

Mr:

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Swimming in the sea of death

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MY MOTHER had lived almost her entire seventy-one years believing that she was a person who would beat the odds, no matter how steep they seemed. In this, as in so much else in her life, she remained determined, and as consistent in old age as she had been in childhood. Above all, it was that childhood, about which she often described herself as having felt “abandoned and unloved,” that remained the touchstone both of resistance and of ambition—two ideas that for her were never entirely separable. “My earliest childhood decision,” she wrote in her journal, “By God, they won’t get me.” What this meant for her, she added, was an “absolute decision not to be done in.”

Obviously, she was not alluding to being done in by illness, though she was crippled by asthma as a girl, but rather by her mother, whose coldness and withholding nature (my mother's words, again) so haunted her, or by her jovial, war hero stepfather (her real father died in China when she was four) who, meaning absolutely no harm, nonetheless would tell her constantly—or at least, so she experienced it—that she shouldn't read so much if she ever hoped to find a good husband. My mother herself never doubted that it was this will to survive, ignoring the conventional wisdom, to bounce back, to thrive against all odds, that had given her this paradoxical conviction of being a lucky person—that is, of having a good chance at being the exception in whatever situation she found herself. It had also, she sometimes told me, turned her into the risk-taker that she would become as an adult.

But all this effort that she had put in to shaping herself into the person she had first dreamt of being while still a solitary, asthmatic ten-year-old in southern Arizona would serve her well when, in 1975, she was diagnosed with advanced breast cancer that had spread into

seventeen of her lymph nodes. In her essay "AIDS and Its Metaphors," written over ten years after her illness, she would reminisce a little proudly of "confounding my doctors' pessimism." And when she spoke of their pessimism, she was putting it mildly. What I don't think she ever knew, what I never told her in any case, was that William Cahan, at that time her principal doctor at Memorial Sloan-Kettering Cancer Center in New York City, never really expected her to live. That was what he had told me either the first or second time we had a moment alone together after he had admitted her to the hospital.

Those were the days in which it was standard practice for doctors to lie to cancer patients. If they were candid at all, it was usually by opting to deliver all bad news to family members instead of leveling with their patients. Of course, attitudes were changing even then, and some American physicians were beginning to take seriously what at the time seemed like the revolutionary ideas of patient autonomy and informed consent that today are routinely taught—whether effectively or ineffectively is another matter—at American medical schools.

But for the most part in those days, most physicians shared a set of assumptions about how much truth to tell and to whom that had led ninety percent of American oncologists surveyed in 1961 for an article published by the *Journal of the American Medical Association* to admit that they would not tell their patients that they had cancer.

Bill Cahan was still very much of this school. What he thought I, as a family member, was supposed to then do with the death sentence he had pronounced was not something he ever said. And I was at first too stunned, and then too frightened, to ask him to elaborate. I suspect my experience was typical for the time. I remember pacing the corridors of the breast cancer floor at Memorial Hospital wondering what to tell my mother and what not to tell her. To do so seemed like sadism. But not to do so seemed like betrayal. In the end, I did nothing.

Still, even if I chose to remain silent (if “chose” is even the right word), and if Bill Cahan and her other principal doctors were not willing to level with her, my mother certainly knew that the odds were that she

would die. Nothing anyone said or didn't say could occlude the fact that her cancer was at stage IV, the last and worst category in measuring the onrush (or, as physicians so curiously put it, “progress”) of the disease. My mother knew how dire her situation was. She just chose not to speak of it.

She did write about it, though. “With daggers lying at the end of my dreams, I [don't] sleep much. . . . I am ill, perhaps irreversibly ill,” she noted in her journal as she lay in her bed in Memorial Sloan-Kettering after undergoing that version of a radical mastectomy called a “Halstead.” In a Halstead, it is not just the patient's nipple and areola and the breast itself that are removed, but also most of the muscle of the chest wall and the lymph nodes in the armpits, which, in my mother's case, had already been shown to be cancerous. It is a brutal operation, developed at the end of the nineteenth century when excision was the only real tool physicians had. In 1975, for breast cancer as advanced as my mother's, it was still being routinely recommended (it is rarely if ever done today), normally followed up with chemotherapy and, in my mother's case, chemicals to

boost her immune system—an approach then in its medical infancy and whose efficacy remains today a matter of dispute among oncologists. In fact, doctors at another cancer center, the Cleveland Clinic, had recommended a far less radical approach. But my mother was convinced that the more that was done, the better her (slim) chances would be, and so she opted for the Halstead and returned to New York.

I do not know what my mother really hoped for or expected during those months, or whether she really believed that she might actually survive. Her two essays on illness are almost *anti*-autobiographical—intentionally so—and in any case were written long after her treatments had ended and all seemed to be well. And after her surgery and during her chemotherapy, she became so opaque to the rest of us, so seemingly encased in her pain and fear, that I felt that to have asked her would have been to sap what little strength she could still muster. But her journals, which she began keeping again quite soon after her surgery, tell a different story. They are punctuated with the repeated notation: “Cancer = death.” In one entry, my mother notes

without further comment that one of the floor nurses, after leaning over “to swab my papery lips with glycerine,” had told her pointedly, “Everyone’s got to die sometime.”

But what she might have known or at least inferred, whether as probability or as fate, was not the same as what she did. If she managed to confound her doctors’ pessimism, somehow she managed to confound her own as well. On the one hand, she could write that she found herself in a state of “leaky panic,” and note: “Save my life? No. Prolong it.” But at the same time, she systematically set about trying to defy the odds and did everything she could think of to survive. She was not ready to die at forty-two; it was as simple as that. And she believed in her own will, and, grandiose though it may seem, in her own star. Such belief is easy to mock. But everything my mother accomplished, and she accomplished a lot, was undergirded by that belief.

And the salient point is that in an essential sense she wasn’t wrong. As her friend, Dr. Jerome Groopman, the chief of experimental medicine at the Beth Israel Deaconess Medical Center in Boston, who is himself a spe-

cialist in blood cancers, commented on her decision to me a few months after my mother's death in 2004: "Terrible as the statistics were, there's a sense in which Susan was absolutely right. The statistics only get you so far. There are always people on the tail end of the curve. They survive, miraculously, like your mother did with breast cancer. Yes, her prognosis was horrific. But she said, 'No, I'm too young and stubborn. I want to go for treatment.' Of course, statistically she should have died. But she didn't. She was at the tail end of that curve."

Groopman is a scientist. It is second nature for him to think in terms of statistical curves. In doing so, however, he never loses sight of where on the curve most of his patients are likely to fall. But while my mother must have known something of this, had her doctors told her that stage IV breast cancer was hopeless, I don't know what she would have decided to do. But because there was some small hope of a full remission of her disease, and because, for our different reasons, Bill Cahan and I were both unwilling to tell her just how bad things were, she could find the strength to tell herself that *someone* had to be lucky, and buttress that statistical

possibility with a lifetime's experience of believing in her own luck. But it was by no means all magical thinking. She also did what she could, as she saw it, to change the odds.

My mother loved science, and believed in it (as she believed in reason) with a fierce, unwavering tenacity bordering on religiosity. There was a sense in which reason was her religion. She was also always a servant of what she admired, and I am certain that her admiration for science (as a child, the life of Madame Curie had been the first of her models) and above all for physicians helped her maintain her conviction—and again, this, too, was probably an extrapolation from childhood—that somewhere out there was something better than what was at hand, whether the something in question was a new life or a new medical treatment. Soon after she got out of Memorial Sloan-Kettering, she began to search for it. Unreasonable? Probably. But the project of looking itself was immensely strengthening to her during her long, painful convalescence after the Halstead. I remember that it was only when the talk turned to new treatments that my mother's face bright-

ened and the flat, demoralized quality of her language postsurgery became at least briefly energized.

At that time, my mother's companion was a French woman named Nicole Stéphane. In fact, it was entirely thanks to Nicole, who literally refused to take not one "no" but many for an answer, that my mother made contact with Lucien Israël, a Parisian oncologist who was then doing research into immunotherapy as an adjuvant treatment to chemotherapy. Dr. Israël was also working with an Italian colleague, Dr. Gianni Bonadonna, on new combinations of agents to be used for the chemotherapy itself. Dr. Israël looked at the slides Nicole had brought him, and wrote my mother simply, "I do not think your case is hopeless." That sentence was the turning point for my mother. It gave her the strength to continue, and she would subsequently attribute her survival largely to Dr. Israël's care. Perhaps there, at least, was a marriage of magical thinking and reason. The great Danish physicist Niels Bohr used to tell the story of a neighbor who "fixed a horseshoe over the door to his house. When a common friend asked him, 'But are you really superstitious? Do you

honestly believe that this horseshoe will bring you luck?' he replied, 'Of course not; but they say it works even if you don't believe in it.'"

But was my mother right to believe? And was Dr. Israël right to hold out such hope to her? Using Jerome Groopman's yardstick, any oncologist could have said what Dr. Israël said to my mother without either lying or betraying his Hippocratic oath, at least in the sense that, indeed, statistically, a few people with stage IV metastatic breast cancer did survive. After all, the Parisian doctor had not told my mother that her case was hopeful or that she was likely to live. But the argument can also be made that what he did, even if technically correct, was to hold out false hope since the main thing that the statistics showed was that the overwhelming majority of people in my mother's medical condition in 1975 died, and died fairly quickly. In my mother's case, what we would today call Dr. Israël's "spin" was a lifeline, a reason to go on. But in another case, one in which the patient was less sure of what she wanted than my mother was? Or were it to serve as a generalized *modus operandi* for oncologists?

Would what Dr. Israël did have seemed as impeccable?

Yes, hard cases make bad law, as the cliché goes, but medicine is not law and every cancer patient's case is a hard case. I was profoundly grateful to Dr. Israël at the time for what he said as well as what he subsequently did, and I remain abjectly thankful to him to this day. But I am not smart enough to know if he did the right thing. More to the point, I am not sure that most doctors are smart enough to know if *they* are doing the right thing. A scientist, a clinician, and a sage. It's a lot to expect—too much, perhaps.

On another level, though, my mother had few options. The treatment Dr. Israël proposed and that even the New York doctors seemed to agree offered the only chance of survival for my mother was experimental (and the immunological component is no longer as accepted as it would become in the years immediately after my mother received it—another magic bullet in the quest to cure cancer that did not live up to its early promise). For my mother, its effects bordered on the unbearable. The doctors at Memorial Sloan-Kettering agreed to administer Israël's chemotherapy and his

immunological prescriptions in New York and, once more, my mother became an exception. Writing of this period, she described how “twice a week I return/haul myself to the hospital and present my opaque body to Doctor Green or Doctor Black [these names, of course, are pseudonyms], so they can tell me how I am. One pushes and pulls and pokes, admiring his handiwork, my vast scar. The other pumps me full of poison, to kill my disease but not me.” Her fantasy was bitter. “I feel like the Vietnam War,” she wrote. “My body is invasive, colonizing. They're using chemical weapons on me. I have to cheer.”

It would be more accurate to say that she *learned* to cheer. Special she might feel, but there is nothing victorious about her tone. Instead, all through the journals she kept during her treatment, she returns again and again to how diminished she feels. “People speak of illness as deepening,” she writes. “I don't feel deepened. I feel flattened. I've become opaque to myself.” But at the same time, she keeps asking herself how she can transform this feeling. Is there some way, she demands, that she can “turn it into a liberation”?

In retrospect, my mother was painfully acquiring the cultural traits that were simultaneously the privilege and the burden of what she would later describe in her essay "Illness as Metaphor" as her new citizenship in the world of the ill. As the months passed, and as she seemed to be weathering both the toxicity of her treatment and the tremendous psychological adjustment to what she thought of as her new "maimed" self—or, more bluntly put, the damage done to her sexuality from which I do not believe she ever fully recovered—she began not only to hope in earnest that she might survive, but also to fundamentally recast in her own mind what had happened to her. Early on in her illness, she wrote that, much as she might reject it intellectually, emotionally she accepted the old claim of the psychologist Wilhelm Reich—the one that had impelled Norman Mailer, after stabbing his wife, to boast that "I got a lot of cancer out that way"—that cancer was mainly the product of sexual repression. "I feel my body has let me down," she wrote. "And my mind, too. For, somewhere, I believe the Reichian verdict. I'm responsible for my cancer. I lived as a coward, repressing my desire, my rage."

But by the time her treatment was finished, this self-flagellating judgment no longer seemed to weigh so heavily upon her days. (I do not, of course, know what she thought or felt in the hours before dawn when we are all at our most vulnerable.) Instead, my mother began to believe not only that she really might survive, but that living in this new realm—the kingdom of the sick, as she called it—might actually be a context for writing better, becoming a better person; in other words, that there was fulfillment to be had as well as death forestalled. My mother's "default mode" had always been the transcendental, or, perhaps more accurately, that of the exemplary student who also aspires to be the exemplary soul. Don't laugh or smile condescendingly, reader: there are more ignoble ambitions. In retrospect I am not surprised that as she began to recover from the chemotherapy, that was where she again felt both most at home and most in control. And even the illusion of control, even if all it consisted of was collecting information as if for a college paper, was paramount in a situation that, when all was said and done, was out of her control.

“We tell ourselves stories in order to live.” This justly celebrated line of Joan Didion’s has occurred to me often as I look back on my mother’s struggles with breast cancer in the seventies, with the uterine sarcoma in the nineties, and, of course, with the MDS that killed her. For as the years went by, my mother began more and more to think of her survival not as a species of miracle, since the miraculous had no place in the way she thought, nor as an accident of fate or genetics, let alone as a statistical anomaly, but rather as the result of medical progress and also of her willingness to have the most radical, mutilating treatment, which was something many people who subsequently came to see her for advice or referrals for their own cancers refused to do, much to her consternation. As she understood her own story, choosing the milder version of the mastectomy that had been proposed at the Cleveland Clinic would have meant not making the commitment to survival that was required. Real commitment for her was always radical.

As her thinking evolved after this utterly unexpected recovery from metastatic breast cancer, fighting cancer

became for my mother a question of the right information, the right doctors, and the right follow-through, and above all the willingness to undergo any amount of suffering. I do not mean this in any primitive, public-library façade, “knowledge is power” sense. It was putting the knowledge to use that was sustaining for my mother. She herself became a militant propagandist for more rather than less treatment—a stance that became harder to sustain as at least some empirical evidence seemed to show that radical treatment did not necessarily alter patient outcomes, and that it was the doctors in Cleveland who had been at the cutting edge of the science. But while my mother might quote Buckminster Fuller’s gnomic aphorism “Less is more” when talking of aesthetics, as far as she was concerned when it came to cancer treatments more was always better. That was how she had survived. How could anyone equally intent on survival do otherwise? I recall her genuine bafflement over the decision of an acquaintance of hers not to have a Halstead for her own stage IV breast cancer. “She’s just throwing her life away,” my mother said mournfully.

The question of whether this woman was really ever

in a position to be the arbiter of whether she would in fact live or die was not one, at least as far as I know, that my mother ever posed to herself. But how could it have been otherwise? How could my mother *not* have extrapolated from her own experience? No one, not even someone who loved reason (and, more crucially, loathed appeals to the subjective) as my mother did, can be expected to be that rational in extremis. But if it was not subjectivity on her part, I do think there was bravado at work as well. If there wasn't, then how to explain the fact that although my mother was medically literate—after her treatment for breast cancer, *Harrison's Principles of Internal Medicine* was added to the essential books that she kept in her work space—paradoxically, she was also medically somewhat incurious—she for whom curiosity was always a touchstone. It was a matter of conviction for her that great advances were being made both in the understanding and the treatment of cancer, and the advice she gave fellow cancer sufferers was based on that premise. But, assiduous student though she was in any subject that even remotely interested her, she did not follow developments in cancer

research, let alone in discoveries in the fundamental biology of cancer, with the care that her intelligence, her considerable layman's knowledge, and even her lifelong interest in science and particular aptitude for biology would have permitted her to do had she really wanted to.

In any case, I am not sure what cause such diligence would have furthered. Would such knowledge have brought her solace or despair? My fear is the latter. For example, if her doctor at Memorial Sloan-Kettering had not conformed to the oncological conventions of the era and instead told my mother in 1975, when she was diagnosed, just how terrible the statistics on survival for stage IV metastatic breast cancer actually were, would she have had the strength of will to go forward with treatment? Reading her diaries after her death, I am overwhelmed not by the force of her will—as I had imagined that I would be since she so prided herself on it—but rather on the depth of her despair. “While I was busy zapping the world with my mind, my body fell down,” she wrote in her journal. “I’ve become afraid of my own imagination.”

I have to believe that for her, knowing these concrete

statistics, like fully taking in the realities about the actual scientific and clinical progress (or lack thereof) being made in the effort to understand and treat cancer, would have meant risking letting loose all the devils of her imagination. So in a way, for the sake of her happiness, even of her sanity, I am glad she did not go further than she did in finding out what the state of play in cancer really was. The news was so terrible. The news is still so terrible. As I would find out. As she would find out. The reality, for her, was that it was less a matter of having a sword of Damocles over her head as it was of having it touching her throat. There is such a thing as too much reality.

In any case, our relationship was not one in which I would have been drawn to ask her about any of this. In 1975, when she returned home from Memorial Sloan-Kettering (I had returned home from university to help look after her), she quickly made it plain, though she never came out and said it so bluntly, that there were “no go” areas on the subject of her illness. She did not literally say that she wanted to be told that she would make it, and that the treatment she had received really

had saved her life. To the contrary, in words she asked for the truth. But her actual wishes were self-evident to everyone who really cared about her. It was to those that I acquiesced; it was in those that I became her accomplice, albeit with the guiltiest of consciences. But leaving my reading of the situation, the story I told *myself* in order to live, as well as the specific dynamic between us, to one side, I’m not sure I would have said more than I did even had there been a green light flashing invitingly.

It simply seemed out of place, almost destructive, even to ask her if she wanted to know more, let alone to sound a note of caution. This was how I reasoned, anyway, again precisely on Didion’s “we tell ourselves stories in order to live” principle. What if, by asking, I inadvertently created doubts in her about whether she really had survived her cancer? What if the Reichians were right and it was how you felt about your chances of survival that helped determine them? I did not believe any of that (nor do I now) any more than my mother did. But I was not prepared to take the risk. Twenty-nine years later, as I tried to understand what it meant that she had MDS, I found I still was not prepared to do so.