

# Euthanasia in intensive care: A 56-year-old man with a pontine hemorrhage resulting in a locked-in syndrome\*

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**Objective:** To describe a case of deliberate termination of life (euthanasia) in intensive care.

**Design:** Case report and review of the literature.

**Patient:** A 56-yr-old man experienced a bilateral hemorrhage in the pontine structures and the medulla oblongata, resulting in a locked-in syndrome. The patient was taught to communicate by eye opening. On day 10 after the hemorrhage, he was informed about his diagnosis and prognosis. He was asked if he wished prolonged care, but this was refused. He was offered withdrawal of fluids and ventilation under sedation or deliberate termination of life (euthanasia). He chose euthanasia.

**Interventions:** The patient was admitted to the intensive care unit and was mechanically ventilated. The patient was euthanized 33 days after the diagnosis by the injection of 30 mg of midazo-

lam, discontinuation of ventilation, and injection of 1.4 g of thiopentone.

**Main Results:** The tetraplegic aphonic patient was declared competent. His refusal of prolonged care was taken seriously. The requirements of due care according to the Dutch euthanasia act were met in this case.

**Conclusions:** Euthanasia is an option in terminal illness in the Netherlands, but it is very rarely performed in intensive care. This case demonstrates that euthanasia is possible in a conscious patient who is unable to speak or write and who is mechanically ventilated. (Crit Care Med 2007; 35:2428–2430)

**KEY WORDS:** euthanasia; locked-in syndrome; pontine lesions; intensive care

The Netherlands was the first country with a law on euthanasia. The term *euthanasia* is used only and strictly for intentional termination of life of an adult patient on his or her request. This presupposes voluntariness and a deliberate active act and excludes every form of intentional, active, direct, nonvoluntary termination of life and palliative administration of opioids and sedatives (1). No evidence exists that adequate use of opioids and benzodiazepines to treat discomfort hasten death (2, 3).

In the *Termination of Life on Request and Assisted Suicide Act*, the requirements of due care are described. The Act requires that the attending physician:

- Holds the conviction that the request by the patient is voluntary and well considered.

- Holds the conviction that the patient's suffering is lasting and unbearable.
- Has informed the patient about the situation and about the prospects.
- Holds the conviction that there is no other reasonable alternative in the light of the patient's situation.
- Has consulted at least one other independent physician who must have seen the patient and given a written opinion on the due care criteria referred to above.
- Has terminated a patient's life or provided assistance with suicide with due medical care and attention.

The legislation requires committees to review the process of termination of life on request. A regional review committee is composed of an uneven number of members, although at least three. In any case, it must consist of a legal expert cum chairman, a physician, and an expert in the field of ethics or philosophy. When the committee concludes that the physician did not act in accordance with the criteria, the case must be brought to public prosecution, which launches a criminal investigation. Committees have the power to personally discuss with the physician.

Given the fact that euthanasia is only possible after a voluntary request by the patient, euthanasia is very rare in the intensive care unit. In this article, we present a complex case.

## CASE REPORT

The Medical Ethics Committee of the Erasmus MC University Medical Center Rotterdam, The Netherlands, reviewed and approved this case report. A 56-yr-old male lawyer was admitted to the intensive care unit after he suddenly fell into a deep unresponsive state. On examination in the emergency department, the patient was found unconscious and tetraplegic, with a bilateral complete facial palsy. Computerized tomography showed bilateral hemorrhage in the pontine structures and the medulla oblongata. The patient was mechanically ventilated because of deterioration in respiratory function.

His spouse and son described him as an intelligent, independent, and active man. His work as a lawyer was his most important life fulfillment. No written advance directive concerning life-sustaining therapies existed. However, his spouse and son stated emphatically that he would reject therapy in case of a totally dependent state. His wife character-

### \*See also p. 2460.

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ized him as a proponent for euthanasia and asked the intensivist about the possibility of euthanasia. The intensivist had no personal objections but indicated that the comatose patient was not suffering and that there was no written request of the patient.

After 6 days, the patient opened his eyes on request. It was concluded that hearing, vision, pupillary reactions, and bodily sensation were normal. The diagnosis of locked-in syndrome (LIS) was made.

In the second week, the patient was taught to communicate by eye opening (one blink for yes, two blinks for no). On the tenth day, he was informed that motor recovery was unlikely, rehabilitation would not substantially contribute to improvement of functional outcome, survival was possible with adequate care, and that he could learn to communicate by a computer. He was asked whether he wished such prolonged treatment. He answered "no." He was asked if he understood that he would die without such continued care? He answered "yes." He was told that he was not dependent on mechanical ventilation and that he would be able to breath under sedation for days, finally ending in respiratory deterioration and exhaustion before death. Another possibility that could be offered was euthanasia. On the question if he would like to end his life by euthanasia, he answered with "yes." The next day, the patient was asked again if he wanted euthanasia? Again he answered "yes." The physician documented these deliberations in the medical chart and asked another intensivist for a second opinion. Questions to be answered included: Is the (indirect) request of euthanasia based on valid grounds, and is the patient's suffering lasting and unbearable? Is the patient well informed about his situation, is the request well considered, and are there any alternatives to euthanasia? He visited the patient and relatives on the eighteenth day. He concluded that the diagnosis was valid, that the condition was fatal without 24-hr care, that the patient's view was well considered (also based on a conversation with the relatives), and that there were no acceptable alternatives. He reconfirmed that all provisions for euthanasia were fulfilled. Because this was a unique situation, a third physician was consulted. This neurologist visited the patient on day 22. His conclusion was in agreement with the others. Neither the patient nor his relatives asked

for an independent expert medical opinion. The case was, on request of the relatives, not discussed with the primary care physician.

The intensivist informed the hospital board about the intended euthanasia. On day 23, the patient was informed about the conclusions and was asked again if he persisted in his wish for euthanasia, which he confirmed. The intensivist discussed the situation with the nursing staff. There were no professional objections. Euthanasia was scheduled for day 33, 10:00 am. Some relatives were present at the bedside. After everyone had said farewell to the patient, the intensivist injected 30 mg of midazolam intravenously, after which the patient fell into a deep sleep. The ventilator was disconnected, and 1.4 g of thiopentone was injected. Within 5 mins, ventilatory arrest was observed, with subsequent arterial hypotension resulting in circulatory arrest. Ten minutes later, the patient was declared dead. The intensivist notified the municipal pathologist of the euthanasia, who reported the euthanasia by completing a detailed report and notified no objection to burial of the body. The regional review committee reviewed the case and concluded that the physician had acted in accordance with the established criteria. Two weeks after the euthanasia, the relatives visited the intensive care unit again and expressed their contentment to the intensive care unit staff, offering some presents for the physicians and nurses involved in the process of euthanasia.

## DISCUSSION

The described case gives rise to three questions:

1. Was the request voluntary and well considered?
2. Was suffering lasting and unbearable?
3. Were there no reasonable alternatives?

First, physicians have the ethical duty to noncoercively explain the prognosis and clinical course patients may expect (4). Most descriptions of LIS mention the lack of any significant cognitive impairment (5). LIS due to purely pontine lesions is characterized by a restoration of a globally intact cognitive potential. We are convinced that our patient with LIS was completely competent. The patient was, after being informed about his medical condition and prognosis, first asked if he

wished for prolonged care. As indicated, *if* the patient was able to speak or write, he would have requested in spoken words or writing for termination of mechanical ventilation and all other treatment, but also for euthanasia. One of the foundations of euthanasia is to respect the individuality of the patient. Due to severe hypophonia, patients with LIS lose all possibility to communicate by speaking. As a result of tetraparalysis, they have no possibility to write. Caregivers can only ask the patient if he or she wants prolonged treatment and mechanical ventilation, and if not, as in our case, how he or she would like the process of end-of-life care to proceed. In the Netherlands, physicians *can* propose prolonged life-sustaining care or palliative care, but also euthanasia. Was the request made after due deliberation based on an enduring desire to die? Did the patient emphatically and repeatedly express the wish to die? Again, the patient was physically unable to express his wish to die in speaking or writing, but there were no doubts concerning the patient's competence. All caregivers and patient's relatives held the opinion that he understood the implications of his physical condition, implications of prolonged care, possibility to withdraw mechanical ventilation under sedation, and his choice for euthanasia. If the patient had asked for continued but completely dependent care, we would have continued all possible treatment.

Second, the patient's suffering included the prospect of not being able to live and communicate independently given the consideration that caregivers could not give him any prospect or hope for improvement or recovery. This conclusion was also based on conversations that caregivers had with his relatives and friends. Although they did not have a decision-making right for withdrawal of therapy, they had expressed the view the patient could not put into words. The dominant nonphysical suffering would, without any doubt, be lasting. We are aware that many patients with spinal cord injury in the acute phase have thoughts that they would be better off dead and later are glad to be alive, but we have serious doubts if this is the same for patients with LIS. Lahrman and Grisold (6) stated that LIS might be called the nightmare of all possible outcomes of modern medicine. The LIS patient awakes into a life without any voluntary motor control, whereas hearing, vision, and often sensation are unimpaired. Very

intensive early rehabilitation can improve functional recovery, although most survivors make very minor improvements of motor function (7).

Third, the source of information the patient received was what caregivers, family, and friends told him. Based on this information, he could conclude that there were three options for his future: prolonged dependent life; deep sedation and withdrawal of fluids and feeding, resulting in exhaustion and death; or euthanasia. With sedation, but without barbiturates, he would die of respiratory failure. Euthanasia is, from the physician's perspective, based on the principle of respecting the patient's autonomy and the principle of mercy. From this perspective, we considered it appropriate to offer the possibility of euthanasia to this patient. The duty to alleviate "unbearable and hopeless suffering" has, via the justification of necessity, become the basis for euthanasia. We think that the medical care and attention in this case was with due care. Critics might say that 31 days is a short period for finding a lasting desire to die, but we think it is not dignified to keep a completely conscious tetraplegic patient alive against his will. In the last 21 days of his life, he persisted in his wish to die every day.

We are convinced that lasting and unbearable suffering was inevitable in this case, with the patient facing a totally physically dependent life with intact cognition. We are convinced that the physicians were not in any way acting coercively. We reason that keeping such a patient on life support against his will can be seen as causing harm. This would thus be in conflict with the principle to cause no harm.

The fact that our patient was suffering from LIS would for some be insufficient reason for deliberate termination of life. Laureys et al. (5) report that patients with LIS report a meaningful quality of life and that their demand for euthanasia is surprisingly rare. The American Academy of Neurology has published a position statement concerning the care and management of conscious, competent patients with permanent and profound paralysis (8). They conclude that such patients have the right to make health-care decisions about their life, including issues concerning acceptance or refusal

of life-sustaining treatment. The physician has an ethical obligation to minimize subsequent suffering and offer adequate palliative care. The committee states:

Once patients have decided to forgo life-sustaining treatment, physicians have an ethical obligation to minimize their subsequent suffering. This is particularly true of profoundly paralyzed patients because cognition and sensation may be intact, and they are capable of great suffering (8).

The wish to die is, according to literature, not an issue in acute or chronic LIS patients. The French Association of Locked-in Syndrome has registered, since March 1997, 367 patients with LIS in France. Only four reported deaths were related to the patient's wish to die (5). None of 15 deaths of a cohort of 29 LIS patients could be attributed to euthanasia or treatment withdrawal (9). The question remains: do patients not *want* to die, or is it that physicians *do not offer* the possibility to withdraw treatment? Suicidal thoughts are found in some LIS patients (5, 10). Nick Grisholm, who had lived with LIS since 2000, reported in 2005:

I thought of suicide often. I never had enough courage then to go through with it. Even if I wanted to do it now I could not, it's physically impossible. I just have to deal with it the best I can . . . I only live for hope of recovery now. I cannot live like this for about another 40 yrs or so and will not (11).

Others intuitively stated in a case analysis of LIS that life-sustaining therapy should be given in view of the patient's quality of life and the burden of the illness (12). We think the patients should "speak" for themselves and through their close relatives after caregivers have explained the prognosis and clinical course. Offering the possibility for prolonged care or palliative care after withdrawing life-sustaining treatment occurs subsequently. In the Netherlands, patients can also choose euthanasia.

In most countries in the world, euthanasia is not possible or allowed, and patients with LIS have to deal with their dependency the best they can. In some countries, these patients are allowed to

die under sedation due to respiratory failure or withholding of fluids. We think it is professionally and ethically defensible to release patients from their suffering from this consequence of a pontine lesion by euthanasia, on their request, with respect to the patients' values and desires.

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