Lessons From the Practice

Notes of a Hospice Physician
Journal Entries of January 23 and February 2, 1994

IRA R. BYOCK, MD, *Missoula, Montana*

January 23, 1994

I met Jacob Edwards today. He is 43 and dying of AIDS.

I first heard about Jake from Francis Flowers of the Intravenous (IV) Infusion Service. She stopped me in the parking lot two weeks ago and told me she'd been encouraging Jake and his mom to call. She hoped I would get a chance to meet them and, possibly, be of some help. He was admitted to the hospice a few days later, and two days ago, I was asked by his hospice nurse to see him. Bob Thomas, MD, his internist, enthusiastically agreed.

The staff of IV Infusion Service and the hospice all like Jake and are a bit protective of him, but he has clearly been identified as a "problem patient." He has been in nearly constant struggles with care providers, including Dr Thomas, who is among the most caring and nonjudgmental doctors in town.

Jake acquired the human immunodeficiency virus in a distant city, but has come home to die. He is living in the home of his mother, who is providing his primary care. She seems consistently loving and notably tolerant. Their relationship in the past was stormy at times, and there is still the occasional "gale." Jake is the only son in a family with five daughters. He left home for the California coast as a teenager and became an accomplished musician. He also lived a hard, fast life that included years of polydrug use. He married, but the marriage succumbed to the drug abuse. Jake says he and his wife still love each other. They have two daughters, a preteen who lives with his wife and another who is off at college. Jake hasn't seen his wife or either of his daughters in the past six years.

During my visit today, Jake lay on his bed, the radio tuned to a commercial rock and roll station. He was alert and oriented, but his affect and expression were somewhat blunted, and there were flashes of irony and anger in the tone of his story. He smoked constantly, alternating between cigarettes and marijuana. He seemed hardly strong enough to do anything else. Even lifting his head to sip water required concentrated effort.

Jake has had a miserable few days of nausea and vomiting. He said he felt better today, though he is clearly dehydrated. He complained only of a mild headache and of generalized weakness. He expressed anger at Dr Thomas and at the health care system. He blames a lot of his problems on the medications he has been given. He has already been through the entire alphabet of antiviral drugs, and, in Jake's mind, the most recent one, ganciclovir, is the cause of all his current problems. He is angry that it was ever prescribed and believes that the herbal medicine he is taking now is a better treatment for the deteriorating vision in his left eye.

Jake clearly knows what a hospice is. He knows that AIDS is ultimately fatal and has seen others die of it. But he isn't focused on dying. He told me he is "going to kick this thing"—at least in the short run. During the visit, we agreed to focus on Jake's primary goal of getting stronger. I said it was realistic to hope that he would gain a bit of strength. Jointly, we arrived at a plan for him to drink as much electrolyte solution as he comfortably could over the next 24 hours, and, as he requested, I arranged for him to receive a liter of saline solution IV tomorrow.

After getting acquainted and attending to the medical aspects of things, I listened to more of Jake's story. We spoke of his daughters, and I was struck by how important they still are to him, despite the years of separation. I asked him if there would be anything left undone if, unexpectedly, he were to die suddenly today, as any of us could. He responded that he needed to make out a will; he told me about the few things he would want to give to specific people in his life. I asked if there were stories, perhaps from his childhood or stories of his life as a musician, that he would want to share with his daughters. Was there anything special he would want them to know? Some bit of wisdom he would want to share with them? Had he written to say how much he loved them? Would he want to write and say good-bye? Would he perhaps be interested in tape-recording some of his stories and saying some of these things? He said that he would.

February 2, 1994

I visited Jake Edwards again today, ten days after meeting him for the first time. There has been a remarkable transformation for this patient and for his family. The family has not always been close and warm, but the at-

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From the Palliative Care Service, Missoula, Montana.
Reprint requests to Ira R. Byock, MD, Palliative Care Service, 341 University Ave, Missoula, MT 59801.

mosphere in the home today would thaw the coldest cynic. Jake's eldest sister has flown in to be with him, joining his mother and the two sisters who live locally. His older daughter, Julie, is also here, and his wife and younger daughter are expected to arrive by bus this evening. His mom continues to give meticulous, loving care, but with more hands to help, she's finally getting some rest. Everybody is pampering Jake, though they are also taking care to give him his privacy.

Jake's condition has deteriorated notably. He is weak and lethargic and no longer tracking all of the time. When he is alert, he is almost always oriented. He knows well that he is dying.

His daughter Julie already has become fully involved in his care. She clearly loves him, recognizes his failings, and understands the importance of what is happening. Jake remains intermittently cantankerous, but is making a real effort to be tolerant and accepting of the loving care he is receiving. "Jacob is putting up with our fussing," one of his sisters said. The women of this house know he has his limits and are respecting them.

Jake's sister Sue Ann smiled as she related an incident from a recent evening. She had walked into Jake's room and touched the skin of his arms, which were folded across his chest. He felt cool. She asked him if he was cold, and he said, "No." Nevertheless, she tucked his blankets up above his shoulders. He frowned and closed his eyes, but when she asked him if he wanted her to uncover him, he said, "No, I'm all right." She then laid down on the cot at the foot of his bed to go to sleep. A few minutes later, their mother came in and, noticing his arms lying across his chest, asked him if he was cold. He said, "No," and weakly lifted his arms, knowing she was going to cover him anyway. She did. Ten minutes later, out of curiosity, Sue Ann lifted her head to see. Sure enough, his arms were back out from under the blankets.

When another of Jake's sisters describes their care as "doting," all chuckle in agreement. They said Jake's tolerance of their doting feels like a gift he is giving to them. He tolerates the caresses and appreciates the spoonfuls of pudding and the cool water they offer. He is still listening to rock and roll, but expresses some interest in the more tranquil, "New Age" music they suggest.

The ambiance in the home is an improbable mixture of solemnity and celebration. I have seen it often before. It is something like the atmosphere in the homes of mourners: sadness suffused with humor and appreciation for the person departed. It is much like times of "sitting *shiva*" among the Jews.

The gathering of the family and the loving atmosphere in the home are the results of conscious efforts and hours and hours of work. Dr Thomas remains involved and supportive. Jake's symptoms are being managed carefully, ensuring his comfort despite advancing weakness and debilitation. The hospice nurse, social worker, chaplain, aides, volunteers, and I have participated in a host of simple, yet delicate, clinical interventions: Listening, mostly; respectfully exploring relationships without prying; and gently encouraging Jake to reach out to others, even those at a great distance. The hardest and most courageous work, of course, has been done—is being done—by Jake, his mom, his sisters, and his daughter.

How can I explain this transformation to others? How will I tell this story?