

## Gazed At: Stories of a Mortal Body

Julie-Ann Scott-Pollock

**Setting:** *The stage is empty, except for a digital backdrop and two black chairs placed six feet apart. The performer, middle-aged, dressed in plain black clothing and bare feet, enters from stage left and slowly makes her way to the middle of the room. The digital backdrop shifts from the sketched portrait of the performance artist that is the poster for the show to a child's drawing of a large, green eye.*

The gaze  
they stare  
sometimes with sadness  
pity  
others with fear  
revulsion  
Always with questions.  
How did this happen?  
Does it hurt?  
Is it getting better?  
Is it getting worse?  
Most importantly  
Can this happen to me?  
Or anyone that I care about?  
They want the story. So here's my story. It's told with my pictures.

*(Backdrop shifts to sketches transitioning to photographs of the performer as a 4-year-old child.)*

**1985, Sanford, Maine**

---

**Julie-Ann Scott-Pollock** is Professor of Communication Studies at the University of North Carolina Wilmington. Her research and performance work focus on Personal Narrative as Performance of Identity in Daily Life with a focus on stigmatized embodiment. She is the director of UNCW Performance Studies which includes the UNCW Storytellers, UNCW Hawk Tale Players, and the Just Us Performance Troupe for Social Justice that perform annually. She also directs UNCW Performance Ethnography that most recently staged narratives from her current research project: Seizing: Personal Stories of Living with Seizures.

In one of my earliest memories, I am getting out of the car to go shopping with my mom at Kmart, and I am so excited because it is the only store with toys within 40 minutes of my house. A stand peeling my legs from the vinyl front seat. It's summer and it's hot and if our car ever had air conditioning, it doesn't anymore. Today, I feel proud of how I look.

I'm not wearing my usual androgynous overalls that dominated my childhood wardrobe, because my mom thought their undefined waist and baggy fit concealed my regular gait, but it's too hot for them. I'm wearing little white shorts with bows on the side and a pink Minnie Mouse tank top that my aunt bought me. My hair is swept up in pink elastic bands. I feel pretty airy. I'm walking a bit straighter, more confident than usual. Out of the corner of my eye, I see a little girl and her mom. They're staring at me. My face gets hot. The little girl whispers something.

The mom says, "Shhh, don't look at her. She can't help how she looks."

I'm close enough to the store that I can see my reflection in the glass door.

My body is thin and muscular and tan from hours of swimming in the river behind my house. I see my deep set, dark eyes, my average non-descript, LaFredo nose that my father says is preferable to both the Tomassi and the Malio noses of this family. My dark brown hair reflects the sun. I also see what that mother and her daughter see. I'm hunched forward to balance on turned in feet, purple scars snake up my calves. It's at this moment that I realize the operation didn't fix me. The doctors slicing into my calves, snipping my tendons to manually lengthen them, and then stitch them back together did drop my heels to the floor. I'm no longer up on my toes, and I don't need those white clunky braces, or the socks that reduce the chafing.

I was so excited to be rid of them. It's only now that I know that the operation followed by full leg casts, followed by walking casts, followed by months of physical therapy haven't changed how I look enough for anyone to notice my cute outfit before my gait. I'm four and I'm so aware of my body, how it feels to live my identity through it, how culture responds to it. I'm just so very, very aware.

*(Slides transition to a child's drawings of a large heart/body cell with sparks coming out.)*

Storytelling, is visceral.  
We feel a moment with a stab  
a sink

a swell  
a flutter  
a punch

We section it off to remember through the embodied telling and the retelling

*(Slides transition to the performer at 12 in a hospital gown awaiting an operation; water-colored and black and white sketches fade back and forth to photographs.)*

### 1992, Boston, Massachusetts

I'm screaming, hysterical, tied down with nylon bands. The nylon bands are soft, but strong. I can't stretch beyond their 3-inch length. Yesterday, the doctors performed a bone rotation. They sliced into both thighs, peeling back the skin, and prying the muscles to the side to reach the femur bones, which they sawed in half, rotated 30 degrees, and nailed back together again. The last thing I remember is the strawberries. They told me I could choose bananas, blueberries, or strawberries and I chose strawberries. I breathe deeply and I counted backwards 25, 24, 23, and I was happy. This was the operation that was going to fix me. I was going to be normal.

Sometime during the night, the epidural that was numbing the pain, it fell out, blood pooled behind me, but the nurses thought that I had just started my period from the stress of the surgery, so they just put towels back there and felt that they would change the bed once I woke up. By the time they realized the blood was coming from my back not from between my legs, the painkillers had worn off. I'm 12, and I'm small for my age and to go back up to the required amount of painkillers would cause my body to go into shock. Instead, they tie me down so that I can ride the pain with my legs in traction, until multiple lesser painkillers can take effect.

Normally, I don't even notice that my body is constantly spasming, my brain sends signals to tighten again and again and again. I don't notice well until the pain pools in my toes and sloshes up my calves, but right now with both of my legs sawed in half, every involuntary movement is excruciating. A woman comes into the room. She has a series of pictures of faces. She wants me to choose which one is my pain level. There's one smiling all the way and one with its mouth open that's crying. She had talked my mom and dad into having me participate in this study on kids in pain after surgery. I can't though. It hurts too much. I can't pick one.

My brother's staying with me well until my parents get back from lunch. He tries to help.

“Ah, I think it’s that one.” He points to the one that has a face with its mouth open and crying, The one that looks like me.

“You can’t choose. We can’t count it in the study unless she chooses.”

I finally fall asleep, a mixture of exhaustion and the lesser painkillers finally taken effect. As I tell that story, my toes curl. My body remembers. That was the worst pain I’ve ever felt.

*(Backdrop shifts to a child’s drawing of people holding hands.)*

Storytelling is Collaborative  
Tellers and audiences working together  
switching roles  
Moving back and forth in this messy meaning making  
The story continues.

*(Backdrop transitions to a series of photos after the birth of the performer’s second son. The images fade back and forth from watercolor and black and white sketches to the original photos.)*

### **2013, Wilmington, North Carolina**

I arrived at the hospital about two hours ago. Before that, I woke up my husband Evan because that dull pain in my back had increased in intensity enough that it was time to cradle our sleepy toddler to the car and drop him off at a friend’s house before heading to the hospital. This is my second baby and I deliver quickly. So quickly that I don’t believe in having any kind of painkiller during childbirth. I actually find the break that I get between contractions to make overall labor pains pretty manageable. Well, a lot more manageable than that operation I had when I was 12. Besides, I don’t believe in epidurals. They fall out. It took about five minutes for me to finally agree to the nurse inserting this IV into my wrist. It burns even though she says it doesn’t.

It’s no use arguing, it’s procedure. I’ll get them to take it out once Vinny gets here. We enter the dimly lit delivery room, and I see the labor tub filling in the corner. I wonder if I’ll get to use it. This hospital only allows water labors, not water births and I have a feeling that Vinny is coming soon, too soon for me to get into that tub. I’m right. I feel a warm stream of water going down my leg.

“My water broke, call the nurse.”

“I will,” Evan hits the intercom. It awakes with static. “Ah, her water just broke. We think it’s time.”

“All right, we’re on our way.”

She doesn’t sound very excited. Hmm, childbirth probably isn’t that exciting when it happens five times a shift.

That’s all right because I’m excited enough for the both of us. It’s been an uncomfortable pregnancy. I’m ready to meet Vinny. The nurse comes in. She’s about 25 with tired eyes and a drawn face. She looks between my legs, “Ah, yeah, you’re definitely ready. His head is right there. You are going to love his hair. It’s dark and thick, a lot of it, just like yours.” I smile. She sees a lot of babies, but not all of them have hair like mine. The doctor comes in and she’s followed by another nurse. Ugh, this is my least favorite doctor in the practice. She never listens to any of my questions during appointments. She just says, “You’ve got the blood pressure of an athlete and the baby’s moving fine, there’s nothing to worry about.”

Still, I’m not all that upset that it’s her who’s on duty. After all, it’s not like natural childbirth leaves a lot of time for conversation anyway.

“Okay, I’m going to need you to scoot down to the edge of the bed, and I need you on your back and you need to open your legs wider.

“I can’t open my legs any wider than this. This is as wide as they go. I have cerebral palsy.”

I wasn’t expecting to have to have this conversation. Dr. Novasal, the doctor who delivered my first baby, Tony, she said that she can catch a baby from any angle to just get comfortable. This doctor, who shall remain nameless, seems more about procedure. I make a mental note that I’m going to schedule my postpartum appointment with Dr. Novasal.

A contraction comes and I get ready to push.

“Pull her legs apart.”

“No, don’t.”

My legs lock in spasm as the contraction hits, and I can’t push, I can’t scream, I can’t even breathe. It hurts too much.

“You are never going to have a baby if you don’t push when the contractions come.”

“Well, if you keep holding my legs like that, I can’t.”

I realize I’m not breathing, and I take a deep breath because my baby, my Vinny, he needs my air. I try to remember that this doctor is not a neurologist and she’s not an orthopedic surgeon. She probably knows nothing about cerebral palsy. I think it’s going to be okay. The nurse’s eyes went wide when my legs locked in that spasm.

Another contraction comes, and another and another, and Vinny’s here. He’s warm, wet, slippery, but I can’t focus on him. I’m not finished yet. I feel the pressure as the doctor pulls the umbilical cord releasing the placenta. It’s warm, wet, squishy. I think I’m finished. With Tony once, I delivered the placenta, I was finished.

“Can you please hold her legs apart well this time, so that I can put a few stitches in?”

“No, don’t.”

The nurses brace for the spasm in my legs and the pain mixes with the sting of her needle, and the dull ache of my organs going back into place after delivering seven pounds, eight ounces of baby and the placenta that nourished him until now. Vinny’s crying, but I can’t comfort him. I’m still inside my body. He’s not quite in this story yet.

*(Backdrop shifts to a child’s drawing of a storm.)*

Storytelling is susceptible  
forever open to change  
All that we do can be undone and redone  
There’s hope in the revisions

*(Backdrop shifts to a photo of the performer in high school that fades from water-colored to the original image.)*

### **1994, Wells, Maine**

I just arrived at high school. This high school is made up of three towns and mine’s the smallest and farthest away. I’m only 13, because when I was in first

grade, my teacher, Mrs. Pettigrow, she thought that my handwriting was weird. She thought I walked weird, and I looked weird. She just thought I was weird. She sent me to the special needs room where they ended up just putting me in the corner to do my work by myself for hours a day, because my learning needs just aren't that special.

I ended up a whole grade ahead and in my small K-8 school at the end of seventh grade, they said I was ready for high school. So, here I am, a whole year early. A mixture of physical and water therapy have me walking with my back straight and my feet facing forward. I still limp. My knees and my ankles are still stiff, but my scars are hidden under my brand new flared jeans. Out of the corner of my eye, I see a group of boys. They're nudging each other and laughing. It's like the Kmart parking lot all over again. This operation didn't work either. One of them's coming over. He's smiling. He has black wavy hair and blue eyes. He smells like a mixture of laundry detergent and cigarettes. I decide I don't mind the combination.

"Hey, I'm Shane. You're new."

"Yeah, my name's Julie-Ann. I'm from Acton. There's not many of us."

"Well Julie-Ann from Acton, where are you going?"

"Um, my first class is freshman literature."

"Well, you are in luck because I know right where that is, and I am going to show you. Come on. Oh, did you hurt yourself at practice? Did you pull a muscle?"

"Um, no, I don't practice anything. I do physical therapy. I have a cerebral palsy. It's a muscle disorder, makes me walk weird."

"Not that weird. I just thought you hurt yourself, playing a sport or working out. You look like you work out. You look great by the way."

"Thanks."

"Come on, I'll show you where that classroom is."

"Okay."

Shane was my first boyfriend. It didn't last long, but it marked a change to my story. You see, after that bone rotation, once I healed, even though I still limped, to the untrained eye, it looked like maybe I had pulled a muscle or sprained an ankle, that maybe I was going to get better. Even when people found out that wasn't the case, they still wanted to be my friend. They wanted to get to know me. They wanted to date me. I discovered theatre. I found out I love the stage.

*(Backdrop transitions to child's drawing of the performer on a stage.)*

The Stage.  
When I first did this performance  
people came up to me afterwards asking me if I would move more  
My limping, gimping body up here on this stage  
Resurrecting a politically correct freak show.  
It made me uncomfortable  
but all right  
I'll walk  
And you can watch  
But also listen  
because my body  
it has a message for yours

*(Backdrop fades to a series of pictures of the performer and her husband when they were dating. The images shift from watercolors and black and white sketches to the original photos.)*

### **2007, Honey Brook, Pennsylvania**

I just finished Thanksgiving dinner at an assisted living facility. Evan is my fiancé. He's been my fiancé for a little over a month. His grandma Mary is holding onto his arm and his sister Rachel is a few feet ahead of us. The dinner was way better than I thought it would be, the turkey, the mashed potatoes, the vegetables, the pie. The room's also prettier than I anticipated, with plush patterned carpets and vaulted ceilings with chandeliers. As we get to the entrance, Mary lets go of Evan to grab onto her walker with oxygen tank attached.

Mary is thick and broad with a raspy voice from years of smoking followed by emphysema.



“\*Cough\* Let’s go back up to my apartment.”

We follow Mary, leaving behind the sign that says, “No wheelchairs or walkers in the dining room. As we get off the elevator, Evan and I hang back a bit and I watch Mary and Rachel walk a bit ahead of us. This is my first time meeting Grandma Mary. Evan warned me that unlike his no-nonsense farm family from Kansas, Mary cares deeply about appearance. I dressed up beyond the flannel and jeans I would have worn to my sister’s farmhouse in Maine. I have on a chocolate cashmere sweater and a camel pencil skirt, and knee-high boots with pointed toes. They hurt. My feet can’t spasm without scraping up against the stiff leather, but they look so good with this skirt. My hair’s blown dry in waves. I have on more makeup than usual.

Seeing Mary seems to verify Evan’s assessment: her perfectly set, dyed brown curls, her silk blouse with tweed blazer and broach with jewels.

“Evan, do you think Mary likes me? I’m having trouble reading her.”

“Of course, Mary likes you. You complimented her apartment, you listened to all of her stories and asked great questions. She loves you, just like everyone loves you.”

“Well from that, at least I know that you like me. “Do you know why they don’t allow any wheelchairs or walkers in the dining room?”

“Well, Mary will tell ya, ‘it’s to keep all the old sick people out,’ but I like to think it’s just so the waiters don’t trip on them or something.”

“I hope that’s it. I mean bodies break down and that shouldn’t keep them out of beautiful places. I mean especially in an assisted living facility.”

“Agreed.”

As we get close to Mary’s apartment, we can hear her and Rachel talking.

“Is Evan worried about what people are going to say when they see who he’s marrying? Does he think it’s going to hurt his job prospects when people see that he’s getting married to a cripple?”

“I don’t think so Grandma Mary. He’s never mentioned it and no one at the university has either.

“Well in this day and age, they don’t mention it. They just think it.”

Evan and I walk into Mary’s apartment. She knows that we heard her, but she doesn’t look apologetic or embarrassed. Rachel looks worried though. She hasn’t known me long. She’s not sure what I’m going to do, but I just smile. Mary’s old and she’s sick, and she doesn’t need to die in an argument with me on Thanksgiving about ableism.

*(The backdrop shifts to a child’s drawing of the performer.)*

Ableism  
the unabashed rejecting of my disabled body  
Culture beams with pride  
Parents say, “Oh, you know we don’t care, well as long as it’s healthy.”  
You mean as long as that baby’s not me?  
It’s okay to not want me.  
Ableism is pervasive  
But it can be dismantled.

*(Backdrop transitions to photos of the performer pregnant with her second son. Images begin as watercolors and transition to the original photos.)*

## **2012, Wilmington, North Carolina**

It’s been two years since Evan I moved down the East Coast for me to take a job as an assistant professor at the University of North Carolina Wilmington. We’ve put off getting our in-state licenses until now. There were just so many changes in our lives. It was easier to leave my little white Nissan, insured with my brother’s insurance company back in Maine, but after all of these changes: new jobs, new state, new house, new baby, we finally need a new car and the gold RAV4 that we chose because it easily accommodates our growing family and big standard poodle on trips back to Maine and Kansas to visit family can’t be tagged or insured, unless we have in-state licenses.

We study for and pass the mandatory written exam. We pose for our license pictures and as the man hands me my license, I think, “Oh, do you have that application for a handicap placard here? Do I get that here at this office, or do I need to go somewhere else?”

“What do you need it for?”

“Um, I have cerebral palsy. I know sometimes people don’t notice right away, but when my hands are full, I can trip when I’m walking, so I have a handicap placard so that I can park closer to places.”

That was way more information than he needed, but I always get nervous talking about my handicap placard that people will hear my diagnosis and think I’m less capable than I am, or that they’ll see me and think that I don’t need a handicapped placard at all, that I’m faking it.

“Wait here.”

The man walks away. He’s big somber, graying. I suddenly feel smaller, younger, less capable than just moments before. I try to tell myself that the nerves are just because I’m tired. My 2-year-old is wriggling down my side. He has already been at the DMV way too long to find it at all interesting. My back is hurting, I’m pregnant, I want to get off my feet. The man comes back.

“We’re going to need to do a road test.”

“A road test?”

“It’s procedure.”

“A road test is procedure for someone you just gave a license to?”

“Driving is a privilege, not a right. And we reserve the right to test disabled at any time. It’s for safety reasons.”

“Um, okay.”

I make my way to his car for my driving test and I am both angry and really, really nervous. I’m angry because I have to take a driving test and Evan doesn’t, even though we have the same exact licenses from the same exact state. I’m also nervous. What if I fail this test that I shouldn’t have even had to take in the first place? My entire body is shaking through the entire test. It has nothing to do with cerebral palsy. I’m just so angry and so nervous, but other than my really jerky 3-point turn, I pass. I’m relieved. Until two weeks later when a letter arrives from the State of North Carolina telling me that I need to travel three hours to take a combined physical and road test at a facility that won’t take my medical insurance. It takes two hours to finally get somebody on the phone with the authority to move this new road test and physical to my local DMV and doctor.

I make an appointment with my physician. He's happy to see me. Most of his patients are elderly, but since his office is right by the university and we can usually get in the same day, Evan and I have him as our primary provider.

"My assessment, you have better overall coordination, flexibility, and balance than I do. I feel safe with you on the road."

I head back to the DMV for my driving test and I pass, even my 3-point turn was perfect. Two weeks later, another letter arrives from the State of North Carolina telling me I'm going to need to travel to that facility for the combined physical and road test. The first person that answers the phone looks up my file.

"Well according to this here, you have cerebral palsy, but it doesn't say anything about what they're going to do to the car to make this safe for you to drive. There's nothing about handheld brakes or some sort of assistive equipment."

"I do have cerebral palsy, but I ski black diamonds, I road bike, I do yoga, and I do not need handheld brakes."

I hang up the phone. I call a civil rights attorney. He writes a letter. Three weeks later, I get another letter from the State of North Carolina and my permanent license is enclosed. They let me know I will not be hearing from them again. I make jokes about the whole thing on Facebook, but really I'm sad and concerned for all the people that might not know that it's time to call an attorney, or wouldn't have the ability to do that, even if they did know.

*(Backdrop shifts to a child's drawing of an angel in the clouds.)*

Mortality  
The inescapable reality of the flesh that we're in  
all that we build  
All That we are  
will continue to change  
We will break down  
And disappear

*(Backdrop shifts to a watercolor image of the performer with her four sons. The photo transitions to the original image.)*

**2018, Wilmington, North Carolina**

I'm walking through Target as I usually do. My two-year-old on one hip my six-month-old on the other hip (because neither of them will ride in the cart). My five-year-old weighing me down, and my seven-year-old bumping into me every few feet. I stop at the after Christmas sales rack, and I look at each of my four boys wondering if I can predict their size at about this time next year with enough accuracy to get an amazing deal on matching gingerbread T-shirts, when I hear a voice.

"You know, you are never going to heal if you don't put those boys down."

"Oh, I'm not hurt. I have cerebral palsy."

"Oh, well I thought all these children were yours."

"They are."

"No, no, dear, I mean I thought you gave birth to them."

"I did."

"Oh, well are people like you usually fertile?"

"Um, yes, cerebral palsy doesn't impact fertility."

"But aren't you worried about leaving these poor beautiful boys without a mother?"

"Cerebral palsy also doesn't impact life expectancy, but just so you know, questioning a stranger you just met at the Christmas sales rack at Target about their choices and family planning and their impending mortality, it's a bit invasive."

And she walked away.

*(Backdrop shifts to a child's drawing of different people holding hands.)*

Marginalized  
some bodies exist on the slippery edge of culture  
Denied the opportunities that the dominant take for granted  
You see

The powerful need the oppressed  
normal needs abnormal  
The center needs the margin to exist  
Without me  
Who are you?

*(Backdrop transitions to a series of photos of the performer in graduate school, transitioning from original photos to watercolors and black and white sketches.)*

**2006, Orono, Maine**

I just arrived at feminist theory. I'm a little bit late. The only seat left is next to the Professor Naomi, but that's fine because I like Naomi. She's smart and thoughtful, and I also really like feminist theory. I look forward to it all week, well except this week. Every student in the class has to lead one of the seminar conversations, and this week is my turn. It's on the relationship between the women's rights movement and the disability rights movement. I didn't have to pick this week, but everybody thought I would so I just did.

"Julie-Ann, are you ready to start?"

"Um, yes Naomi, I am definitely ready.

Thanks so much.

Okay everyone, before we begin this conversation, I think it's important that we understand how disabled people were viewed in socie..."

Julie-Ann?"

"Yes?"

"Do you mean people with disabilities?"

"No Naomi, actually, I don't mean that. I really hate person first language. I am a white woman, not a woman with whiteness. I am a straight woman, not a woman with straightness. I'm also a disabled woman. It's just another identity marker for me, and I think to change the rules of how we do adjectives in the English language to talk about just that one aspect of my identity further stigmatizes and marginalizes it."

"How about differently abled, would that work?"

“Well no, it wouldn’t work for me. To say differently abled is rooted in this idea that we all have different abilities and that is definitely true, but while race and disability have very, very different histories, to me to say differently abled, instead of disabled is like trying to make the argument that because the human race began in Africa that we’re all African, or because we all have pigment in our skin, we’re all of color. And it’s not that that isn’t true, but it minimizes the reality of bodies marked as African, or as Black, and so I just don’t like the term differently disabled. I just like the term disabled.”

“Just so you know, you’re getting kind of angry and defensive, and that’s going to make this conversation really hard.”

Ugh, it’s her, the one student in this class who always lets everybody know when how we are speaking could be making it difficult to have a conversation and she says it whenever there is any sense of urgency in anyone’s voice. And how are we going to dismantle oppressive systems without a little bit of urgency?

“You know, maybe if as a class, we were all a little bit more concerned about the cultural system that is making Julie-Ann angry and defensive, instead of how the tone of her voice is making us feel, we could all collectively use this three hours that we’re together every week to pursue a better world.”

“Thanks Paula.”

Paula is the only Black student in this class and to my knowledge, I’m the only disabled student and while she’s not disabled and I’m not Black, we both know marginalization. And next week, when Paula is leading the discussion about the relationship between the Feminist Movement and Civil Rights. I’ll be here to support her. We work to be the best allies we can.

*(Backdrop transitions to a child’s drawing of the coronavirus.)*

Allies

Those of us committed to dismantling the oppressive structures that  
marginalize bodies in this culture Even the structures that don’t impact us  
Even those structures that we personally benefit from  
It’s difficult  
Complicated  
Uncomfortable work  
But I hope you’ll join us  
Because we’re exhausted and we need you.

(Backdrop transitions to a photo of the performer holding her smiling two-year-old son in rocking chair.)

## 2020, Wilmington, North Carolina

I'm rocking Theo to sleep in front of the TV. He finally is out. We've been in COVID lockdown for a couple of months now and without his brothers and Evan and I coming and going, he lost all sense of time. There was no schedule, so naps disappeared first, and then bedtime got later and later. I've stopped fighting it. I'm tired, and I'm sore. He's heavy against my hips, my heel cords are tight. You see, normally in a regular day, I would be moving as I lectured, moving as I directed. Now, I sit to record my lectures on Zoom. I sit to create and grade assignments, and there's so many more assignments to create and grade in online learning. My body is so stiff and so sore. I look over at Evan. He's on the love seat. He has his legs draped over one of the arms, and I think back to when we got that love seat right after we were married, when there were just two of us and two cushions were plenty.

"How are you doing?"

"I'm sore."

"Yeah, I know."

Evan is a lot like his dad. He has his dad's same broad shoulders, his dad's same kind, patient, sensitive, empathetic disposition. He also has his dad's back. When Evan's dad was about his age, he had to give up industrial farming and go back to school to become a high school teacher because of a back injury. I noticed a few nights ago when Evan reached for the spaghetti seasoning that we add to our pizza crust, that he winced. Evan has his dad's back.

"I really think you should go to the doctor and get it checked out."

"You know I will. I'm just going to wait a little bit. Maybe cases will go down. There's no use risking exposure if we don't have to."

"I guess so."

I try to stand up with Theo in my arms. Normally, I'd ask Evan to take him to bed, but he's as sore as I am. I stumble and Theo's eyes go wide and he grabs on tight. I sit back down and I rock, and I turn on another episode of *This Is Us*



and I wonder with two disabled bodies in this house, who's going to shoulder the load?

As I told you that last story, I wonder if you felt nervous for Evan and me. Know that Evan and I aren't nervous, just thoughtful and planning. Because Evan lives with me, because people have been drawing attention to the vulnerability and mortality of my body for as long as I can remember, I have become what I like to call hyper-embodied, and that term hyper-embodied has some negative connotations for some people.

They hear it and they think of someone with anorexia, obsessed with every calorie and pound. They think of a bodybuilder completely consumed with ideal symmetry. They think of a doctor so hyper-focused on diagnosing a patient that they've lost the person, but I disagree. To be hyper-embodied is to be at ease with the inescapable mortality and the fact that our bodies will change over time, so that we plan for it. If we could all become hyper-embodied, we could build a culture that flexes and changes with our bodies, so that we're all valued and included for as long as we're here and in that hyper-embodied culture, perhaps the fear surrounding mortality could disappear and didn't have to be piled onto the shoulders of disabled bodies like mine.

*(Backdrop transitions to a child's drawing of the performer.)*

Hyper-embodied  
Too fixated  
Too obsessed  
Too focused  
Well that's all nonsense.  
I'm enlightened  
You can be too

Thank you and please stay for a conversation after the show. I'd love to talk to you and get your thoughts.



*This work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike International 4.0 License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/4.0/>; or, (b) send a letter to Creative Commons, 171 2nd Street, Suite 300, San Francisco, California, 94105, USA*