

to request euthanasia and confirmed that uncontrolled pain was not associated with greater interest in euthanasia. Interestingly, despite the importance of emotional distress in motivating requests for euthanasia and physician-assisted suicide, few patients receive psychiatric care. For instance, in Oregon, only 5.9% of patients have been referred for psychiatric evaluation.

Euthanasia and physician-assisted suicide are no guarantee of a painless, quick death. Data from the Netherlands indicate that in as many as 20% of cases technical and other problems arose, including patients waking from coma, not becoming comatose, regurgitating medications, and experiencing a prolonged time to death. Data from Oregon indicate that between 1997 and 2013, 22 patients (~5%) regurgitated after taking prescribed medication, 1 patient awakened, and none experienced seizures. Problems were significantly more common in physician-assisted suicide, sometimes requiring the physician to intervene and provide euthanasia.

Whether practicing in a setting where euthanasia is legal or not, over a career, 12–54% of physicians receive a request for euthanasia or physician-assisted suicide from a patient. Competency in dealing with such a request is crucial. Although challenging, the request can also provide a chance to address intense suffering. After receiving a request for euthanasia and/or physician-assisted suicide, health care providers should carefully clarify the request with empathic, open-ended questions to help elucidate the underlying cause for the request, such as “What makes you want to consider this option?” Endorsing either moral opposition or moral support for the act tends to be counterproductive, giving an impression of being judgmental or of endorsing the idea that the patient’s life is worthless. Health care providers must reassure the patient of continued care and commitment. The patient should be educated about alternative, less controversial options, such as symptom management and withdrawing any unwanted treatments and the reality of euthanasia and/or physician-assisted suicide, because the patient may have misconceptions about their effectiveness as well as the legal implications of the choice. Depression, hopelessness, and other symptoms of psychological distress as well as physical suffering and economic burdens are likely factors motivating the request, and such factors should be assessed and treated aggressively. After these interventions and clarification of options, most patients proceed with another approach, declining life-sustaining interventions, possibly including refusal of nutrition and hydration.

CARE DURING THE LAST HOURS

Most laypersons have limited experiences with the actual dying process and death. They frequently do not know what to expect of the final hours and afterward. The family and other caregivers must be prepared, especially if the plan is for the patient to die at home.

Patients in the last days of life typically experience extreme weakness and fatigue and become bedbound; this can lead to pressure sores. The issue of turning patients who are near the end of life, however, must be balanced against the potential discomfort that movement may cause. Patients stop eating and drinking with drying of mucosal membranes and dysphagia. Careful attention to oral swabbing, lubricants for lips, and use of artificial tears can provide a form of care to substitute for attempts at feeding the patient. With loss of the gag reflex and dysphagia, patients may also experience accumulation of oral secretions, producing noises during respiration sometimes called “the death rattle.” Scopolamine can reduce the secretions. Patients also experience changes in respiration with periods of apnea or Cheyne-Stokes breathing. Decreased intravascular volume and cardiac output cause tachycardia, hypotension, peripheral coolness, and livedo reticularis (skin mottling). Patients can have urinary and, less frequently, fecal incontinence. Changes in consciousness and neurologic function generally lead to two different paths to death (Fig. 10-2).

Each of these terminal changes can cause patients and families distress, requiring reassurance and targeted interventions (Table 10-9). Informing families that these changes might occur and providing them with an information sheet can help preempt problems and minimize distress. Understanding that patients stop eating because they are dying, not dying because they have stopped eating, can reduce family

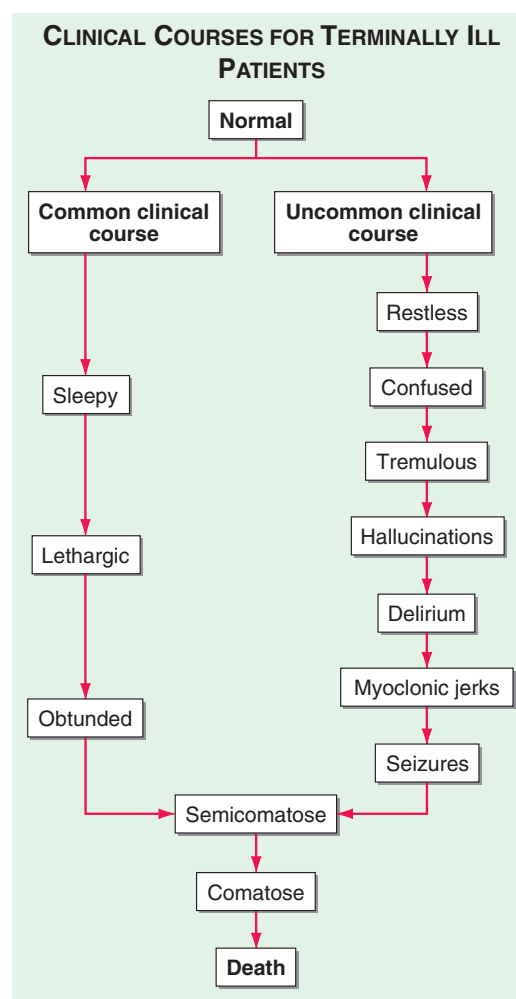


FIGURE 10-2 Common and uncommon clinical courses in the last days of terminally ill patients. (Adapted from FD Ferris et al: Module 4: Palliative care, in *Comprehensive Guide for the Care of Persons with HIV Disease*. Toronto: Mt. Sinai Hospital and Casey Hospice, 1995, <http://www.cpsonline.info/content/resources/hivmodule/module4complete.pdf>.)

and caregiver anxiety. Similarly, informing the family and caregivers that the “death rattle” may occur and that it is not indicative of suffocation, choking, or pain can reduce their worry from the breathing sounds.

Families and caregivers may also feel guilty about stopping treatments, fearing that they are “killing” the patient. This may lead to demands for interventions, such as feeding tubes, that may be ineffective. In such cases, the physician should remind the family and caregivers about the inevitability of events and the palliative goals. Interventions may prolong the dying process and cause discomfort. Physicians also should emphasize that withholding treatments is both legal and ethical and that the family members are not the cause of the patient’s death. This reassurance may have to be provided multiple times.

Hearing and touch are said to be the last senses to stop functioning. Whether this is the case or not, families and caregivers can be encouraged to communicate with the dying patient. Encouraging them to talk directly to the patient, even if he or she is unconscious, and hold the patient’s hand or demonstrate affection in other ways can be an effective way to channel their urge “to do something” for the patient.

When the plan is for the patient to die at home, the physician must inform the family and caregivers how to determine that the patient has died. The cardinal signs are cessation of cardiac function and respiration; the pupils become fixed; the body becomes cool; muscles relax; and incontinence may occur. Remind the family and caregivers that the eyes may remain open even after the patient has died because