RUNNING MCOY'S

By Heather Summerhayes Cariou

Some time when the river is ice ask me whether what I have done is my life... What the river says, that is what I say. ~ William Stafford

Up on the Ottawa, back in the day, they called him "Disco Jeff." A tall skinny white guy with a bona fide 'fro, Cystic Fibrosis and a garrulous smile. He's a river guide, my brother.

Certified in White Water Rescue. For 10 summers he ran that river at 50% lung capacity, solo-kayaking and bringing screaming tourists safely through rapids with names like *Coliseum*,

Butcher Knife, Hell's Half Acre. Ask him about the fat lady who swam McCoy's four times. Ask him about the Chinese girl who out of nowhere sang Over the Rainbow in impeccable English as the raft languished in flat water beneath a topaz sun, her sweet, soaring soprano burning into memory. Ask him how to give a F.O.G. talk.

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Almost no one up there but his boss knows of his condition. He does his treatments in his tent and sleeps 17 hours after a day's work. Otherwise he's a river rat like any other, wrangling clients as they shiver in the chill morning shadow of White pines, waiting to grab their paddles and jump into his raft, waiting to take the ride of their lives. He does the Morning Safety Briefing, otherwise known as the F.O.G. talk. *Fear of God*. He describes what the day will look like on the river, what the plan is for the morning, when rafters can expect to stop for lunch, like that. Then he notes the risks that come with whitewater.

"Remember that you're out in nature and the river changes by the minute and nature can be unpredictable. This isn't some little joy ride at Canada's Wonderland. Things may happen today that no one in the boat can predict, and those things come with consequences. It won't be anyone's fault, it'll just be the way the day unfolds. The raft could flip. Someone could fall out. Okay, the point is that someone could sustain serious injury or die. You can sue if that happens, but you can't say no one warned you. If someone goes overboard, don't try to grab them or they'll pull you in the river. If you fall out, I'll toss you a Throw bag to help you get back on board. Simply put, a throw bag is a bag filled with 60 feet of rope. I'll shout to get your attention and make eye contact, and then I'll toss the bag at your head. If I actually hit you it means I've made a great shot. You grab the rope and I'll pull. If you can't get to the rope then I will yell, "Don't swim over that way, it's Killer Fang Falls!" Just kidding. I will say, "Swim this way, swim this way, and you will calmly swim back toward the raft." So yeah, I'm saying you could get stuck under a raft or break a leg or get a head concussion – but at the end of the day you'll be able to say you had THE BEST TIME EVER!"

He hands out release forms they must complete, reading the text aloud as required by law. He checks each form before loading the bus to make sure they're all properly signed. Every now and then, he sees that someone has crossed out the word *die*.

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My brother trains me like a river guide to be his primary partner in care. The language of the river becomes our dialect. Born 10 years apart, we live 3,000 miles apart. Between us we share another brother and the memory of our remarkable sister who died young but outlived her prognosis by sixteen heart-scraping years. Our parents are still living, but I'm the one who will slay the dragon, as the paddling term goes. Down front, feet against the thwart, torso hanging out over the edge, paddle deep in the water. The Paddle Captain shouts commands - *left paddle, right paddle, hard forward*. The Dragon Slayer quickly responds and the others follow her lead. There is no way, my brother warns me, to slay the dragon and come through it dry.

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On the last day of August 2018, my brother spikes a temp of 103.6. He stashes his oxygen concentrator behind the driver's seat of his red Jeep Cherokee, threads plastic tubing over the rear view mirror and drives over the Malahat to the hospital an hour away. Two days later he Facetimes me from his room on 8 North. I take one look at him and head for the airport. Next morning we trigger his listing for double-lung transplant.

Ask him what it's like to sit waiting at the top of McCoy's. Ask him how to run Phil's Hole.

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So you're lined up at the top of McCoy's. If it's peak season there'll be a string of rafts waiting to go along with a few kayaks. It's First Rapid, there's a long day ahead of you and a bunch of groups are lined up behind so you're not going to scout you're just going to read it on the fly. There are two holes on McCoy's. Sattler's on your left and Phil's on your right. If you're rafting, you aim to shoot straight across Phil's Hole. The thing about rafting Phil's is that you won't know you're going to make it over until you're right on top of it. If for some reason you don't make it, you'll hear the *Oh Shit!* command which means the raft is going to flip and you're going to swim. My brother says you never want to hear the *Oh Shit!* command.

If you're going it alone in your kayak, you've got to thread the needle between Sattler's and Phil's. The tongue at Phil's moves right to left and the thing is, depending on how high the water's running, you might have to take a piece of Sattler's to avoid Phil's. You have to skim the eddy line on Phil's and try not to get caught.

The point is when you're running McCoy's, whether in a raft full of people or alone in a kayak, there are things you need to know - and a lot you can never know - about getting past Phil's Hole. There's always the risk of a beat down. You just have to take your chances, don't give up your paddle and hold your line.

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His work is to breathe. His work is to hold his line, get through this one moment of pain and on to the next. His work, he says, is not to think. His eyes follow the ocean freighters in the distance out his window, steaming through the Strait of Juan de Fuca to the Pacific. His eyes follow the traffic on the road beyond the parking lot. He says he wishes he was out there on his motorcycle.

"It's a million dollar day out there and I'm being forced to waste it."

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What we're listening to in our encampment on this rainy afternoon on 8 North: Relaxing Hang Drum music for Meditation and Yoga.

"Where are we on the river?"

"We're not on the river yet. We're on the bus on our way to the river."

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My work is to hold and to be his legal and metaphysical Power of Care. To advocate when necessary but not rob him of his own voice; to be his pain-in-the-ass big sister, mind-reader, jester, listener, keeper of the stories he needs to tell that remind him who he's been on this earth. Some days my work is just to witness, to *be with*, present to his suffering as he sits up and bends forward and grabs the bedtable, holding onto the pain and the *cry* of pain that would pierce the stale air but is held, held, held as he hangs on, quivering like a branch of aspen. To run

down the hall and fetch him ice water. To run downstairs and phone upstairs and tell him, *Good Earth has corn chowder. They have bean and lentil stew*. To bring this food up in the elevator and watch him eat, praise God, because he is SO THIN, he is thinner than a soda biscuit, he is a wafer. He lifts the cover off the plate on his dinner tray and we stare at the whatever-it-is-we-can't-tell covered in a feeble gravy. He says, "I feel bad not eating it, knowing someone has worked so hard to steam the shit out of it."

To make a run to Best Buy, get him a fan/air purifier, a soft blanket, *real* pillows and a small night lamp, bring them back to his room, hear him laugh and say, "What, you didn't bring wallpaper?"

To have him look at me and say, "You're paddling too hard."

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I watch him sleep. I watch him stare. I watch the river start to run dry.

I watch myself run out of things to say or do. The worst thing, besides the fact that he might die, is that I'm powerless to make it better. He knows he's almost out of time. He's begun to think the call's not going to come. I'm free to believe whatever I want, he says, I'm just not allowed talk about it, at least in front of him. Each night I leave the hospital and gulp enormous breaths of air that tastes so sweet it brings tears to my throat. I look skyward and call silently on God. The almost empty parking lot in front of the E.R. is covered with a damp, glossy sheen. I cross in search of a cab. I do not allow myself to feel hopeless.

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This night, I walk out into a wall of sound. The air vibrates like standing waves at the end of a rapid. Out beyond the building's silhouette a bright light ascends, other worldly, like an

alien ship. It's a medivac helicopter, heading off through smoke-blue clouds above the Strait towards Vancouver. When Jeff gets the call, that's how we'll go.

"GOD," I scream suddenly, stabbing my finger at the sky, "I want to be on that chopper with my brother. MAKE IT HAPPEN!"

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Sunset, two days later. He sits stone-faced in disbelief, staring through the window of a Medivac high above the Strait. I hold his arm. The sun pours silver through the smoke-blue clouds onto the water far below, glinting off the islands as we pass over them. Breathtaking. It feels as if we're flying through eternity.

Thank god I made him get his hair cut this morning.

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They put down at Vancouver International and transfer us to a waiting ambulance. We are slightly pissed we don't get to land on the hospital roof and watch everybody run like *Grey's Anatomy* to meet the chopper. The surgeon and his right-hand-man are there to greet us at the 12th Floor Chest Center. The team immediately begins to prep, pulling out my brother's old picc line and putting in a new one.

My brother winks. "Watch out. We're going to get the F.O.G. talk now."

The surgeon doesn't like to transfuse, danger of blood clots, hoping they won't have to. He has a live donor. The match is good on paper but the surgeon won't know for sure until he eyeballs the organs. The donor is tall. That's important because my brother is 5'11" and he needs lungs long enough to fill his chest cavity, which they intend to lavage within an inch of his life. I imagine they'll have to scrape his old ones out with a melon baller. They hand him a release form. "Sign here." He does not cross out the word *die*.

Around 8pm they roll us down to the pre-op staging area. It is vast. It hums. Not a lot left to say. We are lined up at the top of McCoy's. Nothing to do but wait our turn. My brother owes his spirituality to the Anishinaabe. He wears Mother Turtle and Mishipeshu, the great river panther, carved from bone, on a leather cord around his neck. He takes them off and hands them to me for safe keeping. A man in the next row keeps shouting and trying to sit up. The nurses keep shouting at him to lie down. As many patients as are waiting to receive new organs, that's as many people who have died or will die tonight and give them. Transport arrives. The surgeon has eyeballed the lungs. They're good to go.

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Support comes from shore. When you're out there, says my brother, you're on your own. It doesn't matter whether you're in a raft or a kayak. If something goes bad you're on your own; everyone else has to react from somewhere else, they're not *there*. They have to call the Safety Kayaker to come out, there'll be Throw bags tossed, somebody positioned and waiting downstream for you to flush through. There's always someone on the shore supervising and they don't do anything except monitor the situation. The doctors will be coming out in the kayaks. They're part of the crew, saving everybody. They're all the guides and professionals that are there to make sure nobody drowns. I will stay on shore to run command, shouting *Get the throw bags out there asshole! Get out there and save a couple, kayaker!* It's my job to be aware, to stand in an elevated position so I can know what's going on. In a rescue situation they'd put a rope circle around me and I wouldn't be allowed to leave. Whoever's running command in a Rescue, they can't touch anything. They have to stay in one position where they can get fed

information and tell people what has to be done. People bring them coffee and sandwiches but they can't leave their spot, they must stay vigilant, because something can happen at any time.

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He flushes through. After he's been extubated, he asks me if I've ever had a perfect moment.

"You know, like when you're alone in your kayak on the lake just when the sun's just coming up, and everything is absolutely still?"

Or when you're waking up to Resurrection. A few timeless seconds floating in deep silence, dreamy and full of wonder; before the curtains stir and your eyes are drawn downward to the hustle of green-scrub-clad legs; before you sense the low buzz of ICU and hear the cricket chirp of your own beeping monitor, before the thought forms, *Fuck! It worked!* Before you are thrown back on the Ottawa at high water, the river plunging beneath and *oh shit!*, you've caught the eddy on Phil's Hole.

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For weeks and even months post-transplant, it's Groundhog Day on McCoy's. First a bloodstream infection two days post. His old nemesis, B-cepacia. Not a complete surprise, just a devastating one. 10 days of delirium. The year? 1918. The place? An airstrip in Surrey, England. His IV pole looks like the chandelier from *Phantom of the Opera*. We're told the protocol is historic. One doc strolls in, says, "We're giving you everything we have in the building. It will either save you or kill you," turns right around and walks out.

Next up, 12th Floor Chest Centre and C-diff. He shits and the nurses clean him and change the sheets and he shits and the nurses clean him and change the sheets and he shits and

the nurses clean him and change the sheets and he shits and the nurses clean him and change the sheets and he is painfully, shamefully, gratefully aware of their patience, their tenderness and good humor. He shits again, like a baby, up his back, down his legs, and the nurses clean him and change the sheets.

Reverse isolation. Gown, glove and mask. Gown, glove and mask. Yellow polyester gowns with ties in hard knots or missing altogether. Everyone looks like Big Bird. Blue latex gloves. Blue and white paper masks with tidy pleats. No place to hang my scarf and jacket so I bundle it into the room with me along with my tote bag.

He sees only the whites of his caregivers' eyes; a specimen pinned beneath the Medical Gaze. Their I.D.'s are smothered by their Big Bird costumes and they are bad at introductions. Their lips move like earthworms behind their masks as they perform stiff, muffled monologues. Sometimes they stand five feet away just inside the door, shouting, merely holding a mask over their mouths. No one ever sits down with him in the raft.

Everyone addresses him as Earl. He says repeatedly, "That's not my name. I go by Jeff." It doesn't matter that I've posted a sign saying, *Welcome. My name is Jeff.* They argue as if he doesn't know that *Earl is your legal name!*

"No. That's my legal fiction, the name the institution wants me to use. It's not the name I've gone by all by life or I'm known by in my community, and it's not *who I am.*"

I print pictures of him in his kayak and on his motorcycle and tape them to the front of his door so people know before they enter, if not his name, then something of the man they will encounter beyond transplant, c-diff, diabetes and kidney dysfunction.

My brother is a man who's lived in solitude for over thirty years, for the most part physically quite untouched. The months of touching he endures now in service of his care, intimate in the extreme, feels close to torture. I enter his room. Lying in the dark, he turns his face toward me. His eyes glitter, silvered with pain.

"They are *at* me," he cries out. "They're just *at* me all the time and they won't leave me alone." Like birds pecking.

Later he asks me to photograph his scars. The proud flesh braided in a line above his pecs. The spidery red blotches on either side where he was punctured by the chest tubes. The purple hematomas on his arms and neck where lines attached. He doesn't want to see the pictures. He just wants a record.

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What we're listening to in our encampment on this rainy afternoon on 12 West: PAIN by Three Days Grace.

"Where are we on the river?"

"Can't get past McCoy's."

Cepacia's back. Multi-drug resistant. If nothing works he has ten days, and they don't have anything that works.

For weeks now, I've been getting ready just in case, staying up well into the night watching what I call Reno Porn on TV and piling Throw bags. I have about 50 pounds worth of bio-medical research on antibiotics and bacteriophage therapy. I'm prepared to run command. Tie the rope circle around me and get me some coffee, dammit!

"Get something out of a Phase 2 trial in the U.S.," I say to his docs. "I have a print out of the latest research if you need it." I am very compelling. They squeeze a lot of balls very hard on both sides of the 49th parallel. Something is found. Something is flown in. Something saves his life.

I get him back to the apartment on home I.V. for Christmas. We run two lines three times a day and change them every night. They bolus him five times in one week, because his Tac levels are too high. We end up re-admitting him with acute kidney failure.

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We're both beyond our limits now, fighting with each other. I write *Keep An Active Blade in the Water* on his white board. He shouts at me to "Stop with the metaphors!"

These are my sins: I want to talk about feelings and he doesn't. My ego is too involved. I talk him in circles. I won't let up. I did the Cotazyme wrong. I paid the Telus collection bill when he asked me not to.

What can I do? I can make him Campbell's Chunky Clam Chowder. I can heat it on the stove in the furnished rental on Richards St., pour it in a thermos I bought at Canadian Tire, call

a Blacktop Taxi and take it up to him. I can have bought the wrong thermos. The top pops off in the back of the cab. Hot soup spills everywhere: on the floor, on my pants, on the seat. I can try to mop it up with a pack of Kleenex from my purse. I can cry in the back of the taxi. I can sob. The cabbie pulls over, gets out, comes around opens my door. He says, "Don't cry lady, it's okay, don't cry." He says the clean-up fee is \$75.00 but that's only for drunks when they throw up, he won't charge me. "Don't cry lady." I can give him \$20 just because, over and above the fare. I can run into Shopper's Drug Mart ten minutes before closing and buy another can of soup, but I can't buy a can opener. It is dark. It is pouring down rain. I can stagger through the deluge between tall buildings sobbing, sniffling, hiccupping for breath, gripping an unopened soup can in my wet determined hand. I can wait, dripping, for a slow elevator. I can say fuck it and walk up to the 2nd floor. I can wander into the empty cafeteria as it shuts down for the night. I can dissolve into tears heavier than rain when asked if I need help. I can say my brother had a lung transplant, we've been here for months, I can't do anything right. I can hold my soup can out and beg to have it opened.

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"Where are we on the river?"

"I don't know," he wails, annoyed. "Maybe Hell's Half Acre."

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There's a big yellow sign with black letters a few blocks from here as you come out of the subway. It says, *Lower the Pitch of Your Suffering*. There are enormous green crates brimming with Spartan apples and buckets of rusty Dahlias lined up on the damp sidewalk in front of Farm-to-Table grocery when I get "home" at night. A comforting golden light pours out of the wide-open storefront onto my rain-peppered shoulders. There's the swinging glass door of

Stanford Medical Center Kalanathi Award submission

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my building, Cesar or Alex or Mark at the front desk with their generous listening hearts, a half-

drunk bottle of Chardonnay waiting in the fridge. Rachel Maddow and Love It or List It.

I take my brother's Jack Russell out for a walk and a pee. The dog and I swing by

Denman Park. We gaze across False Creek at the lights melting in the rain all the way up the hill

to where Vancouver General glowers on its crest.

"Look Philly. That's where Jeff is. Wave a paw!"

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A year later and we have both made it back home. Ask if we'd do it all over again. Ask if

it was worth it.

Someone asked my brother once, how do you paddle with Cystic Fibrosis?

"Same as everyone else," he said. "Put my left blade in the water and push forward. Put

my right blade in the water and push forward. And then repeat it several times."

Come Spring, he hopes to kayak the Chemainis. Ask the river what it says...

Easy forward.

Word Count; 3,899