Waves

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IN JULY OF 1990, after complaining of persistent chest and back pain, my mother told me that she had been diagnosed with a recurrence of breast cancer. Sixteen years earlier, she had had a radical mastectomy which not only took her whole breast but also part of her lymph system, so that her right arm became significantly and permanently swollen. Although she enjoyed many good years, following her mastectomy my mother was hampered by the swelling and the awkwardness, discomfort, and pain that it caused. She wore an elastic sleeve on her arm every day, tried to keep it elevated at night when she slept, and “milked” it with a machine that through pressure and vibration attempted to move the fluid out of her arm and into her circulatory system. But the arm stayed swollen and even increased in size and weight so that my mother’s five-foot frame was actually dragged down on her right side by it. Even though she feared surgery, my mother gamely underwent two experimental operations, an unsuccessful attempt to repair the lymph system and then a painful but moderately successful effort to de-bulk the arm, which, however, left her with a long scar running from her armpit to her wrist.

This physical disfigurement did not cause, but to my eyes greatly exaggerated, a peculiar physical characteristic of my mother’s. When she waved good-bye her arm and hand always seemed oddly out of sync with one another, as though her hand were not properly attached to her arm. I remember her down the years since her mastectomy, waving good-bye to me and my family as we left after a visit to return to our home in Maine, where my wife and I taught at a small college. She would stand at the sliding glass doors on the raised deck of the house she and my father bought in Shark River Hills, New Jersey, in 1981, her enlarged forearm going in one direction while her hand, inexplicably and preposterously, went in the other. The gesture seemed to express my mother’s great energy and vitality, her love of the social amenities, as well as a certain lack of attention or control that my eldest sister, Joyce, has always called “ditsy.”

My mother’s recurrence had an especially powerful and disturbing effect on me, for I, too, had been treated for cancer, a rare form called malignant pheochromocytoma. Since 1977, I had had two major operations, chemotherapy, and I had just recently concluded radiation treatment. Although I had long ago intellectually accepted that there is no justice evident in the distribution of illness...
and other misfortunes, I found myself feeling angry that this should have happened to my mother, because she didn’t deserve anything like this after all she had been through. But I also felt disappointed and oddly let down, as well as angry, that my mother was sick again. I asked myself “What have I been doing all this for?” and caught myself out in the mostly unconscious heroic inflation that the reason I had been sick and undergoing all these various treatments and anxieties was so that others, most of all those I loved, would not have to. Underlying these feelings, however, was an even deeper, more pervasive feeling of despair. I felt that something was taking my mother away from me, beyond the reach of my love. My mother’s recurrence overwhelmed me with the feeling that no matter what we do or how well we do, the disease is inexorably persistent and will get us in the end—that it is out of our control. We do not cause nor can we cure our illness. We can only live with it, make what life we can within the arc of its demands on us, and see what it may teach us.

The conventional hormonal therapy for metastatic breast cancer had no effect at all, and by September, my mother’s pain was increasing and she was discussing harsher chemotherapy with her doctors. I had become so traumatized by my two years of chemotherapy that simply going to the hospital for any reason made me nauseated as soon as I walked in the door. I was saddened and frightened of even talking about this with my mother, but I tried to be careful not to project my fears onto her or, by anything I said or did, to encourage her to share them.

We all spent Thanksgiving together at my younger sister’s new house on the water at Packanack Lake, New Jersey. Although Mom was suffering from nausea and diarrhea caused by chemotherapy and therefore was somewhat subdued, she looked good, got around with some of her old energy, enjoyed seeing my sister’s new place and being together with all of us. We were all relieved to see her at least holding her own, and regarded all this as a good sign. There was, however, one unavoidable and ominous note. My mother had always been a superb and confident cook. She made excellent pies from scratch, any kind of pie we liked—apple, pumpkin, lemon meringue, coconut custard, chocolate cream—and we always looked forward to these homemade pies at all our family gatherings. But this Thanksgiving there simply were none. She and my father arrived for dinner with several pies in cardboard store boxes. Embarrassed and ashamed to the point of tears, my mother admitted that at the last minute, her own “just didn’t turn out,” so she had sent my father to the supermarket to buy pies for our dessert. Quietly horrified, we commented on how good they were for “store-bought,” and let it go at that, just as we all continued to take a willfully optimistic view of her chances.

According to my sisters, Christmas was her last good day. By this time, she had begun another chemotherapy protocol and was taking medication for pain. She was uncharacteristically neglecting how she or her house looked, and seemed to have difficulty focusing on what was going on around her. But she rallied for the
day and the big meal prepared by my sisters. After this, whenever I called my mother on the phone, she was in bed, immobilized by the pain and her disorientation from it and the drugs. Once she said to me, “I never thought it would be this bad.” The antecedent of “it” was unclear. Did she mean chemo? pain? cancer? dying? Two weeks later, on January 9, 1991, my parents called to wish me a happy 49th birthday, and I could hear the fear in my father’s voice. Up until now he had always been deliberately putting the best face on everything, not only because if he didn’t, my mother might hear what he really felt, but also, I think now, because he wanted to protect me from what he might well have sensed were my own difficulties in dealing with my mother’s illness. When my mother got on the phone I asked her how she was feeling, and she said she was not doing very well. Her voice sounded weak, and she was having difficulty breathing. There was a prolonged silence, and then she said, “I have . . . I have . . . oh, what is it?” Then she called out to my father: “Dad, what is it that I have?” I heard his voice in the background but couldn’t make out what he was saying. Then my mother’s voice came back with some note of surprise at having discovered what she was looking for: “I have cancer. That’s what it is, cancer.”

AFTER TRYING YET another chemotherapy protocol, the doctors decided toward the end of January to discontinue treating my mother. As they put it, the cancer had “outrun” the treatment. They estimated that my mother had between a couple of weeks and a couple of months to live. Now bedridden most of the time, unable to cook or look after the house, or even take care of herself adequately, heavily medicated for pain, my mother seemed really to be going further and further away from us and to live more and more on what we called the “other side.” She was oblivious to most activity immediately around her, as though she were instead deeply engaged in some conversation in her mind set way back in another time, in another place. The family arranged for my mother to be cared for at home professionally during the day, for my father was visibly shaken by his inability to care for her alone and obviously worn down by having spent so much time watching her decline so rapidly.

FROM THE MOMENT I first started chemotherapy I strove never to miss work unless I had to; indeed, I had developed a tendency to take on more work around the college than I probably should have. I don’t think this was some simple compensatory gesture to prove my manhood; it was more the feeling that teaching was my chosen profession, my vocation, that this was my life, and that I wanted to stay with it and do as much of it as I could while I was still able. I did not want to lose the atmosphere, the rhythm, the energy of the classroom, for even when I did not feel well physically, it gave me a spiritual sense of well-being. But as I worried about my mother, about not being with her and my father and sisters, and about my own disease, I bore down so hard on teaching every day of the January term, determined not to miss a day, to make everything seem “all right” for myself and others that I became increasingly inaccessible myself. I was anxious, tense, and depressed.
I was obviously not an easy person to live with during this time, and part of the reason was that I tried to keep most of my strongest feelings to myself because I considered them too awful, too depressing to share with others. But this strategy failed me, or I failed to execute it, for I would, often inappropriately and irrationally, express my worst fears and anxieties to my wife, who was naturally upset both by my being silent and withdrawn and then uncontrollably morbid, fearful, angry, and resentful. Having lived with me through the chronic maintenance of my disease and the many frightening crises it caused, Susie was struggling to preserve herself and her life from being completely taken over by my illness. The main form this effort at self-preservation took was her going away to do research for her next book, to give readings, and to be a guest teacher at other institutions. This year she was on sabbatical and so she was away even more often than usual. Because I did not understand at the time as well as I think I do now what Susie was seeking, I was often hurt by her absences and found our many leave-takings hard. But, typically, I did not reveal my feelings or talk them through with her. Instead, I masked them by a parodic military ceremony in our driveway as she took off in the car. I would stand at mock attention and give a grotesquely rigid salute as she backed out and headed down the road. My vision of her became focused on her small arm, delicate wrist, and tiny fingers slowly forming a little cupped wave of the hand as she left me there alone. This gesture of hers seemed so perfunctory, almost absent-minded, that I felt as though she were already gone away, living a life of her own, apart from me.

During this month of January I felt emotionally alone and isolated, and what strikes me now as I look back on it is the way this experience with Susie was also repeated with my daughter. Our older child, James, was away at college, our younger at home, a senior in high school. When Susie would go away, my daughter Anne and I would be home alone together. This arrangement, though not always easy or fun, did serve to bring us closer together. Anne was busy at school and active in many extracurricular activities, but we shopped and cooked and ate together, shared accounts of our days, and generally connected in an authentic and often intense way. Anne always wanted to know what was going on with my disease, and she was sympathetic to how I felt about what was going on with me and my mother. Without being intrusive or even asking a lot of questions, she was able to pick up on how I was feeling and respond in an empathetic way. But, every weekend during the winter Anne left to go to Sugarloaf Mountain to pursue her love of snowboarding and to visit with the family of a young man to whom she was very attached. Maybe she, too, just needed to get away for a time. Perhaps because she knew of my good-byes to Susie in the driveway, she parodied the mock-military ceremony through a raucous leave-taking of her own. She would honk the horn loudly and repeatedly as she backed down the driveway and headed up the road. She would also either roll down her window, or, preferably, if the roof of her car was not covered with snow, open the sun roof, stick her arm up through it and wave vigorously. This was Anne: dramatic, spirited, funny. But I missed her too, and I dreaded the
prospect of her going off to college in the fall, leaving me without her bright presence. When she and Susie were both gone during those winter weekends, I would be left alone with the dog to listen to my collection of female jazz singers from Billie Holiday through Ella Fitzgerald and Sarah Vaughan to Diane Schurr.

AT THE END OF January, I left to see my mother for what I knew would be the last time. When I arrived on Thursday evening, Mom looked strangely ethereal to me. My sister Joyce had helped prepare her for my visit, and she was sitting up in bed with her hair combed, wearing lipstick, a nice sweater over her nightgown, and the special earrings we had given her for her 75th birthday in her pierced ears. In these superficial ways she looked very much like herself. But she had lost weight and hair; her face was much thinner; her skin was waxen, clearly showing the shape of her skull. Most of the time she seemed to be living psychically in another world. Everything we did seemed to reach her as though across a great distance. A person walking into her room to bring her medication, something to eat or drink, or just say hello, all came as a surprise to her, almost an intrusion.

Yet she was so obedient, so compliant, when we tried to move her or asked her to help us help her. Her questions were plaintive, childlike. She asked me, clearly suffering, “What do I have? What is wrong with me?” Then, before I could answer, she said, “You can’t say. You don’t know.” When I told her she had cancer, she lapsed back into the trance her life had become, as though she were already gone. We could not seem to connect with her in the present moment, in the actual circumstances of her disease and dying.

Memories seemed to shoot across her mind. When I came in to eat my breakfast cereal with her the next morning, she blurted out, “Oh, I remember that!” When I asked her what it was that she remembered, she said, “Where I used to eat at your house.”

She did occasionally issue commands. On Saturday morning, after getting her up out of bed to pee at 5:30 and 7:30, I was in the kitchen letting my parents’ chubby and indulged Sheltie out, and my mother called for me urgently. When I got into the bedroom, she was calling “Ed, little Ed.” Then, when she was sure I was there and she had my attention, she said, “Get me into the hospital, please.” I asked why she wanted to go and she said, “They can do more for me there.” Given her state of mind, I was unclear whether she meant that they could make her more comfortable, or that, not consciously knowing that she was dying, she believed they could still treat her disease in some beneficial way. But the idea of her now physically removing herself from the house with which she was so identified seemed another attempt to go away from us.

WE HAD A LONG family conference about whether to hire a private 24-hour nurse and keep Mom at home or to go along with her wish to be put in the hospital. It took a long time, but my father finally told us not only that he was worried about caring for her at home, even with the assistance of a professional nurse, but also that he did not want her to die at home. He had witnessed enough of her dying in this house. We decided to send Mom to the hospital the next day, the day I was to leave to go back to Maine.
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My mother rarely drank. She would have a glass of wine as part of the ceremony of her meals, but that was it. Later that day, when I joked with her, as I often did, about having a drink with us before dinner, she looked directly at me and smiled just like her old self. “Are you kidding me?” she said. In her voice was the familiar tone of mock exasperation and delight that appeared whenever she caught us out in an effort to fool her. In this fleeting moment she was herself again, and those were the last words she addressed directly to me, acknowledging the playful nature of our adult relationship.

The next morning we called the doctor, who was out of town, waited for his partner to call back, called the ambulance, and waited for it to arrive. My sisters and I paced up and down the deck, looking out at the Shark River, waiting for the ambulance. It was clear and sunny, with little wind, the temperature setting a record for that day by reaching into the 60s. Finally I went in by myself and got Mom up and to the portable commode and gave her some Italian ice with her pain medication, crying the whole time and telling her I loved her. She seemed not to notice, and I was just as glad, for even now I am not sure whether I was mourning only for my mother, not only because I was her first child and only son and she my mother and I loved her and could not tolerate her suffering and could not imagine life without her, but also because I, too, was a cancer patient with an incurable, progressive disease that in the past few months had seemed to be speeding up. In her drawn, waxen, olive-skinned, skull-like face, whose features so resembled mine, her helpless body, and untethered mind, I saw myself in the all-too-immediate future. I think now that perhaps this powerful seeing of myself in my mother is what we all must see in the suffering and dying of others: ourselves, all of us who, being human, will suffer, become ill, and die. But only by seeing this in those we love, who have loved us all of our lives, whose features resemble our own, do we permit ourselves—because we really cannot defend against it—to be overcome by this recognition.

My mother was taken out of the house on a stretcher, through the kitchen, out the side door, and down the side steps of the wrap-around deck. My sisters were to ride with her to the hospital, and I would soon begin the long drive home. At the bottom of the stairs I stopped the progress of the ambulance crew and kissed my mother for what I knew was the last time. As they continued their procession toward the driveway and the waiting ambulance again, my mother weakly raised her swollen right arm against the restraints holding her securely on the stretcher and waved good-bye to me for the last time, her hand oddly out of sync with her arm.

AFTER MY MOTHER’S death, after the burial mass, and after the end of spring term, my repeat CT scan showed what the medical profession calls with unintended metaphorical accuracy “increased tumor burden.” I had only one damaged kidney so I was reluctant to risk it in further treatment, at least as long as I was feeling as well as I did. Nor was there sufficient data to demonstrate that any of what my doctor calls the “industrial strength” chemotherapies remaining to me would do any good against my strange disease. So the questions of whether to undergo treatment, what kind, when, and for how long, all remained. As my
doctor said to me, "These are not just medical questions, Ed; they are ultimate, existential questions."

For the moment, I decided to leave them hanging, to wait and see, and to continue the familiar struggle not to let my knowledge of my disease, or the fear caused by the knowledge, interfere with my living of my life in the present moment. In the summer months since my first operation in 1977, this for me has always involved sailing on the coast of Maine. My illness and my sailing have been inextricably bound up with one another. So when I returned from the hospital in Michigan in late May, I uncovered, prepared, and launched my boat. Although my children are more willing to sail now that they are older and I do sometimes take friends who enjoy being out on the water, I most often sail alone. I love the concentration that being out there by myself requires, the complete and necessary attention to the act that can paradoxically render things of the world so precisely and luminously, which has always given me an extraordinary sense of well-being while at the same time abolishing my sense of self.

And so it was that one day, sailing by myself in Penobscot Bay out from Castine toward Parker Cove on the northeast side of Islesboro, I found myself once again completely absorbed in the atmospheric tension of wind and wave.

Near land it is sunny, clear, and bright. With winds building from the southeast, the light shatters on the waves, and takes on their motion, while giving them in return a sharp, shimmering, prismatic brilliance. But out in the bay there is thick fog, which the sun’s light illumes as though from the inside, only occasionally and briefly revealing its presence above in the sky. There is a strangely disorienting merger of the elements of water, fog, sunlight, and sky so that, moved silently by the wind in the sails through the motion of the sea, I feel transported not simply from one place to another but into a whole other plane of existence.

As I emerge from the fog in the middle of the East Bay toward Parker Cove, I am approaching a large house elevated on a point with a tall flagpole, the flag blown straight out and fluttering. The flag, combined with the sharp quality of the light, which had the effect of showing all objects in their full roundness and solidity, reminds me of Monet’s Terrace at Le Havre. As I continue close into shore, the shapes and bits of color compose themselves into people eating and drinking on the porch and the steps leading down from it and children playing on the lawn in front of them. Because it is just before high tide at 1:15, I can go in close to the rocky shore and, as I do, I notice a woman get up quickly and run into the house. She emerges from another door with binoculars, to look at me. When she gets me in sight, while holding the binoculars in her left hand, she gives me a big wave, her right arm fully extended and moving energetically in a wide arc. Then all the people, adults and children, wave to me. I wave back, come about smartly and wave again, now going away from Parker’s Cove back out into the bay and the mixture of light and fog.

This was all deeply moving to me at the time. Before I even realized what was
happening, my eyes filled with tears and I was sobbing loudly. The vision had seemed at first like a painting because everything in it was so composed and beautiful, so perfect. But then it all came alive; the people were real and alive in the moment and so was I. No longer subject and object, we were participants in the moment together. And I was there for it, fully present and focused.

And the moment remains in my mind; it endures. I often look up and see again in my mind’s eye the figure of the woman, waving to me. Because I did not have my binoculars in the cockpit when I saw her, I do not know whether she was young or old, beautiful or plain; her actual features remain elusive. In the absence of them, I can project onto her the face of my mother, my wife, or my daughter. But this seems a limitation on the significance of this experience for me. Even though I cannot explain it, I derive from this visionary moment a deeply abiding sense of peace and assurance and joy. When it recurs, I can feel the light and the fog and wind on the water and my boat moving through it, and when I again see the figure of the woman waving to me across the distance I know intuitively that this is not a wave good-bye, signifying death, or estrangement, or loss, but a welcome, beckoning me back into the life of the world. And whatever my disease and its treatment may bring, whatever I may decide to do, in this recurring and abiding moment I am riding the wave of mystery that is my life, and I fully know it.