

Stories from the brainreels podcast

July 1, 2015

Introduction

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CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at info@storyminders.com with questions or topics and guests you want to hear on an upcoming show.

[music]

CHERYL: If you've ever been on a film shoot with me, you know my favorite self-deprecating joke is this: "If I didn't forget something, then it wasn't me doing it." Lately, some folks attempted very sincerely to console me when I made this joke. That's not needed, actually. Sure, it stings, but in the end, the joke serves two purposes. It's my way of showing awe that I still have a hard time even with things I've practiced a million times. It's hard to believe. It's also hard to keep my mouth shut. So sometimes I blurt out a long list of all my mistakes when really those were meant to stay on the inside. The other purpose is self-soothing. I'm blowing off steam so that I don't beat myself down with, "Well, a **real** professional wouldn't mess these things up." It's not about that. It's about having a hard time keeping constant with a routine when my routine gets changed. Even my trusty list of steps becomes unreliable when things around me change.

I bring this up today because I forgot something so gigantic in this podcast. I forgot to record myself thanking my guests for their generosity in sharing with me, for driving 2 hours to meet with me after a full work day, knowing they had to turn right around and drive back to Seattle. I forgot to record a good-bye. There's just no wrap-up to the conversation. I know there was one in real life. But this interview just seems to evaporate into thin air at the end. Maybe it will be my new signature style of podcasting. Nah, I forget different things on different episodes. The brain has an amazing capacity to heal in many ways. But some things, well, they stay difficult.

My gracious and kind guests today are Sonya Lea and Richard Bandy who have a memoir coming out this month called "Wondering Who You Are." The book is a brilliant study of relationship, identity, and how Richard's brain injury led the couple to redefine their lives as individuals and as a pair. The writing is unhurried and thoughtful, rich with emotion, and distinctly honest. Although only Sonya's name is on the cover, the writing was collaborative. This is not a wife speaking for her husband. It's an ongoing conversation and exploration. I've read other memoirs by peers with brain injury but not one written by a family caregiver. So I can't compare this to others. But I know this one says a lot of those things that you wish you could tell someone aloud, you wish you could non-judgmentally allow yourself to think and question. I simply cannot recommend it enough.

This month, local disability arts news is actually coming from Austin, TX, where I have been pretending I still live here for the past several weeks. So on the local front, on Sunday, July 12th VSA TX is presenting a film screening, Disability From Real to Reel. It's wonderful to see this series return after a few years off. I've seen some dynamic and amazing films created by the disability community at this series.

This year, they're showing films created by a young adult filmmaking internship program. I had the wonderful good fortune to be one of three teachers at the camp. You can find all the details about that at WhoAmIToStopIt.com. Thank you, VSA and interns!

The Interview

CHERYL: I wanna thank you so much, both of you, for coming. Let's start out by just having you each introduce yourself.

SONYA: Thank you for asking us. I appreciate that. I'm Sonya Lea.

RICHARD: And I'm Richard Bandy. I guess I'm the one that had the brain injury. It's kind of an interesting story that I'm a physical therapist. I had a positive TB test 15 years ago and went in for a chest x-ray to make sure that my lungs were clear. And it turned out I had a whole bunch of fluid at the bottom of my lungs. It was a false positive TB test. But they found all this fluid at the bottom of my lungs. And I went in for a CT scan, and then they did a biopsy, and they found all this mucus. And so they decided I had this cancer, this rare cancer called pseudomyxoma peritonei. I went in and had surgery. They took a gallon of mucus out of me, took my appendix, which is where the cancer actually starts from. And I was back at work two weeks later. And then three years later, the cancer came back. So they tried to talk me into having these debulking surgeries every few years until they couldn't do them anymore, and eventually I would die from that. That didn't sound very good to me. And so I looked for another opportunity and found this place that was able to do this massive surgery. They call it the Mother of All Surgeries. They do this 10-hour procedure where they cut you from xiphoid to pubis, take all your organs out, scrape all the mucus off, and took a gallon and a half of mucus from me, and then sewed me back up and then did heated chemotherapy supposedly for five days, heated to 104 degrees: do 12 hours on, 12 hours off for five days. I was actually only able to do three days, I think it was.

SONYA: I think it was four.

RICHARD: Four days?

SONYA: Mmhmm.

RICHARD: Just because of some complications that I was having at the time. I've been 12 years cancer free. And that was in 2003. So I'm pretty happy about that. The unfortunate part is that they nicked an artery in my stomach while they were doing the surgery. And I actually bled out, and I guess I kinda died on the table that night. When I came to, which was maybe a day later, I had basically no memory of my life. I had suffered an anoxic insult at the time of that pooling of blood in my abdomen from the abdominal nick. And so, well, not to get ahead of myself, but it was probably a year before I said more than three or four words to pretty much anybody.

SONYA: Mmhmm.

Process of recovering

RICHARD: And then, over the course of the last 10 years, as a result of neuropsychology, speech therapy, and some training and getting back to work, I'm at the point where I wouldn't say I'm fully functional. But I'm probably 80 or maybe even 90% of the way there from where I was. So I'm very happy.

CHERYL: I bet.

RICHARD: It was a long process. It was several years of forgetting and trying to remember and trying to remember and trying to remember, and reading and re-reading and re-reading my physical therapy textbooks, and trying to remember, and forgetting like 90% of it each time I read it. And just persevering and continuing. Now I'm back practicing and actually working on patients, and yeah, I get a lot out of that. That's very important for me.

CHERYL: Do your patients know what you've been through or that you had a brain injury?

RICHARD: No. Occasionally, if I have a patient for a long period of time, or if they've suffered a brain injury, I might explain to them well, one of the things that I've been through just to give them some motivation or some hope that there's light at the end of the tunnel. But that's probably less than 10% of my patients, maybe even 5% of my patients that actually know that I've actually undergone that.

CHERYL: When you do tell one, how do they respond?

RICHARD: They're shocked, I would say. I would say the first thing is, you know, "You look so good" or something like that, or you know, "You seem so normal, and I wouldn't have expected that." And I can only say, "Thank you." I mean, that's all I can say because to me, I guess I feel as normal as I can. But I don't really know how I was before brain injury. And so I really don't have much comparison in terms of how I was before versus how I am now except from stories, and people have told me how much I've changed, that sort of idea.

CHERYL: Yeah.

SONYA: To put that into context of, you know when you say 80-90% back, I don't even really consider Richard as coming back to who he was before. His personality and identity changed so thoroughly after the brain injury that to me, it was like an experience of being with another one in his body. It's been a long process and you know, what he's had to accommodate: new skill development, new ways of prompting himself, new ways of remembering his patients. Previous to the brain injury, he had 21 clinics that he managed as well as having a full-time physical therapy practice. So what the brain injury ended up taking was all of the multi-tasking part of his way of doing things as well as that really strong, competitive, managerial person that was so driven to all of that kind of work. Now, on one side of it, I know that we see that as a deficit because he doesn't have the option of doing that anymore. By saying this, I don't wanna take away from the loss that was experienced by him, by others. But really, what he got was extraordinary because he went from being more of a verbal extrovert who had a lot of energy and a lot of natural authority to being kinesthetic and intuitive and sensitive and gentle. These are the qualities that I hadn't really had a chance to experience before as fully in him.

RICHARD: And I'm definitely more introverted.

SONYA: Oh yeah.

RICHARD: Yeah, for me to go into a crowd of people, I'll just kinda stay in the background or hover against the wall. If I'm meeting people for the first time, I'm relatively quiet. And I used to just--I've been told--I used to go into a room and just kinda take over a room. That's how I've been told that I used to be.

SONYA: Mmhmm.

Volunteering as a physical therapist brought verbal skills back

RICHARD: It's interesting that my verbal skills really did not come back until I started getting my hands on patients. And it was a result of a neuropsychologist that I was seeing down in Orange County, California. He had a friend that was a PT. And I started volunteering at their clinic. And I started six hours a week, and then went up to 8 hours a week, and eventually up to 12 hours a week. And as I got my energy back and started to get my hands on people, my hands started doing things that my brain really wasn't understanding or acknowledging. But it was just kinda doing it as a result of, I don't know if it was muscle memory or what was going on. But as I got my hands on people, I started to notice things and started to get a sense of what was actually going on with their bodies. That came through. And I started to become a little more verbal as a result of that and started to be able to explain some things. And it took a while. It took like six months or a year before I started to feel a little more comfortable with what I was doing. But it's done great for me.

SONYA: It was pretty extraordinary to watch, really.

CHERYL: Yeah.

SONYA: People would come to our house. They would just volunteer to come to our house, our little apartment that we were living in.

RICHARD: Yeah.

SONYA: They wouldn't really tell Richard very much about what; they might say, "I have a pain here" or "my back's been bothering me." And his hands would just naturally gravitate to where the injury was for them. And then, kind of more the intellectual side of your physical therapy practice came back to you after that.

RICHARD: Mmhmm, yeah.

CHERYL: I think that one thing that happens after brain injury is, if you can't do something, then you tend to stay home and do nothing. I don't think people fully recognize how that doing nothing just reinforces more doing nothing.

SONYA: Yeah.

CHERYL: And if you don't have the opportunity to go out and try something, try anything, you'll miss that there is something still that you can do. And like you said, you can find a new way in to things. The way that a lot of people with brain injury get isolated and are just told to rest, rest. I was told to rest constantly, even well past the time I was supposed to still be resting. But I would've rotted away. And you probably would've rotted away if you just stayed home all the time.

RICHARD: And I did stay home for probably the first six or eight months or even maybe even the first year. I was sleeping a lot. I was in my room a lot. For me to go out shopping was a huge adventure. I mean, the first time I went shopping alone, I went to this Ralph's Grocery Store. It took me like 2 1/2 hours just to do a basic grocery shopping just for the two of us just because I was kind of overwhelmed. The stimulus was just kind of, it was too much for me. But I was able to slow it down. I had my iPhone. I had my list of things that I was looking for. I asked for help when I needed it. You know, I survived it. But for me to leave my room was really challenging for the first six or eight months. I was very cocoon-like,

yeah. And I would sit there with my textbook, and I would read my textbook, and then I would fall asleep, and then I would wake up, and I'd read some more, and I'd fall asleep and wake back up.

A gentle reentry to the world and perseverance

SONYA: He had a very gentle reentry to the world. With no disrespect to him, but almost like a baby comes in, he was just it felt like he needed a lot of protection initially and not a lot of stimulation. By that, I don't mean that he wasn't intellectually astute, just that he was very sensitive to everything that was going on. And I would just cajole him let's just go out to the parking lot, and walk around for like five minutes, and then we'll come back out again. And it was just like your big eyes were taking in everything that was in the world and that you could do things in a very limited way. And then we started sneaking him into the movie theater,

RICHARD: [sighs]

SONYA: in the middle of the day [laughs]. And the first time, he was just so just kind of blown away by how big the picture was and the sound. And I was like, OK, that's 20 minutes of a movie. That was good. Let's go. [Both chuckle].

CHERYL: Yeah, bit by bit.

RICHARD: My perseverance, I think, is probably the one thing that has kinda saved me because I was unwilling to say no. I mean, I was told by the neuropsychologist and by several other doctors that I probably should not consider physical therapy as going back to a career because there's so much problem solving and so much involvement, and so much energy, and so much caretaking involved. And they weren't sure I was able to do it. But I was determined that I was gonna go back to that, you know? I'm not able to do the multi-tasking, as Sonya said, to run several clinics. But I'm running one clinic right now when I just have one other staff therapist and just myself and them. And you know, we're doing pretty good, I think.

SONYA: I think people sometimes underestimate the power of community too, you know? I mean family can be there for some support. But family and even partners go in and out of being able to pay attention because they have to attend to so many other things. And for us, it was really about finding that larger community that he could tap into. When you even started doing the practice working, the volunteer working, you were with different people all the time and gave you the ability to be of service to them,

RICHARD: Mmhmm.

CHERYL: Mm.

SONYA: which was really what you wanted.

RICHARD: That was huge for me. There was no question about that, yeah. For me to be able to help somebody else put my own injury into perspective because there's so many people that have been going through as much or even more than I have. And for me to be able to help them a little bit was just huge. It was huge, yeah.

CHERYL: Sonya, you mentioned the power of community. You didn't go to support groups, though, right? That was not the community you sought out?

RICHARD: I did, actually. When I came back to Seattle, which was in late 2005, I did get involved with a brain injury group at UW and went there once a week for like 12 weeks or something like that.

CHERYL: Oh.

RICHARD: And I wouldn't say I really connected with the people there. But it was interesting for me to have an opportunity to hear other people's stories. Some people were much farther along than I was, and some people were not very far along at all. And so I was able to put myself into that kind of spectrum of where I was. And it gave me a little bit of incentive to try and push myself a little bit more, I think.

CHERYL: Oh, that's great. That's great.

SONYA: Well, initially he was not attracted to the support groups at all.

RICHARD: No, no.

SONYA: University of Washington, when you go into their brain injury program, they really insist upon it. They have like four or five different prongs of it that they do, including counseling and meeting with a neuropsychologist and doctors. But the support group was, they didn't really give Richard the option.

CHERYL: Mm.

RICHARD: Right.

SONYA: So and that was part of why he chose to go. But you really didn't want to, initially. Can you remember why that was?

RICHARD: I just didn't....I guess I wasn't really social at that point. I mean, I really wasn't feeling like that I wanted to communicate my story at all and really wasn't interested in anybody else's story. I was just kind of interested in surviving day to day at that point. And it's really now, looking back on it, that I could see it was actually beneficial. But at the time, I wouldn't have said I got much out of it at all, I don't think. Yeah.

CHERYL: Yeah. You know, you do have a list in your book, page 196. "Things we now call homework. Write a plan for making a telephone call so you can remember how to talk to the people you know and love." That's #1. And especially hearing you talk now and how fluently you talk, it's important to recognize that that is where you were. And there's all these items on the list like that. And #6 is "Just fucking survive."

RICHARD: Yeah.

CHERYL: And what...I mean...people...I want people to respect that, that is on the survivor and the family member's mind. Yeah, I need to work on my dexterity and my fluency and my blinking and planning and....Wait a minute. I just have to survive! So.

RICHARD: Day to day was definitely, it was a struggle for me. I mean, I wouldn't say it was a struggle to actually live. But it was a struggle for me to communicate with people. It was a struggle with me to enter the world. That was the biggest challenge for me.

CHERYL: Yeah.

Communicating

RICHARD: And talking on the phone is still kinda hellish for me. I really do not do very well on the phone. I'm much better with you in person because I can kind of respond to you physically as well as verbally. And that works better for me.

SONYA: Initially, what that looked like: our kids were away at college. One was at home and going to college, and the other one was already at college. But initially, in that first year, it was having index cards that I put in front of Richard's face that said, "How was your day?" You know, little prompt lines. And it was really kind of fascinating to be there with him, experiencing that. It was hard because you didn't know that you were gonna have to do something like that. But you could always tell how much Richard loved people and how he really wanted to connect. It was just that the communication and the vocabulary was a stumbling block. To hear him talk now, you would never have guessed that he was so withdrawn and inside. So it was all body language things between us, probably for the first two, three years, right?

RICHARD: Yeah. It seems simple when you think about it, on the card. But I would just have no idea. Initiating things was very challenging for me. Initiating dates was impossible for me.

SONYA: [laughs]

RICHARD: I mean for years and years and years.

SONYA: Years and years.

CHERYL: Yeah!

SONYA: We did two strategies. We had these cards that are like you know for parties where they have different questions to ask so parties or gatherings don't get dull? So we had those cards. And we would use them for family events or dinners between us. And so we would each pull two or three cards out of there and ask each other those questions.

CHERYL: Oh!

SONYA: We started doing it for our dates because Richard didn't have a natural way to make conversation during the date. But it's, now he can do that. And it's still our favorite way to have a date because we've been married for a really long time: over three decades. We've been together for a long time. And it's a way for you to stop pretending that you know, oh, I know who this person is. I know what they're all about! I mean, right? We're in relationship with people for such, even if it's a short period of time, we're making these assumptions that what is going on for them is not changing them. But the truth is that we should probably reintroduce ourselves to each other all the time. Hey, what's going on with you? What was the thing that is most influencing you that's happening for you at this point in your life? One of the great things that happened for me out of Richard's memory going was to really have a fresh experience of what our relationship is and not to dwell too much on what it was.

CHERYL: Mm.

SONYA: But it took a long time. It took some honest to God, deep down grieving. That's really what the book is about for me, is grieving the loss of the former relationship and then waiting to see if I was gonna fall in love with Richard again, so, which did happen.

CHERYL: I mean, this is an audio podcast. And no one can see. But the way you two look at each other?!

SONYA: Yeah.

CHERYL: There's no question. Yeah.

SONYA: [giggles]

CHERYL: And so let's talk about the book.

The memoir, memory loss, and identity

RICHARD: Mm.

SONYA: Sure!

CHERYL: You have a book [giggles]. I have to look at it to remember the title! Your book is called "Wondering Who You Are." It's a memoir. And Sonya, your name is on the book. But I understand it was actually a collaborative writing process. Is that right?

SONYA: It was very much a collaborative process for the two of us. Richard and I would get together during the writing process, which went on over several years. I would ask him a question. I never made the assumption that I knew what the answer was for him. Even though he had memory issues, I still thought hmm, something could come up. Something does come up occasionally. And I don't want to suppose his reality. So I would give him a writing prompt. He would go down to the man cave,

CHERYL: [chuckles]

SONYA: downstairs. And we would each write for 15, 20 minutes about whatever our experiences were. And then we would come back together and share that. We would cry most every time, wouldn't we? There'd be something that would be revealed that would just be so astonishing for us in the whole process of doing this. So do you wanna tell the story about when I asked you what your first memory was?

RICHARD: Well, Sonya asked me what I remembered when I woke up out of the hospital. And I told her my first memory was walking down the hallway with an IV pole, passing several rooms, and going to this window at the end of the hallway. And she looked at me, and she said, "That was almost two weeks into the hospital stay." And I said you know, for me that was the first memory I have actually, waking up after the surgery. And I mean, that was kind of strange to me and, I think, strange to both of us that that was my first memory, you know? Occasionally I'll have little glimpses about maybe one of the nurses or something like that. And I kind of get maybe an image of a face or something like that, which may have occurred a little earlier, but I have no idea when it actually occurred. And so many of the first few months, I really have no memory of whatsoever. And so it's kind of bizarre for me to think about those lapses, I guess, and things that I'll probably never remember.

SONYA: But the things that Richard did remember were quite strong and quite pronounced and were things that I couldn't have predicted, being his caregiver largely. So I liked not having the assumption. It also, because he was writing, I got to get a good sense of what his style of communication is. So building things like dialogue in the book. The book alternates between the relationship before the brain injury and the relationship after the brain injury. It's not just from the hospital on. It gives this kind of braided story of from the time that we first met each other, alternating with the experience in the hospital and then recovery afterwards. But there was so many opportunities for me to really hear the differences between how he communicates now and what I recalled of the kind of man that he was before.

So his communication style allowed me to contrast that, with the writing of the book, which is really important, I think. This is what I teach when I teach memoir writing as well. It really shouldn't be in one person's voice. I mean, everybody is their own character. You have to have that kind of detachment from it to look at the story and look at Richard as a character and myself as a character and how is this whole story playing out? And how do we sound like ourselves? You know, and what specifically is that quality that we are? It was a good opportunity for me to go back and write what I remembered of the previous story of us, for Richard to hear those places again because he didn't remember all of that.

RICHARD: Much of it.

SONYA: Much of it.

RICHARD: Yeah, I don't remember a lot of it. Yeah.

SONYA: Yeah. I wanna bring in this part too, relative to brain injury and also the writing of the book, which is that people think that once you remember something that you remember it concretely, and it's just in there like it's a fixed thing. Well, particularly in Richard's brain injury and the brain injuries of other people that I teach who have TBIs, that doesn't appear to be the case.

CHERYL: No, it's not!

SONYA: Yeah, the case actually appears to be more that you might hold something, and you might hold it for a period of time. But then it slips away. I'm beginning to realize that all memory is constructed that way, that it isn't just people with TBIs. But our memory is quite suspect.

RICHARD: People ask me all the time how much better I am or what I remember now. And I say, I honestly have no idea what I remember. I mean, I have images, and I have flashes of images that I think are my past. But I have no idea if it's actual memory or if it's stories I've heard or pictures I've seen or things that've just kind of grown out of the ether. And I have no idea how the accuracy of my memory is. And sometimes I'll say something, and Sonya says, "No, that's not the way it happened at all." I said, "Well, that's the way I remember it!"

SONYA: [laughs]

RICHARD: You know what I mean? That's what I'm thinking about right now! That's the way it was. But I have no idea what's accurate and what's not accurate.

CHERYL: Is that disorienting?

RICHARD: [sighs] Maybe a little disconcerting when I'm shown up to have no idea what the hell I'm talking about. I mean, that's not good. But for the most part, it really doesn't bother me at all.

SONYA: No.

RICHARD: Because I have my images of my past, and whether they're accurate or not, they're my images of my past.

CHERYL: Right.

RICHARD: And that's kind of the way I see myself in the past, and that's the way I see myself in the present. If I'm happy with that, then I'm happy with that. And I really, I have no image to protect and no reputation to protect. Sonya was worried about writing this book and all the things that she was gonna be talking about and the sort of the exposure to our family and exposure to me and to my life and the past. You know, I was like, pssh. I mean, I have nothing to protect. I'm just here surviving and happy I'm still alive. I mean, that's really where I am.

SONYA: Yeah. It's remarkable.

CHERYL: Wow. You've done a lot of interviews. And Sonya, many chapters of the book have been published under your name in various places: magazines and online journals. And there's an interview in 2014 for an ABC News article. And I'm gonna [chuckles] gonna read the title of this with much dismay. "Husband Forgets How to Have Sex After Botched Cancer Surgery!" And that's how I read that title, in that like boy! Ugh! And while factually, I guess it's true, based on what I read in the book. But I was really taken aback by the headline.

SONYA: Mmhmm.

CHERYL: And I didn't wanna read the article based on that headline. But fortunately, I'd already read the whole book. I knew from the book that I could trust the two of you.

SONYA: Mmhmm.

CHERYL: And it was a great article. But the headline just smacks of this whole circus freak show thing. Ooh, you have a disability? Ooh, can I gawk? And that happens all the time with disability stories. This book is coming out in July of 2015. And you're doing a lot of networking, a lot of marketing, sharing around the story. And I'm wondering how often you're encountering that sort of direction that that headline really reeks of?

SONYA: You know, I mean it was one of the things that I addressed head on in the book by bringing in the example of Phineas Gage and what we've learned about him in the last 100 years. Phineas Gage was a railroad worker who ended up, very famously, getting a rod through his brain. And there were all these tales about personality changes that occurred. A contemporary doctor went in and did a more recent book after I think it was around the year 2004 or 2005. When he looked at the historical events that occurred to Phineas separate from the ways that the other doctors were trying to influence this tale, what he'd learned is that people were just trying to prove a point. People were just trying to take the elements of what happened to him, and just like the ABC article, make them more explosive to make their case. I went head on into that for a specific purpose, which was to examine myself about my own desires for storytelling. And that when we go into any of our narratives and any of our memories, particularly where I was holding a story that was Richard's and ours together, to be very cautious and also very respectful that his story has a meaning to him that I can't reach. And that I don't want to do something that is just for the drama of the story. If I'm going to tell this story--and no one does a memoir for glory, you know what I'm saying?

ALL: [chuckle]

SONYA: It's too much hard work. It's too much putting your heart out there for the public to see. No one does it for any of those kinds of reasons. But if I was gonna do that work to put it out there, that what I really wanted to do was not a confessional but to try and do something as honest as I possibly can,

looking at all the shadow sides that are apparent in the storyteller's toolbox. Now, what happens to the media when they get a hold of it, that's a whole different thing.

CHERYL: Yeah.

SONYA: You know, the places where my story's excerpted, and it's in my own language, or when people pick up bits and pieces from the language, that's something else. But you know, we do realize that once the story is out there in a public realm, people are gonna take it and make meaning from it of their own accord. It doesn't have anything to do with how we live our life and what's private to us. Those were the kinds of discussions that we had when we entered into making this book, is what stays just for us and what is going to be out there and be for public engagement? And not really to allow things like that to influence our relationship. I don't feel like it has. Do you? How do you feel about that?

RICHARD: No. To me, it was kind of a sensationalist headline. But the actual story itself, I think, as you said, was pretty straightforward. There's no question that I forgot certain aspects about sex and sexuality and trying to please Sonya. And you know, I've worked on that. I've worked on that a lot. And I think I'm better now. But you know, it just was what it was, so yeah.

SONYA: You know, also Cheryl, I feel really inspired by Richard in that way. I mean, I didn't start out being that kind of person. And so first of all, it was my writers' groups that made me that way, people who could provide witness to the story and respect for the story and hear it over a number of years as it developed. So that worked my courage that I could say things that were here, previously very intimate and private between us. But Richard just has this remarkable capacity to just hold himself as he is. And he doesn't really care what the world thinks about him. And that's the honest truth of that. [chuckles] I probably ask him now that the book was getting closer to going to publication, I'd ask you, like every couple weeks, "Are you sure you're OK with this? Is this good for you?" He's like, "I got nothin'! I got no reputation to manage, honey!"

BOTH: [laugh]

SONYA: We would just keep having this discussion over and over again. But this is who this man is. What that led me to believe is, what would it be like for me if I gave up these ideas of other people being able to influence me with their thoughts or with their judgment? And that is part of the book, where I talk about this experiment of doing what I want. That was a serious for-real experiment where I was just, you know what? I don't know what I want. I've never taken the opportunity where I haven't been a caregiver, I haven't been....You know, a woman in the world gets a lot of things aimed at her, different roles and responsibilities for this gender. So I just wanted to see what I would be like free of it. And the way that he lived really gave me the...cojones to try that.

RICHARD: Yeah, I don't know about language, but I mean, she wanted to be a person that gave less fucks every year.

CHERYL: [giggles]

RICHARD: I mean, that's really what it was.

CHERYL: Yes [laughs]!

RICHARD: And I support her in that, wholeheartedly.

CHERYL: Well, and you seem like you give very few fucks as well.

RICHARD: I do.

CHERYL: Yeah.

RICHARD: I mean yeah, about anything.

CHERYL: Yeah.

RICHARD: I'm just happy to be walking around and above ground. I mean, that's really where I am.

CHERYL: That's fantastic.

SONYA: Now, I mean, that being said, you're also very oriented to being generous to others and being of service to others. So when we say "give less fucks," I mean, caring less about impressions that you make with other people or things that other people want you to be. But the other side of that is he's in service to people all day long, every day. So in that way, he really gives and gives. That's what I see. And my mode of doing that is through my writing and through my teaching of writing, because I want people to have the experience of what it's like to find themselves through their words. Yeah.

CHERYL: Well, having read the whole thing, it's not some lascivious confessional. And it's also not just a brain injury book. It is so multi-layered and so deep. And because you cross decades in it, I mean it's a book about like you said, grieving. It's a book about marriage, relationship, what is the nature of personality. And you think you know. But then, when you're forced to confront it in a different way, like when your personality changed without your choosing, then all the sudden, oh, you have to become curious about the world again. And I feel like the book covers all those things. It is just...you pack so much into this book, you two. It's just amazing. And I could not put it down.

SONYA: Aw, thank you.

RICHARD: Thank you.

CHERYL: It's just so rich.

RICHARD: Putting words into your mouth, which I'm sorry, but--

SONYA: Go ahead.

RICHARD: I think what she was trying to do was really offer a story about identity and how fragile identity is and how our remembrances of our lives are very tenuous. I don't know. I mean, from my standpoint, I have very little memory of what my past was. And so now I'm just living in the present. And I'm just here now and just trying to do the best I can each day.

SONYA: And it's a very liberating thing to see. It's a liberating things to be with. You know, it's a real opportunity for me to see oh, living in the present without all of that doesn't change your generosity, it doesn't change your love, it doesn't change your ability to really relate to people, it doesn't change your work in the world. You know, it doesn't make you an exception outside of humanity on either side. It doesn't make you more heroic, and it doesn't make you a dufus, you know? It's just an ordinary human experience.

RICHARD: In my case, it might be a little bit of the dufus. But that's OK.

SONYA: [laughs] You're more like the wise fool [chuckles]. I think the book is about a process, because all I experienced was loss, initially, and grief. There's some work in there from Pauline Boss on ambiguous loss. It was great for me to find her along a certain way, as well as it was great for my sister to say to me, "I can see in some ways how you would've had more societal recognition if Richard had passed." And so that people don't know that you're experiencing a death of the former self.

RICHARD: And I was pretty damn selfish for the first few years,

CHERYL: As we are.

RICHARD: out of necessity, I think. You know, because I was trying to just, yeah, breathe and live and eat.

SONYA: I would say appropriately self-centered because you were trying to get back to life again. And that's what any caregiver wants for their person to be, if they're really there and loving them. But I think it's been a really interesting journey for me. And I'm glad I'm on this other side of it now, to have a little bit of perspective. I remember I was in Canadian Rockies. I friend of mine had given me an apartment to write in. I took a month off up there while Richard was working in Seattle. And took my big box of the medical files, you know, and all the journals and everything, all the letters that I wrote and received. And I started going through them. And I looked at that former Sonya in those early days of caregiving him and how controlled I was and how I wanted to sound so together, to help people feel better about our situation. I just had this shame, just this total body shame response, like oh my gawd, I cannot believe that that's who I was in that moment.

CHERYL: Oh, wow.

SONYA: We have this saying in our family that got developed: one brain injury causing another, because it's real [laughs]. It was a felt sensation of his identity causing like this domino effect on the whole relationship of the family and the community that knew us. But the only way that I could really overcome that shame was to put it out there publicly and to not hide from it, and to say you know, I really forgive her. I forgive that one who really was trying to make everybody feel good and trying to be the nice girl and the good wife and the perfect caregiver and you know, all those things, and we are, we're not really being authentically ourselves. And I think that was the stress for me. The stress at that time was so huge that I was just trying to play a role instead of really letting the whole traumatic event wash over me and see how that changed me.

RICHARD: And I was totally oblivious. So I was very little help at all.

CHERYL: Right.

RICHARD: I mean, you know, now looking back, I can see how much she was going through and how the challenges were there on a daily basis. For me, you know, months went by without me really thinking about anybody or anything, you know.

CHERYL: Sure, yeah.

SONYA: Yeah.

CHERYL: And I'm glad you forgave her because she deserves forgiving. When an acquired disability comes into your life, it wasn't there before. How are you supposed to know what to do?

SONYA: Yeah.

CHERYL: And the pressures on you to keep a smile. Everything's great. Daily improvements. Go, go, go.

SONYA: Yeah.

CHERYL: There is this belief and this pressure that's on you that if you don't have some kind of regular daily or monthly improvement to announce, it's your fault. You're a slacker. What's wrong with you?

SONYA: Are you doing the protocol? Are you following what the doctors say, you know?

CHERYL: Yeah, so much pressure.

RICHARD: And we tried everything. We tried shamanic healing, we tried the lamas coming over and doing sand things in my living room, we tried everything. Yeah.

SONYA: Yeah. I mean, why not?

RICHARD: Yeah.

CHERYL: Sure, yeah.

SONYA: Nobody seemed to have the perfect answer at that time. People were coming forward with what seemed like loving suggestions. And then after a time, your own instincts start to accumulate, right, for what might be healing. Richard had really strong instincts at the beginning, which was really stunning to me. He's like, "I wanna do this, and I don't wanna do this." But we both love travel and adventure. That's part of the book as well. One of the things that I started to observe is the first time we went out on a big trip, it was to France. A friend had given us this 400 year old water mill in Brittany. And we had a chance to go and be caretakers of it for a couple months. Could we do this? Would this be the right thing to do? Oh my gawd. And then we went to a neuropsychologist, and he said, "I think it's a great idea" because, in fact, Richard was pushing himself very hard. We needed to find a way for him to just take a break. But to learn how to drive on the French roads. We had to learn how to speak the French language. We were in a completely different place.

RICHARD: And having grown up in Canada, I'd actually spoken French. I was never really fluent in it, but I was pretty conversational in French. So going through the vocabularies and that sort of thing actually sort of expanded my mind and gave me a different way of speaking that I think it was actually beneficial for me.

SONYA: Every time we came back, I would notice some major shift had happened for him. If you go out and try a bunch of things that you haven't tried before, and you really are pushed in that very contained kind of experience, why wouldn't a reaction, a certain new intelligence, new synapses form in a way that would kind of push you to the next level? I can just say that, experientially, every single time we traveled, it happened for him. After France, he was able to go back to work because he could make eye contact and communicate with people really well. I mean, not really well but enough

RICHARD: Better.

SONYA: [giggling] to be able to go to work [laughs]! And then, we did this trip to India six or seven years later. When he came back from that, he could tell jokes and share witticisms. I think that humor's quite sophisticated. So it was a big difference to me to see that he didn't just laugh at jokes, but he had the ability to initiate them, which was fun.

RICHARD: I'm still not really what I would call funny. But you know, but I've tried every once in a while.

SONYA: Yeah.

CHERYL: [laughs]

SONYA: You do well. You do well [chuckles].

Words of wisdom

RICHARD: The only thing I would like to say is that to me, 12 years after the fact, I don't know that we sound very together. But to me, we sound pretty together, like we've got our ducks in a row, and we've really come a long way. It was not that way for the first five or six years or even seven or eight years. I mean, it was a real struggle on a daily basis. There were a lot of roadblocks, a lot of barriers, a lot of recession and falling back. And I mean, it was not a straight uphill kind of climb. So anybody that's listening out there that thinks that we have it together, we really do not have it together. And we did not have it together for years and years and years. It is definitely a struggle. I would just like to say you know, if you're experiencing a brain injury, and you're pissed off at the world, or you're really struggling on a day to day basis, that there is light at the end of the tunnel. But it might not be there today, it might not be there tomorrow, it might not be there for several months, it might not be there for several years. But I think that things are possible. I really do.

CHERYL: Yeah. Yeah. I'm so glad you said those things. I know that people can't imagine what it's like at the beginning or for the rest of your life, how much harder things are. You offered, what I think really is, a gift just now, to brain injury survivors or peers with brain injury. What would you offer to their caregivers or spouse or family?

RICHARD: [big sigh] That's really hard because so many relationships do not make it as a result of the personality changes or as a result of just the disconnect that tends to come in. I would like to say there's always hope, but I'm not sure there's always hope. I mean, sometimes it might be better the relationship actually dissolves because, for some reason, the people may just not be able to get along together anymore. Sonya and I were very fortunate that we found a lot of love after a number of years. I would say we're as strong or as tight now that we've ever been. And so I mean, we're kind of the best possible scenario. And I know that it's not like that for everybody. I know there's a tremendous amount of effort, and a lot of it goes unnoticed or unheralded. And it's a tremendous amount of work. And all I can say is keep trying different things, keep trying new things, and see if something clicks. There may be something that you might try that might click for somebody. And if it clicks, that's your avenue. That's your way of connecting with the person again.

CHERYL: Why didn't I do that?

SONYA: [chuckles]

CHERYL: I know what I did was just keep trying the same wrong thing over and over. Well, this didn't work. So I better keep trying this same wrong thing.

SONYA: Hmm.

CHERYL: But this, yes, try something different.

RICHARD: Mmhm. Yeah, we tried the neuropsychologist. The neuropsychologist was great for me. He was just fabulous. I mean, he really brought me a long way. But it was partly it was the shamanic stuff and the language stuff and the travel stuff and the lama stuff and some of the spiritual stuff and the didgeridoo that I tried, you know what I mean? It was a little bit of everything. I don't know what exactly clicked in my brain. I mean, I can't really say that it was one thing in particular. But a lot of things together have really enabled me to come a long way and I think a lot farther than people would've thought I was able to come during that first year I was out of surgery.

CHERYL: Absolutely. Yeah. Sonya, anything that you would like to give to either survivors or family caregivers?

SONYA: Mm. I think it's important for caregivers to know that they really can grieve. And it's a very real, actual loss to have a radical identity change or even a moderate one, to have a personality or a relationship that they were so engaged with disappear. It's such a huge loss. And to find the people around them in their life. It might be a good therapist, it might be a best friend, it might be a minister. It doesn't matter. But someone who can really hear the depth of that, because I think for us the reason that we bonded is because we could cry a lot in front of each other. Richard wasn't experiencing that loss. But he would cry because he saw me suffering. So I would cry for what was missing. And then he would cry. Or we would have shared moments of anger about what it was that we were experiencing and could clue into that we weren't angry with each other; we were angry with the brain injury and be able to express that. Because you can't make grief go away any faster than grief goes away.

But the space that's provided from those emotions being expressed allowed me to see Richard for who he is now. And that's where the falling in love moment, the bonding with him began. I could look in those eyes and be deeply drawn to the man that he is now and not want the past, because the grief had so fully been expressed. And then the real adventuring begins from there, you know? So I think having the support that you need to experience loss, whatever way that you do. And I think for the brain injury survivors or peers, it's really important to try a variety of different things and to listen to suggestions that other people might have, to a certain point and feel what's instinctively right for you. I feel like that's such a huge part of becoming. I recognize that there is a brain injury, and there is something else going on, is what I noticed in Richard. And that's also partly what the book is about: that new being that is emerging is very tender and unusual. And I was so curious about what was happening. But Richard being able to trust himself to know what he wanted, if I would say, "Let's try this or let's try that." And he would say, "I don't want that. I wanna go over here." And just, I could see his new instincts were developing, were so powerful for him. So the person who is developing the new self really feeling that in their body or whatever way that they experience it, and intuitively knowing that that's the right thing for them, not matter what.

RICHARD: And she was very clear about not forcing me to go back to physical therapy. I mean, she said, "Whatever you wanna do you know, we'll figure it out. If you wanna go back into acting," because I'd minored in drama in university. Or if I wanted to take up playing an instrument or something like that. She said, "Whatever you want to do with your life, I will support you in doing that. We, obviously, need to be concerned about finances at some degree. And so we need to be able to make some money at some point." I was just adamant about returning to physical therapy cuz that's what I thought I was. And as it turns out, that's who I think I am. I mean, I'm a pretty good therapist, and I have pretty good hands. And I do care about people, and I care about seeing them walk out better than they walked in, that sort of idea. And that was really important for me. She wasn't sure what I was gonna be able to do, either, as

well as the neuropsychologist. They had no idea what I was gonna be able to do. But she was willing to let me sit there and read and read and read for weeks and weeks and weeks and forget and forget and forget. But eventually, I was able to get through it. I think that support was really important.

SONYA: And sometimes I think these impulses are beyond us, really. I think they're beyond our willpower, they're beyond our personality selves.

RICHARD: Beyond our comprehension.

SONYA: Beyond our comprehension. I wanna say this one thing, which is I think you and I had a little bit of a conversation about this when we had coffee initially, which is that we talk about disability. We use that word, "disability." And I understand how that's beneficial for our medical system and for people to get benefits and all of those things. And I don't think of him in terms of exceptionalism. I don't think that he's this heroic person who overcame all of these things because he's you know, Odysseus or whatever. But there is something else that's happening here, which is about genuineness that I find that the erasure of the identity is able to expose in the individual. In that way, I feel very fortunate. I feel like what happened to us was a gift to our family because the ways that we were limited in expressing ourselves before the brain injury, we are not limited now. I wanna say that with all due respect that anybody with a brain injury still struggles, they still have to do accommodations and things that I will never understand because I don't have one. But from this side of it, it's been a real privilege to go through that experience with Richard and to witness the changes that happened for us.

RICHARD: And I might not have as positive a leaning on that. But I do appreciate the fact that I am different and our relationship is different, and in some ways it's better than it's ever been. Although, I would not wish this on anybody.

SONYA: Yeah.

RICHARD: I would not wish them to go through what I've been through. I would not wish them to go through the struggles. But I feel, all things considered, I feel quite fortunate with how things have turned out. I mean it was a lot of struggle. It was a lot of struggle. And there was a lot of pain and a lot of frustration and a lot of anger. Now that I'm on the other side of it, it's been a struggle that has been...I hesitate to say "worthwhile," but I'm gonna say worthwhile. Yeah, yeah.

CHERYL: Yeah. No, and when you say "worthwhile," it doesn't mean everybody should try this!

RICHARD: No.

CHERYL: But worth it. Your life, life worth living. It's still a life worth living.

RICHARD: Yes. It's still a life worth living. No question about that. Yeah.

CHERYL: And that is the title of a documentary. I did not make up that interesting phrase. Are there more things you wanna talk about around the book

Book launch, teaching writing, and contact info

SONYA: The book is launched on July 9th at Hugo House in Seattle. And then the next day there's a private party in San Francisco. And then there's two readings in the Bay Area. Then to San Diego, Portland, and Vancouver later in the month. If people want dates so that they can come out, and we'd love to have a conversation with as many people as can come, they can go to my website at www.WonderingWhoYouAre.com. On the first page, there's a little place there where you can request a

newsletter. And you'll just stay on my newsletter list for a few months. I don't pester people, but just enough to keep you engaged in what's going on for the events as the book goes out into the world.

CHERYL: And you have a reading in Portland on July 21st, right?

SONYA: We do. Absolutely. At Powell's, which, the great Powell's.

CHERYL: A full city block of books. Yes, yeah.

SONYA: Yes. There'll be lots of events. There might be some in the East Coast later on in the year too. So if people stay in touch, that would be great.

CHERYL: Now, are you going on the book tour at all, Richard?

RICHARD: [sighs] I'm going on a couple of dates: Portland. I think that's it right now. I mean, I don't think I'm gonna make it to the East Coast just because my work schedule doesn't really allow me to. I would love to be at a few other venues, but I'm not sure it's going to happen at this point. So we'll see.

SONYA: I also teach veterans and soldiers writing, particularly women veterans, many of whom have either TBI or PTS. And also, they have typically experienced combat trauma and/or military sexual trauma. Right now, that's under a program called Red Badge, which is running throughout the state of Washington. We might be in other states as we grow. But if people are interested about that, they can look up [Red Badge online](#) and learn about our programs, both for men and for women. We teach primarily out of Federal Way and are opening a program at the Seattle Center. But people can inquire through Red Badge if they would like to have a program offered for them. Writing is an extraordinarily healing tool. It's really important, I think particularly for women, to know that in these kinds of programs, they don't have to fall within any of the old masculine ideas of what storytelling is. And we bring in lots of models of women's stories and the way that women tell what happened to them. So it's really giving us an opportunity to look at what models are there out there and what kind of language is possible when we wanna tell these new stories? So I find it really liberating. And I think that the women are really something else. It's been an honor for me to teach them.

CHERYL: Yeah. You have a film that's on the festival circuit right now? Is that right?

SONYA: Yeah, it's going out to festivals now, called "Every Beautiful Thing." And that's a fiction film. I'd been writing scripts and selling scripts here and there for a number of years. And I wanted the chance to write and direct something myself and to produce it and just to see how I did. I keep going back to stuff that really influenced me. But seeing Richard go through having to relearn his life, there was something really influential for me. There isn't any age that we have to stop learning. There isn't any age that we can't reinvent ourselves or say, "Hey, wait a minute. I always wanted to make a short film. Why don't I try that now?"

CHERYL: So people can find out more about the book and get on the newsletter at [WonderingWhoYouAre.com](#). But there's other places to find you.

SONYA: [SonyaLea.com](#). Tin House is my publisher out in Portland, fine, fine publisher. They've been really amazing. And you can go to the [Tin House Books](#) website and learn about it as well. I have been trying to get on Good Reads as much as possible and talk directly to the community there. So if people have questions for me, they can just send them along. I'm answering a couple a day there.

CHERYL: Oh great.

SONYA: So yeah, people can find me. And we can get into a great conversation about the book and the parts of it that have an impact for them. I'm also on Twitter and all those places where you social media it up [chuckles].

RICHARD: Everywhere.

CHERYL: Right, right.

[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.

[music]