

Transcript: **Gone From My Sight: Barbara Karnes on What Happens in the Final Days of Life | Part One**

Cause And Purpose Opening

Melody King 0:00

Everything rises and falls on leadership. The ability to lead well is fueled by living your cause and purpose. This podcast will equip you with the tools to do just that. Live and lead with cause and purpose. And now, author of the book *The Anatomy of Leadership* and our host, Chris Comeaux.

Chris Comeaux 0:21

Hello and welcome to TCN Talks. I'm excited today. We have a very special guest. We have Barbara Carnes. She's an end-of-life educator and a true hospice pioneer. Welcome, Barbara.

Barbara Karnes 0:32

Oh, I'm excited to be here. I think we're going to have a good talk.

Finding Hospice Before Rules Existed

Chris Comeaux 0:37

I think we're going to have a great talk. I just want you to know, I'm just honored that you would take time out of your schedule just to be with us. I feel like you're such an amazing icon for the whole hospice field. And also I feel like you're a unique bridge because you knew some of the matriarchs and patriarchs. And so I'm just looking forward to a great discussion. Let me read from your bio first. So Barbara Karnes has had to do with death and dying much of her life. She's an RN. And anything going on in that field, she's been talking about it. Her articles have been featured in the *New York Times*, *USA Today*, *Huffington Post*, *Thrive Global*, and the *Washington Post*, just to name a few. She was awarded the NHPCO Innovator Award for her decades as an end-of-life educator and for her iconic booklet, *Gone From My Site, The Dying Experience*, aka *The Hospice Blue Book*. Barbara's career spans four decades and began as an early hospice pioneer during the AIDS crisis. In addition to many years she has spent at the bedside caring for patients and their families as a nurse. Barbara has also served as the executive director of a hospice in various home health agencies. So she's done the work. She has worked through the

hospice ranks as a patient care manager, clinical director, staff nurse volunteer. And Barbara is a dedicated end-of-life educator, training professionals, authoring resources, materials booklets, movies, and her award-winning blog. So Barbara, again, it's so good to have you. Oh, I'm excited to be here. Well, take us back to the beginning. What first drew you into this hospice work? And, you know, for our listeners, because many of them are like that young generation of hospice staff now. So what did hospice feel like in those early days when the movement was still being formed?

Teaching Communities What Hospice Means

Barbara Karnes 2:19

Well, let's start with the your first question, which was, how did I get started in this? What where did that come from? I grab now, here's a date, 1962. I graduated from nursing school and thought, oh my goodness, I've made a huge mistake. Should have never been a nurse. Actually, I should have been a social worker, but I never worked as a nurse in a medical setting. In hindsight, that's the gift that I brought to end-of-life work because I had no role model on how the medical model took care of people who were dying. So when I got involved, I literally made it up as I went along because I hadn't, there were no guidelines. You know, um, people didn't deal with death. Um, used to be grandma lived at home and she died in the upstairs bedroom. But then our medical model took grandma to the hospital where she died, a nursing facility where she died, and she was in a room at the end of the hall and by herself. And we didn't learn, we didn't have any role models. We didn't learn how people died because we weren't there. We've come full circle now. We are now at home, a lot of us are. And at that same time, Dame Cicely Saunders in England was developing a concept that she called hospice, and that was to take care of people who were dying. Those two concepts um sparked my interest. I thought, wow, this is something I want to do. So that's what led me to um to hospice and to end of life work.

Chris Comeaux 4:50

And just what was it like in those early days? I mean, I know you said, you know, we had to make it up as you went along and didn't have a lot of resources, but just say a little bit more about those early days.

Becoming The Family's Invisible Conductor

Barbara Karnes 5:00

Well, number one, we had to teach people how to say hospice. A lot of it was hospic, you know. Hospic. Yeah, couldn't understand it at all. Um, and the medical model didn't really

understand hospice. So doctors didn't really understand hospice in those early days. Community education was our biggest, strongest tool so that we could teach people that here's what we can do when the doctors can't fix you. So once we taught and got out there, um, then we would get referrals. And um the key there was we were working with people that were struggling with a life-altering, literally, not just for the patient, but for the caregiver. And because we don't have any role models, what it's like to die, um, families are terrified, still are. Um, but when we started, that was the key, the key thing, I hate to use the word thing, but that we focused on was being there and supporting the family and the patient. We learned early on that it wasn't just the patient that we were taking care of. We learned really, really right out of the gate that it was the caregiver, the family, that needed as much support and guidance as the patient did. Because the patient's withdrawing and will be at a point where they're non-responsive. But the family, the watchers are there the whole time. And so education became a key point after we, who are the front runners, learned what dying was like. And we learned because we were at the bedside. I want to say, and this is so important, everything we do in end-of-life work leads up to the moment of death. That's why we're there. That's what it's all about. Before death leads up to the moment of death. Then at the moment of death, our work gradually decreases and and diminishes. But the moment of death, and sadly, a lot of people now are alone at home at the moment of death. And hospice is about the moment of death and what to do and support and guide. So we teach from the moment we're in the door, and that's what I learned when I started.

Chris Comeaux 8:19

That's interesting because I think, you know, I hear it's so cool being with you because I've grown up now in this for 30 years. And so just we think of the two bookends that each of our lives represents. But I'd say a lot more of my peers today would say, yes, it's about the death, but it's so much about the journey, you know, getting to the death. That, you know, one of the adages the first hospice I worked for was you add life to days when days can't be added to life. So there's so I don't feel like you're dismissing that. It's it's almost like, let me tell you, I'm gonna tell you what's in my mind, and you please push back if you disagree. It's like we're preparing for this big show because it is the big thing. The family's worried about it. It's it's the death. All the preparation, when all the preparation sometimes, the show is almost an afterthought because it's all the preparation that kind of made it the show that it was. Is that the way kind of you're framing it? Because you know, if you've got a good three months with a patient and family, yes, 90 days and the death represents just a small moment.

Barbara Karnes 9:20

It does. And we have to concentrate on preparing the caregiver to educate the caregiver. Here's what mom's going to do. And we say that in the months before death, and we say,

here's what you can do uh during the months, the weeks, and the hours before death. So, yes, our teaching and guiding occurs up to the moment of death. How many times have you walked into a room? And I will say I have walked into a room, and the the mom's actively dying. We're talking minutes to hours, and everyone family is standing around the periphery of the room, and generally they have their hands closed and they're standing there because they don't know what to do. And we need to guide them and say, hey, you can get in bed with mom if you want to. Hold her, hold her hand, talk to her, have the dog on the bed, play Rod Stewart. You know, we can give that the instructions ahead of time. However, when the moment comes, the family will be emotionally uh confused, they will not be thinking mentally, probably at all. Their heart is crying and screaming, and they need a conductor. They need a conductor there to guide them, this invisible conductor who stands on the outside of this family circle, who can guide and support the family um during this life-altering time, literally I life-altering for everyone in the room.

Lessons From Elizabeth Kubler-Ross

Chris Comeaux 11:30

That's a beautiful metaphor, the conductor in the room, invisible conductor in the room. I love that. Um, I do want to, you've touched on this, but I want to go a little bit deeper. You had the rare experience of meeting and learning from Elizabeth Kubler-Ross. What was she like in person and what did she say or do that just stayed with you for the rest of your career? Elizabeth was a piece of work.

Barbara Karnes 11:54

She um I spent I went to her life, death, and transition five-day workshop. We went, slept in a monastery. We were, there were probably eight of us, eighty of us, and we were all together. Um and she was dynamic. Um, you know, we all just kind of hung on every word, but she was unpredictable, and she was kind of scary there were because what she thought came out of her mouth. I I just was in awe and she got me there, and she held on to me emotionally in my mind for the rest of my life.

Chris Comeaux 12:44

Um she was a true pioneer. What are some takeaways or pieces or pearls of wisdom that you still draw from?

Barbara Karnes 12:54

Let me tell you a story. At this workshop, she had all of us there draw a picture. Said, you can draw anything you want. Draw a picture. And then so we did. And she took the papers and she's sitting up at the front of this big room, and we're all circled around her. And she

goes through the pictures. She pulled out my picture and she said, Holds this up, and it's a picture of um a field and a tree and the sun and two little birds flying toward the sun. And she said, This picture means that you have two things you've come here to work on. What are they? Well, I didn't have a clue. I came there to learn from her about dying and not about me. And what she said, and I did find the two things that I came to work on. But what the key thing that she said was in order to help others, you've got to know and help yourself first. That we all have what she called black bunnies in our life, challenges that we haven't worked through, and that in order to help someone else, we have to have our slate as clean as we can get it. I think that's the biggest memory I have of her teachings that has the most profound effect on me.

Chris Comeaux 14:47

That's beautiful, Barbara. And I feel like so need it, because I do see we get a lot of wounded warriors that get attracted to this work, I think, because the beauty and the compassion. But if you don't do some of that self-work, it could become a selfish way of trying to deal with it. Like you don't realize what you're trying to do is fix yourself by caring for someone else, but yet you don't do your own internal stuff. And in many respects, that's a whole life journey, right? There's, I like the way you said it, kind of getting your slate clean. But many of these wounds from the past, it's a lifelong process. But many people come to the work that they've never gone there, and just the work is the way they think it's going to heal them. But yet you do the more of that self-work you do, you can show up more beautifully by the bedside and be that amazing, invisible conductor facilitator of a beautiful ending. In some cases, people live in the last 90 days of their life, if we're blessed to get them for 90 days, more than they have in many other parts of their life if we do that well. I see you're shaking your head. Does that resonate? Absolutely.

Person First Not Disease First

Barbara Karnes 15:51

Absolutely. Um we have to know who we are as professionals um or as volunteers that work with end of life, because there will be triggers, there will be occurrences that will trigger our black bunnies unless we've sorted it out and come to terms with it. Um, because we want to be the best help and support that we can for these families and for the patient. That's why we're there. Um, so we've got to clean our house first.

Chris Comeaux 16:35

That's so good. When you think about Kubler Ross and some of the other early pioneers that you got exposed to, what do you think they got right that we've preserved? And what do you think we've lost or drifted away from that maybe we need to return back to?

Barbara Karnes 16:52

Hospice worked outside of the medical model. The medical model takes care or addresses diseases that people have. The medical model addresses diseases. The end-of-life model addresses people that happen to have diseases. Now, with that foundation, what's happened? So in the 70s and eighties and nineties, hospice was outside of the medical model, but gradually it's become absorbed into the medical model, and as it's become absorbed, then we I think are more medically addressing situations than we are um personally um addressing the person that has the disease, addressing the family, the caregivers that are dealing with it. Dying is not about the disease, the pain is not caused by the disease. It is caused by the disease. It is not caused by dying. Make sure that's clear. So we as an organization, I want to see us focusing on the person and the family, and not as much emphasis on the medical.

Why She Wrote Gone From My Sight

Chris Comeaux 18:40

That is so good. Some of the training that I do, Barbara, I'll quite often, because I get to train a lot of nurse leaders, and I'll say, I'll make a bet with you. I've not met you before. I'll ask how many of you were in the hospital, and many of them will raise their hand and say, I'm gonna make a bet that at some point in time you referred to the patient as the heart patient in room 304. And of course, they all raise their hand like, kind of like, how did you know? Like it's the it's the paradigm that you were put in that looks at the patient as a disease. Think about it, they're not even, you know, Barbara Kearns. It's it's this disease down to an organ that's actually this eased. And so looking at someone, their whole story, one of the hospices I worked with, this funeral home did something beautiful for us in a partnership. Of course, what they were after is they wanted us to refer to their funeral home. But they provided these storyboards and they asked the family to give them pictures that told the story and they would put it on a storyboard. So when anyone walked into the home, you walked into their story of their life. It was so beautiful. And I've always joked that I want to work with one of our EMR vendors. So when you first open up the before you get to Mr. Jones' medical record, you walk into the story because it was such a powerful metaphor. And it it was never lost on me of the wisdom of what they were providing to us that then we were providing to our families. And we told our staff, when you walk in that home, you make sure you look at that board because you're walking into that story. Ah, beautiful. I love that. Love, love, love. So at some point you

made the shift from bedside care into writing for the public. What was that moment where you realized families need something we're not giving them? Okay.

Barbara Karnes 20:16

This is during the five years that I was direct patient care. Uh is before I got into administration work. Okay. So I'm at the bedside. Three o'clock in the morning, I'm on call, I get a call. Uh, and what I learned really, really early was if I didn't go to the home at three o'clock in the morning, no, even if I thought it wasn't a big deal. If I didn't go, I was probably gonna find mom uh in the ER at seven o'clock in the morning because families are scared. It isn't so much about what's going on, it's that they're afraid. They don't know what to do. So three o'clock in the morning, I am in this patient and family's home. Uh mom is days, yeah, probably days from death. Um, no real crisis. And I now I'm sitting in the in the living room with the family. And I'm explaining here's what mom's going to do, here's what she's doing now, here's what you're gonna look for as she progresses. And one of the daughters was taking notes, and I thought, ugh, what is wrong with this? She shouldn't have to be taking notes. So that weekend, and this is before computers, um, that weekend I sat with my little yellow legal pad and wrote out what I wanted families to know. And then I typed it up on my typewriter and made copies and handed it out to families. My families that I was working with. And then I thought, as I've been doing this for a while, this is so impersonal to just hand them a sheet of paper and talk about it. So one weekend with my yellow legal pad, I wrote Gone from My Science. And I wrote what I wanted families to know. I wanted it to be fifth grade level. I wanted it to be short and gentle. So that no medicalese, no medical terminology, because most people don't understand med I don't understand medical terminology a lot. So we can't expect our families and our caregivers to. So that's how gone from my side came to be.

Chris Comeaux 22:54

That's so cool. You know, I I would hopefully you would agree. I think it's become a sacred resource in hospice. People call it the little blue book. Did you have any idea that like what you were working on would become as widely used as it is today?

Barbara Karnes 23:10

Absolutely no idea. I had absolutely no idea. I did it for my patients, kind of the rest of that story.

Chris Comeaux 23:19

Yeah, please.

Barbara Karnes 23:20

That I took my hospice director and said, I would like you to print these so that we can use them for our patients, because there was another nurse and he read it and he said, No, no, I'm not gonna do that. And I said, Oh, really, you can do anything you want to with it. I you know, I don't want to little red hen, okay, I'll do it myself. And I did. Um, so looking back, he did me a huge favor. Um, because I left them a couple years well, I was the their I ended up being their director uh and did use it uh in our hospice. But um he really did did uh me a favor. Uh just didn't know it.

Chris Comeaux 24:13

How many copies do you think? How many copies have you sold of the blue book? Gotta be in the millions.

Barbara Karnes 24:19

It is. We're we're looking at maybe 25 to 30 million in 12 languages. It's all over the world.

Millions Of Copies And A Field At Risk

Chris Comeaux 24:27

My nurse mentor, Barbara, I didn't tell you this when we met the first time and asked you to be on this podcast. My nurse mentor, I was 25 when I came into hospice and like I wanted to learn. I I didn't, I took it as a job in full transparency and then fell in love with the mission. I was on the finance side of the house, the CFO of a hospice, but I had this incredible nurse mentor who interestingly was in our finance department. Like, you know, why do you have a nurse in the finance department? But she became my mentor, and the blue book was one of the things that she gave me. She said, as a tool, just to help understand what this was really about. And of course, she made me go out on patient visits. Shouldn't say made me, I mean I wanted to, um, to really understand what this was about. But that was a great gift at the age of 25. And, you know, as part of my own orientation to what this work was all about.

Barbara Karnes 25:13

And wouldn't it be nice if every 25-year-old had the opportunity to read *Gone From My Sight*? Most of us don't deal with or think about or address end of life until we're in a position when someone close to us is dying. Where if we have the knowledge ahead of time, it will give us a more of a foundation for supporting uh the person that's close to us. Um when you don't need the information is when you can really process it. When you're emotionally involved, things get a little muddy because our emotions get in the way.

Chris Comeaux 26:09

That's what you know, you're just making me reflect. It probably was the perfect time. And you know, I've I've had been so blessed to do this for 30 years, and I have such a unique kind of pathway because coming up on the finance side of the house, many people would say that's what's wrong right now with this whole field, is you know, 70% of hospices in America are for profit, meaning uh run by private equity. It's become a bit of a racket in some places in the country, especially when you look at some of the fraud and abuse that is so far away from the essence of what you and I are talking about in this conversation. But I look back and go, it was the perfect time to expose me. And I think over the course of time, it has helped me work through my own stuff. I think it's helped me be a better human just in the work that we're that I'm doing. So thank you. And just I'm reflecting on all that in this moment, just the the the way it's impacted me over the years.

Jeff Haffner 27:02

Don't miss part two of this episode coming this Friday.