

Dr. McPherson: Hello, this is Doctor Lynn McPherson. Welcome to Palliative Care Chat, the Podcast brought to you by the online Master of Science and Graduate Certificate Program at the University of Maryland. I am so excited about our guest today. I am delighted to say we have Barbara Karnes with us who is an RN. You may not know her by her name, but I can tell you she is the Little Blue Book lady. So in other words, Ms. Karnes has authored the book, *Gone From My Sights*, that so many of us are familiar with in Hospice care.

Welcome Ms. Karnes, how are you today?

Barbara Karnes: I am good, thank you for talking with me today.

Dr. McPherson: Thank you so much for joining us. So I've certainly known of your books my entire career. When was the Little Blue Book published?

Barbara Karnes: I wrote that in 1985.

Dr. McPherson: Okay.

Barbara Karnes: I was a Hospice nurse. Hospice was different than it is today in that we started seeing patients ... We had patients five / six months. One of my favorite patients, I had for two years. But our average length of stay was several months. So we were with them on a consistent basis, number one. Number two, our goal was to be with that patient and family at the moment of death.

So I was with literally hundreds of people over the years, before they died and at the moment of death. One night, I was on a dying call. It's three o'clock in the morning, I'm sitting with the family. Mom's in the bedroom and we're all in the living room. I'm explaining to the family what mom's doing. I'm trying to neutralize the fear that everyone brings to the bedside when someone's dying. As I'm telling them what mom's doing so that they understand she's doing a good job and that nothing bad is happening, I notice one of the daughters is taking notes.

I thought, "Oh, no. This is not the way it should go." So that weekend I sat down, it was before computers, with a yellow legal pad and I wrote out what I wanted my families to know about the dying process. Within months, that became the Little Blue Book.

Dr. McPherson: Wow. So what did you hope to accomplish with that? What was your goal in writing all that down? Why did you want your families to understand the dying process? I know, because I've read it a million times, you talk about the physical signs and symptoms months out, weeks out, days out and so forth. So what was your goal with this?

Barbara Karnes: My goal was to teach the families that nothing bad was happening. Because we don't know, most people, don't know what it's like to die. We're such a fix it

mentality with our medical system that our instinct is, if someone's dying then something bad is happening and it's a failure. So what I wanted to do was get people, and still want, people to understand that there is a process to dying from disease or old age.

I want them to really understand there's only two ways to die. That's fast, getting hit by a truck or a heart attack. Or gradually, that's disease or old age. A gradual death has a process to it. If it didn't have a process, if it just happened, it would be fast death. So I outline the process so that people can understand that their loved on is doing what is a normal, natural progression. That this is not pathological, that mom is doing what she's supposed to be doing and she's doing a good job at it. Right there, alive or whoever, has neutralized the fear that everyone brings to the bedside.

Dr. McPherson: You're trying to normalize the experience? Yes?

Barbara Karnes: Absolutely. It says, "Hey, she's doing what ... it's good. All is good." It's very, very sad, but it isn't bad.

Dr. McPherson: Yeah. Do you ever anticipate, and I would think that they would, staff would use this as a teaching tool to really drill down and have those conversations about the use of artificial hydration and nutrition?

Barbara Karnes: I hope they do. I mean, my whole career has been about education. It's been to educate the community, the medical professionals, as well, on the normalness of dying from disease or old age. Dying is not a medical event. It is a social, communal event. We have medicalized dying and my goal is, through education, to show that you don't need a doctor, you don't need a nurse at the bedside. You need someone who understands the normal, natural dying process and can guide that family and the person through it.

Dr. McPherson: Mm-hmm (affirmative), okay. I want to share one amusing, but I'm sure to this family sad, comment about the Little Blue Book. I remember years ago, I was in [inaudible 00:06:20] team meeting and we would always start off the meeting by talking about the death of the people who had died since our previous team meeting. The Bereavement Specialist attended for that portion of team.

When we were discussing one family, the nurse said, "I'm a little concerned about this family because when the patient died, the first thing the wife said is, 'He couldn't die now, he can't die now, we were only on page six of The Little Blue Book!' So what do you think about that?"

Barbara Karnes: Actually, that makes me smile and it makes me feel good. Because number one, the family had the book. They were reading the book. Often I get, "I wish I had read it sooner." That they had the support in getting through this experience. What we all know is that everyone's going to die in their own unique way, and in their own time, and according to their personality.

The Blue Book is just guidelines. Some people are going to do all of it, everything in there. Some people are gonna do none of it. But it is a guideline. I think I say that even in the beginning of the book. I haven't read it for a while, but I think it's in there somewhere.

Dr. McPherson: I'm sure it is.

Barbara Karnes: This is just a guide.

Dr. McPherson: No guarantees, right?

Barbara Karnes: Right, right.

Dr. McPherson: So tell me, how did you come up with this title, gone From My Sight? what's that all about?

Barbara Karnes: Oh, that ... I had the wife of a patient that I had. She and I became very good friends. Part of our bereavement follow up, of course, is staying in touch for a while. I had been in a junk store, really, and found a frame of the poem that's at the back of Gone From My Sight. The poem was in this frame and I thought, "Oh, that is a beautiful, beautiful poem." So I bought the frame and when I was putting together the booklet, I put that at the end of the book.

So Betty and I were out to lunch and I showed her the book that I was in the process of writing. I wanted her input, having gone through the experience with her husband. I wanted someone who'd walked the walk to tell me what she thought about the book and if she thought it would be helpful. So we're talking and it had no title. She said, "Well, why don't you call it Gone From My Sight, because this poem is so powerful."

Dr. McPherson: What was the poem about?

Barbara Karnes: The poem is in the back of Gone From My Sight, which is the Henry Van Dyke poem about the ship that is sailing off. We're waving goodbye and your sad, but then on the other side is people welcoming the ship, and seeing it, and excited because it's coming.

Dr. McPherson: Yeah, I was pulling your good leg. I remember that poem extremely well. I pretty much cry every time I read it. So just as the people on this shore are saying, oh look, she's gone from my sight. On the other side, they're saying, here she comes.

Barbara Karnes: Yes, love it.

Dr. McPherson: It's an incredibly moving poem. Oh, my goodness, I'm gonna start balling again. So I see that you have multiple resources, that you're not a one trick pony here with The Little Blue Book. You've got a Little Pink Book and a Little Green Book.

So just for our listeners, your website is bkbooks.com. So B like Barbara, K like Karnes, books.com. I see you have several things here.

You have one called The Eleventh Hour, which is sadly, closer to what we're seeing now with our average length of stay in Hospice. I see A Time To Live, Living with a life threatening illness. That might be something of interest more to palliative care providers. I like that you've explored the grief arena, too. Can you talk about that a little bit?

Barbara Karnes: Well, what I've done is, I have tried to address all of the end of life issues. I didn't intentionally, thirty years ago, say I'm going to create materials that address all end of life. But really, if I look back over the timeframe, that's exactly what I've done. I started off with Here's The Signs Of Approaching Death. Then, the pink booklet is the companion. That guides the family on what they can do. So Gone From My Sight says, here's what's happening and The Eleventh Hour says, here's what you can do while it's happening.

Then, in the 90s, both of my parents were diagnosed with cancer of the lung within five months of each other, they died. So-

Dr. McPherson: Oh, sorry.

Barbara Karnes: ... for 18 months before they died, I wanted to give them something. I wanted to give them some guidance. So I wrote A Time To Live for them on how to live the best you can within the confines that your body and disease has put you in. That's where that came from. Then, I was getting ... oh, I'd get letters from people all over the world daily. What I would often hear is, mom died a month ago or a week ago and I want five Gone From My Sight. I thought, "Wait a minute. You need something on grief."

So I wrote My Friend, I Care, as a guideline in the grieving process so people can understand the normal, natural process that goes with grieving. All of my work is fifth grade level, short, simple, direct. I've written one on Dementia now, because Hospice is taking on more and more people that have Dementia. Dementia doesn't play by the rules.

Dr. McPherson: No, it does not.

Barbara Karnes: It doesn't. So all of the signs of approaching death don't apply to Dementia until they're not eating.

Dr. McPherson: Right.

Barbara Karnes: Because if you don't eat, you don't live. So families, I felt, needed that guideline.

Dr. McPherson: Sure. I see a picture of a cell phone next to most of your publications. So apparently, there's an electronic version that you can have on your device, as well?

Barbara Karnes: Absolutely. Absolutely.

Dr. McPherson: How do you envision that being used? Do you see that as more staff using it? Or individual family members buying it? Or how do you see that being operationalized?

Barbara Karnes: Generally, it's individuals. It's people who don't even want to wait until the mail system can get the hard copy to them. We get calls saying, mom's dying and we have this book. But I want my sister in Ohio to read this. So they'll get the electronic versions.

Dr. McPherson: Oh, that's wonderful. Can we talk for a moment about your most recent project? The new rules for end of life care, the 25 minute film. Tell me about that. What's it about? How would you envision individuals or a Hospice worker using this movie?

Barbara Karnes: All right, taking care of someone at end of life is different than taking care of someone who is going to get better. We know that, we in the industry know that, but families don't know that. Because they don't know it, they're judging our work on how people get better unless we teach them otherwise. So I created new rules ... they're our new rules for end of life care. That's what we're teaching.

It addresses all of the areas, pain management, symptom control. The dying process, so that people can understand that normal, natural dying process. It touches a little bit on grief. It's done, again, fifth grade level, no medical [ease 00:15:30]. How it is used is several ways. You can use it as an education tool in the community. I have [inaudible 00:15:42] who have shown it and then have discussion. Church groups show it, bring in a Hospice person, and discuss it. Senior citizen communities show it and discuss it.

Then, I have a lot of Hospices that buy it and give it to their nursing facilities that they're working with, so that they can educate the nursing facility staff on end of life. Then, and this surprised me. I didn't expect it, but I love it. That is, I have a lot of Hospices that have ... each of their nurses have a copy of it. It's 25 minutes long, so it's very short. The nurses, on about the second home visit, sit down with the family and they watch it together. Then, they discuss it.

What this does is, aside from consistently educating the family. Because often, one nurse teaches one thing and another teaches ... We all have our styles. Well, this makes consistent teaching and addresses that part of the Medicare compliance under quality assurance that says, are you consistently teaching your families.

Dr. McPherson: So I see the new rules for end of life care DVD kit. It's very reasonably priced. What comes in the kit besides just the DVD itself?

Barbara Karnes: You get a copy of Gone From My Sight and the Eleventh Hour.

Dr. McPherson: I see, okay.

Barbara Karnes: Because in my mind, those two booklets are what can guide every family. Today, most families are alone at the moment of death. So if they have both of those ahead of time, Eleventh Hour says it's okay to get in bed with your loved one. It's okay to have the dog on the bed. It gives them ideas of singing, talking, using this time wisely. Instead of, standing there watching and being absolutely terrified.

Dr. McPherson: Sure. So you and I as educators, Barbara, we both know that not everybody learns the same way. Some are visual learners, some are auditory. Is the movie, along with the publication, your approach to trying to reach as many learners as possible?

Barbara Karnes: Absolutely. You're so right. I have found that having the concrete book. It's the short, short booklets, and all of them are, that they're going to re-read, and re-read, and re-read. It's three o'clock in the morning when mom's breathing funny that they get that book and go, "Oh, yeah. That's what she's supposed to be doing. It's right here on page 10."

Dr. McPherson: Yeah. I think it's, in a way, it's a cost effective way to help the Hospice triage patient and family ... well, family primarily, concerns. It could save an emergency visit from a nurse in the middle of the night, simply by having this kind of a resource available.

Barbara Karnes: Absolutely. If you're on call and you get a call, you try to tell the family over the phone that everything is okay, and you don't go out. Then, you're gonna wake up at seven in the morning and you're gonna hear that they went to the ER.

Dr. McPherson: Right.

Barbara Karnes: The calls are not about, really, what's happening. The calls are about, I'm scared and I need reassurance. So having Gone From My Sight, and The Eleventh Hour, and the Dementia booklet when Dementia is part of the deal. When they have those resources in their hands, then they may not have to pick up the phone and call. Because they neutralize the fear, that mom's doing something she's not supposed to be doing.

Dr. McPherson: I think it would be a good research project, Barbara. What do you think?

Barbara Karnes: It would be.

Dr. McPherson: You should look at that. I'd like to end with what could be possibly one of my favorite publications that you just came out with. Did you know that there's both a national and international Veterinary Palliative Care Association? Which I find very interesting. One of the ... we have two Veterinarians who do palliative care in our Master's program. They're a delight to have in our program.

But your latest publication is A Place In My Heart, when our pets die. I have a 17 year old toy poodle who is blind, and deaf, and has diabetes, and dementia. I am scared to death, is he suffering. I keep asking, and asking, and asking the Vet, because I don't want that day to come. So tell me a little bit about this publication.

Barbara Karnes: Well, I am also an animal person. I, over the years, have thought that there are similarities between pets, animals dying and humans dying. If you think about it, we're all animals, humans and our dogs, cats. We're all animals. So animals, I'm hesitating using that word since we are also animals. So I will pets, but apply that to the animal kingdom.

They die in a similar way to how humans die. But people don't know that. It used to be there was barn cats and working dogs. Now, our animals have come more into our lives. They have become our children in many ways. So dealing with their approaching death and their death, creates the same fears and uncertainties that it creates with humans.

So I wanted, as part of educating and about end of life, let's educate about what happens when our pets die. So in my mind, A Place In My Heart, is The Little Blue Book for pets. I deal with not just the signs of approaching death, but having to deal with Euthanasia. That's a huge issue with pets. Then, burial.

I think that ... I also talk about how to bring in children, because how we deal with the dying and death of our pets with our children, is going to affect how they deal with human death and dying. It's a great source of education for our children if we do it well.

Dr. McPherson: Absolutely.

Barbara Karnes: So I talk about burial and then grief. This is what really prompted the book, was I had gotten several emails from people regarding their pets. Then, I got an email from a gentleman who was really having trouble living since his dog died two years earlier. He was grieving for this dog and saying to me, nobody understands. They just say, it's a dog. It shouldn't be any big deal, get yourself together. I thought, oh my goodness. So I stressed that we grieve for our animals, our pets, the same way that we grieve for anything else.

Dr. McPherson: Absolutely.

Barbara Karnes: There are many deaths, there's the physical human death. But there's the death of a marriage, the death of job, the death of a location. There's all kinds of deaths. We grieve the same way for all of them. So I talk about that grief, and the feelings that the death of a pet is going to trigger, and what we can do about it.

Dr. McPherson: Yeah. You're gonna have to reach out to all the Veterinarians in the country. [inaudible 00:25:18] a good handout in that venue.

Barbara Karnes: I think so, too. I have sent A Place In My Heart to a couple of Veterinarian conferences as handouts in their goody bags. We'll see what happens.

Dr. McPherson: Well, good luck with that. One last question, are any of your books translated into other languages?

Barbara Karnes: Gone From My Sight is translated, I think, we're up to seven languages.

Dr. McPherson: Wow.

Barbara Karnes: My Friend, I Care is in Spanish and French. Then, A Time To Live and The Eleventh Hour are also in Spanish-

Dr. McPherson: That's awesome.

Barbara Karnes: ... as well as Gone From My Sight. So yes, they are in other languages.

Dr. McPherson: That's wonderful. Well, and of course people can check this all out by going to your webpage bkbooks.com. Barbara, I'd like to thank you so much for spending a half an hour or so with us. I've always really enjoyed your products and it's a tremendous service that you offer. So, thank you so much.

I'd like to thank, again, Ms. Karnes. Thank you all for listening to Palliative Care Chat Podcast. This is Doctor Lynne McPherson and this presentation is copyright 2018, University of Maryland. For more information for our completely online Master of Science and Graduate Certificate Program in Palliative care, or for permission request regarding this Podcast, please visit graduate.umaryland.edu/palliative. Thank you.