

Fear Me Out Podcast

Episode 6

Hosted by Clinical Psychologist - Dana P. Saperstein PhD.

Guest Speaker

Susan Saperstein - Death

Dr. Dana 00:11

There are two basic motivating forces fear and love. When we're afraid, we pull back from life. When we're in love, we open up to all that life has to offer with passion, excitement, and acceptance.

Fear Me Out 00:30

Coming to you from our studio in Santa Barbara, California. This is the fear me out podcast. We're not your typical Self Help Program. Our show takes a deep dive into those psychological issues that affect us on a daily basis. We hope to shift your perspective and have you experiencing emotions differently. Now here are your hosts Kim Fauskee and Dr. Dana Saperstein.

Kim Fauskee 00:52

Welcome back, folks. On this episode, we go in depth on a subject no parent ever wants to talk about the death or pending death of a child. Our in studio guest has spent her entire professional career caring for the physical and emotional needs of others. As a registered nurse, Susan Saperstein, spent 40 years working in pediatrics and hospice, not only here in the US, but in Kenya as well. We are honored to have Susan share her experiences and wisdom with us as we continue our discussion on the fear of death. Susan, welcome to the fear me out podcast. Thank you. Like we talked about with our previous guests dureena. Pearson, I want to thank you and give you props for the career chose and for not only helping those families, but the patients of in hospice as well. So you have an interesting story, not only about your nursing career, but how at an early age, you decided you want to be a hospice nurse.

Susan Saperstein 01:54

Yes. Well, I don't think it's any surprise that I'm a nurse, I think that that was just who I was from the very beginning. But the year that I graduated from nursing school, in San Francisco, the interns at UCSF, decided to volunteer in Guatemala after a very, very big earthquake that caused a lot of damage. So they were looking for volunteers to go and help. And I was at a little bit of a loose ends. I just finished nursing school. So I went. And it was such a profound experience to be there, we worked out of a sort of half fallen school. And the interns were the doctors. And then there were several nurses, we lived in tents and slept on cots. And it was rough. But one night, I was doing the night shift. And a family brought a newborn baby and drop the baby off. The mother wasn't there, it was just people from the village, I think, who had brought the baby. And the baby had been born without a skull. So the brain was exposed. And, you know, there was absolutely nothing to do in that remote place where we were.

And I was the night nurse that night, I was by myself. And I held that baby and made the baby comfortable. And you know, just kept his scalp moist and did the best I could for the time that I had with him. And he died in my arms. When I was 21. I had very little experience in nursing, I just come out of school. And the connection that I felt with that little spirit really touched something deep inside me. And I knew that this was something that I could do that I could be with someone who was dying. And, and it was something that I kind of yearned to do. So you know, do you call that a calling? It sounds like it felt like somebody was calling and saying this is something that you can do. So I went I did various types of nursing for a few years. And then I went into pediatrics and I was in pediatrics for 11 years at Cottage Hospital, which is our local hospital. And during that time, there were some children who passed away. Sometimes I was with them, sometimes I wasn't but I had taken care of them. And there was a point where this urge to work with dying patients became more and more prevalent inside me. And it all really stemmed from that experience. When I was 21. And eventually I I went to volunteer at a hospice. And when they saw my credentials, they said well, we don't want you to vote. until we want you to be a nurse with us. And so that's how I started in hospice and was there for 20 years.

Kim Fauskee 05:07

How many? We talked about hospice in the last episode, how many children are generally under hospice care?

Susan Saperstein 05:17

Well, actually, not that many, although I've been retired now for five years. So I do think that that's changing a little bit, that we're beginning to realize, as a community, that children need hospice care as much as anyone. And one of the problems before actually was insurance coverage. Because historically, hospice care has been for people who are no longer receiving treatment. Well, for children, you do treatment, right up to the very end, if possible, and many families wish that. And so I think it's big, it's being realized now that insurance companies need to provide a different kind of care for children, then then, you know, strict hospice that we traditionally have used. So when I worked at the our local hospital, there were not very many children with cancer diagnoses that were treated at that hospital, they went to Los Angeles to the bigger centers. And so the deaths that I experienced were pediatric deaths that I experienced were from other causes. When I worked in hospice care specifically, there really weren't that many children. They didn't, they just weren't referred to us. And there were two of us, maybe three of us who had pediatric experience, and we took on those children. And I think we did a pretty good job with them. But you know, what you're suggesting is that they don't often come to hospice, and that's true.

Kim Fauskee 07:02

Was there a difference of how you cared for them? At the hospital versus at home?

Susan Saperstein 07:11

Yes, in the hospital, usually a death was after a crisis. So a child, even if they had a chronic illness, would come to the hospital because some kind of a crisis had occurred. You know, maybe it was I'm thinking of one particular child, who we had seen multiple, multiple times, he had a congenital neuromuscular problem, he was really incapacitated, and in all areas, except that he was very, very bright. And there's nothing bothering his mind. But when the last time he was admitted to the hospital,

he had pneumonia. And so that was the thing that exacerbated his condition. And he died from that. That was one of the profound moments for me, because the pediatrician, who was a long time doctor in our community, was so good with me, because he and I were on either side of this boy, the boy was about 11, I think, at that time, so he'd lived a long time with chronic illness. And his mother was just outside the room, it was too difficult for her to be there at that moment. So the doctor and I were there, and the doctor kept looking at me and making sure that I was okay. He was comfortable with what was happening. He wasn't sure I was. And, in fact, it was a little difficult because I kept putting the oxygen to the child's nose thinking, oh, you know, I have to do something. And in fact, all we needed to do was just be present for that child, as he left. That was very important, an important lesson for me, that really helped carry me through all the years of work with dying children after that.

Kim Fauskee 09:00

So being a nurse, you provide comfort, right? You take away pain, you hold hands, you talk to patients, and so on and so forth. You talked about the compassionate passing of this young man. How did you deal with his mother either before or after?

Susan Saperstein 09:20

Well, let me start to answer that question by saying that each family is a unique culture of its own, right? We have our ethnic culture or religious culture or you know, various larger cultures that we belong to, that each family has its own culture. So you have to approach working with anybody, whether it's an adult or a child, by understanding the family culture that they come from. And in that particular case, the mum was so busy Side herself, there was nothing to do except be present for her as she allowed her with her anguish, right. And I did stay in touch with her after because she had become quite a friend, we had spent quite a lot of time with each other over this child's condition. Sometimes parents are better prepared. And I think when you are doing home hospice, where you have a team of people working a social worker, spiritual support volunteers, aides, and physicians, you've got, you know, a lot of people helping, and there's more preparation than when it's rather sudden, even though they had been expecting this child to die for years, when it actually happened, it was just so shocking for the family. So I think you look at how the family functions in the first place, you get to know the family a little bit. And then when death occurs, you go from that point of knowing. And a lot of it just you just feel what is needed in this moment. And a lot of what I did when I was working with children came from that internal feeling of knowing

Kim Fauskee 11:21

you make an important point, I think we had brought this up with dureena, as well about if you know, your family members are going to pass. Is there certain preparations you can do ahead of time, in terms of, for lack of a better term, pre grieving or getting prepared for this death. And I think you make an important point, again, if I'm saying you can do all these things up to the point, but when that person dies, it's, it can be completely different.

Susan Saperstein 11:53

You know, I think that happens. So naturally, especially when a child is on hospice, or when any patient is on hospice, because it's a process, dying is a process, whatever the illness is, that moves you to the end of your life, it's a process. And, you know, it starts with general decline, general lack of functioning,

perhaps, kind of going inward, the person you know, tends to go inward, rather than looking to the people around them, they're less interested in the world at large and more interested in just the people at their bedside. Comfort is a very significant part of this, because if we see that our loved one is comfortable, then we can process our own feelings. But if they're, especially if it's your child, and your child is in pain, having a seizure, having difficulty breathing, it's very, very difficult to even be present in your body. But if the child is able to make a child comfortable, then everything can kind of slow down and go down a few notches, and people can begin to deal with their feelings. So comfort, the process itself that you know, sort of makes the person less available to us, where they go more inside themselves, all of that is a part of the grieving process helps you to be prepared for the death.

Kim Fauskee 13:33

And I can imagine in your practice, that you've come across a family or two, that has experienced the loss of a child or experienced the loss of a loved one, and probably something that you deal with,

Dr. Dana 13:48

on occasion. There's a couple of things I want to say first, before I address here, I just want to make sure that everybody knows that Susan is my wife, and that we've been married for a really long time. And I think that's really important, because a lot of conversations that we've had are about me helping people live and about her helping people die. And it's, you know, that some of the people that come to see me have experienced the kind of trauma that you could never imagine. And people often say to me, Well, how do you do that? How are you? How do you hear what these people say? How can you be present to them when, when they're describing the worst of human behavior and nature? And to me, I can do it because I feel like it's my, that I was designed for it. But I still don't really understand how my wife did what she did. It is so inconceivable to me that you could help people die and be comfortable doing that. And that you could do that with a child. I mean, it's like, you know, it's just so far beyond my comprehension. So, I guess one of the questions that I have for you is How do you How'd you do it? I know I've asked you that question probably 100 times. And you've probably answered it that many times. But it's still so inconceivable. Because, you know, you said, Well, have you worked with people who've lost a child? I have, and a person never recovers from losing their child. In some ways, I don't think that it's possible to completely get over that kind of loss. I agree. And I can't even imagine what it would be like to be present in the moment that that happens. And how do you handle the pain and the anguish and the, and the fear and the despair that comes your way. And so I'm just kind of curious about, again, if you could describe that process for you. And how did you got to a place where you could be so present and not be completely bowled over by probably one of the saddest, most tragic moments in a person's life?

Susan Saperstein 15:52

Well, you know, it's not my tragedy. It's the family's tragedy, right. And so, I'm coming in as a professional with certain skills. And I try to perform those skills, really, as well as I possibly can. So I've tried to hone my skills over the years. So that I can provide those measures, which I've just mentioned, you know, comfort, breathing, ease, medication use that eases things for the sick child, for the family. I think it's just different for everyone. I mean, I think about little Bailey, who had Tay Sachs, and she had been born well. And then, you know, at a certain period in her life, I can't quite remember when it was that she started having symptoms, but I'm thinking about nine months, she started having neurological

symptoms, and by the time she was three, she was dying. And that family was on vacation in Santa Barbara, visiting relatives. And when she started to fail, they saw a pediatrician here, and they called hospice. So I was with that child for about 10 days, we were able to get her comfortable, she was having trouble with seizures. But she was so beautiful, and so at peace within herself. That, you know, I connect with that. I also connected with her parents, I had children too, so we could connect on the basis of being parents. They were so open to everything that I had to offer in terms of nursing care, but also in terms of, you know, what we could talk about that would be preparatory for them. I told them what they could expect physiologically from this process. We talked about how they were going to feel how they would go on. Because that was a genetic disorder. You know, there was a certain amount of guilt with that, that they had produced a child because of their own genetics that was ill and that was going to die from it. During the time that they had Bailey they adopted a child. And he was about nine months old, I think when Bailey died, so they had another child that they immediately had to care for, which was actually a gift for them. On the day that Bailey died. She was at absolute peace. She was so comfortable. She was like she was in a little nest on the sofa, you know, all Christiany and she had these beautiful dark eyelashes and little wispy curly hair. And it was just a beautiful, beautiful experience. And when she finally took her last breath, it was as if peace descended. There was no it was not an angst filled moment. The parents of course, were experiencing their own grief, but they were also in all of this experience that they'd had. And they I remember the dad carried her to the mortuary himself when they were ready. I stayed with them. We had a cup of tea, I think afterwards. And he took her in his arms to the mortuary and let her go. So it can be you know, I don't want to ever say that. It's a beautiful experience when a child dies, but it can be an experience that is awe inspiring and as good as possible.

Kim Fauskee 19:50

It sounded like these parents had actually prepared themselves they had for that moment

Susan Saperstein 19:55

they had and they were really just so wonderful about it. And that's not to say that they did not experience profound grief at the loss of this child. But when you've had a child who's been declining, and you've watched this decline in you, and you've been helpless to come for it to come to its natural end, can be okay. It can be okay.

Dr. Dana 20:26

Every once in a while we run into people, Susan, right when we're walking. And I can always tell if it's somebody that she's helped a member of the family die, because they approach it was such a feeling of appreciation and joy, and they're always so happy to see or despite the fact that it was an incredibly tragic event. It almost seems as though you become a member of the family for a

Susan Saperstein 20:51

while, you know, when someone is dying, whether it's a child or an adult. People are their true selves, there is no facade, ie they are in their feelings. And I find that an incredible gift to be present to people when they're, you know, so raw, so much themselves. And and I think that we all recognize that that's, you know, kind of a special experience

Kim Fauskee 21:20

probably doesn't get more personal or intimate than that

Susan Saperstein 21:23

it does not. And, so we can have really intimate conversations. But back to what you were saying, asking Dana about, you know, how do you survive? How do I go through that experience, I am always able to keep that sort of professional persona, this is my job, as much as my calling as much as a gift for me. But I also have to, you know, try to keep professional because it doesn't help the family if I am collapsing with them. It only helps if I can guide them, hold their hands, walk through it with them, provide information for them. And I think that a lot of my focus was in teaching, you know, what is this going to look like? How can we prepare ourselves for this?

Dr. Dana 22:19

You know, that brings up a really good point in that I welcome as much pain into my life as a person could carry inside their body. And people always say, Well, how do you handle being with somebody who's had the kind of things happen to them that that had happened to them? And how do you deal with being present to somebody who's in so much pain, and my response is very similar to what you described. But I also look at it from a bit of a spiritual perspective, in that, if I take the person's pain inside of me, that's not about the other person that's about me being scared, and, and shifting the the emotional focus from the person that I'm trying to help to, to me, so I realized a long time ago that the best way to help is by being present to the person and allowing them to feel whatever they need to, but not messing with their pain, because in my mind, their pain is between them and God or whatever you want to describe it. So I'm wondering if there's a spiritual component to how you got to a place where you could trust that you don't need to take the person's pain on you don't need to collapse with the family.

Susan Saperstein 23:29

Well, in that experience in Guatemala with that, initial that baby when I was 21, I knew in that moment that this was something that I needed to do that I needed to be, this was something I could do to be with a dying person, and something that actually filled me. So the the expat experience was so profound to the rest of my life. And I knew at that point that something in me needed to work with people who were dying. So it took many years before I actually went to hospice. And certainly during the years when I was a pediatric nurse, I experienced dying children, but that it was sort of a calling, I think when I was 21. That kind of led me to this work.

Kim Fauskee 24:22

Is there something that led you to nursing specifically, even even

Susan Saperstein 24:27

Before that, I just really feeling like I needed to be a helper that I had the capability of helping people. And I didn't quite know what it was yet. At first, I thought I wanted to be a doctor, but really, nursing is so much more. What I really hoped it would be because you know you're really helping people. So intimately

Dr. Dana 24:56

isn't ammonia. If you could read what you showed me earlier today. that you've discovered that you'd written in 1996. It's all about how you conceptualize intuition. I thought it was quite beautiful.

Susan Saperstein 25:08

Okay. There is a place inside, we're only on a journey. If I try to describe it, it's a place of contradictions: warm and soft, hollow and dark, cozy, but vast, deep inside. But so near the surface. What is not contradictory is what comes from that space, the voice is clear, purposeful, direct. Sometimes I create obstacles to the entrance of my place, at other times, I cannot clearly make out the message. And then there are the times when I choose my own well before the voice, which knows all things, how wise I could be, if I could really allow myself constant access to the sacred space within me, how serene? How peaceful.

Dr. Dana 25:53

It is really, really beautiful.

Kim Fauskee 25:55

Do you remember what the motivation was for you to write that?

Susan Saperstein 25:59

This was a journal entry, when I was realizing that nursing is not just skilled oriented. So I was realizing that it wasn't just performing procedures, but using our intuition to know exactly what's needed. Asking the question, what does the patient need at this moment? Does he need to be heard? Does he need more education or explanation? Does he need someone to just sit quietly with him? And of course, the answers come from a nurse's experience, but they also come from her inner knowledge. So my practice when I was doing home visits was to go to the door, ring the doorbell, take a deep breath. And just ask that whatever was needed in that visit, would come to me whatever words needed to be used. And I just silently asked for that. And that seemed to be helpful for me.

Dr. Dana 26:54

To learn to trust your intuition, how did you get to a place where you were willing to sort of consider to be a really sacred part of who you are as a person?

Susan Saperstein 27:07

You know, I think I've always done that. And working with people who are dying has certainly broadened that intuition. And it's been so confirming, you know, that when your intuition is right, and you're you confirm it, it makes you all the more intuitive, I think, to remember

Dr. Dana 27:32

having experiences as a kid where your intuition was something that you paid attention to.

Susan Saperstein 27:41

Yeah, probably a lot. I had a very spiritual time when I was a teenager, you know, attending different churches and listening to different ideas. And I think that's where my intuition really blossomed. During those years.

Kim Fauskee 28:01

Can you talk about the spirituality portion of that a little bit more.

Susan Saperstein 28:06

Those who work in hospice would generally agree that the work we do has a spiritual component. It's dealing with something that most of us fear deeply, the idea of dying. I think we're all in a state of denial about it, because that might be necessary in order for us to live our lives fully. But it's interesting that many patients would say that they felt the most alive when they were given a short prognosis and, and that they knew the end was coming. So every moment was really precious. hospice staff have to remember that our patients have their own spiritual beliefs, and we have to honor those unconditionally. And of course, we all come from our own ideas and spiritual beliefs ourselves, but we can never ever proselytize or, or even really share our spiritual beliefs with our patients, because the focus should be on them and their families. So it does feel like really sacred work to walk with someone on the journey between life and death. So I think that's where I come from spiritually,

Kim Fauskee 29:22

your own spiritual path. Dana, and I talk a lot about faith in intuition as your guide to managing fear there. So how about a little bit on your spirituality path?

Susan Saperstein 29:39

Well, I think I started in my teen years really exploring. I had two girlfriends and we used to go to churches and synagogues and lots of different places all over the Bay Area, because we were just interested in what other people thought about spirituality. And I think that's, you know, was sort of the basis of a Um, some of my understanding of spirituality and, and it was a very natural progression, especially after this experience in Guatemala. It was it was just a natural progression for me to want to work with people who were at the end of their lives.

Kim Fauskee 30:17

Have you used your faith as a guide during your professional career? And

Susan Saperstein 30:24

very definitely, very definitely. I have a strong belief in our inner knowing. And I've always felt like I could tap into that. I've always felt that there was a voice inside me that if I listened to it, it would guide me in the correct way. So I believe God really lives within me. And that has helped me in so many ways in my life.

Kim Fauskee 30:59

Did you ever doubt that you chose the wrong career?

Susan Saperstein 31:02

Oh, never. No, I was. I was meant to do this. When you say to him,

Kim Fauskee 31:08

no, absolutely mean, it's been completely obvious. But I was just interested if if you know, when you're dealing, sometimes with the worst of the worst in crisis situations in and constantly having to deal with other people's emotions and stuff like that, that, that sometimes that can be daunting and wearing and, and sometimes you second guess whether this is what you want to do, but apparently, not

Susan Saperstein 31:38

for me. For me, honestly, working with really raw emotions like that is very inspiring. And it makes me feel that life is, you know, really tangible, and, and real. So I've, I've never shied away from those deep feelings that people have, and, and, you know, when someone is dying, when a loved one is dying, especially if it's a child, those feelings are very raw. And somehow I have been able to manage that. Somehow, I've been able to help people when they're in that extreme moment of angst when a child is dying, and not absorb it. Dana and I talk about that a lot. And he's a therapist, he cannot absorb the grief of other people. And somehow I've managed to do that in my career too, because I've been with a lot of people who've died. And children and what could be worse than a child dying. And yet there. How to describe this. You know, when we look at a child dying from an adult perspective, it's a little misleading because a child is only where they are, if a child is three, they only have the experiences of a three year old. And I really feel that children can die comfortably. And accept death. In my experience, that has been really true that there's a certain point where the parents hang on very tight, but the child is actually okay with just letting go. And that I think that the most difficult part of working with families of a dying child is dealing with the parents. Extreme need to hang on. Now, it's not always the case. I also remember a little girl called Kiki. And she, I think she was about 18 months old when she died. She had congenital problems. Her parents were so loving and so kind and I just adored this family. And they were able to let her go so beautifully and so peacefully. But I think part of it was that they had the preparation of hospice care for those families who don't have someone guiding them along the way. I think it's a lot more difficult. But they were so prepared and you know, really, really present to her as she left her body. And it was we had a cup of tea afterwards after she had been taken to the mortuary. We sat down together and we just reminisced about her and talked about her and this family was incredible. There have been other times when parents have not been able to cope very well where the loss of a child is so unimaginable. To lose a child before you die yourself is unimaginable for most of us But for some people, they seem to come to a place of grace about it, a preset place of preparation. Now, of course, working in hospice, those are deaths that are anticipated having a sudden death of a child. I don't know how anybody copes with that. But when you have a child who is in some way struggling with health to begin with, I think sometimes it's easier to let them go because you want them to be released from their pain.

Dr. Dana 35:36

You know, Kim, I don't know that you know this, but I had a sister who died from cancer. And Susan actually was her hospice nurse, so I gotta watch her, help my sister die. I don't think that many of us have the opportunity to see our spouses in action, especially in this way. And it was one of the most beautiful things I've ever seen in my life, I was stunned at how angelic my wife was, it really cemented the notion that I am a true barbarian. And she's an angel. And it was just such an amazing experience.

It was just so beautiful. I gotta see her and my sister who I adored and was really having a difficult time losing. I don't think that I could have handled it without Susan.

Susan Saperstein 36:23

I'm glad that was your experience, because this is an example of how having hospice can really make it okay for families because Shelley's death was not an easy one. We had the benefit of the hospice team. So we had a nurse, we had a social worker, a chaplain, we had a physician. And my role was really more of a caregiver along with my sister in law, Catherine. But she really had a lot of angst, and really unresolved traumas in her life. And it was very difficult for her to let go. We needed to let her have her experience of dying as her soul needed it to be, but it was difficult to watch. And I don't know that all the comfort measures in the world would have eliminated the emotional pain that she experienced in her dying process. But we as her family didn't shy away from those emotions.

Kim Fauskee 37:22

Can I ask you both this question Susan has is kind of turned the narrative on dying, especially young people dying into being more positive than a negative and I and I understand that with a child that has a chronic illness, you know, or cancer or something like that, that, that we have some level of preparation that this person may pass at some time in the near future, versus, you know, tragically, and so on and so forth. But people should be cognizant of death not being such a negative, in my opinion, and more of a positive. And you've already given us a couple of stories of families that actually made it a positive, that, obviously they're going to grieve, they're going to grieve forever for the loss of this family member. But they can look back on it in a positive light, even that child's passing. So maybe you have some ideas of how people that are listening to this that have children that hopefully are not in this predicament right now or have family members that are that potentially are facing in end of life scenarios of how they can make this more of a positive experience for not only themselves, but the their family members as well.

Susan Saperstein 38:51

That is part of the human experience. So perhaps it's better for us to embrace it, rather than pretend that it won't happen. But of course, it's not at all easy to embrace the thought of a child dying that I'm certain of. But when the unimaginable happens, we have to do our best to cope. I think the dying experience is different for a child than it is for the parent. And that depends a lot on the child's age and stage of development. A three year old is not experiencing life in the same way that an adult does. And so we have to really remember that and our care has to be tailored to their level of understanding, which I think we often underestimate. So for preschoolers, for example, who are very wise and closer to their own spiritual selves, and who have antennae for the emotions around them. It's usually better to acknowledge our own feelings and be really honest with ourselves first and then speak as directly and honestly as we can, with a preschooler not in frightening terms, but certainly at their level of understanding. And then when we talk about school aged children or teens, they're really suffering from different concerns than little ones. The hardest thing for them to cope with is the loss of their friends, the loss of their routines, school, the loss of normalcy. And so I think it's important, especially with teens to try and keep things as normal as possible and keep the routines going. Families can create memories with their children right up to the very end, even if they're in a hospital room. And those memories will really sustain them in the future. And with children, we never ever give up hope because

they're very resilient. Treatments can be surprisingly successful and surprising even to the medical community. And just one word about children who have chronic illnesses. This presents a really challenging learning curve for parents whose lives become consumed by the care of this child. The child's bedroom can become like a mini ICU with a lot of equipment and you know, unusual things in the room. But I think that death in that situation can literally be a release for the child after years of suffering many indignities. But it's rarely seen as such by the parents who usually are hanging on very tight to the child. When the child dies, the family feels a lot of fear about whether they have failed the child, whether they failed each other, whether they failed the other children in the family. And, sadly, separation and divorce is not that uncommon after a child with chronic illness passes away. And that's, that's particularly true, I would say, with sudden or traumatic deaths of children. And that really reminds me that suicide is a more and more prevalent situation among children, even those in the 11 to 14 age group now. So those kinds of deaths are really unimaginable traumas. And finally, the grieving process is very long and bumpy. And supportive counseling is really important, if when people are ready for it. So thanks for asking that question. Kim.

Dr. Dana 43:01

Kim, I think that you're bringing up a really good point. And it's one of the main reasons why are you and I are doing a podcast because we decided we wanted to talk about things that most people are not willing to talk about, whether it's death, which is something that we hardly ever talk about, because it's too frightening, out of sight, out of mind, right? And or sexual abuse or physical abuse, or, you know, all the different things that you and I have, are taking a very deep dive into are things that most people would prefer not to even ignore, let alone talk about. And so I hope that you and I are setting an example of, you know, to people that is it's really important to talk about these things. Because if you use your imagination, which is what most of us do, it's a big problem. Right? We use our imaginations in all kinds of different ways that our imagination was not designed for.

Kim Fauskee 43:53

So we're all parents sitting in the room here, we all have children. And I am not going to assume but if you have these conversations with your children. I mean, you're both in the I mean, you're both kind of in the profession, Susan, totally in the profession and an expert in that. But, you know, what kind of conversations have you had with your children about this?

Susan Saperstein 44:17

I think that we've been pretty open with our kids about life and death and the potentials. I think that, you know, they witnessed me talking at the dinner table about, you know, situations that I was dealing with, that were very natural for me, and it was it was part of my, you know, I'm going to say it's really my calling to, to do this kind of work. And so it was very natural for me to talk about it at the dinner table. And, you know, sometimes my family would just say, Oh, Mom, do we have to talk about this? But you know, For me, it's it's just part of life it's dying is part of life. And I think our children grew up with that didn't think

Dr. Dana 45:10

I don't think we held back much of what exists in the world that most kids probably would, would like to remain sheltered from. Because it's just the kind of people that we are that we just sort of figure that it's

way better to talk about things in the open, even if they're extremely uncomfortable, then, you know, to ignore them or pretend like they don't exist.

Kim Fauskee 45:33

And so Danny, you know, we I think we talked about it with Doreen as well, you've, you've dealt with some serious illness, right? You continue to deal with some issues now. How do your kids handle that with you now? I mean, is it we're through these conversations, and you almost a fatal heart attack while surfing, having two strokes, things like that? Do you think that they're actually better prepared, because again, we talked about, you can be as prepared as you can tell, the event happens, and the baby goes out with the bathwater sometimes, right?

Dr. Dana 46:12

You know, it's really hard for me to answer that question.

Kim Fauskee 46:15

Should have Shawn and Erin in here, I

Dr. Dana 46:16

guess for us. And I think that actually Susan can answer the question better than me. But I do know that they both, we have two kids, my son is a bit more stoic and more sort of self contained as a person. I told you that I asked my daughter if she would be willing to come and do our podcasts to talk about what it has been like to almost lose your father. And she started crying. And she said, This is all I could do. I'd be sitting in your podcast and cry for an hour. That's all I can offer you is how scared and sad that I am of losing my dad. But you I'm sure that you've had other conversations with them when I'm not around. And how do they? You know, how do they talk about the fact that they've almost lost her dad a few times?

Susan Saperstein 47:03

Well, I think for our daughter, it's really, really difficult to think of just it's the anticipatory grief that she's experiencing the the anticipation of losing you, that is very, very hard for her, whereas our son is able to compartmentalize it a little bit better. And, you know, I think it would be, it will be just awful, awful. When we do lose you if you go first, right, but

Kim Fauskee 47:36

So how did you deal with it? Susan, when when Dana had that heart attack, or has had the two strokes, I know that you're a medical professional, so you understand what was happening there. But you're also his wife, his partner for many, many years, somebody that you're intensely in love with? So separating that professional Susan, from the person, Susan, or the husband is or you know, or the wife is very hard to be kind of difficult. So how did you kind of deal with? Jeez, I may lose my husband.

Susan Saperstein 48:11

Yeah, that's, that's pretty hard. It's pretty hard. Because how old were you when you had your heart attack? Dana 45. And that was way, way, way, way too young. to even think about losing my husband. And

Kim Fauskee 48:28

yeah, Aaron and Shawn were young kids at that time. Right. Yeah.

Susan Saperstein 48:30

You know, I guess I try to be in the moment. As much as I can. I don't think I've ever been scared to death about something happening to Dana. I have a little bit of a philosophical perspective about life. That, you know, it ends when the right time comes. And, and I think that's maybe why I can work with dying children. So yeah, we just keep going on. And,

Dr. Dana 49:12

oh, well, you mentioned that you were destined to become a hospice nurse. I think I was destined to marry a nurse because I've had so many problems,

Kim Fauskee 49:22

but not to her own husband, was that she wasn't destined to be a hospice nurse around

Dr. Dana 49:27

No, no, I'm not talking about the hospice part, or I'm just talking about the fact that I chose somebody who's been really, really capable of taking care of me and my worst moments. Well,

Susan Saperstein 49:38

what comes up for me when something goes wrong with you, my nursing interior comes to the fore. And you know, I deal very much in the present moment and yeah, let's hope that we have lots of time together.

Dr. Dana 49:54

Yeah, my parent, my friends tease me over time. How do you know you needed to marry a nurse? What just happened?

Kim Fauskee 50:02

It must have been your intuition. Yeah. You know, we talked about life being short. I don't personally don't believe in that philosophy, I think life is exactly as long as it's supposed to be, right. And we can get into predetermined fate and predetermined destiny, and so on and so forth. But Susan had a kind of, I guess, a similar philosophy that she mentioned. So it got me thinking, when I do that, in my own head, as I get older in life, and mortality actually becomes a thing. And as I go to the doctor every year from now, it's not so much to come back in a year, everything's fine. It's like, okay, what's wrong with me now? type thing. Want to know, if I'm just justifying myself with that philosophy is life just, it lasts as long as it lasts type thing?

Dr. Dana 50:59

Well, things have changed a lot. Since I was born. When I was born in the 50s, I was supposed to die at 62 According to the insurance actuarial tables, so I have outlived my expected lifespan. And nowadays, when kids are born, they're expected to live into their 90s. And it's not because evolution

has made us longer living people, it takes a lot longer for evolution to work than just a couple generations. I think it's because we live in the first world, and that we have clean water, clean food, really good medical care. And so we get to live a lot longer, and that has elongated adolescence more than anything.

Kim Fauskee 51:44

Have you both prepared yourself mentally for dying?

Susan Saperstein 51:49

I saw content with my life and feel so complete, that, you know, when it comes, it will be fine. There,

Dr. Dana 52:02

I'm mostly stunned that I'm still alive.

Kim Fauskee 52:07

There are medical miracles, and maybe you

Dr. Dana 52:09

are one of them. No, my one of my brothers in law says to me, you know, you're the cat, and you've got eight lives already in the bag. So you better be careful with the last one. And so I don't know if I'm as prepared as Susan is in a certain way. Because the things that have happened to me have been very, very sudden and unexpected. And that's not a death that you can prepare for. It's been really traumatic, those experiences have been horrible. I wouldn't wish them on anybody. Because you know, when you feel that your life is slipping away, it's, it's immediately you get I sort of had a feeling of panic. And the one time I've truly thought I was dying, it was actually quite peaceful. So that reassured me that, in the moment that it's going to happen, it's actually very sweet. But before that, it was sheer panic and, and fear, unadulterated. That's what it felt like,

Susan Saperstein 53:03

you know, I've been with a lot of people in the moment of death, right? As a hospice nurse, and it, it just doesn't scare me at all. Because the look of peacefulness that usually comes across the face of a person who's dying, makes me feel that it's going to be okay. And even with children, and I know that this is very difficult for a parent to hear who's lost a child, but it just always feels like this is just how it's supposed to be. And if we can make a child as comfortable as possible in the process, then we're doing the best that we can, and to kind of allow things to happen as they will. The most important thing is comfort. We don't want anybody to be uncomfortable as they're approaching death. And there are ways that we can deal with that now.

Kim Fauskee 54:07

You brought up something that I hadn't even really thought about. I had mentioned early on in episode one or two, that I had eight years experience as a first responder. So I've seen more people deceased than the normal person has seen in violent gruesome situations, at home situations and so on so forth, but as I was thinking about looking back on that, while you were speaking there, even in in in people that had passed in car accidents or people that had passed and in other accidents, there was some

calmness and peace about looking at them, that it really what happened to them. The Grant was horrific. But As they lie there, it wasn't that bad. And I didn't really think about that until you just brought that up.

Susan Saperstein 55:08

Well, of course, we don't really know what happens after you die. But there is a process that I think people experience when there is enough peacefulness for a process to occur. So I think in a sudden death, that it may be different, but for the patients that I've been with who have died, for the most part, it is such a process of physical changes, as well as emotional changes, that when it actually comes to the moment of death, everything just seems to fall into place. And it's usually very peaceful. So yeah.

Kim Fauskee 55:51

Maybe that is spirituality and play, right? Maybe maybe, again, going back into my personal belief of this kind of predetermined destiny? And the spirituality, maybe that's maybe there is maybe that is how we die? I don't

Dr. Dana 56:07

know. I can't answer, I don't know. But if it gives you comfort, to look at it from that perspective, then I think that's really all that matters is that we all have to try to figure out a way to come to terms with whatever it is that scares us. And whatever it is that we feel overwhelmed by I mean, again, the premise that you and I are operating from is that we cannot have a life without fear. It's really how we choose to deal with it that determines the outcome. And in this conversation with Susan, you know, she's describing the same process, which is that comfort is fear. You didn't say it exactly like that. But I do think that when you see somebody who's comfortable, they're not in a place of fear. And if you're a family member, watching somebody who's comfortable, I think it will also ease your fear that the person that's dying is not suffering. And I think that that's something that we again want to reinforce is that fear is not the enemy. It's learning how to deal with it with grace and doing whatever we can to help the people in our lives manage their fear

Kim Fauskee 57:13

of having people like Susan holding your hand sure at the process.

Dr. Dana 57:16

I mean, I can attest from a very personal level that I don't think I beat her without her for sure. I mean, I don't have any hesitation saying that.

Kim Fauskee 57:27

So we're bumping up against our hour here, in like we have in previous podcasts, a lot of great information, a lot of great stories about the journey, and so on, so forth. But, Susan, maybe a couple poignant takeaways for our listening audience in terms of, you know, the dying and grieving process that they can kind of take away from this discussion.

Susan Saperstein 57:55

Well, the thought that comes to mind is, I am not a family member, when I'm witnessing a death, particularly of a child, I am not the family member. And I can cope with it from a professional standpoint. Certainly with a lot of feeling. I'm not saying that. But I don't want to diminish the amount of pain that a parent feels when they lose a child. Secondly, we can talk about death with our families, it's important to have conversations about the idea that we all die. It's important to talk to each other about what we would like if we do happen to face the end of life ourselves, and to talk to our partners about how we might react or cope with the loss of a loved one. And kids really do learn about death, just in the natural course of events with pets and grandparents. So I feel that it only really becomes a taboo subject if the adults make it that way. So as adults, I think it's important for us to be more comfortable talking about death. And finally, I think it's important to remember that death is the most devastating for those who are left behind. Because for the dying person. If all the pieces are in the right place, if the family is present, the final words have been said the person is surrounded by love and complete compassion and there seems to be a beautiful piece that descends and allows everything to be okay. If we look at the people who have had near death experiences, they describe feelings of profound love and belonging and even say that it was difficult to return to their bodies. So I personally take comfort in the thought that that death could be such a positive experience as we hear from those who come back from the brink. And I do feel it can be peaceful and natural. Even though what happens next is a mystery. It doesn't appear to be scary. And I feel it's entirely possible for death to be a positive experience.

Kim Fauskee 1:00:19

Susan, before we wrap things up, can you tell us a little bit about your experience in Kenya?

Susan Saperstein 1:00:24

Sure. At the hospice I was working in, we were fortunate to develop a partnership with a hospice in Kenya through an international program. And we were able to have several visits with our partners in Kenya, and they actually visited us here in Santa Barbara, as well. And the goals of this partnership were for us to share our knowledge about hospice care and to learn from each other. For 13 years, we raised funds via Jenko, which was the name of their hospice. And we, they were particularly focused on HIV AIDS and the number of people who were dying from that disease at that time. And many children were orphaned as results of HIV AIDS. So we also developed a program to support children to attend school and gave scholarships to about 250 children over the years. I'm still involved with via Jenko. Privately, I have really close ties with that community. And we learned really as much from them as we were ever able to teach them. So it was a wonderful partnership.

Kim Fauskee 1:01:46

That's really well said, Dana, any parting thoughts from you?

Dr. Dana 1:01:50

I mean, again, I spoke about fear a few moments ago. And that's really what I think is most important is to recognize that, again, we don't have a life without fear. And you and I are really doing our best to try to help people talk about the things that really scary to talk about. And it's a pleasure.

Kim Fauskee 1:02:12

Susan, thank you for being here. If there's truly a wonder woman in the world you're at. You're here.

Fear Me Out 1:02:21

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