Ethics Robert Buckenmeyer

My forty-seven years of teaching Philosophy and my seventy-four years of living in this first home, my body has taught me that the how of a person's death is the how of that person's life. Generally, the way a person lives is the way that person dies.

However, given the technology of today's medical world, both natural birth and natural death have become more technological than natural. Here the morals of a family and a society, be that the society of doctors and/or hospital administrators usually deny the dying a natural death.

Yet ethically, the only requirement is that a fetus receive a natural birth (though we have "pushed back" the ability of delivering a premature birth baby, even into the first trimester which is the good part of medical technology) and the elderly receive a natural death. Personally, I "pulled the plug" on my eighty-one year old father who repeatedly pulled the tube supplying oxygen out of his nose, the tubes providing liquid and nourishment out of his arms and the tube keeping his trachea open out of his mouth. I had left orders to allow my father to die and given the fact that I had legal power of attorney and guardianship of his personal self, the Eskaton administration and staff were obliged to follow my written directive, yet, twice they placed him in a "straight jacket" to keep him from pulling the tubes out and twice I ordered them to take off the "straight jacket". Again, as I left the facility, I renewed the order and showed them the legal documents. As soon as I left, however, they again placed him in restraints.

Why did they countermand my legal authority and exercise their moral decision? I think the answer is simple and also explains why family, doctors and hospital administrators morally disallow people to die a natural death. No, I do not think the reason is the legality of a moral law; I think the reason is that they themselves do not like to witness natural death, particularly as it is explained by Virani and Sofer below so over-treatment is the moral decision, but neither under nor over treatment of the dying is ethical.

New York Times
Facing Up to the Inevitable, in Search of a Good Death
By JANE E. BRODY

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The year was 1958, I was 16 and my mother was lying in a hospital bed connected to all sorts of tubes and was dying of cancer. As her life slipped away, a nurse slapped an oxygen mask on her face and asked me to hold it. There was no chance for either of us to say goodbye or "I love you." I carry this medicalized memory of my mother's death with me to this day. I am hardly alone. Cicely Saunders, the founder of the first modern hospice, said, "How people die remains in the memories of those who live on."

Experts on end-of-life care say that my mother's death was handled wrong, all wrong. Chalk it up to ignorance back then. But 45 years later, despite a greatly enhanced

understanding of what happens to a person near the end of life, little has changed in the way most people die in hospitals or nursing homes. All too often, life is prolonged in pain or discomfort, with medical interventions and instruments precluding an opportunity for loved ones to say goodbye.

Such was the case for 22-year-old Dave Fulkerson, who was hit by a car while he was jogging with his girlfriend. In the intensive care unit, his family was not allowed to see him for three hours. By then, he was no longer able to talk. Further, only one person was allowed in for five minutes every two hours. Eventually, his frustrated girlfriend went home, and his parents fell asleep in the waiting room, only to be awakened by a nurse and told their son had died.

Rose Virani, a research specialist at the City of Hope National Medical Center in Duarte, Calif., and Dalia Sofer, a writer, recounted this case last May in The American Journal of Nursing in one of a series of articles on end-of-life care. They lamented the lack of communication between the health care team and hospital staff and Mr. Fulkerson's family, intensifying the pain they suffered over his death.

"Poor communication is not the only obstacle to a peaceful death," the article noted. "Some patients are over-treated, receiving aggressive care until their last breath. Others are under-treated, so much so that their final moments are steeped in physical pain. Still others receive conflicting advice from doctors and nurses on the best course of action, leaving them confused and unprepared for death."

As deaths from heart attacks decline and life expectancy rises, death has become a protracted process for more and more people. Accompanying this trend is a growing need for medical professionals and families to understand what happens during the last weeks, days and hours of life and what kind of action, or inaction, is most likely to bring a comfortable, peaceful, even beautiful end.

In a 1996 report endorsed by more than 30 health care groups, the American Geriatrics Society listed nine important factors for quality care at the end of life: alleviating physical and emotional symptoms; helping the patient maintain dignity; using treatments that reflect the patient's wishes; avoiding "inappropriate aggressive care"; giving the patient and family quality time together; giving the patient the best possible quality of life; minimizing the family's financial burdens; informing patients about insurance coverage; and helping the family with bereavement.

But six years later, a review of care near the end of life published by the geriatrics society revealed "overwhelmingly disappointing results," Ms. Virani and Ms. Sofer reported. Far too many deaths were still marred by unwanted treatment and hospitalization, inadequate relief of pain and other debilitating symptoms, and inept communications.

The Final Days

When people are near death, physical and mental changes occur that can confuse and

frighten those around them and result in inappropriate responses. When someone can no longer take food orally, the temptation is to use a feeding tube. When a dying person gasps for air, the tendency is to reach for an oxygen mask. But are these desirable? Not necessarily, experts say. In another article in the nursing series, published in July, Elizabeth Ford Pitorak, director of the Hospice Institute of Hospice of the Western Reserve in Cleveland, described what happens when death is imminent and the time has come to shift from healing to relief of symptoms. "Active dying, the process of total body system failure, usually occurs over a period of 10 to 14 days, although it can take as little as 24 hours," Ms. Pitorak wrote.

Usually, she noted, dying patients become dehydrated; swallowing becomes hard; and peripheral circulation decreases, resulting in perspiration and clammy skin that feels cold to the touch. This should not be a sign to pile on blankets, however, because "most dying patients can't tolerate even the slightest weight on the feet or other extremities," she wrote.

Pulmonary congestion can prompt patients to gasp for breath. But, Ms. Pitorak said, supplying oxygen is not the way to relieve this "air hunger" because a dying person usually cannot benefit from it.

Rather, opening windows, using a fan, allowing space around the patient's bed and administering morphine or some other opioid are the best ways to relieve a patient's feelings of breathlessness and anxiety.

When difficulty swallowing makes eating or drinking impossible, the question of tube-feeding arises. But dying patients are usually not hungry, Ms. Pitorak explained, and "the absence of hydration and nutrition may even induce an analgesic euphoria" as ketone bodies build up in the blood. Even a little sugar administered intravenously can counteract this euphoria, she noted.

Furthermore, efforts to feed a dying patient orally can result in vomiting, aspiration and a violent, rather than a peaceful, demise.

Ms. Pitorak observed that while IV fluids can help terminally ill patients who become delirious from dehydration, they can also cause swelling, nausea and pain in patients who are actively dying. But, she added, if patients on opioids have kidney failure — resulting in confusion, muscle spasms and seizures from a failure to clear the blood of the drug — hydration and less medication may help.

As someone nears the end of life, it is not unusual to turn inward and become less communicative, even as much as three months before death. Ms. Pitorak noted that loved ones should not confuse this withdrawal with rejection. Rather, she said, it reflects the dying person's need to leave the outer world behind and focus on inner contemplation.

Experts advise families not to wait until the last hours of life to communicate with dying patients. In a study of 100 terminally ill cancer patients, 56 were awake one week before

they died, 44 percent were drowsy, but none were comatose. In the final six hours, however, only 8 percent were awake, 42 percent were drowsy and half were comatose, precluding any further communication.

As death approaches, oral muscles relax and secretions that accumulate in the throat or chest can result in loud, gurgling breathing sounds — the so-called death rattle — that can be disturbing. But rather than trying to suction these secretions, a process that can be discomforting and is rarely successful, Ms. Pitorak suggests repositioning the patient to one side, elevating the head and, if necessary, administering medication to reduce the secretions.

Dying patients may also moan or grunt as they breathe, but rarely is this a sign of pain, she noted. Appropriate pain relief should always be provided because a patient in pain cannot communicate effectively or die peacefully. She added that there was no evidence that pain-relieving drugs hastened death.

Patients who ask whether they are dying should be answered honestly and reassured that those left behind will be well, which Ms. Pitorak says is more helpful than telling patients, "You can go now."

But she warned that even when a patient can no longer respond to sights or sounds, "hearing is the last sense to leave the body, so one should never say anything near the patient that one would not want him to hear."

How Doctors Feel

Families often complain about being abandoned by physicians when nothing more can be done to reverse a progressive disease and death becomes inevitable. It may help families to realize that doctors, too, experience a loss when they can no longer cure a patient.

In The Journal of the American Medical Association two years ago, Dr. Diane E. Meier and Dr. R. Sean Morrison, palliative care specialists at Mount Sinai Medical Center in New York, and Dr. Anthony L. Back of the University of Washington School of Medicine explained that "a patient's unimproving health may lead the physician to feel guilty, insecure, frustrated and inadequate."

"Rather than address these feelings," the article continued, "physicians may withdraw from patients."

Some doctors may rationalize that their time can be better spent caring for the living, Dr. Meier said in an interview.

For example, a friend's husband was being treated for incurable lung cancer by a leading oncologist. When it became apparent that the therapy was not helping, the oncologist, in effect, disappeared, assigning an underling to the patient. After he died, the oncologist said nothing to the family, made no call and sent no card, infuriating my friend and

adding to her considerable grief.

When a patient dies, Ms. Pitorak has this advice for the professionals: Don't abandon the family. Don't leave the room without expressing your sympathy. And give the family members as much time as they want with the deceased before removing the body.