

Life As It Is

“A Safe Place to Fall Apart”

Episode #36 with BJ Miller

October 16, 2024



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BJ Miller: I think there's a lot of life to be gained from addressing death. And so, one of those things might be the sort of the truth of interdependence and the fact of how we need each other and to normalize that and sort of upend this notion of being a burden in the world, etc. So I think that is a very life-giving truth. And inherently it also, besides just sort of forcing a collaborative spirit among us, it helps right-size me. And so in this world where you're trying to always achieve more, be bigger or something like that, it's great news. It's a relief that I'm somehow not expected to figure it all out by myself. And I wouldn't have felt any of that poignancy if I hadn't come close to death or worked with others who, are, and so just empirically it's not even a faith, I get to see how that sort of can wake us up, right-size us, keep life in perspective, and also touch us into all the crazy stuff about this existence that we can't explain, don't understand, but get to know somehow, nonetheless and find our way to loving it, finding our way to loving life, even as we're losing it. What a juicy creative enterprise that is. And I think we've got death to thank for all of that.

James Shaheen: Hello, I'm James Shaheen, and this is *Life As It Is*. I'm here with my co-host Sharon Salzberg, and you just heard BJ Miller. BJ is a thought leader in the area of serious illness and end-of-life care. He has worked as a palliative care physician for two decades, and he recently cofounded Mettle Health, a multidisciplinary group providing support for people confronting illness, disability, and death. BJ first turned to medicine after a near-death experience at the age of 19 left him a triple amputee and transformed his relationship to pain and suffering. In our conversation with BJ, we talk about his own recovery process and how he's come to view recovery as a creative act, how studying art history and architecture radically shifted how he thinks about disability, what he's learned from Buddhist approaches to death and dying, and how working with dying patients has changed the way he lives his own life. So here's our conversation with BJ Miller.

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James Shaheen: So I'm here with physician BJ Miller and my co-host Sharon Salzberg. Hi, BJ. Hi, Sharon. It's great to be with you both.

BJ Miller: Thank you, James. It's great to be here. Hello, Sharon.

Sharon Salzberg: Hi.

James Shaheen: So, BJ, we're here today to talk about your work transforming how we think about serious illness and end of life care, but first, I'd like to ask you about your own story. So could you tell us a bit about your own background and what it was that drew you to working in medicine?

BJ Miller: Yeah, oftentimes I start with injuries I had when I was 19, a sophomore in college, that was my own near-death journey and made me a patient. And that's where I kind of got tuned in and turned on to healthcare, both all the incredible things it can do, like save my life, and also a lot of things it doesn't do so well, and how do we continue to refine or push this system to serve us better? So in some ways that's where a lot of this began, but really, James, it began really earlier. I was not headed for medicine, but I had always, thanks to living in a household with my mother who had post-polio syndrome and has been pretty disabled much of her life and all of my life. In some ways, this odyssey really started there, being with my mom, being around disability and what that kind of confronted me with. So in some ways, that's where things began.

James Shaheen: Well, you say that after your own injury, you came to regard death and suffering as normal, part of the package deal of being human, in other words. So can you say more about this realization? How did it shape the trajectory of your own life and career?

BJ Miller: As a young boy, trying to make sense of loving my mother and being with her and watching how the world treated her was very eye-opening, very disturbing sometimes, very

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eye-opening. It put in me a lot of sort of basic questions around who gets to be this sort of standard bearer of normalcy? What constitutes a good life, a normal life? As far as I could tell, a good life, a normal life included loss and included things that don't necessarily go your way. And so in some ways, just in the evidence, empirically, just being with my family, gave me a really great counterpoint to what I was otherwise absorbing in daily life, and so I was really well armed in a way to head into my own journey of quote unquote disability. And you know, right out of the chutes, I knew enough that becoming disabled didn't mean my life was over, didn't make me less of a person, et cetera. So I knew that in my bones thanks to my family, thanks to my mom. But of course, I had to test that theory and feel weird and feel the eyes of the world on me and the projections that go with it.

But pretty quickly, back to your question, James, you know, in my own experience, I could just watch how you could play with your frame of reference. Was I less of a person because I had fewer body parts? No. Was I a very unlucky person to lose three limbs, or was I a very lucky person to be alive and have this one right arm that I love so much? I could play with a perspective around framing, and I could play with my sense of reality and see in some frames I fit, I belonged, and in some frames I didn't. So it allowed me to take on this creative enterprise of playing with how I see myself in the world.

That quickly cracked things open. I went back to college and I majored in art history, and that allowed me to dig into what is this thing that humans do with their experience? How do we play with our reality? All the things that were considered disabling or limitations now became fodder for creative work. And I still do this every day. Sometimes I miss having two hands, for example, but I love to look around at different critters on this planet, and I love to think, if I were just born into this body and I just had this one hand, would I be sitting around thinking, “Gosh, if only I had two hands,” or “If only I had three hands”? It's a visceral way for me to get clear on whatever I have, there's enough, and I would be thrilled to have what I have if it weren't for the contrast that I feel when I look around and see others with more limbs. That taught me a lot

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about how to be playful with this. So anyway, there's something of a rambling answer to your question, James.

James Shaheen: That's great. Thank you. Sharon?

Sharon Salzberg: So BJ, you've talked about the challenges you faced in reentering everyday life after your own time in the hospital, and I'm wondering how you work to reconcile those vastly different worlds, almost like different cultures in a way.

BJ Miller: Yeah, well, it's a great question. It's one I deal with every day. I have a real love/hate relationship, you could say, with healthcare. I'm so grateful that it saved my life and so depressed at how often it causes unnecessary suffering.

For one, I got clear on that this was a system, and like any model, it's incomplete. So on some level, seeing it as an invention, as a made-up thing, helped me make sense of its shortcomings and also helped me be engaged around how we might change it, how we might push it, that it's a malleable thing. If it's made up, well, we can make up something else.

So one was just to get clear that this was not an act of the gods but an act of human beings trying to find their way and with some limited lines of sight. So that helps me stay in the building. Otherwise, I can get so pissed off at healthcare that I just want to run away from it and demonize it. But I know that that's not quite fair. And I know that would cause other problems.

So one answer to your question, Sharon, is that that helps me stay in the ballpark. This is a made-up ballpark. Let's keep working on it.

And then for two, it also helped me in becoming a source of compassion. I could look around and see very smart people who helped me survive and also be aware that they don't necessarily know everything either. It helped me not overly vilify or overly laud folks as being superhuman. It helped me get really into what it means to be a human being, and human beings make all sorts

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of mistakes and shortcomings. That doesn't mean I hate them. So it allowed me to think also, hey, there's something here that from my experience, I get to own. My doctors know all sorts of things about my molecules, but I know about my molecules. I know what it feels like to have these molecules. So the jumping off point of healthcare gave me someplace to pick up, and in some ways offered a space for me to play.

Sharon Salzberg: That's so interesting, and I want to go back to what you're talking about with art history and using that system or that way of seeing the world as one way of processing your injuries. I'm wondering about how art history transformed your relationship to notions of disability. How did you come to view recovery as a creative act?

BJ Miller: Well, I remember when I went back to college, I just had a hunch in talking to a very dear friend of mine who studied the arts and philosophy. When I was sitting in the hospital, we would spend a lot of time talking, and I was sitting there with questions around identity and who I was now and how to think of myself in the world.

Two things. One was I became intensely aware of the sort of primacy of the aesthetic experience, that here I was, this body was being challenged to continue to live, and so it made me ask questions like what is a body? Why do I want to have a body? This body causes me pain, this body does all sorts of other things, but why do I want to have a body? Well, the body gets to feel things. I got to get very clear about just the poignancy of feeling things, even pain. And that was very therapeutic. I could almost get not excited to feel pain but on some level excited to feel anything, including pain. It was a reintroduction to my body and a provocation to get clear on why do I love having a body? And so much of the answer to that question is in the aesthetic plane, the felt sense. That got me interested again in my body not just as a source of letdown or something.

Then I went back to college, and I was sampling some art history classes. I remember we were looking at statues from antiquity, and so you have these old statues that are missing an arm or a

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leg, and I was sitting there in this dark room looking at the statues like, “Wow, that's an amputee,” and here the whole class was oohing and aahing how beautiful it was. No one was sitting there saying, “Gosh, this thing would be so beautiful if only it had four limbs.” So just more proof around the context piece and the playfulness that came from that. That made me feel like, Oh, there's a creative juice in here for me if I choose to see it.

I used to have covers that I'd put over my legs that were flesh colored and kept the shape of a leg to fool people into thinking you still had legs, essentially, and I remember after a modern architecture class, I came home and took those covers off, and it was totally liberating. What I used to be embarrassed of or ashamed of now was something I was delighting in. It was a difference that was cool, that I could get into. And I started decorating myself differently in some ways.

So that was another big leap for me that came right out of the arts. Ultimately, it was the big realization that in this life, there's so much we can't change, but the power seems to be in our perspective. We can change how we see things, which then in turn changes things in a sense. And that became really crystal and clear to me. So I graduated armed with that kind of knowing that what had felt like a disability, as a less than, as something that was just pure loss, now I could see it as real way to something that I was gaining a creative edge or a spark to get me to keep revisiting myself in the world and not take it for granted. So that's something of this evolution for me that the arts really helped me with.

And then lastly to say, as I got clear on that, as I started thinking about aesthetics outside of the museum and gallery space, just everyday aesthetics, I started realizing that I had never given myself credit for being a creative person. When you start thinking about it, everyday life is filled with improvisation. You don't know where things are going. You've got to improv all day long. We're making stuff up all day long. And so that was another final piece that allowed me to take on the mantle of a creative person, as any human being, I think, is to get through your day. You

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can see it as a creative enterprise: playful, delightful, consequential. So anyway, there you go.

That's my fuller answer.

Sharon Salzberg: I want to talk a little bit more about shame, the opposite of being creative and playful and full of delight. So you've talked about the shame that comes with disability in response to both physical changes to the body and the challenges of accepting help. So can you say something more about what you've learned from working with shame?

BJ Miller: Yeah, boy, you know, I think of it like dirty fuel, guilt and shame. These can lever things out of us. They can be powerful forces and have a lot to say about behavior, sculpting behavior. More recently, I got tuned in to the notion of shame as really being a very destructive force. But like so many things, nothing is all good or all bad. I think there has been a utility to shame too in a social sense. But for the most part, I want to be careful to not overly demonize anything that is in our experience, including shame, but it's more, I think, to keep it in its place and to question it, essentially. So I'm moving away from being anti-shame. I'm trying to move to be anti-nothing. I don't want to be anti anything if I can help it, essentially. So I'm trying to keep shame in its place. I use it. I feel it when it comes on, but I've also experienced it now by force. Being a disabled person, just to leave your house can feel like a daring act because of the projections you get, because of the projected shame. And so having so much of a volume of that stuff coming at me really forced me to deal with it in some ways. At first, I was bowled over by it. I was really taking the bait. I was embarrassed. I covered my skin. But that was really what I felt. Those were real feelings, projected or otherwise. I was ashamed. But I finally came to realize that as powerful as a sculptor of my behavior shame could be, it didn't need to be so painful. I didn't need such a blunt instrument. I still use it on occasion, but for the most part, I feel like shame is now in its place.

Sharon Salzberg: I'm so interested in this idea of how difficult it can be to accept help. You know, I certainly know many people, I think we all do, who are like the givers in life. They take care of other people, they try to help out, they try to make this a better world. And it is so

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difficult in return to actually receive. So rather than there being a kind of balance, which is probably what we need, both being able to offer and give and also to receive, so many of us are tied to this myth of the independent individual. I'm wondering if you can talk about accepting help and how narratives of individualism might actually contribute to our suffering.

BJ Miller: Yes. That's a biggie. The myth of independence is one of the great lessons that can come with disability because you might say, “Hey, we're all connected. We all need each other. There's interdependence.” I certainly believe that. But I often hear people say things like that where it doesn't feel like it's really tethered to experience.

Becoming disabled, needing so much help in those early days, it was powerful for me, Sharon. It was overwhelming. I needed a lot of help. There were no two ways about it. There was no choosing it. And in some ways that was a great gift that this was such a powerful cosmic spanking that I had no choice but to learn some things. If it had stayed in the realm of recreational or theoretical or just interesting, I wouldn't have learned the lessons. But so, forcing myself, with circumstances forcing me to take things in, to receive care, was humbling. Sometimes I felt ashamed, but ultimately, thanks to the spirit of people who were helping me, the beautiful spirit that people brought to the bedside with me, I remember one day my nurses had let me know somehow—it can be a very passive experience being a patient. You just sort of receive care in some way. You just don't move. That's what your job is. But some nurses let me know that they had learned a lot from my experience, that they had quote unquote taken something from my experience. And I saw how therapeutic that was for me to think that I in this wretched state had something to give. So in other words, I learned that even if you want to be in healthcare and your job is to give, to do that very, very well, you also need to receive. That's sort of the sweetening on the top. That's mandatory as far as I can see it. And the pathological altruism of the typical healthcare medical model is deeply problematic, and we just know empirically it doesn't work. People burn out. Doctors where the badge of honor is “I have no friends, I have no family, I haven't left the hospital in days”—we see how that doesn't work. And remembering my

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time as a patient when I was taking so much and finally got to give something and how therapeutic that was for me, I think of that daily as how it opens up my eyes and reminds me of this reciprocity that needs to happen.

I mean, I just said all those words. But it's weirdly hard. I think developmentally, whatever reasons, nature, nurture. I don't know why it is so hard, but developmentally, I'm pretty clear for myself that before I die, one of the things I hope to get better at is taking in love, receiving the stuff. I still really struggle. I don't know why. I wonder if you guys have a sense of why it's so hard.

Sharon Salzberg: You know it's such an incredibly powerful conditioning for so many people. And it does translate. The real carers, those people who do take joy out of contributing out of, trying to ease pain, you know. The tremendous irony is that it works so much better when it can flow both ways. As you say, we don't burn out when we're fed this resource. It's something that is nourishing us so that we can continue to give, and yet it seems so selfish or wrong. And so it's great work actually learning how to relax those barriers.

James Shaheen: Well, receiving help can always be, you know, at least speaking for myself, from time to time, difficulty in receiving help may have to do with a lack of humility sometimes that I actually need help. And you're talking about being in a situation where there was no question you couldn't even conceal that you needed help, so that must have been a very interesting experience. But there have been times in my life when I have not been able to conceal needing help, and I had, like you, to learn to simply receive it, and that humility developed out of some sort of necessity. It's very interesting.

BJ, you've said that you've come to think about suffering as a gap inside oneself, as you put it, a wedge between the reality one has and the reality one wishes for. You touched on that a little bit earlier. Can you tell us something more about that definition?

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BJ Miller: Yeah, I like it because it's not super loaded language. I like that it's something in terms of interior experience, whatever its source. I also like that definition because it gives us two basic responses: one in the sort of contemplative tradition where you can narrow that gap by quitting wishing for what you don't have. You can put in your line of sight and take on the notion of desire, you might say, or you can change your reality to bring those edges closer together. And I like those two responses. I feel myself doing a little of both, maybe a little bit like the serenity prayer, essentially exercising some sense of control or agency where I can, but developing the wisdom to know where I can't and what needs just plain old beautiful acceptance. I just watch myself devote my life to neither of those poles but some interplay between the two. So the reason I like that definition is because it primes a response in me, and I also like the definition because it describes the feeling, this weird gap in myself. There's some gap between me and my reality, something where I'm held separate from my reality in some way. And that is how that actually feels to me.

James Shaheen: Yeah, it's an interesting balance between acceptance and action. What am I able to do, and what must I simply accept? And I have to admit, I'm not great at that. I don't know many people who are. But you remind me in a sense when you were talking earlier about the medical establishment of somebody we also interviewed, Sunita Puri. I don't know if you know her.

BJ Miller: Yes, very well.

James Shaheen: I imagined you would. But like you, she recognizes how the medical establishment can contribute to suffering, which is paradoxical for a field that is intended to alleviate it or to treat it. So what are some of the ways you see this play out?

BJ Miller: Well, there's a design flaw in the medical model right out of the chutes. I mean, you are intervening. There's a conceit that we human beings are, A, separate from nature and therefore, B, have some ability to control it where externally, we can intervene in nature. Perhaps

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there's a lot of seductive truth in that. And also I think if the stated goal is beating death, if the stated goal is to stomp out disease, which it is in healthcare, these are stated goals, talking about hubris, right out of the chutes, the conceit is you are at odds with your reality, so therefore you can be at war with it. So there's an inborn design flaw, and I also see the limitations of what can be fixed. So as a disabled person with chronic illness, I see how these get short shrift within medicine because why? Because we're not fixable. And that's not as interesting to the medical model. So you see this play out in this sort of second-class citizenry if you have something that's not fixable. And that's a real problem because, as we know, it doesn't take too much power of observation to see that illness and death remain unavoidable. We can talk about how much those forces give us, too, but let's just say for this conversation, they seem to be unavoidable, so it seems like, well, I think we've picked the wrong enemy here. Do we need an enemy at all? So these are questions that are worth asking healthcare, and I've never been impressed with their answers, and I just feel that as a patient, as a disabled person, and I certainly felt that as a palliative care physician, which is something of an orphan within healthcare because of its devotion to the subjective experience, because it takes on faith that we're going to die. It's not at war with death, et cetera. I have felt my experience of working that system. I have felt the type of leprosy that goes with it.

Ad break-in: Coming up, BJ talks about his time working as the executive director of Zen Hospice Project, how language can shape people's experience of illness, and how in his current role he aims to provide people with a safe place to fall apart.

Ad break-out: Now, let's get back to our conversation with BJ Miller.

James Shaheen: You know, you were the executive director of Zen Hospice Project, and I guess given all you said, it might sound like an obvious question, but what drew you to that work and to Zen Hospice in particular?

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BJ Miller: You know, it started in the 1980s in response to the AIDS crisis. I was in medical school in San Francisco in the late 1990s and was made aware of the work that Zen Hospice was doing and Frank Osseskeski. I had just dabbled in studying or reading about Buddhism a little bit, enough to be interested. I was not a student per se, but I knew enough to be interested and also knew enough to see how the medical model was going to fall short on the planes that I cared about. So I had enough suspicion of the medical model and the course I was on, enough intrigue in Buddhism per se, but the two variables that really drove me to take on that job were, one was a spiritual approach to care, or you might say a humanistic approach to care, something other than medical science as the basis of care, and two, that it had a brick and mortar, that had a physical place. I am particularly interested to see what can be done in the environment of care. I think the aesthetic domain is undertapped as a therapeutic modality, and I experienced that in the sweet little guest house on Victorian in San Francisco, which is very much not a nursing home, very much not a hospital, and I got to see how it worked its magic just by people walking through the door, never mind the kindness with which they were met. So those two things, the spiritual basis of care and the design of the place, were what really drew me.

James Shaheen: So you do not consider yourself a Zen practitioner, yet you learned a lot from Buddhist approaches to suffering and death. So what did working at Zen Hospice Project teach you about our relationship to suffering?

BJ Miller: You know, I find a lot of what I've learned from true Buddhist students, and from Zen specifically. There was a lot about the Zen aesthetic that I really admired. A lot of what I've learned I find inarguable. I don't consider myself a Buddhist per se, because I don't have a practice and I am not following a structured course, so I just want to be respectful of those who are. In some ways, I would imagine that in terms of how I try to live my life, it probably qualifies as something like a Buddhist approach. I just want to be respectful of people who have a true practice.

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But anyway, back to the question about what I learned about suffering. Well, one is just further clarity around the suffering we can't avoid, and that's our job is to accept that and work with that, but some of the stuff we are just creating. And so this distinction between unnecessary suffering and gratuitous suffering, pick the words you like, but something like that. I've always shied away from when folks say that pain is essential and suffering is voluntary or something pointing to that ultimately, we don't have to suffer essentially. Well, yeah, maybe one could get to a place where suffering per se is released. I think that a statement like that can be a brutal one for someone to hear who's in the throes of suffering. To say to such a person, “Well, hey, suffering, you don't need that, that doesn't exist.” That's a little rough. So that's why I really appreciate the truth of suffering in this, as made up as it may be. It's an invention that we are all asked to dance with. So I feel it's therapeutic to name the stuff you can't avoid and to try to call attention to the things that you're actually creating. And once my lens got sharpened along those distinctions, I saw for myself and a lot of the patients we cared for in Zen Hospice and a lot of the volunteers who came to learn there, it became increasingly clear how attached we were to our own miseries, how much I protected my misery and I promoted my suffering. It became a currency sometimes. It got me in the doors, and it was my credibility with others. I'd suffered a lot, so therefore people listened to me. I was just watching the myriad ways we actually use the stuff. So that just became fascinating. It deepened my line of sight, or it opened my eyes a little further and gave me a little bit of a lattice work to proceed a little differently than I had inherited in the medical world.

James Shaheen: You said something earlier in this interview, and I guess you do have a certain amount of credit when you say you were grateful to feel anything, even the pain if that's what it had to be. I was stunned by that, even though I've heard things like this before coming from someone in the situation you were in in the hospital. It's pretty impressive. So like you, I do believe that somewhere in here, there is that potential for freedom even within that suffering. But you say that the more you were around death, and I really like this, the more mundane it became.

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So what do you mean by that? You say that you wanted to depathologize death, which is a little bit resonant with what you said earlier.

BJ Miller: Yeah, it just became everywhere, especially when I liberated death from just the technical cessation of cardiovascular function and the ceasing of brain waves. That’s the medical definition of death. As I liberated it to the metaphorical and the world of loss, then death really became everywhere. Death is everywhere. You know, we're losing things all the time while we're gaining things. You look outside, look at the bugs on your windshield, a leaf falling, the loss of identity, the loss of relationships—those are all liberalizing notions of death.

You start seeing it everywhere, and in this way it becomes almost by definition mundane or quotidian. It is just literally all over the place, in us and around us. I mean, that just became increasingly obvious. And then there was also the experience of being in a place like the guest house at Zen Hospice, conditioned to be in this zone that so many people try to avoid. Zen Hospice proactively structured, opened, and made a place for this orphan of death, and I was just watching how by virtue of normalizing it as an organization, people were dying, people were laughing. The circus was just obvious, and being around people who were interested in the subject versus terrified of it or at least interested in addressing their fears. There was plenty of fear still. Just watching how we all felt, like, “Oh, Maury died this morning, and, oh, Jane wants a cigarette.” Just the sweet buffet of life. Once it's through the distortions of our fears and everything else, just sort of laid out calmly and easily, there wasn't some huge distinction between these very vaunted places and these very low places. It was just an undistorted or a less distorted buffet.

James Shaheen: I think we may have to call this episode the sweet buffet of life. But-

BJ Miller: Sounds delicious!

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James Shaheen: You've also said that one of the things you remember most from Zen Hospice Project was the smells. So what did you learn from staying with the smells of death?

BJ Miller: Well, for one, the kitchen in Zen hospice was a magical place, and a lot of hospice facilities would say the same. There's a primacy to food, especially saying goodbye to the body, but one of the things the body has been able to do is take in food and enjoy it, and so it had this symbolic piece for people who couldn't eat anymore. They still might enjoy the smell or the symbolism of it for one. So one way or another, I just watched the magic of the smells coming out of the kitchen waft through the house, and you didn't need any words; you just saw what it did to your own mood to smell cookies or bread or whatever else. I just got to experience how much that could change the vibe in the place, even this house of pain. So I got to see that, and then of course, just as it did with pain, that kind of allowed me to go, “Oh, smell is powerful. That smell is interesting. Oh, wow. I'm so glad to have smell. Oh, that smells like shit. Oh, gross. Oh, but I can smell it. Oh, cool, I have a nose, and it still works,” you know, watching myself evaluate, is this good? Is this bad? Is this positive? Is this negative?

Eventually I let that go. I just got this fantastic thing out of the way and overwhelmed that system and I dropped the adjectives, and it just smells, and then it's just, how cool that I get to smell things as a way of engaging and literally taking in the world. Speaking of taking love in, smell is taking the world into you. And just in this way, it kind of got defanged, this bad versus good, and then I just got to be very simply interested in it. Does that make sense?

James Shaheen: Yeah, maybe you're just quite naturally a Buddhist and don't know it.

BJ Miller: I've been around a lot of you guys, and so I think I've absorbed some things.

James Shaheen: I don't mean to co-opt you. But Sharon?

BJ Miller: No, I'm honored. Jeez Louise.

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Sharon Salzberg: So in our culture, it can be so easy to talk around death, actually I think around suffering of every kind, around psychological or physical suffering or pain, rather than talk about these things. I know I grew up in a family where the word “cancer” was never uttered in a normal tone of voice. It was always whispered, as though it was something really, as we've been talking about, to be ashamed of. It became so obvious when I was teaching, much more recently, of course, in an oncology ward in a hospital teaching the staff. And I found that temptation in me to say cancer, you know, which was ridiculous. So how have you learned to broach these conversations around suffering and death more directly?

BJ Miller: You know, it's one of the fun things about this work, or fun is maybe the wrong word, but we are talking about issues that affect everybody, right? There's this universal sense. And that's just half the equation—it's also incredibly particular and individual, and the experience of it is particular. To just say we all die is just sort of a boring phrase. It doesn't give you much access to the wild variations on themes that happen. So there's this interplay between the universal and individual, the intimate and the infinite. My friend, Michael Murphy, an interesting guy, he's an architect who talks about this intimate and the infinite.

Anyway, you're just feeling these big and small planes interplayed with each other. And so, if you were to study palliative care, one of the things you learn is to go where people are. So rather than trying to have an objective or fixed notion of the way language should work, I still might whisper “cancer” if I know the family I'm talking to has a lot of shame around cancer. I might be very careful to not just bludgeon that concern but respect it and start with a whisper, because what's going to be really therapeutic or important is the relational dynamic between us, not what's in the prescription pad or whatever else. So I quickly dispense with this objective notion of correctness, but in this real time way, this tuning in way, what feels accurate for the person I'm talking to? And that becomes a therapeutic thing, a felt sense you develop over time of doing this work. I'm sure you have access to this in your own work. You feel these things, you try things on, see if it makes a person shift their eye contact or get uncomfortable or change the subject. Well,

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then you know you've bumped into something that might be a growth pain for them or an edge. So I might respect that for the first two or three conversations. And then maybe once we know each other, maybe when trust is there, I might say, “Hey, you know, I found myself whispering the word cancer the other day, but I want to be clear, Mr. Jones, from where I sit, cancer is a very normal thing. Cancer happens, and I'm not ashamed of it. I'm not ashamed to be talking to someone with cancer. What about you?” Something like this. You can align, pull up next to each other, build that alliance, and then you can crack it open and discuss it.

But I guess my point to your question, Sharon, is early on in my training I felt like, “Oh, I'm going to be the guy who says things directly,” and I just watched myself actually cause a lot of pain with that kind of way of being and then develop this much more interesting, real time, nuanced thing, and that, I think, is the craft of so much of this work.

Sharon Salzberg: It's great. So you've also mentioned the power of language, the kind of language that we used to talk about illness, like calling someone a fighter or describing cancer as a battle. I wonder if you can say more about this and how language can shape people's experience of illness.

BJ Miller: God, it's fascinating to me. If I were to go back to college, I think linguistics would be something I might take. I used to get upset at words because they have so much power. We give them so much power. They have so much power that almost upsets me. I almost want to not say anything.

I used to resent words more, but now I'm a little bit more, I don't know, I've just come around to a more playful take on them. One of the reasons I would get upset was we're the ones who say the words, right? I would like to think that you have the feeling, and then you say the word or something like that. But in fact, so often the word leads us down these paths. And so just getting tuned in to that power, I stopped resenting it and instead started to work with it. So that was the prologue of how I got interested in how you can see how much experience would flow from the

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word. So that turned me on to taking the word a little bit more seriously. And that is an ongoing dance. Sometimes we'll name that explicitly with a patient or a family, just a version of the conversation we're having right now, just calling out this notion, like, “Hey, Mr. Jones, when you said this word, I noticed you flinched when you said it. I don't know, is that the right word? Or does that feel right to you?” Oftentimes, it becomes a conversation starter and a way to deepen into the feeling or the thought behind the word. So that's a kind of fun trick to play with.

But also one of the things that all this power of language has taught me was that they're symbols, and we could use them wisely and also keep calling attention to in a very heady field like medicine, with advanced directives, if you say the words of the kind of care you want in the future, maybe you'll get that kind of care, but you've got to say the words. It's part of this reductive force of medicine. As powerful as words are, I love turning attention to the nonverbal part of life too. It helps me understand words and also keep them in their place.

Ad Break

James Shaheen: BJ, you recently co founded Metal Health, which is a multidisciplinary group providing support for patients confronting illness, disability, and death. You describe it as a safe place to fall apart. So can you tell us a little bit about that organization? I like the idea of a safe place to fall apart. I could use one, too.

BJ Miller: I just love that phrase. And again, it's almost normalizing and also getting a little playful with it. This suffering and this feeling disjointed, there's a tough irony in how often we are made to feel alone in these experiences that have the potential to be these connecting forces. The idea of loneliness can be a great connecting force, ironically. You know, I would sit in my clinic room at UCSF, and patient after patient would describe themselves as being lonely, and I'm like, “Well, you have so much in common with the last guy who was in here.” You see the connecting forces with all these otherwise difficult states.

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So Mettle Health, I started with my business partner, a woman named Sonya Dolan. Sonya and I had been working together for maybe eight years now. We were going to start a nonprofit library, a collection of resources to help people not fall down the wormhole of Googling their illness, and just begin a sort of information repository. But then the pandemic hit, and it became clear that the world needed more direct care and a safe place to fall apart. And so we hung our shingles with Mettle Health in this kind of way and allowed people to reach out to us through the internet. We pulled it out of the medical model for all the reasons we've already talked about, and also, strategically, that was a lighter lift for us as a small company to hang our shingles as a nonmedical, social enterprise. And off we went. It became one of our interests around depathologizing these normal states. By taking it out of the medical language and that kind of world, we've loved to see that maybe 60 percent of the clients we have are actual family members and caregivers.

And we've also seen folks who show up at our door having existential crises or crises of meaning. They're not sick at all by some definition. So we're getting our way of just depathologizing these normal states, and in some ways death to us now is just change. Loss is much more universal and does not necessarily have anything to do with illness or sickness. We're finding our way, and this is one hour at a time, people come and have all sorts of interesting conversations. I almost feel like a confession booth sometimes. It's amazing what happens when you just set a safe place to talk or fall apart, and all sorts of things come out. It's been very, very beautiful work. We have loved it. There's a lot to do, to say, to grow this organization and this model, but we are finding our way.

James Shaheen: Where can people learn more about this online?

BJ Miller: mettlehealth.com is the website. If you're into social media, we have a fun Instagram site, and that's just [mettle_health](https://www.instagram.com/mettle_health). For folks who want to pay to be a client and see us an hour at a time, we have a sliding scale and we love seeing folks for just about anything. But we also do

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free webinars, usually monthly and other ways to put some stuff out in the world and engage with the world that don't cost anything. So we love doing those webinars

James Shaheen: So you worked in the medical establishment, and you, like Sunita Puri, the journalist Katy Butler, who's a contributor to *Tricycle*, and many, many others have worked to change the medical establishment so that it can serve people in need the way you describe. Do you have much confidence in the changes that you brought about and their power to change how the medical establishment treats, say, end-of-life care as an example? Or is your leaving the medical establishment an indication that you think more can be done outside of it?

BJ Miller: You know, I think, of those choices, more the latter, James. I'm not sure in my lifetime that we're going to see as meaningful a change to the medical system as I might like, but I also have to note that I've seen a fair amount of change already, just in terms of how to talk about death and the ascent of palliative care within healthcare. That in some ways has been effective. I look now, and when I see medical school curricula and nursing school curricula, they often will include a lot more content around this subject matter than they did when I was a student in the 1990s. So I can see a sense of progress. It is slow and begrudging, and I'm not totally sure I'm going to be around to reach its full realization. I don't know. My faith in the system is mixed. My faith in human beings, to come around on this note, is more optimistic, in part because I see just the preponderance of those of us aging and living with illness as a percentage of the population is reaching historic highs, and just by need, because so much follows the need, and so the need around these issues is going to be less an esoteric subject and more and more just a daily reality for folks. It's already happening, the realities of caregiving, etc. And then you've got existential crises like a pandemic, politics, climate, etc. in the background. So you don't need cancer to teach you some of these things. You don't need an amputation. You've got the context of human existence right now to also point you in this direction. So put all that together, and I'm optimistic that these forces will conspire to offer different ways through, different ways forward with life, different ways to be with these states.

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We'll just have to see how far healthcare can get. If healthcare can't loosen its grip around “death is the enemy and let's focus on what we can fix,” then we've got to develop the social systems to pick up where they left off. So that may be the route.

James Shaheen: Great. Sharon?

Sharon Salzberg: So I know many people who may work in various capacities with people who are dying, and they all say that it changed how they lived their own life, and it may be impossible to encapsulate or express, but I wonder if you could say something about how working with dying patients might have changed the way you live your own life.

BJ Miller: Well, for one, I just definitely subscribe to that. My own life, at age 19, coming close to death and watching how it's opened my life up, it's cracked me open in so many ways. And then I see it with patients and others. So I believe that. I think there's a lot of life to be gained from addressing death. One of those things might be the truth of interdependence and the fact of how we need each other and to normalize that and upend this notion of being a burden in the world. So I think that is a very life-giving truth, and inherently, besides forcing a collaborative spirit among us, it also helps you know that I don't have to have all the answers. It helps right-size me. And so in this world where you're trying to always achieve more, be bigger or something like that, it's great news. It's a relief that I'm somehow not expected to figure it all out by myself. So I love that there's a humility that comes with this right-sizing. Humility is also a wonderful feeling. So there's all the suite of things that go with the truth of that interdependence.

I think related there, too, maybe we haven't touched on it directly, is sort of a decentralizing of identity or decentralizing the ego, of being interested in the world outside of my life, not just for strategic reasons and because we need each other, yeah, that too, but just because I get to see so much, I get to learn so much from others, and I get to see so much of myself in others. You know, there's your immortality. You want to live forever? I mean, connect to the everythingness,

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and boy, there you go. There's your immortality. And so that seems much more exciting and much more realistic to me.

I wouldn't have felt any of that poignancy if I hadn't come close to death or worked with others who are. Just empirically, it's not even a faith, I get to see how that can wake us up, right-size us, keep life in perspective, and also touch us into all the crazy stuff about this existence that we can't explain, don't understand but get to know somehow nonetheless, and find our way to loving it, finding our way to loving life even as we're losing it. What a juicy creative enterprise that is. And I think we've got death to thank for all of that.

James Shaheen: I think ending with being right-sized is great. That says it all, especially with regard to humility. So often we confuse it with humiliation, but we get to a point where humility is something we actually want to develop, and accepting help is the best way to do that, I think. This notion of being right-sized is just wonderful. So, BJ Miller, thank you so much for joining us. We like to close these podcasts with a short guided meditation, so at this point, I always turn it over to Sharon. Sharon?

Sharon Salzberg: Thank you. Thank you so much for being here with us. I invite everybody just to sit comfortably. Close your eyes or not. Take a few conscious, intentional breaths. And then allow your breath to become natural, however it's appearing. See if you can find that place where the breath is strongest for you or clearest for you, maybe the nostrils or the chest or the abdomen. Find that place, bring your attention there, and just rest. See if you can feel one breath without concern for what's already gone by, without leaning forward for even the very next breath. Just this one. And when your attention wanders, you get lost in thought or spun out in a fantasy or you fall asleep, whatever, just notice how you speak to yourself. Are you harsh? Are you punitive? Are you demeaning? Or can you gently let go? And with some kindness toward yourself, shepherd your attention back to the feeling of the breath. We say that the healing is in the return, not in never having wandered to begin with. Don't worry about it. You're with your experience in the present moment, and then you're gone, sometimes way gone. But when you

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realize that, that's the moment of recovery, of beginning again. And when you feel ready, you can open your eyes or lift your gaze, and we'll end the meditation.

James Shaheen: Thank you, Sharon. And thank you, BJ. It's great to be with you both.

Sharon Salzberg: Thank you.

BJ Miller: Thank you, folks. What a pleasure.

James Shaheen: You've been listening to *Life As It Is* with BJ Miller. Tricycle is a nonprofit educational organization dedicated to making Buddhist teachings and practices broadly available. We are pleased to offer our podcasts freely. If you would like to support the podcast, please consider subscribing to Tricycle or making a donation at tricycle.org/donate. We'd love to hear your thoughts about the podcast, so write us at feedback@tricycle.org to let us know what you think. If you enjoyed this episode, please consider leaving a review on Apple Podcasts. To keep up with the show, you can follow *Tricycle Talks* wherever you listen to podcasts. *Tricycle Talks* and *Life As It Is* are produced by Sarah Fleming and The Podglomerate. I'm James Shaheen, editor-in-chief of *Tricycle: The Buddhist Review*. Thanks for listening!