

Volume 10 Issue 1 2014

Waiting, Beautifully

Jean M. Cook

Thursday afternoon

Iim is dving and we are watching. Watching from his bedside to see whether his eyes really focus on our faces as he turns his head to greet us. Watching to see him extend his right forefinger to answer ves to his wife Marian. Yes, he knows David and Jean are here. We are glad to see him and to see by his finger signal that knows we are here. "Hello, Papa," says David, using his term of endearment. We hope our faces don't betray our surprise at the changes we knew we would see; we try to keep our smiles firmly in place. He turns his face to us, but his expression doesn't change. Parkinson's gradually crept in five years ago, causing an occasional stumble and delayed response when he asked his left arm to move. Since then it has tightened its grip on his nerve connections and muscles until they petrified, leaving his face a smooth slate, with pale-coloured marble skin and a stony expression.

His blue eyes and high cheekbones are the same, but he is a world away from the Jim I first

visited here at their apartment in Tucson. He was tan from walking every day. He answered the phone with "another beautiful day here in Paradise Valley." And during our lunches in Mexico, he never failed to beckon the strolling mariachi band to our table, request with a twinkle in his eye that they play "Rio Grande," and sing the chorus along with them.

Even three months ago in August when we were last here, Jim's eyes still twinkled and the corners of his mouth still turned up, although his perpetual tan was fading. Photos that David's mother Marian had sent two weeks ago, though, showed him sitting as usual in his LazyBoy in the living room, which we knew he required a caregiver and a wheelchair to reach, and much of the expression had drained from his face. Now, in early November, we are standing beside the hospital bed in his room, where he has been bedridden for more than a week. We truly are glad to see him after several anxious days since the phone call when Marian said, her voice quivering ever so slightly on the end of the sentence, "His body is going through another change of some sort," as he gained a fever, began sweating profusely, and stopped eating any food, even the smoothest purées of his favourite meals that she had been processing in the blender.

"Would you like cranberry juice?" Marian asks him. His finger doesn't move. "A popsicle?" Again, no change. "Lemonade?" Yes, he would like his current favourite, lemonade. Yes, he would like another spoonful fed to him. This afternoon, Marian is like a hummingbird in reverse, hovering near him with a small glass of juice and a white plastic spoon, administering nutrition, essentially sugar water.

The bedroom had been theirs until the hospital bed and wheelchair required Marian to sell the California king waterbed they'd shared and to move herself to the futon in the next room. As we visit, one of us sits next to the bed on a rented hospital chair, with its sturdy rubber-coated arms for gripping and its thick plastic seat, one sits in the wheelchair, and the third sits on the floor, back against the long Danish modern dresser. The warmth in his bedroom is cloving; high humidity is accompanying the monsoon season rains that are hanging on. We help with the routine of shifting him from one side to the other every hour or so to avoid bedsores. When travel, a time change, and talk tire us, late in the evening we retire three doors down to sleep in the apartment of friends who are out of town.

Earlier today, for a few guilty moments, I counted myself and David unlucky. Unlucky that David is the last of the children to visit. Unlucky that on this visit we will likely say our last goodbye to Jim. We had planned to wait even longer after his sisters' October visits, to be ready in case we needed to come on a moment's notice later in November or December. Now that we are here, I am glad that David woke up one morning two weeks ago saying, "We have to go now." Any later would have been too late.

Friday

Near midnight, just as our heads are hitting the pillow, Marian's head fills with worry as Jim responds less and less to her, his breathing increasing in sound and speed. In the morning, she waits until 7:30 to call us and say, "I think he may have slipped into a coma." We race down the stairs, down the sidewalk past the pool under the unusually gray skies, arrive still wearing our sleep T-shirts with hastily zipped jeans, our hair uncombed, pillowcase creases and fresh worry lines rumpling our faces.

Jim is dying and we are listening. The change in his breathing is dramatic. We can hear it clearly from any room now. It's as though the entire apartment breathes with him; the very walls seem like membranes, inhaling and exhaling. Sometimes I catch myself inhaling in unison with him, but the frequency is faster than normal, faster than I need, so I feel a bit dizzy, as though I were panicking and hyperventilating, and I have to consciously slow my own lungs. We hear an edge of panic enter Marian's voice when she asks Jim to extend his finger to affirm whether he wants something, and he no longer moves it.

At 8 a.m. sharp, the respite service's caregiver, who has come to help, interrupts our worried thoughts and helps us settle into the daily routine of turning Jim every hour.

We watch as Marty, the hospice nurse, arrives midmorning and embraces Marian. She listens to Marian's account of what's been happening. We listen to Marty reassuring us that it is normal part of the process, watch her visit Jim, and hear her speak to him as she checks his pulse and listens through her stethoscope. Her voice jars loose the memory I have of reading that hearing is the last of the senses to linger. Marty gives him a drug to ease his breathing and recommends beginning small doses of morphine to ensure Jim is not in pain, though she quickly adds that he shows no sign of discomfort. She also mentions that we no longer have to shift his position in bed. The one action that provided a rhythm, a vague sense of time to our day is no longer needed.

We return to the living room and listen as Marty explains drug doses and frequencies. She quietly tells us what to expect next, that the drug she gave him to breathe more easily should begin to take effect within 30 minutes. She tells us that she doesn't believe the morphine will cause an addiction; that pain control is the greater concern now. That eventually he may occasionally skip a breath. We hear Marian ask the questions we're all wondering: "How much time? How much longer?" Marty answers carefully. "In my experience, I would say about 48 hours." She reassures us that we can call her any time today, and that on Saturday while she teaches a class, another nurse will be on call. "After my class ends at 5 p.m.," Marty reassures us, "I'll stop by to check on you."

As Marty leaves, the respite caregiver settles into one of the chairs in Jim's bedroom. I sit across from her, next to Jim. "One woman I was with as she was dying..." the caregiver begins a story to reassure us. "No! Don't say *dying*—what if he hears you?!" my mind screams though my mouth is

firmly shut. I find myself suddenly uncomfortable in my chair. Shock or maybe just good manners keeps me pretending to listen, though honestly I no longer hear her. After a moment, the thought dawns on me, so what if Jim *can* hear her? Wouldn't he be more aware of what is happening to him than we are? I look at him and silently ask, "Jim, do you know what's happening to you? Better yet, do you already see what's to come, where you're going next?" I wonder whether he's seeing a light in the distance, whether his spirit has already begun to move on, but my glance at the ceiling, at the closed drapes on the window reveals nothing different from yesterday.

The caregiver was scheduled to come so we could leave for an hour or two to do some errand that no longer seems important or even necessary. She encourages us though, so we reluctantly leave and find ourselves eating lunch at Taco Bell a block away from the apartment. The sounds of people having everyday conversations about everyday things flow around us. We make an effort to do the same, but mostly eat quietly. The room feels too bright, even on this overcast day, and ordinary conversation seems extraordinary. We are overcast, too, and don't belong here as much as we do in the dimly lit apartment.

Jim is dying and we are listening. Listening to his favourite music in lieu of talking much. At least we hope that in our numbed state of disbelief we are remembering all of his favourites. Elvis singing ballads and hymns, Mario Lanza, Ray Price, Patsy Cline, the men's choir from a church in Manitowoc, Wisconsin. Around 5 p.m. David has the courage to play something less solemn, placing a Dixieland jazz CD in the player. All day, the music reminds me of earlier visits to Tucson, when every drive to Nogales, sightseeing jaunt, or ride to a restaurant for dinner was accompanied by music from Jim's favourite cassette tapes or easy-listening radio station. After a few precarious left-hand turns resulted in David offering to drive more often, David claimed "driver's choice" and tried to introduce more recently recorded music into the car. Even from the passenger seat, Jim usually overruled him, grinning as he reached toward the console to return to his favourite radio station. Unless, of course, David chose mariachi or tejano music, which we all enjoyed. Today, David, though brave enough to broach Dixieland, stops short of playing mariachi music.

I look for "Song of India." It was one song Jim and I both loved. When I first learned that, I played it for him on my piano, which made him smile. Later when he played it on a cassette for me, I was surprised to hear that it has lyrics. Today, though, I'm disappointed that I don't find a rendition of it in the tapes and CDs that are handy, even though I know Jim and Marian have several versions of it.

Jim is dying and we are counting. Counting his breaths, trying not to let anyone else catch us watching the clock's minute hand. This morning when Marty visited, his respiration was 42 breaths a minute. After the first dose of drugs, it slowed to 32, the second dose, 30. This afternoon, it reaches 28, where it stays through the night.

We stay with Marian and Jim that night—three doors away would be too far now. We are on the futon, because Marian refused to use it, deemed the living room sofa too far away and would have slept on the bedroom floor until we thought of cushioning a lawn chair and placing it right next to Jim's bed.

Through the night, I wake up every few hours: 11:33, 1:25, 3:26. Each time, I listen for David or Marian, but neither seems to be stirring. So I watch for the bedside clock's red digit to turn and begin a fresh minute. I hear him take one breath, two, three...past the normal rate...20, 21 breaths. Hasn't a minute passed yet? 25, 26, 27. The clock blinks to the next digit. I stop and take a breath myself. Still in the same range, no significant change.

Saturday

At 5:45 a.m., a slight creamy white light touched with pink slips through the cracks in the window blinds. Unable to return to sleep, we lie in the soft light, hesitant to disrupt its calm, listening. We get out of bed at 6:15 as we hear Marian arise from the padded lawn chair. We learn she has been awake since 3 a.m., the chair's supporting metal bar digging through the cushion into her back. She probably wouldn't have slept well on the deepest, finest down mattress, in any case. For months now, she's been in the habit of being alert, listening in half sleep to hear Jim stir, so she would wake in time to help him go to the bathroom.

While eating toast over the sink in the kitchen, we talk about how he seems this morning. One of us lets slip about waking numerous times and counting Jim's breaths, and the other two admit to doing the same. There in the dark, we had kept vigil in our own way, waking during the deepest part of the night, counting breaths and saying prayers, each of us doing so in rotation, much as the clocks' hands were rotating.

At midmorning, Jim's breath count is 26, now with the occasional hesitations that Marty had mentioned would come. With each hesitation, we hold our breath waiting for him to take another. By mid-afternoon, he is down to 21, so much slower, so much closer to the normal 16 to 20 that it provides another cause for worry. "Don't drop too low—what if *we're* not ready yet?" I hear the thought cross my mind.

Despite that thought, today I feel less uncertain and more comfortable with this routine of music, remembrances, and stories. I feel less awkward laughing, because so many of the memories are good ones, funny ones. I am more comfortable with the sense of his bedroom being the heart of the home, each of us leaving only for short spells before returning.

Today, I realize we truly are fortunate to be here witnessing—more than witnessing, *being* with them, with him. Daily life has ceased. We simply *exist* together, as though some deeper part of us has realized this visit, this vigil will be our last shared experience with Jim and slowed us in response to his breathing and dwindling need for care.

Jim is dying and we are praying. Just before 4 p.m., two family friends, one of whom is a priest, and two of Marian's cousins join us. Two weeks ago, right after David and I bought our plane tickets, Marian arranged for Father to have mass at the apartment during our visit. It is comforting to hear him saying mass here in the bedroom, and I am grateful for the voices of friends and family joining us in the responses we all know by heart.

Father gives us all communion, administering a drop of wine to Jim's lips, and then offers us each the blessing of the sick. It is 4:25. We stand as he says a prayer, uses his thumb to make a cross on our foreheads, first Jim, then Marian, David, me, the others. Within moments, we hear Jim's laboured breathing abruptly fall into something much softer, startling us with its gentleness. As the others respectfully move to the living room, Marian, David, Father, and I move closer to the bed.

"Is this it?" Marian asks Jim first, then turns to Father. "Is this it?" She and David each place a hand on one of Jim's arms; clasp each other with their free hands. Father and I put our hands on Marian and David's shoulders. I see the geometry of the encircling arms and find myself wishing I had another hand to touch Jim. Marian tells him she loves him and that it's okay for him to go, even though her voice quavers with emotion as she does. His breaths slow, time creeping in between them. After a long moment, a whisper of an exhalation glides out between his lips, and then he is quiet. The clock reads 4:35 p.m.

Jim was dying, and waiting too. Waiting for David and me, for Father and friends, for mass. Waiting to receive communion and a special blessing before leaving us. I find it touching to realize this. All these years, I had been taken in by his standard Sunday morning joke about skipping church today or going to a bar instead, thinking him less devout than Marian in their faith. I offer him a silent apology for my misperception.

It is Saturday night and we are waiting, no longer for Jim, but for a nurse from hospice to come pronounce his death. Because it is after 5 p.m. now, Marty appears at the door. We are relieved to see her familiar face as she gives us each a hug, and we comment on the timing, as though Iim had also waited for her to be available for us. She listens to his heart, his lungs for breath sounds, feels for a pulse, pronounces his death at 5-something p.m., which seems ridiculous to me, so much less real, less significant than witnessing his true departure earlier. We share with her how he left, and she expresses her amazement. After gently reminding us all that grief visits, then revisits at odd times and to accept that as normal, she encourages Marian to call her whenever she needs and administers another round of hugs to us all.

No sooner does she step out the door than she returns, saying, "You must come see this." We step into the courtyard and our breath is taken away. Much of the week, heavy gray clouds have hung lower than the mountaintops, occasionally dispensing a burst of thunder and rain. But now the clouds are breaking and awash in brilliant crim-

son, orange, and plum—a radiant sunset. "He's telling you that he's arrived, and he's okay," Marty says, a touch of awe along with the certainty in her voice. "Gorgeous, just gorgeous," I think and probably say aloud. David gets the camera and takes a few photographs. We stand there watching until the colours' fiery warmth fades and a dusky blue creeps in.

Eventually, we return indoors to wait with Jim once again, this time for the funeral home people to arrive. David goes into the hallway to call his sisters. I hear the soothing sound of his voice, though I can't make out the words, and I wonder how it is for them to receive a call they knew would come at an unknown time. Marian tucks the sheets more neatly around Jim, strokes his arm, his hair. "You did that just beautifully, Jim," she says, "Just beautifully." And I hear the slightest touch of pride, perhaps a little relief, and so much love in her voice.

Jean M. Cook is an editor in the field of life sciences and writer living in White Bear Lake, Minnesota. She has been published in *Around the Writer's Block* and was a 2003 and 2013 finalist in The Loft Literary Center's Mentor Series. Currently she is working on a book of essays about her experience building a Modernist, environmentally gentle house on a budget. Email: jean@imagesmythe.com