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## Proem 00:57

*Forty-six words for snow in Iceland. How many for physical pain in English? Googling synonyms: suffering, aching, torture, throbbing, discomfort, ache, sore, sting, twinge, shooting, irritation, tenderness… I recall sitting with my mom when she was dying of pancreatic cancer, trying to understand what her pain felt like. 'Ma, is it sharp, dull, aching, constant, ebbing, and flowing?' The more descriptors I tried to come up with, the more frustrated she became with me. No words worked for her. Yet she tried to describe it to the hospice nurse or doctor without success. Granted, my mom was homebound and bedridden. She was past the place where function mattered. How does your pain affect your ability to socialize and work? The way I manage my annoying neurological pains is to get to know them intimately. Meditate on the pain. Sensation, location, travel, duration, what makes it better or worse…. It takes the edge off, helps me be less freaked out, and I can manage with less medication. I find my professional team intrigued by my desire to describe it in such great detail. To them, I'm a bit of a freak.*

*Speaking of amazing, last week I was appointed to the PCORI Board of Governors as a patient representative. The press release dated September 23rd reads in part: Gene L. Dodaro, Comptroller General of the United States and head of the U.S. Government Accountability Office (GAO), today announced the appointment of seven new members to the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI). "Today's appointees bring a range of experiences and perspectives that should greatly benefit the PCORI Governing Board as it funds and evaluates research to help patients make better health-care decisions," Dodaro said. "We had a number of exceptional candidates this year, and I am pleased to name these latest additions to the Board." This career capping opportunity thrills me to no end. I'm humbled, honored, daunted, and raring to go.*

## Introducing Dr. CJ Rhoads 03:43

*My guest, Dr. CJ Rhoads, is the founder and CEO of HPL Consortium, Inc. developing a platform called CIRWEP to help people and groups connect toward health, prosperity, and leadership. Dr. Rhoads speaks*

*and writes about entrepreneurship, business strategy, leadership development, information technology, and the economics of healthcare and integrative health practices. She is a researcher, a book autho, columnist, and a Professor in the College of Business at Kutztown University.*

**Health Hats:** Dr. CJ Rhoads. Thanks for joining me. Everybody, we've been talking for a few minutes, so I thought we would pick up where we left off. You were talking about acceptance.

### Accept it. You won a lottery. 04:46

**CJ Rhoads:** I was saying is that, unfortunately, when you have chronic pain, which is influenced by your outlook, the more you resist the fact that you are living in chronic pain and probably will for the rest of your life, the more you resist that concept, the more pain you feel. One of the turning moments for me was when I accepted that I'm never going to get rid of this pain. It's going to be here forever - every day of my life, I'm going to feel pain.

**Health Hats:** You won the lottery. And you're never going to stop winning the lottery.

**CJ Rhoads:** That's all there is to it. You cannot get around that fact. Once you accept the fact that yes, you're going to be in pain for the rest of your life, you deal with it. When you deal with it, your pain goes down because your outlook so influences your pain. If your outlook is resistant and angry and you're trying your hardest to get rid of this thing, then that's going to influence your body, and your brain is going to increase that pain. Once you say, 'Oh, okay, So I have to live in pain, I guess I'll just have to deal with it.' Then your body reacts, and your brain reacts, and the pain levels go down. They never go away, but they go down. So, your life becomes a daily struggle of doing things to keep the pain levels down. The best thing is to get those pain levels below threshold. Cause they're always there. You can ignore them and forget about them and do other things. And when you do that, the pain goes away. It doesn't really because you stop and think and you go, 'Oh yeah. I guess the pain still is there,' but you're so busy doing these other things that you don't even notice it. That's below the threshold. Pain below the threshold is still there because it's chronic, but it's so low that you don't feel it. And people ask me, how have you achieved so much? Cause if I don't know if you looked at my resume, but it's incredible. I got 25 pages of achievements and awards and books I wrote and things I did, over 300 articles and it just, I got all this stuff and I did this all after my accident. I did a lot before my accident too. I had a good stable foundation for being able to do it, but the fact is I went into high gear after my accident because I recognized if I sat around and did nothing, I would just feel pain. If you get busy and you start doing things, and you join things, and you get involved, and you're doing that all the time, then your pain levels go down.

**Health Hats:** I have several theories about that. One of the theories is that spiritual trumps mental trumps physical, and accepting where you're at is spiritual. The other is that endorphins make a difference, and being involved and excited is endorphin producing.

**CJ Rhoads:** Absolutely. Here's the thing. You've got to know that the brain controls the rest of your body. It controls what hormones, what neurotransmitters are being spread throughout your body. You can get your brain to send pain-relieving transmitters, neurotransmitters, or you can get your brain to send pain-inducing, increasing neurotransmitters. For the rest of your life, if you're in chronic pain, it's

your job to figure out what things you do to increase the pain-reducing neurotransmitters and decrease the pain increasing neurotransmitters.

## Continual experiment 09:16

**Health Hats:** I hear you talk about experimentation.

**CJ Rhoads:** Absolutely.

**Health Hats:** Talk a little bit more about that. So how have you treated this as an experiment?

**CJ Rhoads:** I keep records. I'm a big measurement person, even before my accident caused back pain. It was a whiplash accident that caused mild traumatic brain injury and chronic neck and upper back pain. So, there we go. The accident happened in 2002, so it's almost 20 years after the accident. For the past 18 months now, I've been getting increasing shoulder pain. Now you say, 'shoulder pain has nothing to do with your back.' Yes, it does. The physical therapist tells me that it's still from that accident because of some of the weaknesses in the middle-upper back that's not getting my shoulder any structure or foundation. Now it hurts all the time. I started keeping track. I keep track of what I eat, my pain levels every day. I had a little pain today. Today, it was a lot of pain, I keep track of the pain levels, and I keep track of what I do. I tried the scarf around the neck. The idea was if you warm up your neck, then that'll decrease the amount of pain. That worked a little bit. You sleep with the pillow because this pain wakes me up in the middle of the night. You have to sleep with a pillow in your arms because that puts your arm in a better position. That helps a little bit. Everything helps a little bit; nothing solves it a hundred percent. I believe no single thing in the world will solve chronic pain. It's always a little of this and a little of that and a little of this and a little of that. You get it enough of those littles together; then you get the pain below your threshold. That's what we're always working towards. So even the regime that I keep for my back and my neck, it's a lot of things somebody says. What do you do for your back? It's a lot of things. First, I have to eat. In 2001 if you had asked me whether what you eat has anything to do with your pain levels, I would have laughed at you. What we eat has nothing to do with your pain. How can that have anything to do with it? I was so wrong. What you eat has a whole lot to do with your pain levels. If you eat a healthy diet, lots of green, leafy vegetables and colorful vegetables, some fruit, and I eat cheese and meat too, because I got to do low carb because for my body and I think it's different for everybody. So that's the experiment.

**CJ Rhoads:** Then, of course, exercise. You've got to exercise regularly, an hour of exercise a day, something stress-reducing. I do Tai Chi, yoga, Pilates, walking, swimming, and hiking. I don't think it would be pain-reducing to play racquetball or basketball or any of those. When I say exercise, the stress-reducing repetitive exercises that increase your relaxation response, remember the whole idea is to get your whole body to relax. When your entire body relaxes, your pain levels go down.

**Health Hats:** I know you now for four minutes, and you seem like a very high energy person for whom relaxation is some work. Is that true?

**CJ Rhoads:** It's true. I'm continually working on it. Back in the nineties, I tried to do meditation, and I belong to a church, and at the church, we had meditation sessions. I went in to do the meditation, and I could not sit there, physically,

**Health Hats:** Not your cup of tea?

**CJ Rhoads:** Could not sit there doing nothing. I've learned since I started Tai-Chi in 1990, long before my accident. I did Tai Chi for relaxation, but also for fun, and because I was a competitor. I competed in international Tai Chi tournaments. Some people don't know that Tai Chi can be a competitive sport. Some people practice it that way as I did for ten years before my accident. But because I was doing Tai Chi after my accident, I had access to the integrative health world. I wouldn't have done that if I hadn't been doing Tai Chi for ten years. At that point, I would not have known about this whole other world of pain-relieving practices. I would have just done what my doctor told me to do. Frankly, if I had done what my doctor told me to do, I would be in bed with massive amounts of pain medication. I was on Oxycontin for eight months. I know you've got to increase the amount over and over again. My sister has been on opioids for 15 years, and she takes massive amounts of opioids every day and can't stop because the pain will be awful. If I had done what my doctors told me to do, I'd be in bed taking opioids on disability. I could have easily gotten disability because of my physical problems. And look at where I am now.

### Keeping track. Two week rule. 15:14

**Health Hats:** Isn't that wonderful. I have two questions out of it. The first one is, how do you keep track of all this stuff? Do you have spreadsheets?

**CJ Rhoads:** Yes, I have spreadsheets. Initially, I wrote everything down on a spreadsheet, all the different things I was trying, and measured what the pain levels were. I no longer use the spreadsheet only because I don't need it. Once you get to a certain point, you know that this thing gives me pain relief, and this thing gives me pain relief, and that thing that I tried didn't help at all. Let me tell you the number of things that I had tried that didn't help is massive. I have a massive volume of things that I tried that did not work. You got to go through many things that don't work before you get to the things that do work. So, you write down everything that you try and see if it works. I have a two-week rule. I give things two weeks; whatever I'm supposed to be doing. I did acupuncture for two weeks. I did acupressure for two weeks. I did Botox. If it doesn't work within two weeks, then I drop it and try something else. Lots works within two weeks.

**Health Hats:** Do you ever use any of the many pain apps out there for tracking?

**CJ Rhoads:** Nope. I told you I stopped using the spreadsheet because it was a big pain to get into. For my shoulder, for example, I use my calendar. I use Outlook, and every morning at seven o'clock, you'll see a little entry in my schedule that says, woke up in the middle of the night with a lot of pain and recorded whatever I tried. So, it's there, and then I can print it out and put it into a spreadsheet. I put it into the calendar, and then I print it out and make a CSV file out of it, copy it, and paste it into a spreadsheet. Then I take the spreadsheet to my doctor. So, I do use a spreadsheet as well.

Now a word about our sponsor, ABRIDGE.

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the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

### Collaborative decision-making? 18:17

**Health Hats:** Take that thread of the doctor. Tell me about the evolution; I'm assuming there's been an evolution of doctors and relationships with doctors until you have found the right fit. How has that gone for you?

**CJ Rhoads:** A huge number of doctors. When you're seeing so many different doctors, I couldn't keep track of them. I have a little spreadsheet that lists all the doctors I saw, what I saw them about, and all that other stuff. I'm a technology person. I teach technology at Cookstown University. I use a database, not a spreadsheet. The database is the most structured, where I can get the most flexible, print it out that way or the other way. In the end, everything gets into the database because I want it to be structured. When I got hurt, my primary care physician was wonderful. I love him. He encouraged me to try everything. The only fault that I had with him was that he kept encouraging me to stay on the Oxycontin long after I told him, 'I want to get off this medicine.' When I was taking Oxycontin, I took the 12-hour extended-release thing. Yeah. And so you take it, get in the morning, and you're feeling good. It takes away the pain. You feel no pain when you are on Oxycontin, and you just don't want to do anything. So you sit around and watch TV all day, and you just don't, and you can't remember anything and you, it's that's okay. But my husband took care of me, and I just did nothing for eight months. Yeah, nothing for eight months. I shouldn't say 'nothing'. I did get out of bed and go to my Tai Chi class because that was my one thing connection, but I knew this was not good for me. I knew that there was that I knew, first of all, I ran out of money. When I got hurt, I had a lot of money in the bank. When my husband and I went through that money, it took us two years to need to borrow money to pay for groceries. That was the point at which my husband tried to find a job. But he was older and had health issues himself and couldn't find a job. So, I knew I had to do something. I realized that I would have to go against my doctor's orders and stop taking the medication because I knew I couldn't get a job while taking this medication. I went against his orders and got off of it cold turkey. I thought I could take Neproxin to make up the difference. But that didn't touch it. It was terrible withdrawing because I'd been taking it for eight months. I pity the people who have been taking it for years and have to get off of it. But quite frankly, it wasn't as bad as the withdrawal from coffee - from caffeine. I gave up caffeine in 1995, and that was the worst withdrawal.

**Health Hats:** So back to the doctor relationship.

**CJ Rhoads:** Yes. I did finally tell him I'm off the Oxycontin, and he helped me. He encouraged me to experiment. He also sent me to a lot of specialists. I went to a specialist neuro-whatever brain specialist and back specialist and pain manager. For the first two years after my accident, I didn't have good insurance. The specialists I could see were very limited. Either I had to drive far to see them or they weren't very good. After I got the job at Kutztown, I got good insurance. And I was able to see Dr. Cheadle, the pain management specialist at the Redding Hospital Pain Center. He enabled me to turn that corner by convincing me to stop resisting because it was a mental thing.

## Cognitive Behavioral Therapy 22:41

**Health Hats:** CBT. Cognitive Behavioral Therapy.

**CJ Rhoads:** I found cognitive behavioral therapy effective. I used cognitive behavioral therapy to lose the weight that I gained - like 60 pounds. I'm short. Sixty pounds on me is a lot. Cognitive behavioral therapy is wonderful. I think everybody should do it. So, it was the combination of cognitive behavioral therapy, physical therapy, and occupational therapy. I needed all three. Occupational therapy enabled me to turn the corner in recognizing that I had to accept fully that I was going to be in pain for the rest of my life and that I had to deal with the cause. I had some mild traumatic brain injury, which caused real issues with my memory and ability. I have something called prosopagnosia where I can't, can't recognize faces. I also have something called, actually I don't know what it's called, but it's just a, it's a, it's times and dates. I cannot keep track of times and dates, no matter what, I cannot remember a time or a date. And at the time I was trying to use my end. This was, remember, this was like almost 20 years ago, so they didn't have it quite as good, but I was using a little Rolex thing. it was an electronic date calendar thing. And the only problem with it was you couldn't enter it sure new appointments directly. I had to wait until I could go to my computer, enter the computer, enter the calendar and enter it into the calendar and then sync it with my Rolex so that I could carry my calendar with me. It's me. And the problem was that requires you to remember. Yeah. When you're out and you get an appointment, it requires you to remember that appointment from that point until you get to your computer and that wasn't working, I couldn't remember it. and then, Or I would remember it wrong. That was really the big thing is I would remember dates and times incorrectly and not realize that they were incorrect. So I would constantly be showing up forever appointments at the wrong time or forgetting appointments. Yes. The worst point was when I was supposed to speak to 300 people from it's called global village. And people from all over the world were there and there were 300 of them and I was supposed to speak to them and I forgot.

**Health Hats:** Oh, geez.

**CJ Rhoads:** It just, yeah. Didn't show up. I lost a lot of respect from other people that day. So it was a it was my nightmare. It's like after that, I had to an appointment with the occupational therapist when she convinced me you can't use the electronic one. Sorry, you got to get a paper one, not like that, but it's gotta be a big one. So she made me get an eight and a half by 11 calendar to write everything down. And I cried. I cried in the session because giving up my electronic calendar was really. Yeah, that was hard for me, but it was something I had to do to accept the new world that I lived in.

**Health Hats:** How has your experience with partnerships with clinicians been? Who's in charge, who's making the decisions?

**CJ Rhoads:** Sometimes, they don't realize that I'm the one making decision. I just let them think that they're making the decision. I often don’t tell the doctor what I was planning to do, because some of them have a very old school mentality that says anything that has to do with integrative health is bad.

## Health inequities 26:56

**Health Hats:** In my experience with chronic pain management, I find issues of health inequities and institutional racism affects how people interact with the health care system around pain, whether

they're patients, caregivers, clinicians, or whatever. In your many years of being in this space as a patient, advocate, student, and researcher, can you speak about your experience and what you found?

**CJ Rhoads:** I would say that some doctors are very open and loving to their patients, listen to them and pay attention to what they say, and show respect. Other doctors don't. I don't think it's their fault. I don't blame them. It's the methodology by which they have learned that says, if they can't find a reason for your pain, then it's all in your head, and you're full of it. They don't give you any credence. They don't give you any help. They dismissed the fact that you're in pain. That's terrible, but it happens. I think it happens more often to people who are a different race or class - different than the doctor. Doctors dismiss women more often. A doctor goes in and says, my left arm hurts. Oh, it's the doctor, go all stops out. A woman says my arm hurts they say, Oh, we don't know what's causing it. It must not be real. There's a difference in the way the medical community deals with patients based upon certain characteristics, social dynamics, that prevents some doctors from recognizing that everyone should be dealt with respect. You have to listen and can't just dismiss someone's pain because you don't know how to solve it. There's always a way to solve it. The fact that lowering your stress levels reduces your pain doesn't mean the pain isn't real.

### Advise us 29:48

**Health Hats:** So advise people who are struggling with those dynamics. I've found firing the doctor and moving on effective.

**CJ Rhoads:** I agree. You can't change people's perspectives. If a doctor was trained to think that fibromyalgia is all in your head and, therefore, it's not a real disease, there's nothing you can do with that. Most doctors are up on the research. They recognize nerve pain doesn't have an identifiable cause. Not all doctors are. So, if you're dealing with someone at that level, then you just have to leave that doctor and find another one. And there are always great doctors. One of the good things that came out of the pandemic is the ability to do telemedicine., which would prevent it from many things. there's, you, weren't allowed to do telemedicine for so many years, but now you can. And, more, it's still, there's still some restrictions, but there's a lot of the restrictions have been lifted. And so you can find a better doctor, even if they're not physically in geographically in your, you can travel to them.

**Health Hats:** Thank you very much for spending this time with me. I appreciate it.

**CJ Rhoads:** Thank you. I appreciate it. Talk to you later.

### Reflection 31:21

*Two points Dr. Rhoads make strike me: First, try massive numbers of solutions to chronic pain. Most probably won't work. But some will. That's the gold. Second, the two-week rule. If the potential solution doesn't work in two-weeks, dump it and try something else. I can't think of a better example of control. My control, your control. What works for you when you're in pain and scared? You know the feeling: startled, numb, stomachache, sweating, heart racing, catastrophizing, panicked…… Who can you call? What calms you? Music, meditation, medication, massage, heat, cold, vibration? Nothing works every time. Nothing works all the time. Everything works for someone sometimes. We are not victims; we won a lottery. We just didn't buy a ticket.*