Emily: I'm Emily Kumler and this is Empowered Health.

Sarah Miller: On my 21st birthday, my mom showed up at my friend's apartment and we were about to go out and when I saw her face, I was really excited because I thought she was going to be coming out with me and celebrating. But as soon as I saw, kind of realized what was going on, I knew something had happened and she had come to tell me that my dad had unexpectedly passed away of a deep vein thrombosis[1]. So basically he threw a blood clot. I had known he had a blood clot, but I never in my head did that even occur to me that he would die. So that kind of threw me into this world of what it means to grieve and what it means to lose a parent. And it's a club that at one point other, most people join. But until you're in it, you don't really understand what that means. That experience, I was more in the backseat. I'm an only child and my parents were divorced. So my aunt and uncle were taking over as the executors of the will and the estate. But through a lot of just family turmoil, which often comes you know, floating up to the top after such a significant loss. I found myself two years later in the role of, accepting the role of the executor of my dad's estate, which meant I had to, you know, close on two different houses and clean out his properties. It was a very steep learning curve and it just one of those sink or swim situations. In the middle of that, my grandpa--I was very close with him, he basically raised me, as a kid, he babysat me every day--he was diagnosed with decreased cancer and that was my first experience with having an expected loss. Right. So there's a really big difference in grief and grieving between an unexpected loss and one that you're expecting. You begin grieving the moment that you hear that news. He did one round of chemotherapy and then went on hospice care[2] and he ended up living seven or eight months with pancreas cancer, which really is unheard of because it's usually a really quick disease[3]. But we had some great memories and it was a really beautiful experience. He had an amazing team of people who worked with him at hospice. That really made me super engaged and interested in how we're caring for people at end of life and what does that look like and where are the problems in this and the way that the system is working with that right now.

Emily: That was Sarah Miller. After experiencing those major losses in her early twenties, she became really interested in how we could better manage this end of life phase, I think both for the person who's dying and for their loved ones. And so that sort of led her to do research and find that there are actually end-of-life doulas so much like when you a baby and you're pregnant and you're thinking about all of that, many women hire a doula[4]. The job is to support the mom through the pregnancy and sort of let her know what it's going to be like and figure out individual ways that you can make the birthing experience a better one. The same thing is true for an end-of-life doula. It's not palliative care[5], although they do work closely with end-of-life doctors,

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[1] https://www.mayoclinic.org/diseases-conditions/deep-vein-thrombosis/symptoms-causes/syc-20352557
[2] https://hospicefoundation.org/Hospice-Care/Hospice-Services
[3] https://www.hopkinsmedicine.org/health/conditions-and-diseases/pancreatic-cancer/pancreatic-cancer-prognosis
[4] https://www.dona.org/what-is-a-doula/
[5] https://www.who.int/cancer/palliative/definition/en/

but in this case it's more about everything from kind of like a state planning to also trying to figure out do you want to be buried? Do you want to be cremated? Having some of those conversations that sometimes falls to doctors and sometimes people just don't have because they find them to be uncomfortable or you know, too emotional in some cases. And so an end-of-life doulas job is to really support the person who is dying along with their, you know, sort of family or friends or other people who are important in their life. As we're going to go back and hear from Sarah, in order to be a really good end-of-life doula, you have to be really comfortable with death because your job is to help the person dying feel more comfortable with death. So that was sort of the first step. She had to find a way to become more comfortable with the end-of-life. And so then how has this whole experience, and I think it's important to say you haven't actually helped somebody die as a hired doula yet, right? Like you're in the process of learning all of this stuff, but haven't had that direct experience. Is that correct?

Sarah Miller: That's correct. I've worked with a couple of hospice patients. I volunteer at a local hospice, I've worked with some hospice patients and I was actually, I was with my grandpa when he passed, so I sat, I attended at his bedside for three days. I slept next to him. I held his hand as he took his last breath and it was the most, that moment actually was really one of the most beautiful of my lifetime. And that was kind of the moment where I knew I wanted to become a doula. And the person who ended up giving my grandpa's service was, she worked as a doula for 30 years before doulas were even really a thing. And as soon as she was telling me, you know how she got into when she did, I'm like, wow, that is my calling. That is what I want to do. I want to help the company people through this part of their life. That mixed with being there with my grandpa was just such a powerful experience.

Emily: So how has this made you think about life differently?

Sarah Miller: Oh, I love that question. I can talk about that all day. So I really believe that only through understanding death may we know life and may we appreciate life. It's the duality of our existence and really what brings life meaning is knowing that we will not be here forever. So I think for me, experiencing a lot of loss before, you know, I'm not even 25 yet, experiencing the loss of both parents and my grandpa, it's made me so much more appreciative of the simple things. You know, taking a walk and enjoying the breeze in the air or smelling in the smell of the ocean. You know, those little things that really aren't, don't seem like big things really are the big things. But also I think it's made me much more in tune with what's my purpose on this earth and what am I here to do. In that way I think that I've been given a really beautiful gift at a very young age. So a lot of people don't necessarily come to that conclusion until they're much, older. So I've been given this gift of being able to understand my life purpose and act on that. So I know that I'm here. My purpose on being on this earth is to help people and that's what I'm really passionate about. That's what I want to do. And in this season of my life, I think it's helping people through death. But I'm also very accepting of the fact that things more can change and that's kind of how life works. And I think finally the thing that really has, I've learned from all this and truly is most important is the relationships in our life and the people that we have in our lives. In the past couple of years, I've become an orphan and I've been caring for my grandma

and I'm so thankful to have that relationship with her as trying and taxing as it may be. I'm having her as my family is wonderful, but I also know that I would not have made it through these past years in my life without the incredible system of support that I've built around me and the people who I've surrounded myself with. So I have an amazing team of people I work with on my everyday job who have really shown up and helped me with a lot of things in my life after my mom passed away. I have a really great adopted family through my dad's girlfriend, who I was actually just in Myrtle beach with all of them this weekend and it was just a really beautiful experience of feeling yourself being accepted into other people's families and building your own family of people, a network of people, to support you through life's adventures.

Emily: So I mean I think one of the things that is coming up for me in talking to you is this idea that you have sort of, this isn't the right word, but like embraced death, right? Like as this inevitable, which we know it is, but everybody has, or most people I guess I should say have like a tendency to push away from it, right. To either deny it or when it happens to like sort of want it to be over with. And you know, using the term orphan I think is so interesting because I think when you lose a parent or certainly when you lose both parents, you are sort of technically an orphan. But that term is usually used for children. Right? And that sense of loss is not any different as a grownup. Right? Like you still feel like your parents are anchors for you in some way. Losing an anchor means your whole perspective changes, right? Or that your whole rooting system of having a place that you can then springboard from becomes vulnerable in a whole new way. So it's interesting because I think it just sounds like you're the kind of person that runs towards the fire rather than running away from it to the benefit of other people, you know, which is really profound. And so the fact that you've had all of this death happened to you in such close proximity, you know, in terms of time, I think some people might just become really insulated, right? And not want to feel emotion and not want to be vulnerable because that's a lot of vulnerability to deal with. And that's a lot of concern over, you know, even just things that you think you can count on in life, realizing you can't. And so I mean, I feel like one of the things that I definitely want you to try and explain to us is like when you're thinking about helping other people through this, I guess we could say like transition, right? Or like, I guess transition isn't the right word for the person dying, although maybe some people believe that there is an afterlife or that this is just you know, the final time here on earth or in this world, but in terms of helping a family, what do you think the biggest things are that you have learned both from your sort of academic interest in this and the research you've done, which is extensive, also from your personal experience, that people don't usually think going into it, that you think is profoundly helpful?

Sarah Miller: I mean there's a lot of things, right? So let's kind of take the section by section. I think people grossly underestimate the physical toll that grief[6] will have on them and the length of time you will be grieving, which by the way, spoiler here, it's forever and never stops. I saw this interesting post on Facebook a couple weeks ago. It said I sat with my anger long enough until she told me her name was grief. So very often as we go through the different stages of

[6] https://www.webmd.com/special-reports/grief-stages/20190711/how-grief-affects-your-body-and-mind

grief, which also by the way is not a linear process. It's a very, you know, it's a very tangled web of confusion. As we go through that process, a lot of different emotions will come up for us and some may look like anger, some will look like denial, some will look like relief, happiness, joy, and whatever it may be. I really want to, people don't understand that all that's okay. So whatever you're feeling in that moment, whatever type of emotions coming up, it's okay. And a big lesson for me and something I've learned in this whole experience of life is giving yourself the permission to sit with what you're feeling and loving yourself enough to experience that is extremely profound. And really it's the quickest way to heal.
Emily: I feel like that idea of sitting with something is so popular, but I'm not sure very many people actually understand what does that mean? Because it's intensely uncomfortable, right?

Sarah Miller: Yes. You know, some days, I'm not sure I even do. But for example, after my mom passed away, I was thrown into this role of primary caregiver for my grandma and I had to move her from Buffalo to be with me in D.C. It's been quite the taxing journey and there are a lot of days where I just feel really angry with her and I'm just angry about the situation and how ungrateful she can be at times. And this probably isn't the best side of me, but I'm just very angry and a lot of times I will take that anger out, not necessarily on her, but I may not be as friendly as I want to be to her. And I may not be as bubbly or happy or positive around her as I could be, but I'm also in the back of my head trying to figure out [?] things like, how do I get her scripts picked up? I need to call her insurance company. I need to figure out, you know, selling her house and doing all of these things that she's not really recognizing. But for me being able to identify that anger and say, okay, Sarah, are you really angry at your grandma? Like, she's not done anything in this situation wrong. She's just, you know, she's grieving just as much as you and one not feel guilty for feeling that anger. I think is a big part, and not to say that I don't feel guilty, but actually sitting down something that helps for me is sitting down and getting out a piece of paper and kind of just automatically writing what I'm feeling and recognizing that and giving space for that so that maybe next time when I interact with her, I won't have as much anger kind of festering, but I think the biggest takeaway there is trying not to feel guilty about whatever emotion I'm having and recognizing that this is part of my grieving process.

Emily: After talking with Sarah, we wanted to go a bit deeper and sort of understand is this a new trend or is this like something that's been going on for a long time and what's sort of involved in the training of an end-of-life doula. And so we found an organization that's called International End of Life Doula Association[7]. Perfect. Right? So we called up the president and founder and we asked her a little bit about what is this process and why is this something that more and more people seem to be interested in both hiring somebody to do and also becoming an end-of-life doula.

Janie Rakow: My name is Janie Rakow[8]. I am the president of the International End of Life Doula Association better known as INELDA. We are a nonprofit that teaches people how to

[7] https://www.inelda.org/
[8] https://www.inelda.org/our-team/janie-rakow/

become end-of-life doulas as well as going to hospitals, hospices and communities to teach them how to have an end-of-life doula program.

Emily: What are the things that I thought we could start by talking about. It's just sort of, this seems to be a, I don't want to say like a new phenomenon because I feel like there certainly are periods of history where end of life sort of planning and celebration are certainly parts of cultures, but it feels to me, I'm 42 like this is becoming something and maybe that's why, that is becoming more popular. It's becoming like more of a thing that people are interested in learning about and clearly studying.

Janie Rakow: Yes.
Emily: And also sort of signing up for, can you talk a little bit about how, as somebody who's been in this world for a long time, you have seen this trend develop, if that's accurate, to say.
Janie Rakow: Yeah, no, that's completely accurate. Yes. It's really kind of exploded I'd say in the last three years when we, I've been doing this work for about 12 years specifically as an end-of-life doula. And when I used to tell people years ago, the work that I was doing, they'd say, a what, a who? And what does that mean? And you know, their eyes would glaze over. And now within, I'd say the last three years, there's so much buzz about end-of-life and how we in our society now are really not doing it right. That people I think are yearning to understand how we can do death better or more consciously. And so this whole field has completely exploded in the last, I'd say I've noticed within three years. We started our trainings at INELDA about five years ago. We had our first training and I think we had 25 people there. Now we train across the country[9], about 18 trainings in a year and we go to other countries and we're now selling out. We have to close them down at about 60, 65 people. So you are absolutely correct.

Emily: That demand is coming from people who want to learn how to be doulas, which I suppose we could assume means that there is a demand for people who want to hire people who want to be end-of-life doulas. Is that also correct?

Janie Rakow: So let's just back up a little bit cause I don't, I don't know if everybody understands what a doula is.

Emily: Okay, great.

Janie Rakow: Most people think of a doula as a birth doula if they've even ever heard of it. What we have kind of, I don't want to say developed, but we have, we have honed in on doing this work at end-of-life and an end-of-life doula as we call it, you could call it a death doula, but I like the term end of life doula, is a non-medical person who supports and guides a dying person and their loved ones through the last months, weeks, days of their life. So when somebody is diagnosed with a terminal illness, that's usually the time that the end-of-life doulas will come on

[9] https://www.inelda.org/training-calendar/

board if possible. Sometimes it could be a year before that if somebody wants to think about their death and talk about it or it could be really almost at the end at any, at any time.

Emily: And so, and I think it was probably also important for you to clarify what is the difference an end-of-life doula and a sort of hospice care.

Janie Rakow: Yes. So we get that question a lot. I like to think of it that the end-of-life doulas work in conjunction with hospice kind of hand in hand. Hospice is an amazing system for people that are dying. We always tell people, if you can get on hospice, if you have a diagnosis of six months or less, two doctors have signed off on that, you're eligible for hospice. Hospice has the most amazing services. They have an interdisciplinary team of nurses, doctors, social workers, chaplains, volunteers. But what the doula can do in that situation is spend so much time with the person who is dying and their family. Hospice, the interdisciplinary team, only has a certain amount of hours for each patient. That's just the way the money is structured that they get, they don't have a tremendous amount of time to sit with somebody and maybe to talk about their life and to talk about meaning in their life, to maybe explore legacy projects. Not that they don't want to do it, not that they don't do pieces of it, but the doulas have all the time to be able to create these very special projects during this time that the hospice workers cannot do.

Emily: So can you speak a little bit from your experience of having done this, of what that kind of looks like?

Janie Rakow: I had a woman approach me who was in her 50s, had stage four breast cancer. She was divorced. She had three children. She knew she was dying at some point. She didn't know when her doctor did not put a date on it quite yet. She wasn't at that point, so she wanted to get together with me because she, although she had a support system of family and friends, she wanted somebody in her corner. She wanted somebody who knew her wishes and would advocate for her and was an objective source, so not a sister, not a brother, not a cousin, not a best friend because emotions get involved there. She wanted to say, this is what I want and I know you'll be able to carry that out. And that went from where she wanted to die, how she wanted to die, how she felt about medication, what she wanted to do for her kids before she died. She told me about all the players in the family who could be there at bedside, who she didn't want to be there. Really total picture from beginning to end and that's exactly how it worked. We were able to talk about her kids. I was able to help her create legacies for her kids. She left beautiful, we put it in picture frames, she did sayings for each child and what they meant to her. She asked me to talk to her about what may happen, how may she die in terms of the typical progression of a disease, what would that look like? And so, she really had me there as her advocate and her gatekeeper.

Emily: So it's interesting to me because I'm somebody who just generally believes that the more information we have, the more we feel in control and the less anxiety we have, which I think on this podcast we talk a lot about in terms of women's health, just sort of getting access to good information in general. But I wonder from your perspective, I mean, this idea of dying has been

or is something that is very taboo right?[10] I mean like some people don't want to talk about it. Some people feel it's very off limits, but it's also one of those things where I can imagine, and I mean, I don't know, it's such a personal experience, but what you're talking about or how you're describing this is making me really think what you're doing is you're giving somebody accurate information about what they're going to experience so they don't feel surprised.

Janie Rakow: Exactly. And we don't know everything. You know, I said to her, let me talk to your doctor or a nurse so I can understand. I'm not a medical professional. I've done this long enough that I might know the normal progression of how a death may go, but we've been surprised, you know, usually, somebody stops eating, stops drinking, kind of goes into a coma like state. But there's been times where I've had a patient and I'm talking to them and the next day they died. Totally unexpected. But if you're armed with information, it's so, so helpful. If we don't talk about it, then so many conversations get missed. You know, she wanted to talk to her kids who were in their late teens and early twenties and say, I'm done. I can't fight anymore and here's what I want you to know and here's how I want things to go. And was it hard? Yes. Was it emotional? Extremely. Everybody was crying, but she gave them that gift of saying, you don't have to guess. Here's what I want to happen and here's what I want to say to you before I died. And it can be so beautiful, but those opportunities are missed when people say, I don't want to talk about it, you know, I'm gonna, you know, let's assume I'm going to just get better.
Emily: Yeah. Right. Well in that sort of sense of denial also makes everybody in that state of denial. Right? Like if the person who's leading the charge. I mean it that, again, it's striking to me too, the word doula, I haven't looked up the etymology of it.[11] My mom's a big word, etymology person. So I always like to look up where words come from. But you know, like there is something to me about like reminds me a little of being pregnant. Yeah. You're like, my body's changing what's going on? And everyone's like, oh, don't worry, you're fine. And you're like, fine, I'm fine. But like I still want to know what's happening or like, how is this baby actually going to come out of my vagina? Right. Like that seems impossible. Right. And when people don't talk about it, I actually really think that increases the fear that the mom feels like there is this sort of mystery. Like do people not know? And that's why no one is telling me or is it so awful that no one wants to talk about it, you know, neither of which is the case.

Janie Rakow: Right. It's not only the fear. Another point is failure. So I had another patient I was working with and she said to me, no one wants, I can talk to you about it, but no one will talk to me about what is really happening. Every time I want to say something about how I feel or that I'm dying, everyone says, oh, stop, stop. No, you're going to get better. You're going to fight it. You know you're going to win. It's a battle. You know it's all war talk. It's a battle. You're going to survive, you're going to beat this.

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[10] https://www.artofdyingwell.org/talking-about-death/talking-death/breaking-the-taboo/
[11] https://www.merriam-webster.com/dictionary/doula

Emily: Yeah. And I hate that. I honestly like, that's like a huge pet peeve of mine when people are like, yeah, like I kicked cancer's ass. You're like, what does that say about all the people who died?

Janie Rakow: And it makes them feel, she said, I'm not, I know I'm not going to beat this. I have a diagnosis that I am dying. There's no way out of this unless there's a miracle. So every time I tried to talk about it, they try to turn the conversation around because it's uncomfortable for them. But then again, you miss that great opportunity to say so many things you might want to say before you die to somebody.

Emily: I mean, as a culture, what do you make of that? I mean cause it strikes me that there is something about wanting to appease the other person or like comfort them by denying the, you know, the true diagnosis.

Janie Rakow: I think that's part of it. I think people don't want to open up a Pandora's box of emotions because it will, and that's okay. But, I think people are afraid to go there. You know what, if I make them sad? I don't want to make them sad. What if they start crying? Well, they may and you may, you know, everybody may be a mess for a while, but that will lead to something so rich and deep after that. You know, I don't know how this all started. I do know a hundred, 120 years ago we did death very differently. But you know, maybe once these big institutions came along, hospitals, now assisted living, people live all over the country and the world. We're no longer comfortable with death, we're kind of like spectators. We're told when we can visit, when we need to leave. Many people have never seen a person die. Medical technology and advances have also, you know, created it so that people are living longer. And death was familiar and all around you 120 years ago, it's not anymore. And so I think people have become very anxious and fearful because it's an unknown to many people.

Emily: And do you think that that's a change in our, like sort of comfort with emotions or do you think that that's like a germ theory? Like don't go near dead people kind of thing.

Janie Rakow: I just think that because it's not around you and your, it's not something that's part of your everyday life and that you're familiar with that people have been afraid. Children used to go to funerals. Something happened in the last 50, 60 years where, you know, people would say, oh no, no, no, no, no, they can't come. I don't want them to see what's going on. Wasn't spoken about my mother, who has since died, but she, when she was little, her brother died and nobody ever talked about it. She just remembers her mother crying and he was never spoken about again. So it's somewhere along that line, things really kind of went haywire in our society related to death and dying.

Emily: Well even if you go back and read like Grimms' Fairy Tales[12], right? Or like older kinds of stories. There sort of like this morbidity woven into all of that stuff, that's pretty graphic.

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[12] https://www.pitt.edu/~dash/grimmtales.html

Janie Rakow: Yeah.

Emily: I've always sort of assumed part of that was that the child mortality rates were so much higher.[13]

Janie Rakow: Yeah.

Emily: You know, that kids were dying all the time and so you kind of expected you'd have five kids and three would live. Like it was just a very different way.

Janie Rakow: Right. Even, you know, disease or a plague or something could wipe out, you know, most of a family. It was very, very different. And not that it was better, but some how along the line we've lost our way to be comfortable with death.

Emily: So then on a very personal level, I feel like, you know, one of the things we could all learn from you is how have you learned to be so comfortable with death?

Janie Rakow: I think that the more you talk about it and the more you normalize it and the more you're around it, it just becomes part of your life. Like, you know, my kids who are now in their twenties, you know, it's not unusual for us to have a discussion. Oh, I don't want that when I die, but I want that when I die. My son is in the music industry and about five years ago on Facebook, he created his death playlist, which, you know, people were saying to him, what do you mean? What do you mean? Why are you doing that? And it was really like you know, I'm just being thoughtful. If I were to die, this is what I'd love to hear. So in our house it was just kind of a normal conversation. And so I think that the more you normalize it, that's what's happened in my life. It's not so scary anymore. And I guess because that's what I do now, it's just part of life.

Emily: But there's a difference creating a playlist and being truly comfortable with death. Right? I mean, like I joke a lot with my sister especially that like when I die, I want to be thrown off a boat so that the animals can eat me and I become part of the ecosystem of the ocean. And she's like always like, okay, that's great. I'll be the one to have to rent a boat and throw your body over and like get arrested and you know, the whole nine.

Janie Rakow: Right.

Emily: But the truth is we're joking. That would be great if that could happen. That would be my ideal way to go. But that doesn't mean that I'm comfortable with the idea that I'm going to die.

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13 https://ourworldindata.org/child-mortality#child-mortality-achieving-the-global-goal-for-2030-would-be-a-huge-achievement-but-we-are-currently-far-away

Janie Rakow: You know, I, that's so hard for any of us to say. Am I comfortable with the idea that I'm going to die? Probably not because it hasn't happened to me and I haven't been given a diagnosis, so I'm comfortable around death. I'm comfortable being with people who are dying and their loved ones. I haven't experienced a diagnosis like that, so I can't, I don't know if I'll be comfortable with dying. I have a strong belief for myself of once I'm dead, I'm okay. So that part of it doesn't scare me. Does it scare me to get there? Possibly. Yeah. Who wouldn't be? We have, we have no, we haven't gone through it.

Emily: Mhm.

Janie Rakow: So that part of it actually thinking of the fact that I could be dying or if I had a diagnosis would be tough. I've never been there, but am I comfortable talking about it and being around it. Yes.

Emily: It strikes me that there's so many people who have lost loved ones in this opioid crisis.[14] Right. Where like, you know, the person who's, you know, I don't know if we're even saying addicts, but I would say like the victim of the opioid usage. There's probably a better way to say that, but I don't know what the technical thing is right now. But you know those families that are left behind would probably benefit from a doula. Is that appropriate or is that?

Janie Rakow: Yeah, we talk a lot about sudden deaths and the role of the doula then and it's really to go in and help the family or the loved ones with, you know, grief, talking about it. Maybe doing legacy work, which means something about the person who has died and it living on, you know, for generations can be done at any point that could be done after somebody dies. So a memorial, some sort of, writing letters to the person who had died, gathering stories about the person who has died. That can all still be done after the death. So even though it's a sudden death, there are many things that the doulas still can facilitate. Ritual work, you know, all coming together and perhaps getting into a circle and holding hands saying a prayer, lighting candles, doing something on the anniversary of the death or the birth every year there is lots of work that can be done in a sudden death.

Emily: And I'm sort of curious like having been witness to so many people, you know, while they're going through this end-of-life transition or finality or whatever we want to say. Are there things that you find to be common themes? I mean, I feel like people often will say like, oh, you know, everybody on their death bed wishes that they had spent more time with their family. Right. Maybe that's true. Maybe it's not, but you're actually somebody who's seen a lot of this. Are there any patterns or things that you have been able to reflect on as sort of interesting regardless of the person whose dying that's a shared feeling?

Janie Rakow: You know, I think it's not really a common theme. I'm starting to see a little bit that some people die how they lived, and this doesn't always happen, but I am starting to see this

[14] https://www.cdc.gov/drugoverdose/epidemic/index.html

thread that if somebody had a very, it was very laid back and peaceful, again, depending on the disease. But if it's not, a very painful disease that they're dying from, then they may die in a calmer manner than somebody who was more anxious and uptight. That's not a scientific fact.
Emily: No, that's an interesting observation. I mean, that would make sense, right? Like there's some sort of consistency to how you approach transitions.

Janie Rakow: Right. But there isn't one size fits all. Like, you know, I teach our doulas that every death is different and you have to treat it differently. You know, there's not like everyone at their last breath is not going to say I love you or is not going to say you're forgiven. It's really not like that. Every single one is unique to the person who was dying because we're all unique.
Emily: So when somebody signs up for your course, can you tell us a little bit about what the curriculum involves?

Janie Rakow: Yeah, so the curriculum is two and a half days, three days that we are together and we teach our doula model that my business partner Henry Fersko-Weiss[15], who was a social worker in a hospice that he developed and we talk about structured life review. Talking to the person really about their life, who are they, you know, what have they been through? Tell me about your family. We talk about legacy projects and how to create them for family and loved ones. We talk about a vigil plan, which is really a document, like a blueprint of how they would like to die. And there's tons of elements within that vigil plan. Like where do you want to die, if you could, would you die at home? What room? Your bedroom. Well, was that too difficult? Would you rather be in a living room near the kitchen where everybody congregates or do you want to be maybe in a hospice facility because it would be too hard to die at home?

Janie Rakow: What kind of music, what kind of sounds, what kind of touch? So vigil plans are a big part of it. We teach guided visualization for both pain relief and for the caregivers too, because they're usually very anxious and afraid. We teach about rituals, we touch on grief. Then we talk about signs and symptoms, what they may see, so that the doulas understand what they're looking at when somebody is dying. And then we talk about self care and we do a ton of experiential exercises within that weekend because if doulas are asking people to open up about their lives, they have to understand what that feels like with somebody who they don't know.

Emily: And so when you say rituals, do you mean like you're bringing in different religious traditions that are helpful?

Janie Rakow: It's rituals based on that person. So if that person is religious, okay, tell me about your religion. What does that mean to you? Are [?] certain books? Are there certain prayers? But it could be, there were two daughters whose mother was dying and their ritual was to light these three candles every day, one for each daughter and one for the mother every day. The ritual, while the mother was alive was lighting these candles. And when the mother died, they

[15] https://www.inelda.org/henry-fersko-weiss/

took the mother's candle and lit their own two and extinguished hers. That was a ritual. It could be something so simple, doesn't have to be elaborate.

Emily: And so what is the power of that?

Janie Rakow: So the power of that is really to understand that something meaningful is going on right now. And let's recognize that. And let's kind of memorialize it and remember it. Think about how many rituals there are just in everyday life. Like a birthday. People light candles and they blow them out and they sing happy birthday. When my father died, my father used to have like a little glass of vodka every night when he came home from work to help him unwind. And you know, my sister, my brother and I used to kid around like, don't ask dad anything until he's had that [?] cause you're not going to, the answer will be no. After my dad took his last breath, my brother and my sister and I were there and my brother went over to the liquor cabinet. His wasn't even discussed. Poured a little shot of vodka for each of us. And we just toasted. We sat around my dad and toasted to his life and what he meant to us. That's a ritual. And now every year on the date of his death, it's a remembrance. We toast to my dad. Everyone starts texting each other in the family, you know, a little bit of vodka to toast to dad and tell stories.

Emily: I love that. That's wonderful. And I feel like that's so easy for anybody to do.

Janie Rakow: Right. Let me see. I mean, people think of legacy and ritual as these huge projects and this huge thing. And it could be something that is so basic and so simple. A ritual could be when somebody is dying before you walk into the room, everyone takes off their shoes. That's a ritual. It just brings you into the present moment and makes you understand that something momentous is now happening in this room.

Emily: Yeah. And it's action, right? Like you're taking an action
Janie Rakow: And it's focused and directed.

Emily: Uh huh. Yeah. No, I think that makes a lot of sense. And I feel like it also, there's the honoring part of it as doing it on the anniversary that allows you permission to talk about that person on that day.

Janie Rakow: Yes.

Emily: Yeah. And I'm sure I've said this before on the podcast but I have this sort of internal thing, which I think I really learned from my dad, which is that people's stories are the most important commodities that they leave behind. And that there is this sort of interesting thing that happens when somebody dies, which is that over time you talk about them less and less and that they're sort of, they stay with you in those moments where you're telling a story about them, they're there, right? And they're present with you as you recall those things. And then as you need them less and less, you talk about them less and less. And so, and I think, you know, as a journalist, that really resonates with me as something incredibly important that when somebody

shares their story with me that I am being trusted with their most valuable commodity, right? Like it doesn't matter how much money you leave behind, if nobody talks about you or if they talk about you in a terrible way, then you're kind of worthless, right? Whereas if you serve people in moments of comfort or happiness or humor, you know, people see something and it makes them laugh because they think of you. That's a really wonderful legacy. And I think this idea of doing something as a ritual when they die that you can keep going on probably is a very multifactorial thing.

Janie Rakow: Yeah. And it helps with grief. It keeps the person alive. You know, that love does not go away, that love is there forever. And so to remember them in those ways is really honoring them, like you said before. And that's part of the ritual.

Emily: And so what do you say to the people who sort of say, you know what like that, I don't want to be reminded because it's just going to make me feel sad.

Janie Rakow: It may, it may make them feel sad. We don't, as doulas, we don't push anything on anyone. We may suggest something and we may suggest try it. If it doesn't work for you, then it doesn't work for you. You know, it may not work. But as long--what we teach is: Understand all these possible tools that you could have and use as a doula, they, you're not going to use every single one on every single case, but you may hit one or two that will resonate for that person.

Emily: So if we went back a hundred years, you know, would it be the local religious figure that would be doing these kinds of things or like who was the person who was charged with this? I mean in some ways it sort of feels like a family member, right?
Janie Rakow: It was either the family member or you know, everyone was around who was supporting this. You know, I think really it was almost like the village everybody was pitching in and helping in all different aspects, cooking meals, you know, helping with the burial, you know, up on the Hill. It was just, I feel like it was much more of a community event than it is now.

Emily: Yeah. I mean I had a very close friend growing up and her mom had breast cancer and she died when I think I was like in like freshman or sophomore year of college. And I came back obviously to try and help her with stuff. She was the eldest of three girls and she was stuck doing everything. And it was unbelievable to me that like, she and I went to look at caskets. I mean, it was like, this is crazy that you're doing, you know what I mean? Like this is your mom and you're still kind of a child and what is ha--you know, where is the community? And like, not that you could really delegate that to somebody else who wasn't super close. Right. That's the part that I think is so interesting about this becoming a new kind of field. Because had there been somebody back then who I could have called and said like, hey, we really need some help over here. Like we had never done any of this before. It seems really expensive. I mean, like there's a lot of things that come up that were really surprising.

Janie Rakow: Yes, yes. Yeah. And you know, and I think people, again, people are living longer. It's a lot of medical advances. And so, you know, you're not seeing people die regularly in their forties or fifties anymore[16]. And so maybe it is once or twice in your lifetime that you're dealing with that. And so, you know, people just don't really know what to do.

Emily: Yeah. Yeah. And I think, you know, you also have this sort of idea of like, you're so vulnerable emotionally at the end, right, that like you're not necessarily thinking clearly about.

Janie Rakow: Right. And that's why it's really helpful to have the doula because all those things can be said. If somebody dies and you have no idea, did they want to be buried? Did they want to be cremated? You know, what did they want at the funeral? If you have no idea and it's never been spoken, then it, you know, that's when fights start. Sisters, brothers, relatives. I think they wanted that. No, I don't think they wanted that. If you can make that all very clear beforehand, then it just makes everyone's life, who's left behind, so much easier.

Emily: Yeah. You know? Is there anything else that you feel like has been really surprising or interesting in the course of the work that you've done or even in training people that you can share with us?

Janie Rakow: I don't know if this is surprising or not, but what we tell our trainees and what we have found as is that this informs us how to live our own lives. When you're working with people who are dying and they're so vulnerable and they let you into the deepest, darkest, you know, stories and circle of their life, you hear things that maybe they've never told anybody else. And it kind of informs you how to live your life differently. You definitely look at life, not how you would have maybe through a different lens when you're working with people who are dying. Obviously it gives you a lot more gratitude for just being able to walk, exercise, you know, workout, do the things that you do in your everyday life when you're working with somebody who can't do any of those things and is losing all of that. So we tell our trainees that when you work with people who are dying, the gift is also for you. You're giving them a gift, but you're going to get it in return in your life too. So I think that sometimes people don't think about.

Emily: I mean I'm sure that's really incredibly valuable, but that's also the part for me where I feel like in my own life sometimes I find, you know, especially since having had kids and thinking more about my own mortality, where I become like overly sentimental, I'll look at the clouds and be like, Oh my God, I'm so lucky to be alive. I'm so lucky to have had this day. And that can also feel sort of debilitating.

Janie Rakow: Well, I think if you get stuck in that or you get melancholy about that, then it can be debilitating. But if it's just a sense of gratitude, like how lucky am I that I woke up this morning and I am pretty healthy and I can do whatever I want today as opposed to not being able to do

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16 https://budgetmodel.wharton.upenn.edu/issues/2016/1/25/mortality-in-the-united-states-past-present-and-future

anything like that. Just having those little reminders every day. I think it's just gratitude and it just sets you on a path where you're not whining and complaining about every little thing. Not that you won't, because you know, this is life. Stuff happens and we get caught up. But there's these little reminders when you're working with people who are dying that life is pretty precious.

Emily: As more and more people are choosing to die at home, the numbers are actually the highest right now that they have been since the 1900s'[17] when I would imagine most people died at home, not even by choice but just out of the practical nature of how the medical system was set up then. So more people are dying at home and we also know that women are more likely to be the caretakers of people who are dying. And so I hope that this episode has brought up for you some of the things that's brought up for me, which is a really just sort of a general reminder that end-of-life is always going to be a really hard topic, right? Like it's always going to be really emotional. It's always going to be really sad. The finality of losing somebody that you love or thinking about your own life ending is really, really hard on a number of levels. Yet at the same time, like everything in life, having more information and feeling like you can openly communicate about things probably makes it a little bit easier. So I'm very grateful for these people who are out there training to do this and the support it gives because the hospital environment is going to be naturally more stressful. And even just the sort of sanitized nature of your surroundings in a hospital. Whereas being at home with your loved ones and feeling like this is a process that you are aware of and that you've had some say in and that you've been able to tell people the things that you wanted to tell them or leave them gifts that will remind them of your life or you know, planning your funerals, all of that kind of stuff. It just seems logical to me that you'd want to be an active participant in that. People are obviously going to be nervous about bringing those kinds of conversations up. So it makes all the sense in the world to have somebody whose job is to help facilitate those conversations, both between different people and also with the person who's dying. The person who will be experiencing this and give them some control over it. I think we have such a hard time in this society talking about things that are hard and not wanting to upset people in end-of-life care. That's gotta just be rampant, right? Like you don't want to say the wrong thing to the person who's dying and make them more upset or make them feel sad when they're happy or say, you know, do the wrong thing to somehow have a negative effect. You want everything to be positive, but the truth is dying may not be so positive and so having somebody who can help you have those conversations both as the person who's dying and also as the person who's losing somebody and getting people to communicate and giving the person some control, that makes a lot of sense to me. I'm Emily Kumler and that was Empowered Health. Thanks for joining us. Don't forget to check out our website at empoweredhealthshow.com for all the show notes, links to everything that was mentioned in the episode, as well as a chance to to sign up for our newsletter and get some extra fun tidbits. See you next week.

[17] https://www.nejm.org/doi/full/10.1056/NEJMc1911892