Daughterhood the Podcast
Episode #83
Dying With Dementia
with P.K. Beville

52:41

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Rosanne Corcoran 00:14
Hello, and welcome to Daughterhood, the Podcast. I'm your host, Rosanne Corcoran, Daughterhood Circle leader and former primary caregiver to my mom, who lived with vascular dementia for 12 years. Through that journey, I experienced every phase of caregiving firsthand: the heartbreak, the joy, and the aftermath. That journey showed me how vital support and connection truly are. And that's why this podcast exists. No matter where you are in your caregiving journey, I'm so glad you found us, because caregiving is far too much to do alone. So, welcome to Daughterhood, the podcast, part of the Daughterhood community, where we empower caregivers to navigate both the practical and emotional sides of caregiving together. Here, your efforts aren't just good enough, they're heroic, and here you're never alone. Join me in Daughterhood. Before we dive in, I just want to share a quick note. This podcast is part of the Whole Care Network. The conversations you'll hear are here to inform and inspire, but they're not a substitute for professional advice. The views you'll hear are those of the host and guests and may not always reflect those of the Whole Care Network. If you have medical questions, please talk with your doctor, and for legal advice, check in with your attorney. I'm so glad you're here. My guest today is PK Beville founder of Second Wind Dreams, a nonprofit organization that fulfills dreams for older adults living in long-term care settings. PK is also the creator of the Virtual Dementia Tour, a simulation that has put hundreds of 1000s of people inside the experience of living with dementia, changing the way caregivers, clinicians, and families understand what it means to live with the disease. But PK didn't stop there. She channeled that same understanding and empathy into the one moment that needed it most, the dying. She developed

Empathetic Transitions, a dementia death doula training built on the belief that how we die with dementia matters, and that caregivers shouldn't have to walk into that room unprepared. In this episode, we discuss what social death looks like, what hospice does and doesn't do the impossible choices around feeding at the end of life, what families are rarely told, and what a good death with dementia can actually look like. PK is one of my favorite people in this space, because her empathy doesn't stop at the hard parts. I hope you enjoy our conversation. PK, you created the Virtual Dementia Tour, a simulation that puts you inside the experience of having dementia, and out of that work, you've now developed a dementia death doula training. You watched how the virtual dementia tour changed how people understood dementia from the inside out. What was it that made you think that same understanding needs to exist at the end of life with dementia, too.

PK Beville 03:02
Wow. Hi, Roe, it's good to see you. Thank you for inviting me. I appreciate the opportunity to talk to your amazing audience. Thank you. And what guided me to do this is because I feel like people with dementia across the board are completely misunderstood, and as a result, we tend to make some nasty, inappropriate sometimes decisions about people with dementia based on no knowledge, and one of the things that we learned when the virtual dementia tour was available is that people got a sense of what is going on in the mind and the thoughts and the even movements of a person with dementia, but what happens when we move dementia into a more severe category, advanced dementia, virtual dementia tours for moderate dementia, or right under the umbrella of dementia, but, but we, it does not address how do you engage with someone in advanced dementia. So I felt like we needed to develop a program, a training program, actually, that helped people learn how to connect with those at the end of life when there is extreme difficulty for the person with dementia to connect with anyone, and yet I feel strongly that they still want to connect, they still want to connect, and to me, developing a program to help professionals learn how to make that connection right up until the last breath, and shortly thereafter, is a missing piece in healthcare. So, long answer is that I felt like it was a. Huge missing piece when we talk about dementia care.

Rosanne Corcoran 05:02
Well, and it is, and because dying with dementia is fundamentally different than dying from a terminal illness, say like cancer, where the person can still communicate with

you with dementia that doesn't, that isn't there exactly. So, how is what's the difference of dying with dementia versus dying with a terminal illness?

PK Beville 05:25
Well, I think you hit the nail on the head. A lot of it has to do with communication, but and their inability to communicate their needs. But let's take that a step further, and let's look at what the trajectory of the disease has been, you know, with a terminal illness like cancer, you have someone who is able to communicate their needs right up to, you know, the active dying stage or any other terminal illness. I had the great fortune - I didn't view it as fortune at the time, but when in my work with hospice to be one of their death doulas, I got asked at the last minute if I could attend a person who had congestive heart failure, and he was into the transition phase, not quite to active dying, but right, right close, and so even though I really made it clear that I only wanted to serve those with dementia and their families, I thought, well, I got time, so I went and sat with him. Roe, the difference in caring for him versus a person with dementia was so incredibly different. He could tell me where to put the pillows, he could tell me when he wanted water, he could tell me everything, all of his needs. Granted, it was very difficult to understand him, and there, but I could, and, and I could keep him comfortable better. Look at, look at the dichotomy there, and what happens when a person with dementia, I don't know if they're thirsty, I don't know if they need to turn over, I don't know what their legacy is, I don't know all of those things fall out when it comes to end of life with someone with dementia. Now we have made dreams come true for people at the end of their life with dementia, like people who love to go to the beach. We've recreated a whole beach scene with sound and smell, and all of those, because the key here in every death is this: the more relaxed and at peace a person is, the easier it is for them to pass away now. If we know that, let's add to the problem of a person with dementia who's already scared, traumatized, doesn't know what's going on, fearful, and if we can't, at least after all they've been through over decades, in some cases, if we can at least give them the relief and the comfort to be able to pass on with dignity and respect, there's something wrong with our logic. Yeah, why are they indifferent than anybody else? Why is it that they can be left in a room for hours and hours and hours to die alone when the number one thing that a person without dementia says that they want at the end of their life is not to die alone. What happened? Why is that no longer an issue for a person with dementia?

Rosanne Corcoran 08:45

And that's the question. Listen, we know that there's a shortage, there's a, there's a caregiver shortage, professional caregiver shortage, so for anyone who's in a skilled nursing facility or assisted living, or or whatever, and it's so much harder to try to care for someone who's dying with dementia,

PK Beville 09:03
Right.

Rosanne Corcoran 09:04
That gap, who's responsible for closing that gap? How do we close that gap?

PK Beville 09:09
Education, education, people are scared to death of haints and boogers and dead folks, they just are, and that's a shame, because you know right now anywhere in the world we're at a 100% mortality rate,

Rosanne Corcoran 09:28
Right.

PK Beville 09:29
Why, why are we not educating people about the end of life? There are several good authors out there who are helping to dispel the fear about death, but it's so ingrained in our lexicon, in our culture, that it's going to be quite the journey to get people there. Then you add dementia, who people are already afraid of, on top of that and. This is going to be a tough hill to climb, but it needs to be climbed. That doesn't just because it's hard doesn't mean it can't be done.

Rosanne Corcoran 10:08
No, and part of the challenge with dealing with dementia is a lot, you know, we don't get that guidance from doctors. Doctors don't give us guidance. It's like, get your affairs in order, and I'll see in six months, that's it, or I'll see in a year. So that's what we're working with on a good day,

PK Beville 10:27
Right.

Rosanne Corcoran 10:27

And then you add the dying process, end of life, all of that into it, and it's, it's even less information,

PK Beville 10:35
Right. 70% of doctors have not been given information on end of life care, 70% Yeah, so again, rope, we add to that 70% the lack of information in general about someone with dementia, and now you begin to see the big picture. Doctors are employed to try to keep people alive, and how many times have you and I and the rest of your audience seen a situation like you mentioned, where the attending physician comes in and basically says, without saying it out loud, but the undercurrent is, I'm done here, this person is no longer a valid patient of mine. There's nothing more I can do, and there's nothing I can do is just.. it's just saying basically they're dead to me. They're dead to me. So I'm moving on.

Rosanne Corcoran 11:38
Yeah,

PK Beville 11:39
I'll fill out the paperwork. You can come in every six months, but truth of the matter is you're going to get 15 minutes like everybody else, and I'm really done. And in fact, we know that there are many things that can be done in advanced dementia care, so many things, ways to connect, ways to create happiness, ways to encourage ways to reinforce, you know, I've had the great opportunity to serve beside incredible people with dementia who are dying, and I think an example I could give is that I went to go see one of my gentlemen patients, and he happened to be in the day room slash dining room in an assisted living, and he was at a foretop, and there were two certified nursing assistants sitting there, and he was in a chair, hunched all the way over his head, almost on the table right now, they were talking to each other, so there was an extra chair there, and I wanted to visit with him a little bit, and I tapped him on the shoulder, used his name, and his head raised up a little bit, and I said, "So, how's it been going? And he responded very clearly. It's going well. How about you? Wow, now those CNA certified nursing assistants almost fell off their chairs and said out loud, I didn't know he could even talk. Now these are people who are caring for him all day, every day. They didn't even know this. Yes, he had advanced dementia, but as we all know, who serve dementia, their ability to respond to social skills in social situations is highly ingrained in our brain. So he knew exactly what to say in response. Yep, yep. So then I showed them how great he did when I put a truck on the table, just a truck, little bitty truck, he

even had eye hand coordination, so part of my psychologist brain goes to how much more this man could have still done had he been treated appropriately for his cognitive level, and the other part of my brain goes to this man loved to give responses, whether they make sense or not. He enjoyed that. He raised his head, and he passed away about a week later at the end of his life, to have the ability to converse, even at that level, I think, is essential. I had another guy who he was a minister, and so here he is. I would say mid advanced stage dementia, lots of word salad, which means his words didn't connect well, and you know which I love word salad, because I can pick up on a word and say yes, but, and I can just, the yes, but I can still communicate, right? So this one day I'm sitting with him face to face, and he was more agitated than usual. Well, you can see it on their face, and so I sat across from him, never sit to the side, straight ahead, because of the loss of peripheral vision, straight ahead, and I started talking to him about whatever, and I asked for kind of gave a question, you know, so how's it been going, blah blah blah, and he looked at me dead square in the face, and said, Has anyone ever clear? Has anyone ever told you that you talk too much? Let's see this as a guy who's still there, he's still in there, nobody's giving him an opportunity to respond. And this guy passed away, probably two weeks later. I was kind of surprised he went so fast, but, but he did, because we know, too, I'm talking too much here, too.

Rosanne Corcoran 15:48
No, you're fine.

PK Beville 15:50
That death with dementia is also different in that they are going along at a level, and then all of a sudden they get something like a UTI, a cold, an upper rest infection, and they go way down, and you think this is it,

Rosanne Corcoran 16:08
Right.

PK Beville 16:08
And I'll be darned, they start to do better, they never get back up where they were before, but they start to do better. So, the death is a stepwise thing from the perspective of the family, this anticipatory grief is huge, and that's one of the reasons.

Rosanne Corcoran 16:26
Yes, well, because you don't know,

PK Beville 16:28
No,

Rosanne Corcoran 16:29
You have no idea.

PK Beville 16:29
You never do, is this it?

Rosanne Corcoran 16:31
As much as end of life in other diseases It's a, it's, it feels more clear cut, it feels there are still chances of, you know, whatever, but right, it just, it's different, because you can have those conversations, whereas this is a completely different thing, and PK, you know, I love, I love your stories, and I love when you, when you bring them out, because your empathy and your compassion and your purpose of doing all of this comes through in it, so thank you. Don't feel like you need to censor yourself at all.

PK Beville 17:05
Thank you. It's all spirit led,

Rosanne Corcoran 17:07
You know. You and you talk about that's well, you talk about the term social death, is that what you mean? That

PK Beville 17:14
yYs.

Rosanne Corcoran 17:15
Tell me about that.

PK Beville 17:16
So they died a social death the minute that they have been given the diagnosis, because what happens when that happens is all of the people around them that know this is what's going on begin to treat them differently, and because of that lack of education about the fact that they can certainly still be involved in a lot of different things. Sometimes the family's afraid of what they might say or what might happen, so

they're killing them, they're telling, they're isolating them right away. Now I understand where they're coming from, but if they understood the reality of what's going on in their brain, which is those social skills sticking around a long time, they're more likely to include them in more things, and they're also socially dead, because, like my dad, who had vascular dementia, I knew it was getting to a rough place when he quit going to his men's church services, and the reason he quit going, I found out later. It took me a bit, but I found out later that he said, because I'm the eldest in the room, they ask me to pray every time and I'm afraid I'm not going to be able so so that social death happens across the board for the person as well as those people around them take that a step further and when someone with dementia is in I think there are three stages for them, there's advanced dementia, there's transition, and then there's active dying, right? When they're in any of those phases, I've had a number of families who have said to me, I can't see them that way, I can't, I can't see them that way. To me, that's another educational opportunity for us to begin to help families see that what they're seeing at this stage is exciting. It's the brain is actually taking care of everything. The person with dementia is living in their brain at a time when they felt active and in control. Yes, it doesn't fit with the current reality, but Whose reality is it anyway? In my brain, so, so they just don't understand that, and because of the way that sometimes they look, we have a tendency to shy away from that look. What that look actually is, is a beautiful portrayal of them at a relaxed. Waxed state, they're not able to control their muscles as well anymore in their face. Just because they're not actually smiling or articulating like you and I do doesn't mean they're less of a person, and that's that's also what happens there.

Rosanne Corcoran 20:19
It's a lot to take in. PK,

PK Beville 20:21
Sorry,

Rosanne Corcoran 20:22
No. no, I don't mean that from what you're saying, I mean from the actual experience. It's a lot to take in to go from that, you know, the advanced dementia, because by the time you get to advanced dementia, you're, you're worn out, they're worn out, right? Yeah, and to go from that to then it's like this is where we are, and now we're transitioning. Okay, now what's next? Like, there's just so much that goes with it, and there's so little support for that,

PK Beville 20:52
Right.

Rosanne Corcoran 20:52
Which is also just.. it's horrible, because it leaves you in those really vulnerable positions, and it leaves you in that space of you doubly don't know what to do,

PK Beville 21:02
Right.

Rosanne Corcoran 21:03
You know, and this is a, you know, you want to get it quote right, because it's end of life, you don't get a do over here, but you know there's there's also those parts where you know some people go into adulthood hoping there's going to be this moment of reckoning or apology or some type of tenderness between you and, and your parent, and sometimes that doesn't happen. What happens to that caregiver who's waited all this time for that moment, or some type of moment, and slowly comes to understand that that's not going to happen?

PK Beville 21:40
It's very traumatizing, and this you're making the great point for how important it is that we start to cultivate lots of death doulas in my world. We need to mention death doulas because of all the reasons that I've just talked about. It's a specialty, definitely a specialty, and if a doula is present during all of these things, they're trained to be able to respond in a way that supports the family and supports the dying person. My recommendation is that doulas start working with people with dementia in the advanced stage, so that a relationship, albeit not like a regular relationship, but a relationship can be built, and every time I do this, I'm brought to my knees, because it's incredible how much love and support they have to give, unlike any other population, if I feel depressed and down in the dumps, all I need to do is go visit one of these people in advanced dementia, because they bring me back to center. They're fascinating people, and the families around them are fascinating. Only if you get to cultivate that relationship, it's super important. So I think the more doulas can be that are out there that can kind of close that gap, or at least bridge the gap, not close it, bridge that gap, the easier it's going to be for the person with dementia and the families, because let's face it, hospice is great, I know it's it's got its good sides and it's got its bad sides, just

like anything else, right? But hospice owners have told me when I was researching whether or not to develop a dementia death doula program, we can't be there 24/7 at the end, and most of the time they're not

Rosanne Corcoran 23:39
Right.

PK Beville 23:39
So, who is in attendance at vigil? It's the family,

Rosanne Corcoran 23:44
Family

PK Beville 23:46
And the family doesn't know what to do. Roe, you're a perfect example of that. What happened with you and your mom? Yeah, you know, had a doula been there? This could, you know, your horrible situation could have been averted.

Rosanne Corcoran 24:00
Yep, absolutely, and it happens, and that's the thing, you know, everybody thinks, well, hospice will come in and take care of everything, and that is not, that is not true,

PK Beville 24:09
Not at the end, it's not, no,

Rosanne Corcoran 24:10
No, and especially with dementia, it's, it's triple the challenge,

PK Beville 24:16
And you know, nobody says it Roe, but I think that most hospices are not well trained in the care of dementia at the end of life.

Rosanne Corcoran 24:28
I agree with you,

PK Beville 24:29

And yet the most, the highest number of admitted to hospice at this point is for neurological impairments under which dementia falls in a big way. Yes, so we got a lot of work to do there, even our expectations for hospice are way off in what they can do, especially for those with dementia.

Rosanne Corcoran 24:54
Yeah, the lack of support is staggering, and so is the understanding, and that's where you're putting this together is leaps and bounds ahead of anything that that we have and that's out there and you know, especially end of life care is especially challenging when it comes to feeding people, because as we know, as you know, part of the dying process is not eating, but most people don't realize that that is part of it, and it's even harder because the person with living with dementia may not be able to tell you they don't want it, or they're hungry, or they're not hungry, they can't process it. Now, you've been, you've had this happen, you've been involved in this, you've been in the rooms. What happens in those situations?

PK Beville 25:46
It's heartbreaking. It's just heartbreaking. A person with dementia, when you study how the brain dies and what the impact of the death of cells in the brain actually is physiologically, you'll find that what happens as we die is well programmed. I don't know if Barbara Karn said this or who did, but we have to realize that death is not a medical event, it's a human experience.

Rosanne Corcoran 26:20
It was Barbara Karnes

PK Beville 26:20
I think that's a beautiful way to look at it. It's already - we're pre-programmed, and a person living with dementia, though, at that, as the brain really begins to take its toll on the body, we're not taking the cues from the person, and as you so well put it, row we as a society, though, believe that if we feed them, they'll get better, right?

Rosanne Corcoran 26:49
Right.

PK Beville 26:50

So it's always bugged me. This is nothing new that we, in my mind, and I know this is going to be controversial for your listeners, but I'm going to be pretty bombastic here, because I think it's inexcusable. We force feed people in advanced dementia. Force feed, I see staff members sitting with a person, actually getting the spoon. Open your mouth, open your mouth, come on, open your mouth, and wiggling the spoon or the fork to, because it's pureed food by then, because we're worried about them swallowing, but we're missing the point. They're not swallowing because that part of their brain has begun to shut down, and trying to get them to swallow is causing aspiration pneumonia. And then that's not a cool way to go, but yet they get re staff members and family members feel reinforced by the amount of food they're able to get down the person, and when I use the term get down, I mean that literally, because it takes a person with dementia. It swallowing is a very complex thing in the brain, it uses several parts of the brain just to swallow. Right now, here we got two issues going on. Do we continue to try to feed them and reinforce everyone for the fact that they are eating, or do we become sensitive to the fact that this aspiration is happening, they're in advanced dementia, they're moving into transition. Do we need to keep doing this? So I had the sweetest woman who was in advanced dementia, that I was her doula, and for the family as well, and she liked to pace and walk a whole lot, which I love too, and she was agitated, agitated pacer, until we, we sang, and we would sing "You Are My Sunshine" and she couldn't say it at first, but then after a couple of repetitions, she was there, and she was the best hugger I've ever known, bar none, and she had a stroke, so here she was, she'd moved into the transition stage from advanced to transition, and I went to go visit her, as, as I do, and during transition I'm there a good bit, and this hired nurse, CNA, was there, and she was doing the force feeding, and when I helped her, tried to help her understand that this precious woman's brain was not able to handle any of the nutrition she was moving in. If your listeners know what ketosis is, her body was not not absorbing the nutrition that was coming in, and so she was experiencing abdominal pain, she was drawing her knees up, but the CNA was not making that connection, no matter how hard I tried to help her see what you're doing is prolonging this poor. Woman's life, and making the end of her life uncomfortable. She continued. It broke my heart. It would take an hour and a half to two hours for this woman to get this precious, sweet lady to swallow her food. She's massaging her. She's honestly, it was. I've seen it before, but this was so up close and personal that I really.. I called several nurses in. They tried to explain it to her, and she wasn't getting it. I'm real thankful that new research is coming out about this issue, and I want your listeners to hear me when I say that when a hospice organization, or whoever is caring for your loved one towards the end of life, they do have the option now to be able to

determine whether the person gets comfort feeding and comfort feeding only, and let me just, I want to be sure I get this right, is no more food and liquid than is comfortable, that's it, but if we keep that going, it prolongs their life for up to years, because in our mind we think that if they, we can still get them to get it down, that's comfort feeding, they're more comfortable, and that's exactly wrong. Then there is minimal comfort feeding, and that's with only as much food and liquid as necessary to avoid discomfort. Now, here's the thing: when we start to die, our bodies begin to not want anything to drink, right? I saw a good analogy about how you have a percentage of your body is water as we die anyway as we get older.

PK Beville 32:06
I'm 73 and you can tell that there's, you know, the pinching is there, and you can see that there's not as much collagen, and my body's already doing what it needs to be doing. Now you take the amount of fluid in your body that is at stasis, and then you start adding more fluid to it. What does that do? That backs up the heart, it backs up the lungs, it does all kinds of horrible things. So, so that's minimal comfort feeding, and then, of course, the controversial stop eating and drinking by advanced directive. Now that means that the person with dementia has to have made it very clear to family, everybody else, that when they get to a certain place, they don't want any nutrition or hydration, but that you got to have that signed, sealed, and delivered in advance, and we all know that most of the people we're working with right now, that has not happened. My prayer is that people will start paying attention to that and make sure that they're very clear in their advanced directives, that when I can't recognize you anymore, and I don't know who you are, and all I'm doing is agitated pacing and things like that, you can slow down on everything and eventually let me, let me go, but that's just me. I think the idea of minimal comfort feeding, it's going to take a lot of education for people, people are going to worry that that's getting abuse could be abused,

Rosanne Corcoran 33:40
Right.

PK Beville 33:41
But if you take a minute and you put yourself in the shoes of the person who's dying with dementia, and you think about what we're actually doing that's creating more discomfort, I think it helps to open the door a little bit for minimal comfort feeding.

Rosanne Corcoran 33:56

Well, and it's, it's a lightning rod, isn't it PK?

PK Beville 34:00
Great, great way to say it.

Rosanne Corcoran 34:02
It's one of those issues where it's both sides, and food is always, you know, listen, I'm Italian, food is love, right? If it is, if you're at my house, I'm feeding you till you're full, and even probably past that, because that's the way it goes. So that's the thought process, so to be at that place and think, oh my goodness, they haven't eaten in three days. Well, that's not right. It, it plays with your mind, but it is part of this process. And then what happens when families disagree with it is then, then they, you know, well, what about a feeding tube? And I know there are people that do that, I'm sure you know there are people that do that. What do we actually know about whether a feeding tube at the end of life actually helps or not?

PK Beville 34:51
Yeah, well, the studies are real clear. In fact, I'm starting to notice that it's getting recommended less. And less to family members at the end of life because it's so clear that it creates a higher risk of infection, it creates pain and discomfort for the person with dementia who's who's dying, and it doesn't prolong their life because the body won't absorb all of that, so why would we add something else to their system. If a doctor recommends a feeding tube for someone in advanced dementia, run. Don't walk away from that doctor, because that doctor is not paying attention to what's best for your mother or your father. They're not, they don't have their thoughts in their mind, they just are doing another medical intervention to make you think that something is being done, and it's actually, it's actually a dangerous thing to do.

Rosanne Corcoran 35:51
Okay,

PK Beville 35:51
Yeah

Rosanne Corcoran 35:52
Okay. And that's an advanced dementia, or later transitional, correct? Okay, gotcha. Yeah, now you know, I've, I've heard this from a lot of people. I've seen this. There's a

situation that hardly ever gets talked about, which is the caregiver knows that this is happening, makes the decision to stop feeding them in good faith for the person that they're caring for, even when other family members aren't on board, and then the person dies, and then the death certificate comes, and the cause of death is recorded as malnutrition, and that caregiver has to live with that word and with that thought for the rest of their lives. Can you unpack what that does to someone? Why it's listed like that, all of that.

PK Beville 36:40
Yep well, it's listed like that, because to be very kind, the medical community still hasn't gotten their arms around what's really happening to a person with dementia, and to that point, I want to just a little side thing here, that because of that, we really still don't have a good bead on dementia death, because that stuff keeps happening, and it's not a true representation of what actually happens. I think it's going to take a lot of training for physicians to be able to understand that the bat diagnosis on the death certificate is not a true representation of what happened. Some of them are afraid that, since they never made the diagnosis of dementia, adding that on there makes them look bad, because dementia is a long trajectory, right? So that's one reason. The second reason is statistics. See if they can show that their hospital, or whatever, has these diseases, this, these illnesses that are the cause of death versus dementia, and they don't have those stats within their system, then it makes them look bad. So, I think it's more of an institutional issue once again than it is anything, and lack of education. Now, what that does to the family is a really, really tough row to hoe. I had to with my dad, who died of when we got him to the hospital. They said he is malnourished, suggesting to me that I had not been giving him the right food, and at that point I didn't know all this about how the body dies, and he died five days later, but I didn't know that at the time, and I took it very personally, and I said, well, he just doesn't want to eat, he doesn't, I try to present it, blah blah blah, and because they were not educated about what was happening, they said, well, we're going to have to give him additional meals, see if we can't get that, and he was gone in five days. It didn't, but that still sticks with me. So I understand where the families are coming from, and when we got to the death certificate, they did not put vascular dementia down, they put heart disease. See, once again, it's not what happened. That's not what happened. And so families just, if you have to get into an argument with the attending about what was happening? Ask them to explain to you why it says malnutrition or failure to thrive, or any of those, those things, because if you, if you open your mind to understanding that when they put something like. Take that down. It's not only a falsehood, but you're now a byproduct of the lack of education and

understanding about what's actually happening, and put that in the back of your mind, and realize that it was a stupid thing to put there, and don't carry it. I know that's hard, but don't carry it. It's not your fault. You didn't do anything wrong. You did exactly what you should have been doing for the love of your loved one. Simple as that.

Rosanne Corcoran 40:30
Yeah. Thank you, PK. Thank you. Because it is, it's heartbreaking, it's trauma building, it's horrible that you, that you go on like that, because it's like, well, if they didn't have some form of dementia, they'd be eating, yeah, and you wouldn't, you wouldn't have had that, and then they would ask for food, and they would ask for food, and they would tell you if they were hungry or not hungry, it's, it's a, it's an impossible situation, and it's really, thank you, thank you for that.

PK Beville 40:58
Yeah, yeah, and I think, too, Roe one of the things that we have got to do a better job of, and that is looking at the situation through the eyes of the person with dementia. You know, I think it from a caregiving standpoint, we want to control everything, we want to make sure that we do everything right, and most of the time we do caring for them, loving them, touching them, you know, massaging their hands and their feet, having music on, doing all of those things are the right things to do, but when you look at that person, and you look in those glassy eyes, and you see that they're done, they're they're finished trying so hard. Can I can't even begin to imagine how difficult life is for them. I just wrote a blog about post-traumatic dementia syndrome. I really feel like dementia has to be one of the most traumatic experiences a person can have, and when we shift our focus from their, the way that they respond to life and how things are going from a their problem perspective to a, they've been traumatized, traumatized, and we view it from that perspective. I think our thoughts about the person with dementia begins to perk a little differently.

Rosanne Corcoran 42:39
Yeah. Well said, PK. Well said. I agree. I agree. And that's that's where you come from. You come from that world of empathy, and that world of what does it feel like for you, and how can I make that better for you? And that's, you know, you can see this through the virtual dementia tour, through your, through your dream program, and now through the empathetic transitions and thank you for for bringing all that, what, what does a good death with dementia actually look like? And is it possible?

PK Beville 43:12
Yes, it's possible. It's possible, and it's a beautiful thing. So I've just been so blessed to be with a lot of people as they've died, and I am humbled to be there when it happens. Some people say that if they, that they were there with their mother and just went to the bathroom and came back and she was gone. I think there's so much I can tell you about that, and in my, my thing about those kinds of things are, if you are present at the death of someone that you love, they wanted you there, they wanted you there, and that is a high calling, if you're not there, they wanted to go alone and not subject you to anything. I believe there's a higher spirit thing going on. I can feel it in the room when it starts to happen, and to me, I.. I know that there's something else. I watch visioning, I've seen visioning happen where they reach up. Now that was a really good death, but a good death in general is when their face is very relaxed, where the terminal agitation hasn't been happening, where they are nothing is upsetting. They don't have the elevens at the in their forehead. They're so relaxed, and I think a good death too is when the family is there, when they've been touching her, him, her loving them, making sure that they're covered. And you know, I do a. Of things during vigil that helped me feel that it's it's holy ground, no matter how you feel about spirituality, but let me tell you about one that was absolutely to me gorgeous. I was called in by the hospice that this, my person that I had been a doula for about 18 months, maybe not quite that long, was transitioning, so I got there, and I could hear the death rattles, chain stoking, terminal secretions, whatever you want to call it, out in the hall, it was that loud.

Rosanne Corcoran 45:37
Wow.

PK Beville 45:38
And, of course, that's normal. We, and normal, I don't like to use that word, that's upsetting, but actually it's the body, she can't swallow the secretions anymore, and they get collected there, I don't agree with suctioning them at that point, simply because that's just another thing, I turn them, whatever, so I get in there, and I knew we were getting close because of her breathing, and she had been very still, and kind of lying a little bit to her side. She had the glassy look. I had a washcloth here to catch any secretions, and she had been someone in my relationship with her that constantly said things like, is it okay for me to do this, can I do this? She, she lived an agitated, sort of a scary life. I don't know what happened to her previously, but I can tell you that the family was not present at her death. So, do with it what you want in your brain. So, so here she was like that, and I was massaging her hand. She had one contractured, and

all of that, and I had music playing, and the breathing was getting so far apart that I knew death was getting imminent, and the moment she turned on to her back, literally turned on to her back, her glassy eyes opened up. She reached straight up in the sky. She had a slight smile on her face. She brought her arms down. She went back to her side, closed her eyes, took two more breaths, and she was gone. It was gorgeous. Whoever she was going to, she knew them, and she was happy to see them, and she was relaxed and comfortable, and loved, and TV was off. It was just me and her, and the next, next stage.

Rosanne Corcoran 47:38
That's beautiful,

PK Beville 47:39
Isn't it? Just that's how they should all be, yeah.

Rosanne Corcoran 47:42
Yes, I agree. I agree. Wouldn't that be wonderful?

PK Beville 47:47
Yes, it would.

Rosanne Corcoran 47:48
That's beautiful. Um, PK, I mean, what? What would you say to the dementia family caregiver who's listening right now, and who's carrying that fear and that anticipatory grief and the weight of not knowing how to handle what's to come. What would you say to them?

PK Beville 48:09
Well, first of all, I would love it if you would email me or whatever about anything, because I have resources that are available that I can certainly make available look and see if you've got any doulas in your area that are specially trained in dementia care. I can turn you on to the ones that we have who can begin developing a relationship for all of you, but also the anticipatory grief that you have is heavily seated in not being able to be in control of what's happening, because you don't know, you just don't know, and I experienced it with my dad. I remember breaking into a cold sweat every morning when I'd head down to where he was, because I never knew what I was going to walk into, heart beating fast, all of the, all of this stuff, I get it, I understand it, and all I can

say is what I know now versus then is that it's already in progress, it's already moving in the right direction, the thing that you can control is how much love and support and attentiveness that you can bring to that loved one. You can make sure that there's not many family members in there to create too much chaos, or they come in a couple at a time. You make sure that you keep family situations that are negative out of the room. If someone has something that they need to say, I know there are two schools of thought on that. One is you need to say it before they go. The other is let it go, let it go. I happen to be of the let it go. There's just nothing's gonna come of releasing your issues to someone with dementia who's who's dying. There's a lot there. The the next thing that I would recommend is to make sure that when it starts to happen you embrace it, embrace it. It's a beautiful thing. It is. It's getting a bad rap out there is the problem. You can change that. You can change that, and you can be a really good example for your grandkids and your kids to be able to see someone at the bedside during a traumatic time that you are able to keep calm and you're able to support, and when it happens, when it's done, don't all of a sudden start calling people. Be there, be there, be there with each other, if you can. Funeral home doesn't have to be called right away. Hospice doesn't have to be called right away. This is your time. This is your opportunity to spend these last moments with your loved one, because when the body's gone, that's it. It's never the same after that.

Rosanne Corcoran 51:19
A big thank you to PK Beville for being my guest today. To learn more about PK, Second Wind Dreams, and her empathetic transitions dementia death doula training, visit secondwind.org I hope you enjoyed today's episode and found something helpful, whether it was information, inspiration, or even just a little company. You'll find the full transcript and links to resources mentioned today@daughterhood.org in the podcast section. While you're there, explore more of what Daughterhood offers. We're more than a podcast, we're a nonprofit community providing free services and support for caregivers, including nationwide virtual support groups we call circles. On our website, you can register for a circle, sign up for our newsletter, and read our founders blog. Don't forget to subscribe and review us on Apple Podcasts or wherever you listen. Your reviews help other caregivers discover the support they need. Follow us on Facebook and Instagram at Daughterhood to stay connected, and if you know someone else who may benefit from Daughterhood, share it with them. Also, a very special thank you to Susan Rowe for our theme music, Mama's Eyes. This is Rosanne Corcoran. I'm so grateful you spent your time with me, and I look forward to being with you again next time here in Daughterhood.