

Death and Dying with Eileen Spillane

Candace Dellacona: Welcome to episode 10 of the Sandwich Generation Survival Guide. I am one of your hosts, Candace Dellacona. Our other host, Jody Argentino, is not able to join us today. But great news, we have my friend Eileen S. Blame and also the founder of an organization called Befriending Death, who is joining us today to talk about all things related to death and dying and how we can.

Candace Dellacona: Better understand and talk about the subject that so many people feel is a difficult one. So welcome Eileen. Thanks so much for having me, Candace. It's good to be with you. Yeah, you too. So why don't, why don't you start by sharing with our audience a little bit about who you are and how you sort of got here, and then we'll talk about befriending death and what our listeners need to know.

Eileen Spillane: Yeah, sure. So I grew up in a family that allowed us to see death up close and personal and really normalized it at least, at least from my mother's side of the perspective. My father wasn't as open about bringing. Conversations in around death and dying. But my mother came from a family. All of my grandparents are immigrants from Ireland.

Eileen Spillane: And my mother came from a family that really talked about death and dying. In fact, one of my grandmother's proposals from her sister was, will you share the grave with me? Wow. Like, talk about romance, right? Yeah. So, so it's like it was very alive in their family. And so. We were exposed to a lot of death in our childhood, and my mom kind of, you know, just really made that normal.

Eileen Spillane: We saw grieving, saw open caskets then, because my parents had a pretty limited viewpoint of what women should do. We were told to either be nurses or teachers if you were the girls in the family, and the boys will become cops or firemen. And I found myself working as a nurse very young, like as. Maybe 20 years old.

Eileen Spillane: It was part of my nursing school program. I found myself at Sloan Kettering Cancer Center in New York City, and I was working with patients who had brain tumors and spinal cord tumors and who were very sick.

Candace Dellacona: Right.

Eileen Spillane: I worked with incredible nurses who really took me under their wing, and when I graduated from Adelphi, which was back in 1990, I took a job at Memorial Sloan Kettering Cancer Center.

Eileen Spillane: And you know, I was young. I was maybe like 2021 and I was at times taking care of people who were my age and that was just up close and personal in that way, where I think you can live thinking death is out there and death will come later on. Right. It was a real wake up call for me in that where it was like the Shawshank redemption line of like, you better get busy living otherwise you're getting busy dying.

Eileen Spillane: And I kind of just created this adventurous life and went off to work as a travel nurse in Hawaii and went scuba diving and skydiving and windsurfing and the triathlons and. It really had it an informed way of impacting me personally and professionally in that very first job.

Candace Dellacona: I mean, that's really interesting, Eileen, the way that it impacted you in that here you were as this young professional here in New York City at, by the way, one of the best cancer.

Candace Dellacona: Hospitals in the world, arguably. Right. And you're surrounded by very sick people. You know, in some cases where the recipients of bad luck receiving cancer or certain lifestyle choices related to smoking or whatever, have you resulted in facing these sort of dire health situations and instead of having your world become smaller and allowing the, maybe the fear of the unknown to seep in, you did the exact opposite.

Candace Dellacona: Yeah. Yeah, which is really kind of remarkable actually.

Eileen Spillane: Yeah, it is pretty remarkable. And yeah, it's continues to be the way I look at it and as I've. Gone through my nursing career and death was a big part of it no matter where I worked. Now that I'm doing work with Befriending Death, it's kind of like it just works on you without you even knowing it.

Eileen Spillane: I find that my life is still being impacted just by marinating in the topic of death and dying as I facilitate courses and book clubs and and other things.

Candace Dellacona: Yeah. So let's talk about that for our listeners. Eileen and I have known each other quite a few years, and we had the occasion to have, I think, breakfast or lunch a few years ago when this idea was really coming to fruition for you, Eileen, and you saw sort of this dearth right in society for the opportunity maybe to have people talk about death or have it at least become part of the dialogue of living.

Candace Dellacona: Can you tell us what exactly, if there was one incident or, or a series of incidents following your nursing career that made you find befriending death, and maybe talk about the ways in which you hope it will help people, or you see it's helping people?

Eileen Spillane: I'd say most of my motivation came from my years of working as a critical care nurse.

Eileen Spillane: Right. He's at, some of it was at Sloan Kettering, some of it was in as a travel nurse working in different states. And over and over again I saw that there was unnecessary suffering, that people were not having those conversations. 'cause they're hard conversations. We don't wanna talk about death and dying.

Eileen Spillane: And so what was happening is they're now forced to make these life and choice decisions under duress, under high stress circumstances. When the. In the neuroscience, like your amygdala is running the show, your center of fear rather than your prefrontal cortex where you have like this spaciousness and groundedness to make decisions from.

Eileen Spillane: But instead, you're put into this quick decision of like, do you want to be resuscitated or do you want dialysis, or whatever the circumstances are. And most of the time people don't have that conversation. Most of the time they say, oh, I just, I just wanna die in my sleep. I just wanna go to sleep at night and not wake up in the morning and have a peaceful death at home.

Eileen Spillane: But that's not a plan. Yes. You know. Plan is like having someone appointed to be your healthcare proxy. It's knowing where your paperwork is. Yes, it's having conversations very early with your medical team because physicians are not very good at initiating those conversations. They've been trained. To heal you, to fix you and,

Candace Dellacona: right, right.

Candace Dellacona: I think you know, to that point, Eileen, and for our listeners, we're going to provide your website on our resources page, on Facebook. I'll put it on Instagram and on our firm page. One of the things that you talked about in one of your blog articles, I think it was in relation to your dad's passing and how your mom wanted to give him what she called a beautiful death, and knowing your mom the way that I did it sounds exactly like something that she'd say, you know, she had this enormous heart and really had such a great spirit, and I think that most people wish that for their loved ones.

Candace Dellacona: But to your point about saying something like that and actually creating a plan and putting it into action, people don't know where to begin. Yeah. So as a nurse, you have kind of the inside scoop on what a plan would look like, whether there's a diagnosis of something or not. So could you tell us maybe what the first step should be with a loved one?

Candace Dellacona: Let's say you are diagnosed with. Illness or your loved one is, and it's a life limiting type of illness. What is the best way to embark on that conversation of what a beautiful death may look like for someone so that they're not in this urgent space of having to make these game time decisions in the way that you described when everything is firing in your brain and probably not the most optimal way?

Candace Dellacona: Can you share that with us?

Eileen Spillane: Yeah. I would say the first thing you wanna do is just. Pause and take a breath. This is now devastating information. You're just living your normal life and now you're dealt with this tough scenario. So not to rush into like, oh, I've gotta, I've gotta get this signed and figured all out.

Eileen Spillane: There's some, there's some space, there's some room. The communication is really important because you wanna bring compassion to the scenario that this is devastating for all people involved. And I would just say to open up the conversation of. How, what's important to you? Like what's, what's important day to day in your life?

Eileen Spillane: What is a quality of life? To you, me. Right, right. And that's different for everybody. Somebody just watching Seinfeld on the couch is a quality life. You know, for somebody else if they can't work or if they have a disability or if they can't speak, if they can't

feed themselves, if they have to be in a skilled nursing facility, that's not a quality of life for some people and for others it is.

Candace Dellacona: You're so right. In fact, when we draft. Um, healthcare documents. Aside from the healthcare proxy, we often draft a living will and a living will is kind of an illustrious document. And one of my very favorite clients, and maybe he'll be listening to this episode, said to me, I just want use of one arm so that I can hold my grandchild.

Candace Dellacona: I thought that was such a beautiful sentiment, right? Where, you know, what he said in that really brief sentence was, I don't have very high standards. For what a, a fulfilling life is, where you and I may have a different definition. I think I shared with you Eileen years ago, I, I had a client who said to me, you know, if you told me 20 years ago that I'd be happy with Ty takeout and a documentary on television, I would've told you you were crazy.

Candace Dellacona: But now that I am 80 years old and my husband has Parkinson's, that's a great night for me and I think that's really important. So it's an ongoing dialogue too, isn't it? It is.

Eileen Spillane: It is. And just as we're always changing our views and our beliefs and our quality of life is gonna shift and adapt as well.

Eileen Spillane: Yeah. And I just wanna go back to you bringing in my father, because a lot of people have a tough time. How do I bring up this conversation when there might be some resistance? And so. With both of my parents and I, and I've seen this across the board with patients. You have somebody who's really open to the conversation and somebody who's really resistant to the conversation.

Eileen Spillane: Sure,

Candace Dellacona: sure.

Eileen Spillane: And my dad was one of those people that was very resistant. He was a New York City firefighter. He ran into burning buildings His whole career and death was, was very upfront and personal to him, but when it came to talking about it, he did not wanna talk about it because he was superstitious and thought, if we talk about it, it's gonna happen.

Candace Dellacona: Yeah.

Eileen Spillane: So time and time again, we would just like gently navigate that like. What would you want if your heart stopped or you know, and I even got kind of clever 'cause I brought in, when I was recertifying my advanced cardiac life support, I was with paramedics and firemen in the course and I brought that conversation in and played a little dumb like, dad, how would this play out if you had to go to someone's house and they didn't have, you know, the paperwork on their fridge and pulse form or a DNR form.

Eileen Spillane: He said the appropriate answer of like, well, we would have to resuscitate them. And so then I said, would you, would you want that for you? He goes, I lean, I don't wanna talk about this. So,

Candace Dellacona: so no matter what he caught you,

Eileen Spillane: you'd go over and over and So eventually,

Candace Dellacona: yeah. Get

Eileen Spillane: to the point where you have to surrender what your own.

Eileen Spillane: Agenda is because it's ultimately up to this person to make their decision, and in the end, he was able to go on hospice and he did in fact have really beautiful death at home in his bedroom.

Candace Dellacona: Well, I think one of the things that you touched on too is as an adult child having a conversation like this with a parent, so in addition to talking about topics, maybe that a parent isn't so keen to talk about the interrelationships and the dynamic.

Candace Dellacona: Of a parent and child and the specific dynamics to a family can also play into it. So taking the breath, starting the conversation about what you'd want and maybe trying to come at it at different angles, different ways is, is, is probably a good idea. Now, at what point do you bring in the care provider?

Candace Dellacona: I think my experience is similar to yours with my clients that doctors either don't have the training or. There is sort of, and not for all, but for many, they go into medicine hoping to fix people. So it's almost incongruent for them to talk about death and dying, because that's the opposite of what they wanna do for you.

Candace Dellacona: So when do you bring in the care provider or the type of care provider? What type of care providers should you bring in to set up that plan?

Eileen Spillane: Yeah, so number one. Figure out who your doctors are. So if you're seeing a primary care doctor and you have a long standing relationship with them, start, start with your first appointment.

Eileen Spillane: When you say, this is what my vision is as I'm aging or, or even transfer your care to a gerontologist. A gerontologist is someone who's specializing in someone who's aging. So they're really tuned into reducing your medications, reducing the chance of you falling. They'll put hearing aids on for you to communicate.

Eileen Spillane: They actually look at you rather than the family member, which so often happens.

Candace Dellacona: Such

Eileen Spillane: a little

Candace Dellacona: point, but it really is so important. Right?

Eileen Spillane: Just so important. You actually feel seen, you feel seen by your physician. And, and the thing is, physicians have, they're being run by, by the insurance industry, so they have very finite amount of time.

Eileen Spillane: And as we age and we become sick, we have so many more complicated things to cover in a 20 minute appointment or whatever, whatever's allotted for them. Yeah. We don't actually have that much time to sit down and, and say, what are your wishes? So we have to drive that until. We improve that on the medical

Candace Dellacona: well, you know, as someone who is an avid traveler and a traveling, or was a traveling nurse, do you notice big differences between cultures and the discussions around death and the other countries and cultures you've been exposed to, maybe even your experiences at Memorial and, and, and treating patients from a different country?

Eileen Spillane: Are there stark differences? Totally, totally. I mean, we're all coming from different races, different genders, different cultures, different religions. It has a huge impact. I just was in India in November and was in Vaidya, which is this very special place where when a death happens the family, the men in the family literally carry the body through the village to the Ganges River, and so everyone is seeing it.

Eileen Spillane: Everyone is exposed to this. This is, we don't see this in, in our country. Well, the only thing we see is like go into anti-aging. True. So you don't want, it's all about celebrating our youthfulness. It's not talking about the death. So here they bring the body, they dunk the body in the Ganges, which is the Sacred mother.

Eileen Spillane: The sacred river, and they have a funeral pyre right there. The ashes go back into the, to the Ganges River. In Bali, I witnessed a cremation and you literally see the body on fire, like it is not sheltered at all. Wow. Yeah. And so we don't, we don't really have that in our culture. Yeah.

Candace Dellacona: I mean, and we do, I guess in some ways a wake might be considered something similar where a body is on display.

Candace Dellacona: You're right. It's more sanitized, right? The, the job of the funeral home is to make the decedent look good and look as though they did when they were living, which is probably opposite of the purpose of that ceremony that you describe in India, isn't it?

Eileen Spillane: Totally. Yeah. Makeup on. You're beautifying it and, and I feel like.

Eileen Spillane: I feel like on the East Coast there's even a cultural shift even in our country where interesting. I've rarely see an open casket on the west coast. Where, you know, on the East coast, I feel like it's a little bit more mainstream. And, and that may be influenced by my, because I grew up in a Catholic household where that was sort of the nature, you know, where you had an open casket.

Candace Dellacona: Yeah, yeah. You might be, you might be onto something. I mean, you know, all of those things are so interesting when, when you're talking about death and you're

coming up with a plan. So Befriending Death has these sort of workshops, right? You, you call it, let's chat about death. So why don't we talk about.

Candace Dellacona: What those workshops are and how they help people, and maybe what our listeners might gain from becoming a part of one of those workshops, those webinars.

Eileen Spillane: Yeah. Yeah. I'd say most people are motivated to do this course for their own selves or because they have a loved one who's aging or sick. And I've few people who've come in who are therapists and coaches or death doulas, sometimes financial planners because you're dealing with people who you know are aging or sick, or what's a death doula?

Eileen Spillane: I've never heard of that. Whoa, I'm glad you asked that. Yeah. It's an end of life doula who is trained as a non-medical person to be a support for the patient who's dying and their family and loved ones. Interesting. It's so needed. Like just as, just as in birth. Sometimes they'll have a birth doula who's there as a non-medical support and maybe giving massage or back rubs and you know, you know, and supporting pregnant mom and with hospice, I don't know if you're that familiar with it, but oftentimes you feel like, oh, cool, I finally got hospice on board.

Eileen Spillane: And then you discover. They're not at home with you on a regular basis. A hospice nurse that will come in, do a very thorough assessment and set you up and make sure your medications are set and you've got all the physical aids that you need. Sometimes you'll have a, a, a nursing assistant that comes in for a couple hours to maybe help with some bathing, but it's really on the family.

Candace Dellacona: Right. I mean, just to interrupt you a little, Eileen, you know when, when my clients come in and there is a diagnosis, a life limiting diagnosis, and, and as their D disease progresses there, there is such a disconnect. Between the information that's provided at the care level from, let's say a discharge from a hospital or a rehab when somebody is discharged home through hospice, particularly if it's not inpatient hospice.

Candace Dellacona: There are so few inpatient hospice facilities here in New York City and on Long Island. There's only, I think, two between Kings County and all of Long Island that are just hospice facilities. So think about. You know, it's so rare to be able to, to, to find a bed when you need it. And, and you're right that families think when they're going into hospice, they're gonna have somebody with them sitting vigil and they're not.

Candace Dellacona: Hospice is paid for by Medicare, so that all of our listeners know that, which is terrific and it does entitle you to some nursing care, but it's sporadic. It is not sort of ongoing supportive care, which we call activities of daily living, or in this case, activities of dying as it relates to the care that one receives at home while they are actively dying and actively dying can take months.

Candace Dellacona: Right? I mean, I guess in some ways we all are. Um, so how does one find a death doula though? Eileen? Yeah,

Eileen Spillane: there is actually like a national registry for them, but they, yeah, like I actually trained as a deaf doula myself just to enhance any non-medical learning that I had and I, I did this through the Peaceful Presence Project in Oregon, which was really great.

Eileen Spillane: There's a TED Talk that your listeners could check out with Alu Arthur, who is Okay. Incredible. She, she incredible speaker on Death and Dying. So they're out there. There's a ton in New York.

Candace Dellacona: So, you know, when you talk about the course of Let's Chat about death and it's, let's say it's for your own edification, you know, you're trying to support someone that you love.

Candace Dellacona: Can you tell us a little bit about what those webinars entail and maybe the format and, and what our listeners might be able to gain by attending them?

Eileen Spillane: Yeah. I'm just gonna add one thing about the hospice thing. Most people get to hospice too late. So just to put that out there, to start those conversations early.

Eileen Spillane: Some people are afraid because they're just like, is everyone just gonna give up on me if I, if I go hospice, I'm not gonna have my treatment. Sure. Also, something called palliative care, which can be. Reprioritizing comfort, but still hoping and trying to maintain your, your health as to, to the best as they can while keeping you comfortable.

Candace Dellacona: That's a great distinction then. So there's a difference between palliative care and hospice, and people need to, to understand that, that palliative care means comfort plus a continuation of treatment and hospice means. The seizing of treatment. Is that right?

Eileen Spillane: Yes. It's a perfect example, and Jimmy Carter is a fantastic example of how you can go on hospice and you end up living so much longer than if you didn't go on hospice because some of the treatments.

Eileen Spillane: Really injure us and you know, debilitate us. Sure. So when you optimize your living and you go on hospice, sometimes you're living way beyond the six month expectation. So it was

Candace Dellacona: actually an article, I think on that years ago, published by the New Yorker, and it talked about exactly your point, Eileen, which is hospice is started too late.

Candace Dellacona: Palliative care is generally started too late and by. In large other than sort of outlying, I think situations people do tend to live longer because pain can hasten death. So that's really a really great point for our listeners. So, and I'll let you continue about, let's chat about death. I keep interrupting,

Eileen Spillane: diverting.

Eileen Spillane: So, yeah, so the course is broken up. It's, it's a six session course over 12 weeks, and you have a little bit of homework that you do on your own. And the themes of this

sessions, the first session is your own relationship to death, and you kind of just explore that in different exercises. We've got documentaries to watch.

Eileen Spillane: The second episode, or the second session is about your relationship to aging, sickness, accidents, injuries, disabilities, the stuff that we don't wanna think about that, you know, as we, as we age. The third session is for us to do our own inner exploration of, am I ready? Like if I was to die tomorrow. Is my paperwork in place?

Eileen Spillane: Do I have a durable power of attorney for healthcare? Do I have a power of attorney for finance? Like, which is, you know, your specialty. And then like, do they know where to find those papers? Sure. And have I revisited it? Is it my, my ex-husband's still on that, you know, and I'm not with him anymore. You know, whatever this, right, right.

Eileen Spillane: Yeah. It's worth revisiting. And then we move on to, once we've done our own work, we can ask somebody else to do that work. So we might have a parent or grandparent or a loved one, spouse, children, I. Where we want them to do their own paperwork and find out like what are their wishes? What, what are their wishes?

Eileen Spillane: Also after they die, what kind of burial do they want? There's a lot of new information about green burials. There's mushroom burial where you put a mushroom suit on. There's human composting, there's water acclimation. I mean, there's so much more than that, you know. Burial in a cemetery or cremation. And so you can have stimulating conversations about that.

Eileen Spillane: We talk about actually being with the dying, whether it's you, yourself, if you're actively, you know, going through a terminal diagnosis or being the support person for someone when they're actively dying. Grieving, what's the grieving process like and how do we do that? And then the last session is really about.

Eileen Spillane: Letting death inform living. And it's always the surprise for people because they think they're signing up for this serious, you know, force where we're gonna talk about the hard things about death and dying, but they end up really feeling inspired to live their lives in a much more intentional way.

Candace Dellacona: I mean, that it sounds like it, it summarizes your life and the way that it sort of came to you.

Candace Dellacona: It's almost full circle, isn't it? It really is. So in going through each of the episodes with the participants, what has been the most surprising reaction? Can you share with us any sort of anecdotal, maybe realizations or people that you'd never think maybe it could penetrate and the message really got through and it felt like such a win for your project?

Eileen Spillane: Yeah, it's honestly Candace, I, I'm often it in tears at the end of a session because, you know, at the end of a course, because I can see the resistance start to dissipate where people had panic attacks about the fear of dying. You know, like they. They would literally like get short of breath when the idea came up.

Eileen Spillane: Or they really dreaded, you know, their mom had a horrible ICU death and they were, they were just like, I've gotta have this conversation with my father. I don't want him to relive this and my siblings are not on the same page as me. And you know, to get that checked off the list was dramatic. Yeah. And well, she can just live her life.

Eileen Spillane: He can live his life and just not have that hanging over them.

Candace Dellacona: Yeah, I mean that's such a win, right? Because I think when you're losing someone that you love or, or if your life is coming to an end, perhaps in a way that, that you didn't anticipate or prematurely we're never our best selves. I think the stress of it, the sadness, all the things that are wrapped up in it, it's so nice to have tools like yours to figure out a way.

Candace Dellacona: To really tackle this topic that has been written about, there are songs about it, movies, art, everything you can think of, wars, and I think maybe it's a human reaction to try to avoid it and come I, I've really encounter that quite often in my practice where people say, well, we're finally ready to do our wills or our trusts or our healthcare directives, and.

Candace Dellacona: What I try to do is have people feel empowered by having the conversation. There's not a lot of control that you have over how your life will end necessarily in terms of you know what's going to happen to you. But there are certain things that you can take back the control of, and so to the extent that you can, whether it's appointing the right healthcare proxy to speak for you.

Candace Dellacona: In your case, understanding the best way to start the conversation with a parent who might be resistant in dealing with a sibling who is equally resistant. I mean, I just think it's such a service to have. This course, this series of courses to guide and usher people through the process.

Eileen Spillane: Yeah, and it really is about putting power back into the patient here because you know, when we become a patient, which I have, I have been many times in my life, you know, we take your clothes away, we give you this flimsy little gown.

Eileen Spillane: People don't knock on the door when they come in. You have no, no autonomy. Yeah. And so the least thing that we can do is give people the tools to ask the right questions, to appoint the right people to know when they can say no and, and just choose if allowing a natural death is something that gives you a sense of peace.

Eileen Spillane: Okay, let's, let's make sure everyone knows that that's your wishes, particularly when people as they are sick. And aging are losing things every single day. They're losing friends as their friends die, they're losing their independence. Maybe they can't drive. And it's like, why not give them power back?

Candace Dellacona: Absolutely. And the dignity of that, right? And, and really ensuring that everyone around that person recognizes that they are in fact a person, that they live this beautiful long life, hopefully. And that. The end of it should be treated with tenderness and kindness and respect, and it should start with the person, him or herself or themselves, and I think it's just such an incredible movement that you've started or you've harnessed.

Candace Dellacona: Maybe the movement is around us because death is something that's unavoidable for all of us, but I really am. So happy and proud of you that you've created something that is so needed as, as someone who is aging. I'm turning 50 this year. Certainly things have shifted a bit and you know, our children are getting older and I am thinking about my own mortality, having lost a parent and, and lost people.

Candace Dellacona: Quite important to me. So I'm so grateful for the resources that you are providing, Eileen, and I'm sure our listeners will equally find. Your website, which we will drop here in the chat, but it's, as you know, I've said it a couple of times, befriending death and just the resources you've provided and the guidance are, are really so valuable.

Candace Dellacona: There's also a, a book club I'm seeing Yeah. On the website.

Eileen Spillane: Yeah. And, and the thing, I certainly did not start this movement. I just wanna take that. So maybe I'm moving it along. Maybe you're harnessing it. You're harnessing it. Yeah. Yeah, for sure. Yeah. Uh, but I will say what what is happening with befriending death is that there's a community piece, which is a little different than a one-way discussion out here.

Eileen Spillane: So it's gathering people so that they are having these intimate conversations together, which is really, it's a, a topic that most people avoid. So define someone that you can go deep and have a conversation with this and get over your, the hump of whatever that is that you're afraid of. Is really, that's the piece that, that I think is the sweet spot, is having a community component to it.

Candace Dellacona: Amazing. It's, it's sort of a built-in support group to have this conversation. So like I said, I am just so grateful for the opportunity to hear more about your endeavor and really happy to share it all with our listeners. So I just wanna thank you for the bottom of my heart for coming on today. I know how busy you are and how much good work you're doing.

Candace Dellacona: So thank you for, for sharing your journey with us.

Eileen Spillane: Yeah. Well, thank you so much for having you. It's great to see you again, and happy to be in conversation with you. Terrific. Thank you.