

HANDBOOK ON
CRITICAL LIFE ISSUES

REVISED THIRD EDITION

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HARD DECISIONS ABOUT PROLONGING LIFE

Chapter 13 presented a largely theoretical view of an ethical framework for making decisions concerning the prolonging of life. This appendix presents some practical cases (most of which are fictionalized versions of real situations) which should be studied in the light of the principles enunciated in chapter 13. The importance of case studies on prolonging-life decisions emerges readily if we recall the two criteria discussed in that chapter: “excessive burden” and “without reasonable hope of benefit.” Only by looking at real situations can we estimate what those modifying words (“excessive” and “reasonable”) mean in the common-sense estimate of normal people.

Those who would make judgments within the stewardship tradition of Catholic teaching need a reverence for the uniqueness and transcendence of human life. With this perspective, we recognize that sickness and suffering are both inescapable and redeemable. Therefore, a person does not focus first on suffering and then on how to escape it. Instead, he or she asks which medical options are morally acceptable while at the same time minimizing suffering.

The first series of cases concern competent patients; the second, noncompetent patients.

Hildegarde F.

Hildegarde F. came to a nursing home at the age of seventy-eight. Her husband of the same age was still living but could no longer care for her. She had four children who all remained in touch with their parents and were living in the area. Her

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husband stayed in the family home but spoke of coming one day also to live at the nursing home.

Hildegarde's main physical problem was severe diabetes. The summer after she came to the nursing home, she was hospitalized with a serious ulcer on her left leg, and a bypass graft was performed. By that fall, she was showing obvious signs of physical weakening, and had become nonresponsive and almost comatose. Then, through an unusual set of circumstances, she got a different physician. He studied her problems, including the nonhealing ulcers on her right leg, the abscesses, and early stages of gangrene. He recommended amputation of the leg.

The family and Hildegarde decided in favor of the amputation. It was performed that winter, and Hildegarde came through the surgery beautifully. She returned to her alert and cheerful personality. In fact, she was getting around so nimbly that, the following fall, she broke her hip. She was bedfast as a result.

The following summer, her left leg began showing the same conditions as the right leg had earlier. The same doctor who recommended the first amputation now recommended a second. The family showed less reluctance this time, probably because of Hildegarde's previous great recovery. However, Hildegarde died in the hospital after the second amputation.

Is amputation of a leg an ethically extraordinary procedure? It surely was in the sixteenth and seventeenth centuries, when it was performed without anesthesia or antibiotics. Today it can be done, obviously, much more efficiently, even for a seventy-nine-year-old woman with severe diabetes. This case is not an easy one to decide. However, in general, it would seem that amputation would not have been an excessive burden or extraordinary treatment, although some caregivers and moralists might classify it so because of Hildegarde's diabetic condition.

Forgoing ethically extraordinary treatment can often shorten life. In Christian faith, many people of Hildegard's age do not mind this. They are lonely and look forward to life with God and with the relatives who have preceded them in death. Yet Hildegarde could still enjoy the visits of her husband and children. She apparently felt that heaven could wait. Fortunately she herself was able to participate in the decision about the amputation.

Mrs. B.

Mrs. B., a seventy-year-old woman with deteriorating health, had been receiving hemodialysis (the mechanical substitute for

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kidney function). The procedure was particularly difficult for her because her blood clotted easily and there were difficulties in the maintenance of the necessary shunt. She indicated her desire to forgo hemodialysis. In their concern for a truly informed consent, her physicians set up an interview at a time when her system would be most free of poisons which might cloud her judgment. After a frank and open discussion, they accepted her decision to cease hemodialysis.

This brief case does not convey the pathos that must have surrounded Mrs. B.'s decision. In contrast to the previous case, no mention is made of her family. Nothing is said of her financial capabilities, although, in the United States, special federal funding has supported hemodialysis since 1971. The brief reference to "deteriorating health" tells very little of her actual physical and emotional condition.

However, the case makes clear that she considered the prospect of continual dependence on hemodialysis an excessive burden. Medically, it was very difficult for her. We incline to agree with a judgment of excessive burden. However, forgoing hemodialysis will shorten Mrs. B.'s life.

Could her decision be considered suicidal? The doctors worried about that. But presumably she did not consider her decision suicidal. Inasmuch as a person simply intends to forgo an excessive burden caused by prolonging treatment, that person has no suicidal intention. The death which occurs results from the diseased kidney rather than from any lethal act. Hence, presuming Mrs. B. had no suicidal intention, the chief ethical concern relates to her judgment concerning excessive burden. Presuming that she expected continual dialysis with its attendant difficulties for the rest of her life, she did not decide unreasonably.

Calvin P.

Calvin P. is only fifty-two years old but has suffered from multiple sclerosis for fifteen years and had to retire from his job as a machinist two years ago. He had become morose and withdrawn. He attempted suicide by slashing his left wrist and was admitted to the hospital. He was cooperative and alert in the intensive care unit (ICU), but he insisted that he did not want any supportive treatment. A consulting psychiatrist discovered that his mother-in-law had recently received a diagnosis of inoperable cancer. The psychiatrist helped him and the family deal with the grave emotional issues. Calvin had subconsciously resented

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the loss of attention to his own problems. He soon retracted his request for no supportive treatment.

This account of this case does not present Calvin's full medical condition or the prognosis for his multiple sclerosis. It simply makes clear that his initial disposition to forgo supportive treatment came from his depression. The case was handled very helpfully within that context.

Calvin's condition of multiple sclerosis had handicapped him and forced his retirement. However, the medical treatment for his attempted suicide and the routine care he received did not automatically become ethically extraordinary. When and if some specific treatment for Calvin became a significant burden, the ethical criteria discussed in this book would become relevant. Meanwhile Calvin's situation manifested the importance of family relationships in patients' decision making. It shows that the ethical principles about prolonging-life decisions may easily be misapplied in the face of emotional crises.

Lucy H.

Lucy H. was fifty-six years old and had received outpatient chemotherapy for cancer of the lymph nodes affecting her central nervous system. She came to the hospital because of a seizure and cardiac arrest. A case review by the ICU staff with the family resulted in continued aggressive care. This decision was based on Lucy's previous excellent response to chemotherapy and her often-stated desire to survive until the birth of her first grandchild.

Many of the ICU staff felt that continued therapy was not warranted and was inhumane. A smaller group of ICU staff, plus her daughter and Lucy herself, wanted to continue as long as there was hope. Many hours of staff meetings were devoted to the decision to stop or continue. Lucy slowly survived complications and was discharged after seven weeks. At home she was able to engage in daily activities around her home. She saw the birth of her granddaughter and enjoyed Christmas and New Year's but died suddenly eleven weeks after being discharged.

The last eighteen weeks of Lucy's life are briefly described in this case. She spent seven weeks in the hospital and the last eleven at home. The case conveys the attitude of some staff persons in ICU who knew her condition and saw good reason to consider aggressive treatment ethically extraordinary. The ethical framework for prolonging-life decisions would tend to support their judgment. Both the hopelessness of her condition and the burden of further aggressive treatment could be cited.

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But even if some ethicists found grounds for not considering aggressive treatment, Lucy still wished it. She had her own reasons, which her pregnant daughter supported.

As the case turns out, the seven weeks of treatment provided Lucy with a considerable benefit. Perhaps if the staff who opposed aggressive treatment could have foreseen that, those hours of staff meetings could have been considerably shortened.

Dr. R.

Dr. R. had practiced in St. Z. Hospital for thirty years and was now a patient there, dying of cancer. He had been put on a respirator by the attending physician, who was also his friend. After he became comatose, his wife and his son, a practicing lawyer, requested that the respirator be removed. The physician refused, even after the administrator of the hospital seconded the request. Dr. R. survived another week and then died while still on the respirator.

A clear consensus has developed in both the ethical and the legal communities that respirator treatment need not be used to prolong the lives of patients in the final stages of terminal illness. Hence, an immediate response to the case might be the expression of disappointment at the stubbornness of Dr. R.'s friend, the attending physician.

Unfortunately background information which might explain his conduct is missing. For instance, could Dr. R. have exacted a promise from his friend to "never to give up" on him? Since the case mentions no such promise, it may be that the physician simply could not decide to take a step that might be considered abandoning his colleague.

Realistically, the attending physician may have been more concerned about legal repercussions, even after the hospital administrator gave assurance. However, the likelihood of legal charges or liability seems extremely slight. In Dr. R.'s case, it seems clear that the respirator was a useless treatment. Of course, if he had insisted on its use before he became unconscious, his choice should have been respected.

Mrs. T.

Mrs. T. was a seventy-two-year-old woman living in a nursing home. When her physician discovered a small but malignant tumor in her breast, he recommended immediate removal and felt sure he could excise all of it. Mrs. T.'s daughter persuaded her to

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refuse the surgery, because of the daughter's fear of hospitals. Mrs. T. died a rather painful death after seven months.

It must be assumed in this case that surgery would have prevented some of her suffering, even if it was not totally successful. On this ground of benefit and possible cure, the surgery could easily be judged an ethically ordinary treatment.

The patient's rights seem to have been violated by her daughter, as the case is described. Surely the daughter's fear of surgery or hospitals was irrelevant. Had the mother felt this same fear, it could have made the surgery ethically extraordinary for her. This would be an individual and subjective consideration.

Mildred D.

Mildred D. came to the nursing home at the age of seventy-seven, a widow with two sons who visited her faithfully at least every week. During eighteen years in the nursing home, Mildred seemed content and lived rather serenely. Her physical condition held up fairly well, but her medical records showed an arteriosclerotic heart disease, secondary anemia, a history of an abdominal mass of undetermined origin, and atrophy of her larynx and esophagus secondary to a stroke.

After her ninety-fourth birthday she experienced increased difficulty in eating and swallowing, and became more and more frail. The doctor prescribed a soft diet. She herself remained calm and indicated that she was ready to die and go to the Lord. In fact, she refused more and more to make the effort to eat and became so debilitated that she was confined to bed.

Her eating problems got worse instead of better. Finally the doctor told her sons that he wanted to try a nasogastric tube to give her some nourishment. She resisted this almost from the beginning. Despite her disorientation, she knew what it was and simply did not want it. She pulled it out numerous times and each time the re-insertion was more painful for her. The doctor then suggested restraints to keep her from pulling it out.

The staff at the nursing home knew Mildred well—after eighteen years she was almost a charter resident. They felt it was cruel to keep inserting a tube she did not want. It was agreed that something should be done: the restraints would be removed, and the next time Mildred removed the tube, it would stay removed. The day she was left without restraints, she allowed the tube to remain, but that evening she removed it.

The staff continued offering what nourishment they could, primarily ice cream, for a week. The doctor was uncomfortable

about her increasing malnutrition. He suggested that a gastronomy tube could be inserted in her side at the hospital under local anesthesia if the sons wished. The sons hesitated several days but then authorized the tube. It was inserted but it did not work well. The staff did their best to provide comfort to Mildred. She died three weeks after the tube was inserted.

This case graphically shows the particularly agonizing dilemmas sometimes faced because of artificial feeding. An instinctive outlook of many people views nourishment as the most ordinary of human needs. When modern technology can meet that need, must it not be accepted? The general answer to that question would seem to be yes, according to the position taken by Pope John Paul II in his address of March 2004 concerning nutrition and hydration to patients: “The administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use should be considered, in principle, *ordinary* and *proportionate* and as such morally obligatory.”¹ The pope was referring specifically in his address to patients in a persistent vegetative state, but the principle he enunciated extends beyond those cases.

However, it is also to be noted that Catholic theologians have recognized that there comes a time when supplying nutrition and hydration might be futile and thus not obligatory, for example, when death is imminent or when the body no longer assimilates the nourishment.²

Wilhelm K.

Wilhelm K., a seventy-six-year-old man, had surgery for an abdominal condition. While in the ICU, he told the staff of his eagerness to return to his vigorous and active life. Before experiencing the stomach problem, he had been in general good health.

While in the ICU, Wilhelm developed a stomach infection, blood poisoning, and pneumonia. He required a tube for

¹John Paul II, Address to the participants in the International Congress on Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas” (March 20, 2004), n. 4, reprinted in National Catholic Bioethics Quarterly 4.3 (Autumn 2004): 575, original emphasis.

²William E. May et al., “Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons,” *Issues in Law and Medicine* 3.3 (Winter 1987): 209.

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breathing and became delirious from the blood poisoning. His family requested that no heroic measures be undertaken.

The ICU staff, however, felt his condition was reversible. When they set up a meeting to review the case, the family refused to attend. Subsequently, the family reluctantly agreed to aggressive efforts with a daily re-evaluation. Wilhelm was unresponsive to the efforts and died on the eighteenth day of his hospitalization.

This case shows the dynamics of family-staff relationships. Apparently the family gave up hope before the professional ICU staff did. Families today may well be influenced by the modern, widespread attention to prolonging life situations and the popular slogan “death with dignity.” From the medical information presented here we might judge that the medical staff acted rightly. Even if we were to argue that their efforts were ethically extraordinary, they were relying on Wilhelm’s own desire to get well. While the family members were surely closer to him than the ICU staff, the family may have been following their own intentions rather than Wilhelm’s.

This case might serve as an example of a common oversimplification of the ethically appropriate approach to these decisions. The family may have been correct in judging the aggressive treatment as ethically extraordinary, but a second consideration remains; namely, if the treatment is extraordinary, what evidence is there of Wilhelm’s disposition to forgo it? Some evidence shows that he wished it.

Only when no evidence exists to indicate whether or not a patient wishes ethically extraordinary procedures should the proxy representative fall back on considering the patient’s best interests, or what competent people would consider the patient’s best interests based on the experience of people in similar situations. Wilhelm’s case did not conform fully to that model.

Infant Doe

In April 1982, physicians diagnosed “Infant Doe,” born in a Bloomington, Indiana, hospital as afflicted with Down’s syndrome, with additional abnormalities of the esophagus that required corrective surgery. The parents refused to consent to the surgery and were supported by their obstetrician and the hospital. The infant was also deprived of food and water (the abnormalities made digestion impossible) and of intravenous nourishment and hydration. The baby died at the age of six days.

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A circuit judge held that the decisions to withhold surgery and nourishment were a proper exercise of parental authority and medical judgment. A county prosecutor brought action under a child abuse statute, and private parties sought to adopt the child in order to provide consent for the needed surgery. An appeal to the Indiana Supreme Court was turned down by a 3- to-1 decision.

Infant Doe was not dying, and a frequently performed surgical procedure would have been beneficial. Withholding surgery and all forms of nourishment would not be supported by Catholic moral principles. Good reasons can be given why the medical procedures should have been considered ethically ordinary. Infant Doe could have survived with them.

Very possibly the reason that Infant Doe was denied surgery was the child's Down's syndrome, but it could not yet be known whether he belonged to the small number of such children who are severely retarded. His case seems to exemplify the improper use of "quality of life" considerations. With corrective surgery, he would have had a strong possibility of benefit. The surgery would not have cured the Down's syndrome, but that should not have been the focus.