

Mill Valley Oral History Program
*A collaboration between the Mill Valley
Historical Society and the Mill Valley
Public Library*

BJ MILLER

**An Oral History Interview
Conducted by Debra Schwartz in 2017**

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TITLE: Oral History of BJ Miller
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In this oral history, palliative care physician and Mill Valley resident Bruce Miller, known as BJ, recounts the extraordinary and inspiring story of his life. At the age of 19, while a student at Princeton, BJ suffered a terrible accident that left him physically disabled. BJ describes his experience of coming to terms with his new life and body, including his determination to belong to a world not designed for people with disabilities. BJ explains how the accident launched him on an introspective journey, with sustained reflection on what it means to be a human being and the nature of suffering. This introspection served to deepen his sense of connection to others. BJ recounts how during his recovery process he discovered his vocation, and after graduating from college went on to study medicine at UCSF, developing a specialty in palliative care. BJ describes his subsequent work as Executive Director of the Zen Hospice Project and the TED talk he gave on end-of-life preparation. In 2007, BJ moved to Mill Valley after being seduced by the beauty of the town and falling in love with a house with a view of Mt. Tam. Throughout this oral history, BJ shares his wisdom about how to live and how to die, how to embrace mortality and thereby develop a deeper appreciation for life, and how a community can develop a culture of compassion.

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Oral History of BJ Miller
November 14th, 2017

Editor's note: This transcript has been reviewed by BJ Miller, who made minor corrections and clarifications to the original.

0:00:01 Debra Schwartz: Today is November 14th, 2017. My name is Debra Schwartz and I am sitting here on behalf of the Mill Valley Library and the Mill Valley Historical Society with Dr. BJ Miller. Dr. Miller, may I call you BJ?

0:00:16 BJ Miller: Please.

0:00:17 Debra Schwartz: You are a — I introduce people, but sometimes I feel that's arrogant. I'd like people in a way to introduce themselves. How would you introduce yourself?

0:00:31 BJ Miller: Well, I guess I would just say I'm BJ. [chuckles] It depends to whom I'm speaking. I might add in what I do for a living, which is that I'm a palliative care physician and I practice and teach at UCSF a little bit, and do some public speaking these days, and am working on a book and a few other things. But I guess in answer to your question, I'm BJ and I practice palliative medicine, and I'm a patient and a human being, someone who loves where I live and loves being outside.

0:01:07 Debra Schwartz: And a Mill Valley resident.

0:01:08 BJ Miller: Mm-hmm.

0:01:10 Debra Schwartz: For how long have you been living in Mill Valley?

0:01:12 BJ Miller: 10 years.

0:01:13 Debra Schwartz: 10 years.

0:01:13 BJ Miller: Longest I've ever lived in any one house.

0:01:17 Debra Schwartz: I think we live in the same neighborhood.

0:01:19 BJ Miller: I'm on Hillside. Where are you?

0:01:20 Debra Schwartz: I'm on Cushing Drive right above Eldridge, which is why I think I've seen you over the years from time to time on Mt. Tam.

0:01:29 BJ Miller: Yeah, 'cause we probably access similar trail points up there.

0:01:33 Debra Schwartz: Yes, right. Well, I interview a lot of people, BJ, and some of them are famous and quite recognizable. For you, I believe you have a certain unique

quality about yourself in that you are — well, you leave an impression. I've thought about life, what life might be like for you, having a sort of notoriety. The people that I interview that are famous, they're recognizable and every single day when they go out their physicality kind of holds that fame that people understand who they are based on the way they look. You are instantly recognizable based on the way you look, but people don't know your story. Well, some do, you spoke on TED Talks, but many in our town may not recognize you. And for me, personally, the first time I saw you I was quite struck. First of all, you're a beautiful man, and that's plain to see. That's always beautiful, like a nice tree or a bouquet of flowers, that's God's gift. When I first saw you, I immediately thought, "What a beautiful guy." You're very physical. We were outside. But then in an odd little time lag, I noticed that there was something distinctly different about you. You're missing two of your legs and an arm and I didn't catch that right away, but then one can't deny that. So I imagine in your life wherever you go and whatever you do, you have that effect on the world around you. Is that so?

0:03:33 BJ Miller: Well, you might have to ask them, of course, but I feel present, I know what it feels like to be around others who are present, so I have a sense, and over the years I've gotten feedback, just like from you, Debra. I'm fortunate that I'm aware to some degree, sometimes it's neurosis-making, but I've become aware that I do have an effect physically, just as you described. I guess a way of putting it would be that I'm hard to forget. You don't often forget the —

0:04:21 Debra Schwartz: You have a good half-life.

[laughter]

0:04:22 BJ Miller: Yeah, I do. It's hard to forget the guy who's missing limbs or whatever it is. But I am aware of some version of what you're describing and it's interesting. It's fun. Whether people know my story or not, I get a fair amount — and I think anyone with obvious physical disabilities gets this a lot. I am also aware of the projections that happen when people start having a relationship with me [chuckles] before they've met me on some level. And that's also fascinating. But I watch that as fascinating like I would watch a movie; it's like somebody else. So anyway, there's much to say on that. And being visible in this way has been therapeutic, too. I'm very grateful to have a disability that I can't hide. There are times, especially earlier on where I would have loved to have hidden, I would have loved to have passed, I would have loved to have not stuck out so much. But by virtue of — I can't hide my disability; it's too obvious. And in the end, I think that's proven to be a very useful thing for me because, in a way, I can't help but be honest on some level and vulnerable on some level. And I think we all are, but the contrast is such that I stick out in such a way.

So, I think in the end it can be kind of fun and interesting. Sometimes a little scary 'cause people remember me who I don't remember. And sometimes it's a little lopsided, but a long-winded way of saying that in the end I'm really glad for it because ultimately my job — I think ours as human beings — I want to develop to a point where I can be, essentially, naked in the world. I don't have to put on airs. I don't have to pretend to be

something I'm not. There's so much to delight in and to work with in a life, and not enough time to deal with facades. I'm happy to be revealed [chuckles] in a way, just by standing up.

0:06:44 Debra Schwartz: Well, the one thing I thought when I first saw you was, "There's a story. I'd love to know his story." And, so, I'm very glad to have you here with me today in the library sound room, as claustrophobic as this is, in our own little spaceship, to take a journey together. I was thinking we could take a walk back in history. Would you like to go for a walk with me?

0:07:11 BJ Miller: Sure, Debra.

0:07:12 Debra Schwartz: Into the landscape of the past?

0:07:14 BJ Miller: I'd love to.

0:07:16 Debra Schwartz: Okay, let's go. Let us start with your place of origin and the people that are your family, just a little brief history about where you were born and about your parents, if you would.

0:07:30 BJ Miller: Sure, happily. I grew up in Chicago, was born in Chicago, and we did the suburban migration. In so many ways I was just a relatively privileged white suburban kid. [chuckles] I had loving parents, a great education, had access, and in a lot of ways Norman Rockwell-ish to some degree. But of course, as is always so often the case, a lot of that's veneer. We struggled as a family in all sorts of ways, of course. We can talk about that, but just to complete the grand sweep: born and more or less bred in Chicago. Dad was a business guy, MBA, management, business dude. [chuckles]

0:08:27 Debra Schwartz: What's your father's name?

0:08:28 BJ Miller: Bruce. BJ stands for Bruce Junior. So my dad is Bruce. I've always gone by BJ 'cause my dad was Bruce. Just to avoid confusion. So, Bruce, Papa, my dad. And both of my parents are still together. 52 years of marriage, and they live in St. Louis now. And they, like any marriage of 52 years, have certainly had their challenges, but they're still together and so loving and it's very sweet.

0:08:53 Debra Schwartz: What's your mother's name?

0:08:55 BJ Miller: Mom is Susan. Susan Bacchus was her maiden name and now she's Susan Miller. They were typical of the time. They were 22 when they met. Both of them had just finished undergraduate college. And they were both a little nervous that they weren't already married, like a week out of college. [chuckles] And so they met, they were working at Proctor & Gamble in Cincinnati. My dad was just starting business school and my mom was working full time at Proctor & Gamble. That's where they met. I think the story is, they were working on the Crest Toothpaste Report or something very

unsexy. But they went out on a few dates and I think within something like three weeks they were engaged.

0:09:56 Debra Schwartz: Wow.

0:09:57 BJ Miller: [chuckles] And a few months later, they married, not that unusual a story for the time. Which now just sounds like —

0:10:05 Debra Schwartz: A real gamble. [laughs]

0:10:06 BJ Miller: It sounds insane. Let's be clear. That just sounds totally nuts. To me, anyway. But, lo and behold, here they are and very much in love and very kind to each other, and all sorts of things, beautiful things as a family, that they've set up and created. And a lot of that beauty has come from hardship. My mother, Susan, she had polio when she was an infant back in the epidemic, and she was a year-and-a-half-old. She got wracked with post-Polio Syndrome in her 40's pretty hard. This would have been the early '80s, I would have been 10, 11, somewhere like that. Mom had been walking with crutches and just one brace, and very capable and physical and very active, and then began this slow deterioration march of post-Polio Syndrome.

And so, for all of my adult life, and much of my life in general, Mom's disability has been progressive and it only gets worse. She only gets more pain and only loses more functioning. And it's a huge deal. I have learned so much from watching her work with her own abilities and disabilities; and also my whole family, bouncing around them, and how my dad's been supportive. My dad's one of these guys who's healthy beyond what he deserves to be. [chuckles] He led a very stressful business life. He eats whatever he wants. He doesn't exercise regularly, but if you saw him, he looks 50 years old and has tons of energy. He's strangely fortunate that way. The two of them give the whole picture of how health can play out. But watching my dad love my mom despite of, because of, with her disability, watching them work over time together as she became more and more physically dependent on him, and while he became more and more emotionally dependent on her — it's an incredible ballet they've done, and I've learned so much from watching them. There was a long period in the 1980s where a marriage that came about without knowing each other, at some point it comes to a head, and they were very close to splitting up for a long time. We spent a lot of time in therapist's couch as a family. But here they are, they're still doing it.

0:12:28 Debra Schwartz: Do you have siblings?

0:12:29 BJ Miller: Yes. I do/did. So this is another piece where the family breaks from the Norman Rockwell veneer. I had an older sister named Lisa. She and I were four grades apart, but three years. She was a December baby and she erred up, so she was young for her class. The reason I mention that is 'cause we, with a few exceptions in grade school, we didn't overlap in schools. She'd be moving out of high school just as I was entering it, for example. Anyway, Lisa was my older sister, my only sibling. She ran like a furnace, she was very hot, a very hot temperament, her whole life, ever since she

was a kid. And her swings, her intensity ruled the family in a lot of ways. Between my mom's disability and all that that brought, my dad's career and all the time constraints and stress that that brought, and my sister's — what we came to eventually appreciate — bipolar disorder, those were the three big chunks that ruled the family's dynamic in a lot of ways, and the energy, how we functioned or didn't. There were a lot hard times in the home front, in that mix. And Lisa eventually killed herself when she was just two weeks shy — 12 days shy of her 33rd birthday. I was in my late 20s. So that's obviously a huge rocking phenomenon in the family and one that dominates a lot of our world, still. Lisa died in 2000, so 17 years ago.

0:14:31 Debra Schwartz: Was she on medication, may I ask? Had it ever been —

0:14:34 BJ Miller: She wasn't. She had not been diagnosed. She was posthumously diagnosed as bipolar. But she had been in psychotherapy for much of her life. She was fascinating. She was so smart, Debra. She was just brilliant in every way: super insightful, in tune, and so she was extremely compelling. When she was raging at the world, at least for me as her little brother and for my parents too, we chased her moods around because we took them literally, because we never dared see her as sick because she made too much sense in her way. She was too compelling and we didn't know enough, too. And plus, she was in therapy, but she had everyone fooled. She could have you think whatever she wanted you to think, including her therapist.

0:15:33 Debra Schwartz: Well, it's a funny thing with mental illness, when you're around it every day. I know from my own family experience that that line where it has crossed into something that's very unhealthy, it's very hard to see when you're so close up.

0:15:48 BJ Miller: Yeah, totally.

0:15:50 Debra Schwartz: It just is.

0:15:51 BJ Miller: Totally, I agree. I see lines usually because I've crossed them. That's when I see them. [chuckles] That's usually how it plays out and it certainly was the case with Lisa. Absolutely. She led a very intense life. She was beautiful, hilarious, she was many, many things. She was horrifying at times. It was just brutal at times and that dynamic has a lot to do I think — I probably couldn't even name for you how, but being Lisa's little brother, obviously, it maybe has a lot to do with who I am now, and how I see myself in the world, and what I am interested in, and how I appreciate the challenges of the mind, and how I appreciate life in general. It has a lot to do with Lisa, of course.

0:16:45 Debra Schwartz: So let's continue to walk along this landscape as we progress. You're still young, your sister's still alive and you're growing up in Chicago and you end up going from high school — which high school did you go to?

0:17:02 BJ Miller: Well, let me pause real quick to complete the journey. My father, Bruce, very restive. He's a brilliant, capable man and also impatient a little bit. [chuckles] So he would take another job; he was kind of impatient. We moved around a lot. I was born in Chicago, we moved to suburbia, pretty quickly we moved to St. Louis. Pretty quickly we moved from there, he was transferred. He was working at pet foods and transferred to run old El Paso, so we moved to El Paso. Pretty soon after that, he got bored with that and bought a meat packing company in Roswell, New Mexico. So we moved to Roswell, New Mexico for a little more than a year and then moved back to St. Louis for my dad to pause and figure things out. And then from there, he took a job in the insurance world with a man name W. Clement Stone in Chicago, who ran Combined Insurance. The Stone family became part of our family in a lot of ways.

We landed back in Chicago; that would have been 1980. At that point I was nine years old, 4th grade in Chicago, really in Winnetka, a suburb. But not unlike Mill Valley is to the city, Winnetka is to Chicago in some ways. And I was there and continued in the public school system there until sophomore year of high school, I decided to go to boarding school. I was at New Trier High School, a big public high school, it's kind of a famous public high school. Anne Margret went there, Charlton Heston. It has kicked out a lot of really interesting people somehow. Not kicked out; it's sent a lot of interesting people out in the world, and it's a very competitive public high school in the suburbs of Chicago. Huge, it was 5,000 students. I was swallowed up there. I had the sense that I needed to leave, which was really interesting to look back on. Of the decisions I've made, this was a significant branch point for me: the decision to leave home early and go to boarding school. I didn't know anyone who went to boarding school.

My parents didn't want me to go to boarding school. It was not part of the deal, but I just had this hunch that, I was rotting. I wasn't a self-starter enough to make New Trier work for me as a true educational experience. I was smart enough to get by, and not self-motivated enough to really push myself. I could feel myself languishing, and I knew that that was a problem, on some level. And the other point was, I was really, very much a mama's boy. I was very protective of my mother. I was her chief caregiver on some level. That's the wrong word, but I spent a fair amount of my time running errands for her and doing things with her. We just had a very entwined relationship and a beautiful relationship to be really clear. I learned so much from my mother and I could go on and on, but I also had a feeling like, jeez, I felt like I was languishing in school. I was a late bloomer, I had been kind of good at sports, but at that point, early high school, I was being eclipsed by all these boys turning into men.

0:20:26 Debra Schwartz: Really? As big and strong as you are, you weren't great at sports?

0:20:28 BJ Miller: I was as a kid and then I was very much late bloomer. So it was deep, late in high school until I hit my growth spurt and filled out and became coordinated. But until then, for those years in there when everyone was growing up, I was suspended, and that was true physically and in other ways. I felt stuck. And I could look down the road and look around and see this very ambitious suburbia that I lived in, very

powerful and wealthy people, but I knew I wasn't drawn to being that. I didn't feel the capacity to follow in those footsteps, but I didn't know where I wanted to go, where else I wanted to go. I knew enough to be curious about a larger view of the world and to feel like there's something out there for me but that this wasn't it where I was. And the feeling, given the totality of all that and also my sister raging at this point, the home was a hard place to be, where a lot of fighting was intense. A lot of love, but a lot of fighting.

For all those reasons, I basically had a hunch that I needed to get out now, so I chose to go to boarding school. I went to this little place called St. George's in Newport, Rhode Island for the last three years of high school and hated it most every minute I was there 'cause I was very homesick. I was very dependent on my family in a lot of ways and my old friends back home. Part of being stuck was because it was a familiar place, and now I was in an unfamiliar place and it was really hard and I was not happy.

0:22:02 Debra Schwartz: Your father, he has a condition that I've made up the label for, but you may recognize it as geographical ADD. [chuckles]

0:22:10 BJ Miller: Yep.

0:22:11 Debra Schwartz: Perhaps you have a titch of it inside.

0:22:13 BJ Miller: I definitely do, yes.

0:22:13 Debra Schwartz: You have the compulsion to go out and at the same time, you have the connection which is strong. And any family that has mental illness — when you have somebody who's very large, taking up a lot of air in the room, it's a failure to thrive for others. You have a natural impulse to go out and have some space of your own. Completely understandable.

0:22:48 BJ Miller: Absolutely.

0:22:48 Debra Schwartz: And you must have done pretty well because you ended up going to a very good university.

0:22:55 BJ Miller: Well, what happened at St George's is — I had never taken a book home, I had never done homework. It was a time where, again, I was smart enough I could skate by. But bottom line is, I found myself at boarding school and instead of 30 kids in a classroom, there were four or five, and it was much more serious and you couldn't hide. I was very challenged academically and socially, too. I was still in this late blooming phase. I was so uncomfortable in every way. This New England boarding school scene — I had no idea what sarcasm was, for example, Debra. And the whole New England boarding school humor is biting and harsh. I was immediately confused and flummoxed, and really pretty miserable. But I also was too stubborn. I knew I didn't want to quit. This was a big step for me and my own development to choose to leave, and I was going to stick it out. I knew that. I knew I really wanted to stick it out.

And then I guess I also have a little competitive thing. I needed to show something for my time. And I was not thriving socially, athletically, or any other way. I became very reclusive, and it was a very strange time. The two outlets were — choir was a big one. I loved music my whole life. Music has been a big part of my life and at the time we had this amazing choir at St. George's and so I was part of that and loved it. And then the other thing was — well, okay, you're stuck in this campus. You don't have a lot of freedom. So I decided to throw myself into my studies, and I learned to learn. So, to be clear, the decision to go to boarding school was one of the best decisions I ever made for all sorts of reasons. Not because it got me into Princeton per se, but because I learned how to learn, I learned to become independent, I learned new things about myself and about others at a young age, so that I could run with it.

0:25:08 Debra Schwartz: You learned how to be uncomfortable.

0:25:09 BJ Miller: Yeah, absolutely. It's really nice way of putting it, Debra. It has served me very, very well, that skill. [chuckles] And so, just to complete that thread, I threw myself into my studies, not so much out of a love of what I was studying. I did begin to love them and found myself very curious and realized actually I was a bad student just 'cause I hadn't ever tried and so now I was trying and things were coming slowly. I couldn't write to save my life the first two years there, but then finally, that started to click. Anyway, I did, because of this neurosis, I studied my buns off. On Saturday nights — I would go to the library and open a window, a particular window, so then Saturday night, the one night where we had some social freedom was Saturday night, and I would go sneak into the library.

0:26:04 Debra Schwartz: Oh, wow. No way! You unlocked the windows so you could break into the library to study?

0:26:09 BJ Miller: Yeah. And I love working here at the Mill Valley Library. Ever since then, I've loved libraries. I love being in them. I get a lot of work done and I just feel comfortable there. They're like chapels. Consequently, as a side effect of this neurotic development — I say "neurotic" 'cause it was, it may sound in retrospect like it feels like an enlightened move, but at that time I was driven by pain and neurosis, and being afraid and not knowing what the hell I was doing. But anyway, that worked out very well because it made me a very good student. Ultimately, I graduated and ended up getting into Princeton very happily.

0:26:53 Debra Schwartz: Do you think that this idea that knowing where we're going means we're on the right path may be a little overstated?

0:27:00 BJ Miller: Totally.

0:27:02 Debra Schwartz: If we're on a hike right now, we don't always know where the trail's leading us. We don't always have good visibility.

0:27:09 BJ Miller: Right. And I've come to love that. As a younger person, that would've scared me, I think. It's not like I always loved that. I used to be kind of a, as part of my mama's boy phase, I was a scaredy cat, really. I was afraid of roller coasters. I was meek in some ways. And part of this lesson was to flip that on its ear and push myself into these unknown places. And over time you gain some confidence from navigating them, from getting through them, from learning some new things about yourself and the world, etcetera. And this is ultimately what kicked us towards what my accident did for me in college. But this began me loving the unknown, loving not knowing where I'm going, and embracing that, loving that, learning from it has been a singular force in my life that still compels me.

0:28:08 Debra Schwartz: In hindsight, things are so much clearer, but just hearing your story, I can sense that everything you're talking about now is all the seeds for the growth for what you're doing now in your professional life. Anything more unknown — I don't know. Death is the ultimate unknown. So let's continue on to Princeton and that moment of punctuated equilibrium where you had a life of one kind and you were going along with a certain trajectory, expectations, anticipations based on the world that you have grown up to know and the things that you're familiar with and in one moment everything would change and then you have another life. Tell me about that.

0:29:03 BJ Miller: By the time senior year at St. George's rolled around, I had begun to find new confidence, an earned confidence not just an inherited one. I had begun to do well as a student. We did beautifully as a choir. I made some really good new friends. By the time graduation from boarding school rolled around, I had gotten into Princeton, which was the place I wanted to go for unknown reasons, I just wanted to go there. So things were clicking along. I was starting to hit a stride. Things were coming together. And I finally hit puberty, more or less. I was filling out, I was coordinated. I was athletic again.

0:29:42 Debra Schwartz: 'Cause you are a tall guy. How tall are you?

0:29:46 BJ Miller: I was, at the time, before my injuries, I was just a hair under 6'5". At some point, I was 6'4.5", 210, and got back in athletics. So I hit Princeton, day one — thanks to all this back story, I hit college running, day one. It was like being flushed into the world out of boarding school. The relative freedoms you had now. And I also knew how to learn now. I had this physical and emotional and intellectual confidence. I don't think I was too cocky, 'cause I was still aware of my insecurities and what those felt like. But suffice it to say, literally, the first day of Princeton, I loved it and I seemed welcomed there, and just seemed to find my way. Confidence, whatever the hell confidence is, it's magical stuff.

0:30:50 Debra Schwartz: It's ethereal.

0:30:51 BJ Miller: It's a vibe or it's a thing and people respond to it. Very importantly different from arrogance and other things, but there's something about confidence and all of a sudden, really for the first time in my life, I had some.

0:31:03 Debra Schwartz: Perhaps just by being around somebody that's comfortable in their own skin.

0:31:09 BJ Miller: Yeah.

0:31:09 Debra Schwartz: That's confidence, I suppose, and that's a very soothing quality.

0:31:13 BJ Miller: It is. Yeah, that registers with me, that sounds right. And I was. Socially, all of a sudden, I had friends practically immediately, and good friends, people I loved and still love. And I decided to row crew, 'cause I had the body for it.

0:31:33 Debra Schwartz: Broad shoulders, long limbs.

0:31:35 BJ Miller: Yeah, the archetype body for crew. I walked onto the team as a freshman, the freshman heavyweight boat, was in the first boat and was the five seat. And the five seat is what's called the engine room. The engine room are the big strong guys as a rule, and all these things that made me feel really powerful and good. And we were a really good crew. We had this crazy coach who — his name's Mike Teti — who is a legend in the rowing world. He now coaches Cal, actually, Berkeley team. Having been an Olympian himself three times, an Olympic coach, he's just an insane — we could talk about Mike for hours — he's an amazing man. Really amazing man. His first year at Princeton was our year, our freshman year. So pretty quickly I found myself in these kind of storied shoes and this beautiful Princeton boathouse and being welcomed and appreciated and courted for some athletic potential. And I had friends from the boat and we practiced together every day, and we knew pain together every day, and we had this coach who beat the hell out of us in all sorts of ways, in the best way. We loved and respected Mike and I learned so much from him that year: another layer of toughness physically and mentally. Anyway, freshman year was just — it was awesome. The only year of my life with sort of unfettered confidence and a feeling of belonging and really not questioning it. Life was good. It was humming along.

0:33:21 Debra Schwartz: You were happy.

0:33:22 BJ Miller: Yeah, I was happy. And in part that happiness was because I knew what it meant, dearly, to be unhappy. Those were related. So, yeah, freshman year was delightful [chuckles] and just worked. Then sophomore year came and — let me see, there's all sorts of details along the way, but bottom line, sophomore year rolled around. I was at this point, studying Chinese language and I was going to — as much as I had loved freshman crew experience, I also didn't think I wanted to devote my — it's consuming, so I wasn't sure I wanted to keep rowing. I developed interest in Chinese, I was going to go study the second semester in China, sophomore year.

0:34:05 Debra Schwartz: Had you declared a major yet?

0:34:06 BJ Miller: No, but I was heading towards East Asian Studies. In 1989, when I entered college, Tiananmen Square had just happened and put China on our radar, or my radar at least, as someone who hadn't really given the country much thought before. So now there was a social justice issue, there was a political issue, the human rights issue, an ancient culture that I could see that would be so much to learn from and I just got turned on. So, anyway, I spent the summer between freshman and sophomore year at Indiana University in an immersion Chinese language camp. I came back to college, came back to Princeton sophomore year and I was going to be in China the second semester, so I wasn't rowing that year, I was just having fun, but my buddies were still rowing and whatever, it was fine, it was great. But then November 27th, we'd just gotten back from Thanksgiving holiday, which that year we spent in New Orleans, for some reason as a family with our dear family friends the Chandlers. We always spent Thanksgiving together.

0:35:12 Debra Schwartz: Your sister's around still then?

0:35:13 BJ Miller: Lisa's around then, yes. So that Thanksgiving, we're all together in New Orleans. It would have been 1990. And then I came back to school on a Sunday. I remember we went to the movie, *Goodfellas* that night, and then Monday back in class. And Monday night, I was working on a paper, a comparative religion class I was taking. I was going to the computer lab to work on this paper and I ran into a couple of my friends. We decided to defer the paper, defer the homework and go out on the town for a little bit and have fun, because it'd been four days since we had seen each other 'cause of Thanksgiving, so we were all excited. Anyway, we went out on the town not that long, nothing crazy, and we were heading to what's called The Wawa Market, which is an East Coast version of 7-Eleven. We were going to get a sandwich and we happened to walk the route, you walk right past this commuter train station.

0:36:13 Debra Schwartz: And this was what time of day?

0:36:14 BJ Miller: This would be late at night on a Monday night. So, this would be after midnight-ish.

0:36:18 Debra Schwartz: So it's relatively uncrowded everywhere. You have the space to yourselves, pretty much.

0:36:23 BJ Miller: Yeah. It's a Monday night, nothing crazy's going on. So we had the whole world to ourselves, and we're bouncing around and just loving life, just goofing off, nothing crazy. And so we pass this train just sitting there, and for whatever reason, we decide to climb it. We had done dumber things. We did not think we were doing something very daring. This was a parked train, after hours.

0:36:53 Debra Schwartz: Turned off?

0:36:54 BJ Miller: We thought. We just assumed. And it was just sitting there with a ladder.

0:37:00 Debra Schwartz: It's an electric train?

0:37:00 BJ Miller: Yeah. It's an electric commuter train that —

0:37:03 Debra Schwartz: Does it have a name on the front of it?

0:37:04 BJ Miller: Well it's New Jersey Transit is the parent company, but this train is affectionately called "The Dinky." [chuckles] I don't think it says it on there, but that's the nickname for this little train, this three-car train or two-car train that runs from Princeton to Princeton Junction where the main rail to Philadelphia, New York goes. So, this is a commuter train.

0:37:27 Debra Schwartz: The Dinky.

0:37:27 BJ Miller: The Dinky. [chuckles] You have a hilariously named —

0:37:30 Debra Schwartz: How ironic.

0:37:31 BJ Miller: Yeah, exactly, to lose three limbs to a thing called The Dinky [chuckles] is humbling. Anyway, we just happened upon this thing, there's a ladder on it, I went and just climbed up on top like you'd climb a jungle gym.

0:37:45 Debra Schwartz: There it was. "I shall climb it, I am a young man in the full sap of life."

0:37:48 BJ Miller: Yes, exactly.

0:37:49 Debra Schwartz: And this is just something to jump over on the way along the road.

0:37:52 BJ Miller: Exactly.

0:37:53 Debra Schwartz: Just impulse, playful impulse.

0:37:55 BJ Miller: Playful impulse. Not trying to be daring, it wasn't moving. Again, we didn't think we were doing anything that crazy. But as it happens, we were 'cause the train was still electrified. The wires run overhead, a little bit like the buses in San Francisco. So when I jumped up on top of the train, I had a metal watch on and when I stood up, I was close enough to the power source, and the electricity arced to the metal watch.

0:38:20 Debra Schwartz: This is that unstable for the electricity to arc like that?

0:38:24 BJ Miller: Well yeah, and I was that close to it.

0:38:26 Debra Schwartz: So you're within a foot.

0:38:27 BJ Miller: Yeah, and I don't remember.

0:38:29 Debra Schwartz: Close.

0:38:30 BJ Miller: Close, I was close to it. I don't want to leave any listener with the idea that you standing on the platform or being on the train or on a bus like this, are in any way at risk. You have to be where you're not supposed to be. [chuckles]

0:38:40 Debra Schwartz: Yes. In an unsheathed electrical —

0:38:45 BJ Miller: Yeah.

0:38:45 Debra Schwartz: Yes.

0:38:45 BJ Miller: So anyway, that's what happened. Electricity entered the arm, my left arm, and blew down. Electricity tends to ground down. And then when your legs sort of narrow to the point where it slows the heat, it basically incinerates. So you burn from the inside out. It's kind of gruesome stuff. And that was that. It was all in a millisecond.

0:39:09 Debra Schwartz: Whoa.

0:39:10 BJ Miller: Yeah, that was that. So I landed myself in a burn unit in New Jersey for two plus months.

0:39:18 Debra Schwartz: Were you blown from — I have a friend who was electrocuted, he was thrown 20 feet.

0:39:22 BJ Miller: Yeah, and I was, too. That's the number that actually, I've been told, 20 feet, and I landed — so it was a big explosion. I don't remember any of this, by the way, it's just what I've been told.

0:39:31 Debra Schwartz: Well, I'm sure what you can't remember, others cannot forget.

0:39:34 BJ Miller: Yeah, my buddy, Pete and Jonathan who were with me that night, two boat mates and dear friends. Pete scurried up on top of the train to help. There was an explosion. They couldn't see what happened. And I was flung about 20 feet but happened to land on top of the train, thankfully, 'cause that would've complicated things if I flew off the train and then had fall injuries from that. But I landed on top of my head, so my head was bleeding, and so Pete just thought — he found me unconscious and thought I had just cut open my head. Just a concussion.

0:40:06 Debra Schwartz: You weren't smoking?

0:40:08 BJ Miller: Well, then he noticed that my feet were smoking, literally smoke coming out of my feet. And then he started putting two and two together, and then I came to, and started thrashing about, which is pretty common. You have a huge adrenaline surge and all this heat still in your body trying to get out. And so I'm just freaking out, apparently, and punching Pete and just thrashing. But Pete's a huge, strong, strapping dude.

0:40:30 Debra Schwartz: Huger than you? Wow.

0:40:31 BJ Miller: Yeah, [chuckles] you should see him. He is a brick of a man and with heroic tendencies to boot. So he was in his element. He and a New Jersey cop who came to the scene, Sergeant Dawson, they both got up on top of the train which was pretty daring —

0:40:49 Debra Schwartz: Yeah. They didn't know what —

0:40:51 BJ Miller: Right. So they were up on top of the train holding me down. The paramedics came. The paramedics wouldn't get up on top of the train, but they handed the stretcher up to Pete and Sergeant Dawson who put me in the stretcher and handed me down. And Jonathan, by the way, my other buddy who was with me, he is the one who went and called 911 while Pete was holding me down. So they're all doing this.

0:41:08 Debra Schwartz: No cell phones, really, then.

0:41:10 BJ Miller: No.

0:41:10 Debra Schwartz: He must have gone to a regular —

0:41:12 BJ Miller: Right. He went to a pay phone, dialed 911.

0:41:14 Debra Schwartz: I say so only because those are moments ticking by.

0:41:17 BJ Miller: Yup. Right. And no one knowing what the hell just happened, really not appreciating what the danger was or wasn't. So obviously, very confusing and scary.

0:41:28 Debra Schwartz: Shock.

0:41:29 BJ Miller: Yeah, literally and figuratively. So, I went to the local hospital and got some initial treatment there, and then was flown by helicopter to the Burn Unit in Livingston, New Jersey, a place called Saint Barnabas.

0:41:42 Debra Schwartz: So when did you wake up, if you don't mind me asking, to the reality of your new life?

0:41:48 BJ Miller: Well, I was just talking about this earlier. The first memory was this: When they were loading me into the helicopter because, as I was saying, I was pretty tall, so I remember there was this awkward — pilots were trying to load me into the helicopter and I was too long. I remember there was this, awkward trying to get me situated in there.

0:42:06 Debra Schwartz: Can't really fold you up.

0:42:07 BJ Miller: No. So that was sort of a hazy first memory, but it was really day four or five, the night before my first surgery, that I had any memory that I can recall lucidly. I was conscious throughout, but you're in shut down mode, all energy in your body is going towards the most pressing thing, which at that point was the burns.

0:42:39 Debra Schwartz: So, you have now physically, inside and out on the surface of your skin, burns on both your legs and your left arm.

0:42:46 BJ Miller: Yeah, and there was a big scar on my chest here, too, where the electricity sort of tried to come out, and so there was a big burn here. But no, it just is a scar. Yeah, so right, scarring inside and out, and unstable.

0:43:03 Debra Schwartz: And that heat, that heat that comes with the electrical jolt, does it affect your brain?

0:43:14 BJ Miller: Most certainly. I've always wondered what the lasting effects are. Weeks into it, I remember looking over at the monitor. You're in a burn unit, it's an entirely controlled environment, and so I was always hooked up to monitors. I remember, probably a month in, still looking over and seeing my heart rate at 180 just sitting there, just resting.

0:43:37 Debra Schwartz: Oh, you were like in AFib or something?

0:43:40 BJ Miller: Whatever's been done to your electrical circuit, your neurological and electrical circuits that run your heart, and your nerves, and everything else, is certainly frazzled and injured. And then, of course, the way a lot of people who die from burns are from infections, so your immune system's all jacked up. And also your body's ability, you lose — I lost so much capillary beds in my periphery, in my feet and my arm, which has a lot to do with how we maintain blood pressure. So all the regulatory systems in a body are all on overdrive, or injured, or just screwed up. I've always wondered — now I'm 46 and my memory ain't great, and I always kind of wonder, "Is that normal, or is that 'cause I blew through some of my brain's life?" My kidneys, my heart, they were working extra hard for a prolonged period of time. Will there be any lasting effect from it? I have no idea.

0:44:40 Debra Schwartz: Well, having a mother who has a degenerative disease from earlier polio, I suppose that you're perfectly primed to wonder about what may be

coming. On the other hand, you were a very young man, with a very regenerative physique.

0:44:57 BJ Miller: Yeah, I was in good shape.

0:44:58 Debra Schwartz: Which can make a difference. My father is a doctor, and I spent a lot of times in hospitals waiting for him. And many hospitals are very detached from nature. And in a burn hospital, I imagine, we must have a strictly maintained sterile environment. How was that for you?

0:45:24 BJ Miller: Well, yeah. It's all a part of the odyssey and part of the monumental insecurity in that role. It was touch and go for probably a month. I was in the burn unit for about two months. And probably, the first couple weeks, maybe a month, it was no guarantee I was going to make it through the night. So it was intense, frightening; and what you point to, Debra, too, extremely foreign, you're in this wholly unnatural environment. My room didn't even have a window, there was nothing to orient me to time and place, but the television and getting hip to the cycle of the nurse's shifts. I couldn't tell you if it was day or night. You're dramatically removed from the things that otherwise bring you comfort or at least familiarity. You're wholly vulnerable in so many ways, and you really are at the mercy of the technicians to do their job well. Your job is to not do anything, not to barely move in those early days.

0:46:36 Debra Schwartz: Did you feel the whisper of death nearby?

0:46:39 BJ Miller: No, it's so interesting, I don't know if there's an innate wisdom, 'cause as I've worked around death and dying now for a long time, professionally, you become hip to, in whatever spiritual beliefs you may have or not, even just empirically, the body. We have intuition, we have old knowledge in our DNA, and humans have been dying a long time. So there's a piece of being near-death that is actually natural, and on some level, I believe that we know. Even as foreign and unknown as death is, leading up to it, there's something in our bodies that is — we know we die, we're programmed to die.

And I was aware. I knew things were rough. I was awake, but I really — and I don't know if it was young arrogance or whatever it is, or a deep knowing, but I never thought I was going to die. I was aware that that was mathematically being discussed as a possibility. I knew it was. But I did not hear the whisper of death. I did not see anyone calling me to the light. I did not feel like I was — and, again, that could have been delirium, that could have been pain meds, that could have been arrogance, it could have been denial, or it could have been my body just knew that it wasn't going to die then.

0:48:08 Debra Schwartz: Or it could have been, I suppose, the thought that entertaining those ideas wasn't going to help the situation. A practical way to deal with an untenable situation.

0:48:20 BJ Miller: Yeah, possibly. That could have been just very much adaptive.

0:48:22 Debra Schwartz: You have to conserve your energies to do what you can do and not squander them with what-ifs.

0:48:28 BJ Miller: Exactly. So all of the above. All of the above.

0:48:33 Debra Schwartz: And you're how old now, here?

0:48:34 BJ Miller: 19.

0:48:35 Debra Schwartz: 19. Okay, so you're alive in bits and pieces. How far into it were your limbs amputated?

0:48:49 BJ Miller: I probably had, I don't know, a dozen or more surgeries. Part of the challenge is, it's not clear at the time what tissue is viable versus what needs to be removed, and every day, you're taken to this place called the tank room where you're debrided and hosed down, and it's a real torture. Because every day, flesh will reveal itself — what's going to live, what's going to die — so you constantly need to be debrided, which means removing dead tissue. It was brutal, it was really — when the cart was coming to get you every day to take you to the tank room, when you knew it was coming, you could hear it coming, it was a kind of a torture made palatable, because the people there were so amazing — the weird sense of humor in the room, and these guys whose job was to inflict so much pain to protect you and to save your life, it's this weird mix, and it was a stunning sense. I felt very safe there; I felt very loved and cared for. I felt like I was surrounded by caring people, and very competent people.

So as exotic and foreign as it was, it's also telling and interesting that I was very sad to leave the burn unit. I remember that day, which should be like a graduation moment. Leaving the burn unit is a wonderful thing. [chuckles] It means that you're going to survive, and that you get to see the sun again, and all sorts of good stuff waiting for you. But I remember being extremely sad. It had become my home, and these were people who I could be the most intensely vulnerable I had ever been in my life, except for infancy, maybe. And so it had become a home. It was sort of telling and stunning how we humans — one of the first early lessons of the power of our ability to adapt, and to make a home where we are, and to find toeholds for our hopes, and how we can rest into relying on others to help us if we really need to. So it was just a stunning experience, and not all horrible.

0:51:03 Debra Schwartz: May I see your arm?

0:51:06 BJ Miller: Sure, yeah.

0:51:06 Debra Schwartz: You talk about the skin; I'd like to see you talk about the burn, but I don't see any. Oh, there it is. Yes.

0:51:13 BJ Miller: So what you can see, that's skin graft. There's the bicep. I lost the bicep to infection, so that's just bone there, but this would have — the early acute days, my arm was extremely swollen, so they had to take a skin graft to close the wound, and they took that from my thighs. And so, that's why it looks the way it does.

0:51:40 Debra Schwartz: I'm touching the skin that has been grafted, it's leathery. And it's darker.

0:51:45 BJ Miller: Yeah, and lumpy.

0:51:45 Debra Schwartz: And it doesn't seem as flexible at all.

0:51:48 BJ Miller: It's not. It's much less flexible.

0:51:51 Debra Schwartz: And then the skin all around it is very very soft and pliable.

0:51:54 BJ Miller: That's exactly right. That's the skin graft, and some areas are hyposensitive and some are hypersensitive. I've become increasingly used to it over the years, and it's just part of my body now.

0:52:15 Debra Schwartz: And so you have no bicep on your left arm at all, and your shoulder looks well-formed under the cashmere sweater.

0:52:22 BJ Miller: Yeah, and then there's a little skin graft under here.

0:52:26 Debra Schwartz: In your armpit, 'cause those they can't see.

0:52:29 BJ Miller: And there's a skin graft on my chest.

0:52:32 Debra Schwartz: Yeah, I'm going to look. Not much, though. It's surprising, for what you went through, how so much skin is fine.

0:52:40 BJ Miller: Yeah, totally true.

0:52:41 Debra Schwartz: But that's where the electricity exited.

0:52:44 BJ Miller: This is, right. It tends to incinerate where it enters and exits.

0:52:47 Debra Schwartz: So when you left the burn unit — and now you're a fledgling in a new life — how long did it take for you to get back to school?

0:53:00 BJ Miller: So I got out of the burn unit in, I think, February, and then I was in a step-down unit in Saint Barnabas for a couple weeks. And then at that time my family was in Chicago, and it was so interesting. I don't know how they did this; I've never heard of this, but my parents somehow moved into the hospital. They got a room somehow in the hospital. I've never heard of that. So they lived there, but we all headed

back to Chicago once I was out of the acute care hospital. And then I went to the Rehab Institute of Chicago, which is a top-notch rehab facility, and it was closer to home. So then I was inpatient, in rehab for about a month in Chicago, then out. I got out of there in late March, I think, and then did outpatient physical therapy until the fall. And then I went back to Princeton that September.

0:54:01 Debra Schwartz: I'm a mother, so I have to ask you this. Your parents must have been mortified.

0:54:10 BJ Miller: Yeah, brutal.

0:54:12 Debra Schwartz: How were they through this?

0:54:14 BJ Miller: Well, they were amazing through it, but yeah, it was brutal. This is straight out of movies. In the middle of the night, it was three or four in the morning, they get a call from an ER in New Jersey. And in the ER, there's not necessarily a lot of time for politeness and niceties. The way my mom tells the story, she's half awake, gets a call trying to figure out who's calling and then basically the woman says to Mom something like, "Your son's dying, get out here. But he's probably going to be dead when you get here." Something like this. And so she's just still trying to wake up and she's like, "What? Electricity?" Nothing made sense and it was all horrible and really traumatic. So they got on a plane immediately, and they had no idea what they were walking into, none. Hugely textbook traumatic for a parent.

0:55:08 Debra Schwartz: Did you ever feel that you had to take care of them?

0:55:11 BJ Miller: Oh, sure. [chuckles]

0:55:12 Debra Schwartz: While you were in the ICU there?

0:55:14 BJ Miller: Sure. Yeah, you know how it goes. I think caring works best when it's going in all directions, where the caregiver and the care receiver are linked and they're looking out for each other. But that was already in our dynamic and our bones, thanks to my mom. First of all, we as a family, and I, had a head start. I had been around disability my whole life. I knew at a young age that we are more than just our bodies, that there was no such thing as a perfect body, that disability was, in a way, normal. So I had learned a lot of valuable lessons early, thanks to my mom, as my family had. So they weren't ashamed of me. I wasn't ashamed of myself to be in these shoes, etcetera. So we had a lot going for us in those early days.

You brought up something earlier and which I forgot to mention is that part of the difficulty of the burn unit is that because of the need for it to be sterile you can't have visitors. For the first few days, the only ones who could come in were my parents and then after that it was one visitor at a time where friends could come in. And when they did come in, they had to be draped and gowned and gloved, and all this stuff, so you were so removed from this touch. And that was hard, but I remember my many hours with my

parents at the bed side and us just talking and they were looking out for me and I was very much looking out for them. I remember very early on, after one of the initial surgeries I came out of the anesthesia, and my parents were there and I said something to my mom, I said something like, "Now we have so much more in common." And I remember that moment very well 'cause it just moved my mom so much, she melted. And I wasn't trying to melt her heart, I just felt that way, it was an honest comment and it felt like now we had an even a stronger connection. And I remember that being a really profound moment for her. I can't pretend to know exactly what her thoughts were, but it was a big moment for us.

0:57:30 Debra Schwartz: You're back in school now, you're back at Princeton, you're back with your friends who've been no doubt traumatized by what they've witnessed as well and now they've got a friend who's very different.

0:57:42 BJ Miller: Yeah.

0:57:44 Debra Schwartz: And you're back in school doing the practical aspects. Still, recovery takes a long time to get over these kinds of things.

0:57:49 BJ Miller: Yeah.

0:57:50 Debra Schwartz: How was it?

0:57:52 BJ Miller: It was rough. I made some decisions that I'm really glad for. One of them was the realization that it was going to take me years to emotionally wrap my head around this and for my identity to absorb this. I knew that and so I was patient on that plane, but I also knew or felt the need to get back on the horse physically and get back to school and be back with my class.

0:58:25 Debra Schwartz: Reclaim your place as you —

0:58:26 BJ Miller: Yeah, and if it hadn't been possible that would have been okay, but it was possible, and I wanted to do that, so I took my exams to complete the work for the year. I rejoined my class that fall, which in some ways, was too soon. In some ways, I wasn't ready, but in some ways, it was just what I needed because I could be back. There was a sense of normalcy with my friends. I was with my peers who, by the way had been amazing. They came to the hospital every day. They were amazing. I wanted to be back with them for so many reasons. So I made this decision to get back on the horse physically, quickly, knowing that the emotional stuff was going to play out over time. So that just meant I was very clunky. One day, it would be a good day, a bad day, certain pains — physical pain was still a big deal at the time. The skin hadn't built calluses so I couldn't walk or stand for great lengths of time at any one stretch. I had a golf cart to get around campus. I had a service dog that was extremely helpful to me, mostly emotionally.

0:59:25 Debra Schwartz: Did you have prosthesis at that time?

0:59:27 BJ Miller: Yeah, I had prostheses, but I was not very adept at using them yet. And more to the point, the skin wasn't used to bearing weight in this unnatural way, so pain was a big daily, limiting factor. And then, trying to own this body when people are staring and pulling their kids away from you, and you're getting this freakish treatment. Back then, anyway, my experience was — the way I put it — you're either treated like some Jesus figure, in some heroic way that doesn't feel right or that seems off. Or, you're treated as this Frankenstein thing, that's terrifying and scary and hard to look at and ugly, and people wouldn't want to be that. So, it was this sort of repulsion-attraction vibe that you got, that you're just whipsawed around and all its projection.

1:00:19 Debra Schwartz: And that's the new you?

1:00:21 BJ Miller: That's the new me. So, I'm trying to figure out what the hell the new me is, while I'm getting all these weird signals from the world. And it's not just me; anyone who is in this situation, that's how this goes, especially back then. This is right around the time of the Americans with Disabilities Act, it's 1991. Before that, we may not know this, but before then, disability was not really accepted in the same way as it is now. It wasn't a protected civil right. You were relying on pity and charity.

1:00:48 Debra Schwartz: Yes, you couldn't depend on the wheelchair access.

1:00:52 BJ Miller: No.

1:00:53 Debra Schwartz: You were in an old school where there's stairs up and down the halls.

1:00:57 BJ Miller: Yep.

1:00:58 Debra Schwartz: There's been so many modifications that we take for granted, but there was a time where to be disabled was to be disconnected from the rights that all others could experience without a thought.

1:01:11 BJ Miller: Absolutely. And you can imagine the interpersonal, the confidence, insecurity issues that pop up when you realize you're trying to live in a world that was not built for you and in some ways, built to exclude you. I'm flipping from this privileged, white, suburban, highly educated guy, to this — now I was a member of the other class. Again, I knew enough from my mom's experience to know that those were false divides, so I didn't get too hung up there. But just feeling, trying to navigate all the vibes you're getting from people and all the projections, and trying to demand that you belong in a place that obviously and explicitly was not built for you.

1:01:57 Debra Schwartz: And you're already a big guy.

1:02:00 BJ Miller: Yeah.

1:02:02 Debra Schwartz: My son's your height, and not all the world accommodates. If you have to be helped to be moved, you're heavy.

1:02:14 BJ Miller: Yeah. I needed to rely on others for a long period of time there.

1:02:19 Debra Schwartz: Was there a crisis there of identity at any time, or did you just manage to segue through this somehow?

1:02:30 BJ Miller: Well, it was never an acute crisis, it was a smoldering crisis.

1:02:37 Debra Schwartz: "Smoldering," interesting choice of words.

1:02:40 BJ Miller: [chuckles] Yep, and that's right on a number of planes, I think, thanks to my family's experience, and thanks to what I was learning. When I was studying, I switched my major at that point to studying art. When I was sitting in the hospital bed, I was trying to figure out what makes a human being a human being? Obviously, it's not having feet [chuckles], there are other, better ways to define humanity. And, again, you're absorbing all these signals, you're dealing with all these pains, these real pains. Your mood's all over the place, trying to find the ground and without feet, you're removed from the ground. The whole thing is just disorienting. But I think on some level, thanks to my family, thanks to having a sister who struggled in the way she did and my mom who struggled in the way she did, I was aware that life was not what we thought it was. And it certainly wasn't this pretty picture all the time.

And that, in a way pretty quickly, I felt, whatever club I was now excluded from, I was included in another club that was a cooler club anyway. It was a bigger one, it was one that questioned what makes a human being, a human being. It was one that knew that struggle and suffering was endemic to the human experience, not an aberration, not an anomalous experience. So, I felt like I was joining this bigger, deeper segment of humanity in some way. I believed that. I didn't feel that way, the world wasn't telling me I was that, but I believed it on some level. And so I intuitively pulled myself forward. I knew I deserved to feel okay. I knew I deserved to belong in the world. I set about to convince myself that that was real and to make that real.

1:04:47 Debra Schwartz: Listening to you talk, I see that you're naturally introspective, even from early childhood.

1:04:58 BJ Miller: Yes, I was very much.

1:05:00 Debra Schwartz: And philosophical.

1:05:01 BJ Miller: Yeah.

1:05:01 Debra Schwartz: Which on some level, if these are your natural inclinations, the journey that you're on is somewhat stimulating.

1:05:08 BJ Miller: For sure. If you let yourself feel that and see it that way, absolutely. And certainly, of course, too, sitting here with you, Debra, in our spaceship, [chuckles] being asked to reflect on a life, which implies that it's been of some importance or something good. So now it's all the easier to look back on that, like you'd said earlier, and to see this thread, and to see how it's played out. But at the time, you're feeling your way, and you have these hunches and these things pulling you.

1:05:42 Debra Schwartz: So you're in the dark on the trail on your hands and feet, crawling along, and moving.

1:05:49 BJ Miller: Yeah.

1:05:50 Debra Schwartz: You're just not sure where, what or how but you do know that you're moving.

1:05:54 BJ Miller: Yes. That's really a nice way of putting it. It was why I wanted to get back to school. I wanted to move in every way. I wanted to generate some new momentum. And another thing I think that was very helpful was — again, you know this world isn't created for you, but you know that that's a built world. It's not nature dictating it, it's humans and their limitations making this world. Again, you have this hunch that you could belong, should belong, could actually change the world, could actually teach the world something even as you're learning about it. You have these vibes, you have this feeling, you know that if you looked behind the curtain, that everyone suffers. I became intensely aware of that, intensely aware that not everyone's suffering was obvious. That allowed me to see humans in a different way, and to feel connected to people who I didn't even know, who by rights I had nothing in common with, but because we suffer and because we're humans, we had shared so much.

These kinds of feelings, these thoughts, took time to set up, but one of the pitfalls to avoid — I really want to make sure to say this — some of the challenges, not quite enemies, these challenges were, again this built environment not for you, the discomfort of others being projected on to you, which you're tempted to make your own, and really undermine your sense of self. And then there's a sweet thing that comes, too. It took me a while to figure this out. Early on, one of the early questions you can imagine any 19-year-old heterosexual man had was, "Well, what's my love life going to look like now?" I had no idea. I came to realize that there was plenty of love waiting, but there was also — I became hip that some of the interest in me early on was people who were attracted to me because they wanted to come fix me, they wanted me to be dependent on them, they saw me as sort of a broken — the phrase that came up actually explicitly with one woman was "a bird with a clipped wing" that she was going to nurse back to health or something.

It took me a while to get hip to that, that's not where I wanted to be, and that started making me more and more aware of something that my mom had taught me about, but I was starting to feel it, which was the perils of pity. Pity on its surface can feel sweet. Here's someone who sees you and wants to help you, and Lord knows you need help, and they're not running away from you, and they're even calling you special, and they're

suggesting that you are extraordinary. If you're not careful, you can get seduced by pity and sympathy. It can be a proxy for deeper connections. It's really perilous. If you go down that, if you absorb that, if you accept that, "Oh, yeah. I am special. Oh, I am different. I do deserve and need more attention than others," or if you follow the logical conclusions of pity, you end up in a very lame place. That was a big pitfall to navigate. I don't know how this came up in our conversation.

1:09:15 Debra Schwartz: Well, we're just talking about the claiming of your life. You're a 19-year-old guy. You're thinking this through, but you're also living in a 19-year-old male body, surging with hormones, and all the natural stupid stuff guys are going to do at that age, anyway. And you're really good looking. Your face is completely intact. I imagine you didn't have much trouble getting the attention of women before the accident, and you're still this beautiful guy, so I could see that this would be a bit of a challenge to be with somebody who's fulfilling their own need to pity and take care of. They're in the relationship with themselves at that point if you're not being seen for who you really are.

1:10:05 BJ Miller: Absolutely. You got it, Debra. Of course, these are variations on themes that we all face.

1:10:10 Debra Schwartz: I guess this is not uncommon for all people and all relationships. And it's intense, intense experiences for a 19-year-old guy.

1:10:30 BJ Miller: Very. And part of the recalibration was, actually coming off, for all the reason you just said. I was living in the extremes, and you recalibrate. That is your reality, and I guess it's maybe a version of a post traumatic mindset, where you're not operating on a subtle plane, you're in this very brutally, harsh, extreme plane a lot of times. It took me a while to slow down, calm down, and to feel slowness again, to feel subtleties again, to be still.

1:11:15 Debra Schwartz: To feel the nuances.

1:11:16 BJ Miller: Yes. Exactly, to get these nuances, these other, sweeter, softer layers. If you're not careful, you just override those, and you lose the ability to see those things. That was part of the trick, too, recalibrating, coming back down to earth in a way, that allowed me not to be too addicted or to confuse the extremes with normal life. You also highlighted another major lesson, which was the belief, and then the proving the belief, that these are variations on themes, that we all suffer, that we all die, that life doesn't go how any of us wants it to go all the time. And therefore, to insist on staying and feeling connected to the world, not fall into the traps of anything that pulls you out of it and isolates you.

1:12:15 Debra Schwartz: Making you feel special or different or more entitled — those are all the things that seem okay on the surface but they're very alienating.

1:12:22 BJ Miller: Totally, totally. And the other extreme too is when people are outright repulsed by you. That doesn't happen so much anymore, but back in the day there were times when I was aware that my physical presence was repulsing somebody. But yes, the bottom line is — I can't say it any better than you just said. These are all the lessons that were setting up, and it took me awhile [to learn them].

1:12:52 Debra Schwartz: Crash course.

1:12:53 BJ Miller: Crash course, but they were interesting. You pointed out something. I had made myself interested in these things intellectually, but now this was a moment for me to ply this. This was not sitting in a Princeton classroom, expounding on existential issues or identity in 20th century American males, or however you might approach it in some academic-y, intellectual way.

1:13:19 Debra Schwartz: The ultimate field class.

1:13:21 BJ Miller: Yeah. Everything I was doing, I think, was consequential for my life, period. Studying art was a therapeutic endeavor for me. I used what I learned there and applied it to my life. In that way, it was thrilling and I got to a level of intrigue and confidence in myself that I would not have gotten to otherwise.

1:13:44 Debra Schwartz: And art, because it inspired you or —

1:13:49 BJ Miller: Well, first of all, why do humans make art? What is the impulse in this? It seems unique among species that we have this capacity to reflect on our lives and to create from our experiences, to make sense of our experiences. Before then, art was interesting to me, but as a pretty picture or something that might reveal someone's talent. Now, I was starting to see I was interested in the impulse to make art and seeing this creative impulse in all humans, whether they put it into painting or whatever else. But that we're constantly making ourselves up. We're creating our lives all the time. We're putting them together in a certain way, we're taking the raw material of our bodily and daily lives, and making stories from it all the time. I don't care who you are. That's what we humans do. I was interested in art, for this. I wanted to acquire the skill of looking at my life in creative terms. And I, very explicitly wanted to study art, so that I could learn how to see. The early realization was that, "Okay, I can't control much of what I'm seeing here, but I am aware, thanks to good examples in my mom and otherwise, that we can change our attitude." We can't change everything about our world, but we can change how we see that world. And I wanted to acquire and work on that skill. And that's why I studied art.

1:15:23 Debra Schwartz: And as you're doing this, you're embodying your new body. It's a collaboration between you, yourself and your body.

1:15:31 BJ Miller: Yeah.

1:15:32 Debra Schwartz: As you come into your new world.

1:15:34 BJ Miller: Yes. Inside and out.

1:15:35 Debra Schwartz: That's wonderful.

1:15:37 BJ Miller: It was. I'm very proud of that. Again, it was on a hunch to turn my attention to art history and study art. It served me very well, just like the hunch to go to boarding school. And I remember an early moment when you start getting playful with it. You start seeing your life as raw material. Once you can turn the pain down a little bit, you can feel these moments of playfulness around it, like when I took the covers off the prostheses, that was a real intense [experience]. I had this moment — it was from studying modern architecture and hearing about Louis Sullivan and Mies van der Rohe and others who pulled off and revealed the structure of the building and celebrated the structure itself and didn't shellac it up with veneers. I was like, "Wow, right." And meanwhile, I had these foam covers on my legs that were sort of the norm.

1:16:34 Debra Schwartz: They were long pants and you couldn't tell.

1:16:37 BJ Miller: Yeah.

1:16:38 Debra Schwartz: You've always been, your devices are, they are always just exactly what they are. Every time I've seen you, you don't cover the middle. That's what's very interesting about you. If I may be so bold as to comment on this, it is that you don't seem to have any self-consciousness about this. You are right out there. You're using these wonderful devices that allow you to move as well as they do. And I've seen you riding your bike on Mount Tam with your dog running behind, and you are hauling ass on that bike. [laughs] So obviously, these guys are your friends.

1:17:13 BJ Miller: Yes.

1:17:14 Debra Schwartz: And you stripped off the exterior cover and put them out there and yourself with them.

1:17:18 BJ Miller: Yeah.

1:17:23 Debra Schwartz: And this is me.

1:17:23 BJ Miller: Extremely therapeutic for me. It took me a while to feel —

1:17:25 Debra Schwartz: You came out.

1:17:26 BJ Miller: Exactly. That's exactly what it was. And I learned that from what I learned in modern architecture, studying modern architecture. And there was another day where I'm looking at old sculptures and, of course, you notice a lot of old sculptures, they're missing a limb because just from wear and tear over the years, and then we're sitting there, admiring these structures that are essentially amputated sculptures. And in

that context, you started getting hip to the idea that context is so key, you can play with your context. And so I'm seeing this, we're all studying, admiring this, and they look a lot like I do. And so it was a nice little segue for me to actually see my body and think of it in beautiful terms. There's something beautiful about a human body, period. Not mine, but it allowed me to delight in it.

1:18:16 Debra Schwartz: Oh, I disagree.

1:18:18 BJ Miller: Well.

1:18:18 Debra Schwartz: Don't say anything negative. I'm a mother, I don't like to see people put themselves down. It's a beautiful body.

1:18:24 BJ Miller: Thank you. [laughs] Thank you. At that time, you can imagine I felt, on some level, pretty ugly.

1:18:32 Debra Schwartz: Yes.

1:18:33 BJ Miller: This was a real spring-loaded moment to see these statues. And it might even sound kind of oversimplified because a listener might say, "Well, yeah. Duh. But those statues were knocked over from years ago and wouldn't it've been better if you could see the whole statue with all the limbs and whatever else?"

1:18:48 Debra Schwartz: It is what it is.

1:18:49 BJ Miller: It is what it is. These were lessons I was directly applying in learning from studying art. And I started to feel creative. I started to feel more playful, and I started to feel more safe in my body. And that took between two and five years for me to get there.

1:19:07 Debra Schwartz: It sounds like you were more empowered.

1:19:10 BJ Miller: Right. And ultimately you start realizing that for any of us, the trick is the same. Making the most of what you got.

1:19:19 Debra Schwartz: Taking life on life's terms.

1:19:20 BJ Miller: You deal with the cards you're dealt, period. We all have to do that.

1:19:28 Debra Schwartz: Which is so interesting to say this because you are in hospice care. So let's go forward a little then; let's continue on. You're finding yourself, you're evolving as a human being as we all do. You're growing up. You're 19. You're progressing now. You've had a stall just a bit and a big shock, and you're pulling yourself together, and you're not only just pulling yourself together and having it happen naturally as can happen with healing, but you've got a little bit of a jazz going from the creative process.

1:20:05 BJ Miller: Yeah.

1:20:07 Debra Schwartz: When you talk about it, I see that little sparkle of creativity, that sense that there's something going on here that's unique and exciting, and I'm here.

1:20:18 BJ Miller: These were my variations on the theme. This was my life and I was loving it. My homework was learning to love myself, and I got there. [chuckles] Just to be clear, I have my insecurities. I'm comfortable being insecure.

1:20:41 Debra Schwartz: Comfortable being uncomfortable.

1:20:43 BJ Miller: Yeah, that's it. But yes, so then graduation rolls around. I had no idea what the hell I was going to do to make a living. I was just very much [trying to] get through the day. And another way that accident was good for me, was making me stay in the moment. I wasn't a good art historian and I didn't want to use it as a profession, but I didn't know what else I wanted to do. Just as we're talking, I had become aware that this suite of experiences was very informative to me and compelling for me. And thanks to my mom and the Disability Rights Movement, I was aware, keenly aware, that disability is not something you overcome. That's a narrative of able-bodied people who are like, "Am I gonna overcome this?" No. This is my reality. I'm not putting it behind me. It's my daily reality. That's not a sad statement. I accept that. At some point, you're looking in the mirror, you're not sitting there seeing all that you don't have. You're just seeing what you got and you're working with that.

And so I knew that I wanted to find work that I could use these experiences either directly or indirectly. These were too formative for me and too beautiful for me to not work with, too important. I knew I wanted to be in some service work because I had been on the receiving end of so much love and care and I had been really turned on to what that means. Anyway, long story short, it's medicine that lit up as a way to do that. "Gosh, wouldn't it be cool if I were a doctor?" And then I could work with other people who were newly disabled and help bridge these gaps that I know that they've got — all the gap work that they have in front of them. I would be particularly well-suited, I thought, to work in that zone.

1:22:44 Debra Schwartz: I should think the admissions offices of various universities would think so, too.

1:22:49 BJ Miller: Well, it was an interesting time. And so some were. UCSF was. I remember on the interview trail for medical school — I went back and did the pre-meds after college. Two years. One year in Denver and then I moved to Oakland and did second year pre-meds at Mills College after I graduated college. Then I got into UCSF and that's where I went to med school.

1:23:10 Debra Schwartz: Not an easy school to get into.

1:23:11 BJ Miller: No, it's not. I was fortunate to come from a place like Princeton, etcetera. It's not like I had MCAT scores off the charts. I had a story that I owned and loved and could demonstrate. And I could make the case that my experiences taught me all sorts of things that would make me a better doctor.

1:23:32 Debra Schwartz: I'd like to read your admission statement.

1:23:35 BJ Miller: Yeah, I kind of would, too. I don't know where it is.

1:23:37 Debra Schwartz: There's got to be —

1:23:37 BJ Miller: It's got to be somewhere, in some office. So I was looking for a school but there are not a lot of folks who've gone to medical school with physical disabilities like mine. It's kind of uncharted. And again, this is not too long after the ADA came out, and you could tell. Getting interviews at med schools, I only got a few interviews, but there you could tell that they didn't know what to do with me. They were afraid to ask about it and so I got proactive and would talk about it and make the case that this was a useful thing. And at least one school, UCSF, bought that narrative. They really believed that.

1:24:17 Debra Schwartz: "They bought it." [laughs] I love how you say that.

1:24:18 BJ Miller: Yeah, they really bought it. They heard me and they believed me.

1:24:25 Debra Schwartz: And that's how you came to San Francisco?

1:24:26 BJ Miller: Yeah. And so off I went into med school here and thought I'd go into rehab medicine because I wasn't there for a love of medical science. I was there to learn some new tricks to apply and I thought, "Well, the best way to apply it would be in this rehab setting, work with other disabled people, blah, blah, blah." Long story short, I fell out of love with that when I finally did a rotation senior year of medical school, and I was actually going to drop out 'cause I had promised myself — one of the things I had picked up was I wasn't afraid to fall, I wasn't afraid to fail anymore, not in the same way I had been as a kid. So the idea of going through four years of medical school and realizing it really wasn't for you and dropping out, that didn't bother me so much.

1:25:09 Debra Schwartz: I guess after going through 19 years of being in your body and have it totally switch out, after that you could probably pretty much handle anything.

1:25:19 BJ Miller: Yeah. You've got to be careful. I remember in the early days, in the first two to five year zone, I stepped into this confidence that we're kind of describing and there was a period when, if I had been a little 'fraidycat as a kid, now I was quite the opposite and risk-taking, I loved risk-taking. And part of what I was feeling, I was like, "Well, what are the odds of something else happening?" It just seemed like I'd had my hardship. And so now, somehow, the math of the gods meant that I —

1:25:54 Debra Schwartz: Men's minds! That's all I can say. [chuckles]

1:25:55 BJ Miller: Yeah, it was a dumb mind and maybe those are synonymous. So for much of my 20s, I look back and I was courting more disaster.

1:26:09 Debra Schwartz: Do you think it was "bring it" kind of thing, like "Come on, bring it. You've got more?"

1:26:12 BJ Miller: A little bit. On the good side, it was borne of a hearty confidence and a belief in myself to get through hard things. And if I didn't, if I died, that's okay, too. Part of, I guess, this brush with death made it less scared to die.

1:26:38 Debra Schwartz: Had your sister died then?

1:26:40 BJ Miller: Yeah. So senior year of med school, a lot of things were happening. I'm realizing that I don't like rehab medicine. Shit. I'm realizing that I'm not sure what else I'm going to do, but I had promised my — what I was trying to say was, I'd promised myself I wasn't going to waste a life in a sacrificial pursuit. If medicine was too hard or I didn't enjoy it, I wasn't going to do it just to do it. That was the deal I made with myself. So I was preparing to try to figure out what to segue to next, and then in the middle of that — oh, and then I had to take a semester off to have some revisionary surgery to my stumps, to the legs, so I was holed up at my parents', and at that point they were in Milwaukee. I was on their couch for two months recovering from the surgery, taking a semester off from med school, thinking about all this stuff, and then Lisa killed herself, December 1st. We had been together as a family that Thanksgiving in Milwaukee and —

1:27:42 Debra Schwartz: Do you ever get nervous around the holiday season? Gee whiz.

1:27:43 BJ Miller: Oh, yeah. My family and I, we were just — totally.

1:27:48 Debra Schwartz: And here it is November.

1:27:49 BJ Miller: We're coming up on it. The first 10 years, these anniversaries really flummoxed me, not in a conscious way. I just noticed I was irritable, off.

1:28:01 Debra Schwartz: Waiting for that shoe to drop.

1:28:01 BJ Miller: November 27th was my accident anniversary; December 1st was Lisa's suicide anniversary. Thanksgiving had been the last moment of a previous life in both situations. So, yeah, so it was all loaded. We always fought on holidays, anyway, as a family, thanks to Lisa. So we're all loaded. As a family, my parents and I have just copped to the holidays. We promise we won't plaster a smile on ourselves and we can bitch and moan if we want to and we just let it be.

1:28:32 Debra Schwartz: No expectations.

1:28:33 BJ Miller: Yeah.

1:28:34 Debra Schwartz: The purge.

1:28:35 BJ Miller: Yep.

1:28:37 Debra Schwartz: So you don't like rehab and —

1:28:42 BJ Miller: So Lisa dies and I had already begun my — anyone, I think, who enters medicine with any ideology, which most of us do because there's too much work to do if you're not committed to some sort of ideal, for everyone there's some period of disillusionment where the practice of medicine doesn't add up to what, on paper, what you think it should feel like and should be like.

1:29:10 Debra Schwartz: Is this during the residency where you're doing all the grunt work?

1:29:14 BJ Miller: Yeah. It's brutal. And it was easy to look ahead at the attendings and my bosses and they looked miserable. They were working their tails off and the whole thing was starting to look like not such a great deal and then Lisa's death was just a — sort of, like, "I can't even" — she was so obviously bipolar, in retrospect. And here I am learning medicine, I didn't pick that up. So I was questioning my own capacity to be in this work for a number of reasons, and I said, "Screw it." So I talked to my deans. But I was going to graduate, just at least get my diploma. My dean said, "Well, I hear you, but you should think about doing your internship, which is your first year of residency, one post-doc year, because after your internship at least you can get your license to practice and it's just a better place to stop. You can always jump back in." So I said, "Hmm, okay. Well, I'll go back to Milwaukee and re-group with my parents." And, as you know, Debra, I had left home when I was fifteen, so I hadn't lived at home for a long time. I said, "Lisa just died, let me go back to Milwaukee, live with Mom and Dad, do my internship there and just re-group as a family." And so, that's what we did. And during that internship, I got turned on to palliative care by just doing an elective rotation and fell immediately in love with it for all sorts of reasons. So that's how I got to that point.

1:30:42 Debra Schwartz: How did you come back to California then?

1:30:47 BJ Miller: So I finished my internship. I graduated UCSF, went to Milwaukee for my internship, then had that experience of palliative care, got turned on. It was like, "Oh gosh, maybe I really do want to do medicine now this different way." I came back to San Francisco after my internship to think about it. And a friend of mine and I had started a little tea company in the interim. Part of studying China had turned me on to tea, and my roommate in boarding school who was a dear, a brotherly friend —

1:31:17 Debra Schwartz: What tea company?

1:31:19 BJ Miller: It was called Tribute Tea. It's just teeny little internet — teeny. It still technically exists. Justin still runs it up in Seattle now. We never got anywhere near off the ground, but this was setting up to be my — what I thought of what I was going to do instead of medicine, and we had already got it started. So anyway, back to San Francisco I spent a year or two playing with the tea thing, thinking about "Do I really want to re-enter medicine?" and I decided I did. I then went and I needed to jump into an internal medicine residency. I could have gone back to Milwaukee, but I wanted to stay in California, so I waited for a spot to open up somewhere on the coast and it did in Santa Barbara at Cottage Hospital.

1:31:56 Debra Schwartz: Oh, Cottage Hospital.

1:31:58 BJ Miller: Yep, you know it?

1:32:00 Debra Schwartz: I've lived in Santa Barbara twice.

1:32:01 BJ Miller: Oh yeah?

1:32:02 Debra Schwartz: Lovely, sweet hospital on a hill. It's lovely.

1:32:06 BJ Miller: Yes.

1:32:07 Debra Schwartz: On a hill, it's kind of a rolling.

1:32:12 BJ Miller: The last time you were there, was there was a brand new, ridiculous, amazing hospital campus?

1:32:17 Debra Schwartz: No, I haven't been there for a while, but I've been in the hospital, and it's a great spot. It's beautiful there.

1:32:25 BJ Miller: It is. Santa Barbara is —

1:32:26 Debra Schwartz: You can ride your bike just about anywhere around there and there's the ocean. Now you're living a California life.

1:32:33 BJ Miller: Exactly. I loved my time living in San Francisco and Oakland, but it was living in Santa Barbara, even with the backdrop of doing a residency, which was kind of brutal, but with Santa Barbara coddling me, and learning to love the light in this state, especially that southern exposure you get in Santa Barbara. When you look out on the ocean there, you're really looking south, so you got this beautiful, crazy southern light off the ocean and those hills.

1:33:06 Debra Schwartz: Those hills that just shoot straight up.

1:33:08 BJ Miller: It's just stunning, it's so beautiful. And it was there that I really fell in love with California. That I really felt at home and really deeply loved it.

1:33:16 Debra Schwartz: And now, how old are you?

1:33:19 BJ Miller: That would have been 2004, 2006, so I would've been 33 or 35.

1:33:29 Debra Schwartz: Nature has a way, doesn't it?

1:33:33 BJ Miller: Mm-hmm.

1:33:35 Debra Schwartz: Soothing the tortured soul.

1:33:37 BJ Miller: Totally.

1:33:38 Debra Schwartz: Recalibrating.

1:33:39 BJ Miller: Totally.

1:33:40 Debra Schwartz: Bringing you back home to yourself.

1:33:44 BJ Miller: And feeling part of the natural world, not just a visitor. One of the vexing things about my earlier education was how we would talk about man versus nature, as though somehow humans were not natural. [chuckles] That thinking is so — well, we're seeing a lot of the fallout of that thinking.

1:34:01 Debra Schwartz: Yeah. So you're now a California boy.

1:34:04 BJ Miller: I finished my internal medicine residency just to get to a palliative care fellowship, just to get into the field I wanted. So then I did that. I did my palliative care fellowship at Harvard, so I was in Boston for a year, and then knew I wanted to come back to California. I did, came back in 2007, and joined faculty at UCSF. So that's how I got back here. And when I moved back in 2007, I lived in Oakland to start — and I lived in the Mission for years through medical school — so this time, for all the reasons we were just saying, I knew I wanted more and more nature. Anyway, so I went to Boston, then came back here, joined faculty and moved to Mill Valley in 2007.

1:34:45 Debra Schwartz: How Mill Valley? Now, here we are in the Mill Valley Library, and one of the reasons why I'm talking to you is because in Mill Valley, we like to know our community. I think I told you in the beginning before we had the interview, that I really believe that this: we, the people of Mill Valley influence the area, but as well, this area influences us. Mt. Tamalpais, the proximity to the ocean and all the natural beauty. How was it you found Mill Valley?

1:35:14 BJ Miller: Well, I have to thank my realtor/friend, Elizabeth Kilgore — we call her Bizz. She and I were buddies from when I lived in San Francisco. She grew up

here and she works over here in Marin. And when I was moving back to the Bay Area — I knew at that time, in 2007, that I was really actually serious about my work now. I knew what I wanted to do, and in my mind I was going to live in the city to be near UCSF. I didn't want a big commute. I wanted to just really commit to work. So I looked at a bunch of places, and I love working on my home. I love creating the environment. I love owning a home so that I can play with it and fuss with it.

1:36:04 Debra Schwartz: You're a nester.

1:36:05 BJ Miller: I love creating nests, and I also love leaving them. [chuckles] I am a little bit of a roamer, too. But I love playing with my home. And so Bizz, she knew me well, and she grew up here in Marin. So she showed me a gazillion places in the city, and then one day this place. It wasn't on the market yet. She knew it was coming on the market, and she said, "You know, you should really come look at this place." She knew me and she knew I would love it, and so I have to give her credit for bringing me to Mill Valley. It was seeing that house up on Hillside and driving up that hill —

1:36:47 Debra Schwartz: Are you on the high part of Hillside? Where you look out into the valley below?

1:36:50 BJ Miller: Yeah.

1:36:51 Debra Schwartz: Right below the Elinor Fire Road?

1:36:53 BJ Miller: Yeah.

1:36:54 Debra Schwartz: Because I've seen you on Elinor Fire Road several times.

1:36:57 BJ Miller: I am at 279 Hillside, so it's crested, it's just the long spine of that.

1:37:03 Debra Schwartz: There was a slide there on that section. Is that the area you're talking about?

1:37:07 BJ Miller: There was, not far from me, just a little farther down the road. So it was a combination — she drove me up the hill, and I had been trying to force myself to stay. I knew I wanted to be outside as much as possible, but I was trying to stay close to work, to stay devoted to work for these early years. But in my heart, in Santa Barbara, here, any chance I get, I just go outside. I go to the woods, period, every chance I get. Or just outside. It doesn't have to be even the woods.

1:37:43 Debra Schwartz: Just raking leaves.

1:37:44 BJ Miller: Yes.

1:37:44 Debra Schwartz: Reading a book outside on your deck.

1:37:47 BJ Miller: Yeah. Anything outside. I've always been that way, and I just get more and more that way. And being turned onto the natural world more and more as I've gotten older and older.

1:37:56 Debra Schwartz: And there are many smells.

1:37:57 BJ Miller: Oh, totally.

1:37:58 Debra Schwartz: The bay trees, the pine trees.

1:38:01 BJ Miller: It's so beautiful.

1:38:01 Debra Schwartz: The warm soil.

1:38:03 BJ Miller: It's so engaging. And you get to feel part of this.

1:38:05 Debra Schwartz: In the mist.

1:38:05 BJ Miller: I love the feeling of feeling small. So I love looking up in the night sky. I love being in monumental nature. Because it's sort of a right-sizing. I feel it puts me in proportion. Otherwise, I'm left to my own devices and the cues we get in society and the pressures of work, you start feeling like, "Oh my God, I've got to change the world with my job. I've got to do something." It's very easy to get outsized, and just out of proportion.

1:38:37 Debra Schwartz: Nature recalibrates you.

1:38:38 BJ Miller: Totally. So I wanted to be near that, but I was trying to resist moving far from work.

1:38:45 Debra Schwartz: You didn't want to commute.

1:38:45 BJ Miller: I didn't want to commute. Anyway, Bizz shows me this house, and so we're driving up that winding road. It's so friggin' charming.

1:38:52 Debra Schwartz: Did you go up Hillside, or did you go up —

1:38:53 BJ Miller: Went up Hillside, yeah.

1:38:55 Debra Schwartz: Yes, okay.

1:38:55 BJ Miller: I didn't know where we were going.

1:38:56 Debra Schwartz: Windy, windy, windy turn, hard turn, up you go.

1:39:00 BJ Miller: Exactly.

1:39:00 Debra Schwartz: Up you go, all around.

1:39:01 BJ Miller: You're coming through the old village, a town which is so friggin' charming, and then right when you're entering Blithedale Canyon, the redwoods take over and it's just so —

1:39:11 Debra Schwartz: Through Miller Grove, then you take your right, and you start the twist and turn above the church.

1:39:16 BJ Miller: You got it.

1:39:17 Debra Schwartz: Yes.

1:39:18 BJ Miller: And so every inch was just — from the city and the highway, and then every inch, I was so excited as we were driving, because it was like an odyssey. I didn't know where we were going to land. I didn't know where we were going end up, but each inch was more and more beautiful and more and more compelling.

1:39:33 Debra Schwartz: And more and more you, I think.

1:39:35 BJ Miller: Yeah. It felt certainly more like at home. Early on, I was very concerned about keeping my wants and needs few. I wanted to find something to commit to, to get outside of myself, so I was also not listening to parts of myself just yet. I wanted to stick with the human stuff. I wanted to stick with work for a while. But I couldn't resist this seduction when I saw this house. We walked up the stairs, and it was late afternoon, the backyard looks out over Mt. Tam, and pretty much due west, so you've got that gorgeous red light, that late afternoon light, coming through the house. So we walk up the stairs of this thing, and I'm already in love with it. I open the door, and there's just this baking red glow of light. And that was it. And there's this gorgeous oak tree in the backyard, and that was it. I was completely sold. Resistance was —

1:40:33 Debra Schwartz: The sirens of Mill Valley drew you in and swallowed you.

1:40:37 BJ Miller: Totally. And it was all because of the landscape.

1:40:40 Debra Schwartz: And you went willingly.

1:40:41 BJ Miller: Absolutely, wholeheartedly, willingly, and loved it almost immediately. We're what, 10 miles from the city, and we get to have this kind of nature? It's absurd. It's a daily, pinch-yourself kind of feeling.

1:40:58 Debra Schwartz: So, you'd found your spot, you found your place. But you work as Executive Director of —

1:41:08 BJ Miller: So I was full time at UCSF, inpatient and outpatient, a very busy, young, sort of junior academic. I knew that wasn't really my home in a lot of ways. I'm not an academic, I'm not a researcher —

1:41:25 Debra Schwartz: And that's a research hospital.

1:41:26 BJ Miller: It is, and it's a wonderful place in a lot of ways. But I felt more poised to be a straddler, so I was looking for the exit, not to leave UCSF —

1:41:36 Debra Schwartz: "Poised to be a straddler". That's a really good way to put it. [chuckles]

1:41:38 BJ Miller: I really feel that way. So I have one foot in the ivory tower at UCSF, and one foot out in the community. I like to cross lines. So I was looking for some community role, and then Zen Hospice Project was reopening its doors. It had closed the hospice house for many years, and I got wind that they were reopening their doors, and that they needed a new executive director. And they weren't looking for a medical person, that had never been part of their mix.

1:42:13 Debra Schwartz: Oh, interesting.

1:42:14 BJ Miller: Zen Hospice Project, very much cut from an old cloth. That hospice is largely volunteer driven, not medically driven. In fact, you'll absorb from a lot of the old-time hospices real suspicion of medicine, that medicine has actually got it all wrong and medicine's a little bit of the enemy. So it was interesting to work there, to walk into that, to put myself forward for the executive director job, which is another piece. I had no management skill, but part of my comfort with discomfort means I'm constantly pushing myself outside of my comfort zone — sometimes too much. But for this case it was like I believed in the mission of this little organization. It had a house that wasn't a hospital, it had infrastructure, it had bricks and mortar, it was beautiful and made the point that the environment has so much to do with how we heal and how we feel. It had that in its bones, and so I was very attracted to it.

And then from a professional standpoint, being in the community and also learning new tricks, the idea of being a boss, and trying to raise money, and being an administrator, and manage and all that stuff. I knew that I, like a lot of docs, pooh-poohed the administrators. "Those guys, they sit in their cubicles. They don't understand this. They got it easy in their cush jobs." I probably absorbed a little bit of that junk and was aware too that that was probably BS. I was keen to go put myself in those shoes and learn, and I did. So I worked at Zen Hospice for five years from 2011 to 2016. I loved it in a lot of ways. It was a crazy-making job, too. One of the things I've learned is I'm not much of a manager — and we could talk for a long time about that — but I learned a lot, loved it and then after I felt like I had learned and tried everything I could, it was time to move on. So five years out it was time to leave. And at that time I gave a TED talk.

1:44:12 Debra Schwartz: Yes, so you were featured on TED Talks.

1:44:15 BJ Miller: Yeah.

1:44:16 Debra Schwartz: Many of the things that we've discussed today were in your talk.

1:44:22 BJ Miller: Yeah. And that came about in a weird way. That came about because I'm very interested in crossing the disciplines. So palliative care, this is a field that's devoted to mitigating suffering and promoting well-being and quality of life — beautiful mission, stunning, and unique in healthcare, and super ripe to cross the disciplines. If your subject matter is suffering and quality of life — that's not just a medical thing. Art is in that, philosophy is in that, religion, nature. It's a real invitation to blow up our idea of healthcare in the best way. So, I had come to have some conversations with guys at IDEO, the design firm, and that had come about because I was, on the side, trying to start a little prosthetic shoe company with my friend in Chicago.

1:45:14 Debra Schwartz: No way.

1:45:15 BJ Miller: Mm-hmm. Because one of my pet peeves was — there are these cool engineered prosthetic feet but then —

1:45:21 Debra Schwartz: No tread.

1:45:22 BJ Miller: They always assume that you would want to wear a normal shoe.

1:45:26 Debra Schwartz: Yeah, yours have tread on them.

1:45:27 BJ Miller: Right, and that's not the norm.

1:45:29 Debra Schwartz: Wow.

1:45:30 BJ Miller: It was part of that path, like the coming out of the closet thing, where they had these foam feet to give you the shape of a foot so you can buy normal shoes.

1:45:41 Debra Schwartz: And then look like you have regular legs with normal feet.

1:45:44 BJ Miller: Which is ridiculous. And the dynamics that forces on a normal shoe from a human able-bodied foot was very different from a prosthetic foot. It was just a square peg in a round hole. So my friend Lissa and I were going to try to start a little company that built shoes specifically for prosthetic feet because they still needed some kind of a tread. But we dropped that. I couldn't do that and the other things. Long story short, that project introduced me to the guys at IDEO. And while I was having this conversation with the guys at IDEO about prosthetic feet, I was talking about the therapeutic potential of aesthetics and the senses, and they lit up because, of course, as a

design firm they believe that and they were very interested to think about how their work could be relevant to healthcare and specifically the end of life care and palliative care. So we hit it off, and I had this really fruitful conversation over a couple visits and I met a few guys there and it was just interesting.

1:46:45 Debra Schwartz: And then somehow you ended up on TED?

1:46:48 BJ Miller: One of those guys, David, this crazy, hilarious, wonderful Scotsman who worked at IDEO, then Googled me, and realized my day job. He called me up and he said, “Hey man, we gotta talk more about this ‘cause there’s a lot I think we can do together.” And over that relationship, he then nominated me for what’s called the TED X Prize, which I didn’t even know existed. I didn’t even know he was doing this. Long story short, I didn’t get the TED prize, there’s a million bucks.

1:47:25 Debra Schwartz: Oh, that’s too bad. [chuckles]

1:47:28 BJ Miller: Yeah, too bad, but I was runner up, so they called me, “You don’t get the prize, but would you like to give a TED Talk?” At that point, I was working at Zen Hospice Project and were constantly trying to get our story out there and to talk to people, to raise money, raise awareness, so there was no way I could turn down that opportunity. So I gave a TED Talk, and that thing took on a life of its own. That made it clear to me that the world outside of the industry of hospice was starting to do what we’d all hoped it would do which was start paying attention to our mortality, that our time on earth is precious and short, and that we should all learn to appreciate what we have while we have it. So a subject that has been traditionally taboo in this country, was now there’s a feeling that it’s thawing, that there’s an opening. And that TED Talk proved the point. People watched it. And so, denial, yeah it’s a big issue, but I’m more finding that there’s a pent up interest to talk about death and think about it and prepare for it, which was great. This is exactly what I would ever have hoped for.

1:48:38 Debra Schwartz: Wasn’t there Franciscan monks at one point who would greet each other with “Remember dying”?

1:48:48 BJ Miller: Mm-hmm.

1:48:49 Debra Schwartz: That’s the daily greeting.

1:48:50 BJ Miller: Right.

1:48:52 Debra Schwartz: And then our culture today, where we don’t slaughter animals to eat, many people don’t care for their loved ones as they die — bury, personally bury things. There’s a detachment. Do you ever wonder that there’s a longing that people have to have that kind of connection?

1:49:11 BJ Miller: I’m convinced there is, that not everybody but many people, latent or otherwise, have a real longing to do just that. Once you get past that fear and worry

and absorption, the fact that, “Oh God, someday I have to die.” People that work in a hospice, it’s like we have a secret. You think it’s going to be morbid, and it’s intense, but it’s also very life-giving. It really helps you live your life. So that death can be a teacher, keeping our mortality in plain view. Because it is. It’s around us all the time. Death’s around us all the time whether we see it or not. It’s just in the falling leaf or whatever it is. If you can keep that in your mind, like those monks, you’re more poised to appreciate your life while you have it. You’re more poised to feel connected to other mortals and other things that lose everything. You’re much more poised to prepare for it so it doesn’t take you by surprise. And you don’t suffer unnecessarily.

So it has all these beautiful side effects, once you dare to look at it. And we’ve been cut off from that. In the same way we’ve been cut off from other aspects of nature to our own detriment. And I think we’re in a period where there’s sort of an awakening among many people that, “Oh, maybe we went astray there. Maybe we alienated ourselves from natural forces to our own detriment.” So I feel like there’s this waking up happening. There’s a waking up about the healthcare system and its ills and its problems. So waking up to the fact that we actually die someday no matter how much kale you eat or how many cigarettes you don’t smoke or whatever it is. And there’s that going on with climate, this idea that the planet or whatever I do here can affect people halfway around the globe, and the idea that resources are extinguishable, that we could actually end our lives as a species or that of many other species. That’s a profound realization. And that’s of our time. So in my mind, all those forces are conspired to create a new opening for interest in this subject.

1:51:25 Debra Schwartz: I suppose denial has been a part of the process of imperialism. It’s possible that if you can open yourself to the reality of death, you have the strength to open yourself to the reality of many things. It opens a window to the truth of where we live, what we’re doing here, how long we have and the suffering and the beauty that comes with it. You’ve been involved in helping — do you ever feel like a midwife?

1:52:00 BJ Miller: I feel like an usher. My word is “usher.”

1:52:03 Debra Schwartz: You’re an usher.

1:52:04 BJ Miller: Yeah, I’m with people in this transition zone. There’s part of that journey that they’ve got to do by themselves. But there’s this feeling — I feel like I’m doing a lot.

1:52:14 Debra Schwartz: What people who are hearing this can’t see is that you’re moving your hands from one side to another. The movement.

1:52:22 BJ Miller: Yeah. And that is a midwifery mentality. Just as our birth doulas, they are now death doulas. So people engaging in this subject in new ways. But to answer the question, yes, I do feel very much like a midwife.

1:52:43 Debra Schwartz: Which is, I should think, an inspiring place to be.

1:52:49 BJ Miller: Yeah.

1:52:50 Debra Schwartz: I've seen death in my life. I've lost people I care a great deal for. I've been involved in the hands-on care to the end. And in my limited experience, which is nothing like yours — I imagine maybe hundreds, if not more, of people, maybe a thousand, maybe more, people you've been involved in — I have noticed that there can be a swirl of magical, amazing things that happen, mystical even. Even for the greatest deniers, the most practical, an individual cannot deny the times — things happen beyond our understanding that insinuate within you, a sense that this is truly mysterious and beyond our knowing, but nonetheless what it is. And it inspires you to think of something beyond.

1:53:43 BJ Miller: Yeah.

1:53:43 Debra Schwartz: So have you had any strange, mystical experiences that have informed your philosophical mind as it collects and utilizes what you've learned?

1:53:56 BJ Miller: Much of my life, maybe all of my life — and especially it hit overdrive with my injuries and the experiences that went with those — I feel in touch or aware or witnessing mystical experiences all the time, and wandering around on the plane of not knowing and mystery all the time. I feel so tied in to that and my work just furthers that. I've not had any levitation moments; I've not met any patients who've died and come back. So in the more stereotypical sense, I have not had these mystical experiences. Rather, what's more telling with more of my experiences, is that death, when well-managed, the process of it, ends up actually feeling kind of — it's sort of mundane and stunning at the same time. You lose, you get past the sensationalism of death, and it feels like just another moment. And that's part of the mysticism. It's a continuation of the unknown mystical parts of daily life, and it is part of daily life, and daily life is stunningly mystical and not understood.

1:55:33 Debra Schwartz: I know. Having a child, I remember feeling very distinctly that I was a part of something, that there was a process going on that I wasn't initiating, but I was riding along with, and that I was both involved as well as observing and participating, all at the same time. And it felt uniquely natural. Never doing it before but it felt like very, very much a regular thing. Even though it really wasn't. It was kind of a polymorphic experience on a lot of levels. So in my experience with death, I've felt that there's a similarity that you observe while you're being moved along and that's part of being alive.

1:56:29 BJ Miller: Totally. That's so beautifully said, Debra. I agree with that. If someone was trying to wrap their heads around dying and prepare for it, part of their homework is learning to live with things that they don't quite understand, yet feel part of. Just like exactly what you described, this polymorphism, this polyphony of the experience where you have to — the skill, if there's a skill to cultivate, would be holding

multiple things at once, what can feel like opposing emotions, but they are not really, they're just different emotions. They're just all happening simultaneously. And to be fully integrated and feel part of this larger thing that you still don't know and understand but you know because you're part of it, you're just a small part of it but you're an essential part of it. This is where language gets really tricky and it's hard for me to describe it, but you know it very well and I think most of us, if we're paying attention, should know it because daily life is filled with that.

1:57:26 Debra Schwartz: In a culture that wants definitive, that wants to have one thing or another, the idea of having many things, all simultaneously, and each one of them as valid as the other, rather than one being better than the other, that is to expand your ability to experience life in its fullness, I think.

1:57:48 BJ Miller: I completely agree.

1:57:53 Debra Schwartz: I think some people hearing us today may not understand the difference between palliative care and hospice care.

1:58:01 BJ Miller: Yeah, thank you. It's an important point. Palliative care is interdisciplinary care within the context of serious illness. In other words, we don't call palliative care in when someone's broken a bone. The context is serious illness and that usually means incurable or something life threatening, but it's simply the interdisciplinary pursuit of quality of life and the mitigation of suffering. That's my job, to participate in that. In that definition, you notice there's no mention of death, there's no mention of time. To qualify for palliative care, you just need to be suffering [chuckles] which is pretty much all of us. Hospice is that subset of palliative care that is reserved for the end of life.

So if you were to come to my clinic at UCSF in the Cancer Center, you would meet patients who are years from their death, may still even be cured of their illness or are already in remission, but they're still coming to see a palliative care team because they're suffering. Whereas hospice, to qualify, you have to be near the end of life. It does revolve around death. By virtue of the Medicare benefit, in 1982, to qualify for hospice, the doctor has to say you have six months or less to live, and you also have to give up other modes of care. To go into hospice, you've to give up trying to cure your disease. For most folks, there comes a time where you're not giving up anything that's going to help you anyway. You're beyond treatment. So oftentimes, that is not a fool's tradeoff, but oftentimes it is. So one of the challenges we have in hospice is around the insurance designation that puts this fork in the road and makes people give certain things up to get hospice. There's a problem with that and it's one of the reasons why we elect hospice, if we ever do, really late in the game.

So the average length of stay is just a few weeks in most hospices. And plenty of people are on it for just a day or two, which is really late in the game. So anyway, that's the relationship. Hospice is the mothership, in a way. Modern hospice movement started with Dame Cicely Saunders in the UK in 1967. She started St. Christopher's Hospice. And

then it came to our shores. Hospice of Marin, 1975 was one of the first. Then it became this insurance designation with these limitations. But more to the point, everyone who works in hospice and around it sees people who are battling their disease. And then once they're beyond this battling phase they yield and they soften. And then all of a sudden, they're in hospice and they're surrounded by love and people are tending to their symptoms and tending to their family, and just caring in this other way. And then you see people perk up. You see people thrive in hospice, [chuckles] which is beautiful. And one of the realizations, of course, is why do we wait 'til the end of life to exercise this muscle with each other? Why wait 'til the end? Why don't we do this earlier?

2:01:27 Debra Schwartz: You have to earn it?

2:01:28 BJ Miller: Yeah, right. Things have to be brutally difficult and you have to go through some gauntlet to get to this mode, which is silly. We're suffering throughout our lives and we never know when death's coming anyway. So this kind of thinking spurred the palliative care movement to grow up around hospice, to do away with this six months or less thing, to do away with, "Oh, you have to give up certain kinds of care to get it." Palliative care is much more open-ended. It is irrespective of death, but includes end of life care. So does that make sense?

2:02:03 Debra Schwartz: Yes it does.

2:02:05 BJ Miller: That's a really important point, by the way, for any listener, because right now most people think that palliative care is end-of-life care. And so therefore they don't want palliative care because it means they're dying, or they wait too long and they suffer unnecessarily. So it's a really important point for the public to get. I'm sorry, you were going to say —

2:02:19 Debra Schwartz: I was going to ask you, because your physical presence has import, how has that been for your patients the first time? The reactions when you go to see people that are injured, perhaps cancer, they've had surgery, parts are missing, any number of things. But people, by the time they're getting ready to die, most of them, they are now in a state of disrepair.

2:02:45 BJ Miller: Yes.

2:02:46 Debra Schwartz: And then in you walk.

2:02:48 BJ Miller: Yes.

2:02:49 Debra Schwartz: 6'4", beautiful man, parts missing.

2:02:54 BJ Miller: From all of the things we've talked about, all the lessons learned and the insights gained and the confidences gained, and all the good stuff that's come, I love that. I wouldn't trade this stuff. Of course, it's a silly question. I can't trade this. But if someone were to make it possible for me to get my old body back but I'd have to give

up the lessons I got, I would never trade. The picture you're painting is really right-on. I love it because for the most part, I don't know, 90% of the time, when I'm meeting a patient, you can take one look at my body and you'll know that I —

2:03:49 Debra Schwartz: Understand.

2:03:50 BJ Miller: That I was in the bed. I've been in the hospital bed. I've been through some stuff. Things have gone wrong. I've had to dance as a patient. I don't have to say a word, my body says all that. So I walk in with the benefit of the doubt from my patients. I feel I get to a place of trust much more quickly than some of my peers. Especially my peers who look 25 years old and it's hard to imagine they have any real wisdom.

2:04:21 Debra Schwartz: Who's this young whipper-snapper here telling me what it is to get old?

2:04:25 BJ Miller: [chuckles] Exactly. Right.

2:04:26 Debra Schwartz: It must be palpable. I can only imagine. In my family there's a lot of illness. I've spent a lot of time in hospitals. And there is that sense that you can be just a number in a system that is growing increasingly more heartless and less supportive. Healing is so many things. But when you have that doctor where you can feel the trust, that is one of the — I watched with my father and his medical practice, trust is so much of healing in palliative care. So in you walk. I should imagine it's palpable; you could probably feel it, anybody could, that sense of relief, or that moment — have you ever had patients just look at you and smile?

2:05:12 BJ Miller: Oh yeah, all the time. Again, it feels like such an awesome shortcut. [chuckles] Certainly, I've screwed up relationship with patients. But I get a running start with them. It doesn't often surface into frank conversation about my illness. We'll touch on it, indirectly or otherwise, but I'm always aware that it's registering, and almost always for the better.

2:05:43 Debra Schwartz: For a person that wants to be out there, you know what it is to have the love and support of people that are caring for you at your most vulnerable. It must be so gratifying to walk in and know just your mere presence is already doing something.

2:06:00 BJ Miller: It's very fortunate.

2:06:01 Debra Schwartz: That's very cool.

2:06:01 BJ Miller: I feel very lucky that way.

2:06:07 Debra Schwartz: We live in Mill Valley, this is our community. One of the reasons I like to interview people in our community is because we're in it together.

You're doing good work here. You're doing important things. Your example is an example for all of us. These stories are stories that we can all learn from, and we need to help and support each other's experiences. What can you tell our community about what we can do, or what it is that, through your experience, what improvements can be made, or in your dream of the perfect death, the perfect way to live and be a community member and be supportive of the work you do, what would you say to us in town?

2:06:56 BJ Miller: Well, there are a few layers to answer in that question, Debra. One is more general, it's almost an ethos. It's a way of being, a way of thinking. I guess I would encourage any community to dare to set the right perimeter, to circumscribe itself, to insist that however a community sees itself it includes sickness, vulnerability, death, grief. Not out of some pity or charity thing, but because those are going to be universal experiences for everybody, and that those can be, therefore, these radically inclusive, binding, community-making events, if you lean into them. So as a community that is trying to find and set its vibe, its character, and to claim itself and name itself —

2:08:08 Debra Schwartz: To be where you want to live?

2:08:09 BJ Miller: Yeah, to be where you want to live. And as you're pointing out, people make up the community. You can set these tones. So be ruthless about making sure that you cast a really wide net on what is real, and don't accidentally or purposefully try to orphan the hard stuff or the ugly stuff, or keep it out of your community or something like that.

2:08:33 Debra Schwartz: What a way to put it, to "orphan" that. To cast away. It doesn't serve anybody.

2:08:40 BJ Miller: It doesn't. Especially when you're dealing with a universal subject. It never pays to castigate people based on things outside of their control whether it's their race, or religion, or whatever it is. But when we're talking about suffering and death, 100 percent of any community's members are going to have these experiences, so you are casting yourself out of your own community if you don't capture the right stuff. So one thing in the articles of confederation, in the ethos that makes up a community, is that you embrace that full spectrum of life.

2:09:16 Debra Schwartz: Remember dying.

2:09:17 BJ Miller: And part of that is remembering dying, and that it happens, that it will happen, it's the most natural thing imaginable. And that we have a lot to offer each other in that experience and to learn from each other in that experience. Now, I would love to see communities begin to take pride in how we age and die, rather than get it out of sight or whatever other things we do to further alienate ourselves. So that's a big piece. It's sort of an ethos. This rigorous devotion to a full reality, a full sense of reality, that's a big piece. And part of that ethos that comes from that then is this linkage that you and I know about from our own life experiences, and we touched on it earlier, but how care giving and care receiving are linked. It's not like the well people are up here and they

bestow this charitable kindness to those poor, wretched people down there. No, there's a give and take at all times. It's one of the ways that medicine went astray in its own ethos, that we cultivated doctors who are trying to be machines, who tried to have no life of their own. To be a doctor, the way you showed you cared was you never left the hospital. You didn't eat, you didn't have any needs of your own, you were meant to be a caring machine, like a one-way street, invulnerable yourself. Of course, that's crazy and it doesn't work for anybody. So, explicitly seeking to link the giving and receiving care and uniting those, and seeing those in a full life — I often find myself talking to people about this that we, in some ways, it's easier to love things than it is to be loved. I actually, especially in the healing professions, the caring professions, I meet a lot of people who are not very good at being loved.

It's its own skill. You have to be vulnerable, you have to let someone help you, you have to let it in, you have to realize that you have to be humble, that you can't do everything. So there's some hurdles to get through, but it feels really good to be loved. And so this brings up another piece of this ethos about the community is part of valuing a full reality is understanding that none of us is independent. No one who has ever lived — I would sign my name to this, I would bet the farm — no one has ever lived or ever will live, within the foreseeable future, has ever been independent. There's no one who needs nothing from anybody else, period. It doesn't exist. So, it's another way we separate ourselves. We have the dependent people over here, the independent people over there, that's bullshit. We're all on some spectrum of dependence.

2:11:58 Debra Schwartz: Co-dependent independence.

2:12:00 BJ Miller: Right. That's another part of this ethos. You see yourself in each other, and each other in yourself. And that's the aura I would love to see in the community.

2:12:19 Debra Schwartz: Like a matrix.

2:12:19 BJ Miller: Yeah.

2:12:21 Debra Schwartz: And then also the part about healthcare, in that, in my experience anyway, it's more than the patient. The suffering is so much more than the patient. It radiates all around. Sometimes the patients are unconscious, and the family, the way they sleep at night knowing that their loved one is cared for and seen. And the attention to their suffering as well.

2:12:58 BJ Miller: You got it. And that's sort of the devilish thing about compassion. Compassion is that beautiful, essential human quality. It means "suffering with." If you are compassionate, you are feeling the suffering of others, whether you're a family member, or a friend, or a stranger.

2:13:18 Debra Schwartz: So the capacity to be uncomfortable?

2:13:20 BJ Miller: Exactly. The capacity to sit with suffering and not run away from it, that would be an essential skill to inculcate in a community. Beautiful things flow from that.

2:13:34 Debra Schwartz: How do you see that happening? How do we incorporate that into community, practically?

2:13:39 BJ Miller: Well, right, to get from that ethos to something more practical. One thing is, for all of us, we should probably own our experiences as folks who are sick from time to time. It doesn't need to be you wear it on your sleeve, and we shouldn't make it too much of our identity, I don't think. It's a piece of the puzzle, but it's a piece of the puzzle we should own with some pride. I was forced to with my visible disability, but those of us who don't have the good or bad fortune to have a visible disability, I think we should, on some level, just be owning our suffering and demanding that it be part of any definition of a normal life — that we should be out of the closet, too. Everyone should be out of the damn closet in a community, at least on most levels. I'm sure there are certain things that deserve to be private, etcetera. I'm not saying that we should be up in each other's business all the time, but I do think this demonstrating to the world, showing our sufferings, showing our illness, so we aren't seduced into thinking that, "Oh, there's something wrong with me for being sick. I screwed up, I'm failing somehow." That message of failing, that message of shame, to be ashamed of something outside your control, to be ashamed to be sick, to be ashamed of dying, is so sad and I see it all time.

2:15:06 Debra Schwartz: Ashamed of being vulnerable or not perfect.

2:15:09 BJ Miller: Yeah. Who the hell's perfect? And they'd be so boring, anyway. This recasting healthcare and thinking about societies might be different. The closest thing I have to an enemy is shame. Why we make each other feel bad for feeling bad? We hold each other accountable to things outside of our control. It's cruel, it's just cruel. There's no other way around it. If that's the anti-goal, the goal is really to help each other and to live in a society where we can appreciate what we have, but while we still have it is the trick. Most of us get to that place of appreciation right when we're about to lose it or we have lost it. And it's a daily reminder for me to appreciate what I have, and living in this landscape helps me do that very much. But I think that has to be part of our daily work together to create that community. But you asked about some more practical things. Our public structures: schooling, healthcare, public housing, restaurants. We should, in the best spirit of the Americans with Disabilities Act, we should be an accessible place. So that you're not cast out because you lose a limb, or whatever else.

2:16:29 Debra Schwartz: Or you're in a wheelchair 'cause you're on chemotherapy.

2:16:32 BJ Miller: Whatever it is.

2:16:32 Debra Schwartz: Or you had a seizure disorder.

2:16:35 BJ Miller: When it comes to the built environment where we are actually creating the infrastructure, that infrastructure has to be rigorously, universally accessible. And I think that would help pull people out of their closets. Now kids, kids used to freak out when they'd see me. And they'd have questions, but they weren't used to seeing this. Now you see disabled people on television ads, and kids are fascinated. And it's just because we disabled people are more visible. That's the only thing that happened. And so similarly, if we have the structure that allows people to be visible as they are, then the fear goes away, the hatred goes away.

2:17:19 Debra Schwartz: Familiarity.

2:17:19 BJ Miller: Yeah.

2:17:20 Debra Schwartz: What's alien and what you don't understand seems daunting, but once you do—

2:17:25 BJ Miller: Exactly.

2:17:26 Debra Schwartz: Then it's business as usual.

2:17:27 BJ Miller: Exactly. And I would say, the last structural piece of this, creating this community, besides the accessibility of it, is to take beauty and inspiration very seriously.

2:17:40 Debra Schwartz: Take it personally.

2:17:41 BJ Miller: And take it personally. These things I think if we really want to invert how we treat our elders, for example, if we want to create a society where you can — I really like this phrase — “crescendo to your death,” where you’re not withering away and getting out of the way, but that you’re developing and growing into your death. I love that image.

2:18:05 Debra Schwartz: “Withering away and getting out of the way,” you have a way of saying things.

2:18:08 BJ Miller: This is a lot from seeing —

2:18:11 Debra Schwartz: Vivid, that's very nice. I appreciate this, yes.

2:18:15 BJ Miller: I just feel like I see it.

2:18:16 Debra Schwartz: And the crescendo, where you have somebody — it can feel like that at the end of someone’s life.

2:18:23 BJ Miller: It totally can, and it's mostly that you have to get out of the way. Support the person, but that stuff's happening if you let it and you watch your

assumptions and you watch your projections. But beauty, for me — and I don't mean beauty like prettiness, I mean beauty like something that's real and authentic and true in and of itself, and that makes me glad to be able to even be in its presence, it's not strategic, it's not just purely utilitarian, it's aesthetic for its own sake. So building things, art projects, architecture, building the material fabric of society that inspires us and has us love the material world, even while we're trying to not be beholden to just the material world. You can imagine if any community — if Mill Valley — had a stunning piece of architecture that was a hospice house right in the middle of town, my guess is that that would transform a community.

It happens with Zen houses. You find yourself wanting to be in this building which otherwise you would think should scare you, or be the last place on earth you'd want to be, but somehow it compels you, wills you into it. You can tell a lot about what a town cares about by its architecture. So if you go to Princeton you can see how gorgeous the architecture is and that campus is stunning. It tells you that someone took this very seriously and takes learning very seriously, and it just sends a signal. If we did that with a hospice house, over time I have to imagine that alone would build for a very interesting and much more caring community. So those are my thoughts in answer to your question on what we could do differently.

2:20:18 Debra Schwartz: We've talked about so many things. I really do think that you have vividly and beautifully taken me on this amazing journey today. Have we missed anything? Have I passed over anything that I should be seeing?

2:20:37 BJ Miller: No, my friend, I think that's about all I got. I'm not sitting on anything in particular.

2:20:44 Debra Schwartz: How about what's ahead?

2:20:48 BJ Miller: Oh yeah, so I'm working on a book. I left Zen Hospice a year ago for a number of reasons, but in part so I could be responding to this external call for more conversation on this. So I've been doing a lot more speaking with people, public speaking, and also took on a book project with a friend of mine, a woman named Shoshana Burger, who lives over in Berkeley. I wish she lived here with us, but she's a journalist and a designer by trade. She and I have teamed up to write a book that's tentatively called *How to Die: A Field Guide*.

2:21:27 Debra Schwartz: Like an Idiot's Guide to Dying kind of thing?

2:21:29 BJ Miller: Essentially. What is hospice? What is palliative care? How to talk to your doctor —

2:21:34 Debra Schwartz: Oh, it's such practical, important information.

2:21:36 BJ Miller: It's very practical.

2:21:36 Debra Schwartz: I can tell you, when you need to have simple information at the most important time of your life, that learning curve is a problem.

2:21:46 BJ Miller: It is, and it's absurd. And from the profession's point of view, when you think about how much time I spend just covering the very, very basics with patients and their families, if the public discourse could lift enough so the basics were generally understood, we could get to so much more interesting stuff. We wouldn't be so waylaid just by the basics. So that's the spirit of this book. Simon and Schuster's publishing it. It'll probably be on shelves in about a year. We're still working on it. And when I leave here I'm going to go upstairs and start working on it some more. So that's coming, and hopefully we'll find the right tone and the right amount of information, the right dose, and it'll get out in the world and help. We'll see.

Then, otherwise, besides that, a couple different things I'm thinking about. One might be to build a care facility that's case in point, like we discussed here — to function very locally, build such a place. On the other side, part of me wants to work at a much more universal larger level, and so I've got to figure that out. But the project that's really lighting my heart up the more and more I think about it is a project that a guy — I was at the Aspen Ideas Fest a couple of years ago and this guy was mentioning his idea that he called Care Corps, "corps" like Peace Corps. And the idea was, loosely, a lot of details still to figure out, but what he suggested was that why don't we create this sort of civilian army of young caregivers? Maybe young folks sign up for a year or two of service. And essentially I would start an organization that would train and support these young caregivers to be essentially personal care attendants, home health aides. This level of the healthcare system right now that's covered the least well: the Certified Nursing Assistants, Home Health Aides, Personal Care Attendants, the bottom of the professional totem pole, the pay is lousy. There's no support. But these are the guys who are actually with the patient all the time. And they're poised to do so much good. The idea of Care Corps would be the set this program, sign up for a year or two to function in this capacity and in exchange, they'd be either in college loan forgiveness or some program to get you into college or into the health sciences or something. We'd have to figure all this out. But essentially, you'd be creating a civilian army of caregivers.

Practically speaking, that could do a world of good. That could keep people out of the hospitals who don't need to be there. It could push back on the scourge of loneliness, which I can tell you is a huge, huge deal, especially at the end of life — isolation, loneliness, this would push back on that. This idea that young folks coming up are so in their virtual world and not in the grit of the visceral, and to have young folks working closely with someone who is frail or elderly, it would be hard work but they could learn so much for their betterment. You'd have a pathway for wisdom to transmit from the elders to the youngers. I love what it could be. I've got to figure out if that's really what I want to do — that would be a life's work — and then I've got to figure out how to fund it, etcetera. But as I sit here today, those are the two ideas. One hyper-local, one hyper-un-local. And we'll see, by this time a year from now I hope to have figured that out.

2:25:31 Debra Schwartz: People in your life — almost everybody has somebody in their life or multiple people if you're lucky that have really made a difference for you. Do you have people in your life, those people that for whatever reasons were the conduit for your growth or understanding or inspiration that you'd like to mention?

2:25:53 BJ Miller: Well, for sure. So my family, of course. You've heard me describe them and even the hard times were incredibly formative and supportive, too. Immediately, my parents and my sister. And then from there, I have been blessed with very good friends, and part of these good friendships have come from being forged in some pretty intense experiences. As you know, these can be real bonds. It's like going to war with someone I would imagine. But my friends from Princeton who helped me through the injuries: Jonathan Baker, Peter Austin, Tommy Pinckney, Alex Hemingway, Sue Buck, Ellen Scott and many others. I feel so lucky and one of the ways I feel so lucky was — the feeling that I got to go to my own funeral. I got to see who showed up. I fell apart and I got to see who showed up and lived to delight in that. And a lot of people showed up. And then, my childhood friends who then circled back, Justin Burke, I mentioned him, he was my roommate in boarding school, my tea partner and a true brother, he's been amazing forever in my life. Johnny Burr, my first grade school friend in Chicago, he and I are still close. Julia Muliken, she's now Julie Denapoli, she was my 4th grade girlfriend. [laughs] We're still close.

And so I've been so blessed to have these amazing friendships that have stuck with me through a bunch of stuff. They're forged in the fire and they're durable as hell. I can't say enough about those. More recently, another Mill Valleyan, Mike Rabow. R-A-B-O-W, Rabow. He's technically my boss at UCSF, he developed the clinic where I work. But he's become a real true friend in a really great sense. And so he's sort of a mentor professionally but also a brother and friend. So he's a huge piece of my daily inspiration and others, too. Blake Kutner in the city. Jessica Saffra, who works in hospice and lives in Tiburon, she's a huge part of my life. The woman you've dealt with in just scheduling this, the woman who works for me, technically, Sonya Dolan. She is a huge part of my daily life and has become a really good friend. She's like a sister in a way, too. I could go on and on and keep naming folks, but those are some folks who come to mind, who are daily pieces of my life and I can't imagine life without them. And the way I got to have those relationships was by living through the very things we've talked about. They're part of the upshot, part of the silver lining for me.¹

2:28:41 Debra Schwartz: And what about your dog?

2:28:43 BJ Miller: So, right, beyond the human world [chuckles] there is Maisey, my dog.

2:28:55 Debra Schwartz: Who's a really good sport, 'cause you ride your bike fast. [chuckles]

¹ Rico Cerrato and Matt Giudice are two more daily, dear friends.—BJ Miller.

2:29:00 BJ Miller: She's such an athlete. I've never seen a dog so coordinated, and she's stunning.

2:29:05 Debra Schwartz: Yes, she is, like a gazelle running after you.

2:29:06 BJ Miller: She is. I feel very connected to Maisey. I have two cats, the Muffin Man and Darkness. If you walk up on Hillside, they'll probably greet you outside. They hang out outside and greet people walking by. So those three beasts are a huge part of my life. My first service dog when I got out of the hospital, Vermont, who went through med school with me and finished college with me, died in 2002. He was a huge piece. So the human piece, but connecting to animals and feeling kinship and the rest of the natural world — trees, inanimate objects — I have gotten as much from those connections as I have from the human ones. And I could just talk for hours about those. They're elemental to me.

2:29:56 Debra Schwartz: Yours is quite a story. I've waited a long time to hear this story, and really, it is much more than I thought it would be, I have to say. And at the very end, it really comes down to those people, those few people that you love and love you. And the connection. And nature. And that's it in a nutshell, isn't it?

2:30:28 BJ Miller: Yep.

2:30:28 Debra Schwartz: And then the rest, how you handle it, how I handle it, and the creative forces we use to assimilate and metabolize daily life, that's our earthly experience, I guess.

2:30:43 BJ Miller: Yes, it ain't so bad. Not easy, but pretty amazing.

2:30:48 Debra Schwartz: Yes. When you were singing, did you have any favorite songs?

2:30:53 BJ Miller: I loved choral music. I loved chamber music. There was no particular piece, any one piece in particular, but I loved singing liturgical and chamber music.

2:31:03 Debra Schwartz: Sometimes we close with a song or a phrase. Anything coming to mind?

2:31:11 BJ Miller: Let's see. A song doesn't come to mind. Let's see, what does come the mind? Nothing's popping up. How about for you?

2:31:24 Debra Schwartz: I think we've said it all.

2:31:27 BJ Miller: Yes, maybe that's why.

2:31:28 Debra Schwartz: I think it is. I think this is a natural stop here. BJ, thank you so much. Thank you so much for coming to the Mill Valley Library in your busy life. I know you had planned to spend the afternoon writing and this was a long interview, but I very much enjoyed everything that you've said, the profound wisdom. Thank you so much for sharing and being so open with your experiences. I think this interview is going to be moving to a lot of people on a lot of levels. It certainly has been for me. I'm glad that you're a part of our community. Very, very happy to have you here.

2:32:04 BJ Miller: Thank you, Debra.

2:32:04 Debra Schwartz: And I hope I see you on the Elinor Fire Road again.

2:32:08 BJ Miller: You will. [chuckles] Yeah, you will.

2:32:10 Debra Schwartz: Okay, well, this is the end of your oral history. On behalf of the Mill Valley Library and the Mill Valley Historical Society, I thank you so much for your time, and I'll see you around town.

2:32:24 BJ Miller: Debra, that's sounds beautiful. Thank you so much for having me, and I feel very honored to be invited to do this. And can I mention one more person that I forgot?

2:32:33 Debra Schwartz: Yes.

2:32:33 BJ Miller: Who was part of my Mill Valley experience, too? I had a marriage that came and went while I lived here. And her name's Jori and she and I are still very close. We're much better off not as spouses. But that was another part of my life here in Mill Valley. I got to have a marriage. And we got to put that marriage down in a peaceful, beautiful way, too. And like I say, it was all good, but I love Jori very much and I just needed to name that. It has also been very much part of my life here.

2:32:58 Debra Schwartz: I'm glad we remembered Jori and included her.

2:33:01 BJ Miller: Me too.