HERE’S THE CASE

R.L. was a 58-year-old woman with a history of metastatic rectal carcinoma to lymph nodes and sacrum. Despite several attempts to control her disease with combination chemotherapy, she continued to have progressive disease and pain. Despite attempts to manage her pain as an outpatient, she was admitted to the hospital with extreme sacral bone pain for a continuous intravenous morphine infusion, titrated for pain relief.

PAIN CONTROL

There is a large and growing body of experience and consensus that good end-of-life care, including attention to physical, psychological, emotional, and spiritual needs, should be widely available in the United States. Indeed, this is the impetus behind the hospice concept, started in the United Kingdom by Dame Cicely Sanders in the 1950s. The United States Supreme Court, although they did not endorse physician-assisted suicide (PAS), upheld the right of all Americans to have good palliative care at the end of life, as stated in the landmark June 1997 decision (Vacco v Quill).1

A major focus of end-of-life care is pain control. Long-acting opiates have the benefit of providing continuous pain relief throughout their duration of action. For patients with severe pain (that has not been relieved in the outpatient setting) or for patients with acute pain syndromes, admission to the inpatient setting for titration of a continuous infusion of opiates may be necessary. R.L. had been treated with oral long-acting morphine, at a dose of 1,000 mg by mouth every 8 hours as an outpatient. She also had been receiving immediate-relief oral morphine tablets for breakthrough pain. Because the highest dose available in a single long-acting morphine tablet is 200 mg, she was thus taking 15 tablets daily. Given her current morphine dose and her severe pain, her initial infusion was set at 60 mg/h. She was also allowed additional intravenous morphine boluses of 10% of her total 24-hour maintenance dose every 15 minutes as needed.

R.L. had good pain control with the intravenous morphine and other supportive medications. However, 2 days into her hospitalization, she began to feel quite anxious. Her anxiety was believed, in part, to be due to the high dose of intravenous morphine that she was receiving, but it also appeared to have a psychologic component. Specifically, she was concerned about being a burden for her family and concerned about her family’s burden of finalizing her affairs after her death. She had difficulty sleeping.

ANXIETY CONTROL

Anxiety is relatively common in dying persons. It can be related to pain and concerns about being a burden on others. In addition, it often centers on the fact that dying is something that the person has not done before. The involved person is entering unknown territory, leaving behind familiar surroundings, loved ones, and unmet obligations. Unmet obligations can include routine activities, such as paying bills and taking care of the daily needs of a household or business. In addition, it can include seeking forgiveness for past wrongs and ending unsettled conflicts.

The healthcare provider can play an important part in relieving anxiety. This often means taking the time to listen with empathy to what the patient is thinking, feeling, or fearing. The healthcare provider may be able to facilitate the settling of conflicts with family or friends.

Medications can be effective for relieving anxiety. Although opiates can effectively relieve pain, they are a poor choice for inducing sedation or providing anxiolysis.1 In an effort to relieve anxiety, R.L. also was given a continuous intravenous infusion of lorazepam 1 mg/h, to be titrated for comfort.

R.L. was then comfortable with the morphine and lorazepam infusions. She was being seen by the hospice team and was considering transfer to an inpatient hospice setting. She continued to be concerned, however, about being a burden on her family. This issue was openly addressed with R.L. and her family together. She was overwrought with concerns for the financial burden of her care and quite distressed that it was unlikely that she would be able to return to her home. She asked for a hastened death by progressive increases in the dose of her intravenous morphine.

HOPELESSNESS

Studies have shown that hopelessness is the strongest predictor of requests for PAS.2 Hopelessness is an important diag-
Voluntary Cessation of Eating and Drinking

The decision by a competent patient to stop eating and drinking can be problematic for some physicians and families. It will usually lead to death within 1 to 3 weeks. Although voluntary cessation of oral intake may be morally acceptable in a patient with a clearly defined terminal illness and a limited life expectancy, it is more problematic in patients whose condition may not be imminently terminal but who can expect progressive deterioration with no chance of improvement (such as patients with amyotrophic lateral sclerosis). Yet it is just this group of patients for whom this legal option may provide the control they desperately seek as they contemplate the end of life.

The knowledge that the option of voluntarily stopping eating and drinking is available may be all that a patient, who is slowly dying, needs to keep going. Recent studies in Oregon, where PAS is legal, have reported that the fear of loss of control of the circumstances of death is the major reason patients initiate a request for PAS. Perhaps if more dying patients were made aware of the option to stop eating and drinking, there would be fewer requests for lethal medication.

TERMINAL SEDATION

Terminal sedation represents a conscious decision to decrease a patient’s consciousness to the extent that the patient will no longer feel pain, air hunger, or other distress. Terminal sedation is different from euthanasia in that the dose of medication is maintained rather than increased once sedation is achieved, and in that the intent is not to hasten death but to relieve suffering. General guidelines for terminal sedation have been published and include medical staff input into the decision for terminal sedation, the need for a second opinion regarding the decision, family participation in the decision, diagnosis of a terminal condition with a life expectancy of days to weeks, patient informed consent, and the presence of unrelievable symptoms despite other available best palliative-care practices.

When terminal sedation is considered, it is important to plan ahead. As such, bedside suction should be available, the family should be present, if possible, and nasal oxygen should be provided. Usually, a benzodiazepine, such as midazolam or lorazepam, is used for sedation and anxiolysis. In addition, if the patient is hospitalized, housing the patient in a single room in a quiet part of the hospital floor is appropriate. If the patient is at home, a quiet part of the house may be used. Of note, the median time to death after the initiation of terminal sedation is 1 to 5 days, with a range usually not exceeding 29 days.

R.L. decides to voluntarily forgo food and water. The family, who follows devout Christian beliefs, is concerned about the ethics of her decision. In addition, they are distraught and wish to speak with their minister. They ask for help.

RELIGIOUS OR SPIRITUAL CONCERNS

The religions of the world play a major part in the life cycle of their adherents, and most have rituals and beliefs concerning the care of the dying, the care of the body after death; the role of clergy; the use of autopsy, organ donation, suicide, and eutha-
nasia; and the use of sacraments, prayers, or scripture readings. It is important for healthcare providers to ask the patient about his or her religious or spiritual needs and customs. It also is important that the healthcare provider not assign a stereotype and assume what rituals may be desired by patients and families. The following areas need to be queried: religious tradition and background, desire to have religious leaders (lay people or clergy) present at the time of death, desire to have any particular rites performed, and the desire for specific care of the body before and after death.

In all religions, suicide and euthanasia are either prohibited or strongly discouraged. Similarly, in all religions, the dying person is made comfortable and respected. Clergy involvement and sacramental customs in the postmortem period vary according to the particular religious tradition. There is also significant variation among the different religions concerning autopsy, organ donation, and care of the body after death. Specifically, autopsies and organ donations are forbidden by most Islamic authorities. However, in some circumstances, autopsies are ordered for Muslims for legal purposes. If, by law, an autopsy needs to be performed on a Muslim patient, then all body parts may need to remain with the deceased. Autopsies are permitted in Judaism with the permission of a rabbi, but all body parts are to remain with the deceased.

Some religions have definitive traditions that need to be considered in the end of life. In the Roman Catholic and Orthodox Christian traditions, it is normative that the clergy be present prior to or during death for the administration of the Last Rites. Following death, Islamic regulations require the body to be handled by Muslims, and if not by Muslims, then by only those who are wearing rubber gloves. Among the Orthodox Jews, the body is cared for by the Chevrah Kadisha (Holy Brotherhood). In all three Jewish traditions (Orthodox, Conservative, and Reform), burial generally occurs within 24 hours after death.

Religious customs may thus be important at the time of death to provide comfort and identity for the families of the deceased. Spiritual support at the time of death is one way to show respect and concern for the bereaved family. Spiritual support often continues well beyond the time of death and assists families during the mourning period.

According to family wishes, R.L.’s pastor was called. He affirmed her right to refrain from oral intake. Prayers were said for her in the company of her family. She died peacefully on the fifth day of hospitalization.

Good end-of-life care requires a team. R.L. and her family were supported through the dying process by her physician, hospice nurses, social workers, and her spiritual leader. Her family, postmortem, reported a sense of completion and peace that facilitated their grieving process.

REFERENCES