

## Stories from the brainreels podcast transcript

May 12, 2015

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### Introduction

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](mailto:info@storyminders.com) with questions or topics and guests you want to hear on an upcoming show.

[music]

CHERYL: May is turning out to be one of those unplanned and exciting months where I get to post two podcasts instead of one. I think I'll still call it a monthly podcast though. My guest is Lauren Marks, who is from the U.S. but now makes her home in London. Lauren will be the third UK guest I've had on this podcast, all artists who sustained brain injuries and became involved in creating art around topics of disability because of it. Lauren is also hugely interested in what makes writing and video accessible so that she can be most inclusive of audience members and readers with aphasia, a language disorder she also has since a stroke seven years ago.

A brief warning about the episode: we giggle, chuckle, and laugh nearly constantly. I'm being only partly silly when I give that as a warning. The non-silly part of me warns listeners and readers because I know that many people feel sadness or seriousness around disability issues for a lot of solid, important reasons. You should know that Lauren and I, while we take disability quite seriously, tremendously enjoy laughing at ourselves. It's a sweet luxury to be in that position. We do not take it for granted.

Just a couple quick notes about how awesome Washington State is. First, I have the great opportunity to offer a 10-minute presentation as part of the Pacific and Western Disability Studies Symposium up in Seattle later in May. The focus this year is on disability justice and disability arts. The 10-minute thing is part of an archive they're creating of short papers and presentations from students, artists, and emerging scholars. You'll be able to watch a Closed Captioned version of my presentation on my YouTube and Vimeo channels starting in late May. In it, I talk about some successes as well as difficulties of challenging disability stigma and discrimination through the media when people don't even realize they are discriminating. Yikes! I'll also see if I can get the link to the archive so you can check out everyone's contributions.

The second is that I'll be screening my first two brain injury comedy films along with several shorts I produced made by other artists with brain injury on Friday, June 5th at the Brain Energy Support Team center in Tacoma, Washington. It's a most exciting opportunity. I'm so honored that they asked me up. If you're in the Tacoma area, please come along to this free event 6:30 - 8:00 pm. There will be dessert! Find more info on my blog and at [BrainEnergySupportTeam.org](http://BrainEnergySupportTeam.org) as the date gets closer.

As always, please subscribe to the podcast on iTunes, Stitcher, or [SoundCloud](https://www.soundcloud.com/storyminders) and subscribe to the blog at [WhoAmIToStopIt.com/blog](http://WhoAmIToStopIt.com/blog) where you'll get podcast transcripts, links and more info about podcast guests, and tons of posts about disability arts and media. It's also where you can, of course, keep track of the documentary film "Who Am I To Stop It," due out later in 2015.

Please enjoy my conversation with Lauren Marks.

LAUREN: Hello!

CHERYL: Good morning. I mean good afternoon [giggles]

LAUREN: Yeah, in different parts of the world.

CHERYL: Yeah.

LAUREN: Good morning to you; good evening to me.

CHERYL: [giggles] Lauren, thank you so much for coming on the podcast today. I appreciate it.

LAUREN: It's really my pleasure. Thank you.

CHERYL: Absolutely. So I just wanna start with a brief introduction of you. You got a BFA in theater and acting from NYU's Tisch School of Arts. And then you went for a PhD in theater studies at CUNY. You've been an actor, director, script editor, and dramaturg for a lot of organizations and theater festivals. And while you were still a PhD student, you were at the International Fringe Festival in Edinburgh in the UK. Jealous! I'm so jealous! And this was 2007. And from what I read, you were at the festival. And then one day he woke up from emergency brain surgery. You had a ruptured aneurysm. And that is the type of stroke or acquired brain injury. And from that stroke, you developed aphasia.

### **Describe what aphasia is and your experience with it**

CHERYL: And I really want you to talk about absolutely every single thing that you do [both giggle]. There's a lot of stuff that you do in the arts, with this charity called Connect, and with aphasia storytelling. But what I would love to start with, if you don't mind, is having you describe what aphasia is, because there may be some people listening to or reading this podcast who don't actually know what aphasia is.

LAUREN: Yeah. I'd love to talk about that. Aphasia, in the most basic sense, just deals with wordlessness, meaning speaking, reading, writing, and hearing can all be affected. Obviously, sound is still coming through your ears. But understanding the language. So it's a communication disorder. In my case, speaking, reading, writing were all affected. Hearing was fine, although I was in Scotland, and I had to listen to some brogues and was not always 100% clear what was being said to me [laughing] but not because of my aphasia. That was simply lost in translation moments.

So yeah, I was in Edinburgh at the time of the aneurysm's rupture. It was not in any way anticipated. In fact, I was on stage when it happened. I was mid-duet when the aneurysm ruptured. So I've seen the video. I've seen the second the aneurysm ruptures in my brain. I was, you know, up, smiling, singing. The next second I was down, you know, just down, down, down. And there are a couple of gloaming moments in which I was like, a paramedic was trying to slap me awake. But really, the next clear moment I have is waking up from emergency brain surgery. And I'm not sure the first time someone used that term, aphasia, with me. But it was pretty early on. I had a speech and language therapist coming to my bedside in the Scottish hospital. I received absolutely fantastic care there. And I, I was already at a weird moment for me, you know, because it was like why? Why is there a speech therapist here? You know?

CHERYL: [chuckles]

LAUREN: I didn't think that I had a problem with my speech [laughs],

CHERYL: Uh-huh.

LAUREN: which is kind of, you know, one of the great joys of a brain injury is you don't always know what you don't know. And I mean that in a very serious way: the brain is the organ of perception. So if there's an injury to the brain, there could also be this injury to your perception. So it took a while for me to understand the limits of my language disorder. And that was not resolved in the hospital. In fact, a lot of the things would come quite slowly.

So aphasia. I was not aware immediately what that meant. In fact, to tell you the truth, I didn't even know I'd had brain surgery. I was told that I had. It took a long while, and it was not resolved in the hospital for me to understand the limits of my language disorder. I didn't lose the alphabet. But I had lost the ordering of it. I lost anything I had memorized, you know, all the roles I had played as an actor, all the poems I used to recite, all the prayers I learned as a kid, all that stuff just sort of erased. In the earliest stages, my parents say it was about 40 or 50 words that I had at my disposal. But I didn't know that, you know! I thought I was pretty fine. So in my case, I was pretty lucky to not be aware of how damaged my language systems were. I think I would've been a lot more anxious and a lot more despairing [chuckles]. When the speech and language therapist would come to my bedside, I had this like vague recognition or familiarity; I don't know what to call it, exactly. Like, when she was trying to do these speech exercise with me, they were very much like theater exercises.

CHERYL: Oh!

LAUREN: You know, like puh puh puh duh duh duh.

CHERYL: Uh-huh, uh-huh!

LAUREN: You know, so like it didn't mean that I was in trouble. I had a lot of issues with my memory. But I knew truth from fiction. And there was something about that, that, just that practice was not disturbing, you know. There was nothing in me that was alarmed by that. Although, if I had more awareness, I could have been very alarmed.

CHERYL: Right. I think a lot of rehab people, can--not maliciously, but--take for granted how completely bizarre it is to be a patient, especially, like you said, when your perception is not up to par, and you don't fully understand why you're there or what the problem is that you're supposed to be addressing therapy. I know that happened to me when I was in rehab. Even with my Masters in speech therapy, I could not understand why I was doing the exercises I was. But because I had the degree, she just assumed that I fully understand the circumstances that I was in.

LAUREN: I did feel like I was being pestered a little bit. You know what I mean?

CHERYL: [laughs]

LAUREN: I mean, cuz another was when I lost my external speech, I had also this vacancy in my inner speech as well. Meaning, I didn't have self directed speech. I wasn't thinking to myself I'm in hospital. I'm in trouble. I have a speech therapist. You know, all those things that I can do now. I don't know if I have it at the level that I had before my stroke. I have no idea how to gauge that. But I have it. And I assumed that everyone who had aphasia had this as well. And it was, I thought it was glorious. And I have read about people who have this same experience, or generations or variations of the same sort of

thing. And [Jill Bolte Taylor](#) talks about this kind of glorious silence. I forget the words she uses for it. There's this guy, Scott Moss, who was, I think, a psychoanalyst or a psychologist when he had his stroke. [chuckles] I read about him in my book "Injured Brains of Medical Minds" [both laugh], that I just have on my desktop, like you do.

CHERYL: Oh, I love that title. It's horrendous! Oh.

LAUREN: [laughs]

CHERYL: Please carry on.

LAUREN: He also talked about this vacancy. You know, he didn't have words for anything, not just can't get those words out, but just didn't have them internally. And that, I mean that's kind of like a Zen mind, you know. I don't wanna prioritize it like everybody should go get themselves a brain injury. But there was a lot of peace in it. It was a very meditative state. And when someone came in and "Let's do pah pah pah, pah pah pah," it was like, "What? No! What? No!" [laughs] I'm fine right now. I'm really fine. If I had been in the hospital, I assume as my parents would've imagined I was, you know, for 23 hours of the day I was just fretting. The hours that I wasn't doing my speech and language therapy, I must've been fretting. That is just not the case, you know?

### **An interlude to talk about foxes in Lauren's yard**

LAUREN: By the way, a fox, a little red fox, just crossed my yard.

CHERYL: Stop. Oh.

LAUREN: They're so magical. People think of them as pests here. I love the foxes. I told that to some, you know, group of English people the other day. And the first guy--who I like, actually. He's a really nice guy. He said he wished he could shoot them all.

CHERYL: Mm.

LAUREN: I was like, what!?! He's like, "Oh, they're pests!" To me, they're like they're almost, they're almost like fable creatures, you know? They're almost, they're almost little unicorns to me [laughs]. They seem to be fictional. I mean, I know coyotes. And they are kind of terrifying, you know, growing up in the foothills of Los Angeles. But the foxes, they're glorious! They're these little red little woodland creatures with their little pointy, you know, ears, and their white tufts. I love the whole thing.

CHERYL: You've completely sold me. Believe me.

LAUREN: They had six. The couple--the fox and his vixen--had six pups when we moved here.

CHERYL: All right. I'll be right over.

LAUREN: I know. They're in the backyard. Come on up.

CHERYL: Oh my gawd.

LAUREN: I don't know. Do you have direct flights?

CHERYL: Uh, from my house? Yeah. It's [laughs].

LAUREN: Great. Yeah, then you know, just pack an overnight. You'll be fine.

CHERYL: Listen. You don't wanna talk to me even jokingly about airlines. When I went to San Francisco with Lavaun, I think it was last week. I'm not exactly sure. I can't understand. I do not understand calendars, schedules, clocks, all sorts of things. And I'm very good reading maps. But you know, I just...I just don't understand. And I took us from Portland to Seattle to get to San Francisco. And I didn't see the problem with that. Lavaun was livid. And then coming home we went to Salt Lake City.

LAUREN: [laughs]

CHERYL: So we switched time zone. And what Lavaun helpfully told me a month after I bought the tickets is that it's an hour and a half if you fly from Portland to San Francisco. If you use my ticket, it's about six hours [laughs]. Gawd. That's the kind of thing that I can sort of laugh at. But it's very humiliating. And it doesn't seem to be getting any better. And if there's any speech therapists listening to this, they'll say well, you need to stop and think and plan and make sure that you've covered all the steps. What I don't think they appreciate--and I know they mean well--what they don't appreciate is that I don't have the capacity to recognize when I haven't thought through the steps.

LAUREN: Yeah.

CHERYL: I picked the tickets, and I read the itinerary between six and ten times. And I thought that that meant that I was reviewing it, understanding it, and reflecting on it. And then it turns out I wasn't doing any of that. But I thought I was. So fortunately I think speech therapists are frightened enough of me that they don't offer me advice anymore because they know I'm gonna come back at them with "well, how am I supposed to reflect on reflecting if I don't even know whether I've reflected or not? Leave me alone. I'm gonna go make a movie." So.

LAUREN: I couldn't agree with you more. I mean that's another moment where it's like, oh wow. Finally, somebody else experiences this. Meaning like, it's not exactly the same points that I struggle with. But you don't know what you don't know.

CHERYL: Yeah.

LAUREN: [laughs] That's the long and the short of it.

CHERYL: Yeah.

### **Limits to our perception**

LAUREN: There are limits to your perception. There's limits to everybody's perception. And actually, I think sometimes people who've had brain injuries are actually much more aware of their limitations and like much better than like a hedge fund manager.

CHERYL: [giggles]

LAUREN: But there are moments you go, "I'm sorry. But that's just not the thing I do."

CHERYL: Yeah.

LAUREN: "I'll do everything I can. I'll double check in every way I can." But like, I have great anxiety submitting paperwork. I put it in front of my husband. And I'm like, "Would you please just look at it?"

He's like, "You've done it three times. I saw. It's good." I'm like, "No, I really need you to look at it." I'm not this plaintive, you know, little church mouse. You know what I mean? It's just like I, I just I know that I can make a mistake in there. And it's gonna disappear to me, you know. And I think if it's not digital, and I can't listen to it, then the chances are higher that I'll miss something that's abundantly clear to anybody who doesn't have aphasia.

CHERYL: Right, right. And so another note to the podcast listeners or anyone reading the transcript: this is a perfect example of how there are some of us who can pass as having no disability. There some of us who fit in the category of " but you look fine! But you sound fine!"

LAUREN: [chuckles]

CHERYL: There's a lot going on under the surface that has struggle to it. And we may make mistakes. Or it may turn out that there are no mistakes, but it took six weeks to fill out that one form because of how long it took to read and understand the questions and rewrite them and rewrite them and rewrite them. And that's a lot of stuff that people don't see when they come up and tell you "How could you have aphasia? You sound fine to me." But you do.

LAUREN: Yeah.

CHERYL: You know you do.

LAUREN: Compensatory strategies.

CHERYL: There you go.

LAUREN: Compensatory strategies.

CHERYL: Do you get that from people? Do people ever tell you, "but you look fine. But no, you're just doing so well. You can't possibly have a disability."

LAUREN: Yeah. They do. They do it a lot. And I don't wanna say universally that upsets me. I guess it's a case by case basis. On a day if I'm really struggling, and someone says that, I might actually feel grateful, that you know, I feel like I'm a harried mess. But they don't see it. But a lot of other times, I just say like [sigh] "Give me a break" [both laugh]. "Just give me, just give me a break," you know? First of all, it's a little, it's just slightly insulting,

CHERYL: Uh-huh.

LAUREN: because it diminishes all the work I do just to do what I'm doing. And the other thing is, it's clumping together a group that they have some assumptions about, but they clearly have no knowledge of, you know?

CHERYL: Yes!

LAUREN: "Oh, you don't seem like someone who's got this brain injury." And you're like, "Well, how many people do you know with a brain injury?"

CHERYL: Right.

LAUREN: [laughs]

CHERYL: That's a good point. What I always forget to say, because I haven't practiced it enough, what I keep meaning to say is, "This is what a brain injury looks like. This is. This is my life with a brain injury. Everybody is different." And it's so bizarre to me because if you look at non-disabled society, I think most people would say everyone's different. But you get a label, aphasia, a brain injury, disability, and all the sudden, the differences just seem to be erased. It's the weirdest think. I don't get it. I just don't get it.

### **The benefits of knowing the name "aphasia" and volunteering at Connect**

LAUREN: You know, the nomenclature is challenging because there are really, there with their benefits to it, being able to say "aphasia," you know? I volunteer at this organization in London that is serving the aphasia community. I probably see 40-50 people with aphasia every Thursday, several times a week sometimes. And there are people in there whose doctor never told them that they had aphasia.

CHERYL: Oh!

LAUREN: Like, they never gave them a name. So for years, they just struggled [giggling], you know what I mean?

CHERYL: Yeah.

LAUREN: They beat themselves up. They said, "I can't do this. Why can't I read the newspaper? Of course I can read the newspaper, you know. I had a stroke. I didn't have a steel rod through my head. I mean I should be able to read the newspaper! I read the newspaper." You know what I mean? They beat themselves up until one day this magical word just, you know, is delivered to them, like, "aphasia." They also say dysphasia here.

CHERYL: Mmhmm.

LAUREN: And they just think, you know, they're released by it.

CHERYL: Yeah.

LAUREN: It's like, oh gawd, there's a community. There's a name. There are the resources cuz all those things are at the hub of the wheel. You know, aphasia is the hub of the wheel. And as soon as you know that name, you can look towards all of those resources. I mean, I was very, very lucky to audit a class in Aphasiology [chuckles] when I was actually really still struggling with my acute symptoms. But I had been a PhD student before. And I had a very, very generous--she was not my speech and language therapist, actually. She was a university professor who was a friend of a friend. But she knew how interested I was in the topic of my own injury, basically.

CHERYL: Mmhmm.

LAUREN: And she knew that I would do everything I could to keep up. And she let me cane, come in and aubit, audit her class. That was at Cal State Northridge. I'm gonna say her name. She's fantastic: Catherine Jackson. Catherine Jackson let me came to, come to her class. And like, when I was reading the textbook, I felt, you know I felt like I was reading my own family album.

CHERYL: Wow.

LAUREN: You know, like pictures of myself. And it was amazing cuz I had felt like all of those symptoms were unique to me. Now, I did have the name aphasia. But yeah, I was still struggling with the basic things. I certainly wasn't looking up cognitive neuroscience and Aphasiology. But when I was reading this textbook, I mean I had a really, I was like clutching it close to my heart, you know. These mistakes that were being made, that were being chronicled, that were being tested for, I was like oh gawd, I make those mistakes! I didn't know that other people made those mistakes. And example, just so it's not so vague: I rarely do it in speech, but on the page I very often replace a word that sounds similar to a different word but has a totally different meaning.

CHERYL: Mmhmm.

LAUREN: And if I hear those words, I know it's not that. But like soul and sore.

CHERYL: Mm!

LAUREN: You know?

CHERYL: Mmhmm.

LAUREN: You know. My soul foot. You know, I'm like, "No, no, my sore foot" [giggles].

CHERYL: Right, right.

LAUREN: And that actually, those things do have some correlations because there's soles of your feet and stuff like that. But I mean, it really is just, it's just the sound of it. And somehow that there's a crossed wire in my brain. And I put these words down that are not the right words. I have my computer. I have a text to speech function. And it reads aloud to me. And once I hear the word repeated back to me, I know it's wrong; it's in the wrong context. But like I didn't know anyone else did that! [laughs] I didn't even really understand what exactly was happening until I say that sys- that symptom they called a paraphasia, a phonemic paraphasia. I was like, oh! Oh, yeah. I get that every day. That's like several times a day, you know, a dozen times a day. And sometimes they're beautiful and they're interesting. Sometimes they're funny. But they're every day. And again, I don't usually do it in speech because the speed of speech is about OK with me. But the speed of writing is faster. And I make that mistake.

CHERYL: Mmhmm. So it almost sounds like, in a way, reading that textbook, you found a sense of community: oh, I'm not alone in this.

LAUREN: Yeah.

CHERYL: And is that one of the reasons that you volunteer--Can I say the name of the organization?

LAUREN: Sure. The organization is called [Connect](#).

CHERYL: Yeah. So is that one of the reasons that you volunteer at Connect, is around that sense of community?

LAUREN: Yeah, I guess so. Partially it was, I mean I was alone in London. I was here with my husband. I came with him to his job here. We have a lovely life. But I had never met anyone who had aphasia in the United States.



CHERYL: Oh?

LAUREN: You know, no no. I was really focused on my own recovery. By the time I moved here, I had a little more flexibility and I had a little more ability to work in the world better. So I just said well, I'll check it out. But there is the flip side to having this term as well, that nomenclature. I met another girl there. I was 27 when I acquired my aphasia. She has very fluent language now, much like mine. But she also acquired her aphasia at about age 27, 28. And it was amazing, you know, an amazing connection to talk to someone about what it was like to lose your language [giggles], you know? And now to regain your language. And oh, did you have this problem? Did you have this problem? Like, what about this? Was this a problem? You know, kind of like comparing notes and stuff like that. She was one of the people who didn't know what it was for a long time. And she hid it as much as she could. She was a TV producer. And she lost her job. But she did try to get back to work as soon as possible. And you know, it was a struggle, uphill struggle. But she did what she needed to do to make enough of a living for a while. And when she finally acknowledged what had happened to her, then when she found this community of people who had aphasia, she found herself sort of first of all, relieved. And then sort of doubly injured.

CHERYL: Oh.

LAUREN: Because she had never identified herself as having a disability. And then when she had, she was like putting herself in a different context. And you know, she was like well, should I tell people I have a disability now, cuz I didn't for so long? And she was able to get back to work. I wasn't. And I have been on the job search in a very subtle way because you know, my book is coming out next year. So I don't have to start the job search in a major, earnest way. But I'm more able to do it now. And I want to do it. And I do have to mention it. I mean, I do have to use this software when I work in an office. And again, I know what she means. Like, I know what she means now, which is like, [giggles] it's like OK, if you could pass, should you want to pass? [both laugh] Because you know, it puts you in a strange situation, you know? You don't know how you wanna define yourself and what things are outside of your control and how much your language effects that.

CHERYL: Yeah. And you really, you can never control what somebody else thinks of you. But I think it is important to let people with disabilities define themselves.

LAUREN: Definitely.

CHERYL: Like we were talking about if you have a label and someone else has a preconceived notion of that label, they're gonna put that on you. And they're gonna tell you, "Oh, you don't seem aphasic. You should stop calling yourself that."

LAUREN: [chuckles]

CHERYL: Or my friend, [Nina G.](#) She stutters, and she's dyslexic. And she's in a group called The Comedians with Disabilities Act. And people always tell her, "Mm, dyslexia and stuttering. Those aren't disabilities. You shouldn't be in that show." And it's outrageous to me. But I think, you know, as we move through acquiring a disability, we have a lot of flexing and transition to go through. But what we see so often is that non-disabled people are not ready to flex and go through that transition indirectly and accept our transition. And so I do know a lot of people who try to define us and tell us we're not defining ourselves correctly, and you shouldn't call yourself that. And it's interesting because we didn't have the choice of whether we would flex and transition. It was given to us. It is a real benefit, I think, to being in the disability community. Well, to having a disability or having an impairment is that it does

force you to flex and adapt to an inaccessible world and to redefine things. Oh, this is what a person with aphasia sounds like. It sounds like you [chuckles]. And there's all, everybody's going to sound and come across differently because they were different to start with. Everybody's stroke is different. Everybody's level of impairment is different.

LAUREN: Mmhmm.

CHERYL: And we have the benefit of learning that firsthand. And I do think that it creates a lot more flexibility within the disability community than non-disabled people actually realize we have.

LAUREN: Mmhmm. I should say that I have spoken to other people with aphasia, including that girl who also lost her language at age 27. And she had a very different experience. Again, I assumed that other people with aphasia had had the same kind of inner and external silence. And I asked her, "But what about the quiet, though? You remember the quiet?" And she was like, "What are you talking about?" And I was like, "What do? Really? You don't remember when your internal monologue was off or mute?" And she said, "I never had that. It was always a frustration. I always knew the words I wanted to say. And then I would hear them stumble out incorrectly."

CHERYL: Oh, yeah.

LAUREN: And that's just not what I had. I did have apraxia of speech as well. I mean, I did have some earlier injuries. But that was in the acute stages. And I did have difficulties with receptive aphasia. Meaning like, I couldn't always hear when I was saying the words incorrectly. But in the first month or two, I became aware of self-correcting.

CHERYL: Mmhmm.

LAUREN: But that didn't mean that I understood the nature of my deficit, still. I mean, for months and months I would basically not know I had something missing until it was returned to me. Like, oh, I didn't realize I wasn't using verbs anymore. Or idioms. I'm still not good with idioms.

CHERYL: Oh my word. Yeah, mmhmm.

LAUREN: [laughs]

CHERYL: Mmhmm.

LAUREN: Yeah. Again, I had to try to like practice myself, teach myself how idioms work again. "I'll scratch your back if you scratch mine." Or "needle in a haystack."

CHERYL: I have trouble with the figurative language sometimes. Oh boy.

LAUREN: Mmhmm.

CHERYL: And I get into trouble on Facebook quite a bit in misunderstanding what people are saying.

LAUREN: Oh, really?

CHERYL: Yeah. Now, I am not the only one who misreads tone of voice on Facebook. A lotta people do. It's not specific to brain injury. But it is much, much, much harder for me to understand or recognize figurative language than it was. Not that this show is about me. OK, getting back to you.

LAUREN: The way we communicate at Connect, well often, people who come to Connect can't read at all. But it's a huge variation. Some people can read, but they can't write. People can write, but they can't speak. They can speak, but they can't write. But we do have to send communications out. And they're not entirely pictures. So when we send out emails, there's just a protocol. They have to be shorter. They have to have very active sentence structures. They have to be no long, winding sentences.

CHERYL: Mmhmm.

LAUREN: You bold words that are important: times, places, important bits of information. And a bigger typeface. And it can't be in some weird typeface like Comic Sans.

CHERYL: [laughs]

LAUREN: That should be out, outlawed.

CHERYL: Oh yeah, regardless of reason, Comic Sans should no longer exist. Thank you, Lauren. Oh my gawd.

LAUREN: Yeah, so I was really rolling the dice, like you might've like, "Well, I think Comic Sans is really funny!" [laughs] "Oh, sorry!"

CHERYL: Comic Sans to me is like a universal insult. Like, "Oh, this food is so disgusting. This food is Comic Sans. Aw, I can't eat it. It's gonna make me throw up." Yeah.

LAUREN: [laughs] OK. So that's how we use that language at Connect.

CHERYL: Mmhmm.

### **Writing "A Stitch of Time: Portrait of a mind in construction"**

CHERYL: So you've talked a bit about some of the exercises with your speech therapist. And one thing that your speech therapist did was get you into journaling to help you communicate more effectively. And this was in 2007. I believe it is now 2015. And you're now just finishing up your book called "A Stitch of Time: Portrait of mind in construction. And this book is due out in 2016. Talk to me about the motivation for writing this book and how the stories play out in the book.

LAUREN: It's hard to say how anything begins. We ruminate in so many ways. But the journals are a big part of the book, that's for sure. The first time I started journaling was actually long before, of course, my brain injury. But it was my speech therapist after the brain injury who sort of gently nudged me. And unbeknownst to me, it was often much better for me to write than to speak. So it was this golden word again, this golden phrase, rather, "compensatory strategy," was a very good, effective compensatory strategy because if I could write the word, it was easier to read it. If I write the word, it's easier to say it. And you know, so it was just a communication aid more than anything else.

CHERYL: Mmhmm.

LAUREN: But much like my lack of awareness about my really decimated vocabulary--I didn't realize I could only say 40 or 50 words--I didn't know how fractured my journals were, you know? I assumed that I was just [giggling] sort of, you know, putting some things down that were challenging. Or mainly I was just having something pretty normal. I thought of it as a very normal document. So I left Scotland probably about a month after my operation. My parents had been with me the entire time after the

rupture. They flew from California. And when I came back, I had to leave my PhD program in New York and my apartment and my boyfriend at the time and come back to my parents' home. But you know, really I had no idea how long that would take. I mean, really didn't know. I was like packing a suitcase in New York cuz I had a layover. The surgeons had suggested we didn't do the entire trip in one flight because of the inter-cranial pressure. I went to my apartment. And I kept thinking how many pairs of underwear should I be packing? You know, I had no idea. Like, how many pairs of underwear do you need for recovery?

CHERYL: [laughs]

LAUREN: So I just went back. And I did have to have a second brain surgery about six months after the first, to the same area. Unfortunately, I didn't mention this moment in the journals, so I can never give a date to it. But I think it was around the second brain surgery because I was worried, a pretty just worry, I think, that I could lose my language again. Because I was then told that it was the same area. And in an open brain surgery, anything could happen from epilepsy to blindness to you know, because of the location, losing more of my language abilities, starting all over. After six months of speech and language therapy three times a week, that's a little dis-spiriting. And when I woke up and had very little damage as a result of the operation, I looked back into the journal, I think out of curiosity more than anything. Again, maybe thinking now I'm done [chuckles]

CHERYL: Uh-huh, uh-huh.

LAUREN: And as I looked from page one, which was in late August, 2007 or early September, I mean they were, they weren't sentences at all. There was nothing like that. The words, it was individual words so unrelated to each other. You know, almost all nouns, nothing about my feelings or my environment. It's like words like narwhal and Nintendo and pine tree. You know what I mean? It was like it, it was just, it was, it was so distant, you know. It was like walking through the ruins of an ancient civilization, and you know I'm trying to figure out what was this for? Why did I feel like I needed to say this word? Why was this was the first thing I wanted to talk about? Why not anything about, you know, why wouldn't I write about my mom or my dad or my head? You know?

CHERYL: [chuckles]

LAUREN: Why these words? And then when it started to become sentences, they were, they were just so, they were so damaged, you know? But the content was really fascinating because one of the first sentences I wrote was basically saying I was fine [both laugh].

CHERYL: I love it.

LAUREN: It was like, OK, so I remember. I remember the first line of it: three week no problem [laughs]. I think it was actually longer than three weeks since my brain surgery, the first one.

CHERYL: Yeah. You know what? I have that journal entry here. It says: "Words 3 weeks no"

LAUREN: Yeah.

CHERYL: And the next line: "problem. Sleep. The cloud. After n in seem forever when words back is fever."

LAUREN: Yes.

CHERYL: And at the time you wrote that, you got all your ideas out on paper! That probably just looked fine and--

LAUREN: Fantastic!

CHERYL: Yeah.

LAUREN: [laughs] No, but like seeing that was just like, you know, beyond disorienting.

CHERYL: Yeah.

LAUREN: That was like the, the earthquake, you know?

CHERYL: Yeah.

LAUREN: That was the first time I think that I looked at it all and thought, "Oh gawd. If I was like that then, and I thought I was fine, what am I like now? And what will I be in the future?"

CHERYL: Mmhmm.

LAUREN: You know, I think that is one that I think is almost totemic to the entire experience. There are about four or five journal entries throughout every chapter of the book, just as you watch the mind sort of rebuild itself because you see it change from that kind of damage, that kind of sort of Dada poetry to sentences, you know? And they have mistakes. And it has things crossed out. But it's different, it's better, it's, it's it has a visible change at the sentence level, at the synap- semantic level, at the grammatic level [giggling], at the vocabulary level. It just all changes. I said it's hard to say how the genesis of things are. But because that was both a terrifying moment, right, of saying, "What am I like now? What will I be in the future?" But it was also a deeply curious moment. Whatever this is, it's interesting. And because language had always been at the forefront of my life as a PhD student, as an actress, as a person who loved words, it was a fascinating thing to be part of it. Seeing myself in part of something that was bigger than myself. I started writing about it. I mean, I was already writing about it. I don't think I knew what I was writing immediately. I don't know when that changed, exactly. But I think I did think I was gonna write a memoir soon after the second brain surgery, like oh, I could knock this out.

CHERYL: [laughs]

LAUREN: I'll write a brain book, a memoir! Which has changed so much, you know. First of all, I didn't have the skills that I thought I had [chuckles] to do such a thing. It's a monumental task for anyone to write a book. I want to say this to the world. No one would write a book if they knew how much time it takes.

CHERYL: [chuckles]

LAUREN: Thank gawd that we have that self-delusion because there would be no books on any shelves. That's not just my brain injury,

CHERYL: No.

LAUREN: although it is part of it, you know what I mean? And the first generation of it, I remember not wanting to use any sources, do you know what I mean? I remember thinking well, I don't need to have

any neurology or cognitive-shmakety-shmack [both chuckle]. I just thought, it's my story. I get to tell my story. And of course, you can. That's everyone's prerogative. I think storytelling is invaluable. And I wanna say much more about that, about being in a community of people who have very little language but a lot of story. But going back to the generations of the book, I completely reversed that position, you know. Whatever. I finished a first draft that looks nothing like my draft now. Nook [looks] nothing like my near-final manuscript. Cuz I came to love that stuff too. I came to be very interested in what [Steven Pinker](#) would say about or [VS Ramachandran](#) would say about or [Rosemary Varley](#) would say about it, you know? Cuz language is, it's a mystery. The brain is still a mystery. And language is, well, it's one of the biggest parts of that mystery: how language changes thought and vice versa, that's fascinating. It's a huge debate. It remains a very contentious debate, like can language change thought? And if so, in what ways? And you know, all sides of that debate are fascinating. I felt that as I got more language back, the nature of my thought was changing. And that is a such a complex thing that may have nothing to do with language at all. It may have just been some other brain systems coming on at the same time. But it's hard not to feel like language was part of it. And when I would plumb the depths of the way people would explore how language could change thought, I just felt involved and intrigued. I felt so at sea so often and so disoriented throughout my language recovery. I love being able to explore that and include that and having be part of it. So the book now involves a lot of my personal story. And it also just touches in little bits about what neuro-scientific communities, aphasia communities, therapeutic communities, medical communities might say about brain aneurysms and about aphasia in general.

CHERYL: Yeah, wow! You mentioned a minute ago that you were at sea. How do you navigate your storytelling for the non-disabled audience and still stay accessible to your peers with aphasia, including people who may have less fluency using for understanding or reading language than, say, you do?

LAUREN: Yeah, that's a challenge. It's a really big challenge. I mean, it's been wonderful to get so much of my language back, you know? I'm very grateful for that. But I was aware pretty early that the more sophisticated my language became in the book, the less accessible it would be to the community who I share this condition with, you know? That's a really major catch 22, you know? It's not something I relished, although I did think of it as a motivating challenge as well. So I've never been able to figure it out in the text of the book itself. I can't seem to pull back that the linguistic sophistication inside that text. But I wanted to create a companion for the book, basically, that was hugely accessible to people of all levels of disability, but especially people who have language disorders who wouldn't be able to read the book.

CHERYL: Mmhmm.

LAUREN: Because I was very lucky to be at some wonderful artist colonies on writing grants, including Ragdale, Yaddo, the Atlantic Center for the Creative Arts, Virginia Center for the Creative Arts--the acronym for that is VCCA--and VCCA in France as well. Those are the five. There's so many ways of describing these these communities. But, you know, they're well subsidized. And I was so lucky to meet--it's not just writers at these organizations. You're at a residency. And I would met, would meet a lot of musicians in addition to visual artists. And I was able to, this artistic cross-pollination is so hugely beneficial, especially because I wasn't able to go back to my life in New York. I wasn't able to be a PhD student again. I wasn't able to sort of pick up the reins of the life I had. Nor do I want to. But that had a lot of artistic stimulation. And being able to go to a residency for a short period of time and be immersed in that again was just, you know, hugely beneficial, very stimulating. And I made a lot of good connections there and really good friends, incredibly talented people. Yeah, they understand that I wanted to create--I was trying to create--I wanted to create what I was calling a digital book. Which I still

sometimes call it that. But I don't know what to really, the name is. It's just excerpts from the book, one excerpt from every chapter. So 12 excerpts in total, I hope. At the moment, there's only two that are done; one's in progress. That basically deal with sort of the emotional life of the book, the sensory life of the book so that there is a point of entry for people who wouldn't read. In fact, it will have my narration. But ultimately, that narration can be turned off.

### **Animated, orchestrated excerpts from the book on YouTube and the website**

So this multi-modality of musi-, visual elements, and narration can be disassociated from each other. So most importantly, if people have trouble hearing, if language is a problem for them, they could just have the story from my book to piece of music with the some beautiful art. And that means a lot to me, you know. And hopefully my collaborations are as helpful to people as I hope they can be. But my collaborators rose to the challenge. I mean, they did some incredible work. And they're different from each other. Every story has different people paired up with them. The first story actually has--the animator is also the violinist. She just happens to be a woman of many talents. But usually, they're two different entities. And I like that they're different from each other because that speaks, to me, that disassociation that often comes with a brain injury, like if I'm not that, who am I? You know?

CHERYL: Mmhmm.

LAUREN: And how many elements don't really congeal into a self again? Again, I think it's a beneficial thing. I think that a lot of people could really benefit from a little um, a little shake up of self.

CHERYL: [chuckles]

LAUREN: I think there's a lot of artistic value to letting every one of these artists have their version of the story, because I think it's just as valuable as what the text version is. And people with aphasia sometimes, once they're really familiar with material, they can layer something in. So after they have seen something 20 or 30 times, then they could add the text. But they don't ever have to add the text [chuckles].

CHERYL: Right.

LAUREN: You know, I wouldn't get offended.

CHERYL: Yeah, I watched them yesterday. So what you're talking about, there are two up right now on [your YouTube channel: Lauren Marks](#). So there were these short videos. And this is what you were referring to. Right now, there's two. And I hear your voice reading lines from the book. And I'm seeing this art come up that is someone else's kind of interpretation or experience of the words and then the music. And I'm going to make some Closed Captions for these two.

LAUREN: Yay!

CHERYL: And so that's one more point of entry for people with aphasia who maybe wanna turn the sound off and read the words or listen and read at the same time. Or for D/deaf people or hard of hearing people or English-language learners, or even me who, I just, you know, I don't know if somebody could diagnose something. But I just can't hack it. I gotta listen and read. And that's definitely--what's the opposite of improvement? What do you call? [chuckles] Oh gawd. What's?

LAUREN: Degradation?

CHERYL: Degradation. I'm definitely degrading.

LAUREN: [giggles]

CHERYL: So I could listen just fine in the past. But it's much, much harder for me. I don't have aphasia. But the videos were so beautiful. But I struggle keeping up with the words with the music playing. And so I'm excited to make some Closed Captions for those.

LAUREN: Yeah, I'm excited too.

CHERYL: Yeah, then I'll be able to watch it again and catch all the words. And so there's more opportunity to miss less and to access this stuff in different way. So that's really exciting. And your website too, also there are parts on your website where you can click and hear your voice reading what's on the page. It's so neat.

LAUREN: That goes straight to my father, who helped me set up that website. He and my mom have an advertising agency called [Pasadena Advertising](#) [chuckles], if anyone wants great work, my parents can provide! But no they, seriously, I couldn't have been able to do that without them. And they understood that I wanted to make it as accessible to, again the community who shares this condition with me, as I could. And you and I've discussed how I want to add more accessibles, more accessibility to it. I like this, you have something on your website called an AT Bar, which I wanna see how I can find something like that for my own website. But it was built in a different format. So I have to see what the IT gods can provide. But the Closed Captions will be a great addition. Actually, they've won a lot of awards for that website because of that accessibility and the way that things function on it. I'm still never satisfied, of course.

CHERYL: Sure.

LAUREN: You know, we tried to figure out the best way to have the speech-enable function be accessible and seen by people. And it's like a sort of bluing, sort of glowing neon thing in the upper left hand corner that's like do you wanna turn on the speaker or not the speaker? Do you wanna turn on the speaker, not the speaker? And it's done really artfully. But I think people don't see that. At the bottom of the page, it does say "some of these pages have been enabled for speech. And please click on the speaker icon." But people who can't read, can't see that. So they have to be with someone who reads that who sees that. I just don't like, I really don't like websites that talk to me before I wanna be talked to.

CHERYL: Yeah.

LAUREN: So I didn't want it to come on. I wanted it to be a choice.

### **Future projects: podcasting and book tour**

CHERYL: What is coming up in the next few months or around the next year for you?

LAUREN: Well, part of it is, as a result of you and I discussing the possible future. So much like those animated shorts and orchestrated shorts, I've been very interested, well not just--My story's really, really a very small margin in the aphasic story in general. You know, every person with aphasia has a very different manifestation of it.

CHERYL: Mmhmm.



LAUREN: And since I've been going to Connect and volunteering there, I've met so many fascinating people. And you know, the real discrimination that happens with people with aphasia is when their language is impaired, people assume that their thought is impaired. They assume that they can't think, you know? Because they can't speak, they can't think. Which is, it's deeply insulting and so misguided. It couldn't be any more wrong. You know, every once in a while there is someone who's had a traumatic brain injury or who had a major hit-and-run accident, and you know, they have other, concomitant symptoms. But that's not about their language. It's not their aphasia. If they have problems with their cognition, it's not about their aphasia. So there's this great prejudice that people just can't, they can't tell stories. You know, they lost their voice. And I found this to be so dramatically untrue. When I started volunteering there, a part of my main role is to just sit with people, have biscuits and tea. Punishing! The worst!

CHERYL: [giggles]

LAUREN: And yeah, it's like play time. We sit around. We have tea and biscuits. We tell each other stories. And some of the best stories I've ever heard have been there, you know, the most sophisticated minds, these funny people, intelligent people. And sometimes their language is very little, you know. And sometimes their language is much more fluent. But this kind of dysfluent storytelling just really impressed itself upon me. And I want to start a podcast with people with aphasia telling their stories. I have such great support with people within the community who really wanna do it, you know? They really want to tell some of their stories. And I want people to be able to not be off-put finally, when someone has a different type of speech pattern, but understand that that person is clearly communicating and that they have not just communicating to say, "I want milk." But they can tell you the story of like their first dog. I have to say, I remember there was this guy there. He told me this story of like his first dog. He is a great storyteller. His language is slow. But he has a lot of vocabulary, and his sentence structures are pretty good. [giggles] And he told me that the dog's name was ruff. And I thought, oh you know, ruff, like ruff, ruff, ruff!

CHERYL: Uh-huh.

LAUREN: But actually, it was because of this tuft. He explained because he's completely a sophisticated thinker, it's like, "No, no, not ruff. Like ruff" [giggles]. I was like still not sure. So he explains to me that the dog has this tuft of white hair all the way around the neck.

CHERYL: Oh!

LAUREN: Like ruffles.

CHERYL: Yes! A ruff. A neck ruff.

LAUREN: Yeah. And like I just think that details like that, it's like, no one can mistake that as lack of intelligence. I mean, the guy not only told me an amazing story about his dog and his father, what he was as a young boy, but also corrects me when I think I know what the story's about! [chuckles] No, I didn't! The dog was not named ruff!

CHERYL: Right.

LAUREN: Ruff, like a ruffle.

CHERYL: Like a cravat, like a very distinguished cravat.

LAUREN: Yes!

CHERYL: So you're going to be moving toward developing this podcast. And the book, are you gonna do like a book tour?

LAUREN: I would love to do a book tour [giggles]. I definitely will do a book tour. I don't know what it will look like. I think it will be Spring of 2016. But everything is outside of my control once these final bits of edits are finished. And I think it's Spring of 2016. Hopefully, the UK rights will come right on the same heels of it. That's what my great goal is. And I would go to you know, all the cities that I have good connections and loved ones and crash on couches, go to great bookstores, drink a lot of coffee, break some biscuits [giggles].

CHERYL: That's amazing. Tell folks where they can find you online.

LAUREN: Well, everything is sort of uniformly compact. You can find everything on the website, I think, which is [www.AStitchofTime.com](http://www.AStitchofTime.com). And for people who think, "Ah, a stitch in time!" No. It's a stitch of time, which that does speak directly to that issue with idioms and it's also a sort of a nod to not being able to do plug in the exact word to a phrase. But yes, you can see all of the articles that I'm writing right now. Anything about the podcast will definitely be posted there. The videos are there under News and Events. They'd be under Shorts. And you can look at the journal pages themselves. You can see an image of 12 of the months of August 2007 to August 2008. And you can, actually, a couple of those journal entries you can click on. And then you can see how that develops into actual parts of the book. So you can sort of watch that generation, that development of an idea that was written down, gosh-- now seven and a half years? Oh my goodness. Seven and a half years ago, what the seed was and what it becomes as prose now.

CHERYL: Yeah. Wow. Well, I'll tell you, Google this morning just refused to believe that I was searching for A Stitch Of Time. And it literally asked me, "Did you mean a stitch in time?" And I was like, "Ugh, no, Google. I know what I said."

LAUREN: Lord Google [chuckles], he wants full obedience. Let Lord Google know.

CHERYL: [chuckles] The good thing about the way Google and other search engines work is that the more active you are, and the more people who are going to this site, the more Google is going to accept, "Oh, OK. People really are looking for A Stitch Of Time. OK, OK. I got it." Fortunately, even though it asked me that question, your website was still, of course, the first hit. But I had this moment. I was like, "Look, you don't know me."

LAUREN: [laughs]

CHERYL: "And this language is not incorrect. Why?" And you might be able to tell here, I've got some baggage. But I was like, "Do not assume that everything I say and type is automatically incorrect just because I've had a brain injury. Stop it, Google" [giggles]. So I was having a little bit of a baggage moment. But yes, A Stitch Of Time.

LAUREN: Your baggage moment I find delightful.

CHERYL: Anything else that you would like to share with the listeners today?

LAUREN: [chuckles] I'm just really grateful that strange forces brought us together, people we knew sort of tangentially sort of pushed us together from Portland to London. And I'm just, as soon as I found out about what you do and how you do it, it's been hugely exciting for me and inspirational. And my worldview is just cracking open a little bit in really great ways. So I hope it is something we keep up at because having a memoir is in so many ways a solipsistic endeavor. I think this memoir speaks to many issues. And I think since aphasia affects 1 out of every 300th person, it's certainly a book that, it could be valuable. And not a lot of books have been written by people with aphasia. A lot of times they've done it in conjunction with their spouses. And even so, that's a small, limited group. So I think that yes, it's valuable. But it's so internal. And the volunteering I've been doing really makes the world just so much more interesting. And people like you who open up these conversations. I often call these people around me these "unheard voices."

CHERYL: Mm.

LAUREN: In fact, that may be what I call my podcast.

CHERYL: Yes!

LAUREN: But like every time someone is paying attention to the unheard voices, I'm hugely invested because those are the ones that we need to hear. These are the ones that we want to hear! We don't even know we want them till we hear them!

CHERYL: Yes.

LAUREN: Part of me is bitter, bigger and better because there is something I didn't know anything about but still feels human, still feels related to me. Again, I'm really glad that I've worked on this book. But I really look forward to the next steps in which I can be more useful to a much larger community and because, you know, that's interesting. That's much more interesting than talking about myself.

CHERYL: [giggles] I mean, what you said a minute ago, it's, the feeling is mutual. I'm so happy about the smooshing together. And when I first was watching, you gave a brief lecture at the 50th anniversary of the Communication Sciences or the Speech Therapy department at Cal State Northridge.

LAUREN: Yeah, that's the same place where I audited the Aphasiology course.

CHERYL: Yeah, I watched that. And I was like, "Man, I could email her. But this lady's never gonna respond to me."

LAUREN: [chuckles]

CHERYL: "Well, I really want her on my podcast. UGH!" And I just didn't know what to do. And it was like, I think, an hour later after I watched that, that you just emailed me. And it was the most bizarre thing. And it's just so wonderful because I think we're on a lot of similar, what's the word? Thing?

LAUREN: Wavelengths.

CHERYL: Thank you.

LAUREN: That's a radio word, isn't it?

CHERYL: Yeah. Wavelength, yes. It's a speech therapy word. It's a linguistics word. It's, it's light. Light has wavelengths. It's great. You know, I also have an MFA in theater. And I left that behind to do speech therapy as a speech therapist. But then I didn't. I became a patient. I started out in this arts world, making short films about myself. My story, my story. I have to tell my story and get my story out. And I've just moved away from that so much too. I came to the same, I think, understanding that you did that it feels great to get my story out. And I hope that this thing that I produced is valuable to someone else. But I gotta take this time and make the space to put other stories out there too. And so I think we're making that shift kind of at the same time, too. It's really pretty neat.

LAUREN: Well, let's keep doing it together. I like that.

CHERYL: Let's do it. I love it. I love it. Lauren Marks: thank you so much for coming on the podcast to talk to me today. You will definitely be on again in the future. And...[giggles] what else does someone say to say goodbye? I can't remember the social rules.

LAUREN: [laughs]

CHERYL: What else do you say?

LAUREN: Well, it's been such a pleasure. And I really look forward to coming back as soon as possible.

CHERYL: Wonderful.

[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](http://WhoAmItoStopIt.com).

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