

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

Welcome Part Two Setup

Jeff Haffner 0:00

Welcome to TCN Talks, and Anatomy of Leadership. We continue the conversation in Part Two of *Gone From My Sight: Barbara Karnes on What Happens in Final Days of Life*. And now, here's Chris Comeaux.

Chris Comeaux 0:19

So as we go into this next segment, you know, one of the things that you do brilliantly is explain dying in plain non-clinical language. Why is it so hard, do you think, for healthcare today to speak clearly about death? And what have you learned about what families need to hear that enables you to be so poignant, so plain, so clear?

Saying Goodbye And Easing Grief

Barbara Karnes 0:43

I think a key thing that families need to know is that people don't die like they do in the movies. Um, because what they expect is to see Judi Dench say some profound words and then she's dead. And that's not how people die. And yet we don't know, except for the movies. So when mom is peeing and pooping the bed and talking to, you know, the wallpaper and moving around, and we think something pathological is happening. We think something bad is happening because she's not dying like Judi Dench did. So education to teach and use that example, that's the exact example I will use with caregivers and families. And mom's doing a great job. This is how people die, which is gone from my sight, takes you up to through the moment, the last moment of breath. Um, so that if we take the time to educate caregivers and family that are dealing with someone, their special person dying, we can neutralize the fear that every single one of us, even with all of our knowledge, we're gonna be afraid when it comes time to die. Don't remember having done that before. And anytime we do something new, no matter how much knowledge we have, we're gonna be scared, you know, if not downright terrified. So, education that's the key. Um, and like I said, before we need it's great, but certainly when we need it. And if we have a referral early enough from the time the doctor says, I can't fix you, and you say I still want treatment, so you're in palliative care. That's when

you want to start giving the support and the knowledge. Um, and then for sure, when they come on hospice, you want to support and guide and educate that family so they can get beyond the intense fear that they're gonna bring and have some tools. You're giving them tools on how to live through one of life's most normal experiences. We are born, we experience, and we die. It's the name of the game. We're all gonna do it.

Chris Comeaux 3:47

Something's occurring to me just listening to you. Do you know Dr. Ira Byock? I'm sure you do. Sure. Have you and our ever been like, because you've spoken all over the country. Have you found ever found yourself? Did you ever present together out of curiosity? Or we did not.

Barbara Karnes 4:01

No, I'm assuming he knows who I am.

Chris Comeaux 4:05

Like I wouldn't I'm sure he knows who you are. Here's why I'm saying that. You know, first off, are you familiar with Ira's book, *The Four Things That Matter Most Before Every Person Passes*? You need is probably one of the things I've recommended the the most, the friends and family. Hey, before they pass, I love you. Please forgive me, I forgive you and thank you. If you could articulate those four things, if they get mirrored back, that's awesome. But if you could articulate that, and you know, Dr. Bayak is is pushed the field of hospice and body care. Like there's a whole evidence-based medicine, and so he represents that. But I find the thing people remember him the most for is the four things. Whereas I feel like you you're bringing us back to the beauty, the simplicity of this beautiful thing that we get to be Sherpa's Shepherds, part of that process. Does that feel accurate to you, or would you say any of that differently?

Barbara Karnes 4:59

I would not. I you just said it beautifully, because that's what my wish for every person in the world is that they will have at the time of their death, that their caregivers and their loved ones can know how to say goodbye and to be able to live with their grief, because grief's another whole topic. Uh, but um I think the the more profound and involved a caregiver and family is with the moment of death, then the that emotion is stabilized, maybe.

Chris Comeaux 5:55

The sting is not as bad, maybe.

Barbara Karnes 5:58

Yeah, it there. I like that. The sting is not as bad as we learn how to live without this person in our life. Um, it's when we've had a bad experience with our special person dying, and often that's because of lack of support and education. But when we have that bad experience, oftentimes people carry that memory, the bad memory, with them forever. That just, oh, you know, that doesn't have to be like that.

Chris Comeaux 6:37

No, that's why we're doing this work, right? Or is why we should be doing this work. There's some elements in our field that turned it into a business and a racket, but this is the true essence. We're at the the true point of what this work is supposed to be about. You alluded to this, but I didn't even ask you this when we first met. How many other languages has it been trend translated into? And do you know what your sales are outside of the United States like? And who's buying them? Are people just buying it as a resource, or is it powder cure associations in other countries?

Barbara Karnes 7:10

Other countries, there's I think there's 12 languages that it's translated into. Problem. And yes, we sell all over the world, but the problem shipping, cost of shipping. So that's a challenge. And but we've had you know daughters here from Australia. Australia orders quite a bit, actually. Um, but I think it started, I'm not sure. Anyway, daughters here from Australia, mom dies, she takes a hundred gone from my site back with her. So you can bypass the that's the challenge.

Food And Sleep Changes Near Death

Chris Comeaux 7:57

Yeah. So one of the most painful, maybe misunderstood experiences for families is when they're watching their loved ones stop eating and drinking. You have taught for years that the rules for food at the end of life are very different, very unique when someone, as opposed to maybe someone who's expected to recover. So, how do you help families understand what's happening and how not to interpret this as we're starving them? How do how do you walk them through that?

Barbara Karnes 8:24

Well, education gone from my side. But here's here's the thing. In the months before death, and I can't say strongly enough, never put a number on how long someone has to live. We cannot be so specific as to say six months, three weeks. We can't do that. We can go months, weeks, days, and hours. But in the months before death, you're going to see three things start happening. A person's eating habits change, a person's sleeping habits

change, and their socialization changes. Now, we talked earlier about birth and death, and that they're opposite ends of the life spectrum. But think of birth. A baby gets into this world through labor, works hard to get here, the first thing he gets is water, then milk, then soft pablum kind of stuff, soft foods, and gradually they get to regular foods. Same with sleep. Get here, sleep all the time, then gradually they're awake more and more until they're in their active life pattern. Socialization. First, it's nobody because they're still trying to wake up, then it's mom, then it's family, then it's neighbors, then it's a community, and then it's the world. Now, turn that around. In the months before death, from disease, for old age it takes longer, but from disease, three to four months before death occurs, a person's eating habits change. They stop eating meat, then it goes to fruits and vegetables and soft foods. Then you're doing good to get insure plus liquid down them and then water. Sleeping. First, it's a nap in the afternoon. I'm just so tired months before death. And then they're reach a point where they're asleep more than they're awake. And then they're asleep, they're non-responsive. Socialization. It starts off with, you know, don't have the church ladies come over. Um, I'm too tired. And then it's um don't have the grandkids come over. They make me nervous. And then we go completely within. So you can see the natural progression of leaving this world is exactly like how we got into it. We are born, we experience, and we die full circle.

Chris Comeaux 11:43

That's great. Such wisdom. You know, another fear that we hear in patient family surveys is around the whole pain medication thing. Families worrying about morphine, comfort meds that is actually hastening, speeding up death. How do you explain the difference between comfort-focused pain management, pain medication at the end of life versus treatment that's aimed at a cure? And what would you want families, even clinicians, to understand about that distinction?

Barbara Karnes 12:11

Dying is not painful. Disease causes pain. If pain is not an issue, then in when labor begins, uh, one to three weeks generally, the body may feel tired, um, ache all over, kind of like if you have the flu. Well, you wouldn't take a narcotic if you had the flu, but you could take a couple ibuprofen, a couple advil, um, and that would bring a little comfort, okay, to let if pain is part of the disease process, then you're going to treat that pain until the last breath. Because just because the person's non-responsive doesn't mean the pain's not there. The pain, if it's part of the disease process, will increase as the disease progresses. It's the disease that's causing the pain as it works on the body. So that pain is going to increase. So you've got to increase the pain medicine. The thing is, we have to teach our families about end-of-life pain management. We have to teach our families about appropriate use of morphine. Because weekly I get emails saying a hospice killed my mom and it's because she was dying and they overdosed her and she died. It's their fault. That

tells me there wasn't enough education. That tells me that there wasn't enough contact um with the family. Uh, and that's that's so sad. I mean, that's it's just that says we didn't do our job.

Hospice As Sacred Work Not Business

Chris Comeaux 14:16

You know, Barbara, you're reminding me. Listen to you talk years ago, one of my mentors said that perfect hospice nurse is a combination of a great nurse and a school teacher rolled into one. And I'm looking at you going, oh my God, she's like the poster child. You just have that uh you remind me a couple of my favorite teachers. Um, and just you have a great teaching ability about you. So feel like you're the poster child for that. Exactly. Nurse meets a teacher. Thank you. Which maybe is a good segue to the last couple questions. If you could put one message in the heart and mind of every hospice, nurse, social worker, chaplain, CEOs that are listening, especially at a time when hospice is facing scrutiny change. And there's some people fearful about what the future of hospice is. What would you want them to remember about what hospice is truly here to do?

Barbara Karnes 15:04

It's it's not about procedures, it's not about medicine, it's not even about the regs, it's about a human being that is traveling one of the most significant parts of their life. And we are blessed and have the opportunity to support and guide them during this incredible sacred time, and yet we're getting sidetracked. We're getting caught up in the money and in the regs. And it's it's about the people. And I just it makes me want to cry because we're losing our focus. Uh now I will also say there are ways to to address this um and change. And in my mind, and I appreciate time is a big thing, and that's probably the main reason that family is alone at the moment of death, because hospice doesn't have the time or the employees to let them be there for hours and hours or sleep on the floor like I did. You know, I understand that, but end of life doulas, you can work them um into hospice and into being with the family at the moment of death. Put them on salary instead of hourly, um, and their j introduce them to the family and then say, this person is gonna be with you. Um when mom is is leaving this world in the hours, and here's what you do, and we you tell them, and then they're not alone when when mom dies. There's we can figure it out to get back to being there. Not that doesn't diminish our teaching, it doesn't diminish the visits that we make in the hopefully months before death, but it's just that at that moment of death, in those hours, families aren't gonna remember our teaching. We need the conductor, and that could be if it can't be um our nursing staff for

whatever reason, we can teach, we can use doulas, we can teach some hospices are teaching volunteers. Uh, and it isn't a medical event, it's an emotional, spiritual event.

The Invisible Conductor At The Bedside

Chris Comeaux 18:15

So when you said invisible conductor in the beginning, I guess I maybe misinterpreted. That means like you know, your teaching materials and all of our wonderful work could prepare them that the conductor has is there, but they're invisible because all the preparation. Am I misinterpreting? Because it sounds like you're very much advocating you still need to have the conductor in the room, they themselves should just be invisible.

Barbara Karnes 18:40

Yes, exactly. Um exactly in that there should be someone in the room who is the conductor, but acts like they're invisible. But there's there's healing tools that can be done and offered only at in the hours before death when the person is non-responsive. It's a lot easier to talk to someone who's not going to argue back with you. And in those hours before death, that conductor can get each person there to go in alone and talk to the person that's dying. Talk about the good times, talk about the challenging times, um, talk about the hard times. Um the person that's dying is re has been reviewing their life since the moment of diagnosis. But life is like a billion-piece jigsaw puzzle, and they're putting those pieces together. And by going in and saying, Dad, you know, I wanted to be closer to you, and we just didn't get there. That's another piece of dad's puzzle that he's got. So the person, the conductor, gets each person to go in and say goodbye. It guides them through the moment of death. Okay, dad's gonna take another breath. He's probably gonna move and oh yeah, that spit coming out of his mouth, yeah, that's nothing to worry about. Uh his eyes are, you know, you reaffirm dad's doing a good job. Then that person who's there, that conductor, says, How about everyone go out in the living room, sit there, maybe put the coffee pot on? I'm gonna tidy up in here. Can you tidy up the room, turn out the big ceiling lights, have a have a light on, and go back out and say, before we call the funeral home, how about each one of you go in and say goodbye to dad? You know, we recognized him through his body, go say goodbye and let each person go say goodbye, then call the funeral home. You see why we're talking hours here, then call the funeral home. When the funeral home arrives, you say, you know, you guys stay here. I'm gonna be your representative and I'm gonna go in while they put dad on the cart. You can walk out to the van with them if you want to. So while the funeral home people are lifting that body, you're going to make that bed. And that may be a blanket. That may be a bedspread, you put the pillow there, you make the bed, and then put something special on the pillow. Hospices would be smart if they did this and

had their own special gift to put on pillows. But I've taken pictures off the walls, I put a flower on a flower pot. Put something because rooms have memories. And you want the people to see that room the first time after dad is gone as its own little memorial, as its own little sacred space, because they're gonna carry that first memory of that room with them forever, also. So our work in healing doesn't just end when the person dies. Because the family and the caregivers are part of who we're healing also, and we can really start that grieving process um off on a gentle foot.

Chris Comeaux 23:16

What final thoughts do you have, Barbara?

Barbara Karnes 23:19

That was probably my final.

Chris Comeaux 23:21

It was really good. But and but just any other final thoughts you'd like to share with our listeners. You are you are a often I tell our guests they're they're a treasure. You're a special treasure.

Barbara Karnes 23:33

Thank you. Thank you. Um end of life work is spiritual work, it's heart-driven work, it's a calling, and we in the business administration end of it need to not lose focus on what our job is, why we're doing what we're doing. Um every single person that works right down, I won't say down, but right to the secretary needs to have an orientation, just like you'd give your volunteers, so that every single person working for a hospice has that heart-driven understanding of why they're there.

Chris Comeaux 24:34

That's a mic drop right there. Thank you, Barbara. You're a true, you're a true gift, a true treasure. Thank you for taking time. Um, and thank you for the work that you continue to do, continue to your amazing daughters that work alongside you. Um, you're doing great work.

Barbara Karnes 24:49

Wow, thank you. And you're doing great work also getting this information out. And I thank you for that, Chris.

Subscribe Share And Final Quote

Chris Comeaux 24:58

You bet. Well, to our listeners, We appreciate you. Make sure you hit that subscribe button. And also at the end of each episode, we always want to share a quote, a visual. The idea is it creates a brain bookmark, a thought prodder about our podcast subject just to further your learning and growth and thereby your leadership. What we're going for is for it to stick. Be sure to subscribe to our channel. We don't want you to miss an episode. This is one we really want you to pay forward, your coworkers, your friends. It doesn't even have to be people in the hospice and powder care space. There's so much wisdom that Barbara shared with us. If you're interested in my book, you could check it out on Amazon, The Anatomy of Leadership. We're going to have some great links that Barbara's team share with us that you could get. She has more than just gone from my site, many of her educational resources. So we're going to share that with you. You know, it's easy for all of us to rail against the world and be frustrated by things. Let's be the change that we wish to see in the world. So thanks for listening to today's podcast. And here's our Brain Bookmark to close today's show.

Jeff Haffner 25:55

"This episode is a reminder that hospice is not a business model. It is a sacred privilege. We are not simply managing symptoms, we are guiding families through one of life's most profound transitions. Let us be conductors." by Barbara Karnes.