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## *Notes from a Difficult Case*

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**A**lmost everyone I know advised me to sue. Their advice was not casual, because almost everyone I know is an attorney. As am I.

At 42, I'd been an attorney almost half my life.

At 42, the doctors let it be known that I was far advanced into what would be the second half of my abbreviated life.

These were not just any doctors; these were the doctors at the world famous cancer center.

If I'd been charged with a heinous crime, I would have retained the best criminal defense attorney I could find. Convicted of a rare cancer, I sought the best advocates for my appeal.

The doctors at the famous cancer center pronounced mine a difficult case.

My tumor was inoperable, the cancer had metastasized to my liver, and the only possible treatment was a highly toxic regimen of chemotherapy. If the chemotherapy infusions were not successful, I had no chance of survival.

The doctors at the world famous cancer center were correct in their prediction regarding the chemotherapy: it failed to shrink the twenty pound tumor that distended my abdomen even more pronouncedly now that I had lost thirty pounds after four cycles of chemotherapy.

But they were incorrect about almost everything else.

My tumor was not inoperable.

My cancer had not metastasized to my liver.

Chemotherapy had never been successful on a cancer such as mine. I turned 43. 44. 45.

The circumstances of my ordeal are both simple and complicated. They could be allegations on a complaint, numbered and neat, and augmented by specific dates and quotes from the defendants' own records:

¶1. On such and such a date, the patient plaintiff was seen by the Chief Sarcoma Surgeon, who observed that the plaintiff had a "very large abdominal mass and lesions in the liver consistent with liver metastases."

¶2. On a date approximately a week later, the patient underwent a liver biopsy, for which the cytology report read "suspicious cells present" on "scanty evidence." (emphasis added)

¶3. On a date approximately another week later, the patient plaintiff was seen by the oncologist, who told her that she had an "extensive intra-abdominal, presumed soft-tissue sarcoma, probable liposarcoma, with hepatic metastases," with no "curative potential" and "no role for surgical intervention at this time, given the presence of metastatic disease."

¶4. On yet another date yet another week later, the patient was ordered to have a biopsy of the abdominal mass, the surgical pathology report for which was liver biopsy with the diagnosis of "well-differentiated lipoma-like sarcoma." (emphasis added)

Meaning that within these four weeks, the patient was first diagnosed with liver metastases by the famous sarcoma surgeon, given a liver biopsy to confirm this judgment on "scanty evidence" that showed "suspicious cells," then told she was incurable by the oncologist because of liver metastases, and then given another biopsy of the abdominal tumor, which was mislabeled a biopsy of the liver.

In other words, the doctors screwed up their biopsies.

Later, the complaint would introduce the expert opinions from oncologists and oncology textbooks.

¶32. There has never been a case in which liposarcoma has metastasized to the liver.

¶33. Well-differentiated liposarcoma is a non-metastatizing lesion.

¶34. Chemotherapy is ineffective on well-differentiated liposarcoma.

In other words, the doctors screwed up more than the biopsies.

The doctors at the famous cancer center were wrong when they pronounced me hopeless, incurable, and inoperable because of liver metastases, not knowing that liposarcoma, in its well-differentiated state, does not metastasize. Even if it becomes poorly differentiated, liposarcoma does not metastasize to the liver. I was misdiagnosed and mistreated.

“Screwing up,” translated into legal language, is a breach of the duty of care. “Deviation from the applicable standard of care” is one of the elements necessary to establish a cause of action for medical malpractice.

My complaint would omit facts that are not legally relevant: details that do not establish breach of the duty of care and that may not be objective or provable. I do not recall the dates of these occurrences and if they appear at all in the medical records, those narratives would differ from mine. These are the legally irrelevant facts that subsume my complaint:

¶ The surgeon’s secretary called me and told me the liver biopsy confirmed metastasis. His secretary. Who could not answer my questions. Who did not have a soothing voice. Who was not a surgeon.

¶ The oncologist, when questioned, repeatedly told me that of course she/they were correct that surgery was useless because she/they were at the world famous cancer center. Though, perhaps, she admitted I could find “someone off the street to do surgery.”

¶ The oncologist smirked—I swear—when I lost my previously waist-length hair.

¶ Despite my protests, I was repeatedly advised to take tranquilizers, given prescriptions for Ativan, and referred to a psychiatrist to help me deal with “it.”

¶ A phlebotomist who stuck my emaciated arm with the needle too sharply, jabbing after he couldn’t find a vein, told me I was being difficult and that I wasn’t really hurt.

¶ I had to carry the order for the CT scan to the technicians; an order on which my doctor wrote the diagnosis “huge abdominal tumor.” “Huge” was underlined. Twice.

¶When I asked about the long term effects of the chemotherapeutic agents with which I was being treated, my oncologist replied that “long term effects” were really not the issue—and I swear it again—she smirked.

According to several studies, the decision whether or not to sue for medical malpractice is not necessarily related to the degree of the doctors’ negligence or fault, or to the degree of the patients’ injuries, including death.

Instead, the most consistent variable is something that is named as compassion, caring, or communication.

According to some of these same studies, only one person in thirty-five who suffers what the medical profession calls an “adverse event” decides to sue for medical malpractice.

I did not want to be the kind of person who sued.

By this I did not mean greedy, avaricious, money-hungry, gold-digging, grasping, or craven. I had become an attorney to work for the poor, turning down offers from large law firms which included bonuses of more money than I’d ever made in my life and yearly salaries that seemed, to me, obscene. Then I became a law professor, certainly not one of the most lucrative positions.

By this I did not mean vengeful, spiteful, savage, malicious. I knew I had the best revenge against their misdiagnosis: I had defied them and I was living and well.

By this I did not mean litigious. I admired people who sued, people who had the courage of their convictions, people who used the courts as social reform.

By this I meant damaged.

Damages are the key element in any cause for medical malpractice. It is not enough that the doctors have made mistakes; these mistakes must cause damages to the patient.

Although in some cases causation can be difficult to prove, in my difficult case, causation is unquestionable.

Damages are my difficulty.

In the medical records, the doctors note that “the patient understands that her disease is incurable.”

But I did not understand. I railed and sobbed and protested. I did not sleep and could not eat, even before I succumbed to chemotherapy. I was too young and too otherwise healthy to die, wasn't I?

I lived with my imminent death for months and months. Dark days and darker nights. There were no sunsets and no sunrises during all that time. I read books I can't recall. I cursed my career, devoted to constitutional law rather than molecular biology.

Simple phrases—“planning for retirement,” “after my son graduates high school,” “next summer”—constricted my throat.

Trivial possessions—my hair barrette from Australia, my fountain pen with the lifetime guarantee, my Healthy Living Cookbook—flooded my eyes.

Pain and suffering are incalculable.

In the medical records, the doctors note that “possible chemotherapeutic options were outlined in detail. Toxicities from the chemotherapeutic agent doxorubicin/adriamycin include, but are not limited to myelosuppression and the risk of infection, mucositis, diarrhea, nausea/vomiting, and hair thinning; and from the agent ifosfamide, hemorrhagic cystitis, renal failure, and neurotoxicity.”

But they told me this was my only chance. A slim one, but the only one.

I suffered all the short-term side effects.

I weighed less than one hundred pounds and was so thin it hurt to sit on a chair. I had fevers that clawed at my bones. I was so weak I crawled down the hallway to the bathroom. I lost all my hair, even those sweet little hairs on my toes.

It's become mundane to lose one's hair.

Wear a scarf, tied jauntily. And tightly, so it doesn't slip off the slick skin.

Buy a wig; match your own color as closely as possible.

Or brave it bald and beautiful.

Don't admit to vanity.

But how to explain?

That I'd had hair to my waist for my entire life.

That the first time in my life I went to a hair salon was to get a short cut so that losing my hair would be less painful.

That it was part of my identity: "You'll recognize me at the airport. I have very long hair."

That when I was five years old, I swore I'd never cut my hair. And I didn't. Except for my annual spring split-end trim.

That I still dream of myself with long hair.

That when I see someone with hair as long as mine once was, I have to turn away.

There are long-term effects from the chemotherapy I should not have been given.

Adriamycin, an agent that is amongst chemotherapy's most toxic drugs, damages the heart muscle. My recent CT scans have revealed a new "pericardial effusion," liquid in the cavity around my heart. My regular blood tests proclaim severe and persistent anemia. My heart leaks its thinned blood as I battle to regain my balance.

Ifosfamide causes neurotoxicity. Nerve damage. I have peripheral neuropathy that is so severe some days I cannot hold a pen or strike the correct key on the keyboard. My feet, to phrase it genteelly, tingle. Not so politely, I often crumple when I try to stand, hobble when I try to walk.

Excerpts from the transcript in my possible lawsuit for wrongful chemotherapy:

**Q:** And what was your experience after being administered the chemotherapeutic agent adriamycin, also known as doxorubicin?

**A:** Also known as the "red devil." My long hair began to fall out—not "thin"—and this was accompanied by a sensation of burning on my skin, my scalp and everywhere else I had hair, as if I had been scorched with an iron set for cotton. It also produced an intense and sudden menopause with hot flashes that lasted for hours and combined with fever to make me feel as if I were on fire. I had to force myself to eat,

since everything tasted like the chemotherapy, which seemed to pool in my mouth even though it was administered intravenously. Nausea does not adequately describe the urge to vomit and then the vomiting. I felt as if I was being poisoned. Which I was.

**Q:** And what was your experience after being administered the chemotherapeutic agent ifosfamide?

**A:** There were many physical symptoms, nausea and intense constipation, but what was most difficult to bear was the loss of mental acuity. There seemed to be a great distance between my self and the outer world. Perhaps this is always true, but usually that distance is populated with the effluvia of daily life: a list of things to do, snatches of conversation, the last book I'd read, something I wanted to remember to say to a student or friend. But these things had evaporated, leaving a desert of immense vistas between me and the rest of the world. I struggled to be lucid, to connect, but I was intensely isolated. Everything existed on a mesa, far away and tinged with pink. . . .

**Q:** (Interrupting) Thank you. Now, did you experience any side effects from the other drugs that were administered, drugs that were intended to curtail some of the side effects of the chemotherapeutic agents?

**A:** Yes (crying). Can we take a break?

But if anyone asks me how I am, I say I am fully recovered. After I found a surgeon to remove the large abdominal tumor, I was fine.

After I underwent the experimental procedure of cryosurgery to treat the liver metastases that did not exist, I was cured and in perfect health.

When I am dizzy, I wait a moment and put my head down, casually, as if I were looking at something. When my hands are too numb to type or write and my feet too numb to walk, I am possessed of a sudden urge to read in a warm bath.

If there is a mind-body connection, then I am determined to capitalize on it.

I feel great.

I am well.

Repeat ten times. Turn around and face the four directions.

If there is an opposite term for “malingerer,” that would be me.

My damages are not only impaired by my refusal to be ill, but substantially compromised by my own actions.

The day I decided to leave the oncologists at the famous cancer center and no longer follow their advice and endure their arrogance was the day I—or more correctly, my surviving family members—diminished the claim for damages.

If I had acceded to their (mis)diagnosis and (mis)treatment, I would have died. The tumor would have become so large it would have pushed against my other organs until they were dysfunctional. I would have been strangled from the inside out.

And if it were ever discovered that the lesions on my liver were not metastases but simple hemangiomas, a condition which effects forty percent of all women, and if those surviving me had learned of my non-metastatic liver, there would have been a terrific multi-million dollar suit for a wrongful death resulting from medical malpractice. Economists would have testified about the worth of my life, multiplying my projected life span by my yearly salary with expected increases and the occasional book and honoraria.

But because I disagreed, much too late in hindsight, but still soon enough to save my life, I mitigated the damages and made my case less valuable.

As the studies have shown, the decision to sue for malpractice is not necessarily motivated by money. Whether I could get one thousand dollars or ten million dollars is not the determinative factor, although it might be for any attorney I might hire, dependent as he or she would be on the contingent fee percentage of recovery.

Financially, it would seem fair to be reimbursed for the \$50,000 in needless chemotherapy treatments for which I and my insurance company paid the famous cancer center.

But no amount of money can compensate me for the months I had no appetites, no fun, no joy, no hope. There is no way to pay for the looks in the eyes of those who saw me: despair in the eyes of my partner, disbelief in my adolescent child, shock in my parents, the terrible pity in my co-workers and even strangers. Nothing can buy back the taste of chemical cremation that still smolders at the back of my throat.

Some studies demonstrate that the few people who choose to sue are often motivated by the altruistic desire to prevent the same fate from befalling someone else.

To save some unknown stranger.

But what are the odds that these same facts would coalesce again?

Slim to none, I assumed.

However, I later learn that a few months before I first went to the famous cancer center, a man, a little older than I, also consulted them, and was diagnosed with liposarcoma and liver metastasis. But for some reason, he went to a different hospital and found that his liver lesions were hemangiomas.

When I wasn't crying in the examining room, I argued with my oncologist at the famous cancer center. The little notebook I now carried everywhere with my medical questions was more spotted than my liver. I'd had hepatitis as a college student, couldn't the lesions on my liver be a result of that? Especially since they weren't growing, while my abdominal tumor was?

As for symptoms, I was becoming so debilitated from the chemotherapy that I felt as if my liver as well as all my other organs were barely resisting an acute failure.

No, my oncologist insisted.

No. No. No. No. No.

There is no use in denying it: your cancer has metastasized to your liver.

Even as the contrary evidence was staring her in the face.

My face, to be precise.

My lip, to be more precise. Upper lip, left quadrant.

A hemangioma.

Something that looked to me like a blood blister had appeared after an accident a few years ago. It hadn't gone away, and after I consulted doctors, it hadn't responded to either conventional or laser surgery. When the plastic surgeon suggested plum lipstick, I decided I'd just live with a lesion on my upper lip.

Not knowing that I was also living quite fine with the same purpling on my invisible liver.

Did the oncologist even notice my face? What else did she fail to notice?

Or did she not even know what a hemangioma was?

Should I sue? Should I not?

The statute of limitations ticks like the metronome of my adriamycin-damaged heart.

All states limit the time in which a lawsuit for medical malpractice, or almost anything else, can be brought. The time for malpractice suits is relatively short, often shorter than other personal injury lawsuits, because legislatures have reacted to a perceived crisis—and the powerful medical profession with effective lobbyists. Having a fewer number of lawsuits is considered a good result.

This is called tort reform.

Popular with legislators everywhere.

Limit the greedy plaintiffs and their even more avaricious lawyers; protect our innocent doctors, hospitals, and HMOs.

After a study showing that medical malpractice awards have been larger in the past few years, some legislatures place a cap on damages awards.

After a study showing that one in eight people are seriously injured during their hospitalizations by acts of medical personnel, most legislatures do nothing.

As for medical insurance, any legislative action is viewed as tantamount to communism.

My medical insurance refused to allow me to see a doctor “out of network.” Even after the oncologists at the famous cancer center had dismissed me as hopeless and I had learned of another cancer center having great success with my type of cancer.

“There are forty thousand oncologists in our network. What makes you think you’re so special you need to go elsewhere?” the nurse caseworker assigned to my difficult case asked me.

“I’m dying,” I replied.

She suggested hospice.

“I’ll fight this,” I vowed.

“You don’t seem to understand you have a difficult case.”

I went out of network. I went out of state. I would have gone out of this world. I filed the insurance claims and figured if the company didn't pay, I'd appeal. I'd resort to credit cards with high interest rates, figuring that if I died, I wouldn't care, and if I lived, I'd be happy to worry about something as survivable as debt.

The doctors at the out-of-network cancer center saved my life.

The doctors at the out-of-network cancer center may think I am a difficult case, but they also seem to realize that I am a person who does not want to die. They do not smirk at me, although I am bald and my elbows are like arrows. They do not seem squeamish when faced with my little notebook of questions.

As if they have read my notebook, the first question the doctors at the out-of-network cancer center ask me is: "Why haven't you had surgery?"

I am so stunned that the only response that forms in the cage of my mind has something to do with the First Amendment cases I have taught about Jehovah's Witnesses, Christian Scientists, and faith healers refusing medical treatment. Luckily, this does not escape my mouth.

The surgeon at the out-of-network cancer center is a talented, careful, and knowledgeable specialist in sarcomas. I am certain that the surgery he performed was far better than any surgery that would have been performed by the surgeon at the famous cancer center who couldn't recognize a hemangioma on a CT scan and who had his secretary make his unpleasant phone calls.

This makes my prognosis, not to mention my life, much better.

This makes my legal case more difficult.

My out-of-network surgery and hospitalization cost less than my chemotherapy regimes had cost, less than a prolonged hospice would have cost. My insurance company denied my claims. I appealed. I lost. I appealed again. After a hearing at the World Trade Center, the company agreed to pay the expenses associated with saving my life, even though they were incurred out of network.

When the World Trade Center buildings collapsed, I was at the out-of-network cancer center having a follow-up CT scan performed.

Strapped into the massive white doughnut of a machine, I prayed the images it produced would be tumorless.

Mesmerized by the television sets in the waiting rooms, I prayed the images it transmitted were exaggerated.

The last section of the complaint is called the “prayer for relief.”

If I decided to sue, my damages would be measured by a damages award; my injuries would be compensated with monetary relief.

Money.

I could not ask for an injunction. I could not request that the doctors go back to medical school or receive further training in cancer or compassion. Or that they be administered adriamycin or ifosfamide.

I would never receive an apology. And nothing I could prove would ever mean that the famous cancer center would be ordered to cease and desist its boastful advertisements.

One of the principles of medical malpractice is that the monetary awards will act as deterrents. The theory is that litigation which results in compensation ensures that medical professionals will find it more economically advantageous to avoid future careless injuries to patients than to keep paying damage awards.

If I believed this—if I believed there were enough money in the world to accomplish this—I know I would sue in an irregular heartbeat.

I confer with a colleague who is a torts professor. She has already urged me to sue, but I want to ask her about the possibility of change at the famous cancer center. Would a lawsuit be an actual deterrent? Or would the cancer center, now a defendant, simply circle the wagons as I'd seen other defendants do, not changing policies, practices or personnel lest this be viewed as an admission of wrongdoing. She is less than hopeful about the prospects of reform.

I finally consult an attorney. Reputed to be the best “med-mal” attorney in the state and by fortuity employing one of my former students.

My former student is pleased to see me.

Alive.

“When I heard what you had, I thought for sure you were a goner.”

Obviously, it is not only members of the medical profession who could benefit from an infusion of compassion.

Or at least tact.

She excitedly tells me about an \$8 million settlement for a patient whose stomach was wrongly removed.

I become dizzy and nauseous. My throat burns and my mind recedes. I must look pale, because she offers me a chair.

When she asks me how I am, I respond that I am great. Fine. Recovered completely.

We review the medical records.

“You should see a heart specialist so we can determine the permanent damage. And a neurologist for nerve damage. Do you have any symptoms?”

No. No. No. No. No. No.

She frowns.

An airtight case on liability, no difficulties there. But we need some permanent damages to make the case more lucrative.

“You look good with short hair,” she says as I leave.

Just as I researched my cancer, leading me to the out-of-network doctors, I research malpractice, hoping I will be led to a decision.

The failure to diagnose. The lost chance doctrine, allowing some recovery for terminally ill patients. Community or national standards of care. The constitutionality of damages cap statutes. *Res Ipsa Loquitur*. The admissibility of certain hospital records. The enforcement of a gag order.

What would my gag order provide?

That I, as a condition of settlement, agree  
not to publicly criticize the defendant doctors, medical personnel,  
or organization, or anyone associated therewith,

not to disclose the terms of the settlement either privately or  
publicly,

and not to publish or cause to be published any work related to  
the litigation or the events underlying the litigation, in any form or  
manner whatsoever,

in perpetuity.

To agree—forever—not to talk or write about what happened to me is more unthinkable than what happened to me.

I will not be silent.

I will not be sick.

I let the statute of limitations lapse.

I celebrate by going out to dinner.

How wonderful the food tastes.

How lucid the conversation.

How good not to be a case, legal or medical, difficult or otherwise.

But I live with this terrible knowledge: that if I had been a little less stubborn, a little more awed by authority, a little less economically privileged, a little more charmed by tranquilizers, a little less able to research my own disease, or simply unlucky, I'd be dead now.

And you would not be reading this.

Case closed.

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