

The Art of Asking Everything

BJ Miller: An Expert on Death Talks About Life

Amanda Palmer 00:35

This is The Art of Asking Everything. I'm Amanda Palmer. This week's guest is BJ Miller, an expert on death, talking about life. Doctor Bruce "BJ" Miller Jr. is a hospice and palliative care specialist, who treats hospitalised patients with terminal or life-altering illnesses. He grew up in Chicago, and strangely for a doctor, or I don't know, maybe not so strange, he studied art history as an undergrad at Princeton.

And the backstory here is kind of important. I met BJ at the TED Conference in Vancouver in 2015, where I watched him give a TED Talk called "What Really Matters at the End of Life." And I remember sitting there in the audience, feeling so comforted by what he was saying about how bad we are as human beings at dealing with death and dying people. And he was talking about his work at a place called the Zen Hospice in San Francisco, and how one of the most important things they do there for intervention is to bake cookies every morning, so the air in the hospice smells sweet and comforting. His talk made me want to cry, I think I actually probably did cry, multiple times during the talk. And also there was something about the way BJ put the audience at ease. Because there was an awkwardness in the air. And he started his talk by saying, "I know you're too polite to ask, so I will tell you." And he went on to explain the story about why he looked the way he looked.

So, he had been horsing around with some of his friends in college, and they had climbed atop an electric commuter train, and BJ came in contact with the wires, and it sent 11,000 volts of electricity through his body. And he lost his legs beneath the knees, and part of one of his arms at the elbow. And then he went on to go back to an Ivy League school, and he became a doctor, and an expert in death.

And right around the time we spoke, which we did in a little recording studio that I rented in Marin while I was in San Francisco on tour in May of 2019, BJ was putting the finishing touches on his new book, *A Beginner's Guide To The End: Practical Advice for Living Life and Facing Death*. And I had just asked his permission to please forward a

copy of the pdf that he sent me to three friends that I had in my immediate circle, who were all dealing with parents who were just about to die. I could not wait to talk to this man, and I could have talked to him for five more hours, fifty more hours, and I'm hoping, in fact, I have him back as a recurring guest on this podcast, because there's so much more to ask.

This one is really good y'all. Here we go. BJ Miller, death expert. And he'll probably kill me for saying it, but really, life expert, on top of all of that stuff.

(Music break)

Amanda Palmer 04:09

One of my favourite things that I read that you said in an interview from a few years ago, is that you hate being a poster child. I mean, I think I get what that means, and I can relate. You have to define and describe yourself for people and you have this physical attribute that's really obvious. What do you find that brings up when you have to describe yourself to people?

BJ Miller 04:31

Because the issue of my disability is so obvious, it can be hard for people to see past. It's dramatic. You don't easily forget the one limbed guy you know. So, it just means that it revs up the project-o-meter, we're all throwing things at each other all the time, but I feel now like basically a big billboard walking around that people throw stuff at. And I take that seriously, I take on my symbolic... I think we all have a sort of symbolic life that people see in us and take from us, and that we are tokens for various things for various people, not in a bad way. And I just want to be careful to not... I don't want to take that seriously and not over-ramp it up, because it could be very easy for me to just stop with my disability in some public way, that's a big enough subject. It's interesting enough for people, I could just be that. Just be that disabled guy. Growing up with a disabled mom, I saw how that could happen, and being in rehab, and playing Disabled Sports, I saw that happen with a lot of people and people became flattened. It's kind of easy to forget parts yourself for underdeveloped parts of yourself.

Amanda Palmer 05:39

But if you have one giant attribute of your identity that stands out, you didn't become only gay...

BJ Miller 05:46

Right, if I had huge tits, right? If I were just, I'm all tit to people, right? You know like, yeah, that happens very easily.

Amanda Palmer 05:52

So I'm sort of struggling with that at the moment. Because I mean, my way of going into it is probably your way of going into it, which is I just fucking talk about it all the time. With this album and on this tour, especially because of what's going on politically in America, I have become 'the lady who had three abortions.' Because I'm being really open about it, and I'm going around and I'm talking about it. But there's also this part of me that's really squicked by being 'the abortion lady.'

BJ Miller 06:22

Yeah. I can imagine.

Amanda Palmer 06:23

Because it's this one strand of my life. It's real. It's true. It's useful, just like this is a strand of your life that's useful. But there's a part of me that just... even talking about it with you now sitting here, I'm just like, ugh, like it's just not...

BJ Miller 06:41

It's not because you're ashamed of it in any way, just because it reduces you.

Amanda Palmer 06:45

No. Yes. And because, I mean, I don't know how you feel about this stuff in this regard, but I want people to be able to see through that to the giant whole, to the 12 dimensional human being that I am, who happens to have this one attribute. I had a bunch of abortions. I also just went through a miscarriage. I'm a weirdo artist who decided to take those experiences, mine them, harvest them, put them on a stage, talk about them, because I thought that the act of doing that would probably help other women and help other people. But I almost didn't. Because, unlike what you've got going on, you don't have to talk about your abortions. You could just stick them in the closet, and get on with shit, and no one walking down the street would go "Ohh, look, abortion lady!"

BJ Miller 07:37

Yeah. I get a version of it, for sure. Which is why I also think what you're doing - and frankly, what I'm doing - has some courage to it. I mean, I'll just speak for myself. It does pull me out of my comfort zone to be sort of out of the closet with myself in ways, it does.... to kind of subject myself to the narratives of others in a big way. I do feel that

that is a little bit... it could be either very narcissistic and self aggrandizing, but I think the way we're wired it feels actually a little scary, and means that we're whipped around by the feelings and beliefs of others, in a pretty extreme way. And in that way, for me, one of the ways I feel good about all this is it actually does feel kind of ballsy.

(Music break)

Amanda Palmer 08:31

Well, you've said that you used to cover everything up. And then you got to a point where you realized - actually I'd love if you would tell the story. You were actually influenced by architecture and art.

BJ Miller 08:44

Yeah. I was injured age 19, sophomore year, right? So November. So when I came back to school, the following fall, I had to kind of declare a major. And I had been studying East Asian Studies, blah, blah, blah. And I was headed in one direction. But while I was out, being a patient, art really ascended, in my view, in all sorts of ways. But essentially, for all those reasons, I chose to study art history as my major, for therapeutic reasons. It was explicitly me trying to use what remained of college to help me learn how to cultivate a way of seeing. A way of looking at the world. And it felt like playing around with art would be a very useful way.

Amanda Palmer 09:28

And this is while you were at Princeton.

BJ Miller 09:29

Yeah. So it felt like this would be a very useful therapeutic skill, not a recreational cocktail party skill, like art history can be. No, this was really meant to learn from art and the artistic process, how I might apply that to my own life. So I was explicitly seeking that. I'll give myself credit for that, that was a good decision. I mean, that was a smart move. And it really helped.

Amanda Palmer 09:52

Did anybody guide you in that direction? What happened between 'I need to pick a new major' and 'oh, art history.'?

BJ Miller 09:59

Sitting in a hospital, sitting in a burn unit, with a lot of time on my hand. Time sitting there and you know, you're running through all sorts of thoughts that, really, now I have

the language for it, really relates to identity. This was a shock to my identity, like, who the hell was I now? I wasn't the guy who was rowing crew anymore. I wasn't the six-five dude. It changed my architecture, at least... I knew that persona didn't reside in someone's feet. I knew enough from my mother's example, and just from being in this world. My mom had polio and uses a wheelchair. You met her!

Amanda Palmer 10:39

I loved your mom. I'm sad that your mom's not here, actually, I was hoping she would come to my show.

BJ Miller 10:43

Oh, that would be so awesome. I would love her to. She's in St. Louis though, but I love that you guys met, that was very moving for her, and for me. It was so sweet to meet you after, it was like, moments after coming off that TED stage by the way, and what a weird feeling. And to be received by you and Neil with compliments and love was really kind and helpful.

Amanda Palmer 11:08

Yeah. Well, I had also gone through the weird TED...

BJ Miller 11:12

Hole?

Amanda Palmer 11:12

Yeah, because I gave the, like... I was like the belle of the ball at TED for three seconds. And I remember it being really disorienting.

BJ Miller 11:23

That's the word for it. Not all bad, just disorienting.

Amanda Palmer 11:26

Disorienting.

BJ Miller 11:26

And it was very helpful to find someone like you who could kind of help ground me in a kind way, and help me feel like what I had just done was alright, and anyway, you really did me good, and my mom too, so thank you.

Sitting in a burn unit for months, right? And you have all this time to think about how... what am I now? Am I... Am I less of a person? I have fewer body parts. You know, by some measure, I'm less, you know, around the language of disabilities all about being less than. I had a head start thanks to my mom, I knew that that was all could be potentially a bunch of bullshit, it was very ripe to be revisited. So I was trying to revisit it, trying to explore how I could see myself differently. But between the pain and the newness of it all, I wasn't getting very far.

But I was sort of now imagining coming back to college. I knew I wanted to get back on that horse relatively quickly, for a number of reasons. So I wanted to go back to school that fall. I caught up with my class, I wanted to graduate with my class. That was important to me for a number of reasons. But I was kind of ramming myself forward. The hunch was, physically I should get back on this horse. Because the longer I wait, the harder it's going to be to do that physically. And that the emotional stuff, I knew I wasn't emotionally ready, but I knew I wasn't going to... it wasn't going to be possible for me to be emotionally ready, that that was going to take years. And so I might as well just start somewhere. And at school, I had friends, I had familiarity, etc.

So that was the reason to get back to school. But then this question of, okay, what do I do with college? Part of what you're going through when you come close to death is this sort of re-appreciation of what you have. And I was really trying to love what I still had left. Really trying very hard, because I knew that was a good idea. I wanted to love what I had left. Didn't really feel it, but I wanted to get there.

So all of a sudden, studying Chinese language and East Asian Studies just seemed less interesting to me. So, there was a void. This question of perspective, that perspective was the thing. I needed to find a way to look at myself, see myself in the world that I could love. And that was the word, perspective, that kept coming up.

So when I was thinking about all this stuff, I knew I had been into music and art in a casual way my whole life. And had always been interested in why people make art, and that question starts to set up, what makes a human being a human being? Why do people make art? Why do we refashion our experience? Why do we play with our lives the way we do, and create from them? Why do we represent our experiences? That had been a casual interesting question. But now this was very much what I was asking myself sitting in a burn unit bed.

And then I had my buddy Justin. So, Justin Burke was my roommate in boarding school. And the closest thing I have to a brother, he's a wacky weirdo. Smart, goofy, lovely guy.

And he was a year ahead of me, he was at school in Britain, and he was studying art history. And so he would come visit me in the hospital, and we'd just get in these wonderful conversations about art. And it just was very easy to see as he was talking about art, the relevance to my life became very clear. So it was really talking with Justin, and thinking through why people make art, and seeing how much freedom there was in the creative process, but also as the viewer, as the receiver of art, to look at it differently, to see it differently, to challenge my own convention. All that was lighting up, basically in casual conversation at my bedside in the hospital with Justin.

(Music break)

Amanda Palmer 15:37

Do you have any memories of experiences when you were in the burn unit of experiencing art, whether it was music or looking at anything that spoke to you,

BJ Miller 15:48

Almost in a negative way, it was sort of like the burns unit is a maximally sterile environment. It's like a concentrated version of all that's horrifying about a hospital in concentrate, because sterility is the thing. There was no window in my room. As this happens, right? The negative examples can be so potent, and for me, the negative example was now I was starved for art. I was starved for any aesthetic experience.

Amanda Palmer 16:18

There's no beauty in there.

BJ Miller 16:19

Zip. Zilch. There was plenty of beauty in human behaviour, but not in material setting.

Amanda Palmer 16:28

How long were you in there for?

BJ Miller 16:28

Burn unit for about three months or so, and then step-down unit in that hospital for a couple weeks, and then I flew back to Chicago for inpatient rehab. I was in New Jersey then Chicago for rehab for about a month or five weeks inpatient, and then home for the rest of the summer.

Amanda Palmer 16:44

But three months is a long time to be in a windowless room with no art.

BJ Miller 16:48

It is. I mean, it's a prison, and you can't move much, it really is a hell. There's a hellish nature, the burn units are classically hells on Earth, I mean to work in and be in. The screams coming from patients rooms, going to the tank room to be debrided every day. I mean, it's just...

So one on the one hand, you have all these obnoxious signals of the material world, your body screaming at you. You've got this absence of any beauty whatsoever. And of course that's hard and sad. And as a negative relief, it really makes you appreciate...

Amanda Palmer 17:25

When you've got it.

BJ Miller 17:26

When you've got it. So I remember the first time I went from horizontal to vertical, just that was an amazing experience. Just to reorient my line of sight from, you know, from supine, to sitting up. That alone was a magical experience. The fun part of all this is it reacquaints you with the most basic stuff in life. Your vantage point, and the difference that makes. Feeling gravity. I was all of a sudden fascinated by gravity. I felt like I weighed a thousand pounds, just because I hadn't fought against gravity for a while. I mean, just little shit was helping me be fascinated by the material world again, and be so clear at what a balm beauty could be, because I was starved for it. Does that make sense?

Amanda Palmer 18:14

It totally makes sense. As the person who's thought a lot about art and music, why we make it, why and how we receive it, and just how we feel about it on both sides. And the questions and the answers all get more complicated the older I get, they just don't get simpler. I mean, even just lately on this tour, feeling like I can use music as a kind of useful tool that actually just winds up landing on a person because they're sitting at a show, or they're listening to a record and they're weeping because it's just speaking so directly about loss, or directly about abortion, or directly about... and there almost is like a laziness in that. You know, I feel like like I can't win. if I were a better artist, these things would all be more lofty and indirect, and I would be speaking more universally. And since I'm like this lazy fucking folk singer, I'm just like, and then my friend died and everyone's like, 'No! No! Your friend died!' When I was writing obliquely and poetically, I thought that I wasn't a brave enough songwriter, because I wasn't able to say things directly.

BJ Miller 19:21

You're screwed.

Amanda Palmer 19:22

So, like most artists, I'm just constantly flagellating myself with a whip of doom and it's fine.

So you chose art history, partly because of the influence of your friend and partly because that door opened and it called somehow. But you weren't called to be an artist, which is interesting to me. You didn't decide to go into studio art major, be a sculptor. You decided to go into art history appreciation.

BJ Miller 19:45

Yeah. Because there you go, that was the word, appreciation. Learning how to see it more than make it in a way. Of course those are all related, and some insecurity about feeling that I had any talent to share anything. But really actually, what I think I was doing, I mean, yes, why people make art, the act of appreciation, those were front and centre for me, and so the observer role was very relevant. But also part of this breakdown, the breakdown before building up, the breakdown had me, like I was saying, so reacquainted with the material world and its most elemental basic, like gravity, physics, this very surface, liquid, just basic stuff. I was so re-enthralled with the raw material of material of life, that I was explicitly in my mind, I wouldn't have said it out loud because it sounds goofy, but explicit in my mind, I was going to borrow from the artistic process, and look at my life as an artwork, as a composition.

Amanda Palmer 20:46

Good idea.

BJ Miller 20:48

Yeah, it was a really good idea. Because it's playful. You can change it. It was a really useful way of...

Amanda Palmer 20:54

So you would have been what, like 19? So when you were headed into art history, did you have an inkling of 'and then...'?

BJ Miller 21:07

No.

Aanda Palmer 21:07

'I'm gonna...?'

BJ Miller 21:09

No.

Amanda Palmer 21:10

You're just like, I just went through this insane thing, and now I'm going to Princeton, I have to pick a major and this is the only one that looks like it has real meaning?

BJ Miller 21:18

Yeah, pretty much. I mean, it was either that or philosophy. And plus, I was just very busy with the act of getting through the day, was the other thing. So one of the gifts of the accident was that for someone who had sort of absorbed a driven nature, a suburban white guy with a dad who was successful by some measure, all that stuff, and being in a place like Princeton, you absorb a sort of future orientation. I'm gonna do this on behalf of this future thing. Always. I'm taking this test so I can get into Princeton.

Amanda Palmer 21:51

And be successful.

BJ Miller 21:52

Whatever. Yeah, exactly. You know, I just sort of absorbed, inherited that mode. And one of the great gifts was the accident just forced me, just made much thinking about the future not really possible. It wasn't clear I was gonna have a future for a while, and then I just couldn't imagine the future. So then it made me very one foot in front of the other, get through the day as a creative act, but just get through your day. And this way I kind of inched my way to graduation. It made graduation day terrifying because I realized...

Amanda Palmer 22:25

Now what?

BJ Miller 22:25

Now what? And I hadn't let myself even think of that, cos it was enough to get through, right? So it made graduation terrifying. But it really forced me in a way that I found so useful and has since become sort of very vogue, which is mindfulness, which is being

present, which is being in the moment. I didn't choose that, I just had no choice, I couldn't do anything but that. And that was very useful. That was very helpful.

Amanda Palmer 22:50

So what did you do? You graduated, and then what? You looked around, and what happened?

BJ Miller 22:55

So fortunately, you know, one of the things that maybe a lot of folks who deal with illness maybe don't say very often, but on some level, you're aware that you've got a great scapegoat. I've got a great excuse. You know, I had my excuse, right after graduation I knew I needed some more surgery on my legs. That offered me with a three month kind of recovery period.

Amanda Palmer 23:18

So do that.

BJ Miller 23:18

So I'll do that, and that bought me some time. And people will take it easy on you, you know, you've got this great excuse. You have to be careful because you could grind yourself to a halt with all this excuse, but sometimes you kind of let yourself use it, and my excuse at graduation was, oh shit, well, I can't think of the future yet, even still, because I got to get through the surgery. And then that sort of delayed and deferred things.

Back home in Chicago now, on my parents' couch, I had some surgery, I couldn't wear my legs for a couple months, so I'm on my parents' couch, thinking now, letting myself think about the future. And so I knew I wanted to do something with these experiences, they were too major for me to try to ignore, and I wasn't buying into this idea that you overcome your disability. I knew I wanted to use this, I was very rich in the ways we're talking. It pointed me to new zones, things that I would never have chosen, but was so grateful to have done. So I knew I wanted to work with it.

First, I thought I'd go into sort of disability advocacy work. My mom had done a little bit of that, and we knew folks in Chicago. I did a little bit of that. And I did arts advocacy in Chicago, and I worked in the Art Institute of Chicago in the archive for the fall. Did some disability advocacy work sort of informally, and then I would do that a little bit later on too. The advocacy work was, I felt, sort of like an activist heart. And I felt like the world

needed more art. And I also felt that the disability world was actually a creative world, it just needed to be reframed as such. So I was trying to find some nexus there.

Amanda Palmer 24:47

Of all of the gifts that TED has bestowed on me in weird guises, my understanding of disability as art came out of TED. I mean, just seeing enough talks and enough people doing enough things, and enough areas where I had to admit my own ignorance, pre-TED, and then after TED going like, wow, there's this whole world of insanely creative, open-minded, artistic interactions of human body and experience that I hadn't even thought to ponder. Because why would I? Because it hasn't touched my life.

BJ Miller 25:21

Yeah, you need a reason to. Isn't it fascinating? And that limit, and that relationship between creativity and limitations, like the fact that we have limitations of what gets us creatively thinking, find workarounds, work throughs, reframes. So the relationship between the limitation and the creative act is so...

Amanda Palmer 25:42

Yeah, and I actually have been finding this subject really fascinating lately because I've always had an inkling that limitations would help my art. And then I just started saying fuck it. I'm not getting stuff done, I'm just going to start applying these insane limitations and it's worked out beautifully.

BJ Miller 26:03

How cool.

Amanda Palmer 26:03

And I actually did. My first big podcast interview was with David Eagleman, do you know him? He's a neuroscientist and writer, researcher, and we had a great talk that I'd love to send you about art and time, and process, and it's right up your alley, you would love it.

Great.

So let's rewind because, back to the original question, half an hour ago, which was, there was a time where you felt like you wanted to cover yourself up. And then what happened?

BJ Miller 26:35

Okay so, we're retrospectively describing a process that was very full of peaks and valleys and lumpy and took a while, but early on, I knew I wanted to not be ashamed of my body. I knew I didn't really need to be ashamed of my body, but I knew I was ashamed of my body. I knew I was embarrassed. I had this sort of... It really looked like... my arm at the time just with a skin graft and some open wounds, I mean, it just looked like a slab of meat hanging off. It was just hard for me to look at. This is also different. This is 1990, 1991. This is right around the time where the Americans with Disabilities Act became law. So before that, disability for people that... in wheelchairs are sets of devices to expect to get into Rapid Transit on a bus or into an area, airport, or into a store, you had no legal protection.

Amanda Palmer 27:24

Or a concert.

BJ Miller 27:25

Yeah, or a concert. You're left to the charity of others, you know, and that just begets pity and all sorts of shit. So this is right around this time, but just right when there are becoming legal protections and disability was really conceived of as a civil right, to be in the world. I mean, there used to be laws in the books in Chicago in early 20th century where you could be arrested if you were seen with deformities in public. I mean, just crazy ass shit. Nuts!

I'm kind of going through my own maturation process, society is also in the midst of that same maturation process. I'm still caught with my... I was mildly repulsed by my body then. I mean, I looked absurd. I lost gazillions of pounds in the burn unit. I was still swollen in some places and atrophied in others... just not a great look. And you sweat like a fiend as an amputee, I was just... I would wear a sock on my arm to cover the skin graft. And the legs that I was given, the standard was to put these covers on the legs, these foam covers that more or less take the shape of a leg and more or less have a skin tone color, like they have four or five to choose from. You can be black-black or white-white, and some things in between. And you're never fooling anyone.

Amanda Palmer 28:41

Faux legs?

BJ Miller 28:43

Yeah, they kind of hold the shape of a pant, which is kind of nice. But they're not fooling anybody. It just seemed kind of grotesque, really. But that's what I got from the process, that's what I was wearing, and on some level, I was grateful for the silhouette. The

silhouette looked like a normal leg. Mildly freaked out by it, but also mildly hiding behind it.

Flash maybe a year ahead, I'm back and I'm at school, I'm on an architecture history class, and we're studying Louis Sullivan, and we're talking about how he and others began to strip all the applique off of buildings, and all the ornate stuff, and get to the structure that had been hidden and covered up with all this applique, to revel in the truth of the structure itself, in the material itself, not pretending to be otherwise. I remember sitting in that class, I'm like, hell yeah, right! There it is, man, I mean that was so right on. I had a sense, but hearing this and seeing it lauded by this professor, and these beautiful imageries and something now that they're teaching us, and it seems so incredibly relevant to me, and just humans in general. Like, celebrate what the hell you're made of, who you are, period, whatever the hell it is. What a wonderful message.

And so that day, so it was still slow, but I began by... I moved from a white sock, this orthotic sock on my arm, to I started wearing like paisleys and argyles, and like, fashionable socks.

Amanda Palmer 30:10

Argyle socks?

BJ Miller 30:11

Yeah, on my arm. So I was starting to play with it a little bit. I was still kind of freaked out, but I began to play with it. That was so therapeutic. This thing that you have to wear because you're embarrassed, versus this thing that you kind of get into. Like, that was a huge distinction.

Amanda Palmer 30:24

You jump from medicinal clothing into fashion.

BJ Miller 30:27

Yeah. And there was a such a lesson in that too. Why the hell do we... all adaptive equipment, I mean we use the phrase orthotic shoes to describe ugly shoes. Like, it just seems so silly and anti-therapeutic. Like, if you've got to use a wheelchair, wouldn't you, you might as well play with that wheelchair and sex it up.

Amanda Palmer 30:49

You know what's so interesting here is the paradox between what you're talking about experiencing in the burn unit, like a total lack of ornamentation. But then the freedom on

the flip side of the same coin, the freedom that can be found in lack of ornamentation. And a lot of it is about choice.

BJ Miller 31:12

Choice! Totally! Absolutely it is, yeah. It's a very important point. Feeling agency again, choice again, freedom again, was exactly the things that had felt lacking. I was just aware of what I was losing, what you can't do anymore, all that stuff. And to begin to feel agency again, even on small stuff like an argyle sock, you know, it's beautiful and super potent. And then, from there, you can extrapolate so broadly, so within a couple of weeks or months, I finally realized the foam covers on my legs were not structural. I just pulled them off. That day was a huge day.

Amanda Palmer 31:48

And was it kind of scary? Because you're always having to consider how you're seen. I find this conversation with you so interesting, because you're a man. And women get trapped in this sort of cycle of how we have to present, and it doesn't sound that dissimilar. I mean, there's always scale and everything's relative, but walking around with hairy legs is similar because there's a choice. But there's also the choice of dealing with the person on the subway who's going to say something, or the child who's going to point at you. And I just got a tweet from a woman a couple days ago who's like, oh, it's so liberating not shaving, but these 10 and 12 year old kids followed me down the street the other day to video my legs, jeering at me. And I'm like, actually, you can probably relate. It's because your body is in conversation with the subway. Your body's in conversation with the world and the people that you're passing.

BJ Miller 38:52

Yes. And just like we started our conversation, I mean, we all project, we all receive projection, but this takes it to another level, and the expectations of others, and what's considered normal, and the standards and blah, blah, blah, blah, blah. One of the great gifts of course, is once you join the ranks of the other, like, that's what I did. I went from white Episcopalian, Ivy League, I was boringly standardized as can be.

Amanda Palmer 33:15

Yeah, I grew up in that same town, by the way. I mean, it was in a different state, but the same town.

BJ Miller 33:19

But it's the same thing. Yeah, you know the thing, right. And so here I am going from this standard, to the other. And that's a painful process. But if you can withstand it and

support that, it's an incredibly liberating process too. And yes, you have to deal with the stares and jeers of others. But once you kind of get there organically yourself, then that becomes another thing to play with, and you realize they're learning through you. And what was also true too, people were staring at me with or without the covers on my legs, with or without an arm.

Amanda Palmer 33:53

So why not be shameless?

BJ Miller 33:54

Yes, right. Either way, I was gonna be feeling weird. Either way, I was gonna have pain. Either way, people are gonna be staring. So if that's the case, there's no code to crack here. I might as well find a way to kind of play with it.

(Music break)

Amanda Palmer 34:19

Cos you have so much experience now as a doctor, and as someone who works in hospice, and so is around people who are broken open and sharing all the time, it's not like you're working in a bank. You now have 30, almost, years of perspective on this, right? When you look back at where you could have stumbled and just taken a left instead of a right, or vice versa, and I have a feeling some of it has got to have to do with your mom, what do you think were some of the basic ingredients that gave you the insight and the fortitude and maybe even the privilege to be able to choose and get out and get here, that you might not have had?

BJ Miller 35:05

There is an element of privilege to be at a place like Princeton, and to have a course catalogue, or to have a choice of studying art history, and seeing it as a therapeutic opportunity... There's privilege that sets up even the thought process that would allow that to happen, that is for sure true, without a doubt. But at this point I've lost track of where I'm lucky and unlucky. I feel like I've got a pretty good helping of both. I just do need to acknowledge that. Always the charge, I think, is for us to all make the best of whatever we got. Life is so treacherous, there are so many ways to fall, there's so many ways to go wrong, and so little control. But where we do have control should be taken very seriously. I neither abdicate control, nor do I clutch it. I like to think that I'm working towards a healthy relationship of using it when it's real, and letting go of it when it's not.

So I remember early on one of the first sort of crossroads moments, as I had joined the ranks of disabled, the pity thing. It's a little seductive, because you certainly are aware that you're pulled out of the normal ranks of daily life you as you used to know it. And the shit you're putting up, with the pain you're experiencing? You know, on some level you're like, goddamn right I'm special. Like, on some level, you're aware, what you're going through is pretty big, maybe even unique. Probably not.

There's a temptation to absorb the cues that people are throwing, that somehow you are special, that you are different. But I knew enough to follow that logic, a little far down the road, if you follow that thinking a little farther down, and again, thank God for my mom and all I learned from her, and just having basked in the question of disability my whole life. I knew that that was a trap. I knew that was a trap, because if you absorb yes, I am special, I am different, I am unique, if you absorb that, well then if you're not careful, then you've just invited so much isolation into your life, and you've exempted yourself from the rules that affect other people, and so you've pulled yourself out of the world. You know, you've removed yourself, or let yourself be removed. And that was normal for disability forever, like we would warehouse people, there would be pity and charity involved, but let's just get them out of sight, let's warehouse...

Amanda Palmer 37:35

Well it's almost like we need two words for unique. There's the unique that is beautiful and that captures all the confidence of awesome uniqueness. And then there's the unique of above and apart. And it's almost like we want two words.

BJ Miller 37:53

Yeah, I totally agree with that.

Amanda Palmer 37:54

Because it can be a blessing or a curse.

BJ Miller 37:56

So the language I came to, to try to reconcile, your point is such a good one, is that we're variations on themes, and that we can play with these variations, that we're still limited by default laws of nature and we still have physiology to deal with and blah, blah, blah. But within these parameters, there's incredible freedom. It's like music, perhaps. I mean, there are only so many notes, but you can put them together in all sorts of ways. And you can make a special piece of music, right? That doesn't sound like anything else, but it's still a piece of music.

Amanda Palmer 38:25

Well, and this is sort of like the point of life at the bottom of everything, which is we are all the same. And completely unique.

BJ Miller 38:32

Yeah. And totally unique.

Amanda Palmer 38:35

And it's a fucking paradox.

BJ Miller 38:38

And the problem there is not so much reality, the problem there is language. For my money.

Amanda Palmer 38:42

Language is just so... We're so bad at it.

BJ Miller 38:47

Yeah, we just don't have enough words for what we're actually talking about.

Amanda Palmer 38:50

No, it's incredibly limited. And my least favorite is love. I just fucking hate it. I mean, and I love it. And I love love, but I just hate how clunky that word and concept is.

BJ Miller 39:03

How much stuff hides in there under the banner of love too, like when people mean incredibly different things by that word. But that one word, we have one word.

Amanda Palmer 39:12

We're bad at language. Poor humans.

BJ Miller 39:15

Well, that was my senior thesis, by the way.

Amanda Palmer 39:19

Let's all stop talking, by BJ Miller.

BJ Miller 39:20

Pretty much, yeah! My senior thesis was on this, 'cause this is so apropos of what I was experiencing, this whole conversation, and so to play it out as I got farther... So it's Princeton, you have to write a senior thesis, it's not an honors thing, to graduate you have to write an original piece of work. So my original piece of work was to write about music's influence in 20th century visual art, because I was interested in how these cross pollination things happen, and how to break the dogma of particular arts, and sort of see the interplay. The subtext of the senior thesis was, how lame language is, how lame words are, how inadequate words are, and how silly the process I was involved with, studying art, visual art, and sound art, and trying to ram all that expanse into these stupid little words as, so with my little...

Amanda Palmer 40:09

And there you are trying to write about it.

BJ Miller 40:10

Exactly. So my undergraduate sense of irony everything, I wrote this thesis on this subject, and was constantly sandbagging it myself, constantly torpedoing it to prove the point that language is so flawed and that this enterprise of trying to talk about art was so dumb. So, because art was exactly that, was freed from the limitation.

Amanda Palmer 40:34

Did you call it burn this thesis?

BJ Miller 40:37

I should have, it just ended up being... It was very much a B effort.

(Music break)

Amanda Palmer 40:47

From that gigantic thesis, if you could share one thing, one musical architectural conversation that is unique and edifying, what would it be?

BJ Miller 40:59

The subject was too big for one paper, so I just picked some archetypes. So one archetype was Picasso who used music as sort of iconography, you know, so you would see a mandolin in his artwork. So he was using music as an object in a way, and he painted that. Music as icon. Second group was Kandinsky, typified by Kandinsky, who in a synesthetic kind of way was trying to achieve through visual art what music achieved for him. He was trying to paint sound. And so music as this inspiration, this mega

source. And then the third chapter was music and visual art as part of this sort of sense-o-rama, this sort of aesthetic explosion that was Disney, Fantasia. So, Fantasia was meant to be, the original conception, Disney was gonna have all these theaters decked out with a very special sound system. He was gonna have people bringing flowers.

Amanda Palmer 41:53

Smells?

BJ Miller 41:53

Yeah, exactly. You got it. So it was meant to be this sort of sensory orgy.

Amanda Palmer 41:59

Did you drop acid before or after accident?

BJ Miller 42:02

After, ohh, yeah. Did I drop acid before? Oh yeah, yeah, the summer before. So it was summer between freshman and sophomore year of college, I was at Chinese summer school in Indiana University. And I made a good buddy there and we dropped acid and went to the shopping malls and watched Gremlins 2 a thousand times. It was wild.

Amanda Palmer 42:24

Of all the movies you could have picked.

BJ Miller 42:25

Well, we didn't have much choice in rural Indiana.

Amanda Palmer 42:27

That was what was playing, wow.

BJ Miller 42:28

So the summer before my accident I did a little bit of acid in some sense.

Amanda Palmer 42:31

As someone who did a lot of psychedelics, especially as a teenager, not so much anymore, I remember looking at art. I remember looking at Nude Descending a Staircase, on acid, and going like, oh!

BJ Miller 42:47

You get it?

Amanda Palmer 42:48

I get everything! This is music. This is what music is. And we just have these clunky words to describe it right, but whatever.

I feel like I am really starting to understand, at 43, how beautifully galvanizing loss is outside of the sort of cliché that you would see on the side of a mug, like I actually feel like I get it now. Having gone through especially the loss of my best friend, and he fought, and there's that language again, he went through a four year cancer story of ups and downs and mysteries and surprises, including being in a bone marrow transplant unit for a while, and I was helping take care of him, and I went through the whole journey with him. A few months after he died, my first child was born. And then I had a miscarriage the year after, I guess Ash was two. And that experience in particular sort of changed my life, because I just never expected that an experience like that would be a gift. I would just assume that a miscarriage, like anything, would just be shitty. But I wound up being alone. And it was Christmas Day, and I just had to deal with it. I just sort of found this inner confidence and fortitude that I think had sort of been gradually built because of Anthony's death, because of going through childbirth with no drugs, because of this, that and the other thing. It sounds weird to people but it was actually just a really beautiful experience, to see what I could do. To see what I could see with my own eyes, feel in my own body, and just deal with.

It changed my perspective in a big way. I started thinking about art a lot. And also, not just about art, but about artists. And what we know, and what we don't know. And I think what all artists kind of intuit is what you do learn when you are forced to learn, because you wind up maimed, or facing catastrophic loss. And you just don't have a choice. Sometimes you don't have a fucking choice. Like electricity takes your legs away. Circumstance means that you deal with a miscarriage alone, and you need to deal with a dead baby. Shit happens. And then you must either compartmentalize, or grow.

And I think what artists intuit, is that the dark really is incredibly fruitful. But what fucks most artists up is you stumble around in the dark trying to pick the fruit of the dark, in the dark, and. Everything I've been thinking about and reading lately and especially thinking about you and your life and your story, and I'm reading this amazing book by Elizabeth Lesser right now called "Broken Open" about basically how grief and loss transforms into clarity and enjoyment. These bizarre things that sound bizarre from the outside but once you experienced them aren't. Including a fan of mine that I interviewed a few weeks ago on tour, who is blind. He attempted suicide by jumping off a bridge as

a teenager and survived, but is disabled, and just has no regrets. Just feels like he was given an incredible gift. I hear you talking about it the same way. I feel it. I see Elizabeth writing about it in the same way. And I go, there's something that artists know.

There's a great quote in your book. You say death becomes the soil for the beauty, the reason for the compassion. So many artists know this, that out of the dirt and the dark comes the beauty. But so many artists have to manufacture the dark and whatever form that takes, whatever masochistic, drug induced, sex crazed, my life has to be a fucking dark mess in order for me to be an effective artist. On a level it's true. On a level, without accessing the dark, you can't really get through to the light. But it can eat you. You must have seen a lot of this and especially, you work in hospice and you see a lot of people at the end taking stock, who have or haven't chosen a path of making art, or appreciating art. What do you see from your vantage point?

BJ Miller 47:36

One of the risks is when you turn your attention to the darkness, as you described. And you start realizing the fertility of it, like we're talking. It is possible to become overly enamoured with it, too. And I've watched people, I watched this happen when a lot of folks are on hospice, but I'm just aware of a lot of folks who would not have been interested in end of life things seem to be, there's a wakening that seems to be happening, and meeting more and more people drawn to end of life issues and stuff. There's a real subtle distinction to be had in here somewhere, where you appreciate what the darkness helps you see, you appreciate the power darkness gives to the light.

Amanda Palmer 48:19

The black flashlight.

BJ Miller 48:22

Yeah, the power of this black flashlight. Right. And if you're not careful, you can become a little overly enamoured, and clutching to the darkness you can become overly invested in pain. I think it's very easy to do. I see a lot of folks bring a sort of sensationalism, a sort of ghoulish sensationalism to interest in end of life. And I think there's some important hair to split in there. Yes, I see what you're describing in myself, and in others, especially an artist, but anyone trying to kind of make their way through the day, and especially comes up at the end of life, of folks trying to reconcile these massive forces while they're still here. I think a lot of people think life's over here, death's over here, lightness is here, darkness is over here. And the truth is, they're all interrelated. If I'm enamoured with anything, it's the tension between the two. So I need light, and I need dark. One without the other is problematic. And one without the other is

just a half a reality. It's just not a full picture. I think that's an important distinction. If you need to be hooked on something, get hooked on the tension that naturally exists between these forces. You don't need to manufacture it, you don't need to create pain, there's enough pain. If you're paying attention to yourself and this world, and the world around you, there's no lack of fucking pain.

(Music break)

Amanda Palmer 49:59

There's a phenomenon with many artists who have found the fertility of the dark and have found phenomenal success in harvesting whatever comes out of the dark, that there can be a massive amount of fear with what will happen if you examine the dark too much. If you actually deal with your trauma, if you actually deal with your childhood, if you actually go to therapy, it might de-fertilize the dark. And I see this constantly. And ironically, the more successful the artist, the greater the danger. Because if you're working out of the dark, and you're just sending sparks out into the universe and the universe is paying you in great dividends for the sparks that you're sending out, fucking with the system can be very scary.

I find myself always thinking something really similar, which is working through the dark doesn't mean that you lose access to the dark. You will never lose access to every shitty thing that happens to you, especially if you have the fortitude and you can go, yep, I'm just gonna flick back 30 pages, there's the trauma writ large. I can harvest it as I want, because I am God of my own life. Or, just pick up the fucking New York Times, you're set. There's no way you just escape the dark and go into the light. Doesn't exist.

BJ Miller 51:39

Amen. That's what I mean, like you don't need to over identify with it. You don't need to clutch it, you don't need to try to own or protect that dark thing. It's bigger than you, it's there all the fucking time. As is the light.

(Music break)

Amanda Palmer 51:57

When you say that end of life is now more in vogue, I mean, you said the same thing about mindfulness and I think I know what you mean, which is like, even though Buddhism has been around for thousands of years, and mindfulness has been in vogue in certain parts of the world with certain folks, you know, whitey Western folks are now

opening their eyes up to different possibilities. I'd love for you to describe what you think the book is.

BJ Miller 52:20

The book is many things, I mean it's 500 something pages, the subject's enormous. I mean, the book's called *A Beginner's Guide to the End*. That title does some pretty good justice. The subject's huge, so the book kind of has to be huge. And even as huge as it is, it's still going to be reductive. There's not going to be, there's no way to cover every aspect of this subject. But it is, first and foremost, a guidebook, it is meant to help people navigate what has become an incredibly un-intuitive process, especially when you throw in the healthcare system to the mix.

So on some level, dying is just about as natural as it gets, and on some level, it should be an intuitive thing, and we've been doing it for gazillions of years as a species. But the truth is, we have invented all sorts of spectacular ways to distract ourselves from it so that we don't get to know it earlier in life, and we've invented incredible ways to sustain, to prop up a body, but actually not necessarily promote life. So you're left with, actually, you've got a healthcare system that could make you live practically bodily, give you a heartbeat almost forever, the death becomes a moment of opting out of something system. And it's not intuitive.

So anyway, that's a weird background, but why this book needs to exist is because it's not an easy process to navigate, and people end up, and I see it all the time, just as a person, but also as a physician, people suffering so much more than they need to. Doctors, nurses, social workers, patients, families, administrators, you name it, everyone's sucking. You know, that's kind of exciting too, part of the vogue moment I think is that all roads are leading us to revisit how we die. You could be a bean counter and just follow the money and realize we gotta change it. You could follow the science, you could follow the ethics, you could come into this situation from any angle and land at the same place, which is basically we gotta really rethink how we're dying.

The book is Manta... This may sound elevator pitchy. The basic idea is to lift the floor. It is meant to be a fundamental treatise that is applicable with trying to write to the common denominator, no matter what your belief system, no matter how old you are, that there's a huge denominator among us, simply because we're mortal. And that these forces are knowable and reliable and play out, no matter who you are or where you are.

Because I spend so much time going over fundamentals with my patients and families like what is hospice? What is palliative care? Does it have to hurt? How do I talk to my

doctor? What the hell's a eulogy versus an obituary? All these very basic questions. So the idea would be that this book, if we hit the mark well, and if it gets out in the world, there aren't many books out there that handle this. So it's very easy to stay in the dark on this subject. If this book does what we hope it does, people will have access to basic information so that the floor of the experience, we're not gonna blow through the ceiling, but we could lift the floor so people don't have to fall as far, so people don't have to hurt as much

Amanda Palmer 55:27

Basic death education.

BJ Miller 55:29

Yeah.

(Music break)

Amanda Palmer 55:37

So I just saw parallel after parallel after parallel after parallel between our shitty way as a culture of dealing with death and dying, and the way we deal with birth and birthing. Because my mind has been on this more than... not even more than usual, you know, at all. I wasn't thinking about these things very much until I got pregnant, decided to keep the baby, and have a child. And I talk about this in my stage show a little bit, but I actually am retroactively really grateful that I had so much negative hospital garbage hanging off me from Anthony's long, long, long cancer treatments, and being in bone marrow transplant world, dealing with a very inhumane abortion experience in New York City, that I was fully on board with the idea of getting away from Western medicine, hospital standard prescription, when I knew that I was going to have to choose how to have a child.

The things that I ran up against, and the stories that I've collected, and the knowledge that I now have around childbirth is, most of it is just pretty horrifying to me, as I'm sure it is horrifying to you as you cast your eyes around the country and go, oh my god, we're doing it's so wrong. We're just so bad at taking care of each other. How did this happen? And the parallels are just beautifully poetic. Birth and death just have so much in common! Who's in charge? Where you are? Who's allowed in the room? Who has agency?

There's a great quote in your book, I don't know exactly what it was, I just wrote down a note, but something about end of life patients not feeling like they had agency, and also

just not feeling like they were allowed to make certain gratifying, actually self-loving choices, because making the wrong choices smacked of quitting. That was the phrase that really stood out to me. There's so much of that around, not just around childbirth, but also, I've spent the last couple weeks of my life steeped in the abortion debate. There's a whole other avenue of parallel when you talk about agency, who's in charge of whose body, and who gets to pick what.

Even just reading your quote, our medical system is wired to extend life, as defined by the presence of a heartbeat, whenever possible, no matter how uncomfortable the means. And I'm like, well, there you've also got the heart of the abortion debate. And now you've got an 11 year old girl in Ohio who was abducted and raped and who might have to carry that rapist's baby to term because somewhere, somehow, the right of that unborn child is sort of usurping the human rights of this 11 year old girl, and how did we wind up here? Why do we think that that's care?

Do you hang out with doulas, midwives, people who sort of live on the birth side of the hill, where you're hanging out mostly on the death side of the hill, and see the rainbow of parallels that connect these two worlds?

BJ Miller 58:53

Not per se, but more conceptually, like I think about this a lot. And it's obvious enough through friends of mine, and having been a med student, and been in labour and delivery wards, and been around birth myself. It's not that I have a cohort of friends who are OB/GYNs and doulas per se, but I do, these subjects are just empirically enough so linked. Birth and death and some cycle of life, are absolutely linked, both in the natural way, and also in our artificial, the human applique, the way we treat them, the way we accidentally and purposely sometimes shame ourselves for these very natural moments. And the way we separate ourselves from the beauty of it, weirdly. So basically, I'm just sort of saying that I whole hog agree with your analogy. And I do think about it. I do hang out with death doulas.

Amanda Palmer 59:47

I have friends of friends who were training to be death doulas. Describe what a death doula does.

BJ Miller 59:52

Well, so much of what you're hitting on, Amanda, is so right on, especially from a systems point of view. And the birth movement, I think is just a little bit ahead of the death movement. And medicine has come a long way, it's still got a ways to go, but

gone are the days where the dad's removed from the room, can't touch your own baby. I mean, you know, there used to... the idea we used to dry up breast milk...

Amanda Palmer 60:16

Don't touch the baby! You'll make the baby sick!

BJ Miller 60:19

Yeah, don't give them that gross breast milk, we've got formula! I mean, Jesus, I think we're all aware that those were big fat mistakes. What's happened around birthing, and in this sort of end of life world are directly trying to draw lessons from what others have done around the birth movement. A piece of that is, yeah, that we don't give birth like nothing, none of this part of what, a force that's underneath all this is we keep, especially in this country, we believe that there's such a thing as autonomy and independence. There is no such thing. We can be relatively independent, but we need each other all the time. I don't believe an independent person has ever lived. I think that's the flaw in all of our systems that we keep kind of trying to push ourselves in that direction.

So the truth is, of course, that birthing, you could really use some help sometimes and dying, you could really use some help, right? And our choices used to be the hospital. And so doulas, midwives, old traditions that found new purchase, because in a way, like we've been saying, the negative example of the hospital got so grotesque, in a way it evinced the need for another way. It got gross enough that would force the creative work to find a different way. That's kind of what's happening at the end of life. And so just in the same way as there are midwives and birthing doulas, that same mentality of accompaniment of yes, a skill set, but the primary skill set is being a fellow human being, and not running away and sitting there and touching and all that stuff.

Amanda Palmer 61:50

And on the schedule that is not set by a hospital, but the schedule that is set by the event.

BJ Miller 61:59

By the gods.

(Music break)

Amanda Palmer 62:05

I got to go to this place in Tennessee called the farm. Do you know about the Farm? Do you know Ina May Gaskin? She wrote the book *Spiritual Midwifery* in the 70s. These crazy commune-dwelling, back to land hippie types in the 70s really spearheaded the natural childbirth movement, what was called the natural childbirth movement. And there's actually a movement right now to stop calling it natural childbirth because there's an element of shaming in that, that women who don't give birth vaginally or don't give birth without drugs are unnatural.

I'm an artist, Neil's an artist, we didn't have jobs that we had to clock into. And I got to travel down to Tennessee, and live on this commune slash intentional community just in the middle of the woods for five weeks, with very little intervention, in a cabin, I got to give birth with nothing but a couple of midwives, and the trees, and the sounds of nature, and it was a 24 hour labor.

You know, as someone who did drop acid enough times, I just let go of the wheel, and I would assume in the death experience, it's the same thing, a process takes over. You're just in it, you're going on this ride, and there you are. And you really, really want to trust the people around you and be in a pleasant environment. And I got that. But I also got that because I did my research. I had the resources. I could take five weeks off work. You know, when I graft my own story onto what would have happened if I had just googled and gone, 'I am giving birth, comma, what do I do?' there's no way that as a 39 year old woman, I would have been allowed any of that. So many people were so concerned, thought I was nuts. What if something happens? Why wouldn't you do this in a hospital? You won't be safe, it won't be good, it will be bad. We're also afraid. I just wasn't afraid.

I know that a lot of that is due to all the privilege that led up to it. Just like you quote unquote, whatever clunky word you want to use, overcame, because you were in the fucking position to head left instead of right. Just in terms of birth and death, it feels like right now, especially because of capitalism, money, all the people who have so much shit at stake, to keep us in the dark, or to do things the way they've always, or at least been done in the last whatever... Do you feel like there is a kind of, an activism element of what you're doing, and there will be pushback from the system, and you will have to argue your point, or argue your case?

BJ Miller 64:51

These are active questions for me, because I am part just like, what am I doing? Like, what's my identity with this work? What am I actually trying to achieve? Am I trying to change something? Or am I trying to kind of reveal something? So it's a hot question for

me. Like, for example, the TED talk. I didn't get any, I didn't have one piece of hate mail. No one was angered by it. Some people may have been not moved by it. I mean, a few comments, you know, what's the big deal? That wasn't news to me, kind of thing. But no one... didn't seem to hurt anybody. Or there was not enough there for someone to disagree with. And that was quite an experience, to put something out in the world that seemed to be essentially neutral.

Amanda Palmer 65:34

Universal thumbs up.

BJ Miller 65:35

Yeah, essentially, it's a neutral or thumb up, yeah. And now here I am about to put this piece of produce out in the world. And it's a much more involved thing, much more detailed thing. And it'd be impossible to write a book on this subject and not offer some opinion.

I am really pissed off at our healthcare system, right? I was saved, my life is saved by our healthcare system. I am a doctor who works within, I mean I'm beholden to it in all sorts of ways. And I love it so much, and I demand the right to criticize it. It feels like my version of patriotism. It's a piece of shit in a lot of ways, that system is fucked up, and causes harm.

So I am aware that I'm actively trying to affect the healthcare system, how it's conceived, how it works, what policies, how funding moves, etc. So there is my activism at the healthcare system's level.

I don't mind being controversial. I don't love it for its own sake per se myself.

Amanda Palmer 66:31

That would be weird.

BJ Miller 66:32

Yeah. Well, I mean, some people I think can get off on it. I'll enjoy true controversy if I can really own my piece of it, and I like a good argument. A long winded way of saying, Amanda, I'm very curious to see, when we put this thing out in the world, if it's going to be controversial at all.

Amanda Palmer 66:50

As someone who's read most of your book, I don't think so. I mean, if anything, because there's always haters out there, you're probably gonna get hate for what you didn't include.

BJ Miller 67:02

That I'm aware of. That was painful for me.

Amanda Palmer 67:05

How could you talk about this without addressing what's the most important thing to me, you asshole?

BJ Miller 67:09

Yep. Yep. I already feel that way. I've felt like an asshole for all the things we had to cut. But anyway, yes.

Amanda Palmer 67:16

What did you have to cut that hurt you the most?

BJ Miller 67:19

Well, there was not probably a single thing, but there's so many points of view. I'm so aware of the exceptions to the rules. And so as we try to lay down things that approach sort of a fundamental, or a rule, or a theme, I can only, I can only think of all the exceptions to the rule, all the patients I see who don't fit into that category. And as soon as I try to write about finding beauty in and around loss, you're aware that that might smack someone really wrong, depending where they are in their grief.

Amanda Palmer 67:47

How could you possibly?

BJ Miller 67:48

Yeah, what, you're putting a smile on my pain? You fucker. You know, I can imagine feeling that way. So that's sort of the hazards of, did we find the right tone? Did we use humor and levity in the right moments? Who have we forgotten in the reductive process of writing? I mean, so there's no single thing. I suppose if I were going to write an advanced guide to the end, this beginner's guide is not a thing we get to hide behind, it's a beginner's guide! But if we were ever gonna try to write an advanced one, like a subject that I love, we don't really touch on the aesthetic domain like you and I have talked a little bit about. I would love to put that in there. But that just got too esoteric sounding.

We write to the patient, the person dealing with illness, and we wanna respect the sanctity of that experience. We talk about self, we talk about leaving a legacy. We talk about the power of your own actions in the book, as though self and other were different. A truer treatment of the subject would be to explore all the interplay between caregiving and care receiving, between self and other, essentially. There's so much beautiful overlap to explore in there that comes up in the realm of giving and receiving care, that we couldn't do justice to that piece in the book without putting someone off and adding another couple hundred pages. So that's probably biggest regret

Amanda Palmer 69:15

When I gave my TED Talk, which was about exchange and giving and receiving in music and art world, but effectively, really about fucking everything, I sort of hit upon the same thing writing my book. Because once you start talking about anything, you can start talking about everything.

There's a whole other book in the emotional aesthetics of the room in which you die, which could be another 500 pages. And what's the lighting like, and what does it smell like? What are the volume levels of the visual and audio experience that you're going to have when you're die?

Thank you so much for taking the time to talk to me.

(Music Break)

Amanda Palmer 70:10

This has been The Art of Asking Everything podcast, I'm Amanda Palmer. Thank you so much to my guest, BJ Miller. If you are interested, please, find his book *A Beginner's Guide to the End*. Our interview was recorded by Erin Tadema at Laughing Tiger Studios in Marin, California. The theme song that you heard at the beginning is a song called [Bottomfeeder](#), from my 2012 crowdfunded album [Theatre Is Evil](#). I would like to thank Jherek Bischoff, my soul musical brother who arranged the inbetween-y orchestral music that you heard in this podcast. Those are all little snippets from my latest album, [There Will Be No Intermission](#), which you should listen to if you like really sad songs. For all the music you heard in this podcast, you can go to the new and improved amandapalmer.net/podcast

Many, many, many thanks to my podcast assistant, social media helper, and additional engineer Xanthea O'Connor.

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This podcast would not be possible without all of my patrons, right now about 15,000 of them. Please go to [my Patreon](#) and become a supporting member, and get all sorts of extra stuff including live chats that I am doing with all of my podcast guests, and I have been blogging up a storm over there, so you can also see pictures, and get the transcript, and notes, and all sorts of good stuff.

Signing off, I am Amanda Fucking Palmer.

Keep on asking everything.