

# Daughterhood the Podcast

## Episode #54

### The Final Days of Hospice and What to Expect with Barbara Karnes

Barbara's website to access all of her books – [Bkbooks.com](https://bkbooks.com)

[International End-of-life Doula Association INELDA](#)

[From Scratch](#) – Netflix series about end-of-life care

[After Life](#) – Netflix series about Grief

58:16

Barbara Karnes, Rosanne

00:01

This is the whole care network helping you tell your story one podcast at a time. content presented in the following podcast is for information purposes only. views and opinions expressed in this podcast are solely those of the hosts and guests and may not represent the views and opinions of the Whole Care Network. Always consult with your physician for any medical advice. Always consult with your attorney for any legal advice and thank you for listening to the whole care network.

**Rosanne Corcoran** 01:05

Hello, and welcome to Daughterhood the Podcast. I am your host Rosanne Corcoran, Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they're actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in Daughterhood.

#### **Rosanne Corcoran** 01:54

While we hear the phrase end of life care, what actually occurs in both behavior and bodily changes during the months, weeks and days prior to death is not something that's usually discussed. This leaves caregivers stressed and wondering what is changing and what they are witnessing. Today, my guest is Barbara Karnes, and award winning nurse and end of life educator. Barbara has put her 40 years of experience regarding education, care, and support of dying people and their loved ones into numerous books and resources. One book in particular, *Gone From My Sight: The Dying Experience*, published in 1985, has sold over 35 million copies worldwide. Known in the hospice world as the little blue book, it is the most beloved and widely used resource of its kind. Today, we discuss how to prepare ourselves and our care partners, including how to choose the right hospice, what happens with food and other physical and emotional issues at end of life, and how we can be prepared and present as caregivers for those final moments. I hope you enjoy our conversation. As caregivers, we hear and fear the discussion about end of life care. But then you're at that point, and it's disorienting and confusing and sometimes scary. Barbara, how do caregivers switch gears from regular caregiving for their care partner into caring for them at the end of their life?

#### **Barbara Karnes** 03:23

I don't think they really realize that they're shifting gears. In fact, I really think at that point where the special person has crossed over into the dying process that we caregivers really recognize that moment. We're we're so geared toward helping that we don't realize there's a point where our health needs to change in a different direction. So until well, I need to say that months before death, two to four months before death, a person will actually begin entering the dying process and the caregiver. They're not really going to catch that. And what what occurs is eating habits change, decrease, sleeping, habits, increase and socialization. They start with drawing and not being as interested with the food that caregiver we associate food with love with so many things. Yes, that seems to be the biggest hurdle is like yeah, I can understand he's going to take an afternoon nap and that he sleeps in front of the TV. I understand that and well, you know, he just doesn't feel like talking to the neighbors. I can understand that. But not eating. No, no, you got to eat to live. And the caregiver is concentrating on keeping their special person alive. And that means food. That special person is letting go. They're in the dying process. Unconsciously their body is doing this. If you said to them, Have you entered the dying process, they would say, No, no, no, I'm fine. But there's that blending. So it's not a specific line that a person process that says, Okay, now I do this care, right? Until someone says to the caregiver, Dad's entered the dying process. He's now dying. And here's what's going to happen. And here's what you do.

**Rosanne Corcoran 06:10**

And who that would be the hospice, whoever's on board with hospice would say that,

**Barbara Karnes 06:15**

Well, I would hope that a physician would say that, yes, I would hope that the hospital staff, the nursing facility, staff would say that, and with saying that, that would then lead to an end of life doula, or a hospice referral.

**Rosanne Corcoran 06:37**

It's hard sometimes. Because doctors don't like to say those things. They like to say we can keep going. We can keep trying, but they they don't they kind of get

up to that line. But then they back up from that line. And you're left with that. vague I don't know what's happening.

**Barbara Karnes 06:55**

Oh, absolutely. What we have to remember is that our medical model is about fixing people. It's about fixing the disease that people have. The emphasis there is word is disease that people have end of life care, is comfort care, is about treating, and helping that person that happens to have a disease, some big difference there. And I would like to see the medical model, put more emphasis on the patient, rather than the disease. But I don't know that that's going to happen.

**Rosanne Corcoran 07:45**

Wouldn't that be lovely? Wouldn't that be great? I agree with you. And it's, it's hard because again, that falls on the caregiver, and it falls in the caregivers lap. And then even if the caregiver feels that way, like okay, this is what's going on. There may be other people around that are blowing that off, like, oh, no, they're just, it's fine. And they're okay. And look, they were talking to me yesterday, everything is fine. And it's hard to differentiate that and get other people on board.

**Barbara Karnes 08:15**

Very much so and it isolates the caregiver. And that isolation leads to that questions of doubt. Am I really, you know, seeing what I'm seeing everyone else says he's fine. I don't I'm not sure he is. So that doubt adds more pressure onto the caregiver/

**Rosanne Corcoran 08:42**

And leads to more guilt.

**Barbara Karnes 08:44**

Ugh, Guilt caregiver carries guilt, you know, I'm, I want to take care of my special person. But there are days that I'm so mad at her, I just because she won't do what I tell her to do. And I'm the caregiver. I know what she needs, and that's to eat. And so as soon as that anger arises, it's like, Oh, my goodness, I must be an

awful person. I'm mad at mom, and she's gonna die. What a horrible person I am. So there's a lot of guilt and frustration and anger, that we won't, I'm not going to tell anyone. I don't want anyone to know how I'm feeling because I'm not a nice person. So I'm going to keep my mask on. And that brings even more isolation.

**Rosanne Corcoran** 09:42

Yup, it's a horrible cycle. When it comes to the feeding, and you know, I'm Italian. So food is the basis of everything. So when people say, Well, we could put a feeding tube in. What is that at end of life? What does a feeding tube? Is it a detriment? What is it?

**Barbara Karnes** 09:59

I personally feel it causes more harm than good. And what we have to look at is when the person can't be fixed, when they have entered the dyeing process, their body automatically will cut back and stop eating. Naturally, normally, the person will get to a place where they're not taking in enough calories for maintenance, what you have to think of is all the organs in the body are shutting down. And yes, food is what keeps us alive. But the disease eats before we do before the body does. And by putting in the feeding tube, your and I have to stress once the person has entered the dying process, that's when you can look at feeding tube and skull. I don't think so. Because you'll end up with more complications, then you have benefit, more discomfort for the patient, because you've got a hole in their stomach with dressings that have to be changed and routine changed. So you're doing a disservice if the person has entered the dyeing process. That's your operative words.

**Rosanne Corcoran** 11:36

And that could be two to three months before they actually pass.

**Barbara Karnes** 11:40

Absolutely, absolutely.

**Rosanne Corcoran** 11:43

And again, it comes back to communication, you have to have that ability to have a communication and have that those conversations, but also hear what's being said or what's not being said, from the doctors.

**Barbara Karnes** 11:56

Well, and this is where an Advanced Directive is so important. This is where talking to your family, when you're healthy. And saying, You know what, when I get to this place, I don't want a feeding tube, I want you to keep me comfortable and love me until I'm gone. But let's not try to keep my body alive. If I can't really live in that body, you got to tell your family upfront, really, before you need to, because that's when they'll be able to hear you. If you do it as you enter the dying process. And there's times that you're very clear in the months before death, then they family can go Oh, yeah, you know, he's sick. And he doesn't really mean it. He doesn't feel good today. So he doesn't really mean it. You need to have the talk before you need to have the talk.

**Rosanne Corcoran** 13:04

Well, speaking of hard conversations, when your care partner is in the dying stage, you know, people have questions of, do I have to talk about it with them? Do I have to tell them they're dying? What if they don't want to talk about it? What if you don't want to talk about it? Like does that have to happen?

**Barbara Karnes** 13:22

No, it doesn't have to happen. You're going to let the patient let your person guide you. They know, they live inside their body. They know. And they're going to face this challenge in the same way that they felt have addressed any challenge in their life. So you'll have people that will face this with anger, you'll have people face it with denial, you'll have people face it with charge ahead no matter what. Look at their personality. And that will tell you really, if you can have a conversation about it is if you wouldn't be able to talk to dad about anything. As you were growing up and in your relationship then yeah, you can say dad, you know, this isn't looking good. And you know, you're not going to be here very long. And can we talk about it? You know that if that's your relationship, but if it isn't your relationship, you don't have to. They know, they live inside of their body. They know whether anyone or doctors or family talk about it or not. You

know, you don't necessarily know what's going to happen because we don't have any role models. And that makes it really scary. And so fear is on It's not just the patient, but everyone's heart is going to be there. It's a matter of how much that fear is going to be there.

**Rosanne Corcoran 15:09**

What do you do with that with the fear? If you, you know, if you do say something, and they're scared, what do you do with that fear?

**Barbara Karnes 15:16**

You say, Yeah, this is scary. And we're gonna, you know, I'm going to be here and I'm going to support you. I'm scared, I understand you're scared. And we're gonna live through this. Together, we're going to live with this together, just presence. And I don't mean with a ribbon, and talking if they want to talk, but presence being there, says more than really, any words that you can say. And there will come a point in the dying process in the weeks before death, where generally words don't mean anything, you know, they're so withdrawn it sit by the bed and hold their hand, rub their back, sit and read to them, whatever, play the music, they like, just be there.

**Rosanne Corcoran 16:10**

How as a caregiver do we do we try to remain present, because it's hard. You know, barber, sometimes it feels like you're not even in your body. You're not in your body, you're not in the room, you've gone somewhere else, because it's painful. And because it's stressful. So how can we try to do that in these moments,

**Barbara Karnes 16:31**

I would hope that as a caregiver, you have support, that you have someone that you can call up on the phone and say, Oh, my God, you wouldn't believe what just happened. Or, I am so scared, or I am so angry, you need a sounding board as a caregiver. And we don't always have one. So if you don't have one, then go in the other room and pretend you have fun, and talk to yourself or out loud or right. But you need some outlet to get the feelings out. So that you can go back in and be a presence, a loving, supportive presence. But recognize these

frustrations and anger and scared all of those feelings are normal. But everyone needs a buddy. Everyone needs someone, a friend that they can call and not be judged. But just say what they need to say. And get it out. Because if you carry it in, and you don't get it out, then that is going to affect the relationship you have. Because there'll be resentment. There'll be anger, there'll be frustration, and you'll direct it as much as you don't want to. But just it'll come out. So let it come out with someone who isn't your special person.

**Rosanne Corcoran 18:14**

I love that because it does it has to come out some way.

**Barbara Karnes 18:16**

Yeah. Yep.

**Rosanne Corcoran 18:19**

In your book, the 11th hour, you mentioned someone has to be the front runner, there has to be somebody who delivers who who coordinates with everybody. How do you pick that? If, if there's a limited amount of people, or if you're the only person? I mean, obviously, if you're the only person you're the front runner, but how does that happen within a family unit?

**Barbara Karnes 18:39**

I think every family has their front runner. Yeah, every family has their take charge dominant person. And that's just part of family dynamics. So that person is going to do it. And yet with those family dynamics, that can create resentment and frustration. And she always is the boss and you know, all that we grew up with as siblings as family. And yet that's who probably will step in and be the orchestrator. Even if that person isn't the primary caregiver, you know, there can be the daughter or the son that lives in a different place, even who tries to direct and doesn't have a clue of what they're directing or what they're dealing with. And that just adds another challenge to this whole dynamic of end of life.

**Rosanne Corcoran 19:45**

It's, gosh, it's the same. It's the same when it comes to caregiving with siblings and all of that. It's all just a big stew of emotions and attitudes and opinions and



it's it doesn't help At this point, at end of life care, because everybody has a certain expectation to how things should be and how they want things to be. And sometimes it just doesn't happen that way. One of those things, and it's it's almost a lightning rod for hospice is morphine. You speak of it wonderfully. And I'm wondering if you could, if you could discuss a little bit of how that is part of this process, and how it's not so much that the morphine, quote, killed the person, it is the disease process,

**Barbara Karnes 20:31**

We are so afraid, rightly so, of narcotics, particularly in our society today, that the word morphine creates fear, just the word itself. So dying itself is not painful. disease causes pain. So look at the person's disease history. And if they have a history of pain in their disease, and there's a lot of diseases that cause pain, then you are going to give their pain medicine until their last breaths. And you may have to increase that pain medicine, as death gets closer, because their body is shutting down, and nothing works, right. So if they're taking liquid morphine, it's going to take longer for it to get throughout the body than if they are months from death, rather than being in labor. So there are a lot of diseases that don't cause pain. And if the disease history has no pain in it, then just because they're dying, doesn't mean now they have pain and need a narcotic, what the person's body feels like, who doesn't have a history of pain, in the days in two hours before death, their body feels heavy, it feels tired. It's an ache all over feeling that you have if you have the flu, and I don't mean COVID that ache all over, you wouldn't take a narcotic for that you might take two or three ibuprofen for that. And so if there is restlessness and agitation to the point that you're worrying about them falling out of bed or hurting themselves than had a van or held all is very appropriate. Now, all that said, a little bit. And I mean, a little bit of morphine will help someone who's in breathing distress, it slows down the breathing, and brings a little more comfort. So that's very appropriate, even if a person does not have a disease, history of pain, operative words a little bit. And add to that, and approaching death in the days, two hours, I keep saying the body's shutting down. So it's not processing anything you put in. So it's going there is going to be distress there is going to be breathing distress as part of the natural way we die.

**Rosanne Corcoran 23:40**

That's a it's a lot. And it's there usually isn't just, and I can't I mean, I don't mean to be generalizing here. But usually there's a few things that are happening with someone at the time of death. If they're older, you know, they may have congestive heart failure, and they may have cancer, and they may have something like there could be a bunch of things. So you're really not sure if they're in pain or not if they're nonverbal, or when you're when you're looking at them and you know what their appearance is normally, and then you see either a grimace or just they just don't seem comfortable. Those are the types of instances where you can provide some sort of medication for them. Is that accurate?

**Barbara Karnes 24:26**

Yes. And that restlessness agitation is probably going to begin weeks before death in what I call labor and Labor's one to three weeks before death. And part of that is restlessness and agitation of picking of the the hands of the air, just not being able to get settled. I don't know that that's actual pain. That's just part of what the bodies do. Waiting as labor begins, so you have to be aware and watch, you know, is there. If I move him and turn him does he winced? Does he? Even if he doesn't speak does he we look like that hurts. So there is definitely a place for narcotics at end of life. For me, the biggest feature of narcotics at the end of life is education. If whoever it's taking care of the caregiver of the family and the patient, which would be hospice or an end of life, doula, whoever's doing that their 90% of their work is education, if you educate the family, because we don't have any role models on what it's like to die, if we educate the family, as to what Dad is doing, and he's doing, this is how you die and dad's doing a good job. You know, this is what he's supposed to be doing, then we're not going to have after dad died, someone writing me a letter and saying hospice killed, hospice killed my dad, it's, it's taking the time, to educate, to sit down in the living room and sit and explain how people die. And this is what we're doing to keep them comfortable. While they are in the labor of dying. I use the example of in the days, two hours before death, the person who's dying is like the little chick that's working to get out of its shell. It's working very, very hard. And we see this and we think something must be wrong, something's bad's happening. Also, we equate it to labor, we go through labor to get in this world. Some of us have

easier Labor's than others. And we go through labor to leave this world and be birthed into the other world. And some of us can do it easier than others.

**Rosanne Corcoran 27:21**

I love that. It's, it's hard, because I wish I wish we could put you in everybody's house that has hospice, because the education piece is missing. And I can't again, I don't want to generalize. I know that there are people that have wonderful hospice interactions, and there are people that don't, for whatever reason for location for during COVID. I mean, during COVID, it was horrible, because people couldn't get their their services. And because of that you're left with this nagging. Was it enough? Was this correct? Did we do everything we could have done, because again, as a caregiver, you're in charge of everything, and you're in charge at the end of life, even though you don't have the education and things can happen quickly. Or even if they happen slowly, it's happening. And it's almost like disbelief that it's happening. So you're trying to be present in those moments and make the right decision. But if you don't have that education, it only adds to the woulda coulda shoulda as after the fact.

**Barbara Karnes 28:29**

Absolutely. And that what you just described, is why I wrote all that I've written. And I will say, my husband was sick for two years before he died just recently. And I, in the beginning of those two years, I wrote a book by your side, it's a guide for the caregiver, because I recognized I was in the role of the caregiver. And so I wrote what I wanted caregivers to know, from what I learned, being that caregiver, because education, as you said, that's the key. Otherwise, we're gonna make it up as we go along. And we probably don't know what we're doing, as we make it up. We're doing our best, but our best doesn't mean that it's the right thing or a helpful thing.

**Rosanne Corcoran 29:30**

And it's, it's hard to because of what happens and because of the process, it's hard to know if that's the right thing. And it's also hard because when you do have hospice and and it's almost like oh, well, it's getting late, are they off the clock? Are we going to switch is the next person that comes in? Are they going to

understand what's going on? Like there's that business component? Almost. Of Okay, well is are you are you advising this because we've been here for so long.

**Barbara Karnes 30:04**

What brings to mind is hospices a business. And there are businesses that are good. And there are businesses that are lacking. And if you were going to buy a new car, you would test drive it, you would shop, the different car dealers in order to make your purchase, in how you would feel comfortable with. And from a knowledge base. A lot of people do not shop, hospice, and I advocate, you need to interview before you need them. When you got your special person is, the doctors have said we can't fix you. And even if their receipt still receiving treatment, there's going to come a day when they won't be fixed. So once you've been told, I can't fix you. Go home, put your affairs in order. Start shopping hospices, call them on the phone and have your list of questions what you want to ask them. And then as you narrow that list down, because depending upon where you live, if you're real, real world, rural, you may not have a choice. But most places you've got there's more than one hospice, interview them. After you narrow it down, do a face to face, and then select. If you select one, and you're not happy with them, if you feel your needs aren't being met, find another one. And go to the one you've got and say, Hey, you're not cutting it. You're not giving me what I need. And so I'm going to switch hospices, we have power, it's just that most of us don't know, we have choices.

**Rosanne Corcoran 32:13**

It's so it's so hard. And I can I mean I I had I didn't have the best experience with a hospice. And when I tried to switch I called the doctor's office and ask them for hospice referrals. And they gave me the one I was with. And I said, that's great. Do you have any others? And they were like, Oh, wow, they're the best. And I was like, Okay, that's great. Do you have any others because I'm not really thrilled with this. So I called a couple of the other hospices. And when they asked the hospice that I was with, when I told them, they said, Oh, they're great. I don't know why you would want to switch. I swear to you, Barbara, I'm sitting on the phone thinking this is like a bad dream. And I couldn't I remember hanging up the phone and saying to my husband, I, I can't even believe that this is where we're at that I'm not happy with this. And everybody else is almost like they put their

hands up like, oh, no, well, you're with the best. Don't. You're fine. It was very weird.

**Barbara Karnes** 33:15

That's very weird. I'm surprised that the competing hospices, you know, and I'm as as I'm thinking about this, we are we, as a country, actually, in almost every area are short staffed. Yes. And so it's easier to not take on another. I'm gonna put this in quotes. roblem. Because the message you're giving is, I'm aware, and I'm courageous enough to speak up when I'm not satisfied. And that's really intimidating, and scary. And it's easy, and I'm short staffed to start with, we don't need this. Yep. Yep. I think that element is there.

**Rosanne Corcoran** 34:15

I fully agree with you. And it was 2021 was early 2021. We were still fully in in the pandemic mode. And I knew it. I knew it. But hearing it was shocking.

**Barbara Karnes** 34:29

It's horrible business practice, but I as I think I've I know why they did it. Not that why they did it this correct.

**Rosanne Corcoran** 34:37

Nope. I get it. And I fully agree with you. I totally and I see it and and it just it was it was sad. It was really sad and I and it made me feel even more isolated. Because of that. It was like wow, I can't even I can't even get somebody else to come in here. So it's just it's it's very interesting and it is, like you said You know, if I was buying a car I'd have every I could get a drive thru, I could you know, somebody with a video camera is going to drive that car for me. But when it comes to picking a hospice, for the most important thing, we can't we don't have that information. And I do have like, what's the top three questions you would ask a hospice, when you call them?

**Barbara Karnes** 35:19

I would ask if they have primary care nursing. That means Do you have the same nurse every time? How? How can you learn to trust and feel secure? In a situation where you have a different nurse, every visit? Neat, big part of hospice

comfort care, is providing a sense of security, and I'm not alone. Feeling and you have to bond with someone? And it's like, kind of like baby duck bonding, we need someone to bond with. So that's one question I would ask for. I would ask the same of the home health aide who is doing the bathing, you want the same one? So you really want the same team? And then you ask, How often will you be visiting in the months before death once a week, in my opinion, and if a person is on hospice, they should not be seen less, no matter what, then once a week, as labor begins, you want to look at two to three times a week. And then what would be ideal and is not happening anywhere really, is you really would like someone to be with you in the hours before death. And today, often, you call and they say let me know when he's dead. And we'll do a pronouncement call. And that's not my idea of support, and guidance. So ask, you know, do you do a death call? Or do you just do a pronouncement call? Will you be coming every day as death gets very, very close. Those I think are really important questions. And I'm sorry to say, they may not be answered satisfactorily.

**Rosanne Corcoran 37:33**

And the difference between a death call and a pronouncement call is?

**Barbara Karnes 37:37**

A death call, in my mind is a prototype, I should call it an approaching death in that hours before death, when, ideally, the family have been educated, and have gone from my sight in the 11th hour and can look and go, Oh, yeah, dad doing this, right. In those hours, you call hospice and you say, Dad's doing this. And the hospice nurse says, I'll be right over, whether it's three in the morning, or whether it's three in the afternoon. And stays until death comes. Now there are times when labor goes on and on and on. And you have to say, you know, he could die in 15 minutes, and he could die in 15 hours. And I've got to go home. But you know, you can call. We've talked about what to look for what's going to happen. So there is that element, but I would love Okay, let me say this. The moment of death is the goal of all end of life care workers. Whether it's doula, whether it's hospice, the moment of death is the goal. Everything that we do before the death in the months before death, leads up to that moment. And then following that moment, our support and guidance actually in hospice goes for a year. That's a whole nother topic, but the moment of death, and yet today, most people are

alone at that moment with their family and their loved ones. What I in my heart, my goal is that the family have an experience, that sacred moment of dying That's a sacred special moment. And they will carry that memory with them for ever. And so what occurs at that moment, or hours before death is crucial. And that's why I see it as the goal of end of life workers. And that's not happening in a lot of cases. No. Now, I will say that end of life doulas are now working outside of the medical model. Yes. And they their gift. Beside knowledge is time. They, their goal is to be with the patient and family, if it's three hours or four hours, they're going to be there. And they're going to walk that family through waiting for the funeral home and what to do for the funeral. So end of life, doulas are outside of this medical model, which is where hospice started, right. But if gradually become absorbed into the medical model, and become more medically oriented, than what the original purpose and focus was.

**Rosanne Corcoran 41:26**

You know, Barbara, you've been doing this since the 80s. Right? I mean, you you were back when, when it was just starting, you came through the AIDS epidemic. You've gone through everything and you've seen it change. And now I wonder, after coming through this pandemic, I wonder if there is going to be that shift to the death doulas because of this, and because they're just there's just not enough. There's not enough help. And being like, you know, we have doulas when we give birth, right?

**Barbara Karnes 41:59**

Yeah, absolutely. Unless hospice turns itself around. Yeah. doulas will? Well, now I have to say doulas have to be careful that they don't fall into the medical trap. That hospice has, right, the regulation trap. Those are pitfalls that end of life doulas need to be aware of and watch out for.

**Rosanne Corcoran 42:31**

Yeah, cuz it all becomes its its billing. That's a lot to do with it. Oh, my goodness, well, and the sacredness of those moments because they are sacred? How can caregivers try to prepare themselves for that? Or what can they do in the room or in the environment, whether they have hospice or not?

**Barbara Karnes 42:50**

Okay, number one, read my two books, three books, absolutely. You can have the dog or the cat on the bed, you have family all around, you don't have to have the shades drawn or the lights out, create a comfortable environment, in the hours before death, I recommend that each person there go in and have a an alone time with the person that's dying. Now they're going to be non responsive. But even if a person is non responsive, I believe they can hear really, even in the moments following death. So each person talks, you know, says what's in their heart. Talk about the good times talk about the challenging times. The person that's dying has been processing their life on many, many levels. You know, life is a billion piece jigsaw puzzle, and you're adding pieces to that puzzle. So each person has a loan time and then put on their favorite music if they liked music. You know, it doesn't have to be harp music. If you like Rod Stewart, put Rod Stewart, you know, whatever. music that is comforting. You don't have to have just candle lights. You might want a candle just for the aroma that it gives. Not that this area is going to smell but that's kind of relaxing and subtle. And then kind of have a vigil after everyone has had their alone time. Then you can all sit there and tell stories and look at scrapbooks and reminisce. You can sit on the bed, lay on the bed, fold their hand and that's your visual and you stay and you do that it until the person is gone. Once they stop breathing and and remind me and I'll talk about the scary part when they stop breathing, but once they stop breathing and you go, yeah, Dad's gone. Then before you call the funeral home, each individual person goes in again and says goodbye, alone. You know, you loved that body just like you loved that inside of it. And you're going to miss it. So you go say goodbye, talk in your heart, say whatever you feel led to say, when everyone has done that, and that might be Aunt Bertha that you called and she drove across town. You can wait and then call the funeral home.

**Rosanne Corcoran 45:55**

Okay, and you said to remind you when someone stops breathing?

**Barbara Karnes 45:59**

Oh, okay, when someone stops breathing, because it isn't like in the movies where Judi Dench says something very profound, and then closes her eyes and she's dead. It's not to be like that. There are facial grimaces, there are moans



and sounds and their eyes are partially open. And there's this momentary grim it's, it's almost that tug, to get out of their body. But that's scary, because it's not like Judi Dench. And so we think something bad has happened. Know that there's going to be that momentary disentangle dis attachment. And that it may not be pretty and tear, oftentimes, there's tears or a tear, their eyes are partially open. So the body brings moisture, I don't think it's Oh, I'm so sad that I'm leaving, you know, they're, they're concentrating on getting out of their body. And nothing else. It's like the woman who's in labor, pushing that baby to get out. She's not thinking of how her face looks when she's pushing, or what the the tear means. It's like, I gotta get this over with. And this is how I do it. That's, and I think we as watchers don't think about that at the time, which is why we need to know ahead of time it's going to happen.

**Rosanne Corcoran** 47:46

Because immediately we would we think they're in pain. They're scared, they're upset, there's something because that's what we need to hold on to. Right. That's our part.

**Barbara Karnes** 47:58

It's pathological. Something bad is happening. What are we gonna do? What are we going to do? And then well, hospice didn't do it for us, because they weren't here. If they had been here, it would have made a difference. And the thing is, they could have orchestrated everyone coming in and saying goodbye, they, they could have guided you and reassured you that nothing bad is happening.

**Rosanne Corcoran** 48:24

And without that, you're left with this feeling. You're left with this bag of bro SNESs that you're like, What am I supposed to do with this? And how did it didn't go? Well, it wasn't the right thing. It didn't end the way we wanted it to end, or whatever is running through your head, and you're left with that. And the visual, and that together is really hard.

**Barbara Karnes** 48:51

It is it's very hard, and that will add to our grieving. Because now we think, ah, Dad died wrong, Lee. And oh, my goodness, and we carry that along with just the

UN I use the word just but with the grief that we're carrying, because this person is no longer here.

**Rosanne Corcoran** 49:21

Yes, yes. And I believe it, it affects our grieving process. Because we're stuck in those moments. And those moments become bigger and longer and it and it bleeds into the grief because it's all it's all part of it.

**Barbara Karnes** 49:39

Absolutely. This is one of the what I recommend when people are are having the challenge of not understanding how mom died and that they think it was really bad or I didn't get there or she said whatever I recommend that they write mom a letter, what everything that they want to say, and what have said, if they had the opportunity, down on paper, all the tears, all the fears, all the worry all the words on paper, then burn that letter, and go outside and scatter those ashes to the wind. And let how well you live your life going forward, be the gift of love, that you give the person that's gone.

**Rosanne Corcoran** 50:38

That's beautiful,

**Barbara Karnes** 50:40

Well, thank you, and to think how sad and how much we cry, says how much we miss this person, I want us to concentrate on how well we live our life. Going forward, be the gift of love and show how much we miss this person.

**Rosanne** 51:02

Oh, gosh, that's beautiful. Because it doesn't, it doesn't help you. It doesn't help them. And to focus on one piece of their life, and carry that with you, instead of all of the other pieces of their life. And all of the other pieces of their life with you. It's, it's, it's shortchanging them, and that you're changing yourself.

**Barbara Karnes** 51:27

Exactly, you know, something to think about because grandma used to live at home and died at home. And then and that was our role model. But over the

years, death has occurred elsewhere. And so we've lost the teaching the understanding of what dying looks like. And we're coming full circle in that now. Grandma wants to die at home. And a lot of us are able to give that to her. But we need to have support, guidance, knowledge, in order to make this a sacred experience that death is.

**Rosanne Corcoran 52:11**

Well I thought I think I saw a statistic that said 67% of people want to die at home. But in order to do that, and provide that we have to be educated. We have to know what the heck we're doing and what to expect and what and how to do it. Because you just can't show up and be like, alright, well, we're going to do this today, you have to know.

**Barbara Karnes 52:33**

Exactly and yet think of the number of people out there that are taking care of someone who's in the dying process, who are alone, and who don't know, and don't have the knowledge or the guidance, and the emotional guilt and the emotional stress that that they will then carry with them forever. Which really, I want to less than that as you do. And that's why we do what we do.

**Rosanne Corcoran 53:11**

Yes. And because we really don't have there are no, there are no television shows or movies that show the real, the real deal. And that show anything and then even there just isn't it just they try. And it has to fit in a little package in the right amount of time. And then everybody's happy.

**Barbara Karnes 53:32**

I saw one of The Godfather movies. I don't know, I can't remember which one. Eli Wallace is in, like a movie theater or sitting in some kind of. And he's breathing like a fish breeze. Yes. And I thought to myself, he has been at the bedside of someone dying. And that's the own. Not that I see all the movies, but that's the only movie I've ever seen that I went oh my gosh, this is how it really happened.

**Rosanne Corcoran 54:12**

That was Godfather three. For those of you wondering.

**Barbara Karnes** 54:15

Oh, okay. You remember the scene?

**Rosanne Corcoran** 54:18

I do.

**Barbara Karnes** 54:19

Yeah.

**Rosanne Corcoran** 54:20

Yeah. And it's true. You're right. And it's they just don't, they just don't and you keep waiting even on hospital shows. You keep waiting because you think well, there's hospital advisors. They must. They must have now. No, still the same. Wake up. I love you all dead.

**Barbara Karnes** 54:37

Yeah

**Rosanne Corcoran** 54:38

I don't get it.

**Barbara Karnes** 54:39

I wonder if because really, it isn't pretty well, right. And I think so. And that's probably why they don't want to show that it's not pretty.

**Rosanne Corcoran** 54:52

Agreed. Any final words Any final thoughts or advice to a caregiver who's caring for their care part? No. And they can kind of see it on the horizon. Do you have any advice to give them for themselves for their own feelings for their, their person's feelings, anything.

**Barbara Karnes** 55:12

As a caregiver, it's paramount. And we talked about this, that you have a support system, that you have a buddy, that someone you can verbalize and download and cry with. And, you know, we tend to live either in the past, or we live in the future. Very few of us live in the moment, and really appreciate and get out of the moment. What is there. And what I want people to do is that that's where your energy and that is where you can focus. We should all do it. Every night before the last thing I think when I go to sleep at night, I asked myself, What did I do today? That made it worth trading a day of my life for? Did I find joy, that I've have peace of mind? You know, what was today? Because really, that's all we have. So as a caregiver, we want our special person to be in the moment and let the even if it's dementia, let that any given moment. Be gentle, be love filled, be monos a purposeful but that purposeful can be Did you see the squirrels at the at the feeder? That's really what's important in living is any given moment, so let's give them that gift of trying to keep them in the moment.

**Rosanne Corcoran 57:06**

A big thank you to Barbara Karnes for being my guest today. To find out more about Barbara and access all of her essential books and resources on end of life, visit her website. BK books.com. I hope you enjoyed our podcast today. Head over to Daughterhood.org and click on the podcast section for shownotes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood the Podcast. Feel free to leave me a message and let me know what issues you may be facing. And we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song mamas eyes from her album lessons in love. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.