

Just Being

A bus full of retards, a driver who no doubt harbours a sick fantasy of crashing the vehicle just so he can to put us all out of our misery, a teacher who prefers the responsibility of keeping her Instagram on trend to keeping her charges in check and a couple of aides whose idea of help seems to be to shout slowly, roll their eyes and plug us into our iPods at the first sign of an impending conversation. What a day we're having. Our destination? A playground with a disability swing and low rise climbing equipment. I mean. WTF. We're teenagers. We might not have all our body parts attached or our brains wired the right way but that doesn't mean we don't want to do teenagey things. Like look at our phones. Or stay inside and just be.

Anyway, to make matters worse I am sitting next to Edward. He thinks he's so cool. He wears ridiculous clothes, bow ties and waistcoats, pants with turn ups and shiny leather brogues. He wears a hat, one of those fedora types. And Wayfarers. I mean he is blind, but come on. Wayfarers? And then there's his stick. Not just a white cane, no. A full on walking stick with a curved handle so he can hang it from his arm. It is white. But it's been custom made for him. As he reminds us at every given opportunity.

So here I am, stuck on the bus with Edward Cane the First heading to a kiddy park. And I'm feeling all shades of awesome. He hasn't acknowledged me but he's tapping the cane on the floor of the bus in a rhythm that sets my teeth on edge.

"Can you not do that?" I huff out the words. It's half question, half order.

"It's Morse code." He huffs out his words. Half statement, half arrogant.

"For what?"

"Where's the ejector seat."

I laugh so hard that I end up coughing and one of the aides scoots up the aisle of the bus and appraises me. I think that if I keep hacking away I might be excused but she simply hands me a bottle of water and returns to her front seat.

"Cold?" Edward asks.

"I'm hot actually. There's no air conditioning on this bus."

"I meant, have you got a cold?"

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I laugh again. A wheeze, really. “Oh! No I’ve got CF.”

“That sounds pretty cool when you say it as an acronym. Not that I think Cystic Fibrosis is cool. Because I really don’t. But CF. It’s so much trendier than blindness.”

I snort. “I didn’t realise there was a spectrum for trendiness when it comes to disabilities.”

“I think we just made it up.” He taps his cane again. I notice his hands are trembling.

“What’s that code for?”

“I wish I could see you.”

I turn pink. And I’m glad he can’t.

The sun decides to blaze down on us the moment we are eliminated from the bus and made to play like good girls and boys. I have to wear a hat. A borrowed one. A stupid cap with a juvenile logo of Big Bird on it. Anyway, the one person who would laugh at the irony of my situation can’t see me. Before I can bemoan my headwear situation any longer I get commandeered into helping some of the other kids negotiate the flat ropes course. By the time lunch rolls around I’m too pooped to do anything but sit under the shade of a tree and just be.

When Mum first suggested that I try to the respite thing I suspected it wasn’t really just for my own health and wellbeing.

“Lexi, I’m worried you don’t hang out with people of your own age.”

What she really meant was that my able-bodied friends didn’t want to be held back by their CF friend who got sick, who couldn’t go where they were going, and who would die way before they did if I didn’t get to the top of the transplant list soon. And then of course, she and dad wanted a break too. It’s tough parenting a teen CF

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sufferer. Excessive hormones and attitude combined with not enough airways to breathe is a shitty situation.

I come on these excursions a few times a year. Park, beach, shopping centres, that kind of thing. One time, in the plaza, we managed to lose Lincoln, this big guy with Down Syndrome. It was Edward Cane the First that found him, actually. At the Krispy Kreme outlet.

“I was led there by my superior sense of smell. Losing one sense often heightens the others and the scent of the deep fried batter combined with the strawberry icing was overwhelming. When I got to Krispy Kreme, big Linc was shuffling around, unable to choose.”

“How did you know it was Lincoln?” the teacher asked.

“His left leg is about a centimetre or two shorter than his right and so he limps a little. The sound he makes when he walks in those soft-soled shoes of his, which I believe might be Chuck Taylor All Star Converse sneakers, because of the suction and tread, was a dead giveaway.”

“That is astonishing,” the teacher said.

Even Gerard, the Aspergers kid with an IQ in the 150s, was impressed. He said ‘Edward is excellent’ as an answer to all the questions he was asked, for seven months in a row. And Edward became the sensation of the group.

The tree is a great shade-giver and it tempts me, as shady trees do, to close my eyes. My head grows thick with mid-afternoon fatigue and I don’t hear him sit down.

“Lazy, aren’t you?’ He prods me with his cane.

“Jeez, you startled me,” I squeak.

“So I hear. Are you still short of breath?”

“Are you still blind?”

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“Touche.”

“Are you really this pretentious all the time?”

“Are you really this bitchy all the time?”

I give him a look.

“I know what you’re doing.”

“Tell me.”

“You’re looking down your nose at me, or rolling your eyes, or raising an eyebrow.”

I shift my gaze and lower my eyebrow. “No I’m not.”

“And you’re a terrible liar.”

“How do you know I’m lying?”

“Your eyes shut a little and you have a rising flush that creeps over your chest.”

I move my hand to cover the exposed skin at the V of my t-shirt. “How did you know that?”

“You just told me.” He laughs and I feel irritated. At my own gullibility. I cough.

“Actually,” he begins again, his tone a little contrite, “your breathing shifted and you wiped your hands down the front of your pants. Denim skinny or slim fit jeans, maybe black.”

“How do you do that? The thing with the clothes. Lincoln and his Cons.”

“A magician never reveals his secrets.”

“You’re no magician.”

“I’m cut to the core by your negativity, Ms Westaway.”

I giggle. And cough again.

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“Are you all right?”

“I’m fine. I just want to go home now.” I stand up.

“Home to do what?”

“I dunno. Just be.”

We walk off, his cane tapping the way in front of us. He switches it from side to side, skimming across the tufty grass clumps that grow either side of the path. It makes a comforting rythymical ‘snicking’ sound.

He turns his head vaguely towards me. “I do that too.”

“What?”

“Just be. At home. When I’m just being I lay on my bed and in my mind’s eye I see across oceans with mountainous swells and pink strips of beach, I see volcanos erupting with their fiery spume and rumbling black smoke clouds, I see Wedge Tail eagles catching the thermals and the wind ruffles their brown dotted feathers, I see a girl with honey-coloured curls and green eyes wearing black skinny jeans and a pale lemon v-necked t-shirt who doesn’t know how lovely they are.”

I dry-swallow and my throat is raspy.

“Lexi,” he says. “I can’t see you but I notice you. I noticed you the first time you joined our group.”

I say nothing. There’s a bunch of the other kids yelling at the barbecue shelter. The bus driver hasn’t opened the doors yet.

Edward stops and sticks his cane out towards me. “I’ve embarrassed you. I’m sorry.”

I touch my chest again. Then whip my hand away. “It’s okay.” My voice is loose and my head is wavy, like I’ve been on a boat for hours.

The doors whoosh open and I climb on. I don’t want him to sit next to me. But I do. His cane taps then stops next to my seat.

“Ms Westaway, I presume.”

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“How?”

“Your shampoo or maybe your conditioner. Apples.”

I chew my lip. “Both. Apple Fresh Nature’s Own.”

“Right. And you use some sort of lavender body spray.”

“Dove.”

“Right. And you always sit in this seat.”

“Oh.”

He laughs. “Can I sit next to you?”

“I guess.”

He settles in, shifting his coat tails and pulling up his trousers. He tugs the Fedora down.

“Why do you wear those clothes?”

“Do I not look good in them?”

“I didn’t ask that.”

He turns his head towards me. My cheeks burn, even despite my brain telling me he can’t see me. “When I was younger I had a thing about British shows, you know, Jeeves and Wooster, those gentrified detective shows, that kind of thing. The men always seemed so well-dressed. Before...” he touches his sunglasses, “I wore bog standard boys wear. Trackies and tees. Jeans. But after,” he clears his throat, “after, I decided that I didn’t want to be that boy anymore. I needed a point of difference.”

“And being blind didn’t cut it for you?” I look out the window, not sure if I’ve overstepped the mark.

He chuffs. “Why can’t I be suave and blind?”

I watch the town whiz by, aware that I can see all the life happening that Edward can’t.

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“You can. You are.”

He smiles. “And you are pretty and air-challenged.”

I giggle. “How do you know what I look like?”

He shrugs. “You’ve always sounded pretty.”

“That is stupid. You can’t possibly...” I’m cut off by his hands coming towards my face. His touch is tender, the skin on his fingers impossibly soft. His hands shift over the contours of my features and I feel revered. He lingers with both thumbs on my chin and his other fingers on my cheeks.

He leans forward to my ear. “Beautiful.”

Gerard kneels up on the seat in front of us and yells, “Edward is excellent.” Lincoln on the seat over the aisle starts clapping and that sets the others off. The last kilometre home is all whooping and cheering and applause. And a bit of crying (me).

We grab our belongings from the lockers in the day centre. Cars are pulling in to the car park already. I take my backpack and hook it over my shoulders. My parents are always late. I sit on one of the sofas in the foyer.

“My Dad’s never on time either,” Edward says. He sits next to me. “Are you on the transplant list?”

“Yes. It’s the only long-term treatment.”

“Doesn’t it bother you that you’ll be just another ordinary teenager?”

I raise my eyebrows. “I would kill to be an ordinary teenager.”

“Well, make sure your victim has a good set of lungs, then. That’s a pretty sustainable model to boost transplant lists, I suppose.”

“You’re a sick boy, Edward.”

“But I mean what I said. I’m not sure I want my sight back. I would feel like I was just another one of the crowd.”

“So you’d rather be defined by the things you can’t do for the rest of your life?”

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“That’s not what I’m saying. I just feel that I’ve become the person I was meant to be. And that wouldn’t have happened if I had my sight.”

I see his point. His blindness has given him the opportunity to be a little left of centre not just with his dress sense but with his personality. Dare I tell him that he only really gets away with it because he’s blind?

“You think that people treat me differently because I’m disabled?”

I open my mouth to refute his allegation. But I feel that flush creeping over my chest again and I bite my tongue. “No.”

“Liar.”

“Magician,” I counter.

He laughs as my parents pull in to the parking lot. I wave at them and go to pick up my bag. My mother, so transparent, holds up a hand.

“My mother is currently pretending to take a phone call because she sees I am talking to a boy.”

“What would she do if she sees you kissing said boy?”

I blush so quickly that I’m sure he’ll be able to hear all my veins opening and my blood hissing to the surface of my skin. “But that’s not happening, so it’s a moot point.”

“But if it could be un-mooted, would she be shocked?”

“Edward...”

“I’d like to kiss you. But only after you get to know me a little better. Does that sound like a plan?”

“I guess so. I’d better go.” I stand up and look through the glass doors. Behind us the workers are cleaning up, vacuuming and wiping the tables.

“Is she off the phone?”

I look back at my mum. She grins at me and nods to Edward.

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“No. Would you like me to wait until your Dad comes?”

“I wouldn’t want to impose.”

“You wouldn’t be.” My mum gets out of the car and strides towards us. “Oh God.”

Edward taps his cane. “That was Morse Code for holy shitballs my mum’s going to embarrass me.”

I groan.

“Lexi, aren’t you going to introduce me to your friend?”

“This is Edward. Edward, this is my mum. Judy.”

“Did you both have a nice day?” I’m so glad Edward is not able to see the cheesy grin plastered over her face.

“The excursion to the park was perhaps a little underwhelming, in terms of activities to choose for our age group, but the company today was most stimulating.” He looks towards me and I press my teeth so hard together that my jaw cracks.

Mum looks so happy that her smile could light the Sydney Opera House. “Lexi never tells us about these trips. She just disappears into her room and that’s it.”

“Ah, but that’s the best sign that she’s enjoyed herself, Mrs Westaway.”

I frown and look from Edward to mum.

“How so?”

“If Lexi is happy to just be in her room then I would suggest that all is well in her world.”

Mum’s smile flickers a little. Her silence is all he needs to carry on.

“Tonight I will spend all night in my room, just being, such was the high level of satisfaction gleaned from the excursion today.”

I can’t help but smile. Mum is floundering. Edward is being excellent and I can feel a whole evening of just being coming up.

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Mum goes back to the car. Edward's Dad's vehicle pulls in. He stands up and leans on his cane. I turn to say goodbye.

He talks first. "I can hear you smiling. What are you thinking about?"

"I'm thinking about oceans with mountainous swells and pink strips of beach, I'm thinking about volcanos erupting with their fiery spume and rumbling black smoke clouds, I'm thinking about Wedge Tail eagles catching the thermals and how the wind ruffles their brown dotted feathers, I'm thinking about a boy with black hair under a fedora, with broken eyes under a pair of wanky Wayfarers, with long legs under baggy tweeds, and with a good heart under a white shirt and plaid waistcoat."

"Have a nice evening, Lexi Westaway."

"You too, Edward the Magician."

He erupts into laughter. "I have a confession."

"Oh?"

"I always ask the aides what people are wearing. The only magic is how long I've been able to get away with it. And when I found Lincoln at Krispy Kreme he was actually ordering a six-pack of iced rings. I heard him. Have I gone down in your estimation now?"

I shake my head, knowing he can't see me, but feeling very much like he knows what I'm doing. "See you next time."

"That you will. And wear that shade again, Lexi. It suits you."

"I will. Enjoy your evening of just being."

"Just being just became my new favourite thing to do."

Mine too, I think as I strap the seatbelt over my shoulder.