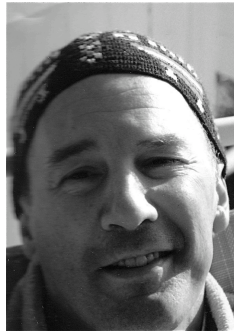


# 16

## Hope Redefined



*July 1997*

Marybeth thinks I'm crazy and she's probably right.

"Really," I tell her defending my sanity, "it's not just because of my bad attitude. It's summer. Come September, we'll have a newborn added to the mix. *That's* when we'll really need help."

Marybeth nods, "Hmmm." She's not completely sold.

"Okay, this is the deal: If I cut the support network, I'll have no choice but to head back East," I say, surprising both of us.

"Go on," she encourages.

I tell her it isn't that I don't want to go. Quite the contrary; I've longed to take respite in the comfort of my large family so far away, but I've been dreading what it means.

"What *does* it mean?" she asks.

I'm bawling before she finishes the question. "G-goodbye," I stutter out between sobs.

The remainder of the session is spent imagining having to leave once there, having to witness the last time my family—now his family—and Tom would see each other. It breaks my heart. Feeling for everyone else is the entry to my own grief. At least it's a start.

There's no hiding my puffy eyes once home. Tom asks if I'm okay and I tell him I talked about going back East at therapy.

"We are going, right?" he says, concerned.

"We just can't afford it," I say, screwing up all the good therapy work I just paid for from our overdrawn medical bills budget.

“Who cares? It’s too important,” Tom argues.

“What if you have a health crisis there, or what if I go into labor early?” I ask, making a second round of valid points that miss the mark.

“Maine’s not that remote. There are doctors and hospitals. Jen, it’s probably the last time I’ll see the family.”

*Bingo.* The tears re-start. “I know. It’s just that . . . well, I don’t think they do,” I say. There. It’s out. This will be his last trip—a goodbye trip. And they won’t really know it until they see him. He motions for me to join him on the bed. As I lay alongside him, he strokes my bulging belly.

“Every second is a last, Jen,” he says and I cry harder.

“You’re their family,” I say.

“And they’re mine. That is exactly why we have to go.” He’s resolved. “Put it on the credit card and I’ll skip the Zophran for awhile. It’ll even out,” he says.

“You’ll be puking the whole trip without it,” I remind him.

“I’ll be okay.” He pats my stomach and kisses my nose.

The next day I charge the tickets to overlap with the family’s time at the beach cottage and make a plea for last minute vacation time at work. Both bosses are gracious and we fly out a week later.

Tom requests an aisle seat close to the bathroom as we board. The culminating side effects of radiation paired with his decision to ditch the only medication that kept his puking under control, makes bathroom access a must.

Squeezing into the window seat beside him, I realize there isn’t space for River. No laps. Mine is huge with baby and Tom’s needs to be unencumbered for dashes to toilet. River runs down the aisle. He is not to be bothered by space limitations. Most everyone else is seated, waiting patiently for us to get settled. Tom puts his arm out and intercepts River on his next fly-by, but he’s got no energy to entertain him into staying put for takeoff. He looks to me questioning, his skin contrasting with the many healthy pink and brown faces around him.

“Sorry, it’s the last time he can fly free,” I say, pulling our screaming child across my knees, wedging his body between my belly and the seat in front of me. He pulls away. I’m desperate.

“Time for nurseese,” I say, unbuttoning my dress. River pulls my breast to his mouth and suckles voraciously, like a newborn upon waking. He occupies his free hand with the long strands of hair that have fallen loose of my bun. All the efforts to wean him from day nursing are blown in one takeoff.

We make it through the first leg with River asleep and Tom only puking twice. I begin to see our situation from other’s eyes as we deplane, on show for all to see: the big pregnant lady with the toddler on her hip, struggling to steer her sickly husband’s wheelchair with one hand as she hurries to the next terminal with diapers dropping from her bag. It makes me want to disappear.

Matters deteriorate when the wheelchair never shows up on the last leg and our plane is boarding at another terminal.

“I’ll try and walk,” Tom says, wobbling on each step.

“No, Tom. You can’t afford the fall. Just wait here, I’ll find someone to help.” I snatch up River and hoist him onto my back, pretending with all my might to be a prancing pony and not an overwhelmed caregiver. I gallop, sweaty and out of breath,

from one counter to another, only to be forwarded yet another. Finally, amongst an incoming crowd, I see a young airline rep pushing an empty chair and I signal him over to where Tom is sitting.

“Hurry, please! We’re going to miss our flight!” I urge when he gets closer.

He swings the chair around behind me. “Have a seat Ma’am.”

“No, no—it’s for *him*.” I point to Tom, who tries to smile over his humiliation.

“Oh, I see. Sorry.” His pimpled face turns crimson.

“It’s okay. It’s just the way it is,” Tom says. This youth is getting a basic life lesson: Things don’t always work the way they’re supposed to. He pushes Tom’s chair briskly to the gate where we are last to board.

I negotiate an aisle seat with a passenger at the bulkhead, hating to resort to pity. “Please?” I whisper. “He needs to be close to the bathroom. He’s got cancer and . . . you know.” I have to look away.

What is normal to us suddenly seems so heartbreaking, maybe even pathetic, as I look in on it from the perspective of strangers. All three passengers in the row surrender their seats and take our two seats and a vacant one at the rear of the plane. Tom nods appreciatively at them and I thank them profusely. We’re utterly dependent on the goodwill of others. *All that’s missing is the cardboard house*, I think.

Only one puke the second leg and River is entertained standing in his chair and making faces at the passenger behind us. We land and my parents whisk us up into their care. It’s only been a few months since they’ve seen us. Still, I can see their shock mixed among the hugs. Chemotherapy and radiation treatments have caught up with Tom, shrinking fast-growing tumors and the rest of his body along with them. And I’ve gained the forty pounds he’s lost. They turn their attention to me.

“You sure you’re only seven months?” Dad jokes.

On the drive from Massachusetts to Maine, Dad tells us we’ll have the RV to ourselves. He’s parked it in front of the cottage so we’ll have an ocean view.

“I bet the neighbors aren’t happy with you. Isn’t that illegal?” I ask.

“Let’s see ‘em move it if they don’t like it,” he says.

*They know it’s a last.* My father isn’t a rule-breaker.

As we drive down Mile Road across the marshlands to the sandbar, where a long row of cottages line the ocean, I can smell the familiar sweet musk of beach roses mingling with the low tide. It brings forth a lifetime of nostalgic memories of family vacations spent here. This time, though, the building anticipation doesn’t hold the flavor of excitement it has in the past. Dread is the flavor of the day. I can’t bear seeing everyone’s hope die the instant he gets out of the car. On the other hand, I can’t endure pretending things aren’t as bad as they are.

Here it is about to unfold, as it will. As we park I squeeze Tom’s hand. He gives a quick pump in return and pulls away, as if he’s gathering energy to buffer the blow.

“Look, Rio, the cottage!” He rouses River from a nap.

Sisters, brother-in-laws, nieces, and nephews who have come from near and far for the reunion, pour out to greet us. We look like Jack Sprat and his wife standing at the car. Dad unloads our luggage and Mum picks up a sleepy River and carries him up the stairs.

They look and they see it. Tom is grey and gaunt. The only color on him is his beanie. It covers the tiny bit of grey-black fuzz that has grown back after the chemo, only

to be fried off in patches by radiation. It's clear he's no longer the suave blackjack dealer or the athlete, going down only ever to one knee. Now, he goes down completely and often, with seizures from the brain tumor. I ask my brother-in-law, Ryan, to spot Tom as he climbs the stairs.

"We borrowed Gram's old wheelchair if you want to take a stroll on the beach while the tide's low," Mum says.

"Oh, I'm good. I just need to lie down for a while," Tom assures her. He's got to be feeling awful if he bails when the attention is on him. They can see that Senior Sanchez, the magician from previous years' talent shows, is long gone, as is the storyteller who has enchanted them late into the summer nights with tales from adventures past.

The family is graceful, trying to catch up with all the changes. "What about the lobster feed?" My sister, Julie, asks.

"He can't eat right now. I think he might be obstructed. Everything just comes right back up. He absolutely wants us to go ahead. Really," I say. When I tell her about the nausea medicine she insists on filling the prescription. It's a way to help, when there isn't much they can do, even with Tom right in their own backyard.

Over the week, a tension of frustration and guilt hangs in the air when we are inside the cottage having a good time—playing cards, eating, or preparing the scavenger hunt, while Tom lay alone in the trailer, miserable. He can't tolerate even one visitor, unless it's me. When he does emerge from the trailer, it's only when he can manage interaction with a smile. Still, he wants them to retain memories of him as the vital man he was. And he knows I need a break.

"Jen, go be with your family . . . just go. I'll be fine. Please, Butterfly, take it while you can. You need it," he says as bravely and sweetly as he can muster. It's the blessing I need to take care of myself and remind River that life goes on, sick Daddy and all. When I leave the trailer, I leave the world of illness. It has become a matter of sanity for me. I'll do my duty of reporting his condition to the family and reassure them he wants the show to go on. And then, I'll do my best to be on vacation.

Late into the trip, after many an enema to free an obstructed bowel, Tom wakes with a mission. "I'm going to make it to the Jetty today," he announces. He's been out a few times to try and lasted only a few hundred yards before needing the wheelchair. Walking the two-mile round-trip is a bed-bound person's miracle marathon.

Word spreads and the family gathers after breakfast, eager to be along for his quest. The sun glitters diamonds off the morning waves as the group of us cascade down to the firm sand of a waning tide. We break into small constellations as we migrate north toward the rock piling in the distance, talking and laughing as always, with occasional cheers for Tom: "Lookin' good!" or "Already halfway, you can do this!"

Tom wears navy sweats with the hood draped over his head, while the rest of us are scarcely clothed. His steps are slow and deliberate. The kids run circles around him with the wheelchair and my sister, Amy walks backwards, videotaping and interviewing on the fly. When he makes it the full mile and come upon the huge rocks, Tom presses his hands on them. Amy asks him to do it again so she can record it. We all stop and watch in silence, recognizing this as a last. I'm thinking how strange it must be, knowing each last of a lifetime—*lucky and unlucky*. Tom raises his fists over his head and we all begin clapping and hooting. *Today it's lucky.*

Tom makes it back to the trailer and sleeps 24 hours, waking only to pee. Time is closing in and the goodbye moment is just a couple days away. The children make cards that say “get well” only the images of suns crying and trees dropping leaves, clearly express “goodbye” and it doesn’t take being an art therapist to see this. Tom’s eyes had welled up when he found them pinched in the screen door. The cards have prompted him to come into the cottage and be with everyone. He lies on the couch watching the world buzz on around him. Dakota crawls over and pulls herself up to get a close look at her uncle.

“Such a big girl,” Tom says caressing, her downy head. “Do you know the last time we were here, was when you came into the world?”

“Baa!” Dakota exclaims in response. Her arms wave wildly, grabbing for Tom’s beanie. He bends forward so she can succeed. It’s hard to believe how many changes happen in ten months time—for her and for him.

“Dakota, you’ve got a little cousin coming to join you soon. Next summer, you’ll have a playmate when you come to the cottage,” he says moving into future territories that don’t include him. Julie squats down with them, tears streaming down her cheeks.

“Oh, Tom,” she muffles out, trying to smile.

“Mhmm,” He sighs, reaching his hand out to squeeze hers.

Others come couch-side throughout the evening, daring to edge closer to that painful place. I strain to hear the exchanges at first as if I could throw in a towel if it got to be too much, but it isn’t my place. These are his goodbyes. *Unlucky or lucky?* I wonder.

Amy organizes a healing ceremony for Tom in lieu of the annual talent show on our final night.

“We have to do *something*. It’s a last for him and us,” she says, calling the elephant by name. I’m relieved, though I feel a twinge of failure for being too exhausted to make his every last special. I’ve resigned myself to letting things be what they are.

Tom is touched by the idea and pulls himself out of bed for the shindig. On the picnic table stage, shreds of his former identity surface for one last hurrah. Spontaneously, Tom makes up a song about our family and sings it in a raspy whisper as he hunches over his guitar. The melody is the same one he sang at his father’s service with the words changed. There isn’t a dry eye in the room when he finishes. We applaud and then dim the lights for the ceremony.

Tom lies down on the bed of pillows and we take our places around him. The children squeeze in front and everyone lays a hand on Tom. Amy gives protocol to the foreign experience our East Coast family has willingly stepped into. She guides us to send him our love and prayers—whatever form they take, as we touch him. Tom’s job is to receive. Eyes close and, after awhile, a palpable buzz grows out of the silence. I can’t tell if it is sound or a sensation. The power of it is undeniable. All sixteen of us are generating a lightning bolt of love and Tom lay in full reception of the infusion. It’s difficult to say what time has passed. My guess is that it can’t be more than ten minutes because I’ve never witnessed River simultaneously awake and still for this long. The kids start to get antsy and Amy wraps up the ceremony. The clock reads 7:35. Twenty-five minutes have elapsed. Again, I realize how much of an illusion time can be. We look around at each other in soft gazes, sniffing and nodding lightly and I feel like I have come to know my family in a new way.

Tom sits up and rips a honkin' trumpet fart and we all laugh, cheeks tight from dried tears. Simple things become sacred and sacred things become simple. This is the gift Tom, in his illness, has offered the family and they—we—are letting it in. In less than two weeks time, hope is reeled in from a distant miracle to the immediacy of each day with Tom. Hoping for one more chance to love him.

Tom sleeps peacefully and in the morning, I pack for our return west. An assembly line takes scattered form between the living room and the porch. Tom moves to each person, taking his time, giving long hugs. Eyes meet and hold as he faces each person and each goodbye. He goes through the entire family, including the youngest children. Moments are so direct and final I can barely tolerate them, yet, I'm so proud of his courage.

Grief, some vicarious and some undeniably my own, has been catalyzed inside me. It's all I can do not to begin wailing on the return flight. If it wasn't for the distraction of a rambunctious two-year old, I probably would. Tom is quiet. Peaceful, in a content kind of way, as if there could be no better way to end his story with these people, who had surely become part of his family and he theirs.