

Alua Arthur:

Death is difficult. It's hard. It's painful. There's loss, people that we love suffering, and that's hard to take in. Also, to think that the life that I know one day is going to end, it's virtually impossible. The human brain isn't meant to do that, at all. So to be with that is a difficult, difficult work to do, and it holds so much promise. I think it's Joseph Campbell that said that, "the cave you most resist to enter, holds your greatest treasure." That's where all of the juice is when I'm thinking about my death. It puts my life into really clear focus. Who am I? Who have I loved? Have I loved? What have I done?

LuAnn Heinen:

That's Alua Arthur, death doula and founder of Going With Grace, an organization that supports people as they strive to answer the question, what must I do to be at peace with myself so that I may live presently and die gracefully? A self-described recovering attorney, Alua came to this work before end-of-life planning was routinely contemplated, never mind a cultural norm. Now the tide is changing. More people seem ready to confront death as a part of life. With this change has come a swell of interest in end-of-life doulas and employers are beginning to take note.

I'm LuAnn Heinen and this is the Business Group on Health podcast, conversations with experts on the most relevant health and well-being issues facing employers. Today, my guest is Alua Arthur, and we discuss the movement afoot that's transforming death from unmentionable to something that we discuss more openly and consider more carefully. We chat about what a death doula is and their transformational role in the living and dying process, why employers are beginning to cover death doulas as a part of their benefits, and what organizations need to know as they consider providing this type of support for their workforce.

Almost everyone has a story about their health insurance. Today's episode is brought to you by Surest, an innovative health plan making waves in the industry for all the right reasons.

Alua, welcome to the podcast. I've really been looking forward to this conversation.

Alua Arthur:

Thank you so much. I'm really happy to be here.

LuAnn Heinen:

Let's start out by talking about what a death doula does.

Alua Arthur:

Gladly. A death doula is somebody who does all of the non-medical caring support of the dying person and the family or the circle of support through the dying process. But we can be instrumental at any stage in life, really. When people are healthy, we can help them complete comprehensive end-of-life plans. When somebody knows what it is that they're going to be dying of, we can support them in creating the most ideal death for themselves under the circumstances. After a death, we can help family members wrap up affairs of their loved one's life.

LuAnn Heinen:

How much call do you get in America these days for healthy persons thinking about dying, wanting some support?

Alua Arthur:

Perhaps more than one might think. I think given the pandemic, when people really started to see what dying was looking like for a lot of people, they started thinking about, well, what happens if I get this virus today and I'm in the hospital tomorrow, who will handle my affairs when I'm gone? People really started reaching out, starting to get some end-of-life planning. It was already a thing before. We had quite a few folks reaching out to get some support there, but through the pandemic, we certainly saw a big increase in it.

LuAnn Heinen

Do you think that we're getting less uncomfortable as a culture with death?

Alua Arthur:

I would like to think so, but I'm also a little biased. But realizing the prevalence of conversations about death and dying in the media, this huge show, *This is Us*, had an episode on preparing for the end-of-life. We're seeing more death themes in music and television and the news. I think people are more open to be talking about grief lately, which all says to me that we're starting to turn a corner in our ability to talk about death and dying. It's still difficult, don't get me wrong, but I think that it's starting to shift a little bit.

LuAnn Heinen:

I agree. I've seen more from the entertainment sector. I'm watching a show called *New Amsterdam*. There's a comedy called *Dead to Me*. That's new.

Alua Arthur:

It's great.

LuAnn Heinen:

There's a death positive movement out there, too. Are you familiar with that and do you think that has legs?

Alua Arthur:

Absolutely. Yes, I'm really familiar with it. I like to think that this wave of death positivity that we're seeing can be attributed to Caitlin Doughty, who is a mortician and undertaker and an author who wrote several books around how we die and what happens to our bodies after death. In 2013, she tweeted something about, well, we have a sex positive positivity, why don't we have death positivity? That started people thinking about it that way. For me, death positivity is less like, yay death, and it's more like, okay death, and how are we going to be with it? As opposed to trying to push death on folks, but rather opening the space, opening the door so that people can walk through when they're ready to talk about death and dying. It's happening. We're seeing a rise in different ways for bodies to be disposed of after death, like natural organic reduction. People are finding new opportunities and thinking through how they want their bodies honored after they die. I attribute that to the death positive movement.

LuAnn Heinen:

Well, the U.S. Post Office has Day of the Dead forever stamps.

Alua Arthur:

That's so cool.

LuAnn Heinen:

Day of the Dead is a holiday when you remember loved ones and commemorate death as part of life. But maybe I have a problem. I have a whole stack of them in my drawer and I think twice before I pull one out and put it on a birthday card to my mom or something.

Alua Arthur:

Oh, you don't want to send the message.

LuAnn Heinen:

If I got one, I wouldn't think twice. But I think it goes back to the we're uncomfortable. You've called it the great human mystery. It defines our life and we're not supposed to talk about it.

Alua Arthur:

Shocking, isn't it? Given that it's the one thing that we all do. Not all bodies do all things while they're living, but one thing everybody must do at some point is die. It's shocking to me that with this only guarantee that we have in life, it's shoved in a closet like a secret, but it's a unifying factor amongst us. Even if we cannot come to recognition that one day we'll die, we're very much aware that people die, our friends die, family members die, people die. So when we can just acknowledge the fact, that goes a long way. Naturally, I'd love it if everybody was doing their comprehensive end-of-life planning long beforehand, but at least even acknowledging the fact that death occurs and that we're going to be touched by it is a nice way to begin the conversation.

LuAnn Heinen:

Do you think part of it is that we're not really seeing death anymore? So much of death in America takes place in hospitals or other facilities. Isn't it true that the parlors we used to have in our homes have been rebranded?

Alua Arthur:

Yes, they're now called the living room because the dying took place in the parlor back in the day. So somebody in the family would get ill and they'd be kept in the parlor, and then when they died, they'd be held in the parlor for a while and there would be what we now know of as a home funeral, the only way of funeral beforehand. After the funeral industry really started to take off about 50 years or so after the Civil War, then there was a rebrand that occurred in death and dying. Overall, somebody dies at home, they're taken off and we don't see them again until they're being buried. In the medical industry now, a lot of people are dying in hospitals, and so we're not seeing death as much. When that started to occur, it was like, well, let's erase this altogether from the home, let's make it the living room now. Living as opposed to dying in the dying room that it used to be.

LuAnn Heinen:

Most of us today don't know that at all. It's really interesting.

Alua Arthur:

Absolutely. I think just the history of how we die has been interesting overall and what's happening in the last a hundred years, there's such a departure from that. I think part of the death positive movement is in an effort to reclaim our dying, to take care of our dying ourselves, and to be with it in the way that we used to be in a way that feels constructive. There's like quite a few folks that have been doing a lot of death awareness, which I'm so happy about. We want to deny death. We want to hang on to life and living as much as possible, but dying is part of living. It's an absolute, just the end of that story. It's part of the cycle that occurs in life. We're born, we age, we die, and some die sooner than others, but it is still part of that natural cycle.

Everything dies. Even Styrofoam will degrade over time, but everything meets its end at some point. And humans, because we're human, want to hold on to this experience and not be a part of the natural cycle, but we're nature itself, we're nature expressing itself, we will die. We must die. It's a difficult pill to swallow that the story as I know it, my life as I know it, will one day be complete. I get so wrapped up in myself, my ego sense of self that says that this is the story, this is the way, but there's 8 billion stories that are currently co-occurring. Then there's been 102 billion already that have occurred. I'm just going to be one – ouch and also wow, at the same time.

LuAnn Heinen:

I like how you said we're all the hero of our own story, and it's hard to forget that it's true for everyone.

Alua Arthur:

Yes, I'm the main character and so are you, LuAnn. It's something that I don't want to gloss over. Death is difficult. It's hard. It's painful. There's loss, people that we love suffering, and that's hard to take in. To think that the life that I know it one day is going to end, it's virtually impossible. The human brain isn't meant to do

that, at all. And so to be with that is a difficult, difficult work to do and it holds so much promise. I think it's Joseph Campbell that said that, "the cave you most resist to enter holds your greatest treasure." That's where all of the juice is when I'm thinking about my death. It puts my life into really clear focus. Who am I? Who have I loved? Have I loved? What have I done? What have I accomplished? What will I leave behind? What will people make of my story when it's over. And less that I'm living for other people, but more that I have an opportunity to think about my life as it is so that when it comes time for me to die, I can be like, you know what, I did it. I did it. I'm proud of who I've become. I've done the things that I wanted to do. I saw a lot of art and beauty and I felt loved and I loved on my niece and my nephew. I was compassionate and I was kind and I made some people laugh. I was also sometimes a jerk, but I apologize. I apologize. If I can be with my death, then I can be with my life.

LuAnn Heinen:

Let's talk about how doulas can help make the dying experience better for the person who's dying and also for the family.

Alua Arthur:

Oh, absolutely. There's so many ways we can be supportive. We can handle all of the logistical, emotional, and sometimes spiritual support that the family members need. Often I'll get a call and somebody will say they have a need. Maybe it's around a power of attorney or figuring out what to do with possessions after somebody dies or something of the sort, and while supporting them with that, a bunch of ancillary issues pop up. Maybe they're not clear on who's going to be their beneficiary after their die or what they want to do with their possessions, but then that might open up conversations about what the relationships are with their family members and maybe places where they still feel stuck or what might be undone in their life that they really want to make happen while they're still alive. I like to think that death doulas really create a space for people to approach their dying in a holistic manner, to look at all the different things that play into what happens when we die and offer some support for it.

I got into this work after being a lawyer for a few years, working at Legal Aid, and growing terribly depressed and trying to find a way to get myself back into my life, get myself back into my body in a way that felt healthy to me. And death was the way. I started thinking about myself on my deathbed and the life that I would have led. Not long after that, my brother-in-law got sick and I got to support him and my sister and my niece in his dying. During that time, what I wanted more than anything was to have somebody who we could ask questions to, somebody who was kind and compassionate and cared that this thing was really hard for us and had some information, had some resources to support us. It was a very isolating experience and the benefit of having somebody there to walk alongside with us would've been invaluable, but I couldn't find anybody. So I figured, well, if I needed it, and there are about 150,000 to 250,000 people dying a day, this is not an isolated experience. It's a universal one, thus people must be seeking this. I was seeking it. I think it's important that we have people there that can walk along family members as they're walking through this really sometimes harrowing experience, which can be made that much more tender by having somebody who's there honoring, validating, acknowledging, and can just do some practical things too.

LuAnn Heinen:

Yes, it does seem like the skillset ranges from the kind of very practical tasks, the paperwork, the insurance, the process kinds of things, all the way to the being a friend, a listener. Spiritual, I guess, but not religious.

Alua Arthur:

Yes, spiritual, but not religious. Just have somebody there who can identify and validate the experience that you're going through. That goes a long way. It's something that I think humans generally reach out for. Just like a kid when they have an ouchy, they're like, look, I've got an ouchy, and maybe you kiss it, you acknowledge it, and then they can move on. We, I think, inherently want somebody to bear witness to our process, to bear witness to our pain and death doulas can provide that as well as practical support through the dying process.

LuAnn Heinen:

Also, in many families, there are family members whose avoidance, denial, difficulty coming to grasp with the situation, can create a problem when death is approaching, maybe even a problem for the person who's dying. Another quote from you is, "honesty is a casualty of serious illness."

Alua Arthur:

Oh, that's a good one. It's true, it's true. Often what happens is that people, they hear what they want to hear, either from the medical care team or their family member. They want to hope for a cure, they hope for a miracle. There's nothing wrong with that as long as there's also some practicality, some realness about what's going on that's occurring. You know, they hide their head in the sand. They don't want to think that death is approaching and I can understand. It's big and scary and difficult and hard, but at the same time, if we can acknowledge it for what it is, there's a lot of space available for healing and for coming to terms with the lives that we've led and perhaps even the relationship with this person that's dying, and what they're dying might mean for me, which might support us in taking the steps while they're still living to remedy what might be difficult about the relationship. Do you see what I'm saying?

LuAnn Heinen:

Yes, and it brings me to just another question, which is, what must we each do to be able to die in peace?

Alua Arthur:

Yes. The centralizing question, the mission statement for my organization, Going With Grace, is what must I do to be at peace with myself so that I may live presently and die gracefully? The question is phrased in the imperative, not that permissive, not what can I do, or what would I really like to do, but what must I do? And the answer to that question is as varied and unique as we all are, what I must do in order to live presently and die gracefully varies from my neighbor, my partner, anybody, my mom, my sister. It's really important that we spend individual time thinking about what's absolutely necessary for us to do so that we can both be here right now and prepare ourselves for the end.

LuAnn Heinen:

Those things we must do are things like heal any relationships that need healing?

Alua Arthur:

We must heal our relationships, take care of our practical matters, think through our personal relationship with death and dying, ensure that everything that we wanted out of this life, we've got. One of the major fears that people have as they're dying is a fear of a life not fully lived. A big question to be asked near the end of life, and even now, it's what's still undone in my life. Some have big dreams of going to Machu Picchu or seeing the Louvre or writing that book or being a superstar on a billboard on Hollywood Boulevard. It's important that we think through the qualities of values of that thing and make sure that we have that as present as we can while we're living, if we're not capable of carrying out the big dream when we die. Does that make sense?

LuAnn Heinen:

Yes, I mean it's more nuanced than the bucket list people joke about or talk about.

Alua Arthur:

Far more nuanced than the bucket list. Often when we're getting close to death, there's no more time left to go do all those big things, so how can I distill down what's important to me about those things and have those present in my life right now as I'm living and also as I lay dying.

LuAnn Heinen:

I'm speaking with Alua Arthur, founder of Going With Grace. We'll be right back.

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LuAnn Heinen:

I'm beginning to be impressed with the skillset that a doula needs to have given that he or she is applying that in so many different settings and situations and personalities, as you said, each of us is different. Talk a little bit about the doula training.

Alua Arthur:

The doula training is a great place for people to start learning about what it takes and not only all the information. In the Going With Grace end-of-life training, for example, we cover 14 different modules in end-of-life care. We look at the relationship with the medical care system, the funeral industry, home funerals, caring for bodies at home, conscious dying, grief and bereavement, burnout. We look at wrapping up affairs after death, advanced planning, everything beyond the advanced directive possessions, etc. and then also self-care. The hope in the doula training program is that doulas will learn the general modalities in end-of-life care. But most importantly, I'd say it allows doulas to be with their own personal relationship with death, because that's one of the indicating factors about their success or effectiveness as a doula. It allows us, when I can see what my fears are dying are, when I can be clearly with my relationship with my own death, it allows me to not cloud the space between myself and the person that I seek to serve. Because in that case then I know that this fear that I have is coming up for me and it might not be what this person's fear is. So I can make space to hear theirs and respond to it appropriately. It also requires us to really beef up on our listening skills. We talk a lot, we listen a lot with our ears, but it's wildly important that we also listen to what's not being said. That we listen to the context from which the person is speaking from, that we hear the nuance and the things that they're sharing so that we can fill those needs as expressed, and the ones that aren't yet expressed, because they haven't been articulated,

LuAnn Heinen:

As you said before, give space.

Alua Arthur:

Give space, give a lot of space. I've mentioned this before, but the time of dying is such a ripe time. It's so tender and so much comes up during that time. It's also really important that doulas are able to hold the space, acknowledge what's happening in that room, be comfortable in emotional depth, be able to be with anger and sadness and grief and even sometimes joy and laughter when it seems inappropriate. But to honor and hold the uniqueness of the human experience for what it is and not what we think it should be or what society dictates or etc., just to be human. To allow people to be human when they are and they feel very human when they're dying.

LuAnn Heinen:

What do you think are the essential qualities that death doulas should possess to be really engaged in active listening and not judging and not showing their own cards or fear? What else might get in the way?

Alua Arthur:

I think that it takes a lot of awareness of your stuff for starters. You know, because if I know that one of my fears of dying is I don't want to die before my book is done, for example. I feel like I still have some work that needs to be accomplished. If I'm sitting across somebody who has been creative their whole lives and still has

works of art that they want to put out or something, I'm going to think, oh no, maybe they're worried about dying before their work is complete, but that's mine. Maybe they're saying that they're going to miss their kids the most, or they're really worried about this relationship. I have to constantly be thinking about what mine are so that I don't cloud the space. Part of the work is to become as clear a channel as possible. That doesn't mean that I don't have my own stuff at all, I got plenty of it to spare, okay, I got a lot of stuff, because I'm human like we all are. But if we can walk into the door, treat each death like it's the very first one, and stay really curious, stay very, very curious about this person in front of me, it allows space for their stuff to come up naturally. And if I'm paying attention to mine, I can hear the difference in what they're sharing from mine. It does require a bit of aptitude, but I also think that it's a very basic human thing that we all know how to do. We all know how to do it. It's just we get in our own way. We make things about ourselves when they're not. When somebody's in pain, we want them to get out of pain, and so we fill the space, we say things, we say platitudes that don't mean anything to anybody or it can be harmful, like she's in a better place. When that might not be the reality and the truth of the person sitting in front of us, because we want to make it better with them somehow. It points to our inadequacy. I feel inadequate in the face of this loss and so let me say something that I think is going to make you feel better so that I don't have to sit with the fact that you feel bad, but I can just sit with that. I can feel powerless over somebody else's pain, but I have to be aware that it's my stuff that says, I don't want you to feel bad anymore, so I'm going to fix it for you. We can't fix it. There's no fixing pain, there's no fixing grief, there's no fixing death, there's no fixing loss. My work is to be with the hugeness of it, the difficulty of it, as best as I can. We know how to do it, we know how to do it. We just have to practice a lot.

LuAnn Heinen:

For a doula to allow space for the dying person to share and not project her own issues and concerns, does that mean she needs to overcome her own fear of death and is that even possible?

Alua Arthur:

Well, I think it's also important that we don't think of overcoming it necessarily, but rather just being present to it. Overcoming our fear of death, overcoming our discomfort with death is a really high bar. The best that we can do is to be present with what is, to be present with what's coming up for me, because when I can bring conscious awareness to it, I can own it and I don't have to put it on somebody else. The first step is not thinking of overcoming it, but rather acknowledging it, continuing to acknowledge it, and that creates space for me to put it down when I'm in the presence of somebody else.

LuAnn Heinen:

Are there particular equity challenges we should know about related to the dying process?

Alua Arthur:

A lot of them. Even though it's a unifying experience, the way that we die is largely dictated by how we live. Just thinking about the fact that there is societal inequity that exists in life, it naturally carries through into death, there are different medical biases, biases in the medical care system so that people don't receive access to health care in the way that others do. Then also that relates to pain management at the end of life or even treatment that people are receiving, certainly how folks are receiving the dying person. Since the doula's role is to support and empower those that are dying, what we can do is also honor the unique lived experience of each individual. That means looking at their unique intersections of identities, which means that some identities which may not be highlighted or accepted in the larger society. So I think that the doula can really be supportive by looking at the person holistically and honoring all parts of the person. As so many in the end-of-life space right now are largely white, cisgendered, upper class or so, that necessarily marginalizes other communities. It's important that those of us that are in this work are doing our best to make sure that everybody who needs access to care can have it regardless of ability to pay, because right now it's also self-pay. People have to pay for it out of pocket. I'm hoping that changes soon as more employers start to think about ways that they can support their employees so that everybody can have access to quality, end-of-life care.

LuAnn Heinen:

Can death doulas attend a patient in a hospital or other facility the way a birth doula can?

Alua Arthur:

Absolutely. Death doulas can do our work anywhere the client is - it can be in a home, in a health care facility, an elder care facility. I've been in memory lockdown units before, hospitals, home health care. Any place where the person is doulas can enter and be of support there, provided that they're welcome to do so. That's sometimes a challenge, but overall I like to think that that's shifting too.

LuAnn Heinen:

Yes, I was thinking if there's a chance, an opportunity to run interference, if you see something that's not going to advocate for the patient.

Alua Arthur:

Absolutely. A big part of our work is patient advocacy, making sure that our client has a dying that feels best for them and the dying that I think supports the family members and their needs. We're excellent patient advocates. I mentioned listening as an important skill and so often I can hear what the client is saying, maybe hear what the doctors have said and recognize that maybe there's some misinformation or some information to make it from a mouth to an ear and run interference there and also help clear that out. Encourage the client to write down a list of questions perhaps for next time they talk to the doctor, or repeat, this is what I heard, what did you hear, in order to make sure that everybody's on the same page.

LuAnn Heinen:

You mentioned coverage. Are you aware of employers providing coverage for death doula services?

Alua Arthur:

I am. One in particular, which is so exciting to me. I think that as more companies start to recognize the value of supporting their employees holistically, that hopefully more will start offering death doula benefits for their employees.

LuAnn Heinen:

What do you think they should understand that they may not be aware of when it comes to offering a death doula benefit?

Alua Arthur:

Oh, that's a tough one, because I think on some level, certainly if you've walked through it yourself, you understand how difficult that time is. I don't think employers give enough space for grieving right now and the period before the death actually occurs. I would love it if employers could offer people the financial support so that they don't have to think about how they're going to pay for this care that they might need. So many people double as caregivers while they're still working, and so to get some additional hands-on support for the person and also for the family overall is wildly important. Not only will they be more supported in this journey that they're taking, I think that it creates space for folks to start to alchemize grief, which leads to ultimately healthier and happier humans, which leads to healthier and happier employees as well. The benefit is universal. It's important for our organizations, our businesses, but also important for the world.

LuAnn Heinen:

Yes, bereavement leave has been expanding. In many companies it's much more and more flexible than three days for a close family member-type thing, but still an issue, to your point.

Alua Arthur:

Yes, we know that grief goes on for a while and three days isn't even enough to begin to integrate this massive change that has occurred in one's life, but then to start to move around the world in that way in the days after a death. I remember after my brother-in-law died, I couldn't figure how to put pants on. I was like, hey, put one leg at a time, you sit down on the edge of the bed, and then the zipper, and said forget it, I'm just going to wear a skirt instead, I can't deal with this. To think that people in a state like that are then also having to go into the workplace and handle their obligations is overwhelming. I'm really happy that bereavement services and leave is being expanded in places as we begin to understand the toll that grief takes on the body and the brain.

LuAnn Heinen:

Well, I understand you're working on a book. Tell us about the book. What can you tell us?

Alua Arthur:

Well, I'll tell you that writing a book is quite the process. It feels like birth. I think I need a birth doula for supporting this. It's been such a revealing ride to look back on my experiences in death care and also to look at the journey from practicing law into becoming a death doula. The book looks at the key elements of life itself and the qualities that we need that make dying a little bit more accessible and how to apply those to our lives right now, looking at my life and perspective. It's a memoir looking at my life and then looking at my experiences with dying clients. It's been fun to write, but it's also been such an undertaking and I entirely intend that pun. It's been quite an effort to get this thing done and out and we're getting close. We're getting close.

LuAnn Heinen:

That's awesome. Well, when do you think it'll be available?

Alua Arthur:

It'll be available in early 2024 and it's entitled, *Briefly Perfectly Human*.

LuAnn Heinen:

Briefly Perfectly Human. All right, we'll look for that. It's been really great talking to you, Alua. Thank you so much for sharing this with us.

Alua Arthur:

Thank you so much. I'm really excited about this opportunity that you've created for me and I hope that there's some value that comes out of this conversation.

LuAnn Heinen:

I've been speaking with Alua Arthur, death doula and founder of Going With Grace. Check out the website for information about doula training, end-of-life seminars and retreats, and to access a doula directory and matching service. Don't miss Alua's videos with fun, yes fun, video commentaries.

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