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Introducing Barby Ingle 00:52

Before her auto accident that caused chronic pain and subsequent surgeries, Barby Ingle was no stranger to pain. She was an athlete, a business owner, event coordinator and head cheerleading coach at Washington State University's [Spirit Program](#). Barby authored the Cheertec Coaches' Handbook and a six-part DVD Series on cheerleading. Barby now lives with reflex sympathetic dystrophy (RSD), migralepsy (a rare condition in which a migraine is followed within an hour by a seizure), endometriosis (inflammation of the uterus), and other pain disorders. After her accident, Barby felt overtreated, untreated, and mistreated. She took control of her medical management and replaced drug pain solutions with physical pain solutions. She repurposed her media savvy to heal herself and engage others with the *Ken and Barby Reality TV show*; wrote [From Wheels to Heals: A Chronic Pain Patient's Story of Hope, Help, and Understanding](#); [ReMission Possible: Yours. If You Choose To Accept It](#); and [Aunt Barby's Invisible, Endless Owie](#); and founded the International Pain Foundation. Barby and I met several years ago online through WEGO Health, then recently in person at the Expo Health Conference in Boston. Meeting Barby virtually does not prepare you for meeting in person. Buckle up, here we go. I will break in several times to explain some medical terms Barby uses. I couldn't keep up during the interview.

Health Hats: Hi, Barby. It's great that you could join me today.

Barby Ingle: Thank you. Thank you for having me. Thanks for letting me tell a little bit of my story and sharing resources and tips and tools for other people. Hopefully, it will help them to hear what we have to talk about today.

Health Hats: How do you introduce yourself?

Barby Ingle: Hi, I'm Barby. I am from Phoenix Arizona. I'm the president of the International Pain Foundation. And I also am a best-selling author and a reality TV personality.

Health Hats: You're a reality TV personality? Tell us more about that.

Barby Ingle: I have done multiple reality shows over the years, and I've been in the media over a thousand times. I lost count how many times I've been in the media. But I have had shows specifically built around me. Other shows have a segment specifically relating to health. I do some fun things, too.

Health Hats: Where were you when you first realize that health was fragile?

Barby Ingle: Oh goodness. I had an auto accident. Before that accident, I had been through many injuries. I was an athlete. I was a collegiate cheer and dance coach. I had gone through injuries - blew out my knee, all kinds of surgeries. I was totally fine, and I could always overcome them and get through them. I had endometriosis at 24, and by 26, I had a full hysterectomy and oophorectomy, and I overcame it. I got past it.

[8 seconds changed my life 04:35](#)

When I was 29, it was eight seconds that changed my life and showed me that health was fleeting. Do not take life for granted. Do what you can do. Live the fullest life you can. Live in whatever moment you're in.

Health Hats: What were the eight seconds?

Barby Ingle: Yes, the eight seconds was an auto accident. I was sitting in my car waiting to park. In my rearview mirror, I saw a van starting to back up. I put my hand on the horn. I put my other hand on the seat next to me and twisted my body. The guy never saw me. He never put on his brakes. He was probably going 10 to 20 miles an hour. He never took his foot off the gas until after he hit me. I hit my head, got a concussion. They told me I had whiplash and I'd be better in three to four days. That was September 26, 2002. All these years later, with over a million dollars in medical bills, I now know it triggered a neuro autoimmune disease. Nothing's been the same since. Every day is about taking care of me. Living the most life I can, whether that is a day in bed vomiting from pain or out speaking at a conference raising awareness and sharing my story.

Health Hats: That's pretty dramatic.

Barby Ingle: Eight seconds changed my life.

Health Hats: You don't have pain, meaning "oh my knee hurts." You have this whole constellation of stuff that's uncomfortable. You have all these different pains.

Barby Ingle: Uncomfortable would be a good day. On my worst day, it feels like somebody put lighter fluid on me. Caught me on fire and I can't put it out. I lived like that for many years. I was in a wheelchair for seven years. It's called Dystonia.

Dystonia is a movement disorder in which a person's muscles contract uncontrollably. The contraction causes the affected body part to twist involuntarily, resulting in repetitive movements or abnormal postures. **Dystonia** can affect one muscle, a muscle group, or the entire body. Sounds awful.

Overtreated, untreated, and mistreated 07:08

Health Hats: How do you manage all this?

Barby Ingle: It didn't start that way, though. It took me three years to get a proper diagnosis. I was over treated, untreated, and mistreated. And during those three years, I would go into each providers office - 43 providers - and I would say, "help me fix me. I'm in so much pain." I wasn't doing what I needed to do to be the chief of staff of my medical team. I wasn't a patient advocate. I wasn't responsible for my own life. I was expecting other people to fix me during those three years. I would cry. I would say I'm in pain and they would say where does it hurt? I would say everywhere. After I got my diagnosis and I learned about it, it made a lot more sense. I also started learning the vocabulary that I needed so that I could get the care I needed and get access to proper treatments.

Finding words to describe pain 08:08

Health Hats: Can you give me an example of some of that vocabulary?

Barby Ingle: Sure, when you say pain, you need to be able to describe your pain. You need to be able to say it's muscular. It's burning pain. It's joint pain. It's deep pain. Sometimes it feels like electricity is hitting me. Sometimes it's sharp. Sometimes it's stabbing. Sometimes it's searing.

Health Hats: Being descriptive about location and sensation?

Barby Ingle: Correct, and the more adjectives you can give to your providers, the better the treatment options they can offer you. Because those are keywords and magic words to those doctors. Then they can help you find better treatments and options. And now I do have a plan, and I know if I have a migraine or if I have shooting stabbing electric pain, I know what to do in those different situations.

Health Hats: Is all that information in your head?

Barby Ingle: Now it is. But when my pain is at its most severe, I need my caregiver to know this information as well. But in the beginning, I kept journals. I would say this is what happened today. These are the things I did or tried to do. This happened as a result of whatever. I would keep track morning noon and night. My pain levels were based on the pain scales 1 through 10. I don't like that pain scale. I think that a pain scale needs to be redone and not be linear. Needs to be more of a wheel or a circle. I'm working on a project that does just that. Quantify and qualify what pain is and what it means. As a child we're taught the doctor knows everything. Now I know there are over 7,000 rare diseases. The doctor doesn't even know all of the nonrare diseases, let alone the rare diseases. You have to be your CEO. You have to be your chief of staff. You have to be involved so that you are getting the best care and that you don't get stuck in a pattern of care where you've been doing the same treatment for 5 to 10 years. Because new things are coming down the pipeline and if you're not up on technology and you're not up on the treatment options and medications you're going to get stuck. There could be something better for you that could give you more in daily life.

Physical solutions to pain 10:35

Health Hats: What's something that you commonly use that's not pharmaceutical?

Barby Ingle: Every day I use things that are not pharmaceutical. Most of the treatment options, in the beginning, they offered me were pharmaceutical. Now I use posture apparel. I use an oral orthotic. I don't have it in right now because it does change my speech a little bit. But it's this little device that my neuro-dentist, a specialized dentist, makes that lowers brainstem inflammation. I use that daily so that I don't have to take medications daily. And I use heat therapy. I use Aqua therapy or water aerobics therapies, stretching, massage, virtual reality. I love virtual reality and mind games.

Corsets and back braces are examples of posture apparel. I'm not sure what Barby is using. A neuro dentist takes the approach that teeth, muscles (associated nerves) and the joints, are taken into consideration as an interdependent unit. I use a foot ankle orthotic to prevent foot drop. Barby uses an oral orthotic. People getting braces put in often use an oral orthotic. The brainstem is responsible for vital life functions such as breathing, heartbeat, and blood pressure. Inflammation of the brainstem is life-threatening.

Virtual reality therapy 11:20

Health Hats: How do you use Virtual Reality?

Barby Ingle: I use virtual reality in my everyday life, but I also used it during infusion therapy. I also have an epileptic condition called migralepsy which is a rare type of epilepsy. So, I have to be careful with the videos I do watch. My husband and I create videos that are soothing and visual. Something like going through an aquarium, swimming with the dolphins or the manta ray. I know what I'm going to be watching, so it doesn't set off the seizure but are smooth and take me through a moment where I can escape from thinking about the pain or focusing on the pain,

Health Hats: Did you have an experience where you happen to be looking at dolphins swimming, and you felt better, and then you thought, "oh my goodness this helps?"

Barby Ingle: I was on stage. I used to be on stage all the time. I had gotten back on stage a couple of years ago, and when I got off of the stage, I had the highest level of endorphins that I've probably ever had in my life. I took all my other performing for granted and this time getting back to performing I walked off the stage and had this most amazing feeling. If you could bottle this, you wouldn't need medication for pain. I started looking for things that could increase my endorphins. Being happy, laughing, soothing myself through virtual reality, putting myself in another world, because you can't just create a stage in your living room. Being in an environment with virtual reality - finding ways to increase my endorphins which being in that virtual environment has helped.

Health Hats: Wow. How about the mundane logistics of there is so much to manage? Whether it's appointments or it's treatments or its just whatever - life. Not only are you dealing with all your medical stuff, but you have a busy advocacy and other life. How do you manage all that? Do you use tools to manage that or are you a calendar person? Are you a list person?

Reality TV 14:49

Barby Ingle: My superpower is organizing. I was already organized in life before I got sick. I had this time in my life where things went bad, and I had given up my life to let other people try to make me better instead of being my advocate. So, when I got back to organizing and color-coding my calendars and scheduling everything, and I mean everything in life you can imagine. That's one of the reality shows we did was Extreme Time Cheaters.

Health Hats: Extreme Time cheaters?

Barby Ingle: When we sign up for the show, it was actually Time Savers was the title, but then they wanted to be sexier and more appealing to the public and make them think that we were talking about cheating. Really, we were talking about cheating time. It was a great way to show that if you are a chronic patient, this is some things that could happen to you in your life. They took it to the extreme and the show didn't necessarily say the reasons why I wear flip-flops. They used it as a time-saving tool, but I wear flip-flops because shoes give me a worse day. They physically make me nauseous and vomit from binding my feet. I wear flip-flops or no shoes at all because it feels better for me and they put it into the storyline. But being on a reality show was a way to share my advocacy and create endorphins.

Color-coding my life 16:26

Health Hats: As you're going through your day and you have questions for your team, how do you do that?

Barby Ingle: I keep lots of lists. For instance, with my medical providers, I created a one-pager. In between appointments, I write when the questions come up. I write them down. Or I text myself a message.

Health Hats: That makes sense.

Barby Ingle: I do have papers all around me and notes and things that I need to get back to. Or I'll put them into my calendar in the color-coding. My closet is color-coded. Everything is color-coded. I create that one-pager for my provider, and I will mark down all the things that the doctors asked you on your medical visits. They'll say list all your surgeries. For ten years you're asking me about all my surgeries. I'm not going to write them down every time, but then when you get into an insurance situation, if you don't complete the information fully, they will say why are there these discrepancies? So, I have that one-pager and all that is vital information is on there along with the questions to ask the provider at that visit. I don't want to leave without getting information that I need or discussed.

Not everyone wants, needs help, your help 19:59

Health Hats: Let's shift from inward-looking to outward-looking. You've been talking about being the chief of staff. You've learned to do that. So, when you work with people and do your advocacy work, how do you gauge where people are in being their own Chief of Staff? How do you do quick assessments?

Barby Ingle: I would give them a small task or a small idea and see if they would follow through on it. I had to learn that as an advocate, not everybody wants help. Not everybody needs help. Not everybody wants your particular help. I try not to take that as something against me. It's just the fact that not

everybody's ready for it. One of my best friends has a port-a-cath like I do because I have vascular constriction. She has the same condition. I got mine and she saw how easy it was for me to improve the care that I was receiving yet she wasn't ready for something like that.

Health Hats: I missed what it was. a port-a-cath? Like a central line?

A port-a-cath is a device placed under the skin in the right side of the chest. It is attached to a catheter (a thin, flexible tube) that is threaded into a large vein above the right side of the heart called the superior vena cava. As Barby said a port-a-cath is used to give intravenous fluids, blood transfusions, chemotherapy, and other drugs. It is also used for taking blood samples. Vascular constriction is narrowing of blood vessels. I don't know for sure, but vascular constriction likely contributes to Barby's brain stem inflammation, migraines, and epilepsy. None of this is fun.

Barby Ingle: I had a period of almost three years where they could not do a blood draw. They could not give me medications. I woke up during a surgical procedure because my vessel constriction was so bad. It was horrifying. It was a horrifying experience, but since I got the Port-a-cath placed I've been able to do my infusion therapy, surgical procedures, testing, blood draws all of that through there. She saw me go through this process. I gave her and other people the information. Here's my story. Then finally one day she was ready to do it. Now she says, "I don't know, I just was afraid. I wasn't ready. "

Health Hats: What you're doing is you're assessing where people are at by asking them some questions, by describing a scenario and see how they respond?

Barby Ingle: Yes. And saying this might not be right for you. Don't do it because I did it. Do it when it's right for you. To do it when you're ready. When I first started advocating, I would be upset that somebody wouldn't take my advice. Like I'm literally giving you the key to life, and you don't want it?

Health Hats: We've been in that situation where my wife has got great ideas. Half the time I'm not interested, and I think oh my God, I'm such an idiot, but whatever.

Barby Ingle: My caregiver is my husband. He'll say, "you have a migraine. Have you done this? Did you do that?" giving me reminders. But he's had to learn. I want my options, but then I have to be responsible for choosing what I'm comfortable with. That's what I try to let other people know. Learn about their condition. Learn about what the options are for them. Go through the research. Don't be afraid to ask for help if you need it. I know people that are afraid to use a tool in their life - technology or even a cane or a motorized scooter - because they're afraid of what other people are going to think. I say to them, "Do what you need to do to live your best life. Don't feel guilty for riding a scooter. You're not taking somebody else's moments in life away. You're a part of the situation, and you're getting more interaction if you were going to say that.

And now a quick break to hear about our sponsor, Abridge. I see many clinicians on a regular basis, way too many. I'm appalled at how little I can remember when I get home. My wife asks, what did she say? What about this medication or that test? I'm happy to remember half of it. To help me remember everything, I downloaded a new smartphone app called Abridge.

Now, when I go to the doctor, I ask if it's okay to record our conversation. Nobody has said no yet. I push a big pink button to record, and after I'm done, the transcript from our audio appears -- not the whole thing that's too much, but sections around medical keywords like fatigue, pain,

tests, exercise meds. Now when I'm done, I can share my visit with my wife, and she can listen to exactly what the doctor said. Abridge was created by patients, doctors, and caregivers. Check out the app at abridge.com -- [a b r i d g e .com](http://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!

Kids learning to take charge 24:27

Health Hats: Do you have kids?

Barby Ingle: I don't, but I have seven nephews and a niece.

Health Hats: Okay, so if you think about your nephews and niece and your thinking about them being more ready to take charge of their health. How would you think about doing that?

Barby Ingle: I have a very good example of this. So, there are eight total kids in the family. I did not interact with the first four. All their parents knew was, "don't touch Aunt Barby. Keep quiet don't play around Aunt Barby. They couldn't have fun with Barby. So, I have virtually no interaction with them even to this day almost 20 years later. With the four youngest ones, we set them down and took them from birth what to how to interact with me. How you participate with me. I can play Connect Four. I'm the Connect Four Champion. So, we taught them Aunt Barby can play. But this is how to do it. Now they know when they're having a bad day, they can stop and say, "oh, I need a break. I need to calm down my senses." Teaching them from youth made all the difference in how they helped me, but also, how they verbalize and help themselves when they have a stomachache or a headache or something that a child doesn't necessarily know how to verbalize. To verbalize it and they live better lives because of it. So, I think the younger you can teach or set the expectation the better off everybody's gonna be with their own health care.

Hope and help 26:50

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

Barby Ingle: People need to know that there's hope and help out there. Hope and help.

Health Hats: Hope and help.

Barby Ingle: Hope and help are two things that even the smallest glimmer of hope can get you through the worst situation. I guess where I find my hope and each person would find theirs in a different place. I've realized what my purpose is in life. Knowing and living and acting towards my purpose increases my hope and asking for help. It's coming up with the vocabulary to ask for help that takes practice and patience.

Health Hats: It does. You know that putting it at a different light. So, we had a son who was sick and died of metastatic melanoma. People are lovely. During his last months' people wanted to help. We had no idea what to say. We had to practice with Mike. "Here's a menu of things that would be helpful." We had to come up with three things, a range of things - not just food or not just the Marx Brothers movies or could you do this errand? But a range of things because people want to help.

Barby Ingle: You have to think biopsychosocial and maybe even spiritual. What's missing from your life in those areas that other people could help. It could be something that means the world to you and

gives you a better life, a better moment — time changes when you have a chronic illness. Time goes from unlimited to moments. When someone says what can I do to help or when you're specifically asking somebody for help if they say sorry, I can't do that. Well, could you do this? Just because they had to say no in the moment didn't mean that there was something against you it wasn't first. They made that may not be their expertise, or they may not be able to provide you that resource, but they could do something else.

Health Hats: When my mom was dying, people would say, what can I do? And she said you want to sit here for five minutes and hold my hand. Who can't do that? It's great. I have a grandson who lives upstairs. He's 12. For Christmas, he gave me a coupon book that has walks with him. He's known since he was young that I'm trying to get my steps. He could be buried in his video game and whatever screen. I'll say, "you want to take a walk with me?" And he will put it down and go, "Yes, I can help you get your steps." Even though I never said anything about steps. Then when he wanted to think of a gift for me, it's this coupon book with five coupons to take a walk with him. It's just beautiful.

Barby Ingle: That's amazing. That's the empathy and the understanding that you're instilling in him. You're planting a seed. When he needs someone to take steps with him, he'll better be able to ask for it and recall it and know what to do in a situation. It grows into a tree. We need to refocus how we talk to children about health's different aspects. Health means posture and drinking water. I drink enough water. Most people are not drinking enough water.

Health means drinking water 30:55

Health Hats: I think it's just I love that 50% of what ails me if I drink some water? I feel so much better. I think, oh my God, there are no side effects. It doesn't cost me anything. Water.

Barby Ingle: Yep, I even put an app on my phone for drinking water. I do drink plenty of water, but it was how I was drinking the water. Every time you drink the water, you put it in the app. Well, I don't like drinking water. I just know that I need water. I will down 8 to 16 ounces in a minute less than a minute. That's not the same. My app said, "great job on your water intake you need to slow way way way down. Do this over time." Because your body has water and then it doesn't have water. That's not what your body needs. It needs water slowly over a while. And so I use that app to help train me to spread out the amount of water I take in. The app said I was in the top 100 percent of people that water themselves.

Health Hats: I'd like to see that on your resume.

Barby Ingle: I took a screenshot and posted it on social media. I'm in the top 100. I'm in the top 100.

Health Hats: Barby, that's a riot - water. All right, one more question. Do you want to ask me anything?

A bit about me 32:40

Barby Ingle: Well, do you have a medical condition assign a are your health hats? So you wear a lot of hats. Do you have multiple sclerosis?

Health Hats: Secondary progressive multiple sclerosis.

Barby Ingle: And you're able to walk? Have you found something for yourself that has stopped the lesions from forming or helped you, that sharing might help other people?

Health Hats: I have secondary progressive multiple sclerosis. It's progressing very slowly. I attribute that to a couple of things. One is the infusions I get. My mobility is probably my most visible and dramatic effect of multiple sclerosis. I've gone from no canes to 1 cane to two canes. Now I'm a two cane and electric wheelchair guy. But I have my 3,500 minimum steps walking a day. I have a trike that I ride. I believe that I got to use it or lose it. I play the saxophone. That helps me. It helps my brain and my spirits. It helps my lungs and my dexterity because a baritone saxophone is a big horn.

Barby Ingle: I can see how that would help with the breathing oxygen into your body.

Health Hats: Taking deep breaths and the dexterity. It affects my intercostals, my chest muscles, and my fingers. I feel like I've held off the progression with that.

Barby Ingle: That's amazing.

Health Hats: Well, Barby, thank you for taking the time. I appreciate it. I'm glad we got the chance to meet after our virtual relationship.

Barby Ingle: Absolutely. It's a little different when you meet in person. The most common comments I get when I meet people in person is, "you're so short." I'm five feet and well-proportioned. So in photos, I look six feet tall. But I'm five feet.

Health Hats: I won't hold that against you. Thank you. Take care.

Reflections 35:30

I'm breathless. Barby has always been a dynamo – think cheerleading, public speaking, writing, videos, color-coding everything. I particularly appreciate that Barby harnessed her inner dynamo, endorphins, turning that engine into solutions to manage her pain and grease her life frictions. Her transformation from her eight-second life-changing accident and feeling overtreated, undertreated and mistreated to reality TV, hope and help, virtual reality. Let me take a breath. What's the lesson from Barby besides go, go, go? A repeating thread in the tapestry of chronic illness, disability, and pain management: take control, be the CEO, and drink water (don't gulp it, sip it)