband. Enough's enough. No more doctors, no more looking, just let me be. After graduating from the program, I realized that people can learn how to live with pain, not take it away. It's not about taking away your pain. It's about learning to live with it. A couple of things happened while I was there. The first one is I realized I wasn't the only person in the world with pain. There were so many more people who were living with pain. Before that, I isolated so much that I thought I was the only person in the world. What they taught me was too good to keep to myself. And I knew I had to tell someone else. It's like a good secret; you have to tell someone else. The main reason that I started the organization is that I will never forget how much pain takes away from a person, how controlling it is of our lives, and how it just takes away who you are, and you become this thing that's controlled by pain. Every thought, word, deed, emotion all go through your pain. I had this huge fear driving home from that inpatient program. In that controlled environment, I could manage my pain. They taught me how to do it, but what was going to happen when I went home? I had two school children, all the work I had to do. Could I still do it? I had this huge fear of falling back into the patient

role. I knew the only way to maintain my wellness was to continue to do what I had learned, and the only way to do that is to share it with others and get that positive reinforcement and continue talking about it. So that's how I started the [American Chronic Pain Association](#).

Tools in our toolbox 07:42

Health Hats: Wow. Back in your youth. The thing that drew me to your work was this idea of tools and a toolbox. I'm a nurse, and in my experience in physical rehabilitation, home care, intensive care, and Behavioral Health. I'm attracted to this idea that's helped me in my career and as a person with a chronic illness and chronic pain that I need tools in my toolbox, and that it's an experiment, a never-ending experiment. One of the things that I like about your website is that there's that section where you have all these tools. I'll tell you the things that I use the most. I probably use the video, [The Car with Four Flat Tires](#), most externally to share. If I want to turn somebody onto your site, I'll say, look at this. If you like this, you'll enjoy the site, and it's so short. Then, you have the pain log app, which I used for a while, and then I didn't need it. But it was good to have that frame. It helped organize my thinking. Then you have that [Art of Pain Management](#) for people who want to get into the nuts and bolts. I found that to be good. Then I'd try to give the [Proactive Effective Communication Kit](#) to some clinicians. I can't tell you that I was successful because I feel like they patted my head and said, 'yeah, yeah.' But it's an excellent clinical communication tool. My question for you is, so you have this whole slew of tools. What are the ones that you think people use the most and why?

Four flat tires 10:06

Penney Cowan: The [Car with Four Flat Tires](#) captures people's attention. I'll tell the story only because a lot of your listeners may not know what that means. We describe the person with pain like a car with four flat tires. The problem is everyone expects that all I need is one simple thing, and I'll get rid of my pain. Put air in one of my tires, just give me a pill, and I'm good to go. And it puts air in one of our tires, and it may give us the 30% or 40% relief it's designed to do. The problem is we still have three flat tires. So, we ask ourselves, what else do we need? Though it will be different for every person because we're all so different, our needs are different. Perhaps we need physical therapy, nutritional guidance, maybe counseling, maybe acupuncture, or a support group. It can be several different things. And when we get all four tires filled, it's our responsibility to take care of the car. We don't take it back to the dealer and say, 'wash my windshield and fill her up.' That's our job. If something goes wrong with the car, then we take it in for a checkup. You see, it's a combination of treatments and therapies—the person with pain at the center that gets you up and going again. The problem with so many people is that they'll put air in that tire, and if it doesn't give them the appropriate relief that they're expecting, they let the air out and put something else in or they overinflate the tire. People try everything. That's where I was when I went to the Clinic. I tried everything, and they kept emptying and filling the same tire. That was the problem. They put it all together. So, I think the car with four flat tires is probably a good introduction to basic pain management.

Quality of Life Scale 11:54

Penney Cowan: One of the main tools that we had translated and validated – most recently, in Czechoslovakia - was our [Quality of Life Scale](#). I always hated when people ask me on a scale of zero to 10, what's your pain? Zero being no pain, ten being the worst. I thought ten doesn't come close to what

it's doing to my life because it wasn't about the pain. It was my whole life. It's not about the pain; it's about what it's doing to us. We needed to measure our function, interpreted in many ways. So, we flipped the scale. Zero means you can't get out of bed, all the way up to ten, where you can do near-normal anything you want—acting normal. Each of those numbers now has a function involved with it. That helps people and clinicians. I will tell you this now that many clinicians have used that tool repeatedly, they like it.

Pain log 13:00

Penney Cowan: One of the tools, as you mentioned, was the [Pain Log](#), which is my favorite tool. The reason for that is everyone thinks it's just about the pain, but it's not. There are so many things that impact that pain score. You'll see all of our graphical tools. We still have the zero to 10 pain scale because that's what providers have to use to chart in their charts. However, other things also impact our pain score -our stress, exercise, activity, sleep, and fear of that pain (which is the most significant controlling factor). Can you describe the side effects, constipation or sexual activity, appetite, mood, how isolated we become, how much alcohol we consume, and how worried we are about finances? We've even added smoking. That allows people to begin to track all of those things and equate them with where their pain score is. What's nice about it, because it's interactive, is that they can begin to see their pain spikes every time; what components contributed to that? And they can share it with their providers. Their providers can look and begin to see, 'okay, so you're not sleeping well, you're isolating, your mood is all these things. Maybe because you're depressed and maybe that's where we need to focus or because every time they exercise their pain spikes, we may need to get them to some physical therapy and see what they're doing wrong. It's a whole picture that has allowed them to look. Because when you go to the doctor, and the doctor asks you how you're doing, you tell them how you are today, but you don't remember how you were a week ago or three weeks ago, three months ago. What happened between? So, by keeping that pain log, you can now give them a little history of exactly what happened and how you felt. That's why that's my favorite tool.

Even more tools 15:00

Penney Cowan: There are lots of other ones. There are the fibro tool and the one for cluster headaches and migraines, but the pain maps are also unique. With the pain maps, you can point and click where the pain is, how it feels, and its intensity. They can go front, back, right, left. We have them for our head, back, a diabetic peripheral neuropathy, fibromyalgia, and neuropathic pain. I remember trying to think of the best way to describe my pain to my providers. The problem with that is the more I thought about my pain, the more I suffered. That's not helpful. That's not at all helpful for anyone. Pain maps and printing out a picture of your pain in advance of your appointment is helpful. A picture's worth a thousand words. It helps validate. People need the validation of their pain. It also helps the provider see the location of their pain and how it feels.

The other one I would say is most helpful was the first graphical tool I ever did - the [Care Card](#) that helps people take their medications. It's graphical - take it morning or night or what time of the day, and it's got empty time clocks that they can put the hands-on, plus with food and an empty stomach, things to avoid, possible side effects, how to store it, dispose of it. We get those medications, and do we even hear what our provider's telling us? Our providers' visits are so emotionally charged, stuff going in one ear or out the other. Then we go to the pharmacist, and they say the same kind of thing. Yeah, you just

want to get out of there because people are standing around, and you don't want to talk to them and don't hear what the pharmacist is saying. Then you go home, and you look at it, and you go, 'I don't know.' We were getting a lot of calls from people who wanted to know what the medication was for? So, we always tell them to go back to the prescriber, talk to the pharmacist. I knew that we needed to do something to help them.

Pain month 17:17

Penney Cowan: So, we started September Pain Month back in 2001. We called it [Partners for Understanding Pain](#). One year we focused on the pharmacy. We worked with the [American Pharmacist Association](#) and did a toolkit for their members. And after I designed the tool, I remember showing it to them thinking, they're probably going to laugh at me, and they loved it. We've done three projects with the American Pharmacist Association using that tool because they use it. I'd like to see it on all pharmacy bags.

Health Hats: It's way better than the drug inserts. As a nurse, a quality management professional, and writing the thesis for my master's in public health, I know in my career in public health that I fell in love with pharmacists. I became impressed with the amount of knowledge they had relevant to me, whether I was trying to help other people or help myself. I can't overstate how much help that's been. You've done this for 40 years; what tool will you develop next? What's in your queue that you're thinking about or on your wish list? Where do you see it going? You don't seem like somebody happy to sit at one spot.

What's next? 18:45

Penney Cowan: No, I'm not because there's so much more we can do. Unfortunately, a lot depends on funding. I'm saying that because we are a nonprofit. They're starting to film today. This is the first time we've ever done a video that I've not been there. I'm not traveling because of COVID. We're doing an exercise video for people who have COVID or who are at home because they can't get out who are living with chronic pain that couldn't go to their physical therapist, couldn't get to their acupuncture, couldn't get to their gyms, couldn't get to the pools. What do they do at home? So, we're working with therapists, and we're doing a video with three parts, different levels.

Health Hats: Oh, that's great. I'm looking forward to that.

Penney Cowan: So that's one of them along with a lot of other things. I would love to do more work on back pain, arthritis, and osteoarthritis. We have a program called [Growing Pains](#) for kids, a separate interactive website. I would like to connect more with kids and teach them better body mechanics, better nutrition, and all kinds of things that might prevent pain as they go forward—especially something like arthritis when they get injured due to the sports injuries. Let's look at that and see the problem before sending them back on the field—and working with coaches for kids, for these youth teams. I think that it would be crucial to educate them. I also would like to do more work this series we have called [Pathways Through Pain](#), and we have, what we call, our [Ten Steps from Patient to Person](#), which is not like a 12-step program. They're the basics of pain management. The first two steps include accepting the pain and then getting involved in the recovery process. We've done goals, and we've done priorities and would love to do a more extensive one on exercise. We'd like to do one on emotions in pain—one on basic rights, just people's basic rights.

People living with pain quite often takes away our self-esteem. It takes away our sense of worth because we all equate our value by what we can accomplish in a day. So, these basic rights. Usually, when we start a new group, I'll tell them that's where you start. It's like chapter five or six or something in the workbook we use. Start there, and let's see how these were? Let's let them realize that they are just as equal, and pain has not changed who they are at all. Too many people define themselves by their pain. That's why I hate the terms, *chronic pain patient* or *pain patient*. Because that's not who we are. We're people living with pain, but we're more than just our pain. So, I would like to change that terminology, get rid of those phrases. Working, I can see it every time I read it in the literature. I have to smile when they call you're a person with pain; you're a patient with pain. I don't want to read chronic pain patients or pain patients anymore or want them to recognize that we're people like anyone else, and their pain is not what defines us. There's so much more to us than just our pain.

Health Hats: I think, for me, the huge point was, and it went both with the Multiple Sclerosis and with pain is, 'look, I love myself. Let's just hang on to that. Okay, now what? You know, so this is me.' I need a better understanding of it. Since I like to write, it made me realize that there are 200 words for snow in Greenland. So, how can I be creative about describing pain? It felt like the more I could get in touch with 'this is what I'm experiencing. This is how I can describe it.' It just made me feel more, 'okay, I'm going to motor on.'

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Health equity and bias 24:08

Health Hats: The other thing that I wanted to talk to you about is that in my work now, the one thing, and I think it came to a head with this whole COVID pandemic, is that we have an epidemic of mistrust. This led me to a better understanding of trust characteristics, including health equity and institutional racism. Just thinking about how those monster issues play on health in general, but how do you? Here, let me tell you one other little story, and then I'm going to ask you your take. So, I don't know, five, six, seven years ago, I worked with a young lady who had Sickle Cell Disease, and we became good friends because we were both dealing with chronic illness. We bonded over the management of that. Her struggles were that her family was from Nigeria, and when she moved away from her regular health team, she couldn't go and get relief without profound discrimination as a drug-seeking person, even though she had Sickle Cell. It opened my eyes to us, as individuals, can do a lot for ourselves, but there's this societal part of it, this bias, this discrimination. With your involvement in all these years, how does that come up in your work?

Penney Cowan: It comes up a lot. People judge: 'Those with pain are lazy.' All of those kinds of things, trying to get out of work. They're also quite often labeled as drug seekers, which is precisely what you're saying. I think that the whole issue of opioids impacts that, but I think the biggest problem with pain, Sickle Cell, Fibromyalgia, low back pain, any of them, is that they're all invisible. You can't see it, so how

do you believe someone is in that much pain when they look perfectly normal? So, that's the first thing we see in our eyes. They look normal. And if you think about that, not every day, even if you have the worst pain, you can imagine, not every day, is a 10, right? We have threes; we have eights; it's up and down all the time. And so, our level of function goes up, and it goes down, and it goes up, and it goes down. And that's what is so very confusing to everyone around us. They see us one day, we're able to work, and you can't do anything the next day. And the problem is it doesn't only confuse them, it confuses us as well. So how this be? How can this be that is so confusing? Part of the problem, for a person with pain, is that we don't listen to our bodies. We feel at first out, especially on a good day, we're going to keep pushing, and we're going to keep pushing because we have to prove our value and our worth to everyone around us. We have to let them know that we are valuable. We could still contribute. I can do this. And that's part of the problem. We don't listen to our bodies. If we would just stop and begin to tell our body how to relax. Use the relaxation techniques, use stress management. That's why all those combinations together are so very important. But there's a huge amount of stigma associated with pain. More than anything, I think, because it isn't visible, you can't see it, there's no way to measure it, smell it, taste it. There's nothing you can do to prove if a person is six, eight, or ten or whatever. Which all those numbers are, you know, what they are.

Health Hats: Interesting.

Penney Cowan: This problem is that we believe what we see. You can see somebody's broken arm. That's part of it.

Health Hats: What should I be asking you that I'm not.

Family and caregivers 28:47

Penney Cowan: What should you be asking me? One of the things that people don't think about is its impact on family members and those around the caregivers. For three years, I interviewed family members and even a couple of kids. I asked them all these questions about living with a person with pain because I know exactly what it's like to live with pain. I have no clue what it's like to live with someone who's living with pain. It's going to be difficult. But what struck me? The first thing that struck me is I thought I was talking to people living with pain. Because there was only one difference between a family member and a person with pain, and that is a family does not feel the physical pain, but everything else is the same. The confusion, the frustration, the anger, the doubt, all of those things are exactly the same. So I think if we're going to help the person living with pain, we can't forget about the families. I heard from some of the kids that they misinterpreted that pain that their parent was feeling like a punishment for something they must have done wrong.

Health Hats: Yeah. I can relate to that.

Penney Cowan: So, we need to explain to our children why things are the way they are. You need to be able to have that conversation. And I think that's just as true. And it goes back to why did I develop all those graphical tools? Because I wanted a meaningful conversation with healthcare providers. They don't speak the same language we do. We don't understand what they're telling us. So, let's bring that together and bridge the gap. But I think family and caregivers are the same way. We need to be able to communicate with them. We don't know how to do that. When you think about it, the well spouse they

have to maybe take on all the family's jobs, that the person with pain can't do anymore. Maybe they get half of the income they used to have, but they still have to go to work and after come home to cook meals, take care of the kids, take care of them, the house, and take care of the yard. They have to do it all. It's exhausting. So, we wrote the family manual. But then, because I know people don't read, we actually converted that to a free video series, and that's on our website, and it's free. It's called [Family Matters](#). And it's an amazing video that took us quite a bit to design. We won an award for that video of Family Matters, and it's on our website. The tools we've talked about are on our website. They're free. We have videos on Naloxone. [What is Naloxone?](#) How do you recognize an opioid overdose? What do you do? Obviously, call 911 first and then how to administer Naloxone.

Opioid-induced constipation 31:42

And this is another topic that people rarely talk about, but it comes with many people living with pain and even other medications. But [opioid-induced constipation](#).

Health Hats: Oh yeah, that's a big one. Oh, my God.

Penney Cowan: We have a graphical tool that we designed so people don't even talk to their provider about it. We did a survey, and we know that they don't. They'll struggle until they're the worst, they could be before they even talk about it. And so, we designed a tool to help people. It's a graphical tool. All you have to do is circle the different things, whether the amount of opioids they take as prescribed as needed, the water they drink, fiber, and all those things said that impact. The laxatives they use, bowel movements they have during the week. All of those are on this graphical tool. They can just hand that to their provider, and they don't have to talk to them about it. And then they know there's a problem. And then we did a video of that.

Your team: pharmacists and nurses 32:39

But I wanted to get back to the other one. You talked about pharmacists. And so we did a video, and it's a very long one that we did. It's probably more than five minutes. It may be six or seven with the American Pharmacist Association on why go to a pharmacist?

Health Hats: And yeah, that's a good one.

Penney Cowan: It's called [Taking Care](#), about the amount of education they have, what they are qualified to do, and how to help you. So they are because people don't talk about it, but they're part of the treatment team that too many people don't think about using them. And I think the other piece is the nurses. I always call them the worker bees because they're the ones that talk and listen to you the most.

Health Hats: That's great. Okay. this is wonderful. Thank you so much. I appreciate you taking the time out of your day.

World Patient Alliance 33:28

Penney Cowan: The only other thing I probably wanted to mention is that we've just started the [World Patients' Alliance](#) to bring people together. Because if you look at pain, it encompasses every disease there is because it's all associated with pain. That's usually the reason we go to providers. So I knew that, and we had lots of people from other countries start being in our support groups. We had two

groups in Russia. Our materials have been translated into several different languages. But to reach people worldwide, which, because our world is getting much smaller, we have started what we call the World Patients' Alliance, which is an organization of a number of different patient groups. So our steering committee, our board of directors, two founders are from the US and Peru, Pakistan, Poland, and Uganda. I think it's important to realize that pain's not exclusive here to the US, but it is a global issue. And so, we need to look at worldwide. I was just talking to somebody in Australia yesterday, and their issues are the same. And their frustrations are the same as ours. We get calls, and people say, 'I'm going to go to Canada, that healthcare is better.' Then people in Canada get calls, 'I'm coming in. America.' The grass always looks greener on the other side. I think it's important for us to focus on what we have and how we have to do and what we can do with that. So, I always talk to people about looking at your abilities, not your disabilities.

Health Hats: I'm with you on that.

Penney Cowan: What you can still do. What are your abilities to spend a lot of time on that as well? So that's all I wanted to say.

Health Hats: That's great. Thank you.

Reflection 35:24

Life with chronic pain can feel like a stranger in a strange land whether you have the pain, live with someone who experiences chronic pain, or treat people with chronic pain. You all have much in common and little in common. The more we can speak the same language, use the same descriptors, and shortcuts, and understand each other's dreams and pressures, the better we function as a team. The moment of acute pain is not the time to align and learn. Pain consumes everything. It's all about the pain – right now. Rather, when we are below our threshold and can think and function, that's the time to learn, listen, teach, and align. Penney Cowan's American Chronic Pain Association is for the whole team when below threshold.