

Stories from the brainreels podcast transcript

November 1, 2015

[music]

Introduction

CHERYL: Welcome to Stories from the brainreels monthly podcast about brain injury and disability with a focus on art, culture, and disability pride.

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I'm headed off to Minnesota in a few days to give my talk on TBI storytelling for Mt. Olivet Rolling Acres, and the timing could not be more amazing for bringing on today's guest, a poet, facilitator, and much more: E Amato. I'll tell you why in just a minute. My presentation there celebrates storytelling for what it gives storytellers and what it gives society. A big part of the talk, though, is my critique that I really, really think that the TBI storytelling landscape is simply too narrow. Too many stories are left out: people of color, people in poverty or who are houseless, people incarcerated in jail or prison, LGBTQ people, people getting TBI from intimate partner violence, and people whose experiences don't follow a miracle recovery trajectory for whatever reason. I don't want to push any stories out. I do want us to recognize that there's room for all of them and for us to find ways to amplify the stories that aren't getting airtime or press, especially the ones being told by people with limited resources. And especially the ones that aren't being told, that are locked away inside of someone because they don't have the supportive community to tell it to or because their way of communicating or what they want to say isn't accepted. (Actually, this isn't just TBI. This is any disability community.)

One of the many things that stands out about today's guest is that you're not ever going to hear how or when she got injured. It's not part of today's storytelling. Instead, we focus on art, performance, feminism, race, trauma, pain, and self care. We talk at length about what it means to be asked to "tell your story" and how the brain and body can respond to following through with that. And you'll learn about spoons. If you don't already know about spoons, you really gotta. Great stuff.

As always, you can subscribe to this podcast on iTunes, Stitcher Radio, and SoundCloud. (SoundCloud is the best route to get audio files you can easily share with others.) More details about guests, links, and screen-reader accessible podcast transcripts are at the blog at www.whoamitostopit.com. Don't forget to check out swanky brainheart swag at cafepress.com/whoamitostopit. All proceeds from sales there go toward the documentary "Who Am I To Stop It" about artists with traumatic brain injury.

And now on to the interview.

The Interview

CHERYL: I'm here today with E Amato. Oh, I'm not actually here with E Amato. She's in Los Angeles, and I'm here in Portland. Just a quick intro about E Amato: she's worked in film as a script supervisor and produced and curated performances in a variety of disciplines. She's a poet and spoken word artist, a writer, teacher, consultant, and editor. And she's worked and lived abroad and uses her experiences around the world and across the US to reframe her community, worldview, and sense of compassion. E Amato's been producing events since 2001 with a lot of different organizations like the Silver Lake Film Festival, Highways Performance Space, Peace4Kids, Youthspeaks' Brave New Voices, the Fringe Festival

in Edinburgh and Brighton Fringe. She's had her own venue called Down Home, giving stages to poets, spoken word artists, musicians, and visual artists. You do so much! You're the editor of [Zestyverse](#) and a publisher at [Zesty Pubs](#). You keep a blog called [Writing Is Not A Mystery](#), and you are currently a content writer for [The Body Is Not An Apology](#). So welcome. Thank you so much for coming to be on the podcast with me today.

E: Thank you. Thanks so much for inviting me.

CHERYL: So on your website you have this description: "unapologetic feminist, dulcet-toned poet, activist, filmmaker, and editor of Zestyverse." What a great description. Why do you think there's an expectation that people might be apologetic about being feminist?

E: Well first, I have to say it is a fantastic description, and it's not mine. I did not write it. It was given to me as a very special present on Twitter from the two people who run Loss Lit, which is [a Twitter account](#), [a Twitter hashtag](#), and [a magazine](#) now. Loss Lit is this amazing writing party where we write tiny Twitter poems about loss. And people meet up on Twitter, and you just hashtag it. And then you can read everybody's pieces and write your own. [Aki Schilz](#) and [Kit Caless](#) are the editors, publishers, and they run the Twitter account. And they were promoting Issue #1 of the magazine, which has [one of my audio poems](#) in it. And that's what the tweet said about me. And I tweeted back, and I'm like, "I'm stealing this! This is the best description ever."

Unapologetic Feminism

E: Unapologetic feminism is just a great thing to have in the world. I feel as though feminism has gone through all these waves, and that's sort of socially documented. But the truth is, the values of feminism have never changed, and we haven't made a whole lot of progress in my lifetime. And it's sort of about time we stopped being nice about it.

CHERYL: [chuckles]

E: It's sort of time for us to stop asking for permission to be at the table. We're at the table. I think if we learn anything from our allies from people in the current civil rights movement and people involved with #BlackLivesMatter and people involved with undocumented immigrant struggle, we need to learn to be unapologetic. And that's a gift, I think, that I've been given by other movements. Women keep apologizing for asking for equal pay or equal rights or just what we deserve. And that has not helped us. I think watching other social justice movements is very empowering because you can see the difference. They know that they're not embraced by power. So they have a different way of fighting that power than we do, or than we have traditionally. And I think we always think, as women, oh, we'll we're women. Of course they don't hate us.

BOTH: [laugh]

E: That doesn't help us in our cause, unfortunately. I'm not saying they hate us or don't hate us. I'm just saying that way of looking at things that people in power are our allies has not helped us.

CHERYL: Right, right, the apologetic-ness: "Well, I'm sure you didn't mean this, but, this kind of isn't working. I'm sure you didn't mean it." And you know, there's a lot of coddling that people do. And I also, I'm with you that I don't see value in apologizing for stepping up and speaking about injustices.

E: Saying that I'm unapologetic has made me see how many times I try to apologize [chuckles] for things that have nothing to do with me!

BOTH: [chuckle]

CHERYL: Right!

E: And so I'll be sending an email to someone and be very close to saying, "I'm so sorry that such and such." And I'll just go why are you apologizing? I don't know. To make them feel better. Why? You didn't do this. It has nothing to do with you. And you're taking responsibility for someone else's bad action and not moving yourself forward. Once you say you're unapologetic, you have to be unapologetic. So that's been really helpful because of course, I think I am an unapologetic feminist and social justice--I don't want to say "activist." I'm not somebody who goes out and does marches and pickets, but I do my own work. But I feel as though in my own life, in my own interactions, it's become really important to not apologize for saying what I feel or think or telling my story just to smooth something for someone else--

CHERYL: Mmhmm.

E: make something more palatable. And as a woman, I believe I must've been socialized to do so. I know that in my job I had to do that. I was often telling people in power what they did not want to hear, and it was my job. It was what I was getting paid to do. In order to do that, I would do exactly what you just, the example you just gave: "Oh, I'm sorry. But I was thinking maybe...."

BOTH: [laugh]

CHERYL: Yeah.

E: "But you might like to consider...." And it takes a really long time, and it's easy for them to discount what you're saying. But they want it to be easy to discount what you're saying.

CHERYL: Yeah.

E: And there are a lot of women in my position on-set. And when I talked with a guy who I've known for a while who was also a script supervisor, he's like, "Oh, you're too easy. I just scream at my directors."

CHERYL: [chuckles]

E: And I was like, "Oh, I'll never do that." But on the other hand, it would be nice to not feel like you had to phrase everything in the most mild way possible all the time.

CHERYL: Mmhmm, mmhmm. And there's that expectation that if your status is lower or it's perceived to be lower, you get more apologetic as you--

E: Right.

CHERYL: "Oh, I don't mean to ask for this maybe earning a dollar for your dollar. I'm sorry." Yeah [laughs].

E: In my job, it was even stranger because I was actually helping them, but often in ways they did not want to be helped and often in ways that put me between the producer and the director, which meant that I was always sort of apologetic to one of them.

CHERYL: Uh-huh.

BOTH: [chuckle]

E: It was constantly that. I don't know what it would be like if I was working in my job now. I don't know if I'd just suddenly be very unapologetic [laughs]--

CHERYL: Mmhmm.

E: or if I'd immediately go back to my old ways.

CHERYL: Right. Do you keep up at all with the, there's been two big ones on Twitter recently, which is when Nicki Minaj was standing up for herself, and Taylor Swift got her white panties in a bunch. And then I can't remember the woman's name who went on record on Twitter attacking Viola Davis for giving a beautiful speech. Have you kept up with either of those bizarre arguments?

E: I decided not to look at the interaction between Nicki Minaj and Taylor Swift because I just, at that moment, didn't wanna be pulled into that kind of thing. In general, I do follow that kind of thing. I think Taylor Swift is really besieged on both sides [chuckles]. She's so not taken seriously as an artist and as a self-motivated person. And she's so looked at as a blonde singer. And that's terrible, but she does do some really questionable things out in the world that make white feminism look like a really bad thing. And this idea of demonizing white feminism is problematic for me anyway. But it is in existence, and there are problematic white feminists out there. I didn't read what the tweet said that actress sent about Viola Davis, but my feeling about Viola Davis is that she's just one of the most talented people who's ever been doing her job. And she deserves every accolade she gets. And that speech, what I saw of it, was really moving and important. Attacking that in and of itself is just a condemnation of who you are, and it's interesting gossip maybe. But the truth is that Viola Davis has two Tonies, an Emmy, Oscar nominations, and this woman is an actress on "General Hospital."

CHERYL: Yeah. I think what stands out to me about both situations is, in both cases, Nicki Minaj and Viola Davis were being unapologetic.

E: Right, and I think Nicki Minaj in general is great for that. I don't care if she says something really stupid sometimes because she says what she feels like, she says what she's thinking. She's never gonna tell you what you wanna hear. I like her for that. I mean, I like her music for that. As an older feminist, I feel like I need people like Nicki Minaj because she keeps it really real. And we have been trying to speak truth to power in an apologetic way for so long that we maybe have lost our edge. And we've lost the ability to just say what we're feeling, and we've lost the ability to condemn people for doing something wrong. And I feel like I can model on someone like Nicki Minaj. I can say wow, you know what? She's completely right that she said that. And why shouldn't she say that?

CHERYL: Yeah.

E: We are subjugating ourselves when we stop ourselves from speaking that truth. And so to see people who are engaged in a movement now who are younger, who don't have a track record of failure, which quite frankly, we have a track record of failure in social justice movements. And so the longer we've been in them, the longer we've been failing. I think we need to own up to that, and I think we need to own up to the fact that people who are coming into it now at a younger age, with more energy and new ideas, might be better at it than we are. And so we should learn from them and not constantly be trying to school them on how to behave.

CHERYL: Yes, yes. It's so ironic, the backlash that these two Black women get for being unapologetic. Like they're not allowed to but white women are.

E: Well, this is a big problem with white feminism, this idea that only white females can speak, white women can speak is very wrong [laughs].

CHERYL: Yeah! I'm with you.

E: And that we all have the same idea of feminism, and that we all need the same thing from feminism. That's also very wrong.

CHERYL: Yeah. Yeah.

"The Body Is Not An Apology" and reliving trauma

CHERYL: And you know, that is a truly lovely segue into the next thing I wanted to ask you about, is to get--well, we're still on apologies--but now back to [The Body Is Not An Apology](#). Is it a magazine? What is it called?

E: Well, it is a magazine. The part that I write for is the magazine. But it's also a community, and it's a movement. There is [a social community](#) similar to something like Facebook where you can join, and there are forums. And you can have a profile, and you can source information, talk to other people, ask questions, answer questions. There is a live event community as well. Sonya Renee does [webinars, and she does talks and workshops](#). And there is the sort of movement, the [unapologetic radical self-love movement that is I think the core value of the community](#).

CHERYL: Your most recent post on there that just, I think I read it five times. And partly because I'm forgetful.

E: Oh, wow.

CHERYL: But mostly because I was just, I just...it just gave, it was such a gift. It was such a gift. One of the points of it, one of the many points of it, is that we don't all need the same thing. We don't all experience things in the same way. I would love to talk about that post.

E: It's the "[Why I Don't Want to Talk About It](#)" post, right?

CHERYL: Yeah, yeah. This is something that I notice about storytelling in the brain injury community. It's really common that people are expected to tell everybody who asks about the incident-- when you got hurt, lots of detail--the first time you meet them. I mean, I get it all the time. It's outrageous. What I have found is that almost everyone I know who has a history of brain injury actually enjoys this kind of storytelling. They enjoy, "Oh, well, here's the date and the time, and here's the vehicles involved" and like all these details. Most people actually like to tell them and to hear other people's stories, but I don't. And I have often felt kind of isolated, both in my desire for privacy around my own stories, but also my desire to not become upset and frightened by hearing someone else's stories. I would love for you to talk about this post or tell the story or talk about why you also feel that you're not obligated to share your personal stories about your body and your mind and your health.

E: Well, it's ironic because I do get up onstage and talk about a version of me. I don't ever think of the poems that I do onstage as me, mostly because in order for me to get up onstage and do them, they had to be written in the past. And that person I was when I wrote them, that thing that I experienced, is a

certain number of miles from who I am now. So it always feels a little bit like I'm playing a character who is me when I'm onstage. There is the ability, with certain pieces, to reconnect in that moment in a new way to the material, as you would as an actor. But it's not really me. And it's the me that I'm willing to show the audience. Because they think that person is me, and they think that I'm being 100% real with them in that moment, they think I should be 100% real with them in every moment. But again, the truth is, if I've crafted that poem, if I've written that poem, if I've memorized that poem, if I've performed that poem 100 times, is it or is it not me in that moment? Sort of. But I've moved beyond it, and part of the reason I create art is to move beyond certain experiences. So the same thing is sort of true about talking about personal injury, talking about trauma, going through that narrative. It belongs to me. And I get to choose where and when and what I consider safe for that narrative and when I consider myself safe to bring it out.

One of the reasons I think I haven't written a lot of poetry about injury or trauma or brain trauma is the dexterity that I have with words as a poet was not working in the way that I liked it to through a lot of the time that I was recovering. Therefore, a lot of what I wrote didn't feel very good to me as poetry. Whereas, talking about it as narrative--the way that I do on *The Body Is Not An Apology*--felt more communicative. And I think I'm getting a bit better in terms of how my brain puts things together now, but I still I've been writing a poem all week about something. And I still keep feeling like ooh, it's so clunky. It's so arrhythmic. What's wrong with it?

You know, the reality TV show idea that we're all onstage, and we all have to tell our stories all the time, is not very healthy. It's borderline gossip. And it's giving people parts of you that they can take away and do with what they will. That's only that side of it. The other side of it is the very real physical and documented response in the body to telling these stories. So people with any kind of trauma--whether it's a physical trauma or an emotional trauma--have a tendency to relive the trauma when telling it. That's not something that I knew until I read about it.

So I was telling people my story. You know, I was going to see friends, and I was excited to see friends, and I wanted to share cuz that's what friends do. And then I'd get back from telling my story, and I'd have to take a really long nap. And then, the next day, I'd be in pain, like the level of pain that I had right after my injury, or the level of fatigue. And I'd be confused. What had I done? Eventually, I found my way to the information that I needed, not through doctors or anything like that. I did a workshop called "[The Trauma of Social Injustice](#)" online with an organization called Off the Mat, which is a great outreach from a yoga organization started by three yoga instructors to kind of bring yoga into the world or the principles of yoga into the world.

There were two facilitators, and one of them mentioned [Bessel van der Kolk](#)'s work. And there was a quote from him, and I immediately sought the work out. He has a recent book called "The Body Keeps the Score," and it's all about trauma. There's a lot of research on PTSD, work with veterans; he's been working in this area for decades. And one of the things that I read in that book that was really enlightening was the physical evidence of how the body relives trauma in people who have survived trauma or have PTSD who haven't fully processed it. His idea is that we're never going to clear that trauma just with talk therapy or just with drugs, but the body has to be involved in clearing the trauma. And for many, that's where yoga can come in or other practices. I know I do a lot of meditation. I really hate meditation.

BOTH: [giggle]

E: But it works [laughs]. I hate to sit still. But I do it cuz it works. It puts your self in another frequency. One of the things I discovered really early on in my most recent injury was that my body was on the wrong frequency. When you think of like a throbbing pain or pain in your body, it's actually a kind of movement within. Rather than you're moving your limbs around, things inside--for me, it was my bones--were moving. And I kept thinking nothing that I'm doing is getting them back to their right frequency. I'd had different kinds of pain killers and homeopathic things and whatever I did, chiropractic. It just wasn't working, and then one day I just thought, well, this is ridiculous. And I sat down in a garden, and I meditated. And immediately there was like a 30% reduction in the pain, and I could feel that throbbing stop or slow to a place where I could manage it. And I thought oh, OK, that's what this is. When I am telling the story, I'm bringing that up. I'm putting myself back on that same frequency again. I'm recreating the injury within my body or the terrible time or the traumatic event, whatever it might be and whatever my body's tagged into. If my body has decided that a scary event in my life is somehow tied into this pain, then that comes back too.

CHERYL: It makes sense to me. I mean, it makes perfect sense to me, but I thought that's not what's going on for me. What is? I've never experienced that. And as you were talking, I had this memory of somebody interviewed me for a project she was doing. And of course, even though it was completely irrelevant to the project, she asked me how I got my brain injury. And of course, I answered because you're on camera; you're gonna do what the nice lady asks you to do. And I told the story in gruesome detail. And when she left, I started jumping uncontrollably, jumping and hopping and skipping. And I grabbed some food out of the fridge and threw it up on top of the cupboards, where there's no way to get it without climbing up on the kitchen counters. I was physically out of control, and it was my partner who was like, "OK, look. Do you understand that you're jumping, and you're throwing things?" And I didn't even fully recognize I was doing that. But I think now I know why that was happening. You know, you sit there, and you open up and you open and you open, and you share these things that you hadn't planned, you hadn't written down, you hadn't expected to share them. And you're just giving these stories to someone with nothing in return.

E: No context.

CHERYL: No context, yeah. And I just, I literally lost control of myself in response to all that opening up.

E: Well, you've also experienced something that we call a "vulnerability hangover." I've been reading [Brené Brown's](#) first book. And she uses that term, but I had heard it before. And it's a really good way to look at what happens when you share in a space that isn't necessarily safe or without boundaries and parameters. And getting up onstage is often something that can produce that for people cuz we will tend to over share.

I'm differently careful about where I do my work now. I used to do anything anywhere. And now I know that I do certain things in certain rooms. If people are drinking, there are pieces I won't do. If they're really drunk in a room or something like that, I won't perform those because I know I'm asking for trouble. I'm asking sometimes for heckling. Sometimes I'm asking for a stalker, and sometimes I'm just asking to feel really bad about it the next day because I put something out before people that they didn't really get or they didn't fully receive in a way that was helpful for anybody. So that vulnerability hangover, it can come out in a lot of different ways, and that is part of it.

So it's like a three-pronged reaction: it's the emotional vulnerability hangover that you can have from telling your story, it's the physical recreation you can have within your body from telling the story, and then it's the giving that story away for someone to take with them and do with what they will. And then

therefore, that story can come back to you in maybe an unhelpful way later. So it's a little bit complicated.

Finding Your Own Healing

E: But I resonate with what you said about things making sense. When I felt something in my body or when I heard someone say something that made sense, I just believed that it was true, and I would follow that path. And eventually, for almost every route that I've taken, I've found the substantiation I needed somewhere. I've found the research to document what I'd been experiencing or doing for myself. And that has also been very validating. I think that, in a way, helped me get much better because I thought oh, I'm not really crazy because I'm doing all these things. Cuz everyone's like, "Why aren't you doing this, that, and the other thing?" Because everyone feels like they can treat your problems for you.

CHERYL: [laughing] Uh-huh!

E: And this is such a big thing with the differently-abled community: stop telling us how to take care of ourselves [laughs]!

CHERYL: Yes.

E: And I knew, I mean in my gut, I knew I was right. I knew I was doing things that were helping me, even if they were slower at producing results. And I knew that maybe other people didn't know, but that didn't mean it was wrong. And even in finding such great documentation, much of which is recent, I realized there's still very few practitioners using this information.

CHERYL: Mmhmm.

E: And that's the shame of it. Because when you go to someone for help, they're not necessarily going to have this information even though it's readily available to them, and they're not gonna know how to turn that into a therapy for you.

CHERYL: Right, right. That's been my experience too. I do a lot of presentations at conferences for speech therapists. And I'll get feedback that, "Oh, wow. I hadn't heard that stuff before." I'm like, "I got it out of your journals." The speech therapy, neuropsychology, neurological rehabilitation journals.

E: Mmhmm. That's an area where I really do get involved with Twitter because I follow a lot of science accounts, I follow brain accounts, I follow people who are interested in that, I follow [Anat Baniel who has a movement method](#) that's based on brain-body interaction. And I learn from reading journal articles as well and books, and I also share that information. I am somebody who's interested in self-care and self-healing and nutritional healing. But I'm also someone who's really a lover of science. So what I'm gonna do is find out the science behind the things that I'm trying to do and heal. And I did that because nobody was doing that for me. I wasn't getting that. I was getting, "You can have pain killers."

CHERYL: Mm.

E: Which of course, I mean what does that do except perpetuate the problem and break down other systems in your body? It just doesn't make any sense as a method for healing something.

CHERYL: There has to be a point where people respect that you know yourself better than they do, even if they are experts and have advanced degrees in their area. You know yourself better than anybody.

E: Well, I don't know that I feel that. I feel that that's a big empty space in the medical community; validating their patients is not something that most doctors do.

CHERYL: No.

E: So I actually think that would be nice if they said, "You know your body."

BOTH: [chuckle]

CHERYL: Yes.

E: But I don't think that, in general, that's something that they do. And it's not something I've experienced. So for me, whenever I'm not finding it outside, I just find it somewhere else [laughs].

CHERYL: Yeah.

E: I know I wanna be proactive, and I know I wanna change things. So I'll find the solutions; I'll try things.

CHERYL: Right, right. I also find that I've got some mild cognitive impairments they found on tests. And I find that that seems to discredit me when I have gone to a provider and said, "Hey, I think it's this." "Well, you couldn't possibly know because you're just the patient, and you're slightly cognitively impaired. So of course you couldn't know." I find that that has happened to me many, many times. I mean I just don't really go to the doctor anymore.

E: Yeah. Listening to your podcasts and hearing other people talk, it was very validating for me because so many people were saying the same thing, that you're not getting the help you need so you just don't go. Because you feel like either you know more--which you shouldn't, of course--or they're not taking your personal situation into account, or they're not giving you solutions, or they're just invalidating you.

And as you, I'm sure, feel--I feel--some days are better than others. So when you took that test, you might not have been having your best day. But that doesn't mean on another day when you're relaxed and not stressed and you're focused, you can't read a journal and learn what's in it and then apply that.

I mean, my goal is to have more better --I used to call them "pain days" when I was first really injured, and I'd put them in my little calendar. Was it a pain day? Was it a half-pain day? And how many of those was I having in a week? And so my goal was to not have pain days. And a pain day for me was a day where all I could do was the pain, whatever that meant. All I could do was manage it, or all I could do was sleep through it, or all I could do was watch streaming video through it, or maybe I couldn't even get out of bed to get myself food. And so the goal was to reduce the number of pain days: reduce the number, reduce the frequency, create a gap. And it doesn't mean I don't have any pain on a given day, but anything that's below a 4 on that 0-10 scale that practitioners like, wouldn't constitute a pain day. Once you get above 5, 6, 7, 8, 9, 10, you're at a point where you can't function. And so for me it was OK, how can I reduce the number of these days where I'm not functional? And once I get to that, how can I reduce the number of days where I'm registering pain? If you've had chronic pain, you know that you block out anything below a 3 probably, on a daily basis because you're so used to it. You just go on with your life, and you know that you have a certain amount of pain. But you just ignore it. What I've learned to do is sort of at least check in with it instead of just ignoring it. Part of that I got from the Anat Baniel method, which is really concerned with monitoring change, really noticing tiny, subtle differences as ways to help your brain process healing. Because there are some kinds of chronic pain which are actually just misfires by the brain, which are residual from the response the brain had to protect the body

initially. And so I worked hard to get rid of as much of those as possible, because those are the easy ones to clear. Those are the ones that are just the brain having a bad message.

CHERYL: Mmhmm.

E: It's still protecting the area that got hurt even though maybe years later, that area's not hurt in that way anymore. And that, too, is what comes back around to telling the story. If you tell the story [laughs], you re-experience the pain, you retrigger the brain, you have to re-erase that pattern again.

CHERYL: That's right.

E: I had to learn that, and that was one of the articles I felt like people needed to read [laughs]. Because nobody will tell you that. Once I saw it validated in studies, I was like, oh my gawd, why? Why? We're so attuned to tell somebody your story; that's how you heal.

CHERYL: Mmhmm, mmhmm. And also just demanding that that's the story. You have other "your stories." Why does it have to always be that one about--why is it that people are always asking for the trauma stories and expecting that that's the only story you'd want to tell?

E: Well, that's a whole other thing about how we've constructed our culture and how we don't accept people who are different and how we want to only connect with people in their wounded state, whether that's a psychological or emotional wound, a physical or financial wound. We have created, particularly in America, a culture that wants to connect with the wound. I find that to be a little bit toxic. Part of it is that we don't accept people who are different, even if the difference is a disability or an economic disparity or an emotional history. It's not just, yes, women are different, and people of different ethnicities are different, and we have issues with that. But we also have person-to-person issues with people who aren't just like us. And the way that we connect with people who aren't just like us is through this wound. They expose their wound, and we expose our wound. That's what reality shows are.

CHERYL: Uh-huh.

E: That's what a lot of television drama is. We as a society has always valued strength and adventure and courage. For some reason, we've come around to a place where the only way for us to take someone seriously is through their drama [laughs].

CHERYL: Mmhmm.

E: We have a problem emotionally connecting, and we've created this way in that's sort of debilitating for everyone.

CHERYL: Yeah, well said, yeah.

E: I feel like I'm very new at this whole "not being able" thing because really I lived with chronic pain for a long time, but I just came to accept it as part of my life. And so it's only really in the last two years that I've been dealing with the other issues, maybe three years. And so I don't really know all the language, and I don't really know what everyone else's history is. And so I often feel that I'm on the tip of the iceberg, really. So when people who have been in this world for a long time are reading and still getting something from my writing, that's just such a great feeling.

CHERYL: I'm glad. I can't thank you enough for writing those things and for writing them in that particular place.

E: I've known Sonya Renee a long time, so I knew about the project. And I just thought it was about body image, and I didn't think it had anything to do with me. And then I read this article by a woman named [Toni Bell](#) about having an abusive mother, and it just resonated in a way I was really amazed by. It was just very deep resonance. I put it up on my Facebook, and she liked it. And I'd been looking for her online; I couldn't find her. So I tentatively wrote her a little message. And we talked, and she said, "You know, they're looking for content writers."

CHERYL: Oh!

E: And I thought, here's this stranger [chuckles], telling me that Sonya's website is looking for content writers, and I should be a writer for them. Then she sent me all the stuff, and I applied. And one of the things that they sent me when I started talked about The Body Is Not An Apology and what content writing would be and what they were looking for. And there's this sentence it's like, "We are not afraid to be wrong." I just highlighted it in the pdf, and I kept it open on my desktop for like a week. And every time I was trying to do something in life that was on some edge that was uncomfortable, I just read it over again. We're not afraid to be wrong. It's OK to be wrong. You can point out that I am wrong [laughs]. That's a conversation. That's how this works. And so, what I think is great about that site is I don't have to be an expert to write these pieces, and maybe I'm wrong. But maybe what I'm writing is resonating for someone anyway, or for someone who's like me. So that, I think the not afraid to be wrong part is really big. And I think that that's how we move forward together really, find new solutions to things.

CHERYL: Yeah! Absolutely.

The Spoon Theory

CHERYL: So I want to point out that we've been on longer than we had expected to. And I wanna be super respectful of your time and your energy and your spoon supply.

E: You keep saying "spoon," and I don't know what you mean. So I wanna know.

CHERYL: [gasps] Oh my goodness! I'm sorry! So there is this woman named [Christine Miserandino](#), and she has lupus. And she came up with this metaphor. Cuz she had a friend like, "Well, you look fine. You look fine. I don't understand why you're tired. Why do you say you need accommodations?" And they happened to be at a diner. And so Christine grabbed a handful of spoons and sorta walked through. She's like, "This is my energy for the day. I got out of bed and stood up straight," puts a spoon down. "I took a shower," puts a spoon down. And she gets basically to lunch, and she's out of spoons. And she said, "But look. I still have to finish the work day. I still have to interact with people. I have to do all these things and then go home and take care of myself. But I don't have any more spoons of energy."

And that's what a chronic illness or a disability does is everything that you do takes more spoons, and your spoons get taken away quicker, and you can't replenish your supply as fast as someone who's very healthy. Sorry for assuming that you knew that. But in my social media circles and in my live friendship circles, everybody's always, "Do you have the spoons?" It's sort of code for acknowledging that it's going to take energy away from something else that you need to do later. So that's what the spoons is about, The Spoon Theory.

E: Well, I appreciate that, and I think it's a really adorable way of saying it.

BOTH: [chuckle]

E: I like it. And it's really accurate. I saw a friend of mine who has epilepsy, she's a poet--SaraEve Ferman. She's amazing. She posted something on Facebook a few weeks ago, which was basically a battery with charging levels.

CHERYL: Oh, yes! Yes, mmhmm.

E: And that's such a great graphic because it starts out not full [laughs].

CHERYL: That's right.

E: And then you took a shower, and then you did this, and now you have to go out, and you're all the way down to 1. For me, that whole idea is where the chronic pain part and the brain part come together in a really bad way. When you know that your energy is flagging, and you might be bringing on physical pain, you start to get anxious [laughs].

CHERYL: Uh-huh!

E: Right? You start to go, "Well, now that I'm tired, I'm showered and ready to go out. But then, how long will I be out? And what if I can't get this, and what if I have to wait longer for this? And what if this happens? And then I'll be really, really, really tired. And then I'll be in pain. And if I'm in pain, I won't be able to walk from here to there." And so you kick in your own little PTSD reaction [laughs], previous to even doing this thing.

CHERYL: Right [chuckling].

E: And so you're making it way worse. But that's what happens because you want to not create pain and more fatigue. What you want in that moment is to rest, right? You wanna stop. But no, because you've made this commitment to do something.

So I find that the battery really worked for me. It really gave me a mental image to check in with, and also gives me a moment to diffuse that brain reaction. I think the biggest thing is that I do have a lot more friends who are less-than able now because we communicate really well, and we know what it means. And when I say, "I can't, I'm done," they say, "Go." And they don't let me keep going. But you can't just suddenly turn to a friend who's more able-bodied and say, "I can't anymore; I'm done." They just don't know what you mean [giggles].

CHERYL: Yeah! It's excellent self-care to monitor your battery or your spoons.

E: I know. It's hard, though.

CHERYL: It is, it is, for sure. Yeah.

What You're Working On and Where to Find It

CHERYL: Would you like to share with folks what's around the bend or where people can find your work online or anything along those lines?

E: Zesty or the Zestyverse started as a blog about my being a nomad because I had a Myspace blog that was very well-read. And I was just gonna keep posting there, and one of my friends--this amazing poet, Ellyn Maybe--she sent me an email and said, "I really wanna follow your travels, and my mother and I don't have very good connectivity. And Myspace is really hard to load. Have you ever considered starting a blog?" I love Ellyn, and I didn't want her and her awesome mom not to be able to read what I was posting. So I started a blog [chuckles].

CHERYL: Oh.

E: And I started posting the blog. And suddenly, I got all stiff and weird because I felt like oh my goodness, this is searchable, and the whole world can read it. And I don't know if I want them knowing all these things about me. But eventually, I kind of found out how I wanted that to be and what voice I wanted to have. But after a while, I just thought all right, enough about me.

BOTH: [laugh]

E: So I started different series like the [Women You Should Know](#) series, which goes in March for Women's History Month. The first year I did all of them, and then the second year, I just invited writers I really liked who I didn't feel like had enough exposure or who I thought would have some great insight. And I said, "Would you be interested in writing a piece? You pick a woman who maybe you think people don't know about but should know about, and you write this piece." And so from there, I just started soliciting contributors. So now, I'm moving away from writing. So I'm really just managing the content and editing and publishing and kind of getting contributors to write about the intersections of art and social justice. We have a series called [Dear Able People](#) where people who are differently-able get to kind of share their experiences but in a way that is accessible to people who are able, so they can understand what it's like. We have a music writer, we have someone who writes a lot about digital content. And I just wanna make it available to other writers who might have great things to say but don't have an outlet. It's an ever-evolving thing.

What's coming up for me, hopefully, is that I will be going to London to get an MFA in Creative Producing at the Royal Central School of Speech and Drama, which sounds really fancy. But it used to just be Central. This is a kind of jumping off point for me. It's sort of leaving my film career behind for various reason, one of which is physical energy, and moving fully into live events to create the kinds of experiences that I think can be created, based on things I've done in the past. I believe there is a way to create events that are sustainable for artists and audiences and communities and the organizers. And I mean energetically, creatively, and financially sustainable.

I am not a fan of the pay to play model, and it is prevalent in the US. And it's starting to become prevalent in other places, and it severely limits diversity. It corrupts the relationship between the audience and the artist. It puts up a barrier. This idea that you're out there to make money or that you've put money into it, so you have to make a certain amount back, there's a kind of 'us and them' that happens, both for the audience and the artist, that I don't think is the best way for art to be shared. I have some ideas about how to make a different experience around sharing music and theater and poetry and other live arts. And that's what I'm hoping to explore.

CHERYL: That is fantastic. Where can folks find you and your work online?

E: They can find me at [EAmato.com](#) (e-a-m-a-t-o). Zestyverse is a Blogspot, but it's also [Zestyverse.com](#) (z-e-s-t-y-v-e-r-s-e). I have [a tumblr with poetry](#) on it. [I have a Twitter](#); I really like Twitter. I've put up a

lot of stuff about writing at [WritingsNotAMystery.Wordpress.com](https://writingsnotamystery.wordpress.com). That's just things I've learned about writing from working with clients and doing my own writing. There's a lot of tips and insights and--I don't like the word "inspiration" so let's just say something--good energy around writing and creativity.

CHERYL: Yeah, yeah.

E: I can see a lot of trends from helping writers through projects, how people get stuck. A lot of it's in the way that they think about the project or the writing. A lot of it is taking on too much or not taking on enough; those can be a big problem. It's a blog. So it goes backwards. So if you start at the beginning, you really wanna start at the end.

CHERYL: Uh-huh [giggles]. That's gonna be my new motto for life: If you start at the beginning, you really wanna start at the end.

E: Well, it's very Beckett, isn't it.

CHERYL: [laughs]

E: The end is in the beginning, and yet you go on. So it's a little bit "Waiting for Godot"-ian.

CHERYL: I'm still waiting. We're just waiting.

E: Yeah, we're still waiting.

Wrap-up

CHERYL: It has been so delightful to talk to you, E Amato. It's just wonderful to talk to you about social justice and art and the Zestyverse and all the things. It's so generous of you to be on this show. I'm really grateful.

E: Well, I really appreciate that you put so much into this, into sharing insights into disability. And there are a lot of things I learned from listening to the podcasts that you sent me, and also just that feeling of wow, other people are going through this, too. You know, the "I'm not alone; I'm not crazy," it just can't be over-rated [chuckles].

CHERYL: Oh, no. It's one of the best.

[music]

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, [WhoAmItoStopIt.com](https://whoamistopit.com).

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