

**Communication Lab By Ira Byock and Anthony Shore
End Well Symposium, December 6, 2018**

Start of Transcript

[Crowd Applauding]

Ira: Hi, Anthony.

Anthony: {Whispering} Hi, Ira! I'm characteristically quiet today.

Ira: We have a mute linguist with us, I'm so glad that you exist.

[Crowd Laughing]

Ira: This is — I have to start by thanking two of the producers, Tracy Wheeler and Liz ___ for coming up with this idea. This is for me a dream come true. I have been, not just been interested in language around talking about illness, dying, caregiving and grieving for years, but it would be more appropriate to say sort of an obsession. And it turns out there are actual scientists and professionals who are interested in this stuff so it's really a play.

Anthony: {Whispering} Ira, it's really the opposite for me because while I'm obsessed about language all the time, I have been very averse **[00:01:00]**. It's a topic I've avoided my whole life as much as I can but in the research I've done for this, I've completely transformed and turned around, and embraced the inevitability and the transformation that can attend that last phase of life.

Ira: So we— this is it...

[Crowd Applauding]

Ira: There is a cure for death aversion [Chuckles] and Anthony has literally become a dying whisperer. It's remarkable! This is a — it's a miracle!

[Crowd Laughing]

Ira: So let's get serious for a bit. I wanna just acknowledge that language, words, are the primal human tool, right? And I wanna reflect on something that Peggy McGuire said in a just the last hour and I would say that she touched on what for me is the primal **[00:02:00]** question that human beings are asked, which is whether to act out of fear or out of love. In acting out of fear, you kind of constrict, you protect yourself, you flee or you freeze. If you act out of love, you have to be open. You are inherently vulnerable and so as we talked about different choices of language and whether language kind of — the terms that we used, the metaphors that we used, either constrict what we are thinking about in our consensual frames or whether they open us up and expand. Think back that there's also this dialectic between fear and love.

Anthony: {Whispering} Oh, Ira. There's a couple concepts I wanna talk about with you. The first is priming. So priming is when we hear. We're exposed **[00:03:00]** to words and ideas, and those words in language predispose us to feeling or acting or perceiving a certain way later on. The second concept is framing. So a frame is a conceptual framework and the way that we frame an idea and the words we use activate those frames and those frames govern how we

perceive or believe or act on something and that has a great deal to do with what the end-of-life experience can be for people.

Ira: Do you have examples of — that come to mind and resonate?

Anthony: {Whispering} Sure. Oh if someone who is — those dying, hears others talking in a way, that dehumanises the person or denies what their experience is, they will come to believe that about themselves. It will be more difficult for them to have a transformative experience at the **[00:04:00]** end of life. So if someone is talking about the Alzheimers in room 3, right? First is Mrs. Robinson in room 3, that's actually gonna have an effect on what they believe of themselves. If they believe that they are hearing frames about death, that it's an end, that limits what the possibilities are for them, then that's also gonna have a limiting effect on them if relatives or friends deny how they're feeling or deny the power of transformation. All of that is gonna limit the possibilities of transformation in the person who is dying.

Ira: Beautiful, beautiful. So this is pernicious. It can be pernicious, that things, the language that constricts us. We've heard of it even today so there's no ill intention here but just notice the power of language. Everytime we say "the dying", "the sick", we have separated ourselves **[00:05:00]** from our fellows who are going through a stage of life that we will also go through. It would take very few characters more to say "the dying people" or "dying people", "sick people", just that still retains their humanity and changes our frame. I have railed for years against that phrase "good death." We've heard it today here all the time but it conflates dying with death. Dying is a part of living, death is beyond life, right? I don't know anything about death. Have frankly never met anybody who can convince me that they knew a lot about death. I know a fair amount about dying because like so many of you, I've hung out with people who were dying for years. I've asked them to share their perspective with me. So instead of the "good death", and notice that death there is the noun, I've often used the term "dying well." Thing in American culture that you can be well during the time **[00:06:00]** that you are dying. This is really groundbreaking, you know? And we can carry that forward but the language that we use, the aphorism — I know you wanna talk about aphorisms — the metaphors, this is all fundamental to this traumatic, transformative cultural change that's available to us.

Anthony: {Whispering} Well, and you may wanna take at Alzheimer's disease to start and maybe start calling it "a late life learning disability."

Ira: Yeah [Chuckles]

[Crowd Laughing]

Anthony: {Whispering} It completely reframes what it is, right? People will feel differently and treat people differently if they see that person as have a life learning disability.

Ira: Yes, yeah. If you talk about a dignity as being inherent, worth as being inherent, that automatically changes your relationship to the person. They are inherently worthy, inherently dignified, and now how can we care for them in ways that honour **[00:07:00]** and celebrate, right? Honor and celebrate. Honoring and celebrating — are like gems — people through the end of life, waking them out of life if we use the Irish term. This is a, you know, there's one other consequent I get in here. There's a certain healthy defiance toward mortality. We're all gonna die, right? We gotta get over that but we can be defiantly joyful and full of loving and life. The quote that Alexandra used from breath becomes air of Lucy and Paul deciding to have a child. For me, that was a healthy defiance, a defiant act that even the force major cannot take this from us. Thank you for that. It's just culture change, dramatic. Aphorisms **[00:08:00]**?

Anthony: {Whispering} Yeah. Yes, let's talk about what language people believe, okay? Because to have something that's repeated and to have something planted, it's something that is going to have an influence. Now it is true that people believe and abide language more if it is poetic and if it is familiar and that's why aphorisms use a line, a iteration, as the next and that if it sounds good, we are more inclined to believe that it's true! So when we hear expressions of aphorisms and proverbs, if they are poetic, and if they're familiar to us, they're gonna have a profound effect on what that person believes of themselves and what is possible, right? And if you say the same idea, expressed beautifully, or expressed without any other poetry, one is gonna influence and people were believable than the other one **[00:09:00]**. So are the aphorisms be expressions that are used, are they gonna contribute to a sense of transformation and the hope and respect and belief and the power of change or are they gonna shut the person down and believe that they're limited because we've heard something that confines what is possible? So what is the main aphorisms you are familiar with?

Ira: So I have two that I wanted to bring to the attention of this group. First is, forgive and forget. This is ridiculous!

[Crowd Laughing]

Ira: Right? This is absolutely absurd. I hear it all the time, right? Forgiving is a sophisticated emotional strategy for getting rid of the emotional baggage that you carry, right? But it requires remembering. Forgetting is amnesia.

[Crowd Continues Laughing]

Ira: If I don't remember you harming me or you doing me wrong **[00:10:00]**, what's there to forgive?! Right? I have to remember, to forgive. And again, you know, forgiving is about my well-being, about all our individual well-being, not fundamentally first and foremost about the other person. They involve the other person but it's first and foremost about us. So there's one, but it's common. The other one in our field that I've been sort of pointing attention to for a while is this notion of "People die as they have lived." Well, they might. They might pull that off, they might not change but the fact that you're seriously ill and you know that things are coming to an end and you're gonna lose all that you love and all the people that you love, that's true! Man, and often so that is a catalyst for remarkable human development for people to change, for people to grow, for people say they feel intensely alive and they do things, they say things **[00:11:00]** that they hadn't done before. Right? So in fact, many people change in profound ways; ways that are important to them and to people they love during the months, weeks, days, sometimes moments before they die. And if we believe that forgive — that he's gonna die as he lived, that sets a potential for therapeutic nihilism. Like why bother? What about this life if we — who cares! You know, let them, right? And just let's end this as quickly as painlessly as possible, there's no opportunity there, but no, people can change.

Anthony: {Whispering} These low expectations are a tyrant and the imprisoned people to assert faith that doesn't have to be that way.

Ira: Right, right. There are — I could keep going. You know, all things always turn out okay. They do not!

[Crowd Laughing]

Ira: You know? That's absurd **[00:12:00]**! I mean that's just disrespectful, right? Things will work out in the end. They may not! Stop saying that. [Chuckles] We can hope for it but be cautious about your language.

Anthony: {Whispering} I wanna talk a bit about metaphor. Metaphor is an important part of a transformative experience. Something that goes beyond expressing what we are normally be able to express. People who are at that phase of life, they can speak in that sense. And they speak in metaphor because metaphor is capable of transmitting and capturing dimensions of understanding and a nuance that just brand old descriptive language cannot. And so metaphor can be a powerful and helpful way to getting back with people who are at the end-of-life experience. People who **[00:13:00]** are speaking metaphors, we shouldn't deny that that's happening... better to embrace it, lean into it and ask the person to talk further about that because it may be the only way that language could possibly transmit the profundity of this experience that they're having.

Ira: Absolutely, boy, we need more of you.

[Crowd Giggling and Applauding]

Ira: So I wanna come back if we can into this notion of connecting ourselves to the notion of wellness and well-being. This is very powerful. It's a powerful stream in our culture, right? As we're — as we gradually are growing the rest of the way up as a culture. Acknowledging finally that we're mortal, that we're gonna die. Get over it. And let's get on with a living as fully as defiantly as joyfully **[00:14:00]** as possible.

Ira: Here's my dad and my — at the time just a few months old daughter, Lila. Dad at this time was living with a pancreatic cancer. He knew he was dying. He loved children more than anything in the world. Oh it's not up there, okay. I — they're queueing it up. I'm gonna show you my picture of my dad. He's here in front of me, there he is.

[Crowd Respond In Awe]

Ira: So I wanna talk to you about what wellness is as people are approaching the very end of life .You know, Freud once says — I asked about “What's mental health, Dr. Freud?” And he said it's the ability to love and to work. It was kind of a toss offed comment.

Anthony: [Inaudible_00:14:48]

Ira: What?

Anthony: [Inaudible_00:14:50]

Ira: Yes. Thank you.

[Crowd Laughing]

Ira: What he whispered and I've thought about this for a long time. I think it was brilliant: **[00:15:00]** to love and to work but what — I would've, by the way added “to laugh.” If you can love, you can work, laugh, well you're probably pretty healthy emotionally at the basis. You may have bad days and all that but how about when you can no longer work? My dad couldn't work here. How about because of frailty, of age, or illness or beyond that? For me and I thought a lot about this. Well-being is the ability to love, to feel loved, and to have the capacity to feel joy. Here's my dad — who hated the idea that he was dying — Looking at his first granddaughter and he's ecstatic! He's sad during this time. This was awful, but he's ecstatic. They're connected to one another **[00:16:00]** in a way that is mutually joyful. I sat with my dad during the last days of his life. Had the privilege of caring for him through the end of his life. My dad

was well during the time that we consider him dying. He died well. Not just in the process of it but well within himself. I think this is our great cultural opportunity to shift the way we think about human beings, human caring, well-being through the very end of life. I hope we get to work together because this work is so fundamental. We're down at the very essence of what makes us human. It's not just our opposable thumbs or our 46 chromosomes, it is the ability of language [00:17:00] and our ability to care well for one another.

Anthony: {Whispering} And the language we use can have a profound effect on what that last phase of life is, that transformation.

Ira: So let's act out of love, not out of fear. Let's expand rather than constrict of the potential for human beings through the very end of life. Thank you all for the work that you do and for joining us today for this wonderful conversation. Thank you.

[Crowd Applauding]

Ira: Abby, thank you very much!

[Crowd Still Applauding]

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