

Reframing Our Relationship to That We Don't Control by On Being

What follows is the audio and transcript of an onbeing.org interview between Krista Tippett and Dr. B.J. Miller:

MS. KRISTA TIPPETT, HOST: "Let death be what takes us," Dr. B.J. Miller has written, "not a lack of imagination." As a palliative care physician, he brings a design sensibility to the matter of living until we die. And he's largely redesigned his own physical presence after an accident at college left him without both of his legs and part of one arm. B.J. Miller's wisdom extends to how we can all reframe our relationship to our imperfect bodies and all that we don't control.

DR. BRUCE (B.J.) MILLER: There's a big difference between things that happen to you, that are forces larger than you. I can yield to Mother Nature. I can yield to 11,000 volts. That's a very different prospect than is shutting down your imagination or rolling over altogether. So there's a challenge to our sense of proportionality in all this, and I've loved that theme. That word "proportionality" comes up for me a lot, trying to right-size myself.

MS. TIPPETT: I'm Krista Tippett, and this is On Being.

[music: "Seven League Boots" by Zoe Keating]

MS. TIPPETT: B.J. Miller is the executive director of the Zen Hospice Project in San Francisco, and he's an assistant clinical professor of medicine at University of California San Francisco. A self-described "suburban boy," he moved all over the U.S. growing up with his family until he attended Princeton. And there, the accident that nearly killed him set him on a path to medicine, but first to studying art.

MS. TIPPETT: Design is such an important word for you and such an important notion that I feel runs through all your life and your work, and, to me, there is a spiritual aspect of that, expansively defined. And I'm just curious about where you trace the origins of that. Would you say that you always had a "design sensibility," even if you didn't use that language?

DR. MILLER: I would say yes. I would say I always had an aesthetic sensibility. I think one of the great things that moving around the planet did for me at a young age was, as my wiring was setting up, I was exposed to a bunch of different landscapes. And people, too, but much more diversity of landscape is at least what stuck with me. And that led to noticing changes in light and sunsets and terrain at a young age that really deeply informed me, and that later turned into interest into art. But I think at first was the natural world and the world of the senses.

MS. TIPPETT: So I know you've told this story so many times. You grew up, as you say, all over. You went to Princeton, and then in your sophomore year, 3:00 a.m., I believe, you climbed — was it over a subway train?

DR. MILLER: No, it was a commuter train, above ground. In November sophomore year, we were just back from Thanksgiving holiday, and I was away from my friends for four days, and I'd missed them. We had quite a loving group of friends at that stage. And we went out just to hang out. And it wasn't a big night. It was a Monday night. But we decided to go get a sandwich at a place called the Wawa market, which is a New Jersey phenomenon and open 24 hours. And we were walking our way to the Wawa market, which sits on the edge of campus, and in our path is this thing called the Dinky.

The Dinky is a small commuter train that runs from Princeton to Princeton Junction for all the commuters. So it was just sitting there. It was not operating hours. It was just sitting there. We climbed it like you would climb a jungle gym, not at all thinking — it was not feeling like a very daring stunt at all, but I happened to be the first one up. And when I stood up, I had a metal watch on, and the electricity arced to that watch, entered the arm, and blew down and out my feet.

MS. TIPPETT: 11,000 volts, I read?

DR. MILLER: Yeah. [laughs] I giggle because...

MS. TIPPETT: Yeah, I know you're giggling ...

DR. MILLER: ...for a couple of reasons.

MS. TIPPETT: Clearly you have worked your way through this memory.

DR. MILLER: Well, it's 25 years old, and so much has flown from it. So much good has come from that experience it's remarkable. I also don't want to be Pollyannaish about it. That sends the wrong signal. But part of my chuckle is that the thing was called "the Dinky." [laughs] Part of my pride is wrapped around losing three limbs to a thing called the Dinky, but anyway.

MS. TIPPETT: I have to say the particular moment in my life in which I read your story is when I have one child off at college and the other heading off, and even as you're telling this story, I think it would be horrific no matter what, but it's just this innocuous, playful moment. Right?

DR. MILLER: Yeah, yeah.

MS. TIPPETT: After which everything changed. [laughs]

DR. MILLER: Yup.

MS. TIPPETT: Yeah, and 25 years later, you can see so much — that is, it's a change that defines your life in wonderful ways, but very dramatic.

DR. MILLER: Very dramatic, yeah. That is true. But a version, a variation, on a theme that so many of us have. Little, unexpected moments, things we think are innocuous, as you say, which aren't, the surprises of a daily life that aren't always of such dramatic

consequence, but they're happening all the time on various levels. And that's been a way into some curiosity, in a sense, of a little bit of mystery around it. One of the pieces of fallout that I love is this cognizance, this awareness of — I guess "fragility" is the word. It's not really "fragile," it's just that we turn on these dimes all day long, and where they all collectively lead us is just fascinating.

MS. TIPPETT: And then it's so interesting that after you had a period of recovery and returned to Princeton, you studied art history. So tell me about that decision. What went into that?

DR. MILLER: Yeah, it was — like a lot of — there was an intuitive piece of it, for sure. And there was also an overlay of — a very conscious overlay of sitting in the hospital bed, trying to wrap your head around this turn in your life and, to a degree, trying to make sense of it. But mostly just trying to process it at all, and reframe myself or, really, reframe my relationship to the world around me so that I could fit into it.

So I've lost these body parts, but I remember this question: does that make me less of a person? By volume, yeah, but not in any other way. But I didn't really know how to frame it. So a long-winded way of saying, I circled to art as this peculiar thing that humans do as they process their reality, or they make sense of their world, or they affect their world, or just reflect on it. And the hunch was that art was a vehicle. Learning about art would help me learn about perspective and how to see.

MS. TIPPETT: You have such an interesting phrase, "perspective making." Somewhere you said you had this loss of your limbs, you lost both legs below the knee and one arm below the forearm, and you said that you could no more reject this fact than reject your whole being. So it's almost like you also were getting a new sense of the perspective yourself, your body's perspective in space.

DR. MILLER: Yes, totally.

MS. TIPPETT: And the analogy of art is wonderful. I just recently interviewed this anthropologist named Mary Catherine Bateson. Are you aware of her?

DR. MILLER: I'm not.

MS. TIPPETT: She's the daughter of Margaret Mead and Gregory Bateson, and her phrase is "composing a life," which is very — I hear echoes of that with what you're saying. And as you're saying, you had a reconfigured physical self, but you were composing a whole. Right? Your life as a whole, yourself as a whole.

DR. MILLER: Yeah. That language resonates with me. I like that very much, the word "composing," and I like its overlay with music, which has always been important for me. But, yeah, and seeing it as a creative enterprise, as well as an adaptive one, was really very rich, and it was really like an excuse. I wasn't — I was sort of a melancholy child — my internal world was a little bit at odds with my external world, with the way I presented to the world. And I'm sure many of us would say that, but this radical change to my body really, in a way, offered this great excuse to refashion my perspective, refashion and "compose" my sense of self.

MS. TIPPETT: And it's so beautiful, and clearly you lived this, but I have to wonder, what did it take for you to come to that? That must have been a process.

DR. MILLER: It sure was. Yeah, it sure was. I'm sorry to cut you off.

MS. TIPPETT: No, no, I just ...

DR. MILLER: And actually, I really appreciate you mentioning that, because sometimes I hear myself talk, and of course, it's funny how we remember things, and my mind wants to go to the beautiful side, the creative side. And part of it's born of a gratitude, the way life has played out, and I want to acknowledge all the good, but it's almost a disservice in a longer conversation, because it took a lot to get there, and sometimes I hear myself talk when I speak with others who are going through some hardship. And, certainly, the message isn't "Well, just change your perspective. In a couple minutes, you'll see the world different. Everything is great. You know, quit complaining." There is a ton, I mean, buckets of physical pain, and this reworking — as if late adolescence isn't hard enough, and trying to find your way in the world as something of an adult. That's plenty hard. So all that was going on, and it really took years. This was a process that took years, and I would say, of course, is still ongoing.

[music: "Fabrique" by Auditory Canvas]

MS. TIPPETT: I'm Krista Tippett and this is On Being. Today, I'm with Zen Hospice leader B.J. Miller.

MS. TIPPETT: There is a wonderful line — I think you said it in your TED talk. It comes up on the Zen Hospice Project website. "Let death be what takes us, not lack of imagination." Those are your words?

DR. MILLER: They are, yeah.

MS. TIPPETT: It's a stunning, wonderful sentence, so talk about how you how came to that and what that means for you, what that holds for you.

DR. MILLER: Well, it's very much along the lines of what we're talking, that there's a big difference between things that happen to you, that are forces larger than you. I can yield to Mother Nature. I can yield to 11,000 volts. That's a very different prospect than is shutting down your imagination or rolling over altogether or losing yourself altogether. So there is a way, there's a needle to be threaded here of both acknowledging these forces much larger than ourselves and, for me, bowing before them. There is an allegiance, in a way, to these things that are much larger. And at the same time, any sort of proportionality and right-sizing in that math also means — it doesn't mean you're nothing. You may be a speck of sand in time, but a speck of sand is something. You may be a drop in the bucket, but the bucket would be different without your drop in it. So there's a proportionality - a challenge to our sense of proportionality in all this, and I've loved that theme. That word "proportionality" comes up for me a lot, to right-size myself.

MS. TIPPETT: Say some more.

DR. MILLER: We have this capacity as human beings to change ourselves and change things around us. And if you're not careful, that capacity and then expectations that flow from it can run away with you, and all of a sudden you feel like, gosh, if I don't change the world today, I've failed. Or if I don't cure cancer tomorrow, I've failed. Or if I don't beat death. Trying to find enough gumption and wherewithal to respond and to try to do things while not being so overblown in your expectations that you feel bad for not changing something that's unchangeable. And for me, that's a really tricky and dynamic equation

that's changing all the time.

MS. TIPPETT: And that particular form of suffering — let's call it that — that challenge of proportionality is a burden of people who are privileged, in a way, right? To even have that aspiration or that sense handed to you that you have so much that you should be able to change the world or defeat whatever obstacles are put in front of you.

DR. MILLER: It's true. It's so funny. I watch when people try to wrap their head around it when I talk to them. Am I, B.J., the least lucky person in the world or the most lucky person in the world? And I don't know, sometimes I think I'm a little of both, as I'm sure many of us are. Most of us are, to some degree. Depends who you're comparing yourself to, et cetera. For sure, just think about my backdrop. Again, I was not — think about my education and whatever personality threads and through-lines there have been that I've inherited. Much of what we're talking about here, which — and this sense of proportionality and changing anything — it's a very privileged position to be speaking from.

And, I would also add, Krista, I think it's also true — although I want to be careful that I'm not speaking for people whose situations I don't understand — but there's something about just getting through the day. Being a human being, I don't care what your circumstances are. Some of the most miserable people I know are by some measure the luckiest. I think being a human being is just inherently difficult, and so getting through the day is sort of a creative process and a proportional — a process of proportioning yourself. Anyway, there's a lot to say about that, but I don't think it's all about privilege.

MS. TIPPETT: No, I don't, either. I actually think there's a subtler point, which you just got at. You said something really important, I think. You said a minute ago that you were a melancholy child. And I don't think you used the word "relief," but you said you had always — there had been kind of a disconnect for you between your inner life and what you maybe thought you should be in the world, and I think that's true. As you say, that's a human characteristic, and it comes with whatever conditions or circumstances we have. You said that when you had this accident and this trauma and this physical suffering that you finally had some suffering other people could see. I think that's really important, right?

DR. MILLER: Amen. Yeah, I was thinking about that driving over here, actually, Krista. The part of the difference in my experience of being alive has a lot to do with how the world responds to me. And the fact that I have these very obvious disabilities means that people treat me differently, so that's a huge piece of this equation, and a very interesting one, and one that's out of my control. And especially in my role in medicine, I find it's very useful, that my body and its obvious suffering is very useful. It's a means of building trust with people who are also suffering from their body failing in one way or another. So it is interesting to note how much of this transformation we're talking about, A, isn't really much of a transformation, and, B, has to do with people outside of myself more than inside of myself.

MS. TIPPETT: But the transformation that you were compelled to — as much as we all carry whatever our suffering is, and it has infinite variety, we are taught to hide it, and to hold onto it. But what you were compelled to do is let it — is for it to be seen. And that's a huge move. Now you work in hospice, and that's this unavoidable move that people have to make in accepting that they are dying.

DR. MILLER: Yeah. I will — speaking of proportionality, trying to find, for my own sense of

confidence, I often wonder, what can I take credit for? This stuff. And one of those decisions is to come out of the closet, in a way, as a disabled person. And I think about this idea of normalcy a lot. I and many, many others before me have been agents of normalizing disability, and that's really potent. And I also think there's a second half to that equation, that we need - that doesn't mean that we fit these other things into our idea of normal, it means we expand our idea of normal. And I think that life is weird. Life's hard. Life's weird. Humans are weird. And I worry, sometimes, that we exist in such a narrow bandwidth of accepted behaviors and thoughts that we really clip off so much of the strange beauty that can be part of the human experience.

And back to your point, I remember I was about two or three or four years into my odyssey in these shoes, and the norm for lower limb prostheses, the norm was that you put these flesh-colored foam covers over your legs so that they look more natural, and they have the shape of a leg. And I remember studying architecture at Princeton, modern architecture in particular, and about Louis Sullivan and others pulling the appliqué off the buildings and delighting in the structure itself. And that was just such a mind-blower for me. And so I pulled the covers off my legs and started to force myself, and then to genuinely delight in this weird structure that now was my legs. I love these legs. These legs aren't some cheap imitation of what I lost. These are wholly new things. These are different things that deserve their own space and credit. I love them, and I am interested in how they look.

So that was very therapeutic for me, and I will take a little credit for whatever courage that day helped me do that. And, similarly, for my arm, I have a lot of skin grafting on my arm. And I wore a sock over it for years. At first, it was this white medical stocking, and then I got a little creative and started wearing paisley or argyle socks on the arm to have a little bit of style around it. And then, maybe, again, around the same period, maybe five years in, I just pulled the sock off one morning. I didn't feel the need to cover it up anymore, and that was just a spontaneous moment. And, subconsciously, I think I had been working towards that for years. And one day I just didn't need it anymore. Those moments — there was some courage in those moments.

MS. TIPPETT: Wonderful.

DR. MILLER: There was moments of just willing myself out into public view that I remember was very awkward and uncomfortable, but I knew it was a good thing for me to do, and perhaps a good thing for others around me to see.

MS. TIPPETT: I'd love to — I've seen pictures of your prosthetic legs, and this image is becoming — as these things are more out there and available to people, it is becoming part of our imagination about the human body, I think, so interestingly. But I'd love to hear how you would describe your legs. Tell me what you see when you look at your legs, that beauty that you see.

DR. MILLER: Well, there's the beauty of the carbon fiber weave — carbon, our basic, organic substrate. Here it is in these sheets of woven material that are so strong, so light, such a nod to both Mother Nature and to human ingenuity for harnessing it. So we've got this beautiful, black carbon weave. If you buy your sports car, you'll pay extra to have a carbon fiber door or panel. It's an acknowledged aesthetic. So, first, I noticed the color. Then I noticed the sculptural quality of the piece, what's called the socket, and the socket is what goes around my stump, what's left of my fleshy leg. And that is sculpted to my leg, so it is a piece of sculpture. This is where the craft comes in, and it has sculptural qualities to it. It reveals the shape of my stump.

And then, below that, you've got this — I've had various feet over the years. Some of them have these very narrow, skinny little ankles. It's almost a version of what I feel like when I look at a horse — that incredible power, those beautiful thighs on these teeny, tiny little ankles. And it's similar, not quite that dramatic, but it's a little similar with prosthetic feet, because, in a way, we are able to construct things which are stronger than bone and don't need all the support structures. So that's what I see when I look at my legs. The piece that has bummed me out for years now is what's left to chance at the level of the shoe. And shut me up here, Krista, because I could go on on this one for a while.

MS. TIPPETT: No, it's great. I love it. Keep going. [laughs]

DR. MILLER: Well, the shoe — you've got this incredibly engineered, crafted leg that I was just describing, and then at the final moment where that leg is interfacing with the ground, with Mother Earth, with the thing that it's meant to affect, it's left to chance. There is this thing called the "foot shell" which is this pink-colored — very often it'll have these faux toes on it — rubber thing that goes over your prosthetic foot so that it will take on the shape of a, quote-unquote, "normal" foot so that you can wear normal shoes. And as we've been talking, I don't want to pass. Darn it, why this final element is left to this compromised design state has always bothered me greatly. And the fact of it is, really, no one has built shoes for prosthetic feet before. I don't have all those little bones that you guys have. It doesn't need to have that silly shape. It can look totally different. But we haven't gotten there yet.

[music: "Neo" by Ryan Teague]

MS. TIPPETT: You can listen again and share this conversation with B.J. Miller through our website, onbeing.org. I'm Krista Tippett. On Being continues in a moment.

[music: "Neo" by Ryan Teague]

MS. TIPPETT: I'm Krista Tippett, and this is On Being. Today, I'm with B.J. Miller. He's the executive director of the Zen Hospice Project in San Francisco. And the personal passion for design that he takes into his thinking about living and dying and medicine was galvanized by a freak accident while he was a college student in which he lost both of his legs and part of one arm.

MS. TIPPETT: So many of the ways you talk about and seem to think about and just approach what you do, palliative care and hospice, is also completely interwoven with this design sensibility that we've been talking about all the way through, and these aesthetics and the language you use and the images you use. For example, you say, "Our shared mortality is a source of great beauty." What do you mean when you say that?

DR. MILLER: The fact that we have these bookends of birth and death and in between feels like a guitar solo — in between, all sorts of crazy things can happen. But the song begins and the song ends, at least for this bodily life. And the fact that we share, that 100 percent of us across time and space, across cultures, that all of us share that version of fate is compelling to me.

So finding a purchase, a toehold in what we share and all that we share opens me up in a way that I feel — that feels beautiful, that makes me love people more, not less, that makes me more open to people, not less, makes me more open to myself, not less. So it's an observation of what — when I start thinking about this common fate, looking within

myself — what does it do to me? Well, that's what it does to me, and that seems very good.

MS. TIPPETT: Yeah. And “quality of life” is an overused phrase, which is not to say that it doesn't have meaning, but it's an overused phrase. But I feel like when you paraphrase it in this way — you talk about — that hospice is about living fully into our last breath. And the fact that this — hospice and palliative care, which are so new, that hospitals were never designed to do that, to help people live fully into their last breath. I mean, you even pointed out that the word “anesthetic” is literally the opposite of “aesthetic,” that hospitals assault the senses.

DR. MILLER: Yeah.

MS. TIPPETT: You've also talked about time as such an important concept for you. Say something about that.

DR. MILLER: Yeah. Existentialism, being in ...

MS. TIPPETT: Yeah, and it kind of flows out of that.

DR. MILLER: Yeah. Being and Time, right? Heidegger and others have talked about — our relationship to time is foundational for the human experience, and that makes sense to me. Why? Because we have this weird facility to imagine the future and remember the past. And right there, that set us up to have some relationship to the clock. And when we — as conscious human beings, we know we die, and we therefore know our clock ends on, some level. So time just seems foundational. And I think a lot of the gymnastics that we do as human beings has to do with our relationship to the clock, or lack of a relationship to the clock. We squander time until it's too late, et cetera. I love looking at the building blocks, the raw material, the irreducibles. So space and time are two components that I want to feel and I want to work with. And watching the clock is, I think, a big part of my job as a palliative care and hospice doc. That's how I see a big chunk of my job.

MS. TIPPETT: And, somehow, when you are dying, you have no choice, or there's a particular urgency about facing that. But aging is something we're all doing all the time and not necessarily choosing to face it.

DR. MILLER: Yeah.

MS. TIPPETT: You said somewhere you want to think about aging and dying as a process of crescendo through to the end.

DR. MILLER: Yeah. This is where the aspirational, and reconciling the aspirational with the realities on the ground is tricky. And from my love of design and aesthetics, beauty, I have to be very careful that we don't set ourselves up for yet another thing to fail at. So it's tricky, but what I want to do — and it's partly that comment about I don't want to die of a lack of imagination — I don't want to have our systems predetermined that we fade out. I don't want to have our systems designed and predetermined that I peak in my life when I'm most productive.

So when there's ever a moment to design the context, to create the construct, I want to make sure we take that very, very seriously, and don't accidentally predetermine misery that doesn't necessarily need to be there. So that's really what I'm calling for. We can't all experience aging and dying as a crescendo, but if we make space for that possibility, then

it's much more likely to happen. And I do think from some — as your body ceases to be your best friend, as this painless agent that takes you all over the planet, as your mind may fade, there is always something, whether it's a sense of smell or touch or a thought, there's something living in you until you are dead, and one of the conceptual things — it sounds kind of silly, but I love saying this people, to students — dying people are living.

We talk about “the dying” as though they're some other species over in the corner. We are the dying, and seeing ourselves in that mix is very fruitful in a number of ways, but it also allows us to see dying as a part of living. And therefore, we can design that as an experience. For me, it gets very interesting to define death. What is death to me? There is a legal definition of that. I cease to have any cardiovascular function, and my brain no longer talks to my body, or whatever. There are clinical ways so that my doctor and my lawyer can pronounce me dead, but when am I — for my own purposes, when am I dead? When am I really done with this life? I don't know. We'll see as I get closer to it, but from where I sit, at this point I'm very clear — when I can no longer sense anything, whenever I can no longer take in the world around me in any way, then I'm dead.

And that brings me back to this life of the senses and the immediacy of the senses. And the one thing I know is that the body dies. This body dies, and this body is just a big sack of sensors. So that's the big loop for you right there.

MS. TIPPETT: We've talked about this all the way through the conversation, about the matter of disability. And I just want to read something you wrote, because I feel like this is very fluid, also — how we are thinking about disability, what we're calling it. And in your lifetime, in our lifetime, this has been very fluid. You wrote, “Back in 1990, I was treated as a Frankenstein figure or a Christ figure, and it was ridiculous at either extreme. Sometimes I got congratulated for going to the bathroom. Then somewhere along the way, amputees seemed to bust out and a handful went out and did extraordinary things, competing in Ironman triathlons, and the expectations changed. If I didn't climb Mount Everest, I had failed.”

DR. MILLER: Yeah, I still own those words very much.

MS. TIPPETT: And again, I'm thinking about the aesthetic. Sometimes, when people write about you, they use the language of — they describe you as a “triple amputee,” which is technically true, but to me, it's just such — it doesn't really describe you. It's very antiseptic language. So I'm curious about how you think about even the language of disability, but also how we're working with that and struggling with it.

DR. MILLER: This is where — really, disability and chronic illness was my way into hospice and palliative care, much more than death, per se, by the way. But disability, it points us — a big theme for me back as an undergraduate and my senior thesis, a subcurrent was my frustration with language. That words can point to things. I know words have their own life as well, but I still struggle with how much potency words have.

MS. TIPPETT: Like what are words that you struggle with?

DR. MILLER: Well, just the whole — well, let's just start with you asked about disability. I mean, I'm OK with it, but what was not discussed is, compared to what? What's the frame of reference? What's the “dis-”? That's implied. We can step back and discuss it, and I love when people do, but otherwise you just accept on face, “disability,” that you are less, that it's something pathological happening. But compared to what? So this relativism of language and the idea of words as signposts, as imperfect reproductions of the reality

they're trying to point to, I just want that to be acknowledged whenever I'm in a serious conversation, that words are the best we have, but they're so flawed. I just need that to be acknowledged somewhere.

MS. TIPPETT: I mean, it's kind of back to that idea that we're all carrying around whatever our forms of suffering and struggle are, and some of them show on the outside. And those we call "disability" ...

DR. MILLER: Right. Again, "wounded healer," "disabled." If everyone considered themselves disabled, I'm all for it. Same thing. I remember when I would go — I haven't done this in years, but I would go to — people would invite me to come speak to their classroom, schools, often high schools, or when kids would approach me in a park or something and say, in, invariably, the same way, "Hey, don't you miss having two hands?" Some version of that question would come up, or "two feet?" or whatever. And I would say, "Well, sure. Yes, I do. I really miss having two hands." Oh boy, do I miss having two hands. I mean what a treat. You can keep the feet, but I would love — I mean, hands are remarkable.

But I would say to these kids, "Yeah. Well, don't you miss having three?" They're like, what? They just look at me kind of funny. And I don't know how many of them ever — I don't know if that retort ever did any good for any child, but the point was, this is my reality. Having one hand is my complete and total reality. It's not a half a reality, and I don't see too many two-handers ruing the fact that they don't have three hands. And, yet, it's basically the same relationship to something you can't control.

[music: "City of Lights" by Languis]

MS. TIPPETT: I'm Krista Tippett and this is On Being. Today, with B.J. Miller of San Francisco's Zen Hospice Project.

MS. TIPPETT: You've talked about love and joy and great hope as experiences of dying when it's done well. And I wonder how you would — what does great hope mean at the end of life, as you've experienced hope at the end of life?

DR. MILLER: Hope is such a funny thing. It's such a squirrely thing. We can do damage with hope, too. It's a powerful thing. A lot of the data around why some physicians don't share the full truth of a prognosis with their patients — and, invariably, you'll hear some version of, "Well, because I don't want to take away their hope." And they know that hope is what gets them out of bed in the morning, and wills them to try the next therapy, or whatever it is. Hope is very potent thing. But in my training in palliative care, I learned, whenever I hear that word, whenever I hear the phrase "I hope for," I'm trained now to ask, to inquire, "Hope for what?" And that, too, is a relative phenomenon that needs to be contextualized, and is much more fluid and malleable than we in healthcare often give it credit for, or we humans give it credit for. It seems to be like a monolith. Either you have hope, or you don't.

The truth is, we can change what we hope for. And you watch in palliative care, for example, and hospice, that sort of medicine is done well when these informed, skilled conversations play out. You'll hear providers work with the person's hope but redirect it. So when I ask someone who is facing the end of their life, if I'm trying to help them understand that time is short, I will talk about what they hope for in their life. And if I hear them say, "Well, I hope to live another 30 years," but I know they've got three weeks, there is a big red flag for me to say, "You know what, man? What if that doesn't happen?"

Then what might you hope for? If time is shorter than that, what's at the essence of your hope?" And invariably — well, not invariably, but very often you can get folks to a place where they say, "Well, gosh, given that reality, what I really hope for is to get to my daughter's graduation." And then I say, "OK, well, there's a goal we can work with." And if someone says to me, "Well, I hope to live forever," then I call that a miracle, and I say "Well, let's hope for miracles together." It's just — there is a lot to say about this word, "hope." It's something that there is a lot to work with there.

But back to answer your question, when time is short, when people are facing the end of life, it's not necessarily a hopeless endeavor. They may hope to have one more piece of pizza, or they may hope to see that last episode of a show they love. But it can be realistic, and it can pull people along so that they are actually able to play themselves all the way out. And that's that "living until your final breath" thing.

MS. TIPPETT: It's interesting to me. You work with death as this normal thing, this practical reality, something we're all — we're all dying, right? That's another reason that the physician is a patient, too, right? We're all dying.

DR. MILLER: Yeah, exactly. Yes.

MS. TIPPETT: But you seem to hold it together with this enduring kind of reverence, or honoring the mystery of death itself. Do you feel like you understand or that you reckon differently with death as part of your life, differently because of this life you've been leading? Is it less of a mystery?

DR. MILLER: It's a great question. There is a history in my field of some spectacularly difficult deaths of people who worked in hospice. I think the admonition to us — "us" meaning those of us who work in this field, whether volunteer or physician or nurse or whatever — is that you don't seduce yourself into thinking that you know death, that you understand, oh, I've got it now. I've been through — I've been around this block a million times with folks. I got it. So when it's my time, I'm going to be fine. That is really dangerous. That's like jinxing yourself. Some of this is knowable, and, for example, teasing out dying and the implied suffering. Dying is different from death, and teasing — most of us are afraid of dying because it implies suffering. And when you get down to it, that's what most people are worried about.

MS. TIPPETT: The dying rather than the death of the being.

DR. MILLER: Yeah. So there is a lot I have learned that will help me suffer less, that can help me help others suffer less in that dying process. But I do not pretend to know or understand death per se. And part of what I do, the reverence that you point to is, again, back to this mystery, this thing that I don't understand that's much larger than myself, and that — what happens after I die? I don't know. And, boy, isn't that interesting? So part of my work, and, I think, when we talk to students, is, yeah, familiarize yourself with the concept of death, and certainly with the concept of dying, but don't seduce yourself into thinking that you totally know it. Because, otherwise, you're going to find yourself standing at your horizon one day, and you're going to be really, extra shocked to learn that you're terrified when you just assumed you wouldn't be. So it's easy, just make a little bit of space.

MS. TIPPETT: That's the mystery to it. Yeah.

DR. MILLER: That's the mystery, too. Right. You've just got to protect a little bit of space

for all that you don't know.

MS. TIPPETT: So you know, my last question, you've had an extraordinary life. A lot has happened to you. You've taken a lot, and you have this great accident early in your life, the kind of redesign of your life, and the career you've had and, now, working with people. And in some ways, you could talk about — what you do is help people design, compose their dying, the end of their lives. This is a huge question, but how would you start to think about what all of this is teaching you about what it means to be human? And I think that another way to ask that is how you carry all of this into the way you spend your days, your life.

DR. MILLER: Yeah. It's a hot question, and it's an ever-present one. It's interesting. I'm 44, and I look back and, by most measures, I have had a pretty extraordinary life. And at the same time, one of the most adaptive skills I picked up over the years is really — when you all of a sudden become a triple amputee or anything like that, you're sent a bunch of signals that you're different, now, from people around you. And if you stop there, you can really hurt yourself. And you get treated specially, and that has its own seduction, too, and pity. And you can get stuff from pity, and it's really one of the great graveyards in traversing all this for me. If I were to really yield to this idea that, "Oh yeah, I'm different than those around me," and just leave it at that, I would have just inserted a wedge between myself and everyone around me that ultimately would not serve me.

We are social creatures, and one of the most important things I've ever done was to hit on this idea of seeing variations on themes. So, sure, my body is different in a lot of ways. In a lot of ways, my life is different. But ultimately, I see them as variations on themes, and that allows me to acknowledge what's relatively unique in my life, but also to see myself as just like anybody else in a very truthful and real way, not just made up. So that's part of my answer to your question. But this idea — I struggle with this. I'm a very busy person, like so many of us. Stupidly busy. Here I have — from my own experiences, but I have what I call all these vicarious deathbed experiences all the time. I'm around people who are dying. And I, of all people, know that time is precious. Don't squander it doing things you don't care about. Don't give it away too cheaply, blah, blah, blah. Spend less time at work, more time with family, whatever it may be, you know. [laughs] I have no excuse to forget that. Zip. And, yet, I find myself incredibly and increasingly busy, sometimes out on limbs doing things that I don't necessarily want to do or even believe in, on some level. And there is some real moral distress in that.

I think that is part of how we burn out, is you have these lessons, but we find ourselves still unable to actualize some of these lessons. So it's a hot question for me right now, Krista. I've got to figure out — I've got to constantly retool myself and rejigger how I spend my time. I'm aware that I have too many friendships that have gone fallow. I'm aware that I spend too little time with my parents, and there are other examples. So I've got to reportion myself again.

MS. TIPPETT: But you know, what you're just describing, I mean, you have a consciousness about, what did you say, that we know what we want and, actually, what we should do, and what would be good for us, and we have trouble aligning reality with that. I mean, that is the human condition. That's the nub of it. You're working with that.

DR. MILLER: I am working with that. But you're also pointing to — as I get frustrated with how I'm spending my time, sometimes, or not spending my time, not treating it with the preciousness I know it deserves ...

MS. TIPPETT: Not designing your time.

DR. MILLER: Yeah. That's right. And, ultimately, I'm landing back, and this is where it is. And this is a creative pursuit, one that takes — sails which need trimming all the time. And seeing this as a creative work that is never done is great, is beautiful, and I'd like to land there. It's probably a good stopping point. And so all that we just described, even if I can't honor every minute of every day in this most precious way, well, ultimately, it's just another thing I get to forgive in myself and to keep trying tomorrow.

[music: "Broken Monitors" by Bernhard Fleischmann]

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[music: "L'Espionnage Pomme de Terre" by Turatara]

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