

Friday November 7, 2003

Helping my mother die — with dignity and compassion

by stewart florsheim

My mother started to fall a lot. At first, she attributed it to her heart. She was 77 and thought she was just getting winded more easily, and it was therefore getting more difficult for her to pick up her legs. When the diagnosis was finally confirmed, I told the doctor not to tell my mother — but she knew.

She was sitting in a chair in his office, just staring at me, as the doctor rattled on about what she could expect: Most of her muscles would probably become paralyzed and, finally, she wouldn't be able to breathe without the assistance of a machine. My mother had ALS, Lou Gehrig's disease.

Usually a fighter, my mother was also a realist. She was a refugee from Hitler's Europe, so the course of her past prepared her to accept the worst. She told me she did not want to live with the disease. She knew people who had had it, and she did not spare details of the slow, torturous death. She wanted me to help her. I said, sure, we could post a directive that said she would not want to be resuscitated, but I knew what she meant.

My Jewish mother was placed under the care of an ALS clinic. For months, my mother insisted that the clinical director promised to help her end her life, but my mother misinterpreted the response. The only point the clinician made was that she would be able to keep my mother comfortable and, if absolutely necessary, make her so comfortable that she would slip into unconsciousness.

My mother was also immediately placed under the care of a hospice. Hospice is a wonderful concept, but the staff often walks a very fine line between palliative care and total sedation. They are clearly dedicated to making patients comfortable but do not even want to discuss where "comfort" might end.

I found out about Compassion in Dying, a group with affiliates in various parts of the country. Its message is one of support, education and choice. Only if a patient is suffering from a terminal illness and is still mentally competent will the staff even begin to discuss the legal options available to hasten the patient's death.

My rabbi, Mark Chester of Temple Sinai in Oakland, told me that he and the Reform movement both support the ideas that Compassion promotes — so long as the organization doesn't advocate euthanasia or suicide, which it doesn't, and that any hastened death would be within the law.

Ultimately, two volunteers from Compassion came to see us, a geriatric social worker

and a psychiatrist. My mother and I listened intently as they discussed all the options, including the self-administration of high-dose pain medication, cessation of eating and drinking and total sedation.

Compassion in Dying — not surprisingly — is based in Oregon, the only state that has a Death With Dignity Act. The law allows terminally ill patients to receive prescriptions for lethal medications that they must take themselves, without help from a doctor or anyone else. Before a prescription can be written, two doctors must certify that the patient is of sound mind and has less than six months left to live.

The statistics from Oregon reveal very few patients die as a result of taking lethal medications themselves. Similarly, in situations like my mother's, very few patients end up hastening their deaths. What aid-in-dying organizations offer is a way for terminally ill patients to re-gain a sense of self-control. In some cases, they facilitate a more peaceful death. My mother wanted control, not because she wanted to die, but because she wanted to go on living — until her life had no quality and the suffering became unbearable.

Unfortunately, Attorney General John Ashcroft is contesting Oregon's act in the 9th U.S. Circuit Court of Appeals. The 9th Circuit panel will probably present a ruling sometime before the end of the year. Whatever the outcome, the case will probably end up in the Supreme Court. Although similar legislation has been introduced in states like Hawaii and Vermont, the repeal of Oregon's act would ripple through the country.

Likewise, the case of Terri Schiavo, comatose and on life support since 1990, raises profound ethical questions related to advances in medical technology, as well as end-of-life choice. It also highlights the importance of advance directives — one of the only tools we have to state our preferences for end-of-life care when we are no longer able to do that ourselves. My mother was able to express her wishes; in the current political climate, even that does not often suffice.

My mother got worse quickly. After only a few months, she could not get out of bed and into her wheelchair without help. She could not use her legs. She started to have a hard time swallowing foods and talking. She had an increasingly difficult time breathing and started to use a bi-pap machine to force air into her lungs. When the machine stopped being effective, the doctor increased her dosage of morphine to facilitate her breathing.

Toward the end of my mother's illness, she started to experience some dementia, and claimed that she did not know how to hasten her death anymore. I reminded her about her options, and she would nod.

The last conversation we had was on the eve of one of my semi-monthly trips to New York. My mother could barely talk, but she was suddenly clear as a bell: "You're coming home tomorrow, right?" My mother passed away peacefully in her sleep that night, while I was in the next room — only eight months after she received her diagnosis.

I still ask myself if I would have been able to help my mother hasten her death, and I always come up with an unqualified yes. When my mother was lucid and wanted to discuss her options, we decided that she would probably put several morphine patches on

her body, and she would drift off into unconsciousness. The drug, along with no intake of food or fluids, would hasten her death.

During those conversations, I recalled the image of myself as a child. I did not like to eat. At one point, I became too weak to walk up stairs. The pediatrician told my mother to make me egg creams, with raw eggs. I saw my mother beating the yolks into the chocolate milk, to try to make them disappear. At the end, she would just give up, and plead as she handed me the drink laced with the yellowish wisps: "Please, it's good for you." Ironically, I would withhold my mother's sustenance to bring dignity and peace to her final days.

Stewart Florsheim is an East Bay writer who is also on the board of directors of the local chapter of Compassion in Dying at www.compassionindying.org.