Jan Booth & Trish Rux Interview

Karen Wyatt: [00:00:00] Today I'm so excited to welcome two guests to the podcast, Jan Booth and Trish Rux. And let me tell you, we've been trying to schedule this for months, and so we're all so excited we get to be here having this conversation. Jan is an end-of-life nurse with 40 years of experience. She's also a coach and an educator.

She serves as faculty for the Conscious Dying Collective, the Integrative Nurse Coach Academy, and formerly with the Art of Dying Institute's Integrative Thanatology Certificate Program, all re- really important programs. And she is the co-author of Dying Matters: Eight Conversations That Can Change Your Life.

And Trish Rux, Patricia, is also an RN. She's been a nurse since 1982 with experience in many aspects of nursing, including hospice and palliative care. She is an end-of-life [00:02:00] doula and educator. She serves as faculty for the Conscious Dying Collective and presents workshops on end-of-life planning and care.

And she's also the co-author of Dying Matters: Eight Conversations That Can Change Your Life. I have this beautiful book right here in my hand. And it's such a good book, and we'll be talking about it today. You can, find out more at the website deathdoulas.com/dying-matters-book, or you can just go to deathdoulas.com if that's easier.

I'm sure you can find the book from there. So welcome, Jan and Trish.

Jan Booth: It's great to be here, Karen.

Karen Wyatt: Yeah, I'm so glad we're finally able to t- to talk and to meet you, Trish, for the first time.

Jan Booth: Yeah,

Trish Rux: thank you.

Karen Wyatt: I thought maybe we, to get started, I would just ask each one of you the journey that you've been on, to come to this place where you wrote this book together, and what inspired you to [00:03:00] write the book.

Trish, maybe you could start there. Just tell us a little more about your story.

Trish Rux: Sure. Yeah, I've been curious about death from a really early age, so it's always been a part of me. And as a nurse, I knew I wanted to work in hospice, but life interfered in lots of ways and I had lots of other nursing experiences.

And when I finally got in the hospice realm, it was like, ah, this is it. And then all of the things that I saw and experienced there were things that led to wanting to write this book.

Karen Wyatt: Yeah. That, makes so much sense. I've, I resonate with that totally. It opens you up to a whole new aspect of life and how to live life.

Jan Booth: Yeah.

Karen Wyatt: and Jan, h- how about for you?

Jan Booth: Yeah. I knew in nursing school that I wanted to w- [00:04:00] work in hospice, and so that part of a, a kind of a call was very clear. What I wasn't prepared for was, over those first couple of years in particular at the bedside, of realizing how- almost completely unprepared families and patients were for dying, for the experiences that waited for the family there.

And it became clear to me that there were these really important conversations that clearly, for the most part, were not happening in the hospitals, the ICUs, the oncology centers, emergency rooms, wherever. And so we would do the best we could in, people coming in at the last minute, as both of you know, who have worked in hospice.

we did the best we could, and I think we did it mostly pretty skillfully in trying to catch up to a lot of [00:05:00] these really important conversations about what mattered, t- processing emotions, trying to understand what levels of care and comfort were gonna be best for the person. And so over the years, it just became more and more clear to me that this idea of simply talking together about the things that matter to us was so important, and that it needed to be embedded in all parts of our lives.

Certainly within healthcare, with our healthcare colleagues, but also in schools and in faith communities and around the kitchen table. So I feel like from that hospice experience, when I left the bedside and moved out into the community, what drove me was a desire to help create a different model where talking about

dying is normalized, it's not just seen as a bummer, where death is not just seen as a failure, where we really take [00:06:00] m- more, ownership over this cultural transformation that's happening that's saying, dying is part of life.

How do we have more conscious living and more conscious dying and more conscious caregiving together? So that sort of big picture is what has really propelled me.

Karen Wyatt: Yes. I, totally resonate with that as well. and again, having, gone through kind of our conventional medical s- Western medical system, we all had a chance to see that, how even when patients were dying in the hospital, it wasn't fully talked about or addressed with families.

And I still feel somewhat baffled by it. Like, how is it that this thing, this big event that happens to every single person in life, how is it that we never talk about it in our society? It's still ... That, I still can't quite get over that. I haven't figured that out yet. I understand- Well- ... there's fear, and we've been culturally conditioned to just ignore it [00:07:00] now and pretend like it doesn't happen.

But- it's really the source of a lot of our problems in healthcare, that we've never talked about it

Jan Booth: Yeah, I agree and I r- I remember over those many years in hospice, periodically it would come up as an initiative that we need to help doctors have difficult conversations, right?

And so all kinds of really good initiatives did happen that I think did help a lot of physicians and others. but I think what became more clear to me over time was this is not take one piece and tweak it and it's gonna make it all better. That the, just what you're speaking to, the resistance to these conversations, the fear, the, the n- not having the skills or the comfort with it, that we just in kind of the modern medicine age when so many diseases could be cured, we, lost something fairly quickly, I think, in our ability to be with [00:08:00] dying and to be with aging.

And, it's had some really significant consequences, I'd agree.

Karen Wyatt: Y- yeah, 'cause I guess we have generations now of avoiding death or living in a magical world where we have medicine, we have advanced medicine that can cure things. We don't have to think about death anymore, and that has been, that mindset has been handed down now from generation to generation.

No one anymore has the tools and the skills except those of us who felt called to somehow go learn about it- and develop the skills. And is that how you see it as well, Trish?

Trish Rux: Yeah, that, I'm seeing so many people that think having their living will means they're finished- talking about it, even if that was 10 years ago.

And so for Jan and I, it was that thing of there's so much more, and if people can talk [00:09:00] to these things in a little bit of depth, how much more valuable that is at the very end of life, that we can bring it up again and-

Karen Wyatt: And I, I-

Trish Rux: Just dig deeper. Yeah ...

Karen Wyatt: I think that's the knowledge that you get from working in hospice- and palliative care, is that you see the difference the conversations make. And your book- Yeah ... has a lot of stories about that, comparing a patient who was able to talk about it and had, planned for years and had open conversations with family members versus a patient who'd never discussed dying with their family members.

It makes a huge difference.

Jan Booth: Yeah. Yeah. And it's fascinating, the, there's a phenomenon that we're seeing in who's coming into these death doula training programs. and often they're younger people, they're often women, some men, but this is clearly drawing a lot of women. And it's often people who have just had maybe [00:10:00] one or two experiences of someone dying close to them that profoundly change them.

Mostly, sometimes it's a not great experience, and they're coming in saying, "There's got to be another way." But often it's because they've witnessed a more, open, caring, emotionally, how would you say, a healthier emotional approach to grief and how we can walk together with each other to the end of life.

Could be a grandparent or a friend or whoever. So it's like for this younger generation in particular, there's been this kind of awakening to this system that is no longer working. Excuse me. And, I'm really encouraged by that because it's not like they spent years in hospice like we did, right? This was like one or two experiences, and it really changed them.

So I love that part of it, that [00:11:00] helps me to see that this kind of hold of, "Don't talk about dying," and, "Dying's a failure," really is cracking with some of this input from the younger generation and many people in communities around the country who are serving as an of light. they've taken a class, they've listened to your recordings.

They may be doing home funerals or funeral celebrant, all kinds of roles. But I'm so encouraged by the curiosity that many people are bringing in to say, "How can we do this differently in a more human community way?"

Karen Wyatt: Yeah, it's-

Trish Rux: Yeah, th- those people are really touching into the sacred part of it, I think.

Yep.

Karen Wyatt: Yeah. And it's gratifying to see 'cause we've all been doing this work for a long time, and so we've been through years when it felt like nobody wants to hear this. Nobody wants- Yeah ... to be part of what we're tr- trying to share and trying to teach. So it's nice to [00:12:00] see that there's a whole new generation of people who are more willing to listen.

But I wanted to ask- you, Trish, about, in your book, you talk about the medical system, which is still, I think, a big obstacle, a big stumbling block. Because when people get a serious illness diagnosis and they be- they get in the hands of the medical system or i- in a way, you use the term in the book, the medical superhighway, and it, it is really hard to, include these conversations, include talking about the end of life and death when you're in a medical system that doesn't allow for that.

And, you mentioned the idea of having an off-ramp, so would you talk a little bit more, about that concept?

Trish Rux: Sure. Yeah. It- We start our book talking about values and priorities, and I think it keeps coming back to that. And when people can discuss those things or know that about [00:13:00] themselves, they have a base of making decisions.

And certainly there are conflicting priorities, conflicting values that come about. having a long illness is a really dynamic kind of thing that's happening, and it changes you as you go. But one way of thinking about it, I think, is saying, "Let

me refer back to my values." And I've had these conversations with my people, and so they know where I started from, they know what challenges I'm having now.

and then especially when there's a new diagnosis or a change in symptoms or you're seeing a decline in abilities, then it's easier to bring that up again if you've had those initial conversations with somebody. The family or caregiver can be more comfortable saying, do you feel like things are going the [00:14:00] way you want them to go?

Is there anything you want to do differently?" Whether that's aggressive care or moving into comfort care, to have that touchstone. And then, too, letting your medical providers know what you want and how you want to be talked to about that so they're not afraid to bring it up as well. I think that's a big piece of it.

You're on that super highway and it's, "Let's have another test. Let's have another treatment," that might not be in alignment with your values.

Karen Wyatt: That's such a good point, and I... It ma- it reminds me of with my own mom as she got older, it was really just as simple as saying, "How... What do you think about your last day, your last days?

Where would you like to be and how, do you want that to be?" And she just told me, "I want to be home in my own bed, and I want you to be with me." And it was amazing how that, just that tiny bit of information- Yeah ... guided so many decisions because e- every [00:15:00] single possibility for treatment that came up, I could...

We... I'd talk with the doctor, "She wants to be at home when she dies," and the doctor would say, the surgery's a little risky. There's a good chance she could have complications and never go home again or die during the surgery." And we said, "No, then that- that's not what we need then. We're going a different direction."

A- and it was, as you said, it's just so helpful when you've talked about it to go, always go back to that, th- those few values, and it does guide you.

Trish Rux: I'm really seeing it change recently. Caring for somebody who's 99 years old, and I've known her for more than a decade. And initially, very clearly I would never hasten my death, and just two weeks ago she said, "I'm tired and I wanna talk about that now."

So it, that shift for her

Jan Booth: Well, I can imag- I, I can [00:16:00] imagine, Trish, that it's a r- partly a result of those conversations with you and that being a normal thing to be able to do, that she then could be comfortable saying that kind of thing. 'Cause I, I think that's ... Th- there are two things that I can see are, are real roadblocks and, to having these conversations, and one of them is fear.

So if I haven't talked about these things before, and there I am in the medical system, in a, we're moving towards a crisis where a decision is having to happen, right? And n- none of us have really talked about this before. That's a really hard time to try to calm the nervous system when real, serious, often existential fear is arising.

It's hard to think straight, right? And also, the dis- the complexity of medical care now where there are opportunities or, "We could try this," or, It's a super highway for a reason. We use that reason we use that for a reason. It's fast-paced and it's complicated, and there are a lot of cars on it, [00:17:00] and you have to really keep your wits about you.

So- I think for me, having seen other examples besides the last-minute crisis conversations, starting over the years to see families who took a step back and said, "Wait a minute, let's pause." like with your mom, Karen. I had the same thing with my mom, to step back when things were starting to heat up and m- her doctors were saying maybe it's time to come into the hospital and do some tests.

We just paused, and something that had been really important to my mom was when she first heard me talk about this acronym AND, Allow Natural Death, and that really helped her. That was like a compass. Like Stephen Covey says, "Live, live your life by a compass, not a clock." it's like what is it we're tracking?

And it's so hard when emotions are all stirred up and fear is in there, and I don't understand what's happening. These are complicated decisions that the medical [00:18:00] team is talking to me about. So I just, I think that's really why, just to underline what Trish said, why we start the book and keep coming back again and again to what matters most to you and how can we help you to lay enough of a foundation that you have these conversations with your friends and family that it's not going to be so hard to step back into, to pause and to say, what have we been talking about all along?

and how can we help, how can we help with the fear and the complexity here by coming back to some of the simple values that have guided me.

Karen Wyatt: Yeah. And, I think there's still, there's a mindset in our society in general, at least for older people, incl- I mean my age group. I'm older, I have to admit now.

but also the medical profession, that well, we should talk about this, but not until later because- Yes ... we [00:19:00] don't want to talk about it till we have to, and that's- right in the, at the very moment of crisis, we'll talk about it then. It's okay to talk about it, but we don't want to talk about it until it's the right time because there's some magical belief that if you even s- say the word death, we're, not being positive, we're not keeping hope alive, and your book helps dispel that notion as well, Jane.

Yeah.

Jan Booth: Yeah, and there's a, one, a quote that we really love, both of us, and so we had to put it in the, book, which is, Talking about sex won't get you pregnant, and talking about dying won't kill you yeah, I think it's, I think what you just said is a really important piece, this idea of it's too soon.

And I find myself talking more and more about that with people because I think that it's a strong feeling. It's a kind of protected feeling, like not now. We're not ready. She's not ready. and mostly I think it has to do [00:20:00] with emotional readiness, that if I haven't really dealt with the reality of what's happening and the emotions involved and felt some of that grief, then I, of course I want to put it off.

Karen Wyatt: Yeah.

Jan Booth: I think that's very natural for us as humans to not want to feel pain.

Karen Wyatt: Yeah. And the, and I think the irony, probably those of us who've worked in this area for a long time, we've realized that we've been talking about death for years, and even before we were clo- felt close to it or had a serious diagnosis, we've acknowledged it and talked about it, and it actually is a wonderful change in your life to be able to just talk about it.

It helps- with the fear. It helps remove some of the obstacles. We know that, but it's so hard to convince anyone else- that that's the case.

Jan Booth: Yep. That's right. that's one of the big reasons right there why we wanted to write a book that could be accessible, [00:21:00] that could offer conversations way beyond advanced directives, as important as those are, but to offer a, a, a more holistic approach of a variety of conversations that have to do with what matters, including spiritual and emotional aspects of our lives and creating community and forgiveness and gratitude and all these things that we miss the opportunity to have those conversations when we say, "It's too soon," right?

All these ways that we might connect more with each other, more authentically, telling the truth, not all staying in our silos, not wanting to feel sad. I think once you've seen the impact that more open conversations can have, it, it's hard not to be, a bit of an evangelist. So we tried to channel that evangelism into, a book that hopefully will invite people, rather [00:22:00] than hit them over the head with, "You gotta talk about this," That doesn't seem to work.

Karen Wyatt: A- and you're actually teaching people how to talk about it, which I think is a- That's right ... is another missing piece. Some people want to talk about it, but they have no idea how or what to say, and they're actually really afraid of the reaction of other people. They don't know how it will come across, so they say nothing because it feels hard to bring up.

Yeah. And Trish, I don't know if you have a comment about that.

Trish Rux: I was at a table doing an event for an aging expo, and I was next to a funeral home table, and two different times I saw very elderly people walk past and say to both of us, "I'm not ready for that yet." and I wanted to run after them and say, "When will you be ready?"

Or, what is stopping you from having this conversation?" [00:23:00] Yeah.

Karen Wyatt: Yeah, I think that is a notion that we need to dispel, is that we all should... We're all ready. It's the time right now- really for all of us, no matter what age we are, and partly 'cause we, none of us really knows when death is coming.

And, so somehow if we think we're avoiding pain for ourselves by not talking about it, it- that's just a misguided idea because it actually will make things less painful if we've already been talking and already had awareness around it.

Trish Rux: Absolutely.

Jan Booth: Yeah, I think that's part of what we need in our, in the evolving conversation about more conscious and compassionate end-of-life care.

I think talking about the gifts of these open conversations rather than it being a should or something more on a legal or last-minute preparation, but to, that's what we're trying to do with this [00:24:00] book really, but it i- is to, somehow say talking about this is not just talking about preparing to die.

It's really talking about how we live knowing that our life is precarious and that we don't know when we're gonna die. How we love each other and care for each other when we know we're going to be saying goodbye in one way or another to everyone important in our life. how we make decisions when we feel stuck in life or uncertain.

that to me, these conversations about dying are as much about how we live and how we care for each other. They really are. That's, I'm not just saying that to make it sound better, like putting a cherry on it. It's, I think that's the, that was one of the fundamental changes for me when I realized this, this idea that, was really, I would say taught to me by Christine Longacre in a, workshop back in the [00:25:00] '90s where she said, "Preparing to die and living fully and healing ourselves is all the same work."

And I had to sit with that. I've sat with that for years-

because of this, wanting to incorporate living fully and healing, which many people are committed to, right? Incorporating that in preparing for die belongs right at that table. It's not off on the side. Belongs at that table. And so how do we, those of us who are in the work, how do we help individuals and communities and a culture to reframe- that conversation.

Karen Wyatt: I just, I love that. I love that thought that it isn't that dying is a path that one day you'll step onto. One day that will be your path, and you can deal with it all then when you step on that path. But you're already on the path right now. Yeah. That is the path for all of us. [00:26:00] And, it s- actually s- makes it somewhat simpler when we can acknowledge that and see that.

Yeah. Yeah.

Trish Rux: Allowing for that, the changes that occur in life, the impermanence of our path, and knowing that's part of the human experience, and we've seen it with other people, so why wouldn't it also happen to us? And to me, that emotional piece of I don't wanna have regrets.

And I wanna do that while I have the energy and the ability to make sure of that.

Karen Wyatt: Yeah. It seems to me too, there's a certain cost to maintaining denial of death, in a way, in our life. Oh, yeah. we have to put a certain amount of our energy into shutting out a- that realization, 'cause it's all around us all the time, reminders. And that really, it really [00:27:00] subtracts something from life and from the joy of living if we have to constantly protect ourselves against that awareness.

Jan Booth: Yeah, I think that's really important what you just said. I think that's really important. So what gets shut down when we don't talk about dying? Yeah. What part of living gets shut down? Yeah. and how do we stop our skill in learning to deal with the many losses of our lifetime, not just our death, our physical death, but all the losses and changes and transitions of life?

Like, how do we, build a skillset around loss and grief and change and resilience if we don't somehow talk about it and acknowledge it? And, and I think the same is true with grief. When you push down grief, which our uber positive, upbeat, optimistic culture, tends to have us do. When you [00:28:00] push down grief 'cause you don't wanna feel it, what else gets pushed down?

And many people talk about the, the kind of sister relationship of grief and gratitude or grief and joy, and you can't push down one without pushing down the other. And I, I think d- Trish and I, in the years we've known each other, have just had endless conversations about studying all this because it's fascinating.

And, Karen, I'm sure you're in this, y- I just know enough about you and the conversations you're a part of and your own curiosity that, it's hard sometimes for me to imagine why other people aren't as fascinated by this part of being human. Like, how do we deal? It's a lot to ask of human beings.

Come and get yourself two feet in life and really, try to live as consciously as possible. How do you do that without talking about dying and loss?

Karen Wyatt: Exactly. Exactly.

Jan Booth: I don't know ...

Karen Wyatt: [00:29:00] I just got back from, we took a little road trip, and everywhere I went, it seems like if you open your eyes and look, there's, grief everywhere.

We're walking by the ocean, and there's a bench, and it has a memorial quote, and it says, "Just remember I will always love you, Mom," on the bench. And I'm just like, "Oh, my gosh." I just can't take my eyes off of that. Wow. It's so beautiful, and it's a sign of grief. And then I think, how many people sat on this bench and never even read that and were never touched by it?

But for me, I look around and I see little shrines and memorials everywhere. I see evidence people are grieving. There's been loss here. I always read history and the stories of communities and find out about what, what losses have happened here. What have they been through as a community? Because I think it's really fascinating how we go on after loss.

Yes. And when you hear about a community was wiped out by [00:30:00] a horrible fire, and yet here it is today, and people are resilient, and they survived that. And, like, how much would be missing in my life, at least, if I was never able to hear those stories and see that?

Jan Booth: Yeah. Oh, that's beautiful. That is beautiful.

and, how much would be lost if we only talked about where we got to? the kind of triumphant human spirit, which is a beautiful thing to witness. And what led to that triumphal, beautiful, resilient human spirit was some time, for many of us, in dark night of the soul or, in the hero's journey, the really confusing, disorienting landscape where I've lost a sense of who I am and who my people are through this tragedy.

And, and I think we are getting better at talking about that. I see more of these stories that include the hard parts [00:31:00] and not just the triumphant ending, like in social media. Certainly movies, any good movie or good book is gonna be full of that kind of story. But yeah, that- Yeah ... that in itself is a conversation that I want to be a part of.

Karen Wyatt: Yeah. Yeah, definitely. And I wanted to, I just want to give an- another shout-out to your book and tell everyone it says Eight Conversations That Can Change Your Life, so it's framed around eight different types of discussions that you can have about different issues, which is actually a, a really wonderful way, I think, to present the subject matter because someone could, be aware, I need to ask my mom to fill out an advance directive."

They don't need to have all the conversations all at once. They can read that chapter, get some pointers and some really practical suggestions, what to ask, what to talk about, what needs to be decided. There's still a, a lot more to

discuss, but they can focus in on what they [00:32:00] need, and I love the way that you've broken out the eight different conversations 'cause they, they cover different aspects of this whole issue, and I think it makes it simpler for people who are thinking of, talking about that.

, And Trish, I don't know if you want to tell us how you, guys decided to do that, to break it down into those conversations?

Trish Rux: Yeah, it really was from a holistic approach to say there's all these different facets, and we did want to make it simple, and that's why we put a discussion guide in the back so that, book groups could do it, families could do it together.

And like you say, they can just pick what's most important to them to start. They don't have to go from number one to number eight sort of thing. But a framework For people to ponder and discuss was really important for us in that regard. Yeah. And we have the discussion guide [00:33:00] on our website, so people can just download that.

Karen Wyatt: Yeah, it's just a, it's a really helpful book. I think it's helpful for, care providers to use a- as a g- a guideline for how to teach people to have these conversations, and then, for anyone else to read who's longing to talk about it but doesn't know how. And, I, I wanted to... Another thing that you bring up in the book that I think is so very important that we talk about is the, that we have a lot of people in our society right now who are solo agers.

A lot of baby boomers are people who- Yeah ... either never married or no longer have a spouse and have no children, and they're going this route alone, and that's a real- that's a really big concern I have- Yeah ... of how people are going to find care for themselves in the end. And talk a, a little bit about that, Trish, 'cause that's [00:34:00] something important that you bring up in the book.

Trish Rux: Yeah, it, and w- every time I talk to a group these days, somebody says, "But I don't have anybody." And that may be true. I encourage people to still make a list. Is there anyone i- that in any way might help you out? And usually they can come up with somebody. and then they might be afraid to even ask- for help. So there's that aspect of it too. It's really a vulnerable place to think, "I don't have this in my life." So I'm lately am thinking about it a lot as a cautionary tale for younger people. Like- You gotta do this upstream. You gotta establish and cultivate community in every way possible, but also at every stage of life.

So whether it's a faith community or a [00:35:00] neighborhood or a civic organization that you're part of, some place you volunteer, those are places where you can reach out and invite a little baby step of a conversation about care. But the truth is there are lots of people who don't have that in place, and they're gonna need more paid care.

They're gonna need to, get that figured out if they've waited a long time.

Karen Wyatt: Yeah. So, true. I have-

Trish Rux: There's no place to really look up stream ...

Karen Wyatt: a big concern for those people getting good end of life care. they may end up on that medical superhighway and not be able to go home because they don't have the help they need at home.

Jan Booth: Y-

Trish Rux: yeah, I mean- And it could be value for them to say, "I don't wanna end up in a nursing home," but that's the next step for them if they don't have a way to be at home or have other care[00:36:00]

Jan Booth: And this is the part that keeps me up at night, I think, is where we are in our country right now with, and we all can acknowledge that our healthcare system is pretty broken. And, what's also broken, and has, we have not found a way to recreate, is, care in the home, our home care, our h- even hospice care, services.

And I'm hearing more and more from people, that it's really hard to find home care even if you have the resources to be able to pay for it. And, some of the rural communities here, I live in Colorado, and some of the, the rural communities here, hospices are no longer serving, and, home care services are really hard to find.

even people who are in families or are in a couple or have some friends that can help out who might [00:37:00] also be elderly are really struggling because we're at a, I would say we're at a real crisis point, and I think there's so many crises right now on our plates, nationally and internationally that it's, kinda hard to know where to go.

But that's why we devoted a, a whole conversation and chapter to community death care, this concept, because I think it, this, as Trish said, this holistic

approach, I think it comes right up against the crisis of isolation in general in our society, and w- where some of these- Values, at least in the, the US around independence and not needing to ask for help, and pull yourself up by your bootstraps, and, don't ask for help.

We can take care of our own, and all of that, it can serve us to some degree, but it really doesn't serve us when it comes to caring for, each other. So we tried to put into that seventh [00:38:00] chapter about creating community, not just the care around the bed and that community, which is really important, but, how can you upstream, like Trish said, how do we start today in taking small steps in looking at doing an assessment of my community?

What's strong here already? Where are the gaps? What am I going to do about some of that? Where might I offer to volunteer? Where, who in my neighborhood might I look in on? how can we, help each other over that vulnerability of asking for help, and people who can model that? Because I think this is a, much bigger issue.

it's a societal issue of how we have lost the collective sense that we're in this together, that we, I think, did better, maybe before the Second World War. Communities were smaller.

Karen Wyatt: Yeah. I have, [00:39:00] im- I imagine in my mind what it might have been like, more than 100 years ago when, everyone in the neighborhood knew each other.

Everyone knew when, Grandma, who lives with her extended family, is getting ready to die, so who might need extra support? How can we pitch in? It seems like it came more naturally back in those days, and it feels, that feels so far away from how most of us live these days and barely even know our neighbors, you know- are barely connected, and it w- I do feel like that this needs to be something we constantly talk about to one another, and that we're- Yeah ... we remind each other to look out in our, within our communities for who, who is gonna need to be part of some sort of a, of c- a, a community death care system.

And, I, I did an interview earlier this year with a woman. She wrote a book- [00:40:00] About an experience of community death care. She was part of a book club, a death and dying book club that met regularly and read books, and one of the women in the book club who was a solo ager announced to everyone that she had a terminal diagnosis and, only had a few months to live, and she was in the book club to learn about dying.

But she said, she asked her book club, "Would any of you be willing to help me?" And they ended up forming a little community around her that shared the care for her. And, it was really challenging, but I loved that little model. We, once we, w- when we find people we connect with- are we able to ask those people to become a community that helps each other in that way?

It still feels like a, a big step, like we're far away from that happening very often, but I think there's a vision there that it's possible.

Trish Rux: I'm in a group [00:41:00] that's a lot of solo agers. some have children, but they live far away, and we're all about the same age. And we covenanted with one another to say we're gonna try to be there for each other.

Not that we'll do everything, but we'll do what we can. And we started out giving each other rides to the airport, and then rides to cataract surgery, rides to colonoscopy, and then a few months ago, one of our people became very ill, and people got together and helped care for her till the end of her life.

It was a profound experience that really informed everybody-

that this is important, and this is something that I someday will need as well, and h- what more can I learn? How can I help even more?

Karen Wyatt: Oh, I love the idea that you started [00:42:00] with smaller ways of asking- Yeah ... for help and giving help.

Yeah. Very doable things, giving someone a ride. But it gets us in the mindset of it's nice when someone asks you for something and you're able to help them out. And, you start to enjoy giving that to one another. I think that's really beautiful. I would love to see that be modeled in more and more communities.

Trish Rux: And we were really clear. It doesn't mean that because I gave Jim a ride, Jim has to do something for me.

Jan Booth: Right.

Trish Rux: it's just in the group, in the milieu, and that it's okay to say, "Can't do it this time." Yeah.

Jan Booth: Yeah. And the, the other part about starting upstream, I, I see that in a group I, sing in, a threshold choir which sings for people at the end of life.

And we've had these conversations o- over the years with each other about, a similar ... We haven't called it a covenant. I love, Trish, when you call it a covenant, 'cause that's [00:43:00] just, it's such a beautiful sacred term, I would say, for caring for each other. But anyway, we talked about that, and we realized that we're practicing it now when someone is sick or when someone has a parent who's dying or, someone has a pet who's dying or someone needs some help because they've just had surgery.

We're, like, practicing in these smaller ways. And one of the other things that I have found so interesting that working upstream helps us with is recognizing each one of us in that group are different. And some people want people around, some people don't want people around. Some people want to share more emotionally, others not so much.

And so it's also helping us to remember, that th- the person who we're caring for is not necessarily going to want the same things or done in the same way as we do. So it's opening up kind of a, a different level of, you might say intimacy around, how do I want to be cared for, and can I ask for that?[00:44:00]

So this is just an- an- another benefit, that I hadn't really counted on. I was more focused on the sort of task part of helping each other. But this other level of connecting us a little more deeply, around some of these vulnerabilities is, is- Yeah ... is powerful.

Karen Wyatt: I love that getting to know one another in a, deeper way, and then giving each other permission to really be who they are and, let everyone know what their preferences are.

We don't have very many spaces like that w- where we're able to actually show that to each other.

Jan Booth: That's right. That's right, and give, permission to be able to say no, as well as permission to be able to ask for something that I used to be able to do myself.

Karen Wyatt: yeah ...

Jan Booth: and, a lot of us very independent people that have prided ourselves over years of being able to do things for ourselves, or those of us who are the [00:45:00] givers and the healers and the, carers, there's a special challenge in that.

So any way that we can practice that ahead of time, this is yet another kind of upstream practice that I think will serve us when things do get more intense, as they are likely to as we get closer, to the end of our lives.

Karen Wyatt: I, just love that your book included this because it is such an important thing for each one of us to talk about and, to, maintain awareness about when we're looking at these conversations about end of life is really when it comes down to the nitty-gritty, who is there to take care of each other?

And how can we come together in ways that, will make sure everyone has someone when they need help. A- and that idea of compassionate communities as well- of, how do we make our entire community, [00:46:00] a safe place for someone who's a solo ager and someone who's facing these challenges?

Jan Booth: That's right. That's right. And I, think, what it shows, us is that, these conversations have different facets. There's a very practical part, what I write in my advance directives, the specific conversations about my disease process, who's gonna care for me, funeral plans.

there's a whole practical piece that, can be very helpful to have talked about. And, then there's the, you know, em- emotional side of how do we, in some way, authentically walk through this together, being able to allow grief into the process and not try to just push it away. The spiritual side of what is- What are my beliefs about what happens when we die?

What do I draw from, [00:47:00] when I'm in hard times or I'm scared? What would be comforting to me in a kind of spiritual advance directive? And then this community part that so often dying in healthcare is seen as a medical event, right? Not only as a failure, but as a medical event. It's a physical dying of the body, and what we're trying to uplift here is that we die, yes, we are alone in our dying in one sense, but we also die in community, whoever the community is.

And the community could be people that we don't know who care for us. I think in hospice, taking care of people who might have been living on the street who didn't have people, and we became that community, right? That caring community. that's, that felt really important to both of us that we can elevate the conversation in a sense to, to reflect these parts of who we are as humans, and that community piece I think is a really [00:48:00] important part of it.

Karen Wyatt: Yeah, and I love that, that you included it as the seventh conversation and the eighth conversation being, talking more about w- we've already alluded to this, but, the spiritual aspect of dying and how much it can

change how you live your life, and it's such an important and valuable change to make.

and I think that we stand up and say that 'cause we've experienced it in our own lives having worked in the end of life field for years and years. that's sometimes for me it feels like a hard sell sometimes. It seems like it's hard for me- Yes ... to get other people to understand that, and, I, don't know, talk a little bit more about, what you write about, Jan, in the book.

Jan Booth: Yeah. Yeah, that we really wanted to end the book with this connection again of dying to life, and that this concept of [00:49:00] befriending death is an old concept. It's found in many spiritual paths, maybe with slightly different words, but that idea of befriending death. how do I live with death on my shoulder, or with that skull on my altar, or whatever the particular memento mori, whatever reminds me of my death?

And, and- Probably all of us have an experience, either ourselves or knowing someone who received a really serious diagnosis where it was clear now their time was limited, and how people talk about the kind of sharp focus that gave to what really matters. All this other stuff I've been worried about, it turns out that did not matter.

What mattered is I wanna spend time with the people I love. I wanna be outside. I wanna, be able to feel cared for in the last days of my life. So if that's what matters most to me in however many days I have, why, do we reserve that just for dying [00:50:00] people? What if we were to take that same consciousness, which is to me what befriending death is, facing our mortality, talking about dying.

All of it is about trying to keep that same consciousness to the preciousness of life. And listen, even 40 years of doing this, I still fall asleep to life, right? I need these reminders just like anyone else. Maybe I just have a little more exposure to a variety of how other people have walked this. But, how do we stay awake to the preciousness of life, to what really matters in the moment?

How do we care for and repair, as needed, the relationships in our lives? How do we have enough curiosity and courage to ask big questions like, what am I afraid of? What do I think happens when I die? What are the regrets that I have, and what can I do about that? I don't know a way around befriending death.

I don't know [00:51:00] how to have those really important reflections and conversations without this concept of befriending death as if it is part of me that

I can care and love and not part of me that I shun. befriending. What would that mean? What would that ... What could that look like? So I hope that for people who might not have seen it that way, I hope that last chapter helps to inspire a different way, a different context for putting this whole reality and the challenges and, the emotional pain of, dying into a, a bigger picture,

Karen Wyatt: I love the term befriending death because it already, it just feels intimate and warm and not frightening in a way.

And, I, I, really like that. I think [00:52:00] that's a good way to put it. And are there ... You were saying, Jan, that you need reminders, and I'm just curious, are there things that you do sometimes to remind yourself, memento mori, that you have and use that, I know you do the work all the time, but as you were saying, we all still need our own little reminders.

Are there any practices or things that you do?

Jan Booth: I'll tell you a practice I'm doing right now is watching these beautiful leaves. I love to be outdoors. And, it's one of the ways I both ground myself and ins- inspire and elevate my spirit. So I'm looking at these trees that are going through this magnificent

Some of these maples right now are going through this magnificent letting go, right? And, it's a beautiful ending, and then they're gonna fall down, and we're gonna be in winter. That's one small way in the natural world that I can not only remember [00:53:00] the impermanence, like I can't hold onto those beautiful green leaves or those beautiful red leaves.

They're gonna fall, right? I can't stop the seasons from turning. But if I can practice, like, recognizing the cycle of living and dying here, and notice the pang in me that the sort of bittersweet, poignant feelings that are evoked for me in the fall, one reason I love the fall. that's just one, one example that's on the top of my mind- because I was just looking at that this morning on our walk and thinking, there it is.

That's- There it is.

Karen Wyatt: That's beautiful. for you, Trish, any, any ways that you have of, just bringing yourself back to that place of befriending death?

Trish Rux: Yeah. I, look at the pictures I put on my altar of ancestors and, some of them I never got to know.

But I see that picture, and I know [00:54:00] I was born into that story, and my grandkids are born into my story. They're not gonna know me in the same way that my daughters know me or friends, that sort of thing. So that's one of the things And I have a bumper sticker on my car that says, "Don't postpone joy."

Karen Wyatt: Oh, I love that.

Trish Rux: Yeah.

Karen Wyatt: Because if there's anything that befriending death tells you is make the most of every moment you have 'cause you don't know how many there will be.

Jan Booth: Yeah, that's right.

Trish Rux: Yeah.

Jan Booth: And, and- They ask. Yeah, that's right. and that, in itself, that way of approaching life can be part of the legacy that we leave behind, which is something that Trish and I also talk about in the book.

A, a legacy is so much more than, money or things or, even an ethical will, which is a [00:55:00] beautiful example of a way to leave behind something that says, "These were the things that mattered to me. This is what I did when I faced hard times. this is what I hope for the world." that, those are all beautiful things to leave behind.

And adding to that, how we live, how we faced serious illness, how we faced aging, how we accepted help or didn't, how we died, how we openly or didn't openly talk about this, all of that is part of our legacy, And so not to have that be a burden, but instead to see that as an opportunity, that my kids are watching, whether they realize it or not, whether they can take in the lessons now or not- They're witnessing something that gives a certain permission, and those, you know, our kids who grew up with moms being in hospice probably get a little lot more- Yeah

of that maybe than other kids. But so it's part [00:56:00] of a legacy, and I love the idea that if through this book, through the work that I've done, that we've all done over the years, we can help to nudge humanity forward a little bit. I love that that's part of a legacy, not just my legacy, but those of us who feel called to this work, that that's part of a legacy that we're all carrying together.

We stand on the shoulders of some incredible people before us. Other people will stand on our shoulders. I love that.

Karen Wyatt: So true. That's so beautiful. And, I just, want to mention the book again, Dying Matters: Eight Conversations That Can Change Your Life. It's an easy book to read. That's ... I wanted to emphasize that, so because sometimes- Good

people who are at the moment of needing to, figure this out, they don't have time to read a 600-page book. It's easy and it's short. it's really well organized. Every chapter has questions, and you've [00:57:00] also left some blank spaces and pages. People can write little notes i- in the book, a- as they go through it.

And then the guide in the back, and you have a discussion guide on your website. It's very practical, but it is also inspirational. And Good ... I think it's a wonderful book that should be on the shelves of people who work in, this field, but it's a great gift to give to someone. I'm, There's someone in my life right now who's starting to deal with these questions b- because- of her own health reasons, and I think this is actually what she needs to guide her through, how do I start talking about this?

Jan Booth: And we say that in the beginning of the book, Karen. I'm glad you said it that way. Just as a reminder that people would often come to us and say, "So what... m- my dad was just diagnosed with blahdy blah.

what book should I read?" And i- it's really hard to know what to say, 'cause there's so many good books out there. But we were realizing [00:58:00] just what you said. What if we were to, write that shorter, accessible, practical, gives context, but also can be inspiring, that isn't just about a checklist, although it includes a checklist, right?

Yeah. So I'm really glad to hear that. And that's the feedback we're getting from people. I'm, really glad to hear that, that people are finding it accessible and, that it is sparking lots of different conversations. One other thing I wanted to say that, anyone listening might find, interesting is that on our website, the, the deathdoulas, .com website, we've listed, I think 11 different professions, and a downloadable one-pager of how they might use this book.

So certainly you can imagine healthcare and hospice and funeral directors, grief counselors, but we've also included things like teachers, educators, l- life and health coaches, wellness influencers. [00:59:00] I'm blanking on some of the other ones. Nur- we have one just for nurses. thinking outside the box of this

isn't just for hospice people, this isn't just for death doulas to be talking about, although it could be very helpful for them, but this is really for many people.

Faith community leaders, we have one for them. to think about how can I use this book in a way that in my particular sector this might be a helpful conversation that is much bigger than, how do you want to spend your last couple of days, and do you have your advance directives done? So hopefully people might be inspired by, "Oh, I hadn't thought that I might use that book in that way beyond my own exploration."

Karen Wyatt: Yeah,

Trish Rux: thanks for saying that, Karen. It's, really heartening to know that people are using the [01:00:00] book in that way, gifting it to others. And one of the words I've heard is that it's digestible- and I love that.

Karen Wyatt: Yeah, I like that very much. There's like beautiful inspiration, but there's honestly like no fluff.

there's no- Yeah ... e- extra words to make it a longer book. It's, concise and easy to read, but you come away reading the book with just a really good feeling inside about what you've learned from the book. so I heartily endorse it, and I hope listeners- Thank you ... will buy the book.

And so the website- Thank you ... a- again is deathdoulas.com, and then people can find everything they need there.

Trish Rux: Yeah. That's right. We have a new one, too, dyingmattersbook.com. So they're, the two are linked together around the book, but...

Karen Wyatt: Okay. All right, I'll post those on the show notes for this episode- Thank you

so people can check it out. And,

Jan Booth: That'll be great ... Trish- We also have on there other, [01:01:00] podcasts and interviews that we've been on, and we have, our bios. We have a media page. just some things that for some people might be helpful in, spreading the word. So there's a lot of good digestible content even on the website.

Karen Wyatt: Yeah, that's wonderful. Trish and Jan, thank you for the work you've done. Thank you for writing the book and for taking time out to talk to me today. I'm so glad we finally got to talk and, promote your book.

Jan Booth: Yes. Thank you so

Trish Rux: much, Karen.

Jan Booth: And Karen, you have been a real leading light in holding these conversations over many, many years.

certainly through the podcast and End of Life University, but I can only imagine all the conversations as a, you know, hospice MD. just a- another moment of honoring the work that you've done in such a beautiful way and such an inclusive, generous way. So thank you for that.

Karen Wyatt: Thank you. we're all on this path together befriending death- Yes

and - [01:02:00] Yes ... trying to introduce death as a friend to more people. And, it's really good work. It's good work- Yeah ... for all of us.

Jan Booth: Yep, agreed.

Karen Wyatt: take care. Many thanks. Thank you.

Jan Booth: Okay.

Karen Wyatt: Thank

Jan Booth: you.

Bye.