

# PREFACE

## DEATH AND DIGNITY

*A Case of Individualized Decision Making\**

**D**iane was feeling tired and had a rash. A common scenario, though there was something subliminally worrisome that prompted me to check her blood count. Her hematocrit was 22, and the white-cell count was 4.3 with some metamyelocytes and unusual white cells. I wanted it to be viral, trying to deny what was staring me in the face. Perhaps in a repeated count it would disappear. I called Diane and told her it might be more serious than I had initially thought—that the test needed to be repeated and that if she felt worse, we might have to move quickly. When she pressed for the possibilities, I reluctantly opened the door to leukemia. Hearing the word seemed to make it exist. “Oh, shit!” she said. “Don’t tell me that.” Oh, shit! I thought, I wish I didn’t have to.

Diane was no ordinary person (although no one I have ever come to know has been really ordinary). She was raised in an alcoholic family and had felt alone for much of her life. She had

vaginal cancer as a young woman. Through much of her adult life, she had struggled with depression and her own alcoholism. I had come to know, respect, and admire her over the previous eight years as she confronted these problems and gradually overcame them. She was an incredibly clear, at times brutally honest, thinker and communicator. As she took control of her life, she developed a strong sense of independence and confidence. In the previous 3½ years, her hard work had paid off. She was completely abstinent from alcohol, she had established much deeper connections with her husband, college-age son, and several friends, and her business and her artistic work were blossoming. She felt she was really living fully for the first time.

Not surprisingly, the repeated blood count was abnormal, and detailed examination of the peripheral-blood smear showed myelocytes. I advised her to come into the hospital, explaining that we needed to do a bone marrow biopsy and make some decisions relatively rapidly. She came to the hospital knowing what we would find. She was terrified, angry, and sad. Although we knew the odds, we both clung to the thread of possibility that it might be something else.

The bone marrow confirmed the worst: acute myelomonocytic leukemia. In the face of this tragedy, we looked for signs of hope. This is an area of medicine in which technological intervention has been successful, with cures 25 percent of the time—long-term cures. As I probed the costs of these cures, I heard about induction chemotherapy (three weeks in the hospital, prolonged neutropenia, probable infectious complications, and hair loss; 75 percent of patients respond, 25 percent do not). For the survivors, this is followed by consolidation chemotherapy (with similar side effects; another 25 percent die, for a net survival of 50 percent). Those still alive, to have a reasonable chance of long-term survival, then need bone marrow transplantation (hospitalization for two months and whole-body irradiation, with complete killing of the bone marrow, infectious complications, and the possibility for

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graft-versus-host disease—with a survival of approximately 50 percent, or 25 percent of the original group). Though hematologists may argue over the exact percentages, they don't argue about the outcome of no treatment—certain death in days, weeks, or at most a few months.

Believing that delay was dangerous, our oncologist broke the news to Diane and began making plans to insert a Hickman catheter and begin induction chemotherapy that afternoon. When I saw her shortly thereafter, she was enraged at his presumption that she would want treatment, and devastated by the finality of the diagnosis. All she wanted to do was go home and be with her family. She had no further questions about treatment and in fact had decided that she wanted none. Together we lamented her tragedy and the unfairness of life. Before she left, I felt the need to be sure that she and her husband understood that there was some risk in delay, that the problem was not going to go away, and that we needed to keep considering the options over the next several days. We agreed to meet in two days.

She returned in two days with her husband and son. They had talked extensively about the problem and the options. She remained very clear about her wish not to undergo chemotherapy and to live whatever time she had left outside the hospital. As we explored her thinking further, it became clear that she was convinced she would die during the period of treatment and would suffer unspeakably in the process (from hospitalization, from lack of control over her body, from the side effects of chemotherapy, and from pain and anguish). Although I could offer support and my best effort to minimize her suffering if she chose treatment, there was no way I could say any of this would not occur. In fact, the last four patients with acute leukemia at our hospital had died very painful deaths in the hospital during various stages of treatment (a fact I did not share with her). Her family wished she would choose treatment but sadly accepted her decision. She articulated very clearly that it was she who would be experiencing all

the side effects of treatment and that odds of 25 percent were not good enough for her to undergo so toxic a course of therapy, given her expectations of chemotherapy and hospitalization and the absence of a closely matched bone marrow donor. I had her repeat her understanding of the treatment, the odds, and what to expect if there were no treatment. I clarified a few misunderstandings, but she had a remarkable grasp of the options and implications.

I have been a longtime advocate of active, informed patient choice of treatment or nontreatment, and of a patient's right to die with as much control and dignity as possible. Yet there was something about her giving up a 25 percent chance of long-term survival in favor of almost certain death that disturbed me. I had seen Diane fight and use her considerable inner resources to overcome alcoholism and depression, and I half expected her to change her mind over the next week. Since the window of time in which effective treatment can be initiated is rather narrow, we met several times that week. We obtained a second hematology consultation and talked at length about the meaning and implications of treatment and nontreatment. She talked to a psychologist she had seen in the past. I gradually understood the decision from her perspective and became convinced that it was the right decision for her. We arranged for home hospice care (although at that time Diane felt reasonably well, was active, and looked healthy), left the door open for her to change her mind, and tried to anticipate how to keep her comfortable in the time she had left.

Just as I was adjusting to her decision, she opened up another area that would stretch me profoundly. It was extraordinarily important to Diane to maintain control of herself and her own dignity during the time remaining to her. When this was no longer possible, she clearly wanted to die. As a former director of a hospice program, I know how to use pain medicines to keep patients comfortable and lessen suffering. I explained the philosophy of comfort care, which I strongly believe in. Although Diane

understood and appreciated this, she had known of people lingering in what was called relative comfort, and she wanted no part of it. When the time came, she wanted to take her life in the least painful way possible. Knowing of her desire for independence and her decision to stay in control, I thought this request made perfect sense. I acknowledged and explored this wish but also thought that it was out of the realm of currently accepted medical practice and that it was more than I could offer or promise. In our discussion, it became clear that preoccupation with her fear of a lingering death would interfere with Diane's getting the most out of the time she had left until she found a safe way to ensure her death. I feared the effects of a violent death on her family, the consequences of an ineffective suicide that would leave her lingering in precisely the state she dreaded so much, and the possibility that a family member would be forced to assist her, with all the legal and personal repercussions that would follow. She discussed this at length with her family. They believed that they should respect her choice. With this in mind, I told Diane that information was available from the Hemlock Society that might be helpful to her.

A week later she phoned me with a request for barbiturates for sleep. Since I knew that this was an essential ingredient in a Hemlock Society suicide, I asked her to come to the office to talk things over. She was more than willing to protect me by participating in a superficial conversation about her insomnia, but it was important to me to know how she planned to use the drugs and to be sure that she was not in despair or overwhelmed in a way that might color her judgment. In our discussion, it was apparent that she was having trouble sleeping, but it was also evident that the security of having enough barbiturates available to commit suicide when and if the time came would leave her secure enough to live fully and concentrate on the present. It was clear that she was not despondent and that in fact she was making deep, personal connections with her family and close friends. I made sure that she knew how to use the barbiturates for sleep, and also that she knew

the amount needed to commit suicide. We agreed to meet regularly, and she promised to meet with me before taking her life, to ensure that all other avenues had been exhausted. I wrote the prescription with an uneasy feeling about the boundaries I was exploring—spiritual, legal, professional, and personal. Yet I also felt strongly that I was setting her free to get the most out of the time she had left, and to maintain dignity and control on her own terms until her death.

The next several months were very intense and important for Diane. Her son stayed home from college, and they were able to be with one another and say much that had not been said earlier. Her husband did his work at home so that he and Diane could spend more time together. She spent time with her closest friends. I had her come into the hospital for a conference with our residents, at which she illustrated in a most profound and personal way the importance of informed decision making, the right to refuse treatment, and the extraordinarily personal effects of illness and interaction with the medical system. There were emotional and physical hardships as well. She had periods of intense sadness and anger. Several times she became very weak, but she received transfusions as an outpatient and responded with marked improvement of symptoms. She had two serious infections that responded surprisingly well to empirical courses of oral antibiotics. After three tumultuous months, there were two weeks of relative calm and well-being, and fantasies of a miracle began to surface.

Unfortunately, we had no miracle. Bone pain, weakness, fatigue, and fevers began to dominate her life. Although the hospice workers, family members, and I tried our best to minimize the suffering and promote comfort, it was clear that the end was approaching. Diane's immediate future held what she feared the most—increasing discomfort, dependence, and hard choices between pain and sedation. She called up her closest friends and asked them to come over to say goodbye, telling them that she would be leaving soon. As we had agreed, she let me know as well.

When we met, it was clear that she knew what she was doing, that she was sad and frightened to be leaving, but that she would be even more terrified to stay and suffer. In our tearful goodbye, she promised a reunion in the future at her favorite spot on the edge of Lake Geneva, with dragons swimming in the sunset.

Two days later her husband called to say that Diane had died. She had said her final goodbyes to her husband and son that morning, and asked them to leave her alone for an hour. After an hour, which must have seemed an eternity, they found her on the couch, lying very still and covered by her favorite shawl. There was no sign of struggle. She seemed to be at peace. They called me for advice about how to proceed. When I arrived at their house, Diane indeed seemed peaceful. Her husband and son were quiet. We talked about what a remarkable person she had been. They seemed to have no doubts about the course she had chosen or about their cooperation, although the unfairness of her illness and the finality of her death were overwhelming to us all.

I called the medical examiner to inform him that a hospice patient had died. When asked about the cause of death, I said, "acute leukemia." He said that was fine and that we should call a funeral director. Although acute leukemia was the truth, it was not the whole story. Yet any mention of suicide would have given rise to a police investigation and probably brought the arrival of an ambulance crew for resuscitation. Diane would have become a "coroner's case," and the decision to perform an autopsy would have been made at the discretion of the medical examiner. The family or I could have been subject to criminal prosecution, and I to professional review, for our roles in support of Diane's choices. Although I truly believe that the family and I gave her the best care possible, allowing her to define her limits and directions as much as possible, I am not sure the law, society, or the medical profession would agree. So I said "acute leukemia" to protect all of us, to protect Diane from an invasion into her past and her body, and to continue to shield society from the knowledge of the

degree of suffering that people often undergo in the process of dying. Suffering can be lessened to some extent, but in no way eliminated or made benign, by the careful intervention of a competent, caring physician, given current social constraints.

Diane taught me about the range of help I can provide if I know people well and if I allow them to say what they really want. She taught me about life, death, and honesty and about taking charge and facing tragedy squarely when it strikes. She taught me that I can take small risks for people that I really know and care about. Although I did not assist in her suicide directly, I helped indirectly to make it possible, successful, and relatively painless. Although I know we have measures to help control pain and lessen suffering, to think that people do not suffer in the process of dying is an illusion. Prolonged dying can occasionally be peaceful, but more often the role of the physician and family is limited to lessening but not eliminating severe suffering.

I wonder how many families and physicians secretly help patients over the edge into death in the face of such severe suffering. I wonder how many severely ill or dying patients secretly take their lives, dying alone in despair. I wonder whether the image of Diane's final aloneness will persist in the minds of her family, or if they will remember more the intense, meaningful months they had together before she died. I wonder whether Diane struggled in that last hour, and whether the Hemlock Society's way of death by suicide is the most benign. I wonder why Diane, who gave so much to so many of us, had to be alone for the last hour of her life. I wonder whether I will see Diane again, on the shore of Lake Geneva at sunset, with dragons swimming on the horizon.

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