

## Podcast 349 Stein Transcript

Karen Wyatt: Today I am so excited to welcome my special guest, Kathleen Vallee Stein. And I'll tell you a little bit more about Kathleen. She worked for the California Department of Aging where she trained volunteer peer counselors in Medicare and related health insurance and then helped place them in senior centers throughout Los Angeles County. Her opinion pieces on caring for aging parents among other subjects have appeared in the Christian Science Monitor, Los Angeles Times, Los Angeles Daily News, Pasadena Star News, Orange County Register and the Jewish Journal for more than 20 years. Kathleen also wrote a book about her family's journey as her father faced the end of life called *Loving Choices, Peaceful Passing: Why My Family Chose Hospice*. And for those of you on the video, this is the book cover and what it looks like; a beautiful book, which we'll be talking about today. And this book was awarded the Independent Press NYC Big Book Award in 2021. You'll find Kathleen's writing and videos on a variety of topics about her family's hospice experience, podcast, interviews and more about the book at her website which is ValleeView.com. And Vallee is spelled like her name, V-A-L-L-E, ValleeView.com. So, Kathleen, thank you so much for joining me today.

Kathleen Vallee Stein: Thank you for inviting me. I'm excited to be here too.

Karen Wyatt: Yeah. Ever since you reached out to me and you sent me a copy of your book, I've really wanted to interview you because the information that you share from a family member's perspective about hospice is so important. And that's a perspective, we don't always hear. There are lots of us who have worked in hospice, who are out there talking about how hospice looks from our perspective, but to hear from a family member is really vital. And it's important for all the other people out there who might be considering hospice for their loved one.

Kathleen Vallee Stein: Yes, I was in charge of an agency that advocated for Medicare beneficiaries. And in my professional life, I knew all about the hospice benefit, but then when it was my family - my dad - who was dying. I just couldn't find the words to talk to him about it. So even having known how great hospice was, I couldn't even talk to my dad about it. So that was one of the motivations for writing the book.

Karen Wyatt: And I think that's so true in our society in general. For one thing, a lot of people have misconceptions about hospice and what it is, and what it does. Some people are very afraid of it and equate it with hastening death. And other people just really don't know anything or have experience. So it's no wonder that there's a lot of resistance toward getting into hospice in the first place. But I understand this dilemma of not knowing how to talk about it with your dad. Were there other members of your family who were also resistant to hearing about it?

Kathleen Vallee Stein: Not really, my sister was my main helper. The two of us were a team, and when she saw how sick dad was... When we realized how sick dad was and that he wasn't going to get better and the radiation was probably going to kill him before

the cancer did, I mean, we knew - the three of us, mom, my sister and me - we knew he was dying. Nobody was disagreeing about that. And so I had volunteered to talk to dad's physician about it. And so they're like yeah, we were all in agreement that we needed to talk to dad about it. But we had to figure out a way.

Karen Wyatt: And did the physician bring up hospice in the first place or did you have to bring it up with him?

Kathleen Vallee Stein: No, I had to bring it up with him. And I actually tried to get him to say it, and I failed because when I... When mom and my sister Anne and I all agreed that dad was dying - that we wanted to take him home from the hospital - we had to talk to the doctor about it. So I volunteered to talk to him, and I called him at his office from my dad's hospital bed. And I told him that my father had told me about a month previous, even before the radiation, that he didn't want to live like this anymore. He couldn't eat or drink. He was pretty much blind. He had a condition called rotary nystagmus and his eyes jiggled like jumping beans. He could only see forms and shapes. He couldn't see his computer screen or the TV. He was bedridden. He was miserable. So I told Dr. Archer all of this, how sick my dad was. And he said, well at that point - because he couldn't eat or drink due to the radiation - they were going to put a stomach tube in his stomach so that he could go back and get more of this radiation. And so I was telling him, we don't want to do that. And then I said again, I just reiterated how sick my dad was and that he had told me he didn't want to live like this anymore. And Dr. Archer just came right back with the stomach tube. So finally I just took a really deep breath and I got my courage up, and I said we think it might be time for hospice. And then he said, at this point, that's a good thing to consider. It's best when the family decides. I have that on the back of my book: when the family decides. And so I said, okay, Dr. Archer, can you help us talk to dad about this? And he said, doesn't your dad know he's dying? And I was too discombobulated at the moment to, you know, emotionally to really process that. But later when I reflected on it, he knew that my dad was dying. He knew it, but he wouldn't bring up the word hospice.

But later that day, he did come to the hospital at 5. He said, I'll come to the hospital and talk to your dad. The four of us will talk: me, mom, Dr. Archer, and dad. And so my mom said to me, we need to tell your dad Dr. Archer's coming to talk about hospice because he sort of kind of knew what it was. But at this point we hadn't really talked to him about it because, like I said, none of us could even get it out of our mouths. And so we went into dad's room, and mom said, Dr. Archer is going to come this afternoon and talk about hospice. And then we pretty much walked out. We were really... We were from the Midwest. We were people that did not express emotions, but she gave him the information. And I'm so grateful to her that she did because, when Dr. Archer came - we told him in the morning - and then it was 5 p.m. He had several hours to really understand and think about what we were going to talk about that evening. So Dr. Archer came into the hospital room; no stethoscope, no pad, no nothing, just him. And he asked my dad how he was feeling. And my dad said, I feel like hell, and I just... You know, I'm just miserable. And they talked a little bit more. And then Dr. Archer said, Mr. Vallee, we consider people like you terminal, just like that. Because I told Dr. Archer my dad was a

plain spoken man and to give it to him straight. So he did. And after he said that, it was one of those times where the world stops revolving and you stop breathing, and I felt like the worst daughter in the world. Because I asked Dr. Archer to do that. And my dad said, thank you Dr. Archer. I've had a good long life and I'm great.

Karen Wyatt: Wow.

Kathleen Vallee Stein: I cannot... I've never found the words to explain how our worlds just shifted all of us. Everyone. I think even the doctor, he accepted. He accepted it, that this was the end of his life. He was 80 years old. He was grateful for his long life. And he was ready to do whatever we were going to do next. And none of us really were sure what that was going to be. But the relief... I guess it's just the relief of, okay, we don't have to try to send him back into that radiation. We don't have to put a stomach tube in. We were free. We were just free. I still get emotional about it when I talk about it. Because I want people to know, if you just say it, you know, you're going to get a reaction you never expected. I think a lot of people in his situation are relieved because we're saying you don't have to try to beat this anymore. It's okay.

Karen Wyatt: It's interesting to me. Well, for one thing that the word itself, the word "hospice" is challenging for people to say. And it has to be because there are some negative associations with that word itself and whatever it might mean in people's minds. But as a doctor, I also feel disappointed that one of my colleagues wasn't able to bring it up - that you had to bring it up to the doctor, the doctor couldn't say, here are several different options available, and hospice being one of them to consider. The doctor couldn't go there himself, but he seemed fine with it as soon as you mentioned it. So there's something there. Doctors need to recognize that people may be just waiting for them to say the word, waiting for them to bring it up. And the doctors have to be the ones to get over that obstacle.

Kathleen Vallee Stein: Mm hmm. And that's why I wrote the book too. And I say, when I talk to groups, ask a doctor: do you think it's time for hospice? And if he says no, no, it isn't. Then you go forward. And if my dad would have said, when Dr. Archer came in, I'm going to fight this Dr. Archer. I'm going back for more radiation. I would have supported him in that. But I kind of thought he wouldn't because he was so miserable and he didn't want to live like that anymore. But just because you mentioned it to a physician doesn't mean you have to do it. You're considering it.

Karen Wyatt: Exactly. And it can and should be just one of the options that's out there on the table. But I remember with my own mom, in spite of me having worked in hospice for all of my career and talking about it all the time and writing books about it, when my mom got diagnosed with biliary cancer, she said, oh, I don't want to be on hospice. I'm not ready to die right now. I don't want to be on hospice. And so we had to put her on home care first and kind of ease her into hospice. Because even she had this idea that hospice itself was the death sentence. If she went on hospice, she would die right away. That was what was in her mind. So, I feel like that's one of the misperceptions about hospice that we're trying to overcome.

Kathleen Vallee Stein: Exactly. Exactly. And my dad lived longer. I believe he lived longer in hospice than he would have with continuing the radiation. And he lived some of the richest days of his life in hospice.

Karen Wyatt: And I want to give some honor to your dad because, from the book, I gathered that he was a really special person. Because it seemed like you kept hearing from all the care providers who worked with him how special he was and what a positive interaction they had with him. And you know that's not just something everyone says about every patient. So that tells me that your dad was really someone special.

Kathleen Vallee Stein: Well thank you. You know, he was a very traditional mid-century man. He was the boss of the family. He was the boss of mom. He ran everything. He used to say to us when we were kids, I'm the king and you're nothing. You know, he kept himself at the top of the heap. But when he went into hospice and he knew he was dying, he just let go. He just let go of all that authority. He showed me his financial records. He trusted me to... You know when he came home from the hospital and he walked - he didn't walk in, he came in in a wheelchair - the hospital bed was there, the oxygen concentrator, the suction machine. Everything that he needed to be cared for at home was there, and he knew I had done that. So he started looking at me differently, and he started trusting me and treating me like an adult. He was one of the original male chauvinists too. He didn't think women could do things. You know, we're talking about a guy who was born in 1920, and then all of a sudden I was the mama bird. We reversed our roles. He got home the first night, and the next morning my husband called him from Los Angeles to see how he was doing. And he answered the phone, and he said, where did you get such a good wife? Kathy set everything up, and I'm relaxing here at the home. He called that retirement community "the home," and he was telling me, you're gonna take care of me now, you're gonna help me. And he just became another person. He used to tease those home health aides and they did love him. And he called the lady that brought him breakfast the muffin lady; the lady that brought him lunch, the soup lady. And then he called the lady who took him to the bathroom the pee lady. The night he got home and he saw everything was there and everything was okay, he just relaxed. He was giddy. You know, I tell these stories because it's something I never would have dreamed of.

Karen Wyatt: I've seen that so many times that when, well when the roles get reversed, but when patients have this time in hospice at the end where their symptoms are managed and everything's taken care of, it's like they have this opportunity in some ways to blossom into maybe their better selves. And it's wonderful and beautiful for loved ones to be able to experience that and to see that happen.

Kathleen Vallee Stein: Yeah, we did and they did not want home health aides. They told me, do not hire home health aides. They did not want the prescription service. I was really glad they were living in a retirement community because - they were in active retirement - but the assisted living RN kept track of his medication and then an aide delivered it to them. So they didn't have to worry about that either, and they didn't want to spend the money because they were frugal people. But then when I went and did it

anyway, they thanked me. And that's another thing I often say is, be the adult your parent needs because your parent needs an adult now.

Karen Wyatt: And I think that was such an important decision, deciding to hire paid caregivers to come into the home because the services that hospice provides are wonderful and great. But it's not 24/7 help whatsoever in the home, and many people struggle to be a caregiver for a loved one. It's overwhelming and as you found, it took a number of different people to play that role. Your mother couldn't possibly have done that.

Kathleen Vallee Stein: No, she couldn't. And I lived in Los Angeles, and my sister lives in Scottsdale, and they lived in Prescott, Arizona. My sister was an hour and a half away by car and I of course was, you know, six hours away. So we knew we weren't going to be there all the time, and we knew that mom didn't have the physical strength or the emotional strength to care for him. Their roles had been set in stone for 56 years, and there's no way she could have taken him to the bathroom. I was kind of surprised he let another woman take him to the bathroom, but he knew it had to be done. And so he just went with it.

Karen Wyatt: And so if I remember correctly from the book, you made the decision to hire the caregivers and didn't really discuss it with your parents first knowing that they would say no anyway, is that correct?

Kathleen Vallee Stein: I was so afraid. I mean, my parents yelled at me and they spanked me, you know - not anything big - but you have those hardwired ideas about your parents. But I said to myself, I know better. Like when they knew better when I was a kid, I knew better that they couldn't do this. They weren't wealthy people, but they were careful with their money. And I knew that they could afford it, they could afford the service. And my sister and I talked about it, and she phoned around. She looked for the home health agencies for me because I was doing a lot of stuff there. And they were just wonderful. And then the prescription service, they added the cost for that onto the rent of the retirement community so we could kind of hide that part. But they did have to write a check with the caregivers. Another thing that surprised us was that those caregivers took care of my mom, too. Because my dad - of the three weeks when he was going through radiation - he was asleep almost all the time when he was home. And they would sit and chit chat with her, and they were from the same generation. So they kept her company too. It was just a good situation all the way around.

Karen Wyatt: Oh yeah, I'm sure it was. It was so positive. And it makes sense to me that sometimes you have to do the right thing and work through it later because it seems like as soon as your parents experienced what it was like to have help, they knew it was the right thing. They had no argument against it at that point.

Kathleen Vallee Stein: Well, thank goodness because we actually had a note for the caregivers by the phone, you know, instructions for them. And it said, if either Bob or Marianne tries to cancel your service, call us. But they didn't.

Karen Wyatt: Yeah, it is true. I like what you said. You know sometimes we become the ones who know the best. And we do have to take that power into our hands and make the right choices and then deal with the consequences, if there are any, down the road.

Kathleen Vallee Stein: And I never dreamed that the consequences would be so wonderful that they would thank me. And I hear so many adult children saying, no mom won't move into a retirement community. Or, mom won't wear those little alert necklaces. And I said, well just do it anyhow. And they often say no, no it's mom. Well it's not mom, it's somebody who's ill and needs you.

Karen Wyatt: Yeah. Yeah, that's such a good point. And I know you already mentioned you're the person who had to get the home ready before your dad came home from the hospital. You acquired all of the equipment, and I was curious to know what that was like for you getting set up. And then also did you get any training at all from the hospital before you left? Did they give you any idea of what your family was in for bringing your dad home?

Kathleen Vallee Stein: No. Now the discharge planner was supposed to come the day we left - right before we left, and we never saw anybody from the hospital. I was really on my own. The hospice nurse gave me the list of things to do. And so she told me, go to the DME store - Durable Medical Equipment store. Order this, this, and this, and then you have to make sure that the retirement community knows to let people in to deliver it in which apartment. Get dad's bed out of the apartment so the hospital bed can go in. There's just a million little details. And one thing I did was I bought a legal pad and a bunch of pens. And I would write everything down because there's so much to do so quickly that you just can't keep track of it. And then when my sister would come to relieve me, I would give her the notepad. And I highly recommend that because it has to be done all at once. It took me a couple of days. I thought I could do it in a day but I couldn't because I had to get back. I had to interview the home health aides, and I didn't get that done that day. It had to be the next day. But Dr. Archer let dad stay another day in the hospital.

Karen Wyatt: Oh that's nice. Well that's such a good idea of the notepad that you would leave for your sister because I think that especially happens when family members are trading off shifts, in a way. You don't necessarily remember everything that happened while you were there to pass on to the other person. So you're so wise to write everything down so it's in writing, and the other person can sit and read through what has happened while they were gone.

Kathleen Vallee Stein: Exactly. Yeah. And on one of my Youtube videos, I actually hold up the legal pad so people can see it where we checked off everything we had to do.

Karen Wyatt: Yeah, that's really great advice. I did want to say, it's a big concern of mine that hospitals don't get involved in offering any training for family members when they discharge people. And where do they think people are going? Do they have no sense

whatsoever that we're sending them home with a family member who doesn't have the slightest idea how to do any of the things we've been doing for this person?

Kathleen Vallee Stein: Well, it was a small regional hospital, so maybe they just didn't have the personnel. But again, being in the retirement community was very helpful. That's where I got my help. The manager of the facility, he knew what we were going through and was helpful. And then of course the RN and the aides, so that's where I got more help.

Karen Wyatt: Yeah, that makes sense. So we've been talking a lot about the burden for caregivers and how challenging it is when you've never done anything like this before to suddenly come home with an ill person trying to provide care and figure out what they might need. But it sounds like between the hospice nurse and then the retirement center staff, you've got at least enough information to get set up.

Kathleen Vallee Stein: Yeah we did, we did. That we worked out.

Karen Wyatt: And then I think you mentioned this a little bit ago that your dad did disclose to you all of his financial issues. But I was wondering if there were challenges there to work out during hospice and if there were challenges that came up for your family members in general and siblings around financial issues. Because that's another thing I hear often that causes conflict for families.

Kathleen Vallee Stein: Well first I'll talk about the financials and then my two estranged siblings because that was quite a thing. He showed me all of his financial dealings and he had an accountant in town - and that was another shocker. He had a female accountant, and that was quite a growth experience for him. And he really liked her, and she was wonderful too. So we went over to her office. You know, Prescott is a very small town and so she saw us right away. My sister and I went together, and she showed us all the papers. She had his trust and his legal papers, too. And it turns out my mother was the executor of the trust, and mom didn't want to do that. That was not something she ever wanted to do. So we had that changed over. So my sister was the executor and then the accountant told us where a lawyer was. She called the lawyer she knew, and he came over; everybody just helped us. And so we were able to get that accomplished while he was in hospice, and we would not have been able to do that if he had died in the hospital. And he wouldn't have had a chance to show it to me. So it was a real smooth transition financially for my mother and that was his concern: to make sure she was taken care of. So that went well. And then the accountant's assistant would come over after dad passed and go over the bills with my mother on a weekly, bi-weekly basis.

As for the estranged siblings, my parents had five children and two of them had not spoken to my dad for a decade. So actually, in a way, it was good because when we were making this decision - mom and me - we didn't have to consult anybody else because they weren't involved. But when my sister told them dad was in hospice, they wanted to come and visit him. So they did, they did that. My brother came two times and my sister came one time. And I have to say, I'll be honest; I was furious. My sister was furious

because, you know, we were the people on the ground. Nobody should criticize the person on the ground that's doing the work because they may be making mistakes but they're there and they're trying. So we weren't there when our siblings visited. We stayed away. Although my sister did communicate with them to the extent they needed, you know - when was our flight coming and things like that. And we did not know what was discussed during that time.

But now as the time passed, I'm glad that we did it the way we did it; we complained to each other but we didn't get into a fight with our estranged siblings. We didn't say, hey, well, you know, we didn't confront them. And that's one of my pieces of advice too. Because at the time you're really, really emotional and your feelings... I'm a little more hot-headed than my sister. She kind of kept me calm, and then I did things that she wouldn't have done. So that's why we're a good team. It's good to just stay away if you can, and then we would vent to each other our angry feelings. And we never said anything in front of mom and dad because that was their children too. You know, that was their business.

Then our number five, the youngest child, had young kids. It was really hard for him to come. But he wrote a beautiful, beautiful letter to my father, a testimonial letter. It was so beautiful, and he sent it to mom. We got to the retirement community, one night. She opened up the letter, and she said I can't read this. And I said, I can't read this - because it was too emotional. So after dinner I read it to her, and we both said well we've got to find somebody to read this to dad because he was pretty much blind. He couldn't read it himself. So the hospice agency sent a pastor to visit dad during the hospice time, and he hit it off with my father. And so we asked the minister to read that letter - or the chaplain - to read that letter to my father. You get things that happen when you're going through hospice you never imagined you would have to deal with, like that. A letter comes, who's going to read it? What are we going to do? But you just kind of go through, find help where you can get it, and you cope with it.

Karen Wyatt: And it seemed like that was another surprise to you that your dad allowed the chaplain to come in and then got along with him. Well, because it seems like that wasn't something you expected either.

Kathleen Vallee Stein: So funny. I walked in - I came over from Los Angeles - I walked in, the door was shut to my dad's bedroom. I said, hey mom, how's dad? And she said he's talking to the chaplain. And I started cracking jokes because the only time he ever went to church was when his kids got married; that was five times. But you know, I thought about it later. He was surrounded by women during that time. The caregivers were women, his daughters, his wife. And this was the first chance he had to talk with a man, man to man. And I don't know what they said. When I walked in, you know, mom told me go ahead and go in. They were talking about... Dad said, hi, this is Pastor Dan. And Pastor Dan had on a bolo tie and desert boots. You know, he wasn't in the black garb. And dad said, well we're talking about how much cheaper it is to get cremated these days than buried. That chaplain knew how to talk to my father and, you know, I had a feeling that my dad probably had a chance to unburden himself and to talk with the pastor. The pastor

came back another time too, and he officiated at the funeral because we were not an affiliated family.

Karen Wyatt: That is one of, I think, the beautiful benefits of hospice is that the hospice care is provided by a team of people. So you have diverse people coming in with different perspectives, and who'd play different roles in hospice care. And I've seen that often. Sometimes a patient will especially bond with one member of the team. But it makes the care so rich when you have various people coming in to do different things. And I think that's a really good example of... Who knew your dad would bond with the chaplain? And yet it turned out to be perfect.

Kathleen Vallee Stein: It really was. And it made the memorial service so much better because we didn't want to have some anonymous person come in, and he loved my dad. He said, I got to know Bob Vallee and he said, I couldn't have talked about politics with him, but we talked about a lot of things. And he really admired him; another one of the people that interfaced with him that really admired him. And he read my brother's letter, so that was part of that ceremony, too.

Karen Wyatt: Yeah, that was really beautiful. And so it turns out it was the chaplain who brought up cremation versus burial with your dad, because I was curious if you had talked to your dad about any of his wishes prior to that time.

Kathleen Vallee Stein: Well, all he told me was I want a cardboard box. Well he had decided after, you know, after the pastor... He wanted to be cremated. After the decision was made, he said I want to go out in a box. I want to go out in a cardboard box. That was my dad; don't spend any more money than you have to - when we did the pre-planning. I said to the person, the coordinator, my dad wants to go out in a cardboard box, and he did.

Karen Wyatt: So was it you, your mom, and your sister who did the planning for the funeral in advance? Or was your dad part of it?

Kathleen Vallee Stein: Yeah. It was my mother and me.

Karen Wyatt: Okay.

Kathleen Vallee Stein: And part of the book is... My mother and I got closer during that time than we've ever been in our lives. And we fought more bitterly than we ever had in our lives. And we were real with each other I think, you know? We just said what we thought.

But one night we were planning the funeral - and I'm Jewish - and I brought over a book of psalms. And I would read a little - I picked the short ones, and I'd read something. And the first few lines she'd go no, or if she liked it she'd say yes. So we picked our readings out and who was going to talk - the four grandchildren talked. And I remember that night with my mother was such... I just cherished those memories because we were just so

close and open. And we wanted to make the best tribute to my dad and her husband that we could. It was just, it was a sacred moment to me.

Karen Wyatt: Mmmm that's so beautiful. And I love hearing that you and your mom got a chance to get closer. And it seemed like you had a closeness with your dad that may not ever have happened if he hadn't been at home on hospice too, if he had still been in the hospital getting treatment.

Kathleen Vallee Stein: That's true. I would not have, I mean, he wouldn't have switched over where he trusted me. He would have died thinking I was his girl child. And what he thought of me when we went through that process together was that I was a fully drawn human being who loved him and took care of him and provided him a peaceful passing. That's why the book says loving choices, peaceful passing.

Karen Wyatt: And these stories of the things that become possible that you could never have imagined when you're with a loved one at home on hospice, I think they're so powerful because the average person would have no idea, that think that this is how it actually is when you bring someone home on hospice. And I think that makes your book so helpful in terms of educating people who might be curious about hospice and wanting to know more about it. And I'm so I'm really grateful that you were so forthcoming and vulnerable and able to tell this story so well in the book.

Kathleen Vallee Stein: I was honest. You know, what people tell me when they read the book is they say, I feel less alone; I feel like I'm not alone. Because I don't pretend like... I go, oh I was scared, I didn't know what to do. And then when my dad said I want to eat in the kitchen the night he got home, I thought, I don't know how I'm going to get him from that hospital bed into the wheelchair. And the home health aide came to give him his pills, and she taught me how to do a bear hug. That's one of my favorite memories. Giving him a bear hug. We never hugged each other. But I hugged him to get him out of the wheelchair and not on the floor in the chair.

Karen Wyatt: That's so sweet. Just those little moments it seems like are the most special things that happen, that you now cherish about your relationship and that it would seem to me were helpful with your grief over your dad's death, as well.

Kathleen Vallee Stein: Well, I was talking to a men's group a couple of weeks ago, and a man said, is it hard for you to talk about your dad now? And I said no, I love it. I love those memories. My memories are a comfort to me. You know, of course I miss him, of course. And I kind of wish I could have had him back that way for a longer period of time. I wish we could have let our guards down and been closer, you know, earlier. But I took what I could get. And it doesn't make me sad to think of those memories.

Karen Wyatt: And I wondered, are there things that you wish you had known before you started this hospice journey? Things that - in looking back in retrospect- oh, if only we

had known this at the beginning... Anything that you learned later that you wish you had known before?

Kathleen Vallee Stein: Yes. I wish when my dad told me he didn't want to live like this anymore - and he told me alone, mom wasn't there; it was just the two of us. And then he was prescribed that radiation treatment for the Non-Hodgkin's lymphoma... If I had it to do over, I would have sat down with him and said, Dad do you really want to do this radiation? And that would have saved him three awful weeks of his life where he got sicker and sicker every day and sicker to the point he couldn't take the treatment. I don't know what he would have said. I think he would have said, I'm going to try it. I'm pretty sure that's what he would have said. But then he would have had it in his mind: I don't have to do this. You know my daughter said, Dad, you really don't have to do this or do you want to do this? I think he might have thought of it sooner. But I don't know.

Karen Wyatt: I think that's such a good reminder for all of us as we're looking at our own health in the future and treatments that might be available to us. There's always an option to say no to the treatment. It's just, the doctors may not tell you that; they may not emphasize that. And so I think it's good for all of us to remember, it's ok to consider that. Do I really even want to go through it or is this other option something that could be better for me? So I'm glad that you recognize that and, you know, you see that as something valuable. But I was wondering if there's any specific advice that you have for families out there who might be considering hospice or any tips you have. I know you give those on your website, but I just wanted to give you a chance to talk about that.

Kathleen Vallee Stein: Yeah. I think, make sure your parent has an advanced directive and that you know where it is, and they know where it is and that you've talked about it. And also just try to keep an open mind and work up your courage to talk about it. And say, look, we need to have a talk and we need to do it now. And we need to understand each other because even my own children - when I try to talk about things - no, mom, it's too soon, no. I say like, do you want the antique furniture I inherited? No, mom, it's too soon. And just get around that. No, it's too soon. No, it's not too soon. And let's talk about it now.

Karen Wyatt: Exactly. Because once we open the topic, it's there. It's available for us to consider. And you can also change your mind later on. You're not stuck with any one thing that you discuss right now. You can always add new information and make different decisions down the road, too.

Kathleen Vallee Stein: Yes. Sometimes when I give talks, people don't understand that you can get out of hospice at any time. There's so much misunderstanding about hospice. There just really is, you know. They say, my loved one went into hospice and they died. Well, that's what happens when you go into hospice. Or they think they don't feed you. Or there's just... I was really surprised when I got out and started talking to folks, how much they misunderstood. I was constantly correcting misinformation. As I said, keep an open mind to hospice. Don't make a judgment. You hear the word, you make a judgment. I

hand them my sheet that tells what hospice covers. And then they can maybe consider it a little more easily.

Karen Wyatt: Yeah. It's surprising how much stigma there is against hospice. And it's concerning, especially when you experience it and find out that it was beautiful. And it was a really wonderful alternative for your dad and the best choice you could have made for him that some people miss out on because they have other ideas in their head about what hospice is and decide not to pursue it.

Kathleen Vallee Stein: I agree. Yeah, I agree. And I talk to so many people that... They'll put their loved one on hospice, and they get home and they die the next day. They wait too long and then they don't get the benefit. I thought we had a really wonderful amount of time with him, with my father, considering how ill he was and his diagnosis was so dire. But we had a lot. We had relatively a large amount of time with him.

Karen Wyatt: Yeah. And that is so true; it's never too early to start talking about it because early admission to hospice is better because of the time you have to spend. And you can always, as you said, get back out again if it turns out it's not the right time.

Kathleen Vallee Stein: Well, he did get better when we put him in hospice. He got better, and my sister and I said, oh, what's going on here? Because when they stopped the radiation, his throat, the swelling in his throat went down and he was able to eat and drink again. And he had his share of martinis too. I made him a lot of martinis, and he wouldn't have had that at the hospital.

Karen Wyatt: Oh gosh. I'm sure that made a huge difference in his last weeks of life that he could enjoy food and beverage again and not be deprived of that.

Kathleen Vallee Stein: Martinis and ice cream. That was the diet.

Karen Wyatt: That sounds good. Well, I wanted to mention again the title of your book, ***Loving Choices, Peaceful Passing: Why My Family Chose Hospice***. It's an excellent book to read. I think it's a really good kind of a wake-up call for hospice providers to read it, for one thing, to remember the perspective of family members engaging with hospice because sometimes I think we lose that. We only see it from our point of view. But also it's a great book to give to people who have an aging loved one and who might be considering hospice in the future. Because by telling your story, you walk people through step by step, what happens and what's involved. And I think it's very reassuring to get this information from you. And I'm sure you've had feedback about that.

Kathleen Vallee Stein: I have yeah, a lot of people ask me for a copy. I give, you know, friends and family that I give it to. And I had one friend that it really helped a lot to be able to think about it that way. And then my son - who's an RN - he said that too. He doesn't work with hospice, but he said the book... Because I'm his mother, he's going to say nice things. But he said it helped him as a professional to understand how the family is thinking, what's going on in the minds of the family. And I think that would be helpful.

Karen Wyatt: Yeah. So true. Because the majority of the hospice experience happens when the hospice providers aren't there, they aren't around. It's happening behind the scenes when the family's all together and what you were experiencing. So these are all the things we may never know about. We may not even be aware of the dynamics and what's going on. So it's really wonderful for anyone to read. And then I also wanted to recommend, I know on your website you were mentioning you have some podcast interviews, Youtube videos there where you share information about caring for parents. And that sounds really valuable also.

Kathleen Vallee Stein: Yes, the Youtube videos I made actually during Covid when we were all locked up in the house. One is me and my mom: what's the difference between hospice care and palliative care. My sister and I: we're a team. Just the different topics. They're 4 to 7 minutes. They're short.

Karen Wyatt: That's perfect though. A perfect way to spread information. And then you mentioned that you have a couple of handouts available on your website too that people can sign up to receive.

Kathleen Vallee Stein: No, they just click it and download it.

Karen Wyatt: Tell us about those.

Kathleen Vallee Stein: Okay. The first one is called Medicare Hospice Overview. And when I give talks, people love them. It's just: when is the right time to ask about hospice; Hospice covered by Medicare Part A; Where do you get it?; Plan of care created by a team. That will help people, especially if people say, well, my sister doesn't want my mom to go into hospice or my uncle doesn't want it. Just hand them this. This is what it covers. And it's just an information sheet. It's all from Medicare.gov. And then this another one - I was inspired by you - Hope in Hospice; when I watched your seminar, I was so inspired about it. But again, it's just what's the difference between false hope and realistic hope? How can families shift from false hope to realistic hope? And I've got a little box here with different examples, tips for talking to the physician, what is realistic hope, the goals, the whole thing. And I threw precious time in there too from Jennifer O'brien.

Karen Wyatt: Yeah, I love that concept of the precious time. That's actually what you ended up having with your dad. Precious time.

Kathleen Vallee Stein: Yeah. And that's why when I read her book, I said yeah, that's it. It's a beautiful word for it because it is precious time, and it's very limited. And it needs to really be experienced.

Karen Wyatt: And I did want to say on that topic of hope... It seems to me the book makes it clear that, even though your dad was told he's terminal and the treatments aren't going to help him, choosing hospice and deciding to go home was hope for him because

he had hope that he could eat and drink again. He could have fewer symptoms. He had time with his wife and time with his daughters, and that's beautiful hope. That's wonderful. And in some ways that's the very best that any of us could hope for ourselves.

Kathleen Vallee Stein: You know, it's so true. There was so, I mean, just those little things like he had a family ring that he'd gotten from his dad that he wanted to go to his oldest grandson, and my sister made that happen. And we returned the car - he leased a car. And you know those guys, you know, he drove a model T to high school. So cars were a big part of his life, his whole life. And just to know that was taken care of... As we took care of his earthly affairs, I felt him being able to let go and to have the closure he needed so that he could pass peacefully. And he did, he passed in his sleep.

Karen Wyatt: That's very sweet. It's very nice to hear that. Well, your journey with your dad was just so special. And the way you've written about it is really wonderful. The book is very interesting to read and compelling to read - the whole story - and I highly recommend it. So I hope people listening will get your book and also get a second copy and give it away to someone because everyone probably knows someone who will be considering hospice at some point in the future.

Kathleen Vallee Stein: Well, if they order my book on my website, I sign it and ship it for free. But you can buy it on Amazon or Barnes and Noble, anywhere books are sold online. But if you order it off the website, I'd sign it.

Karen Wyatt: And I want to make sure I get your web URL correct...  
<http://Valleeview.com>.

Kathleen Vallee Stein: Or they can google my name or whatever.

Karen Wyatt: Okay. Yeah, Kathleen Vallee, V-A-L-L-E, Stein. So, Kathleen, thank you so much for joining me today. It's been wonderful to talk with you.

Kathleen Vallee Stein: Well, it's been a pleasure. I'm honored that you had me on your podcast.

Karen Wyatt: Yeah, I'm looking forward to sharing it with everyone. And maybe we can stay in touch. Maybe someday we'll meet up in person here in California. Who knows?

Kathleen Vallee Stein: That'd be wonderful.

Karen Wyatt: Yeah, that would be great. Well take care and thanks again.

Kathleen Vallee Stein: You're welcome.