Voices in the Band

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Etta was admitted ten days ago with PCP. She spent five days in intensive care initially getting worse with treatment. She improved and went to the floor but earlier this week she developed fevers again and grew yeast in her blood. She’s on IV fluconazole for that now as well. Overall she’s better but her T cells are twelve and she’s refused to take any medicine offered her as an outpatient. She’s been too sick to protest here in the hospital but now that she’s feeling better she’s starting to refuse things again and I’m concerned that if she gets well enough to discharge she’s not going to last long.” I looked up as I ended my recitation.

“Nursing?”

“Etta’s afebrile this morning and sat up in a chair last night.” Judy looked down at her clipboard. As she continued her report I thought back on the time during my pregnancy when Etta insisted on going home from the emergency room to do her laundry despite her life-threatening anemia. Eventually she came in for a blood transfusion but even after that she wouldn’t take iron to support her blood count. She’d give me one of those sneering looks of hers, as if saying, “What are you bothering me with this shit for?” then say she didn’t need anything. She did take notice of her continued weight loss, however. For some overweight people the transition from a size eighteen to a size eight generates a fantasy of a magazine advertisement for magic weight
reduction, but our patients don’t mean to advertise HIV as a weight-loss formula. In Etta’s social circle of hard drinkers and people in low-paying jobs, only the real losers used drugs, and HIV was something for the weird gay guys. Etta didn’t do drugs and she thoroughly resented that people in her neighborhood assumed that her weight loss meant she had become a “crackhead.” Of course HIV was in her community, yet there was so much stigma and secrecy around AIDS that she didn’t worry as much about her real diagnosis being discovered.

But not even weight loss got her to take her medications. Etta persistently treated her HIV as an annoyance more than a concern. My efforts to get her to take her illness more seriously, to keep her appointments, to take the medications I prescribed for her always fell flat. Now it was early summer and her attitude was catching up with her in a bad way.

Etta lived in an apartment above her grandparents with her six-year-old son, Joey. About ten days ago the grandfather called upstairs and the little boy answered the phone saying Mommy was sick and couldn’t get off the couch. The grandfather called CSS and an ambulance was sent to her house. I saw her in the emergency room, where she struggled to breathe despite the oxygen mask. She admitted that she’d never taken the Bactrim I’d prescribed for her, not even three times a week. Even with years of low T cells, until this admission she’d never had an opportunistic infection. Before now she’d never gotten anything but skinny and anemic. We could probably treat her PCP this time but what about the next time? The yeast in her blood shouted like a carnival barker that her immune system couldn’t handle much of anything at all. Still, Etta made her own decisions. Now that she was improving she’d regained a good deal of her feistiness. When the nurses came to check her vital signs in the middle of the night she told them to get lost and complained to me about it in a disparaging tone when I saw her in the morning.

After inpatient rounds ended I went to see her. She was sitting in an armchair next to her bed wearing a pink bathrobe and fluffy pink slippers. Tubing ran down into her arm from the three intravenous bags hanging from the pole. On the lunch tray in front of her I saw she’d eaten some soup and part of a turkey sandwich. She stared at the television up on the wall opposite the bed. I glanced at it and saw one of those talk show hosts who gets people to cry or fight or both on the air. The camera panned to an obese woman who held the hand of a much younger, very skinny man. Both were crying.
The caption read “Son wants to marry his mother.” Etta’s mouth hung partly open as she watched the screen. When she saw me she gestured toward her lunch tray and in an aggrieved tone said, “I can’t eat this. The food here really sucks.” Then she looked back at the television.

I motioned for permission to sit down on her bed and she nodded. Picking up the TV remote, I asked if I could turn down the volume. Etta turned to me and then looked back at her food disgustedly. “I’m not kidding, this stuff is nasty. And I’m hungry for a change. My grandfather’s bringing food later.”

“Great. We always say that the patient is getting better when she starts complaining about the food here. It’s a kind of test.”

“Yeah, well, look at this soup.” She picked up her spoon and dipped it into the glutinous orange liquid in the little plastic container. Appetizing it was not.

“Etta, you look great. So much better. And no fevers, right? How is your breathing?”

“It’s fine. I’m fine. I’m ready to go home.”

I almost laughed. A laugh of relief that she was better and a laugh at how crabby and tough she could be. “Listen, it’s going to be a few more days. You’re doing great, I’m really glad, but we’ve got to continue the IV for a little while more.”

She made a tsking noise with her mouth and rolled her eyes. She looked back up at the television.

“Etta, once we stop the IV you’re going to need to take pills. The treatment course for PCP is twenty-one days of antibiotics and so far you’ve had eleven days. The yeast in your blood can also, we feel, be treated with pills, but you’re going to need to take them for a long time, maybe forever.”

She turned toward me, a familiar, put-out look on her face. “Forever?”

“As long as your T cells are this low your body can’t fight off the infection and so you’ll need this medicine.” She looked back at the television without saying anything. I went on. “There’s some new HIV medicine also, and I want you to take it.”

“More pills?” She looked as if I’d stabbed her.

“Yes, more pills. It’s going to be a lot of pills. The new medicine is something we’ve been waiting for. It’s called saquinavir.” Later in the summer I was going to the International AIDS Conference in Vancouver. I looked forward to seeing the presentations and hearing the details of the studies on these new HIV medicines from the best AIDS researchers in the world.

She sneered. “I don’t want to be a guinea pig.”
“I know you don’t. The testing has been done, the trials and everything. The government approved it and now you can get it in the pharmacy. You won’t be a guinea pig.”

“So how many pills are we talking about?” She looked up at the television again.

“A lot. Several pills three or four times a day.” I knew this sounded utterly ridiculous for someone who would not even take one pill three times a week, but she wasn’t going to get more chances if she didn’t start to turn things around at this point. “We’ll get you started while you’re here so you’ll be used to everything before you go home.”

I watched her for a bit to see what she’d say. She continued to watch the TV without looking at me. I glanced up and saw a small man running across the studio stage with a cameraman following close behind. After a while Etta said, “I’m not going to stop eating from this, right? I’m finally eating decent again.”

I thought for a moment. “You know, that’s a good question. I can’t tell you for sure, although I haven’t heard anything about that being a problem. Everybody’s different, though, and we’re going to have to see how you get used to things. How your body adjusts.” I took her question as an encouraging sign that she might really consider taking medications. “The steroids that you’re on now for the PCP are helping you have an appetite but I’m hopeful that as you continue to get better you’re going to want to eat more even without them.”

I watched her face. Then I said, “Etta, this has been a really serious illness and I’m not sure if things will work out as well for you if you have to go through it another time.” She looked down at her lap. “I don’t know for sure that these new pills are going to help you get better but I know that if you don’t take them you definitely will not get better. Your system has really taken a beating, especially in these last few weeks.” I couldn’t be positive but it seemed she was listening. My pager started beeping. I shut it off and we sat there for a while, neither of us saying anything. Etta hadn’t looked back up at the television.

“So—”

She interrupted me. “I’m going to take the pills.” She looked at her food tray, not at me.

“OK. Great.” I paused, thinking that it would be better not to say any more right now. Neither of us spoke for a while. I stood up.

“This food really sucks, though. I’m going home.”

“OK. I know. Soon.” I smiled a little as I said it and walked out of the room.
Upstairs Stewart sat in one of the chairs by the elevator and looked up as I got off. His thin, scraggly hair needed a wash and he wore an expression of calamity. “Oh, Dr. Ball, you’re here. Did they tell you about my leg?”

“No, Stewart, they paged me. Wait just a moment and I’ll come back out.” I went through the waiting area and the door to the corridor to find Mary Rose in the hallway. She told me that Stewart had shown up saying his leg had been bothering him for a week. She’d paged me after looking at it. “It’s pretty swollen and red. He doesn’t have a fever, though.”

I brought Stewart back to my office and looked at his leg. His right calf was warm, swollen, red, and tender. Stewart looked like he was going to cry.

“Is it another blood clot, Dr. Ball? It’s not another blood clot, right? Why would I have another blood clot? The last time I had a fever and I don’t have fever so it couldn’t be another one but what is it?”

“It looks like you have a blood clot.” I looked at his leg and shut my eyes so that he wouldn’t see me roll them. Damn! Another blood clot in his leg. With a sense of dread I realized it meant another stint in the hospital, and this time he’d need blood thinners forever. I braced myself inwardly, anticipating the wave of his repetitive questions and my unheard answers.

HIV, as a chronic illness, could predispose people to an increased risk of blood clotting. We’d seen an occasional stroke in a young person or tiny blood clots in the lung that caused pulmonary hypertension. Stewart had had a blood clot in his right calf a year ago and been treated for three months with a blood thinner after a week in the hospital. His tremendous anxiety during that admission infected the floor nurses and the residents. Everyone found his constant questions hard to take. Although I joked about needing Valium to care for him, at the same time I felt somewhat defensive of my patient. He could be difficult but he wasn’t a bad guy; he was worried.

Now I said to him, “Well, listen, let me get you an ultrasound so we can know one way or another if it’s a clot. It does look like a clot, Stewart, you made the diagnosis on your own. This started a week ago?”

“Yeah, about a week ago.”

“You didn’t bang it or fall or anything?”

“No.” Stewart sat in the chair in my office looking down at his leg with his khaki pants pulled up over his knee. He’d taken off his sock and sneaker and his damp yellow toes wiggled as we both looked at them. It seemed vaguely obscene and I looked up at his face instead.

“But no fever.” I said it more as a statement than a question.
“No. I don’t need to be admitted, do I? If we know what it is I can just take Coumadin and then I don’t need to be in the hospital. Can this be fatal? I mean what are the complications? I know last time you told me I could get a clot traveling to my lungs. I don’t feel short of breath but you know, my ears have been clogged for a few weeks, do you think that’s part of it?”

“We need to have them do an ultrasound. Then we’ll know if there’s a blood clot and we’ll go from there.”

“But I haven’t had any fever!” His eyebrows rose up ever higher on his forehead.

“I know. Maybe this isn’t a clot but for right now let’s proceed as if it is. OK? We’ll get an ultrasound. Let me make a few calls and then we’ll see what we need to do. I think you should be in the hospital, though, with this.”

“In the hospital?”

“Yes.”

“Now?”

“Yes, now, Stewart. If it isn’t a blood clot there’s at least a skin infection going on which will need antibiotics. I think you’ll probably need both heparin and antibiotics so let’s assume that you need to be admitted. I’ll set up the ultrasound and from there you’ll go to the emergency room.”

I almost jumped up from my desk, feeling that I could not bear to go through another round of the same questions. I cajoled him to get his sock and shoe back on and walked with him down to the lab to get his blood drawn before going for the ultrasound. Back in my office I made the arrangements for his admission. All the while I lamented the fact that now Stewart would need to be on blood thinners every day forever. We’d have to watch his medication levels, which meant he’d need to come to the lab on a regular basis. It was like anticipating indefinite weekly visits for orthodontia adjustment. I could imagine what the nurses were going to say.

Back downstairs on the inpatient floor I went to see Roman, a patient whom I’d met six months ago, sent from the office of a doctor friend of mine when Roman’s insurance wouldn’t cover his visits. Roman had one of the worst cases of Kaposi’s I’d ever seen, chiefly because of how grossly the purple swelling deformed his eyes. Whereas Sabir’s KS was sprinkled over all parts of his body, so far the lesions had barely touched his face. The confluent, violaceous lesions that covered Roman’s back didn’t avoid his face. His eyelids
and cheeks puffed with the puckered reddish-violet masses. He had no pain from these lesions but the disfigurement made life very difficult. He wore sunglasses everywhere but still people stared at him on the street. He told me that he felt as if he constantly carried a big blinking sign over his head that announced, “Watch Out, This Man Has AIDS!” Roman worked as the driver and handyman for a wealthy woman who well understood his story. It was her physician who had sent Roman to me. Her work in theater advertising involved dealing with lots of gay men and so HIV did not shock or repulse her; she’d seen plenty of it. She came to Roman’s first appointment with him and continued to employ him despite his disfigurement.

Several weeks ago Roman developed shortness of breath and a cough, and I admitted him this week assuming that he had PCP. He refused to have the pulmonary doctors look down into his lungs to investigate the fluffy white patches revealed by his chest X-ray. Roman insisted that he never missed his Bactrim dose. It would be very unusual for him to have PCP if this were the case. I pressed him to have the bronchoscopy so we could know for sure. For a week I treated him with powerful medication against PCP, using something other than Bactrim. He didn’t improve but his laboratory results and his symptoms seemed less like classic PCP. Our diagnosis shifted to the next likely illness, Kaposi’s of the lung. I was worried.

I walked into the bright room with its view of the Empire State Building. Roman was sitting up in bed wearing striped pajamas and horn-rimmed glasses, reading the New York Times, his white sheets and cotton blanket all neatly tucked in around him. He put his paper down.

“Dr. Ball,” he said, with his lilting Brazilian Portuguese accent.

“How are you feeling?”

“I’m feeling OK.” He smiled a bit, his eyes disappearing behind the purple swellings that crowded one another all over his face.


“I’m coughing when I lie flat at night. I find that I’m sitting up more to be comfortable.” He leaned forward and helped me lift up the back of his pajama top. He took some deep breaths in and out while I listened. Then he sat back against his pillows and breathed quietly while I listened to his heart. He knew this ritual well after a week. I draped my stethoscope around my neck and sat on the end of his bed.

“Well, you sound about the same to me. There are areas that don’t move air so well. The X-rays haven’t changed really at all in this week. Are you still sure you won’t let anyone look down there?”
“You’ve said there’s no treatment, only some chemotherapy that doesn’t work.”
“For KS you mean.”
“Isn’t that what you think it is?”
“Yes.” I shifted as I sat there. “It’s just that I don’t know that that’s what it is. I think it is. I think all other possibilities are pretty remote, given how much KS you have on your skin. But it’s just white patches on the X-ray; it’s not actual tissue to stain and really look at. Without that I can’t say absolutely it’s KS.”
“Dr. Ball, you said you wanted to give me some new medicine for HIV.”
He was changing the subject but I didn’t mind. We’d been over the bronchoscopy issue more than a few times and he wouldn’t budge. “Yes, I think we should get you started on the new medicine. Maybe if we get your T cells up a little they’ll help fight against the KS. It’s definitely worth a try.” I’d hear the specifics in a few weeks at the Vancouver conference, but with FDA approval I didn’t have to wait to start my patients on the new medicines. I just hoped that they’d work as well as the initial reports were claiming.
“OK. I’d like to get out of this hospital.”
Roman seemed remarkably fine despite his alarming appearance and his nasty chest film. Short of breath if he moved around a lot; just sitting there in bed he had no complaints. Sometimes I wondered how, with their T cells in the single digits, some patients looked fit and healthy whereas others looked like skinny wrecks. I didn’t kid myself about Roman’s appearance. Patients with KS of the lungs did not survive for long.
“Roman, I need to ask you, with this whatever-it-is in your lungs, your breathing is already affected and there may come a time when you are unable to breathe on your own. I don’t think that is going to happen today, but if you can’t breathe on your own do you want to be placed on a breathing machine?”
He gave me a perplexed look. It appeared that this thought had not occurred to him before and I felt disappointed in myself that I had not brought it up until now. “This is something I should have spoken with you about sooner,” I said.
He shook his head. “No it’s not that, it’s that Olaf died after being on a machine for four weeks. It was awful.”
“I’m sorry, I didn’t know. That was three years ago, right?”
He nodded. Neither of us said anything. I waited as Roman looked down and smoothed the blanket. After a bit I said, “If we aren’t treating this thing in your lungs, I’m not sure that putting you on a breathing machine would serve a purpose. It could keep you alive but not indefinitely.”
“What would happen instead?” He looked up at me and squinted through the purple swellings of his eyelids.

“We would keep you comfortable. We’d give you small doses of morphine so that you would not feel pain or feel anxious.”

“And I would die?” He looked out the window past me and I watched his face, wondering what else there could possibly be to say.

Finally I said, “Roman, we just don’t have a cure for this. Not yet. I will say, though, that the people taking the new medicine you’re starting are doing super-well. This is not a done deal.”

“I know I don’t want to be on a breathing machine. Definitely not.”

“OK, that’s important for us both to know, and as I say, I don’t think you are anywhere near being at that point right now. I’ve ordered the medication for you. It’s a lot of pills but let’s see if they can help.”

“OK.”

Months passed. I went to Vancouver and came back, as we all did, with an unfamiliar sense of optimism. This optimism contrasted sharply with how we usually felt after international AIDS conferences, when we came home decidedly glum as the numbers of cases always rose, the poor and needy suffered increasingly, and none of the treatments in development ever worked. This time the data on the new medications, the protease inhibitors, confirmed and augmented what our own clinical experiences were starting to show—that patients on these medications could do well. Finally, finally, a significant positive advance in the treatment of HIV. People were almost giddy with excitement.

September came. Etta stayed out of the hospital and Roman called for medication refills from his job in the Hamptons with the rich lady. At home Jules explored the sandbox in the park and loved being read to in the evening. We read the usual classics: *Good Night Moon, A Fly Went By, Harold and the Purple Crayon*. At less than two years old he didn’t talk much yet and he tended to be shy with strangers. Our gray cat, Kitty, watched over him. My mother’s cancer spread to her spinal cord and radiation therapy only proved exhausting for her. I was spending increasing amounts of time in Florida. By the early fall she could no longer get out of bed. I went back down to see her.

“Mom, give a cough.”

She coughed a puny little cough. I didn’t expect anything thunderous.

“That’s good, cough a few more times.” I couldn’t see her face. She lay with her back to me and I stood at the side of the bed wearing surgical gloves,
with one hand holding her hip and two fingers of the other hand exploring her rectum in order to help her move her bowels, something she hadn’t done in a week or more. She hadn’t asked me to do it. But she couldn’t move or feel anything below her waist. The visiting nurses wouldn’t do this, or maybe they weren’t allowed to; I’m not sure.

“Poor Suze.” Mom gave a low laugh as she said it. Her voice was muffled by the pillows around her head.

“What? Why poor Suze?”

“You have to change Jules’s diapers and now this.”

“Oh. Well, this isn’t so bad, really.” I almost had it. “Am I hurting you?”

“No.”

“Can you feel it?”

“No.”

“It’s not the first time I’ve had to do this,” I said. “I guess life isn’t complete until you have manually disimpacted your own mother.” I could hear the tone of my voice. I sounded relaxed. I tried to ignore the part of me that felt like hanging my head and crying. My son was not yet two and of course I changed his diapers. Yet I thought of my mother as discreet and elegant, not someone who needed this sort of help. Ever gracious and reserved, she calmly answered when I asked her about her bowels. She took such pride in my having chosen medicine for a career and if I, as her doctor daughter, recommended something she did not complain or object. We both understood that cancer was winning this battle.

“Lucky you.” I heard her voice from the pillows.

“Lucky me.”

“Who’s lucky?” Margo came into the room and stopped. “What’s going on?”

“I’m helping Mom poop. Mom, give a couple more coughs.”

Each cough resulted in her muscles bearing down and after a few more I had delivered a soft little mass. Margo looked at me with raised eyebrows. “Eew.” My sister worked in the accounting office at the exclusive Florida resort three miles up the road from my parents’ house. She came over to the side of the bed where I stood. She looked and gave a little giggle. “It looks like a Tootsie Roll.”

Mom’s muffled voice answered, “Delightful. Don’t eat it.”

“Mom!”

This activity had produced the desired result so Margo and I cleaned her up and helped her roll onto her back. We lifted her to sit up against her pillows.
I sat down on the little chintz chair next to her bed and Margo stood at the end of the bed, watching Mom. Absentmindedly her hand rubbed her belly. A boy. She and Ray were having a boy. She had the name picked out and the room decorated. She had her baby car seat, a crib, and a high chair. She talked about onesies and birthing classes. Months ago my mother helped Margo with the maternity shopping and the planning for the new baby’s room. Jules lived far away in New York and came for visits; she’d only once met the newborn son of my oldest brother, Fred, who lived in Virginia. This baby would be right here and it was hard to tell who was more excited, my mother or my sister. But as her cancer progressed, Mom’s attention shifted. She didn’t have pain and certainly she knew all of us, but the radiation and the brain lesions took their toll and part of her was leaving even now. It seemed she couldn’t bring her thoughts to focus anymore, and none of us could talk of her missing the birth of a grandchild.

“Muggs, I’ll sit here for a bit.” Dad gave my sister her nickname years ago. “Dad’s out fishing. Are you feeling OK? Do you want to stay for dinner?”

“No, I’m good. Ray is at home. We’re going to a baseball game later. By the way, I can’t poop either.”

“Don’t look at me.”

Mom lay there with her eyes open, a few wispy hairs on her otherwise bald head, her misshapen jaw a reminder of another surgery six years before the cancer. What was she thinking now?

“Mom, Margo can’t poop either.”

“I heard.”

“Want some more ginger ale?” I held out the can to her and put the straw to her lips. She took a couple of sips from the straw.

Margo came around and kissed Mom on the cheek. “Bye. I’ll call you later.”

“Bye, honey.”

“Mom, try and eat something, OK?”

“I will.”

“Sure.” Margo rolled her eyes at me.

Mom wouldn’t eat and we both knew it. I pushed her to drink but she refused to eat and I couldn’t make her. It drove my father practically insane that she wouldn’t eat. He’d get mad at her and start yelling, which didn’t help and certainly didn’t make her hungry. I found myself yelling at everyone else: at Dad, my brothers, my partner, at Margo. My yelling bounced off my aching heart and clanged around in my hollow chest. A dull, loud clanging. I saw
myself waving my arms and shouting, hurling, desperate, desolate, no sound but the din in my ears. Standing on a cliff. Aren’t we always standing on a cliff? She was leaving us. She didn’t want to go, but some weeks ago, I don’t know when, she’d found herself on a raft in a steady, ebbing current, swirling slowly, gently even, being borne away from us. She didn’t wave. And so we sat with her. Day after day. In these last weeks I’d been in Florida a lot, just to sit with her. Dad couldn’t bear it. He ran errands or dashed out to go fishing. He rummaged around in the garage and appeared in the bedroom doorway, his skimpy gray hair standing up on his head. “Everything OK?” he’d ask, and then he’d go out again.

Margo worked at her job and stopped by nearly every morning and every afternoon on her way home. My brother Jim and I tried to alternate our visits, coming down from New York to be with her. Fred could not come as often. I missed a lot of work. Sometimes I brought Jules with me for a few days. He found her bald head very curious and he patted it with his soft little hand. Although he knew very few words, he’d say “Granny” in a precious small voice. When he patted her head she looked at him with heart-aching pale blue eyes. She smiled with her misshapen face and her hands reached out to touch him. “Hello, Julot,” she said.

I liked sitting with my mother. We sat together for many hours, often silently. Sometimes I read to her. Once, when sitting by her and holding her hand, I said, “Mom, you have been a good mother.” She let go of my hand and reached up to put her arm around me and said, “Oh, honey, there’s so much I want to say but I can’t say it.” And so I imagined that even though she tended to be so quiet she had many thoughts whirring through her head.

After Margo left I sat by the bed. I liked the comfortable little chintz chair next to her bed and I put up my feet on the matching ottoman to sit next to her. The TV on the dresser blinked without sound. We both watched the flickering screen. Sometimes I talked to her about the news. She listened to me and made an occasional comment. But she drifted away. She wasn’t coming back. None of it mattered very much at all to her.

“Mom, you know I was in Vancouver this summer.”
“Mmmm.”
“I was there for a conference. The International AIDS Conference. Remember I went to Japan a couple of years ago?”
She seemed to be listening. I kept going.
“So it was very interesting this year. A bunch of us from work went. I had a presentation and work paid for us to go. There is some new medicine now
for AIDS. It seems like it works very well. The patients in the studies who took
the medicine stayed healthy and didn’t get sick.”

She licked her lips. I reached over with the can of ginger ale and she took
a sip from the straw.

“I have a couple of patients on the new medicine. I have a patient named
Etta. She’s taking all these new pills. She’s been hard to take care of because
she has a mind of her own and doesn’t do what I ask her to do.”

Mom reached up to her lip and wiped at it with her finger.

“She has been super-sick. I really thought she was going to die this sum-
mer. I think of her because she has a little boy who is just a little older than
Jules.”

“Jules?”

“Yes.”

“Oh, that’s too bad.” I wondered if she knew what I was talking about or
if she was just responding to my voice saying the name of her grandson. I
almost laughed. Should I just keep talking? Could she even say what she was
thinking about? Was she suffering? Was she aware? All these questions went
across my brain like a ticker tape. I had no answers. I looked down at the can
of ginger ale in my hands and kept going with my story.

“It’s sort of amazing, really. She’s been on this medicine and she’s doing
better. I really thought that she was going to die. I always think of Jules when
I see her and I worry about that little boy. So now I feel a little better because
Etta is doing so much better. It’s really been remarkable. Anyway, in Van-
couver we heard about the studies on these new drugs and so we’re all hope-
ful that there’s something for our patients finally. Maybe everyone won’t die
now.” When Etta had finally been discharged after a slow recovery from PCP,
I had not been optimistic. She’d complained about all the pills she had to take
in the hospital and I thought she’d stop them all once she got out. A month
later, just before I left for Florida, she had an appointment with me. She com-
plained about everything, but how delightful to see her ten pounds heavier,
wearing glossy pink lipstick and her blue eye shadow once again. There could
be no doubt that my patient was getting better.

Mom didn’t say a word. She kept looking at the silent television.

“Vancouver is very beautiful. It’s right on the water.”

“Nice.” Maybe that was all she heard. She loved the water. She loved their
house in Florida, looking out over the water. Once when we were walking on
the beach together, a few years ago, after they’d bought the house and moved
away from the freezing, endless upstate New York winters, she said she felt so
lucky to be able to be in that spot and to see the water every day.
I sat next to my mother and watched her face. Can I hold her here, I wondered, can I remember this moment and all its awful greatness? She is here next to me and I am holding her hand. She knows I’m here and my love surrounds her; I know she knows it does. Then I thought of Etta and realized that if not for the protease inhibitors Etta would most certainly be dead by now. Instead she was putting on makeup and complaining about her pills. Taking them, but complaining. No pill was out there for Mom.

I thought about my trip to Vancouver last July. I had rented a bike one day after the conference sessions and rode along the water on the bike path that circles Stanley Park. The park is full of the tall, dark pines of the Northwest. Moss and green ferns cover the forest floor and fallen trees. The bike path goes right under the Lions Gate Bridge. Huge ships coming into the harbor go through that narrow stretch with the bridge high overhead. They seem almost close enough to touch. As I rode along I saw a sailor standing far up above me, puffing on a cigarette, looking down at me from the rail of his enormous red ship as it passed under the bridge, heading out through the Lions Gate. I wondered where they were off to: somewhere to the west, to Asia maybe, or Australia. Maybe they were headed to Bora Bora or Tahiti. Around the northern end of Stanley Park the water opens out and there is no land on the horizon. I got off my bike and sat on the rocks looking far across at the blinding afternoon sun sparkling on the water. The big ship I’d seen with the smoking sailor headed out there, out to sea. The Pacific Ocean seemed vast and unknowable. I sat with my rented bike for a long time and watched the big red ship move slowly, steadily off, getting smaller and smaller. The light glinted and the water sparkled dark and brilliant.

Earlier that day I had called my parents at the Florida house. My mother’s CT scan results were in. She’d already had radiation therapy to her brain in the spring. She couldn’t get any more. After four weeks of radiation therapy to her spine she was done with that as well. It had thoroughly exhausted her. My father told me the results of the CT. His voice was quiet and sad. I hung up the phone in the hotel room in Vancouver. She still had evidence of cancer in her brain. I went outside and walked down to the harbor and rented the bike to go riding in Stanley Park.

Two months later I was in Florida with Jules, sitting by my mother’s bed in the afternoons, watching the silent television while he napped. The summer tourists had gone back inland and the island enjoyed the golden days of early fall. I took Jules to the beach early every morning on my mother’s bicycle to look for shells and watch the gulls. One morning the water fairly glowed in the first rays of the sun. We stood at the edge of the Gulf of Mexico. I held
Jules in my arms and he held his little orange rubber lion in his hand. The sun glanced up over the Australian pines behind us. We looked out at the bright green-gray water, watching for the fin of a dolphin. We’d seen one yesterday morning. Jules looked intently, his white-blond feathery hair lifting off his brow. The water gently curled in waves at my ankles, the smooth sand wearing away beneath my feet. Our shadows stretched out into the water in the first morning sunlight. A lone silhouette in the distance bent to pick up a shell. I put Jules down and he squatted on his little legs and poked at the sand, holding his lion carefully in his fist. We walked north along the edge where the sand has a ridge of tiny shells and gifts from the night tide. We found a whelk, bright orange, smaller than a peanut. We found a baby crab skeleton. We stood for a while watching the pelicans soaring and plunging into the gulf. Jules smiled and pointed. After a while more we went back to the house. Jules rode in his seat behind me as I pedaled.