

Transcript of Kimberly Paul episode

[00:00:00] Welcome to We Really Need to Talk, a podcast about the conversations we could be having with our loved ones. These are conversations with the power to improve the way we live, the way we age, and the way we die. Talking about what we want for the end of our lives is not easy, but we found it to be useful and powerful.

And suspect that others may as well. My name is Elizabeth Bergman, associate Professor of Gerontology at Ithaca College. And I'm Lisa Richards, the program coordinator for the Finger Lakes Geriatric Education Center. We are co-hosting this podcast from the studio at Ithaca College where we work. Together in the Gerontology Institute, we spend our days immersed in teaching, studying, and developing programs on topics many would prefer to avoid altogether or maybe just whisper about fearfully.

We have seen firsthand time and again the consequences of not talking about the end of life, but we've also witnessed the power of [00:01:00] talking about it, and that is our motivation for making this podcast.

Hi, and welcome back to, we Really Need To Talk. We're so glad you joined us today. Today we're gonna talk about how death can redefine how you live your life with our guest, Kimberly Paul. She's been in town for a couple of days doing some local talks and speaking in classes about some really interesting stuff, and we wanna keep these conversations going with her.

So let's just get to introducing. Great. So Kimberly Paul, welcome to the podcast studio. We're so thrilled you're here. Thanks, Kimberly. Paul joins us from North Carolina. She had a long career in film and. After a career in television, found herself volunteering for a hospice organization, which led to a calling and a [00:02:00] career working in hospice and palliative care.

And in the last few years, Kimberly Paul has been left working for hospice formally and has been on tour of the country in an rv. We're going to hear about that and talking with people about, Life and death and how those two things work together and how we can reclaim our life by talking about death, by being open, by making space for conversations that aren't typical in our society.

So welcome. Yeah, thank you. This is weird for me because usually I'm doing the interviewing, but I have to say, I've only been here a few days and I'm just so in love. Ithaca College and what they're doing in this field, and I too them,

and I hope they keep putting resources into you guys because this is going to be in the forefront as the baby boomers still keep aging.

And we need [00:03:00] to be more aware of a, how we hope to live, but really how we hope to age well. So I'm really impressed. By the college and what they're doing supporting your institute and bringing someone like me in to connect with your community. So that really should say I, that's what I wanna say, cuz there's not a lot of colleges out there or universities doing that, and I'm really impressed by that.

Thank you. Thank you. Yeah. So tell us a little bit about the podcast. The podcast is called Death by Design, right? They came, the whole title, death by Design came from design thinking so about thinking about things in different ways and inviting a lot of different people around the table to have that perspective and to share that perspective.

So death by design was, it's high. How do you just design your own end of life or how. Design a life in order to die well, but also how many people can we get around a table to look at this topic in a different [00:04:00] way? Artists, creatives, writers, physicians, just not the medical community, but the everyday person who is on the end result of what I call, healthcare, which is disease management system.

And so I thought collectively, how do we have a language. About a similar subject or the same subject, but see things from different perspectives, not just from the physician, not just from the physician that's writing the book, but actually the caregiver that is falling through the cracks and the patient who's falling through the cracks or feels like they're falling through the cracks and collectively have a joint conversation.

Now what I've done is just interviewed people and we're in our fifth and most likely final. Because I'm moving on to a docu-series called Why Wait, is How Do, how does the Dying Push Me Outside of my own comfort zone? And it's hopefully gonna be between, four to six episodes of me journeying with people who are actually [00:05:00] in those final stages and really, Still pushing me with not living with a chronic disease of how I can live better and live more boldly in the present moment and sharing some of their wisdom.

I try to get away from being creative, but I just think that I was born that way and I love to share stories. And this is what I've been sharing the last 22 years. And really that's what it's all about, is connecting with people and telling an

authentic story, which. A real story, not creating a story like I thought I would love to do, and still a part of me wants to do that for television and film.

It's all about telling that story. And I think the human story is really what's intrigued me. Because it's flawed, it's imperfect, it's broken, and I think that makes it be. And Kimberly really does have so many great stories that we've heard over the past few days, and the one that keeps springing to my mind is the host by story.

So do you think that you could [00:06:00] just for our listeners, let them know like how you got into it? It's really interesting. When I had a death in the family, I decided to volunteer with Host Spice and I was sitting in the lobby. Yeah. A lot of people like, what is she talking about?

I'm like, yeah, it's I Mispronounced Hospice, called it Host Spice. So I'm in this host Spice Little lobby waiting for someone to come interview me to be a volunteer. And actually, I guess they. Inter actually interviewing for a paid position of volunteer program management. And they confused me and they invited me back into this interview and I was like, they kept shooting questions.

There was like five or six people and asking for my cv. And I'm like, what I mean? And at one point I'm like, this is really crazy. You guys care a lot about your volunteers, don't you? And they're like, of course we do. And all of this. And. And I think someone in the interview is wait a minute, you are very much aware that this is, we're interviewing for a paid position.

And like any good [00:07:00] trained social worker, I'm like tell me more about that. And before, before I left they just were really intrigued and they offered me the job and so that's how I tripped into this. I just love that. Yeah, I, I've never really wanted to work in healthcare. But it desperately, I think, wanted me to be a part of it.

And with all things, I think just my personality, when I start believing in something and start really hearing stories, I'm the person that dies on the sword. I'm gonna fall. I'm, I've picked aside and it's aging side and hospice and palliative care. And I feel like I'm a warrior.

For those who don't know what, how the system can be, and they get lost in it and they get confused by it. And I feel like I have that superhero cape like, I'm gonna save the day because I'm not going to allow you to get lost in a system that is going to perhaps, [00:08:00] Lower your quality of life and not always tell you the truth.

But I have to say in the same vein that there are a lot of clinicians out there working in this field that find themselves very distraught about what the healthcare system and how it operates, the medical atmosphere. And I've seen many clinicians just disturbed. Of what the system has done to prolong suffering and prolong death.

So I don't think it's a black or white. I think there are many people as clinicians being just as big warriors like myself to, to make sure that people understand in a, in the ICU that what we're doing to prolong this. But I have to say that I think I have the Trump card, and that's the individual, the patient and the family.

If we know what we want, we can direct a care. When we don't know what we want, we allow others within the system [00:09:00] to navigate that for us, which can be very dangerous. And I think things that we talked about yesterday at your talk about having the healthcare proxy name, the person that can really speak as you, right?

Not even for you, is so important in this and not letting the person get lost. Cuz you hear a lot about person-centered care, but are we really doing it? Yeah. And I don't know. I don't know what the problem is, why people aren't upset. When pe when someone tells them, no, I want to be that three year old again.

Why? Why? Why? Because we hire individuals to. Advise us, and that's what I see clinicians doing or should be doing instead of projecting what they feel, the care and the trajectory. I say lay it all out, educate people and let them make the right decisions. But if we're not speaking the truth that hey, you can take this treatment and you most likely will die even quicker, or we can send you home with comfort care, [00:10:00] but either way.

This will take your life. And I don't like to talk about battle. I don't like to talk about losing. I, it just sucks. A chronic disease is sometimes genetic, sometimes not, but anyone with a chronic disease, Especially upon diagnosis. If it's early stage, learn about it. Know the options. Get someone to sit down with you and say, okay, we all are gonna die.

We know where we're going, but how does this chronic disease play into. How we do that and be educated. And not to say that you won't change your mind, but the education and the research will guide you, and I believe that's the key. I don't believe we should ask our clinicians to be our sole provider of guidance, and I don't believe the individual.

Unaware of really tra the trajectory of what a chronic illness can do to a human [00:11:00] life and lessen the quality of life. I think we just, we both know that we are dying, but we're not having the conversation about what might cause that. And here are the many multiple roads that it can take based on your knowledge of what's going on, as well as your decisions.

In that knowledge. So I just say that this healthcare system is an intersection with no stop signs. And if you are aware of what the role you play, you put up that stop sign. And if the physician is a true seeker and a true. Truth teller, he will put up a stop sign and maybe we have a chance for everyone to pause and not have emotional reactions, which most likely if you are emotionally driven and don't have the conversation, you will wind up in the hospital on event and icu, never really having the full knowledge that you are dying and really stealing away those moments of goodbye.

And I love you and I think that's what I'm fighting for. It's not. [00:12:00] For, it is aging well, but I'm fighting for connection. I'm fighting for people to speak authentically and knowing that hard conversations, that's life and how we embrace them and acknowledge them, and how that plays a role in our decisions moving forward is vital in our quality of life, and that's what I'm fighting for.

Is that human impulse and that human connection, and how do we protect it? I was saying something and I, I read something recently with everything going on in the media these days. It's if we want a collective humanity, we gotta stop justifying what that threatens it. and I so believe in that.

And that means making people sometimes uncomfortable, like physicians, like our caregivers, like saying to our healthcare power attorney, no, that's not what I want. This is what I want. And if you're unable to do that because you're not speaking for me, you're speaking as me, you have no decision, but I need you to be my voice when I don't have one.

And so [00:13:00] that is probably one of the key decisions you will ever make in your life. But, We, when we're 15 or 16, we make a end of life decision as a donor on our license. And it's, we say we've normalized that it, people aren't, don't feel like that's an end of life decision, but you're talking about your death and if you're found in a car wreck, Your organs are gonna be gone.

How do we get to that point? And, I really want us to even take that license a little bit further with a code or something to say, I do have a healthcare power of attorney, and here's how to find that in a registry. And so we can contact them and navigate it with communication, but, I'm so confused with America

sometimes because we make it so much harder than it is by, we have 50 states, we have 50 different ways to talk about advanced care planning and titles and what we call it and who to be and right now in a mobile society, people are living sometime in Florida, sometimes with caregivers and.

And we've gotta get on the same page [00:14:00] and not continue to make it harder than it is cuz it's already hard. And we just raise that level. And as you can tell, I'm very passionate about it because I've seen too many people prolong and suffer at end of life. And I've seen too many families look like they, this is the first time they're hearing that their mother or father is dying.

And how we die. And please listen to this, how we die and face our end of life is, We leave the world in a state of grief behind us. How we die is how people are gonna grieve us. If it's shocking, it's gonna take a long time for them to understand what happened. Many of times I would walk into an ICU room with my hospice badge on and their eyes.

You could see the pain, like mama's dying, and I wanted to grab them and say mom's been dying for two years. And they had all this time to process that and it was stolen from them, not necessarily by a physician or someone in the medical community, but their own [00:15:00] cells without asking the right questions and it's very important that I feel like we own our collective responsibility.

And these days, it's so important to blame someone because of our own actions, and I want to reclaim that. I don't wanna blame anyone and I want to know, and then I wanna make decisions, and then I want to. Take a breath knowing that if something tragically would happen to me, that everyone knows, a how I feel, how I'd approach it, and I have someone to speak on my behalf if I can't.

And that to me, frees me up and brings me right back to this moment and makes me live life more boldly. So when you ask me about this, I'm really talking about life and how I live.

We've talked over the course of the last couple days, I've shared stories with you. We've shared stories with me and we've talked a little bit about my own mother's death in 2017, and I was not her healthcare proxy. My father was but he and I were [00:16:00] both at her bedside, the whole time she was in the ICU and very much working as a team and.

My dad was a, my dad is a really educated man. He's a smart man. He thinks critically and yet in that setting, interacting with healthcare professionals who

were, as we've talked about, speaking a different language, right? I was witness to just how challenging it can be to be a healthcare proxy, not knowing.

Or in the emotion of the moment, not always feeling empowered to say, Hey, hold up, time out. What are you saying? What does that mean? Where do we go from here? How do we empower healthcare proxies or healthcare power of attorneys? Those people who are speaking as us enough for us, the bedside, or in the healthcare system?

How do we empower those folks [00:17:00] to really take the time? To dig deep and get what they need to make sure that they are speaking as someone who can't speak for themselves. Yeah. We forget that being a healthcare power of attorney, we really have no decisions and it has to be a conversation. Not even the form itself is like what if scenarios.

So it's not a one convers. It's not a two conversation, it's an ongoing conversation. And I have challenged many people when they have asked me like, okay, I use a card deck called the death Deck here. Here's one. If you came back to life and you wanted to sleep with a famous person, who would it be?

And it starts off like that. And then it's okay, if you are. In ICU and you can't speak and there's no, you're not gonna improve, what would you do? It's all of these scenarios because it's so important to me to make sure that I don't have any decisions. And you bring up a really good point about being in the hospital, [00:18:00] being downloaded with all of this information about what's going on.

And I encourage the healthcare power of attorney just to say, Hey, is this gonna really. Her quality or his quality, is this gonna change the results of the road that we're going down? And it really allows the clinician to be like, no, it's not okay then I don't need to know that crap. We're going to do this.

And I feel we all become. Children again, if there's an authority figure being even me, 22 years of hospice and palliative care, my grandmother told me exactly how it was gonna be and it, she gave me an eye opening. I'm like, oh my God, I'm projecting what I want for her onto her. And I don't think clinicians.

Have a bad intention. I think that sometimes they know more and they want to project, Hey, there is a little bit of hope, but a little bit of hope with it all. All this whole other suffering aspect of it. That's not what this person wants, nor do I, am I interested in watching [00:19:00] that? Okay, so you wrote a book?

I did. Bridging the Gap, Life Lessons from the Dying. Even though I am a social worker, I don't see myself as clinical. I see myself as an interpreter of medical speak, and so I do bridge the gap from interpreting what doctors and clinicians talk about and then interpreting that to. In an understandable way for caregivers and families being a storyteller, I like to tell that in stories.

And so the book evolved around 15 stories that really profoundly impacted me by just being present. And one of the greatest lessons that I've learned by these stories and being present with at the bedside of the dying is showing up is so difficult. But it is one of the easiest things to do and showing up and being present.

[00:20:00] I, I'm so grateful. Part of me was there because I would maybe, perhaps not have. The stories might have not had the impact that they did. And I do remember driving away from the hospice care center and my work every day, every once in a while and thinking, did that happen? Did this really happen?

And yeah, the dying have become my greatest teachers about life by sharing their stories. And I just felt so empowered that I could not let these stories die maybe. They could impact other people. And I just thought that, I wanted to open the door to all individuals knowing that dying individuals are still living.

And death is just a moment, and I feel as people grow older. They become less respected and I think we should pay homage to those who [00:21:00] have been through so many things. I think we, we lessen the impact of what the greatest generation has shown us, and that's being pliable in all different generations.

Right now you've got elderly people on Zoom and death cafes and we. Try to limit oh, they're not capable of that, and we push what we think onto them and this was a way by telling these stories in this book to say that they are just as much alive as they ever were in their life.

And I'm so grateful whatever sort of occurred that I was there in that moment and was able. To hear the stories and then later be a vessel for those stories. And people say, your book, it really isn't my book, it's the 15 individuals and maybe even the 20 individuals that appear in this book. That really radically changed how I live and how I will die.

And I feel that they journey with me every day reminding me of, yeah, I know you wanna stay inside and watch Netflix and you're an [00:22:00] introvert and you should do that. But you know what, if you miss this opportunity to connect

with other human beings and it just pushes me outside of my own comfort zone and I feel like I'm living for.

Like some of the individuals that I don't think it showed up in the book a lot about, talked about regrets, and they made it very impactful. Like they kept asking me, what are you waiting for? What are you waiting for? Say you're sorry, say it doesn't, don't get caught up in, in all of this minutiae.

It doesn't matter. You're going to die and how you die, even if you ask for forgiveness and they can't do it, it's playing. You're playing your role and they've just built me in a way. And I'm still evolving, but, and the person that I truly desire to be. And so yeah, those are the lessons and I just didn't want those stories to die with me.

And there's personal there. I do share a couple of personal stories about my grandmother and Rob and things like that. So it's my journey of going from a [00:23:00] career of wanting to be in television and writing stories and. Taking a 360 degree turn to the left and putting in a position that it's about living and I think that it's, And I'm still learning.

They've those individuals, the dying have taught me to always be a student that I'm never solely right. That it's always looking at someone else's perspective. And it's made me very soft to human beings and I love that. I really do. That reminds me of the Carl Pier's book, right? The Cornell Gerontologist, where he interviews all those people.

And I always, what reminds me of is when people get in these like midlife crises modes or they're stuck or whatever in their 40 or 50 or fifties or whatever, and they're like, I can't do that. I can't do that. I think, are you gonna. When you're 80, are you gonna be like, why didn't I do that? You feel like you're too old to do things now or whatever.

And that's what they talked about too, like not having regrets about things you don't do and not staying in a job you don't love. Cause you spend so much time at a [00:24:00] job or worrying about money all the time. When you'll get by, you'll live your life. Don't you get so caught up in these things that you just are stuck and frozen in one place. Yeah. I love, and I keep a record of when people, the first, and I can't remember who they are, but so and so published their first book at 55 and it's like those things that I just turned 50 and it's oh, I feel like I have a chance to slide down the slide down or keep climbing and make the slide taller, and I choose to keep.

To me, this moment in this room with the two of you guys is the most important moment in my life connecting with you. And if we can live our life like that, then maybe we can change the world, one person, one connection at a time. Go back to our roots. Wouldn't that be nice? So speaking of Back to the Roots and Best Life and doing all those things you wanna do, we gotta talk about the Live Die Tour, because really this is how we connected with you, because one of our former staff members, Zach, oh yeah.

He [00:25:00] saw you on that tour and he came to us, oh, this woman's so cool. You gotta check her out. And that's when we first approached you about, we gotta get her hair. That's right. Yeah. So tell us about that. Tell her first of all, I never want to do again. It's never say never, because I did not see myself driving across the country in a RV with a German Shepherd alone hauling my car behind it, and I never thought I would have 37 sponsors around the death positive movement supporting me and my efforts.

The book came out and I. I knew that I had to be the number one marketer of that, and I was like, how do I do this? And just circumstances a conversation with a friend and, a burning bush, which is a whole nother story. But I challenge I'm never gonna do this and I am a spiritual person and some things occurred.

I didn't wanna test that. I think it was the way it was supposed to go. And I, and every step of the way, I was like if it's meant to be, then I'm going to get an rv. [00:26:00] And the RV came, and then if it's meant to be, I'm gonna be able to rent my house really easy. Then I was rented it out and it became okay, then how am I gonna pay for this?

And then if it's meant to be, people are gonna find me. And Cabo Cheese comes and says, poof. Hey, we wanna be your number one sponsor of the tour. And then it just evol. And I started plotting where I would start and how I would end. And my goal was to drive to 49 states. And one of the most painful things in my life is on State 46 in Portland, Oregon.

This pandemic happened and four states short of the driving tour goal in five states, short of 50 states. I found myself reeling from grief of, and I'm not the only one. It didn't affect just me and, but it, the tour ended, but yet, What really got me through the entire ending of the [00:27:00] tour and not coming to fruition of let's meet in Washington and change the world and get a congressional hearing and get people to really listen to us in the, in this field was the connections along the way.

I could not. Really embraced that the tour was a failure because it ended short because there were so many triumphs of human connection along the way. So can you talk about like a typical, like some state you pulled into or some campground you pulled? So just to get the listeners' idea what was happening.

Of course the RV was wrapped and Cabo cheese wrapped the rv. So it had this like NASCAR look to it, but it had logos of. Positive and let's talk about the Michael FTE's nonprofit and just all of these things. So when I rolled up in like a K O W and every, especially on a Friday when I had a couple of days off and people were like, cracking open or brew ski and they just stared at me like walking, driving in and when you have a wrapped rv you forget that it's wrapped and you're like, oh hey.

And people are like, what is this crazy [00:28:00] person doing? And of course, Because it is a 29 foot wrapped rv and I have a German Shepherd and it has live, die well on it. People will come up and let me go ask this chick a question first. And they're like asking me, can I help you with this because you totally don't look capable of taking this car off this and doing all the, but I

And so they, it started off like that, but then they started asking like, Hey, what are you doing? And. I would tell them, and I would tell them that I was inspired by being at the bedside of the dying to tell their stories and here's my personal story. And suddenly people were around a fireplace and. For the first time just sharing their story.

And I thought, man, the more I talk about my story, I think it gives and opens a door and gives permission for people to share their story. And I remember in Hollywood, Florida, I'm sitting there and there was, I think it was the Super Bowl. No, it wasn't the super [00:29:00] cuz it was right before Christmas cuz I was in the Keys at Christmas.

But I'm with two, I, all of 'em are strangers. But I, someone brought their guitar and someone brought chili and someone we were, had the football game on and we were all sitting there and my friend Fabian we mention, I had mentioned something about my grandmother and he just starts crying. A grown man starts crying and he starts telling the story about his grandmother, and I'm like, holy cow.

And then the, then my, the friend that was playing the guitar, now they're friends, they were complete strangers. Then he starts playing like a little softer music and someone kind of closes the television. And we come around this

bonfire that is, About connection and loss, and people are crying, people are laughing, and Fabian at one time started laughing.

My grandma would kick my butt if she knew I was crying over this. And then we started laughing about that. And to the point that now Becky and Fabian are married and they welcome their first baby. And it's, they're down in [00:30:00] Virginia Beach now. And the connection and the explosion of keeping in touch with people.

And the people that I've met. And to see them growing and living life beyond their grief is probably the most rewarding things I've ever seen. But we had to talk about it, and I believe that the one thing we forget is that conversation in, even if we don't have words and we just cry, it's a way to express.

And I think that we grieve as differently as our fingerprints are, and we have to make room for that and be okay with people sharing their feelings because I believe. Our stoicness and keeping it all inside has created so much mental trauma for us. And I, I want to, and again, that gives me another lesson of just I don't want to create mental trauma.

And next door [00:31:00] neighbor in Wilmington walked over and is my mom died. And my sister and I are trying to get him to clean out the closet and he's going to the cemetery every day. What do you think? How can we help him? And I just said I ask you one. Does it make him feel good to go in the closet and to smell the clothes and our perfume?

Does it make him feel good to go to the cemetery? And she's I think so. I'm like, then let him do it. Who cares? Let those clothes stay there until he's ready, and if he's never ready, then unfortunately you will have to get rid of them. But right now, if that's what he needs, then let him walk that journey.

Just say, dad, whenever you're ready, we can help you with this stuff. But only when you're ready and so many times we want, in America, we want to skate through grief. Oh, your mom died. See you in three days. Good, go pay. We're go pay for three days. Come back. And it's just not, it forces us back into a role that we're not ready to be.[00:32:00]

Because when you have an inner circle, an immediate family that you're close to, let's just say your mom, when they die, I believe you die too. And grief is the rebirth of you becoming the person you are without. And that is hard. That's really hard. And so if we realize in ourselves that we as a person, when we lose someone that intimately, we die with them.

A part of us and who we see ourselves. I remember my dad after he lost his mom and his dad died years ago, he said, I'm an orphan. And he just felt like I, I. I'm an orphan. I don't have anyone. I'm like, I don't know what that feels like, but one day I will. And being homeless a little bit right now, trying to figure out the next things in my life.

Having moments with my father watching Duke basketball or watching Star Wars, which was a, it's so valuable to me because I will never regret that [00:33:00] and I think that we try to scoot through grief and we don't pause and just meet people where they are. If you live well, you might just have a chance to die.

And if you lean into life, then maybe you might just lean into death. And as much as I've been traveling and being homeless in the last few months, you know what? I don't even know what's next, but all I know is that it's going to be great. And I look forward to the unknown. You just I hope it's not gonna be in an RV though, but if it is, I hope to do it well, but I hope to be settled sometime in the next 30 days, and I've got so many amazing opportunities that I feel so honored that it's gonna be hard to pick.

The last two days have been so powerful, and I know that I'm not unique. There are a lot of other people, students and community members and my coworkers who feel the same way. So I wanna say thank you for spending this time with us and for being so [00:34:00] generous of spirit and so generous with your time and your stories and your vulnerability.

And we're just really glad you could spend this time with us. For listeners who want to know you better how can they connect with. You can always reach out. I have a website called death by design.com and you can email me through that. I can't express what you guys have meant to me. I feel like I'm gonna be back at Ithaca and you never know what kind of role.

I feel like this is just the beginning of our story together, and so I look forward to what that means too. So thank you for hosting me, for making me feel valued and my stories. Thank you for that and just for being present yourself and being open to hearing a different way to think about these hard, what people seem to see as taboo subjects.

So thank you. Thank you. You are a connector, . Yeah. Thank you because I pride myself on that and thank you. Yes. I am a connector. [00:35:00] Thank you so much for listening to, we really need to talk. You'll find more information and links in the show notes. We hope you'll continue to tune in as

we talk with end of life experts and champions of tough conversations, who will teach us more about the important questions and how to ask them of our loved ones and healthcare providers.

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