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## **RE-CALCULATING**

**By Lucas Foss**

*Jonathan (wearing a hat) is sitting behind his drum set playing something while the audience comes in. Ideally his wheelchair can't be seen by the audience at this point. When the house lights go down, he starts to speak.*

*(he is still drumming while he speaks part of this first paragraph – feeling the joy – background beat etc)*

This is my favourite part of the show. This just sitting here, playing music, *(rim shot – drumming stops for a beat or two)* before I start to speak. *(starts drumming)* Of course I'm speaking right now but you know what I mean. I'm just explaining something to you, telling you something personal about myself. *(stops drumming)*

Our relationship of sorts has started just by you coming in and sitting down and seeing me on stage. And as I'm speaking, your mind is starting to organize who I am to you; categorize me in a way that makes sense to you. That's the way minds work. And we are doing it all the time. And the more time we spend together, the more refined a category I will become. If I didn't speak at all, it would be harder but you would find a way. If I didn't speak at all, someone might think, I was trying to be funny and they may laugh, someone else might think I was trying to do some kind of avant guard theatre, if I didn't speak at all someone else again might get irritated, with this perceived waste of time and start to think of me as a... jerk. There would be lots of different interpretations because there are lots of different people here, who come from different lives.

*(Jonathan comes out behind the drum set and rolls over to centre stage and faces the audience and as he takes his hat off he says)*

What do you think of me now? Your mind is likely re calculating. It reminds me of the GPS voice when you make a mistake driving, "Recalculating"

*(Sudden realization - drink) You know what? I'm recalculating too, recalculating you, in your recalculation of me. But I don't know you at all. All I can see are a bunch of faces and I can't even see your faces very clearly from over here. And so what is it that I think I know? (thinking) I don't know you or what you are thinking. (pause) I've done all kinds of shows before and I notice that if someone from the audience isn't looking at me or looking down or they are texting, or they have their eyes closed or they don't laugh when I think they should, or they look bored, or they're sleeping, I feel rejected and hurt because I take it personally. But really, none of those people are rejecting me.*

*(discover) I've made everyone in that audience my rejecting father. And that's true off-stage as well. Anyone who is in authority or is unkind, I project my father onto them. And maybe 10 percent of that projection is true but mostly it's false and so I'm living a false life in a certain way. I'm making decisions based on the wrong information. And if I can catch that falseness when it's happening then I... (pause, feel into a moment of insight) (what you were going to say.) Hold on a second... something in me has just changed. I was playing my music, which I just love doing and then I stopped. I was feeling really good, so comfortable and relaxed being myself. I'm coming from a different place than my mind and I'm not worried about anything (pause – realize)... until it's over. (Take a couple of beats – pick up cigarette but don't smoke it yet) I don't*

really use my mind when I'm drumming. It's coming from somewhere else, maybe it's my body, I don't know, but then when I stopped drumming, my mind came back in, like a sling shot that's been held back and must release. And it flooded me with all the busyness that a mind has and then I lose that space I was in... and now I'm feeling this deep emptiness all of a sudden and I don't like this feeling and I don't want to stay here, it's way too much pain... (*realization*) ah... so then I started talking to you about recalculating, trying to distract myself and I'm desperate to find something else to fill me, to feel better. And I start looking for something outside of me that I think I don't have (*find it*)... This is my suffering, that I think I'm deficient. Yes, I think that there is something wrong with me. And I'm not talking about being in this chair, I'm not talking about having quadriplegia. These feelings were there before my injury... (*intensely*) I'm talking about my heart. I'm talking about my defended heart. Everyone is not my father, every hurt I feel does not have to be infused with my father's hatred. The problem I have is all my history gets triggered more often by being in this chair because I get to feel rejection more than the average bear. And that's because I don't seem to be the average bear, I seem to be something different and some people don't know what to do with that.

(*picks up cigarette and takes a drag*) This isn't a real cigarette by the way – I'm not smoking tobacco – so please don't worry. It's a green cigarette, actually electric – there's nicotine in it which releases with each drag and I get a little kick in my lungs. I'm only blowing out vapor or steam but it does do the trick – helps distract me from the pain of the emptiness sometimes.

*(Take a drag or swig)* One of the things I used to really like, when I could get away with it, was when I was sitting in a regular chair at a house party or somewhere and people come in who don't know me and they look at me like anyone else in the room. It's somehow such a *liberating* feeling. I like it so much, just to be looked at in a normal way by strangers. I suppose it's not the most self-accepting state to be in but I can't help how much I *enjoy* that experience. I can't get away with the chair thing at all anymore, as my body has lost its form over the years. So I don't look that normal, sitting in a regular chair. But now that I remember, *(find it)* one of the more enlightening things about that 'sitting on the chair experience' is that some people acknowledged me and others didn't. Some people smiled and others didn't. Some people didn't actually see me at all. This told me something. It told me that it's not just this disabled me that doesn't get connected with or rejected, lots of people have that experience. The last kid picked for the baseball team or not picked at all kind of thing. One time, at a house party and I was sitting there like a regular person and I was having a conversation with Janice, this really fun woman I'd just met, when this other woman came through the front door to the vestibule and was taking off her coat and Janice said "oh no, hope she doesn't come over here." I just said 'what's wrong?' and Janice says "...she won't stop talking about herself and her problems, you can't get a word in edgewise, her favourite expression is "ya but". The woman *didn't* come over and something in me felt relieved even though I had never met her but the mood had changed somehow between Janice and me and I was sorry about that.

Later in the evening, when it was time for me to leave, my chair got rolled out from the spare room and I transfer over and when I look up, Janice is coming out of the kitchen and is standing there staring, with a shocked look on her face and she literally can't speak, the silence went on forever it seemed, although likely just a few seconds. Now, that other woman Janice didn't like, she's there too and she laughs and says "hey nice ride, where can I get one of those?" I really hate those kinds of comments but she was cute. Her name is Barb and we ended up in relationship for a year or so and we still are great friends. I remember how shocked she was to find out that me being in this wheelchair meant more than 'not walking'. That it meant no bowel control, no sensation, no normal sexual function and intense muscle spasms. Barb taught me a crucial life lesson. One day we were driving to the beach and I'm angry and complaining that I want to walk my own dog and wash my own car and masturbate and have regular sex. I'm yelling with frustration. Barb just listens, she doesn't react or take it on or get defensive and this is the first time I see there is another way to be, other than reactive. I'm not enjoying my life with this anger. I hate myself in this situation but there were others that didn't.

I start to hear this acceptance more and more But Barb is the first person to say to me: "I like you, Jonathan, I don't see your disability." That really surprises me because actually, that's all I thought about.

I've only ever been in relationship with *able-bodied* women. I just don't see how a relationship with a woman who has a disability could possibly work. We would have double the trouble with barriers and limitations. There are lots of great women out there

who have disabilities, but I've never given it a chance, not to say they would want to give me a chance either.

I always liked the Sadie Hawkins dances, you know when it was up to the girl to do the asking. Then I don't have to worry about my awkwardness or embarrassment or stupidity or being rejected, it's out of my hands. So this was in grade 11, and before my injury, I was asked out by a girl named Julie, she has braces on her legs from polio and she limps quite noticeably when she walks. God I still remember how hard it was, I don't want to go out on a date with someone who has a disability, even if she is really cute. I want to go with a "regular" girl. I lie and say, "I have other plans that night but thanks for asking." So I don't go to the dance, we might have had fun. I wonder if she's still around.

Appearance is crucial in our culture that's for sure – things like clothes, cars, and people. It's an endless list. I get attracted to someone by the way they look and they get first opportunity to be invited into my life. Sometimes the idea of who this attractive person is, well it turns out to be not quite what I thought, when I get to know them a bit. I'm not saying that attractive people can't have as much inner beauty as anyone else. It's just that appearance isn't telling the whole story. And who is it that decides who and what is attractive anyway? Love is going on all over the place with all kinds of people with different shapes and sizes and colours. (*maybe another drag or swig of water*)

I get into so much trouble when I can't separate myself from the feelings I'm having. I remember when I was 13, being wildly, passionately in love with Shannon. It ended badly and I was in 10 different kinds of pain and I thought I was this love sick, suffering

suicidal adolescent. There is no other inner voice or observer to give an objective perspective. Right after I swallowed the pills, something happens... *space* popped in and I know I am *more* than my suffering, *more* than my feelings. I got lucky, well maybe it's not luck but Grace, I don't know but ever since then I've always had enough space to not take myself to be my feelings. Sometimes I get identified with a role, like being a good student or being someone with a disability, or a good son or loyal friend. When I think I *am a role* I have in my life, how I see things is limited. I used to think I was the best possible friend any person could have: loyal, true blue and all that. My buddy Rick, got really depressed when his parents broke up and I'm always trying to cheer him up and give him other perspectives but what I find out later is that he didn't want that at all, he wants someone to listen and understand what he was going through, not to try and fix him and make him feel better. I'm devastated to learn that I'm not being the friend that he needs. When I lose that 'good friend' identity, it feels like I'm *dying*, like I'm losing my sense of who I am. (*pause*) Of course I have so many identities, (*pause*) but none more powerful than with my body.

You can relate – we love our bodies, hate our bodies, change our bodies. We wish we had a body like “that” or we're glad we *don't* have a body like “that”. We judge ourselves and others because of their bodies, their appearance.

And I notice when I judge, *my heart is closed*. And I can't see the person, their beauty and how much we are alike. And I know a lot of people don't see me. All they see is 'this' and they don't know what to do or say or they avoid me.

And it happens in an instant sometimes, an aversion of the eyes – they are trying to be respectful – not to stare, or they don't know what to do or how to be or what to feel but they are feeling something, even if it's numbness.

All the false smiles – being ignored is almost better, just a different kind of hurt. It bothers me that I'm not even given the chance to be seen or known beyond this body.

And I get it, but it hurts me, stirs up all those ideas I have about myself. I know that critical voice, same as you, I know the self hatred and that hopeless giving up place, same as you and I know the fear, same as you.

I'm the same as you. I am you.

Do you even know what makes you uncomfortable?

Is it the feeling you are having that is saying "God, I'm glad that's not me" Poor guy he'll never get laid. "Christ, I wouldn't want to live", couldn't do this or that. Ok these are feelings you are having or what your mind is saying but why does a feeling of discomfort mean a wall has to pop up between us? How will you find out what the truth is if you don't check it out? Let's have a conversation and you can be uncomfortable and maybe I will too. What's so wrong about being uncomfortable? Sometimes I just want someone to come and talk to me without it being some kind of sense of duty.

I mean these are the *very same* feelings I had about myself when I got injured. I lost a lot of friends immediately after it happened, some I never actually saw again, others I did see one more time, when they said "I can't bear to see you this way", don't want to

be around me – it's too uncomfortable for them. Later on I lost friends because everything I do takes me four times as long: getting up and going in the morning, getting in and out of my van, anywhere I go needs to be accessible, they have no patience for me. But I'm still basically the same person inside, only my body had changed. I don't mean to say that was a small thing, it fucking wasn't and isn't. My whole life, present and future was altered forever. Even the past was altered. How could I enjoy memories of friendships I no longer had after they had rejected me? I even rejected myself. And in the beginning I had the very same attitude, if I saw a person with a disability I'd avoid them, go across the street, I didn't want to get lumped in with them.

I guess we all lose friends, basically because someone changes, and someone makes a decision, at some level, to end it or let it slip away. My change was the injury but for me it wasn't a choice. *(drop water bottle – watch it)* Ah the dreaded dropping of the water bottle, this is not my favourite part of the show. Can someone get that for me? *(this may not be applicable to every show)*

I have a friend of mine who has a bit of a pot belly and he says that he can go months at a time without looking in a mirror below his chest. He is so disgusted with his stomach. I don't know what that self-hatred is about for him but I get it. In the beginning when I was faced with the reality that I can no longer walk, have regular sex, get myself in and out of bed, bathe myself, pick up anything, get through most doors, and a thousand other little things that are huge barriers for me, I was filled with anger and disgust. All of these rejections from the environment, I took very personally and they were very much an

invitation to self-loathing and hatred. And for a long time it was an invitation that I embraced, because it really felt like someone had died here.

But you have to remember I had a life before the injury. I have something to compare to and remember.... I have a young friend of mine, Sheila, who was in a snowboarding accident and got a head injury, when she was 18. It was pretty serious and she has real limitations in memory, social skills and fine motor dexterity. It happens just after she graduates high school. She's accepted into Queens University but now she can no longer do grade 8 math or English. She has to start all over again and she did. But it was hard and at first she hates being treated differently, even at school when she needs a note taker in class, a tutor and extra time for exams which meant she had to leave class and write in another room. She didn't want to "stand out". Sheila lost friends too. They slowly stop hanging out or calling. She sees them all heading on with their lives, moving out of the family home, getting careers, relationships, marriage and even children. Sheila can remember everything about the way she used to be and even with her courage to start over in so many different ways, she feels left behind and she is in a certain way, until her own life starts to take a new form and among other things she finds love.

How many of you actually know someone who has a disability? If Michael J Fox (*Back to the Future actor*) is your classmate and not famous – what is your response to someone who has uncontrollable spasms all over his body, who has Parkinson's Disease.

I remember this guy who was in my class when I went to Guelph University. Goo as we called it. Anyway, Jason has Autism and Tourettes syndrome and he's always waving his hand for every question the teacher asks and he makes funny noises quite a bit of the time. Jason is the smartest student in the class actually but he seems oblivious to anyone else around him. Maybe that's good because, eventually all the seats next to him start to be vacant and some students snicker. Jason didn't *seem* to notice and his feelings didn't *seem* to get hurt, I don't actually know if that's true. One day when no one wants him in their group when there was group work to do, he gets quite agitated. We bump into each other in line at lunch and end up having a conversation. I think maybe because I have a disability too. It surprises me to learn that school is his whole life and all he does is obsessively study and how challenging it is for him *not* to make his noises and *not* to put his hand up all the time. Jason being upset about his initial exclusion from the group work is not about *not* being liked but rather that it is a barrier to getting his assignment done with an A grade. If he didn't get an 'A' he became really upset. The interesting thing that happens is that he has to give an oral presentation as part of his group work and this kind of public speaking is *terrifying* for Jason. But he did it, *(pause feel this) with his eyes closed, my God and everyone sees his tremendous courage and heart and then the classroom energy starts to change and seats fill in around him.*

I get confused too. I never know what to do when I pass by a 'little person'. I don't want to 'not' look and have eye contact as I might with anyone else but on the other hand I don't want them to think that I'm staring at them because of their size. I never know what to do. What would be so wrong to just talk to them and explain my discomfort and

my 'not knowing what to do' feelings and hear their perspective because I actually don't know what it's like being them.

Half of the time I don't even know what it's like being me. You know, I think that I'm afraid to be angry or depressed around people, even friends because if I show *those* emotions like anyone else, then I really would be cutting down on the odds that anyone might want to get to know me, like having the disability is *enough* of a drawback. I can't have anything *more* on that side of the scales. (*pause – swig*) Because as you know, us folks with disabilities don't have any other problems like alcoholism, other addictions like porn or drugs, we don't struggle with parenting, or cheat on our taxes and we certainly are never criminals and we never judge other people with disabilities as lesser than ourselves. Ya, I don't like to feel the feeling of being rejected but I also don't like this fear running my life and holding me back.

Doesn't everyone have some worry or fear of rejection. Have you ever gone into a bar or a club or pub or maybe you're at a wedding reception and you see someone across the room you're attracted to? Now, you don't know this person from a hole in the wall but even from across the room 'you can tell', there is *something* about them and you want to meet them but there's the fear you'll be rejected. So you plan what you might say, a good opening line that has humour in it. Sometimes I think that all you really have to do to make someone like you or see you is to make them laugh. You give them this great gift of themselves. Anyway, you remind yourself of how you are looking, what you are wearing, maybe check your teeth and breath and your heart races a bit at the prospect of going over and you're hyper-vigilant about the optimal time to approach this person,

make sure you go over when there is an available chair so you can sit, this is *no longer an issue for me* or if you're cheap like me, you wait till after they pay for their last drink. And then it's now or never and you either go over or you don't. You have the courage to face rejection or you don't. Maybe your fear stopped you from even leaving the house in the first place.

I was 19 going on 20 when I was injured. I was in my rebellious phase and angry all the time, drinking and drugging a lot. I had dropped out of high school and at 17 came west on my own. I can't remember what I was so angry about.

One summer day my friends and I are going swimming over at Wreck Beach, pretty loaded on drugs and alcohol and goofing around and "last one in is a rotten egg" kind of thing and I dive deeply into a shallow wave and that was that. My head smashes into the ocean floor and the impact severely damages my spinal cord. I can remember just after it happen I can't move anything, can't feel anything – face down in the water – there is no fight – I can't even struggle. I feel quite... calm. My girlfriend Stacey and my friends think I'm pretending to be dead. Stacey dives in and sees that my eyes are open and then they drag me onto the beach. About a half an hour later, the hovercraft arrives but before that we all had to wait. All I could see was a sea of faces. My big concern is I had heard war stories about soldiers who would get spontaneous bowel movements and reflex erections in some traumatic situations. This is what I am actually thinking, and I ask her to check, her eyes dart down quickly and back up and she nods, I did have one... an erection that is. She puts a towel over me. It looks like a pup tent. I remember getting to VGH and throwing up and the next day I was in the Shaughnessy Spinal Cord

Unit, they had just opened and I am their first acute patient. And we can smoke in our rooms. They have these head striker frames, it's like a stabilizing vice grip on your head, which is how they move me, and turn me. After that I have a Halo Brace, which they don't use much anymore. It's a hard shell vest that attaches to your head and around your chest, so you can't move. I'm still in a state of shock. I have no idea that this is going to last my lifetime, I haven't started any recovery yet. It took such a long time to know to what extent I was going to recover, I'm thinking of it like a broken arm. Stacey would come into my room and close the curtain and have sex with me, not like we used to but I definitely still have the urge. *(aside) We work out a few things.* And there are a bunch of guys in Rehab and I develop a strong bond with them and we have a pretty good time, considering. They were a different kind of peer group than I was used to. I'm in an acute care ward for three months and in rehab for nine months. Then I start to overhear conversations that made me think I'm not going to fully recover and I start to make deals with God. *(prayer) "I'll change my bad ass ways Lord, if only I can be like I was"*. Looking back on it now, I can say that the injury likely saved me. I was pretty reckless with my life up to that point and I had a few very close brushes with death. Some of my drinking and drugging buddies did die and others went to prison. Then all of a sudden Stacey wants to marry me. *Why* did she want to marry me now? I'm 19 and she's 26. And I'm also cheating on her. I want to end it and don't know how except to be quite cruel, *(feel this a bit)* which I regret. *(pause)* Independence, is now my core value and purpose. Dependency is something negative. *(intensity)* I'm going to be the one deciding how I want to live my life, who I want to see, what I want to do and when I want to get up and

go to bed. Every time I feel even a flicker of movement in my toe, I demand to be retested but the results were always the same. After a while I stop asking.

After my partial recovery, I go back to Ontario for a high school upgrading program but quit that too and then I apply to Guelph and get in as a mature student, starting off taking one course. You know, when you have a spinal cord injury, again it's not only about not walking like I said before, but it's also about the loss of an adult identity, and having bladder and bowel accidents, is not what adults do. I don't get the same kind of "I have to pee or I have to poo" message. The peeing goes into a bag strapped to my leg. In fact, I could be peeing right now and you'd never know it. But defecating, that can just happen. And this is my greatest fear that I would be trapped in public somehow, like in class and I'd have a bowel movement. And in fact this did happen one time on stage and all I can do is just sit in it. I can't feel it but I sure can smell it and even if no one else notices, I still feel humiliation and shame, like a helpless child. (*drink or drag*). Back when I was doing my undergrad, I have to sit at the front of class where there's space. In those days with the big lecture halls, it meant I'm at the same level as the instructor. If I'm not already exposed enough, I have to be right at the front with the teacher with all my muscle spasms. And I have the same reaction as Sheila to needing a note taker and writing exams in a different room. I am centered-out again. What really used to piss me off though was waiting for an elevator in a three or four floor building. The elevator doors would open and it's full of healthy able bodied students and not one of them offers up their space and uses the stairs. I would never take another elevator my whole life if it meant I could use my legs again.

You remember when I said I had a life before and that I could compare and remember? Well, I became aware of my self-hatred because I could point to it, at my disability, and this made me see it. And in seeing it, I realize it was also there before my injury. I wasn't very conscious back then but I remember I always... felt this... (*find the word*) void. I don't know what I'm doing or where I'm going. It is not a carefree life. I have huge resistance to authority and intellectuals and I'm in a lot of some kind of pain and I'm contemplating suicide on a regular basis.

Because my body is so altered and the change so drastic and so in my face, I realize how I only see myself as my body, live *through* my body and all my sensory experiences that I'm abusing. It made me realize that I'm acting out all my emotional pain with: affairs with older and married women, drugs and alcohol, taking risks and other reckless and dangerous activities. (*drag*) Mind you, *that* realization did not make me change my behaviour at all... But still there was this gradual movement towards a more conscious life.

My avoidance of feeling emotional pain has always been a big obstacle for me in my life. And even though I know now and have experienced that the imagined pain I was afraid of feeling is never as bad as the constant pain I'm actually in, from not allowing myself to feel my pain I'm afraid of feeling. I still stop myself again and again from feeling my pain. Does that make any sense?

A few weeks ago, my neighbour Patty asked me to look after her two goldfish Brittany and Bob for a week while she was away. This involves feeding, and keeping the water levels up. So I'm looking at her, straight in the eyes but I'm not with her at all, I'm not in

the moment, I feel myself getting lost, foggy and disconnected from her. And I don't have the courage to say: I don't have time right now, or hey, I'm not interested in taking care of your fucking fish or I don't want to talk to you, ever again. I'm too busy being good. I want to be perceived in a positive way. I just nod and pretend I actually understood her directions. If I could have just told the truth – that I didn't want to babysit her fish, Brittany and Bob, would be alive today.

I'm still afraid of my father or at least there's that small child in me afraid of being held by one hand, over a cliff by the neck, dangling, being annihilated... always waiting for the other shoe to drop my whole life. He's what one psychiatrist coined "narcissism gone bad." My mom had left my father in charge of me one day at a summer cottage. He warns me not to go near the cliff, that the fence is unsafe. But being almost two, and he's tired of having his work constantly being disrupted, by keeping me away from the cliff and so he wants to cure me of going near the cliff once and for all, which he did. I remember him saying years later, that "it sure did the trick."

What are you afraid of? What's happening in your belly right now or your heart? Can you notice what's going on anywhere in your body? Is there tightness, a softness, a relaxation, a contraction, an expansion?

When I *catch* myself feeling uncomfortable, and that's an important first step – noticing what I'm feeling and (*higher energy*) there's that space again, I have the time to see what that feeling is about. The other day I met a burn victim, her face is really disfigured and she's missing part of her lower lip and I'm totally uncomfortable looking at her. I look away as gracefully as I could, but she feels it, I can tell. And I feel her hurt and my shame

and then I know that this is just a normal first time experience and I'm able to forgive myself. I go over to her and ask if she has a minute to chat. She's quite cold towards me and I feel hurt and misunderstood and then a flash of anger and I almost tell her to fuck off and walk away, then I get confused and sort of frozen. I completely forget that she is having her own experience and I'm not the centre of her universe. But then the silence is broken when she says, "I only have a few minutes." I have to dig pretty deep to connect to my heart again but I did sort of and I tell her of my experience and that now I know the hurt from both sides and I ask her to forgive me any hurts I may have caused her. She tells me that it happens so often that she keeps her heart pretty closed in public, most of the time and that yes she is hurt. She says she appreciates my apology and my coming over but that it's not her job to make me feel better. As she left, I realize the truth of what she said and yes, mixed up in my genuine feelings of compassion for her is the wanting for her to think of me as a good person. And I see the role again, the identity of a good person I need to maintain.

*(pick up cigarette)* I quit smoking a while back because I sensed it was in my way. My life is all about when I can have the next smoke. I love it too much: the best possible distraction, the best possible way to numb myself, especially if I add the drink and the drugs and the women. The best part is that I have a lot of company, bars full of people just like me and we all have a deal, we all have an agreement and we never speak of it because we didn't know. And the deal is *not* to know. Of course electric cigarettes don't count.

After my injury, I make *lots* of deals with myself to stay alive, I become totally future orientated: looking forward to the Super Bowl or sleeping with women I haven't slept with yet – anything to keep me going. Of course there is a part of me that wants things to be different, the way they “should” be. Where did I get the idea that I know, what *should* be?

Do you remember a few years ago that incident with our first openly gay politician Svend Robinson. What was he doing when he stole that ring from the store?

Remember that? And then a while later he returned the ring and took responsibility for what he did. Well I don't know, but I can guess that when he was in the store he went unconscious – went to sleep. Something triggers him and he takes himself to be a younger identity, he unknowingly is feeling some pain and he needs to fill the hole inside him. In that moment he is the little kid again and he has to do something so he takes that ring.

I'm on Granville Island one Saturday last summer, outside the main food court by the docks and it's quite lovely with all the folks and children and live entertainment. A few of these kids are throwing bread to the pigeons in the centre of all this and an elderly man comes up to one of these kids and intensely scolds him for feeding the birds. I didn't hear what he said but I see the result, the child – maybe four or five years old walks away and sits by himself on a bench with his back towards everyone and I can see he's been shamed. The elderly person, sees this too as he looks over his shoulder on the way back to his seat. I see the confusion in his face and the regret, but he doesn't know how to fix it. The man and the boy don't know each other. As I'm leaving, I go over to the

boy who is now with his mom, and said that I saw what happened and that the man was wrong to have yelled at him. I want to deflate the shame a little. I say it as gently as I can and go to touch his hand but he pulls it away. And then I realize he didn't want me there and I had extended his shame by going over and trying to fix it and make him feel better. *(pause)*

That old man sort of reminds me of my father. When I first start to wear an ear stud, my father thinks it means I'm gay. He is so upset, he can't talk. I finally decide to take it out, I don't want to give him a heart attack. It kind of feels like emotional blackmail but I'm not strong enough to continue wearing it in the face of his pain.

I guess everyone relates to things from their own perspective. And I think that's a problem. How many times have I discovered that my feelings in a certain situation were actually about something else, often coming from a younger me. I always think I know the truth of my feelings or what they mean, but I don't always.

I've come to recognize that underneath the surface of let's say – not wanting to learn how to sail or pursue relationship, there are the feelings going on that protect me from being hurt. You know, like the feeling I can't do it so I don't try, or I have to be perfect, the feeling that I'm not worthy and I'm unlovable, the feeling that says it never works out for me. There are hundreds of them. *(disgust)* It's suffocating. None of *this* is *who* I am.

But even when I recognize these feelings, it's hard to let them go, they feel like old friends that helped me survive my childhood. As a kid and even as an adult to be honest, I'd always try and avoid my father. I *remember* just wanting to be invisible so I

wouldn't get embarrassed or humiliated. And so I make myself small when I'm at home, around people, in the neighbourhood and especially at school and I never try anything new and it works, this belief about myself, keeps me safe. It's like I'm a kid drowning from the pain of being unlovable and I find a life preserver for being invisible. Later when I was older, I see a choir at school, I'm excited and I want to sing in the choir too. I see this strategy of staying small for the first time. This life preserver had saved my life in my younger years but now I'm standing on the dock with a wet life preserver on and it doesn't feel so good. I *had* survived but now it's in my way. It's hard to leave my old 'lets be small' friend, I feel lost for a while, but I do leave it, I take off that life preserver. And I start to sing.

*(Jonathan just bursts into song – it doesn't matter what song - could even be inappropriate as long as he loves singing it)*

Blue skies smiling at me  
 Nothing but blue skies do I see  
 Bluebirds singing a song  
 Nothing but bluebirds all day long

*(An awakening moment full of insight and discovery) Oh my God where did that come from. I love that. I love that. I feel like I'm me, (realizing what you know) It's the very same thing that happens when I play music, go sailing or laugh out loud. Yes I now go sailing, solo. I faced that fear and I found the joy underneath.*

*(delighted with insight) I'm beginning to understand something. This is what life is really all about for me – feeling alive and it only happens in the here and now. This is so exciting. I realize that it's during these times that having a disability doesn't matter,*

*nothing matters at all. The more I experience myself, the more liberated and carefree I am. The more I am, the more I am..... (long pause)*

*Ya, that makes me think of my discomfort with the burn victim – her name is Claudia. (a real questioning)* I don't know why I didn't say her name before. With Claudia, I notice that when I feel my discomfort, there is a sharp pain and tightness in my chest and I breathe into it and something remarkable happens. It starts to open up. I flash on this memory: I'm 14 just starting high school and it's the first time for showers after gym and as I'm changing, a bully points out to everyone that I don't have any pubic hair and they all laugh and I put my clothes back on and run out of there. It seems like just a little thing, but it plants yet another seed and that seed gets watered by other hurts and I never let myself feel them fully and I start getting small and shutting down. But with Claudia, this old wound comes back and later that night I did let myself feel it deeply and when I did, all this space opens up in my chest and I feel a distinct joyful lightness.

It's hard to stay there though, even now I'm involved with arranging to have a live in attendant. My biggest fear is the exposing my body openly. I wrestle with how I can still have my privacy and preserve some kind of self image when they are cleaning my body and wiping my bum. Right now I've got four to ten different people coming in during the week. It's so easy to fall into the trap of thinking and feeling I am my body. But again, when I get quiet and connected, I feel less oppressed by it all. But then, *another* fear comes in about when I'm older, what if I'm in more pain or face more limitations? What will I feel then?

And I ask myself sometimes, you know when I watch certain films or slam into some physical barrier or get rejected, if I want to be someone different than who I am, have someone else's life, do I want your life, do I want to be you? And from that deepest part of me, a truth arises with pristine clarity and it's so clear, that I want to be me, the unfettered me. I need to be. I don't want to lose my new sense of self and things that I have learned that are liberating me: *(lightly)* I have a body but it doesn't define me. *(pause)* I guess I really don't know who I am, but I'm excited and curious about this journey... it seems to be never ending.

And I get that I'm not everyone's cup of tea. But don't like me because I'm an asshole not because I look different. Like me because I've got a sense of humour or for my intelligence – you can even love me if you get to know my heart a little. Well, maybe we all need to get to know our hearts a little bit better. I think love is there all the time and mostly I don't let myself feel it much unless there is an external stimulus. I am still so externally focused, in everything I do and every way. I always thought that love starts from the outside in but it doesn't, it doesn't, it comes from inside out. And it's mine or it's me. *(feeling confusion)* I'm starting to feel confused a little, but I sense this love, that is me, is somehow boundless, limitless and it can't be depleted. I don't know but it's interesting... I know I am not my body, am I my personality, my heart, my soul, my mind, it's so interesting – who am I?

*(Jonathan starts to roll away and then stops and turns and as an afterthought says...)*

Think of the person you love most in your life: your best friend, a girlfriend or boyfriend, a sibling, a parent, a child and what if this person suddenly became severely disabled. How would your heart be. What would it mean?

*(Jonathan starts to sing Blue Skies and rolls off stage)*

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