

society figure of her hometown who had amassed quite a nest egg. After numerous chemotherapies, she worried that her treasures might divide the family. She wanted to make sure that everyone got a memento that was treasured and deserved. After another intensive conversation, she decided to throw a give-away party and allow people to choose the things that would remind them of her. She had me paged upon her last admission to the hospital; she had news about the party. We were both in tears in the end, but deeply grateful that she had found a way to take charge of her dying. She did not give away her decisions, but offered a personal farewell to each of her loved ones.

Except for sudden accidents and loss of consciousness, dying does not have to be a passive act. I sat with countless families as their spiritual guide and experienced the difficult, but healing process of actively saying good-bye. It was always hard, but without fail there was a deep sense of peace.

Leaving things undone and unsaid and ungiven complicates grief. I continue to live with a family in our ungrieved losses. We are left with a truckload of work, physically and emotionally speaking. For those who die, that might be acceptable, theologically speaking. Nevertheless, finalizing advanced care planning is more than a couple of boxes ticked on an advanced directive document. It is an act of beneficence and care for us who stay behind. It is time well spent saying good-bye and practice anticipatory grief. Unfortunately, Aunt Sally's death is one more story about how not to die—unprepared.



Informed Consent, An Ongoing Conversation

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Ten years ago, my lover was diagnosed with a glioblastoma multiforme (glio) stage four brain tumor. We were members of the department of bioethics and humanities at a medical

university; we taught bioethics and literature and creative writing electives to medical students and nursing students. We had many physician and nursing colleagues with whom we shared classes and spirited discussions about the connections between the practice of medicine and the humanities.

Falling down the rabbit hole of a terminal illness, however, throws one into a new world of stark choices and endless uncertainty. Suddenly, bioethical principles embodied in white coats and blue scrubs present in your hospital room. Theoretical ethics slam into clinical ethics, and the experience is both explosive and transformative.

In the classroom, we tell students that informed consent is an actual process, not simply a form to be witnessed and signed. Although a decade has passed, I can easily conjure up the ER where I met the neurosurgeon who rattled off the medical terminology and then said—"Look, this is the worst of the worst: worst kind, worst location, worst outcome." So much for bedside manner, but he definitely got my attention. The case was urgent, but he needed to stabilize Bonnie first so we would have two days to talk to him about our options which were a) do nothing and die or b) commit to surgery and see what happens.

Quickly I learned that "can do" summarizes neurosurgery's approach. After a seven-hour surgery, he triumphantly assured me he had gotten 75% of the tumor (seven weeks later he would downsize that number to 14% with no explanation about that discrepancy) and that she was doing very well. Eight hours later she had a seizure and lay in a coma. He, however, remained unflappable: "quite common, happens all the time, she'll come back." And he sent over his colleague the oncologist whose mournful look and sole question, "How can I help you?" became not only the surgeon's foil but also my eventual standard for deciding how to move us through diagnosis, treatment, and outcome.

If one looks up glio on the web, one discovers after wading through paragraphs of prognoses and treatments that most people live an average of 11 months after diagnosis. I don't think we heard that statistic during the weekend. Nor did we

hear what those 11 months are like for the patient. Under the pressure of “the tumor is growing,” the initial surgery was presented to us as all that can be offered in the face of the worst of the worst. So who among us would refuse that “solution”? We all agreed we wanted a solution to this terrible event. But it was only and always a temporary solution to an insoluble condition, and so I find myself still thinking about what the informed part of informed consent actually means and when it should occur in cases like this.

We could reconfigure St. Paul’s epistle for the modern bioethicist as follows: “right now these three things remain—beneficence, non-maleficence, and autonomy, but the greatest of these is autonomy.” Medicine, bioethics, and many patients worship at the altar of autonomy. It is certainly seductive in its idealized version of an educated, informed patient in consultation with the physician working out the treatment plan. That patient can give informed consent because she has been told what is happening, what is at stake, and what the chances of success are.

But, what does autonomy mean if the patient/proxy is *mostly* being informed about treatment? If we receive lots of information about what kind of surgery or chemotherapy is recommended and a little bit of information about what kind of side effects may occur and next to no information about that elusive character “quality of life,” does that create informed consent? Do we then have true autonomy to say, “Yes, that is what I want”?

Bonnie’s case was even more complicated by the coma. When she came out of that after 17 days, she began an arduous rehabilitation program while also undergoing chemotherapy. Radiation therapy skulked to the side “until she was stronger.” First, she had to relearn how to feed herself, how to walk, and how to speak. She had to live with the short-term memory loss her tumor and the surgery caused; she had constant pain that we never could fix, and she had to live without the sense of taste. In addition, she was plagued by new fears that I could neither explain nor assuage: dogs, the possibility of seizure, the wearing of the face mask she had to don when radiation began, the pure confusion she had

every time we went to the radiation treatment area. This is only a partial list of the accommodations she had to make, but you get the idea. “I want our life back,” she used to say. Today I know that was never a possibility, but back then I was driven to try and make it happen. No one on our health care team discouraged us from doing so.

In the rehab unit, we met dedicated therapists, physicians, and nurses. Yet there too Bonnie was seen first as a traumatic brain injury (TBI) who was supposed to fit into prescribed protocols. For example, to work on her cognitive skills, the occupational therapist was giddy with anticipatory delight the morning she told Bonnie they’d be working on “planning your dream wedding.” Bonnie looked from the therapist to me; I began laughing. How to put this delicately? She loathed weddings. I explained to the therapist that such an exercise would not benefit her and suggested they work instead on planning a trip to Florence, which was what we had hoped to do in the summer. The therapist wailed, “but I don’t know anything about Florence.” I thought but did not say that the exercise might then give the therapist a sense of Bonnie’s daily frustrations, a good chance to practice empathy.

There was the physician who prescribed a session with the dog who was brought to rehab once a week; he said she could work on her throwing skills with Pharaoh. I explained that Bonnie had developed a fear about dogs; they were appearing in her dreams. He shook that off; it would be good for her; everyone loves Pharaoh. I said no. I also said I would throw a ball with her and added that we had loved to do that together after work in the summer. In my notebook, I have written, “Resident uninterested.”

I said no quite a few times during Bonnie’s stay in the hospital: no to the shopping expedition they wanted her to take with four other people suffering from TBI to the mall, another place Bonnie never went; no to the blood draws that were occurring two and three times a day when no one could explain to me what their purpose was; no to the reinsertion of the Foley catheter when I was told she was taking “too long” to get her control back.

What I think about now when I teach bioethics is informed consent and its relationship to autonomy. Informed consent means having real and sustained conversations with patients. Informed consent means that physicians and other health care professionals are informed about their patients, their lives, their dreams, and their hopes. It is, in other words, a two way process and document. Autonomy means very little if the decision I am being asked to make has not been fully explained to me, if the treatment's effects have not been fully explored with me.

My students say, "But this would take so much time." I ask them if they want to be characters from the voiceover in the pharmaceutical commercials: a mind-numbing recitation of benefits and risks that permits no room for thought. No consumer is making informed choices from those commercials.

We met with the neurosurgeon for almost 90 minutes the day before the surgery. He described what he would do and what the risks were; here are some of my notes: "small cut, some risk of seizure, little scalp flap, all kinds of complications, maybe diabetes, maybe hormonal, paralysis on one side, comatose, penthouse surgery, short term memory." My writing in the notebook is rushed; I have question marks and dashes everywhere. Bonnie participated in the discussion; she told him that writing poetry and teaching were essential to her. I asked him if she could expect to return to teaching and writing after the surgery. In my notes, it says, "he describes a patient he had who still enjoyed reading." Was that the answer to our question?

During the time she was in the coma, I again asked him this question and was told that he had every hope "she would sit in the garden with me and walk in the neighborhood with me." So now, from a distance of a decade which ironically provides more clarity, I see that the answer to our questions about a return to our lives was no. And that perhaps he couldn't say that clearly to us because we might then wonder why we were prepping for surgery. We all wanted her to live; he seemed to be offering to save her life. But I'm not sure that medicine comprehends that how we live should also be part of the equation.

Bonnie did live the requisite 11 months. She got through four rounds of chemotherapy and six weeks of radiation. She had three major seizures, memory loss, and constant pain. There were medications for all of this, of course, each of them with its own side effects that sometimes required another medication to counter. On the day I was told the tumor was growing again, I was offered a different chemo treatment possibility. Eleven months wiser now, I asked what it actually would do, and my very kind oncologist said, "Honestly? Nothing." Finally, informed consent. Informed consent to use the autonomy granted me as her proxy (at this point she had no ability to process what we were looking at in her scan or talking about) to say no and to ask that medicine help her, help me to make the final days easy or at least as painless as possible.

Bioethical principles mean nothing when they are divorced from the persons they are supposedly meant to protect and benefit. Medicine can provide an almost endless supply of treatment and yet never understand its impact on the patient's life because beneficence and autonomy are more closely connected to treatments and to physicians' assessments than they are to a patient's history and ongoing story. In my classroom and in my own life, I focus on making informed consent a much more visible part of a medical exam, encounter, or procedure.

I want my students to realize that they can't practice beneficence if they don't understand what their patients define as a good life. I want physicians to realize that autonomy is much more than some determination of capacity; a patient only has autonomy when a physician engages in a real dialogue by moving well beyond visiting the TBI into spending real time with a poet who has TBI and trying to figure out with her what kind of life she wants and what kind of life medicine can offer. And beneficence means having the courage to discuss when those two perspectives are far apart and destined to remain so.



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