

Podcast 350 Johnson Collins Transcript

Karen Wyatt: Today I have two wonderful guests to introduce to you, Elizabeth Johnson and Erin Collins, and they are both the founders and creators of the Peaceful Presence Project which we'll be talking about. Elizabeth is the Executive Director of the Peaceful Presence Project. She has a masters degree in community and urban planning and is a Certified Advanced Care Planning Educator for the Institute on Health Care Directives. She's a member of the Board of Directors for the National End of Life Doula Alliance. Erin is the program director for the Peaceful Presence Project. She's a hospice nurse who trained as an End of Life Doula with INELDA and the Being With Dying and Grace programs at Upaya Zen Center. She's a member of the NHPCO's End of Life Doula Advisory Council, and you can find out more about the wonderful work they're doing at the website, <http://thepeacefulpresenceproject.org>. So Elizabeth and Erin, welcome and thanks for joining me today.

Erin Collins: Thank you.

Karen Wyatt: Well, I wanted to start, as I always do in my interviews, just hearing your stories, first of all. And maybe Erin you could begin by telling all of us how you got interested in working in the end-of-life arena and as a hospice nurse, and even what led you both to create The Peaceful Presence Project.

Erin Collins: Great, yeah, thanks for having us, Karen. So my work, when I became a nurse... Nursing was my second career but it was something that was always in the back of my mind. When I was about, I think I was 24 years old when my grandmother was at the end of her life and was in hospice care in Colorado. At that time it was a hospital-based hospice unit, and I went back home and spent a few days just sitting with her. And what I watched was just the tenderness that the hospice nurses provided in their care. And for some reason, a light went on that said, that's how I want to show up in the world. And so I had kind of an adventurous twenties decade and then went to nursing school in my early thirties with the intention to become a hospice nurse. But it took a little bit of a roundabout way. I worked in oncology for adults and pediatrics for a few years and then eventually came to hospice care and worked as both an inpatient hospice nurse at an inpatient unit at our local hospice and also in the field. So I would go and visit patients in their homes. And after a few years of working in hospice, what I noticed was that a lot of my patients were showing up in hospice care and they were really afraid of dying, that most of them had done little to no preparation for it. And there was so much suffering around that for them and for their caregivers. And so for me it felt like there was an opportunity to almost perform a nursing intervention for the community. Like how could we do this? How can we do better for folks at the end of life? And so around 2018, I took a little sabbatical from bedside nursing and started doing trainings in end-of-life work and end-of-life doula care. And then shortly thereafter met Elizabeth and three other women who also came together to form this nonprofit organization, The Peaceful Presence Project.

Karen Wyatt: Mm hmm. So very interesting, isn't it? I love hearing these stories because, first of all, just knowing that you were inspired by a hospice nurse and by witnessing the work that someone did is... I think every one of us needs to remember, we have no idea how many people we're touching and inspiring through what we're doing every day. And we may never hear about it or get that feedback. But one of the ways we make a difference in the world is just showing up and doing our work with compassion and care.

Erin Collins: Absolutely.

Karen Wyatt: Yeah. That inspires me to hear that that's how you ended up deciding that that's what you wanted to be one day. But then it all seems synchronistic in a way too, the way you and Elizabeth came together. And so I want to hear your story, Elizabeth. And I know that you started as a community and urban planner, which is really interesting. So I want to hear how you ended up here and working on this project.

Elizabeth Johnson: Yeah, thank you. It's great to be here, as well. Well as Erin said, you know, I think back to the initial roots... When I was young, my grandmother lived with us, and she and I actually shared a room when I was 1 to 3 years old. She died when we were living together. And so I just have this sort of early memory of that feeling of loss of somebody really important to me not being there. Fast forward, I've spent most of my adult life working as an experiential educator in an international context. I've lived and worked in India, Guatemala, a couple of different countries in South America. And those experiences, I always say, really highlighted for me what felt like was almost a deficit or of a lack of closeness to death in my own culture, this recognition that we - as I can speak as an American - those around me just didn't know how to talk about death. A lot of people hadn't really been close to or experienced death. And this recognition that, in so much of the world, the death and dying process happens for people on a daily basis. And so, you know, whether it's being in India and seeing a dead body kind of moved and paraded through the streets on the way to the funeral pyre, or living in Guatemala and Dia de los Muertos - the Day of the Dead - and the way in which people gathered for multiple days around community cemeteries and gravesites, celebrating and acknowledging the death of their ancestors and just keeping those relationships alive. And so I really just felt this question of, what does it mean for us that we just are so unversed and sort of untethered when it comes to death and dying? I studied as a community and regional planner and that's really fed into our work around a lot of the community or systems support that we offer up.

About 10 years ago, I was pregnant and got to a full term birth, and it was a long labor. And the last five minutes or so of my son's descent down the birth canal, he had a true knot in his umbilical cord. So he was born with heart beating but not breathing. And so we were moved to the emergency room, and he died the next morning after his birth. And so that was really the experience for me that put me on this path of recognition that death will happen to all of us, we will all grieve. We will all be impacted, yet we're living in these communities and in a culture that doesn't really know how to support each other in that process. And so I was confronted with this experience of some people being able to be there with me, most people not. And so that, you know, that need to rethink and

re-create opportunities for people to really be more connected and death-literate and be able to act as resources for one another, which really is what brought me personally to this work.

Karen Wyatt: Wow. So this, I mean... I understand this is really born from your pain but also recognizing that everyone has pain and how tragic that we don't do a better job of sharing that and supporting one another through this type of loss and grief.

Erin Collins: Yeah.

Elizabeth Johnson: Yeah. And that there is a way for us to do better. It just takes a bit of, you know, orienting and giving people the opportunity to learn how to do that.

Karen Wyatt: Exactly, exactly. And that's why the work that you're doing is really powerful because you're stepping out into the world and making a difference, and creating the channels, and helping people have these conversations and get more familiar with their own grief and loss. Maybe we should talk about it now because you've already mentioned, Elizabeth, about being community-based, which I think is something really impressive. And as we go through talking about all the projects you're doing, it will become obvious to everyone that you are responding to needs in your community with creativity in the things that you're doing. But maybe you could say something just a little bit more about the importance of being aware of our entire community and the needs of the community.

Elizabeth Johnson: Well, yeah, you know, as an organization, community education is really important to us - the way that we serve our own community and then from there, kind of the web out to the rest of the communities around us. And our work is really inspired by the Compassionate Communities Model of care. And interestingly this movement, or care model, has its roots or foundations, in a lot of ways, in Australia via the work of a doctor, Allan Kellehear. And it's oriented towards the social promotion and integration of palliative care into everyday life. So one of the goals is really to sort of celebrate and prioritize and value lay experiential knowledge so that all of us - as friends, as family members, as co-workers, as community members - can be involved in much more active ways when it comes to showing up for one another, including around end-of-life experiences or death experiences, grief experiences. Looking at the model particularly, it highlights that, for an individual navigating a serious or terminal illness or some experience where there's a lot of need, the research shows that on average only about 5% of that individual's time is spent with a healthcare professional. So for us in our work, the question that really has emerged here around this statistic is, as communities, what are we all doing with this other 95% of the time? Knowing that, because of this ratio, there are so many people who are really in a lot of ways... in hidden ways are experiencing isolation, loneliness, fear, anxiety because of the disconnect and the disenfranchisement that shows up for people around experiences of illness and loss. So, you know, for us in our work, I think the question is, how do we transform experiences of death and grief in a way that individuals feel more empowered in their communities to really reclaim death-care as a social event with a medical component,

right? We oftentimes approach it as a medical thing that happens to have a social component to it. And so we're trying to flip it and say, you know, that we all have a role in this, that this is something that will impact all of us in communities. So for doulas, you know, this is less about adding on another layer of expertise when it comes to caring for people at the end of life or around a grief experience and more about building capacity within communities so that we are experiencing the opposite of what I experienced, what my loss was - this retraction. But instead, there's sort of this practical wisdom that people have to show up for one another in these spaces. And so that's what, in a lot of our compassionate presence trainings - as we call them, they're really dedicated to bringing about more death-literacy within communities. And what that looks like, as you said, can be different community to community. For us, you know, inspired by the Compassionate Communities Model, we've sort of done a scan of our local communities here in Central Oregon and said, you know, what are the existing organizations, what are the resources and the assets that we have here, and then what sort of holes exist? And how do we step in as partners in all of that, recognizing that our involvement will be offering up more learning around death-literacy so that more people can really step in and be a partner in that process?

Karen Wyatt: Mmm, that's really beautiful. And I wanted to ask you, Erin, I know that you've been trained in the medical model, as I have. And when we come from that background, I think many of us have seen the gaps within medicine and how medicine falls short so many times of addressing these issues, addressing death and dying and grief. And so I just wanted your take on how it feels to be part of this organization and this movement taking a different approach.

Erin Collins: Yeah, it's a good question. I definitely see our work as collaborative, right? And I still really value the medical model in certain cases, in certain aspects. And I think what's interesting is... Why didn't we all learn all of this, right? Why wasn't this part of our education? And so for me, that's what's really interesting. And I'm really passionate about infusing this type of education for medical providers as well, so that... How can we get nursing and medical students to have these similar skills and to really learn about what it means to just show up and just hold space, to not have to fix someone? You know, it's not just about fixing somebody or healing them, that the healing is actually just in showing up human to human. And so for me, that's what's really important. And the question that comes up, right, is like, gosh, why wasn't this a part of what I learned when I was in school? And so I really feel passionate about infusing more, not just palliative and end-of-life education into both medical and nursing schools - because I think that was also very lacking; it was kind of just a side thought or just a nod to that - but how do we infuse within palliative and end-of-life care this concept of being a companion and a partner and empowering patients? And that you can be an advocate for patients by working with them, and that your patient is the expert, if you just listen. So for me that's what's really exciting. It's just, you know, getting the opportunity to teach people how to communicate by listening.

Karen Wyatt: Yes, yes, that's beautiful. And there are so many changes we need to see in medicine, but I guess we're just starting where we are, trying to make a difference in our

profession as much as we can. Well I know that, as one of your projects, you've created this Endnotes Guidebook for end-of-life planning. And so I wanted you to tell our listeners about it. It's so beautiful. The graphics are just lovely. It's a really beautiful booklet. So I thought maybe you could talk about that. I don't know, Elizabeth, if you would like to start telling us how you created this.

Elizabeth Johnson: Well as end of life doulas, you know, a significant focus or area of support for us and our work is around what we oftentimes refer to as holistic advanced-care planning. And I think the term end-of-life doula can sometimes be a little bit misleading in that, you know, people have this image of a doula only showing up at the bedside right around the dying process. And the reality is, so much of the work for us with people actually happens upstream of the dying process. You know, I think because we're so embedded in such a fast-moving and in many ways sort of death-averse, death-fearful culture, it's an interesting challenge for us to really pause long enough and give thought to the things that really matter to us in our lives, right? What we really value, what speaks to our uniqueness as a human, what is precious about our relationships in our life, and then also how does this translate or play out for us around our dying process? So we created Endnotes. We oftentimes refer to it as a guide book or a road map where people can really communicate their preferences and their visions, and all that really feels integral to them, particularly when thinking about their end-of-life experience. Because the truth is, we don't always know when this will happen, and we don't automatically know what people might want. There's a real diversity there. So we always say, this is preparedness work that is something that people can give thought to in a state of wellness, which is actually ideal because it's in these windows that we have more energy to ponder and really kind of take a slow walk with this process, in this life review. But it's also something that we can do in the face of illness. So we spent a lot of time thinking through what might be most valuable to have in an end-of-life guidebook, knowing that it is inherently a pretty overwhelming process in the sense of, where do I start? So we, as a doula team, sat down and did a lot of research, gave it a lot of thought - different iterations - and manifested what we think hopefully is a really user friendly product. It feels contained, it's not a really, really long, involved document. Like you said, we wanted it to feel like it was beautiful, something nice to hold in your hands, something that felt special. And we've broken it down into four different main sections with the goal of helping people take this kind of pondering or this walk with these considerations in little bit-by-bit ways. So starting with peace of mind, all the different life-logistical considerations that you might want to have put together in one place: healthcare, financial, legal, some of the household details. And we found that, you know, for a lot of people, getting into these more mundane or practical details allows you to start getting into what might feel like more of the vulnerable considerations. The other sections are peace for my body, where people can really articulate, you know, what you would want the dying process to look like, to feel like, different spiritual religious practices that would be important, poems, prayers, meditations. When you hear comfort, care, what might that mean to you? And you know, remembering that death is this process, it's always really unique for each person. We've had people say, well, when somebody is with me, I want them to put a hand on top of my hand because I know that will give me the sensation of being cared for. And other people say, do not put your hand

on top of mine, put it below mine because with that sensation, I know I'll be ready and able to leave my body when I want. So you know, moving through this process is really just allowing people and their uniqueness to be able to really clearly articulate to loved ones, ideally, what this process will look like for you. And then there's a peace for my heart section, post-death wishes. There's prompts for writing love letters to family that would be kind of a legacy or something that you leave behind. And then finally peace for when I'm gone. And this is a section with reminders for your loved ones. You know, things to do right after death, several days after death, ways of caring for themselves. And we have it both in pdf and hard copy. And it's something that we regularly use as a means to guide conversations with people.

Karen Wyatt: Yeah, it's so lovely. It's a keepsake and so it's something that people will keep handy, whereas if they were using scratch paper or a spiral notebook, it could easily get tossed aside and lost. But this won't be lost because it's beautiful. So it's something people will be sure to save. And one of the questions that I had wanted to just discuss at least briefly - and, Erin, you could weigh in on this; lately I've been seeing articles about people saying, oh no, advanced care planning doesn't work. Like after, you know, a decade of having people fill out advanced directives, it hasn't changed anything about how people are actually dying. And so I think we need to keep talking about this so that people who read this don't say suddenly, oh well, let's not do any advanced care planning then; it doesn't make any difference. And to really talk about the underlying reasons why maybe we're not seeing those changes yet for a lot of people. And I don't know if you have any thoughts about that, Erin.

Erin Collins: Yeah, I mean, I actually find myself these days really immersed in the field of advanced care planning. And yeah, I think it's interesting. It was actually just a couple of weeks ago... There was a Jerry Powell podcast; I don't know if you heard it or if any of the listeners have heard it. But four of the leaders in advanced care planning were on, talking kind of about, what are we doing? You know, does advance care planning work and kind of each weighing in on that. And I think what I took from that was that... And really what we believe and the way that we do, what we call, holistic advanced care planning is, it's not so much about completing an advanced directive. Yes, that's a piece of paper that can be put into your health record. But really what's important are these conversations. And as an organization, part of our mission is reimagining the way that we talk about serious illness in the end of life. So can we get people talking? And I think that, pardon me, what I took from that conversation on Jerry Powell was that, instead of measuring the effectiveness of advanced care planning as the number of people who have completed advanced directives or the number of people who die out of hospital now, really the way to measure the effectiveness is, did the health care decision maker feel prepared to make a decision in the moment? And that's the effectiveness, right? And for us as an organization, having these community conversations, having Endnotes that gets conversations started so that people can, at a minimum, name a decision maker. And then hopefully the biggest goal is that they have a conversation with that decision maker so that everybody's on the same page. So that that decision maker says, okay, I know what they would want, because it's really hard to make these decisions in advance, right? As a healthy person to say, well, yeah in, you know, 15 years if I get cancer, I want this, this

and this. Those kind of decisions come up in the moment. However, if I have spoken to my decision maker over and over again and we've had really candid conversations about what quality of life means, then that decision maker can feel like, oh I know that this is not what she would want. I know that she feels really good about the life that she has lived and that this outcome... I can talk to this physician and understand that the outcome that's going to come from this treatment is not going to give her quality of life, okay. So I really think that it's about the conversations. And it's about embedding these high quality conversations equitably with every patient for clinicians right? That the conversations can start outside of healthcare; that's what Susan Hickman said on Jerry Powell. These conversations and naming that healthcare decision maker, that can all happen outside of healthcare. Then when that patient is in with the healthcare system, there's a foundation for these conversations that happen equitably with all patients, taking into consideration: what role does culture play for you in making these decisions? Who needs to be in the room when we're having this conversation or making these decisions? How can I, as your healthcare provider, help make sure that you get the quality of care and the type of care that you want? So I just think that it's all about conversation and not having such a taboo about, you know, that yeah, we're all gonna die. We don't know how, we don't know when. So let's talk about it, and let's make it less taboo. And let's have these conversations with our communities, with our loved ones, with our decision makers. And then we're prepared to have that conversation with the healthcare provider, and we feel prepared to make decisions.

Karen Wyatt: That's such a good point and I love that. You emphasized, how are we measuring effectiveness? And actually, are we just looking at, oh look, here's a piece of paper with checkboxes ticked off, which means someone made their advance directive, but with no information about, but did they talk about it? Did they have a conversation with their loved ones? And then we're comparing that with who dies in a hospital or not. But there's so many more factors to consider and so much more beyond, as you said before, beyond just what the medical system is doing or offering to people. And even though we know the majority of people say they would rather die at home, I have spoken with a lot of people who said, no no no I don't want my grandchildren to be there when I die. I don't want my house to be filled with a memory of me dying there. And so we're all different. So we can't use any of those statistics. I think, as you said, to measure the actual effectiveness of the planning we're doing and then what the Peaceful Presence Project is doing is actually encouraging the conversations, and that's what matters more than anything.

Erin Collins: Yeah. Well and going back to the earlier question about, how is this different than the medical model? And you know, and how do we shift the medical model to have these conversations? That instead of advanced care planning being about, how many times did you use the code for ACP, that as a student you learn about getting to know your patient and what's important to your patient; what matters, right? And that's a big movement now too, the four "M's." And so how can we instill in nurses and physicians that getting to know your patients and having those conversations and really understanding what matters to them is a much better metric than how many times you documented that conversation using that code?

Karen Wyatt: So very very true. So maybe these articles saying that advanced care planning isn't working, they're a little bit misguided because they're measuring the wrong things and not quite recognizing what's valuable here. And also it's a transition time. Like all of this is something really new that we're working on and we're trying to grow in our communities too, and it takes time to see things change.

Erin Collins: Yes, a slow shift.

Karen Wyatt: Yes, very much so. Well, something I was really interested to read about on your website is that you have an advanced care planning outreach to the un-housed and the housing-insecure individuals in the community. So I'm really interested to hear, I don't know which one of you wants to answer that, but to hear how you came up with that idea and how you are accomplishing that.

Erin Collins: Yeah, I can start and then maybe Elizabeth, if you want to add anything... It goes back to looking at the community, and what are the needs of the community? And ultimately, our foundation as an organization... We've always believed, from our first days, that equitable and compassionate end-of-life care is a human right and that we would always provide our services to anybody who wanted them, regardless of their ability to pay, right? We would figure it out, don't worry, we will show up. And you know, we found that with that model, with having a sliding scale and being able to work with people, that people who could pay, paid. And people who couldn't didn't. And we were still there for them. And so what happened was, last year we heard about a grant program in our community through a group of independent practice providers. And we really noticed... I mean, the numbers, as you know, for advanced directive completion and advanced care planning conversations are low in the general population. And for someone who is experiencing homelessness or, you know, has resource insecurity, that number is even lower. And so maybe there's not as many people necessarily who need a doula in the un-housed community, but they absolutely can benefit from advanced care planning conversations and having the opportunity... And research shows that people who are un-housed, when given the opportunity, they are able to have those conversations. They are able to consider what matters to them and what type of care would they want, and who would they want to be their decision maker. And after working in the hospital - and I'm married to an ICU nurse who has told me about, you know, individuals who come in with nobody, with no decision maker named. And they just start calling. They're calling all across the country trying to find somebody, so who ends up making that healthcare decision in the moment? Could be somebody that they haven't spoken to in decades, maybe. Maybe they want that person to make a decision, maybe they don't. And so through this grant program... We were fortunate to receive the grant, and with Elizabeth's amazing community building and coalition building skills, we just started reaching out. Like we just started identifying, okay who makes sense in the community? We had a person from the county health department, or from the county, who oversees a lot of the services for individuals who are un-housed, had done our doula training with us... And so getting to know her, that was like a perfect match. And then with her networking... And we just, we found that when we started talking to people

about it - these different service providers - they were all like, yes, yes, this is needed. Yes, this is needed. So that's kind of how the outreach, how we saw the need and started doing the outreach. And then Elizabeth, do you want to add anything to that?

Elizabeth Johnson: Well, part of the consideration for us was really, how do we do this in a way that we can formally track how these conversations are happening and be able to really both report the number of where somebody gets in this process, and then how do we in our best way possible, ensure that these documents are connected to somebody's electronic health chart and all of that? So we are part of the Coalition to Transform Advanced Care, C-TAC. And through that, we're connected with an exceptional group based out of Texas called Code of Health. And they have been an amazing collaborator and partner on this project and have developed an advanced directive or advanced care planning online platform that we're using for this project. And it's a really beautiful platform in that, it's built from a real kind of health literacy standpoint. It's got educational videos that somebody can go through to understand the ins and outs of what this process looks like. And one of our partners is part of a medical mobile van that goes out and does outreach for people living in encampments. And they said, you know, the extent that we can do this work with people is we hand them a 10-page advanced directive. And who's actually able to really, you know, sit down and fill that out? And so our hope is, through this being a very facilitated process, you know, that it's presented from a more health literacy standpoint. That going through this platform, it will be a combination of people making referrals and us doing pop-up clinics in the community that will be able to lead people through this process. And then in the end help them, you know, have a printed document and also connect it to all of their electronic health records, and yeah.

Karen Wyatt: That's really exciting. Well, I love the creativity of it. And then I love the collaborative piece and being able to record the results and the outcome. I mean, and actually measure the impact of it. I think that will be really important down the road for other people to learn from the work that you're doing.

Erin Collins: Yeah, I was gonna say too, I think another piece of it that's really exciting is that a number of these partners are like... It's called The Family Kitchen and they provide meals in the community, or a couple of shelter sites where they have daily meals. And so the idea is to sit down with someone over a meal and, again, have a conversation and get them to have to talk about what might that look like for you. What would be important to you? So, again, we have that metric of, here's what they've completed and here's how we can report on that. And this is how many conversations we've had in the community. And so, regardless of how many documents get completed and turned in, we will be tracking how many people we actually sat down and had a conversation about end of life issues with.

Karen Wyatt: Wow, that's really exciting. I can't wait to see what comes of it as you get further along in that project and can report back on it. And then I know you're also offering what you call Compassionate Presence Training, and you mentioned it earlier

Elizabeth. So would you talk a little bit about that? What does that training consist of and what inspired you to want to offer it?

Elizabeth Johnson: Sure, Well it comes from, you know, as I said earlier, our work being informed by the Compassionate Communities Model of care. And you know, there's research that shows that communities with high levels of death literacy are really able to benefit from, what's known as, context-specific knowledge about death and dying. And the consequence of that is that people are able to put that knowledge into practice as a form of mutual aid and social action, right? So people are more resourced and have this practical wisdom around the death and dying process, which you know, as we've talked about, has sort of been removed or sort of edged out as the dying process has become more medicalized. So the benefit of the pandemic in some ways is that we have to get really creative with this process. So all of our trainings are online, which means that people can take them from any geographic location. And they're meant to serve or be useful for somebody, you know, no matter what community you're in, if you're in Austin or New York or LA, or a small rural community in the midwest. One of our trainings is a three-part Compassionate Presence Training, and it's broken into three modules. The first being relationship to self, so really spending time understanding self - this foundation - and exploring, you know, what are your understandings or experiences around death and dying? What are sort of those fear points or the biases or the ways in which you relate to death and grief? And so using that as sort of the entry point into a lot of this. The second module is relationship to other, so exploring the ways in which we are prepared or not prepared to show up and support one another. So much of this seems really obvious just being a human in the human body, but there is so much that, you know, we've all missed in terms of what it looks like to presence, to turn towards - as opposed to away from - suffering. And how to be with one another, how to companion. So the second is, you know, sort of the skill and knowledge-building around how to presence each other. And then the third is relationship to systems. So exploring, you know, what are the systems in a community that exists to really support, whether it's hospice palliative care or all the other, you know, kind of wrap around services and systems that are important for all of us to be aware of? So that when we encounter somebody in need, our next door neighbor a coworker, you know, we have enough kind of wherewithal or a foundation from which to say, hey, have you thought about, you know, checking out this resource? And then we have another eight-part training that takes the three-part training as the foundation and then really builds out to get into advanced care planning, into a lot a lot of the skills to go into the end-of-life doula care model. And that's for community members that are interested in showing up in a more profound, informed way in their circles or for people that may be playing with the idea of serving as an end-of-life doula in their community.

Karen Wyatt: Uh huh. So that's really wonderful. And I love that you're continuing this approach of making it community based and keeping everyone's focus on the community as a whole. Because we know from our past history that death has always been a community event in the village, in the past, and it's so tragic now that we're so far removed from that notion. So I really like this emphasis on community. Was there anything else that you wanted to mention about that, Erin?

Erin Collins: Um I think that Elizabeth really covered it. But I think, like she said, that that was really a benefit of the pandemic. I think, you know, people keep kind of saying, what was the light that came out of that? And for us, it was increasing access to this information and being able to connect with people. We originally created those trainings because we had clients here in central Oregon, which is like a 10,000 square mile region. And we had clients who were really living pretty rural and pretty far out. And we thought, we need more doulas in this collective because it's really hard to get to all these different places. And so, originally it was like, okay, let's do a training. And so then we just know there's people in the community who are aligned with us. And when it all went online, we were shocked that we had, you know, more than half of the people were from all over the country. We had a woman in Canada. We just recently had a woman in Guatemala. So, you know, we ended up having this broader reach, which was really exciting because, like you said, about finding out in these different communities, right? And we've had people in small communities and in big cities. And how does this kind of public health approach to end-of-life care and serious illness care, palliative care shift into a public health approach where it's embedded in communities? And it's really exciting to say that, gosh, it's not just about us here in central Oregon. Although this is where, you know, the hub of our work is, that the spokes are going out across the country and into other nations as well. And that's pretty rewarding to think that we're on this kind of cusp of this shift in a lot of places.

Karen Wyatt: Oh yeah, I'm sure that's really gratifying to see and that's only going to continue now that you've created the training. I'm sure that you'll be attracting people more and more from everywhere to take part in it. Well, I know you have a vision for some other projects that you plan to work on, if you wanted to talk a bit about those.

Erin Collins: Yeah, I mean, it plays off of this all that we've been talking about, which is this embedding of compassionate communities and looking at, beyond just training doulas in our trainings, what else? Where else is there education? I mentioned really wanting to embed in clinical education as well, whether that's continuing education or in foundational trainings. And so, also looking at access in rural parts of our state and how, yes, there's a lot of palliative care in the urban environments, but we have patients who come for palliative care from hundreds of miles away. And then they see their palliative care provider and their oncologists or their specialist, and then they go back 150 miles and they're alone. You know alone, but without that support. And so what does it look like to create kind of statewide rural networks of palliative support that don't have to be palliative physicians and nurses? But what other roles in the community could be embellished or kind of enriched with these skills, these practical skills, for providing palliative support and understanding of what it looks like to live with serious illness? And to be arms for the palliative care physicians in more urban environments who are seeing patients from hundreds of miles away. What if they go home to a compassionate community and a community where there's somebody there who can provide palliative support? So that's kind of where we have one initiative going into these next couple of years is looking at, what do those arms look like and what are those roles? There's a big move towards embracing and working with community health workers more in palliative

care and you know, in home-care in general, and so what does that look like? So that's one aspect.

Karen Wyatt: I love that idea so much because, already we're facing this shortage of medical providers and we can't even begin to meet the needs of the population. So we have to be creative about... So often we don't need a person with clinical training to be there. That supportive piece is so important to everyone. So I just, I really love this. It seems like this is something needed everywhere because we have rural areas in every state that I think are facing the very same issues.

Erin Collins: Exactly, exactly. And you know, just like we said with our Compassionate Presence Trainings, we hope that we can kind of develop this program that can be replicated in any rural community.

Karen Wyatt: Yeah. Oh that's really exciting to me. So I'm just so glad to hear that you're working on that and thinking about that.

Erin Collins: Yeah. Elizabeth, what else would you talk about?

Elizabeth Johnson: Well, I think the other thing we're really excited about that is a jumping off point from all that we've touched upon... The next step of the advanced care planning outreach really is connected to, what we're currently calling, a No One Dies Alone central Oregon program, where we are in the process of creating a coalition of service providers who are kind of keeping our eyes on the most vulnerable individuals in the community, who are either un-housed and dealing with a serious or terminal illness or maybe vulnerably housed but living without a lot of wraparound support and really, you know, in a pretty precarious situation. We have had conversations with the PEACH team up in Toronto the Palliative Education and Care for the Homeless, Dr. Naheed Dasani and his team. And we're really inspired by that model where it's not so much about needing to identify our own brick and mortar locations where this end-of-life care would be provided, but really approaching it, again, from this compassionate communities coalition model and saying, let's all work together. It's going to take this collective resourcing to identify physical locations. So somebody is dealing with a life-limiting illness and is getting towards the end and wants to die in an environment where they've got compassionate 24/7 dignity-conserving care. And so we're also working with local community partners and looking for more funding to be able to take that to the next level. And part of it is, you know, again, not just having this be trained medical professionals, but community members that have received this knowledge set for this practical wisdom and really can step in and support, as well. I'm on the board of the National Electoral Alliance and we're partnering with the collective for Radical Death Studies in May to do a four-part series called Too Poor to Die Well, exploring the invisibility of interment death. And so I think a really important thing in our own country right now is to look at who has the opportunity to die well, to have the good death and who does not. And what can we all do as community members and humans to really step in and play our part around giving people a different end of life experience?

Karen Wyatt: Wow, it's such a crucial issue. And also I'm just happy to hear that you're addressing it. And I'm kind of blown away because you seem to be so forward thinking and yet you're so well grounded, as you spoke before, in the needs of your community and being able to envision where to put your energy and your efforts. And then this ability to bring the community together in collaboration, it's really beautiful. And so I hope that just hearing about what you're doing is an inspiration to other people out there in other communities as they're listening.

Erin Collins: Mhm I hope so too.

Karen Wyatt: Yeah, because I'm sure these are ideas that you would love to share with others. So I'll mention your website again, it's <http://thepeacefulpresenceproject.org>. And then what can people find there? Is there a way to... Do you have a newsletter or a way to connect through the website?

Erin Collins: Yeah. So if anybody is interested in Endnotes, there's a big button at the top where you can find Endnotes in both the printed and digital form. There's information about all of our trainings, all of our community education events. There is a contact page that has a button to subscribe to our newsletter and be informed more proactively about what's happening with us and just general information about our organization.

Karen Wyatt: So what if someone in another community says, I want to learn from you guys how I might make a difference in my community? Are you open to being contacted if someone just wants to reach out to get more resources from you about how to do something similar where they live?

Erin Collins: Yeah, yeah. We've actually spoken a lot about that. One of our team members on the more "business-y" side lives in Idaho and is really looking at, how do we replicate, in Idaho, a similar model? And so we would love to open that conversation with folks about, you know, how can we help them to create a similar model? And a lot of times, you know, if you come and take a training with us and kind of get a feel for our philosophy, then from there we'd be delighted to help replicate this in other communities. For sure.

Karen Wyatt: Well, may that be so. I would love to see that happen. And so, is there anything else that we didn't cover that you wanted to just say in closing that I might have left out or not asked about?

Elizabeth Johnson: I just, I think that I love this work because there is something that feels really innovative about it, and at the same time remembering that there's nothing new about this. That this is us showing up in the fullness of our humanness and our humanity, and remembering to not overthink any of this, right? To trust that we all have the innate wisdom and desire to know how to be there for each other and that it will look different relationship to relationship, community to community. But that it really does take all of us, and everybody's part or what is ours to do will look different. But just to remember that we all have a part to play in this work, and so it's an important

discernment process as things change on the planet, as our baby boomer population blooms, there's gonna be more and more need around this. And so I think it's a really worthwhile sort of personal discernment around, where am I called to step up and love and be compassionate in this way?

Karen Wyatt: Yes, absolutely. And Erin, any last thoughts?

Erin Collins: Yeah, I would just say that everybody is welcome, right? We often get that question of like, well do I need any sort of health care background? And no, right? Like again this is practical wisdom that comes from being human and so everybody is welcome in this work. And we get so much richness from the variety of perspectives.

Karen Wyatt: So very, very true. Well what a pleasure it's been to talk to both of you about the Peaceful Presence Project. And I just want to thank you so much for joining me today.

Erin Collins: Thank you, Karen.

Elizabeth Johnson: Thanks Karen.

Karen Wyatt: And we'll stay in touch because I can't wait to hear what's next and how this goes for you.

Erin Collins: Great. Thank you.