

Introductory episode with Bergman and Richards

Elizabeth Bergman: 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've 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.

Today we're introducing you, our listeners to our goals for this podcast. We'll share a bit about what you can expect and who we are in the episodes to come. We'll be joined by experts who will share important information about advanced care planning. Hospice, palliative care, but also about making the most of our lives right here, right now.

Our guests will be sharing their stories with us, stories that will drive home the power of having these tough conversations. They'll offer knowledge and real life experiences that will hopefully inspire you to open up a dialogue with those in your life. Who matter most. We're going to dive right into the deep end with a series of podcast episodes in which we explore questions like, how do we determine and figure out what really matters most to us in life and death?

A lot of people say they want more time with their loved ones. If you suddenly found out you only had a year to live, what would you prioritize? And what can we do today right now to ensure that the end of our lives happen in accordance with our wishes? That the end is what we want, how we want it to be?

You could plan your memorial. Write your obituary, fill out a living will or something else. So who do we need to talk to and about? What exactly, Elizabeth, we could talk to our doctors, our loved ones, our therapist, maybe

members of our faith community, just to name a few. And then how do we even begin to wrap our minds around what choices there are to make?

So that's why we're here to try to bring some important issues out into the open and to learn from one. So we hope you'll subscribe and stay with us to learn why it's so important to broach these subjects. Let us help you gain the know-how that will empower you to approach these explorations. But first, we really do need to talk.

Elizabeth, I don't know about you, but [00:03:00] I'm often asked how I ended up working in this field. Do you ever get that question? And if so, what do you say to people? , I get that question all the time. It happened in two stages. I got really interested in aging as a young child. I played the violin in a Suzuki violin group in elementary school and I grew up in central Florida.

And so one of the things that we did a lot of was travel around to retirement communities and perform. And so that was really where I figured out that I really liked being around people of all different ages and older adults in particular, and. It wasn't until I was almost finished with an undergraduate degree in psychology that I discovered that studying gerontology and working formally with older people was something that I could do for a career.

So I did a master's degree in gerontology. And my very first semester in the master's program, I signed up randomly for a course called Death and Dying, and that class was really transformative for me. One [00:04:00] of the things that class prompted me to do was to become a volunteer for the hospice organization where I went to graduate school.

When I signed up, I became what was called a patient care volunteer. So I was matched with one hospice patient at a time, and I would visit them in their home sometimes, depending on. What their circumstances were. Sometimes I would run errands for them or help them get to and from doctor's appointments.

Other times, I would sit at the bedside and provide respite to care partners or family members who were involved and needed a break. That experience of working with people who were hospice patients at the end of their lives, that was really impactful for me. I found it incredible that people who were at potentially the most vulnerable time of their lives would be willing to.

Open themselves up to me, a perfect stranger, and allow me to walk aside them through part of their journey. And that's really how it all began for me. I'm always so impressed with people who get involved in the stuff at [00:05:00] a

young age, an early age that you knew you liked, working with all ages of people and were drawn to older people.

I have a neighbor who does hospice work and she's a chaplain. Counsels people and visit them at the bedside, and she feels like it's the honor of her life to be able to share stories with these people at the end, and it's just really amazing to me. How about you, Lisa? How do you answer the question when you get.

The question about how you got into this field. So my story's really different from yours because I came to this stuff really late, much later in life. Like I didn't even know there was such a thing as working in this field necessarily. And I'm the kind of person I think who selfishly tends to get involved with things as they begin to affect me in my own life, right?

So about five years before I came to the Gerontology Institute, my mother-in-law, and my father died within three weeks of each other. And it was a hard time, and one of them was a completely medicalized, heroic measures type of situation. The opposite of what my dad wanted. And then my mother-in-law died at home with hospice in these relatively.

Peaceful surroundings. So [00:06:00] after living through that, which was really pretty traumatic, I started thinking a lot more about how we treat death and dying in this country. The experience with the I C U death and battling with the doctors to honor my dad's wishes, that stuff's repeated all over this country.

When I tell this story, people like they nod. . I know. I know. I've been there. We had no support. There was one nurse who suggested that we maybe needed a social worker. She got in trouble with a doctor, so told her that they would decide when this was over, which is pretty stunning in retrospect, so that's a roundabout way of saying how I came to working in this field. I started the Gerontology Institute in 2018, about three years ago, feeling, pretty burned out from stressful jobs in university marketing communications. I spent a number of years in higher ed administration at some, pretty interesting places.

But as I got older, I just wasn't feeling. Filled by the work I was doing. So I was aware of the Gerontology Institute and had, poked around the website and considered the certificate program at one time. And then as fate would have it, there was a job opening right when I was feeling especially ready for [00:07:00] a change.

So it was more of a administrative role than I'd really done in a long time. But I applied anyway, deciding that I'd really rather be working with the people that were doing good things than to continue what I was doing right. So at the

interview, I think I was able to express my growing interest in aging and end of life issues.

You know, because I just felt so strongly about things. And I think that combined with the experience I had in communications and grant administration was really what what will landed me here. And then less than a year later I moved into the grant funded position I'm in now. Organizing education and training for those, working with and caring for older adults, which has been really so fulfilling.

Nice. As gerontologists we often talk about how great it is that life is long, right? Because we get a chance to reinvent ourselves time and time again. And it's been really neat to see you in this short period of time, really reinvent yourself and, grow the role that you're in. So I'm glad you're here.

Yeah. I found such an amazing community of people doing this work and who've been doing it for a lot longer than me. And these are the people who get it. When you say things like, why isn't caring for the elderly and dying, given as much [00:08:00] importance as. Birthing babies and caring for babies, right?

I never really thought at this stage in my life that this whole new world would open up, and the people I found there would be so welcoming. And I think I've basically concluded that people who care about aging issues and older people are just good humans who care about others.

So we thought it might be interesting for each of us to share a story with you, our listeners, a story that helps you get to know us a little better and gives you insight into why we are so passionate about this set of topics. So Lisa, I'm curious to hear from you a story about. What brings you? Okay, so part of how I come to all this is the experience of losing my mom at a fairly young age.

She died in the mid nineties, 13 years of breast cancer, and she was in her fifties originally. She did pretty well with her treatments and her chemo, although, not an easy time. And then, She had some cancer for years and even was deemed in remission for a while. So I was living in Boston about six hours away and she didn't really [00:09:00] want us to change our lives.

She wanted my brother and sister and I just keep, living our lives and we did. So was it pretty easy to visit in the last couple years of her life? Her disease started spreading right. And she didn't really wanna talk about it much. She would talk about. The everyday stuff, like what's happening today, the nuts and bolts of, what was going on with the tumor and her finger, or she was going to dialysis of her next chemo.

Really living day to day, which makes more sense to me now. Also protecting us, she didn't want us changing our lives or coming back home to take care of her, but she also just really didn't wanna talk about it, at all. And if I would get upset, she would get mad. If I'd cry, she'd get mad.

And sometimes she would joke a little bit about, leaving the house in a pine box or something. Or she, how the big party we were gonna have after her funeral, and at the time I was young and didn't really understand how much it was probably on her mind, of course it was on her mind, it was her whole, existence. So fast forward to March of 1995. My sister and I arrive at my parents' house late at night. We had just been there a few days [00:10:00] earlier. But got a call from my dad asking us to come back and my dad's the kind of person. He doesn't really call you and ask you to come back unless you know he really needs you there.

So we knew that something was happening. Hospice was supposedly coming in within a few days, and as usual, it was too late. They didn't get involved soon enough. So we pull in at 3:00 AM It's a bright, cold, clear night. It's hard to forget, when my father comes hustling outta the house to tell us our mother.

Gone, and I'm doing air quotes here because when he said gone, we knew by gone it meant a couple things. It meant that she was, she had died and that also that her body had removed from the house. Hard to forget that night. I think we knew on the trip what was going on, but we couldn't really quite process that.

A few days before when we were there was probably the last time, that we were gonna see her. But even knowing that and preparing ourselves in some ways, we were still, pretty shattered. It's your mother, right? So being the mom that she was, she knew that we would be shattered and lost.

So this is why she left us a note, and this note she left us was a [00:11:00] thing that really got us through the next really unthinkable hours and days. She wrote down what we needed to do, who to call, what clothes she wanted for her funeral, what equipment needed to be returned, what to do with her medications.

I mean like everything. And it was just an incredible. Incredibly generous and courageous act on her part, and I'm still so grateful for it. Now, it inspired my dad many years later to do a similar thing and his was even more detailed based on, what he learned from her death. But it's hard to describe what a gift that note was.

Cuz I'm here, I am still talking about it. 25 years later. Yeah, absolutely. You use the word gift and that truly is what it is for her to have done. I know that you have a story to share with us too, Elizabeth. Yeah. Kudos to you for being brave to share a story about your mom.

At some point I'll share a story about my own mom, but I'm not ready yet to do that. The story I'm gonna share with you is about a student that I had. So I started teaching at Ithaca College in 2008, [00:12:00] and the very first semester that I taught here, I had, I taught a class called Introduction to Aging Studies, and in that class I gave a homework assignment when we were talking about end of life issues.

And the assignment was to go home and fill out a living will student. Did it, in pencil or whatever they wanted to, and they didn't have to officially enact this document. It was just a thought exercise for them to work through what would I want at the end of life, what wouldn't I want, right?

And so we did this homework assignment. Students brought it back. We had some discussion around it. They put them away. That was that. And we moved on to other subjects. One of the students who was in that class a couple of months later, tragically and unexpectedly, had passed away and it was a very short illness.

Nobody saw it coming. And it was a really difficult time and we got through it. We moved on, and a few months [00:13:00] later I got, An envelope in the mail, and it turned out to be a card from the student's parents. . And the card said basically that in the days after their daughter's stuff, they came to campus and were tasked with cleaning, boxing up and cleaning out their daughter's dorm room.

And so they put. All of her books and notebooks and schoolwork and things into one set of boxes and all of her personal effects and clothes and all of her other things into another set of boxes. And they took them all home and they set them aside and they did all of the other things. They went about living their lives and grieving their daughter.

And many months later when they were ready to open some boxes and start looking through, , they decided they would start with her schoolwork. They would start with the books and the notebooks and things first. That felt easier to them, and I can understand that. Little did they know that when they cracked into those [00:14:00] boxes, they would find her homework assignment, her living will, that she had completed for homework in my class.

And so the cards. Explained that they, how grateful they were to have found this living will, and to have found out after the fact that all of the decisions that they found themselves having to make in those hours, as deciding what was going to happen. Were consistent with. The, with her wishes that she had written down in this living will, including things like whether or not to donate her organs, et cetera.

So they just found that document to be something that was incredibly comforting to them to know that the things that they had done were consistent with their daughter's wishes. And that was a really powerful experience for me. And something that reinforced how important No. What age we are, no matter where we are in this journey in life, to have thought about some of these things and to have had some of these conversations with the people that are likely to find [00:15:00] themselves in decision making capacities for us.

Exactly. It can be so helpful. Wow. What a story. I can't imagine losing a child at that age, but also just having found that and. Having the realization that they did exactly what she wanted or what she would've wanted is, it's a comfort to people to be able to carry out the last wishes of somebody to do things the way they would've wanted them done.

It's, it feels like the one thing that you can do at the end. Yeah. And when I'm having a rough day, sometimes I still pull out that card and reread. It helps me remember why I'm here.

In this podcast series, we'll be digging deeper into the most current research being done in this area. You may be familiar with advanced care planning documents, but it turns out that having these in your medical record may not be the silver bullet it was once stopped to be. They don't guarantee you'll get the care you want, and they also don't guarantee you [00:16:00] won't get the care you don't want at the end of.

Situations are fluid, emotions are running high, and there will often be lots of opinions in the room. It turns out the best way to achieve a reasonable outcome really boils down more to conversations that we have at our dinner tables on walks with friends and other everyday ex. That note that your mom wrote for your family, Lisa?

Exactly. In other words, communicating with the people who know us best. We have a great deal of control over. So that's where we're headed. We hope you'll continue to join us for future episodes of, we really need to talk. We know these are hard topics to grapple with, and we commend you for being open, for just being here, listening as we dig into the research, the facts, the tools, and the

controversies, we promise you also to try our best to bring some light, some love, and some humanity into the discuss.

We would love to hear your suggestions, ideas, and questions. We really want this to be a conversation. Our contact information and social media information is in [00:17:00] the show notes as well, so please do get in touch with us. That's it for today's show. Thank you so much for joining us. Listeners, we'll be back again with another episode in two weeks.

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. Them of our loved ones and healthcare providers.

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