

# Audio and Video Recording

Due to technical difficulties, the first half of this conversation was recorded with audio only and not video. Future conversations in the series will include a video link for the full conversation.

For this first conversation, the recording is split in two files and may be viewed below. The first half includes audio only, the second half is audio and video. There is a short break between the two where a few sentences of the conversation are not recorded.

You may also read the entire transcript below.

[Audio \(1st Half\)](#)

[Video \(2nd Half\)](#)

## Summary

Courtney Smith introduced Jan Booth and Trish Rux, authors of "Dying Matters: Eight Conversations That Can Change Your Life," discussing their roles as death doulas. Jan and Trish shared insights on the medical superhighway metaphor for end-of-life care, the importance of community support, and the need for befriending death. They emphasized the significance of early conversations about quality of life and the role of community in end-of-life care. Jan highlighted the evolution of end-of-life care roles and the need for younger generations to engage. Trish discussed the importance of community death care and the challenges in rural areas. The conversation underscored the value of intentional living and community support in facing death.

### Introduction and Welcome

- Courtney Smith welcomes everyone and mentions the purpose of the meeting.
- Courtney introduces herself as the cultivator of abundance and belonging at Emberlight.
- Courtney introduces Jan Booth from Colorado and Trish Rux from Western North Carolina as the first guests of the series.
- Courtney highlights the contributions of Jan and Trish to Emberlight and their roles as death doulas.

### Meeting and Collaboration

- Aditi welcomes Jan and Trish and expresses admiration for their decades of experience in hospice and palliative care.
- Trish shares how she met Jan in a doula training program in 2018 and their decision to write the book "Dying Matters."

- Jan discusses the evolution of the role of end-of-life doulas and the importance of community-based conversations about death.
- Aditi transitions to a reading from their book, "Dying Matters."

## **Readings from "Dying Matters"**

- Jan Booth reads from the first chapter, "Making a Plan," discussing the medical superhighway and the challenges of navigating end-of-life care.
- Jan explains the concept of the medical superhighway and the challenges of navigating it, including resistance from family and friends.
- Jan reads from the third chapter, "Heart Matters," discussing the fear of emotional pain and the importance of befriending death.
- Jan shares insights from Francis Weller on the relationship between grief and gratitude.

## **Trish's Reading and Community Engagement**

- Trish Rux reads from a chapter called "Reclaiming Community Death Care," emphasizing the importance of community support and resources.
- Trish discusses the concept of a death-caring community and the role of doulas in providing support.
- Aditi reflects on the importance of community-based care and the challenges of accessing resources in rural areas.
- Trish shares her experiences with the Asheville community and the importance of community support for end-of-life care.

## **Community Support in Rural Areas**

- Jan Booth discusses the differences between urban and rural communities in terms of end-of-life care and community support.
- Jan shares her experiences in a small rural community in southern Colorado and the importance of grassroots organizations.
- Jan emphasizes the need for younger generations to be involved in community-based care and the importance of building compassionate communities.
- Aditi reflects on the unique needs of rural communities and the importance of adapting care models to meet those needs.

## **Befriending Death and Practical Applications**

- Jan Booth discusses the concept of befriending death and the importance of being awake to life's opportunities.
- Jan shares examples of people who have woken up to the preciousness of life after receiving a serious diagnosis.
- Trish Rux emphasizes the importance of living life fully and not postponing joy.

- Aditi reflects on the importance of practicing everyday ways of embracing death and the role of community support in end-of-life care.

## Practical Tips and Final Thoughts

- Jan Booth discusses the importance of practicing through smaller losses and changes to prepare for larger losses.
- Jan shares her gratitude for the lessons learned from working in hospice care and the importance of sharing those lessons with others.
- Trish Rux emphasizes the importance of community support and the role of doulas in providing resources and support.
- Aditi reflects on the importance of community-based care and the need for younger generations to be involved in building compassionate communities.

## Transcript

Courtney Smith 0:00

Good morning, good morning, and welcome. We're, we're just going to take one minute to let folks come on in, and then we'll get started. I've seen some familiar faces. Welcome, everyone.

Courtney Smith 0:31

Yeah, so I'm going to go ahead and launch on in. Welcome, my name is Courtney Smith, and I'm the cultivator of abundance and belonging here at Emberlight, the Center for Conscious Living and Dying. And at Ember Light, we believe that how we die is inseparable from how we live, that the conversations that sometimes we are most afraid of happen or of happening are often the most important, so today we are so thrilled to launch our stories from the thresholds, voices on death, dying, and living fully, and we're especially excited to welcome Jan Booth from Colorado and Trish Rux here from Western North Carolina, that many of you know as our very first guests, because both of them have been instrumental in this early visioning, imagining, and support of Amber Light, so these two women know this territory incredibly well. Trish is a long time supporter and is a registered nurse and death doula who has spent years sitting at the threshold with people and their families, and Jan Booth in Colorado is also has a master's and an RN, and has walked that same ground. Both of them are incredible voices in our field of death and dying. Together they have written *Dying Matters: Eight Conversations That Can Change Your Life*, a book that doesn't ask you to make peace with death from a distance, but invites you in to have those conversations that can actually transform how you move through this one and precious life. So, in a few moments, Jan and Trish are going to read a selection from their book, and then there they and Aditi, Dr. Aditi Sethi, are going to have a conversation, and so I'd love to invite our founder and executive director, Dr. Aditi Sethi, into the conversation.

Aditi 2:58

Thank you, Courtney, and welcome Trish and Jan, such an honor to be with you in this space today, and you both have decades of experience in hospice and palliative care, end of life

doulas, and educators, and I have deeply admired you from for many years, initially from afar, Jan, but I'm so glad to be weaving together, I'd love to start by just asking you to share how you two met and how you decided to combine your experiences in into this beautiful book that's this work of that is a culmination of a lot of experience, I'm assuming, and I know anything you feel to share

Trish Rux (She/Her) 3:42

number one, thanks for having us on this inaugural series event, and we really appreciate the opportunity to talk about the book. Jan and I met back in 2018 in a doula training program and recognized each other as kindred spirits, and we did a lot of online teaching in small groups, and the book is an outcome of us saying we need to reach more people, we need to give people the tools to do this work on their own, and so that's where the book came from the Dying Matters book. I'll let Jan see if she has anything more to say.

Jan Booth 4:29

It's interesting for me to think in terms of an evolution of ideas or process of change, and you know, back when Trish and I were both working for hospice, you know, the hospice professionals and palliative care professionals really were the experts that everybody looked to, and then this really cool thing happened, you know, in the 20-first century, early part, which was the advent of this old role, renamed, you know, end of life doula, death doula, right, where people from within a community became voluntarily wanted to be part of be having a more open and compassionate conversation about end of life, and so what we're seeing this book be the next part of, which is to say we don't just need hospice palliative care clinical professionals, we don't just need doulas. We, as members of the human family and within our communities, can initiate these conversations. So, I like that sense of how things grow and change.

Aditi 5:34

Beautiful. Yeah, that's so much of what we're exploring here at Amberlight Center for Conscious Living and Dying, so very much aligned, maybe we can segue with that into a reading, if you, which one, whatever you feel to share, and then we can continue.

Jan Booth 5:55

I'll start. There are three short readings that I thought I would do just to get a little bit of flavor. The first two are from the first chapter, which sets a kind of overview. What's the context in which these conversations are happening right in modern life? So the first one, first reading here is called Making a Plan. Dying is often seen as a failure within the medical system rather than as a natural part of life. Our experience is that most people living with chronic and advanced illness want quality of life as a goal of care, but they don't always know how to find that within the healthcare system. It's often a challenge to describe what quality of life actually looks or feels like, and how it's connected to care decisions. When you're living with serious illness, early conversations help map out the kind of care and treatments you want. That clarity is like a compass that's unique to you, it sets a direction and allows the goals of care to be in line with what matters most to you. And then switch over to this concept a little bit later in the chapter, what we call the medical superhighway, that we have found a really helpful metaphor for what

many, many people experience, I can see some heads nodding here on the screen, like, oh yeah, I'm familiar with that. So, here's a little bit about the medical superhighway. A diagnosis, or even a search for a diagnosis, will usually serve as an on-ramp to the medical superhighway of modern healthcare. This metaphorical superhighway is fast-paced and involves lots of different healthcare professionals. It could involve testing, treatments, medications, chemotherapy, radiation therapy, immunotherapy, more testing, surgery, medication changes, new therapy options, more testing, more changes, trips to the hospital, ICU care, and at some point death. There are off ramps at any point on the super highway, but you may have to navigate across many lanes of busy traffic to get to them. You may face resistance from family and friends who want you to fight medical providers may counsel you against stopping treatments. You may have doubts about the right thing to do. You may have been raised to trust doctors and don't want to challenge the direction in which you're heading. You may not know you have the right to change your mind or to stop. You may not have considered when would be the right time to take an off ramp in a different direction, or if you truly do want to stay on the medical super highway until your death. Off ramps usually lead to a slower pace and different vistas. It's an opportunity to pause, reflect, and decide about the course of the rest of your life. It's possible that you still want to try a less intense treatment or intervention and see if it helps your quality of life. You may choose to integrate holistic therapies more consistently into your treatment plan. You may see a path to comfort care and the possibility of allowing a more natural death, you are the driver, even if it doesn't always feel that way. And then, lastly, I thought I would skip over to the third chapter, which is called Heart Matters, and I'll just read a short little section here, but what really interests me about this chapter and these themes is the question, why is it so hard to have these conversations? Right, I mean, that's the age-old question for people in our line of work, right. And there's a lot of answers, there are as many answers as there are people on the planet, but this one area of the fear of emotional pain, the fear of engaging with emotional pain and grief. I feel like is a really important one, and not always skillfully talked about within our medical treatments and decision making conversations. So, let me just read a little bit about that, I it's only natural to experience feelings of grief and loss at the end of life, but we encourage you to befriend death in some new ways. The loss of those you love can be a huge change to life as you've known it. In your grief, you may encounter regrets and fears along with a heightened awareness of your own mortality. It's not easy to look into these harder emotional places, because it's often painful.

Jan Booth 10:50

It can involve regret, fear, judgment, and shame, as well as grief. These complex feelings are not easy to sit with and to contemplate. For that reason, they're not often something we can make peace with at the last minute. Christine Longacre writes in her book, *Facing Death and Finding Hope*, about many people's deep fear of grief, and she writes the avoidance of acknowledging death generally stems from one of two problems: either the family members view death as something very negative, hopeless, and tragic, or they fear experiencing the sadness and grief which will be released when they first face the truth together. Resistance to speaking about the oncoming death may stem from an awareness that doing so may bring them face to face with a deep pool of pain. So then we go on to talk about, well, what is the intelligence and the healing potential of experiencing grief and moving through it? It just seems like a basic life

skill that many of us never learned as young people wasn't modeled for us, etc. So we talk through the rest of that chapter about anticipatory grief and how it can be not just a tool but really a practice, a practice for being with with grief, and the last thing I'll read is another quote from one of my favorite teachers, Francis Weller, who's a psychotherapist and a writer. The wonderful book, *The Wild Edge of Sorrow*, highly recommended if you don't know it. Anyway, this is his insight on the relationship between grief and gratitude, which is one of the ways that the intelligence of grief can inform us by also invigorating gratitude in our lives. Right, so he says the work of the mature person is to carry grief in one hand and gratitude in the other, and to be stretched large by them. How much sorrow can I hold? That's how much gratitude I can give. If I carry only grief, I'll bend towards cynicism and despair. If I have only gratitude, I'll become saccharine and won't develop much compassion for other people's suffering. Grief keeps the heart fluid and soft, which helps make compassion possible. So, I'll leave it there.

Aditi 13:25

Thank you, Jan. Yeah, so much there to reflect on, and it's nice to get a taste of what is in your yearbook. So, thank you. Before we open the conversation, Trish, I'd invite you to share anything you'd like from your,

Trish Rux (She/Her) 13:41

sure, thank you. I'm going to read from a chapter called *Reclaiming Community Death Care*, which feels pertinent to the Amber Light community. Certainly, for many of us, we've been taught general Western cultural values of independence over interdependence, self-sufficiency over needing help and individualism over collectivism. Our work as advocates for end of life care is part of a growing movement to build death-caring communities where it's natural to ask for help and to show up for others. In fact, many people want to help out wherever they can. We've often heard that it's a gift to be asked to lend a hand to another person. It gives purpose, builds trust, and creates a sense of community, and it's an exchange that could benefit us when we're needing support, so we often talk about who will care for us, and really taking a look at that for each of you as individuals, who will be there for me, who do I want to be there for me, how might I need to supplement care, another part of that is a definition of a death-caring community, and I think that one especially applies to ember light. A death caring community is one that is friendly towards death, dying, grief, and bereavement, empowers families, biological or chosen, to care for their dying and deceased loved ones. Normalizes death as a meaningful stage of life that has value and purpose. Builds layers of support, education, and advocacy within a variety of community groups. groups, I'll go ahead and stop there.

Aditi 15:47

Thank you, Trish. Invite us all to take a deep breath as we soak in those words and I have so much to consider as we explore this realm of death and dying, and in all the ways that we collectively, in our modern world, have have avoided the conversation, which is what I love, you know, conversations that can change your life, dying matters, the title of their book, *Dying Matters*, and there's so many directions we can go, because it is such a vast topic, and you've, you've managed to distill and capture so much in a very easeful, easy to read, accessible way, so I honor you both. I know that sometimes takes more time to distill, so I can imagine it's been

a journey. I think I'd like to start, actually, with you, Trish, just as you speak to community and the importance of exploring this question of who will be with us as we navigate not only aging but also dying, because you know dying can come, we know dying can come at any age. I know you've done so much in our region, and Western North Carolina is lucky to have you, and I'm just curious, if you could share a little bit about your work with the community aspect, and how you've seen that show up in this community in Asheville, Asheville area.

Trish Rux (She/Her) 17:33

Sure, yeah, it's Asheville community, Western North Carolina is so rich with resources with death and dying from way back when you started that Arches group many, many years ago, and a number of doulas that are here in this area. So one of the things I do is maintain an email list of the doulas I know about, and there are more that I don't know about that are here, a doula directory as well, and to be able to have resources for people in the community when they need it, because people often don't think ahead, which is something Jan and I really are wanting people to do, like be upstream as much as possible, that doesn't always happen, and so to have people that can respond, like the people who answer the phone at Amber Light, and make connections for people, so the community here is so rich in that, and yet I go out and talk, and people don't know what a doula is, people don't know that Amber Light exists, so we have our work cut out for us.

Aditi 18:46

Jan, what are you seeing in terms of community in the Boulder area around this movement of community-based caring, caring models?

Jan Booth 18:56

I think Trish and I are very fortunate to be living in the places we do. Boulder is very similar in that way that Trish was just speaking, a lot of resources here, a lot of early work being done a number of years ago to open up the idea of conversations being important and being embedded in hospice programs as part of their outreach, but also community grassroots organizations, so there are a lot of doulas here, and in fact the doula training program that Trish and I both teach in is based in Colorado, although it's online now, so I'm not sure what you call what you call that, but when we used to do a lot of in-person teaching, it was in, it was in the Boulder area, so I feel very lucky to be a part of that, but I want to just say something that just occurs to me that's kind of fascinating. I also live part-time in a small rural conservative ranching community in southern Colorado, and it's a town of about 500 people. The whole county is maybe 1000 and it's a very different place from Boulder. But what's fascinating to me is that even though Boulder is so rich in this understanding of conversation and of community and of resources like doulas and many others, Little West Cliff. This is all really new, and they're lucky if they can even get a hospice program to go out and visit people there. Right, so in some ways I am finding that I am more useful in being able to plant seeds in that little tiny town than I am in Boulder, so it's just to open my eyes up to, you know, to remain open to where our work can take seed and be grateful for the communities like Boulder and Asheville that in Western North Carolina would say, you know, that are open to this and look for the opportunities to plant seeds where there are some real deficits in terms of support and care, but there are also still some very intact strong community

models of care through the churches and the faith communities there, for example, the women in the women's groups in these churches who are still the glue of care in these rural areas, so I'm kind of fascinated by by being open to other communities. I'm wondering, Jan, is it also true in West Cliff that there's that underground communication, you know, who needs help? What can I do? Absolutely. absolutely, and without any of the benefits of these wonderful new innovations in roles like doulas. Yeah, my concern there is the same concern I have everywhere, which is that some of these models seem to be dying out with an older generation, I consider myself in that older Boomer generation. You know that a lot of the glue that is there is being held by women and is being held by older people, and so this is part of, well, you all, you know, who are involved in community building, both Emberlight and in the general community, know this, but this is why I really feel that the future for a more honest and collective end of life caring is going to have to bring the skills of community building and bring it to younger generations, and it may be doulas. We see a lot of younger doulas in our programs, right, but so we need the younger generation to be on board with this, and many of them are because they are recognizing in the younger generation the isolation that so many people are living with, and the consequences of that isolation for mental health, emotional health, and caregiving.

Aditi 23:06

Yeah, I appreciate that you added information about compassionate communities in your, in your book, because that's what I'm hearing, that the importance of, as we, as we move forward in this modern world, and the needs in a rural community might look very different from an urban setting, but there it's important to recognize that as well, access to just basic hospice palliative care in the rural communities is limited. We have a community here, and it's called Cielo, and in communication with them, their needs are very unique, and their ability to access volunteer support is different, etc. And so, and I also wonder, you know, what comes up for me as I hear you speak of the rural communities is that, you know, this shift in our approach to death and dying is really just is very recent, you know, in our human evolution on this planet. So we're talking about 100 150 years that that have shifted how we approach death, so how, what is it going to take to return in a way to a way of being, and this book offers a way of engaging, like at that community, family, friend level, rather than waiting for the medical system to to guide us, usually when we're already in that, what did you say, the high super highway, what do you call it, the

Jan Booth 24:22

medical super highway? Yeah, yeah, yeah, yeah, yeah. Thank you for saying that that way. That really got my mind going, because this is what's so interesting, right, that we want to reclaim a lot of that wisdom and community spirit from the past, and I don't mean that it was perfect and nobody was afraid of death and everybody cared for each other, but we know enough about smaller collective communities in our own country as well as around the world that that's the model that a smaller community can hold that kind of caregiving, whether it's parenting and having many, you know, aunties and uncles who are part of your, your growing up, or it's caring for a disabled person, or all kinds of ways that caregiving beyond end of life, right, is part of a community, so, so I don't want to idealize that, and at the same time I know how much we've lost, I've seen it even in my lifetime, how much we've lost. So it's kind of a fascinating point to be

to to draw from the wisdom of those practices that are also intact in many parts of our country and the world, right, that aren't as individualistic as we are, so reclaiming that in the way that makes sense for 2026 because we're not going back. I don't see us going back, right? So it's, it's going to take, so what's the skill set, you might say, what's the thinking and the feeling and the envisioning that is going to help us to bring some of the best practices we know from, except for this 100 150 years, it's like millennia of human history, like we know how to do this, we really do, and even if we do it imperfectly, so what does it look like in 2026 and what are the skills we're going to need for that, and who are the people to engage with in each of our own areas, and we are those people, right? We are the people we've been waiting for, right? We are them, and sometimes it just helps to name these things, so we kind of know, yeah, that's why I'm feeling so drawn to be a part of such and such, right? Is because I want to be part of rebuilding this future that draws from the wisdom of the past but meets who we are now.

Aditi 26:52

Beautiful, Jan. Yeah, I think about how much has changed in the world since this journey with the Center for Conscious Living and Dying has emerged. I mean, the use of AI, even, is transforming so much of our society in good ways and in some challenging ways, and I'm sure there's more to be revealed there, but just to name, yeah, this is a unique time in our human evolution, in our history, so there's not like it's a return, but it's also an adaptive adapting to what is, and how do we preserve some of these elements of being human, of our shared humanity, and how do we show up with vulnerability and an open heart as we navigate these different seasons of life, and that segues into a question that's been kind of percolating around what you talk about is befriending death, and how accepting our mortality helps us to live more fully, which is very much present as we engage in community here at the Sanctuary, which is the home of Amberlight. So, I'm curious, and I loved how you touched on the anticipatory grief and that avoidance of the pain that keeps us from engaging in these conversations with our loved one, particularly, but I wonder, in your, as you dove into this topic, kind of was anything revealed, anything new, did anything new emerge, or was it more of a synthesizing of your experience, how of how that shows up in your life, or in your, the patients you've cared for, lives, or the clients you've had, so just more of a curiosity around that piece of the gift of befriending death. I would say,

Trish Rux (She/Her) 28:37

Gwen, that go ahead, Jan.

Jan Booth 28:40

No, Trish, I was just talking. Please go. One

Trish Rux (She/Her) 28:43

thing that emerged has been the amount of people who say they don't have anybody as a real concern for me in terms of this idea of community death care, and, and how can we elders model to other people how we can reach out, and hopefully the book helps people do that, but to show that the skills are not complex, it's often holding space and listening and gathering

resources, so that emerged for me, and especially as I've taken calls from people in the community and in the outer areas of really difficult situations, because people didn't plan, yeah,

Jan Booth 29:38

and speaking to the, yeah, your question about befriending death, two things come to mind. One is I'm sure there are those of us on the call who've had this experience, but certainly I bet all of us know someone who's had this experience of receiving a really serious diagnosis that was going to limit the life that they thought they had, right. And there's a waking up that often happens, maybe not always, but often happens, waking up with that diagnosis to the preciousness of life. I've just been on automatic pilot, some people say, and now I'm realizing I want to be in my life, you know. Some people have put off what is really important to them, they've not used the voice that they had, because they were afraid to take up too much room. We've got limitless numbers of things that that are kept small, and so the idea of befriending death to me is to say yes, that may happen, that I receive that serious diagnosis that wakes me up further. What if we didn't wait for that? Life will bring us things, no worry about that. Life will bring us opportunities to wake up, but what if we took more of this upstream, like Trish said, you know, this more intentional approach to saying I want to acknowledge that I don't know when I'm going to die, and I may not age into my 80s or 90s, like the statistics. What is it that I'm not doing now that I want to do more of, are there parts of me I want expressed? Are there decisions I've been stuck on? Are there relationships that I want to build differently or repair differently? Are there hobbies that I really want to do? You know, used to play a musical instrument and just have been too busy to do it, but that's really what I want to do, and again, just so many examples of that, that we've seen over the years of people who wake up to their lives differently. So, to me, befriending death is a practice that is, in parentheses, part of many spiritual paths, by the way, but befriending death is this practice of being more awake to what is now right, and what what opportunities are there for healing? What opportunities are there to be more present in my life? What opportunities to love more or differently, and and to spiritually awaken, and to ask questions that maybe I've been put off, but putting off like a big one for many people is what do I think happens when we die, you know, some of us are been asking that question for a lot of years, and that's probably why we're doing this work, but many people don't, so I love the idea of a practice of befriending death as a way of really two feet in our lives, and that