

Denying Food and Water

The Real-World Implications

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Abstract. Life-support technology may become a death-prolonging horror, and some people may fear that an over-intellectualized interpretation of traditional moral teaching has led us astray from what a compassionate God wills for the dying. The author addresses this fear. Those who defend “orthodox” teaching on end-of-life issues have a serious obligation not to obscure the compassion implicit in the traditional distinction between ordinary and extraordinary means. There is no medical or moral obligation to prolong dying or make it more burdensome with interventions that offer little benefit, and there is nothing immoral about pain relief. What is prohibited is killing: any action or omission that has the express or implicit purpose of ending a life. *National Catholic Bioethics Quarterly* 10.4 (Winter 2010): 695–705.

Family members and medical caretakers of the severely handicapped, the comatose, those suffering dementia, and those in the so-called persistent vegetative state often enter a new stage of grief when it appears that the condition is going to be endless. Death is the only end. The blank, dark hopelessness between now and then can easily appear as pointless suffering. Even those who have the gift of a religious faith that values obedient and patient suffering may understandably wonder what plan God might have. The afflicted person is not capable of being patient or obedient. It is only the caregiver who is obedient and patient. And a caretaker may well wonder

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whether this obedience is to God or to medical life-support technologies that God had nothing to do with.

Technology, after all, is man's creation, not God's, and is, or ought to be, created to do good, not to drag out an already grinding dying process. And if, with all good intentions, we apply a life-support technology that circumstances have changed into a death-prolonging horror, the technology is still our creation and we, not God, remain responsible for its consequences—consequences which are the result of our decision to apply the technology in the first place. Surely the original decision is revocable if circumstances have changed radically. It is not surprising, then, if even very “orthodox” theologians who must witness a loved one in one of these sad states may come to suspect and fear that some over-intellectualized interpretation of traditional moral teaching has led us astray from what a compassionate God wills for the dying.

My intention in this paper is to take this fear seriously and respectfully and yet be on guard against finding an escape from the burden of such distressing end-of-life conditions, an escape that honest and open-minded secular observers see quite rationally as an evasion of the obvious.

At the same time, those who wish to defend orthodox teaching on end-of-life issues have an equally serious obligation not to obscure the compassion implicit in the traditional distinction in Catholic teaching concerning ordinary and extraordinary means, especially in the cases of persons who are truly dying.¹ There is no medical-moral obligation to prolong the dying process or to make it more burdensome with medical interventions that offer little benefit. And there is nothing immoral about pain relief, including medically induced coma, when it is needed. What is prohibited is killing: an action or omission with the express or implicit purpose of ending a life.

Secular Acceptance of Killing

American judicial practice has no absolute or blanket prohibition on the deliberate ending of life when convincing documentation exists of a patient's will to have medical interventions withdrawn, as became clear in the case of Terri Schiavo. The elevation of patient autonomy to the principal value is commonly held to include calling for the removal of life-support technologies, not just to escape their burden and accept death, but to cause death, regardless of the burden of the technology. Certain thinkers—let me call them secularists—who have no scruples about causing the death of a severely handicapped patient certainly know the difference between letting a person die of an underlying condition and causing the person to die. They know the distinction. They just do not think it is important if they feel sure about the patient's intention.

¹ The distinction has been part of the tradition since at least 1957, and was reaffirmed by the Church in 1981. See Pius XII, “The Prolongation of Life,” Address to an International Congress of Anesthesiologists (November 24, 1957), in *The Pope Speaks* 4.4 (Spring 1958); and Pontifical Council *Cor Unum*, “Question of Ethics regarding the Fatally Ill and the Dying” (June 27, 1981), reprinted in *Conserving Human Life*, ed. R. E. Smith (Braintree, MA: Pope John XXIII Medical-Moral Research and Education Center, 1989), 286–304.

Since no one will deny that it is possible to kill a dying person, say by strangling someone in end-stage renal failure or by delivering a gunshot to the head of someone with terminal cancer, let us define *to kill the dying* as “to introduce intentionally a new cause of death,” and distinguish this from *letting die*, defined as “choosing not to resist by any means the active process of dying from an underlying cause which we are morally certain will cause death.”²

Catholic and other orthodox Christian ethicists arguing in the hearing of secularists must not seem to be unsure of these definitions and the clear distinction between them. Such uncertainty will make the ethicists appear insincere or, worse, bent on obtaining freedom for the caretakers or the patient from the burden of the dying process by obscuring the fact that some action or omission is really a killing. And if it is a killing and clearly seen as such, then the secularists will publicly question why the withdrawal of assisted nutrition and hydration (ANH) should be chosen as a way to end the life of a person in one of the sad conditions noted above. Since some of these persons are not dying but rather are severely handicapped, the range of persons now made vulnerable to killing has been expanded dramatically. The recognition that withdrawal of ANH can be a particularly gruesome and painful way to die, in spite of all intentions to the contrary, will almost certainly lead to its being outlawed in favor of direct euthanasia.

Slippery Slope to Active Euthanasia

In a heart-rending tale that appeared in the 1975 *New England Journal of Medicine*, James Rachels made a convincing case that almost any form of painless direct killing of a newborn would have been immensely more merciful than what happened under the extremely thin veil of “letting die.”³ In the article, since reprinted in many undergraduate ethics anthologies, Rachels argues for active euthanasia because it is obviously more compassionate than the gradual starvation and dehydration of a healthy newborn with Down syndrome. The case actually occurred at Johns Hopkins and was first described in 1972 in a *New York Times Magazine* article by an attending surgeon, Dr. Anthony Shaw.⁴ Shaw spoke from the perspective of medical staff *who had to stand by* at the bedside of this baby who needed nothing more than the breaking of a thin membrane in its lower esophagus to be able to nurse normally. They had to listen to its excruciating cries of hunger and then whimpers until its death. Shaw writes,

As a surgeon, whose natural inclination is to use a scalpel to fight off death, standing by and watching a salvageable baby die is the most exhausting emotional experience I know. It is easy at a conference, in a theoretical discussion,

²It is understood here that the means by which we might resist or slow the approaching death have no actual therapeutic potential in this case.

³James Rachels, “Active and Passive Euthanasia,” *New England Journal of Medicine* 292 (January 1975): 78–80.

⁴Anthony Shaw, “Doctor, Do We Have a Choice?” *New York Times Magazine*, January 20, 1972, 44, 52, 54.

to decide that such infants should be allowed to die. It is altogether different to stand by in the nursery and watch as the dehydration and infection wither a tiny being over hours and days. This is a terrible ordeal for me and the hospital staff—much more so than for the parents who never set foot in the nursery.⁵

Paul Ramsey, commenting on Shaw's observation that this "death by neglect" is similar to a second chance at an abortion, said that it should more properly be called "choice and promotion of death, which is no part of a physician's vocation."⁶

I note these things because of the difference Shaw noted between discussing a policy in a learned, "rational" way and intimately seeing a policy in action, which often means coming to know the policy's real-world character, its moral horror and incalculable heartlessness. I note it also because we see how Rachels and Ramsey, who have opposing opinions on what should be done, both strip off the verbiage and call the death of the child what it is—a killing. One of them calls for a more compassionate way of killing, and the other points out that killing is not (yet?) a part of medicine.

I doubt that theologians who have dissented from Pope John Paul II's allocution on life-sustaining treatment and the vegetative state⁷ intend to expand medical practice to include direct killing, but that is the inevitable slippery-slope outcome of their position. Their careful explanations will count for nothing with secularists, just as similar arguments did not impress Dutch secularists.⁸ And if they retain their compassion, they will end up calling for inducing coma in patients who undergo withdrawal of ANH.

Withdrawal of Respiratory Assistance

Supporters of the withdrawal of ANH, especially those who happen to be Catholics and conservative Christians generally, know that their opinion needs defense. One defense that seems promising is the similarity between withdrawing respiratory assistance (RA) and withdrawing ANH. Occasionally the two withdrawals are identical in intent and in moral failure, when the intention is to end the life of a patient for whom RA or ANH has the potential to support recovery.

At a discussion I was facilitating once, a nurse described the following real case. The nurse was present but not in charge when a woman in her early sixties

⁵Ibid., 54, quoted in Rachels, "Active and Passive Euthanasia," 79.

⁶Paul Ramsey, *Ethics at the Edge of Life: Medical and Legal Intersections* (New Haven, CT: Yale University Press, 1978), 193.

⁷John Paul II, Address to Participants in the International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas" (March 20, 2004).

⁸In the context of Dutch secularization, I find nothing surprising or indicative of moral collapse or corruption in the fact that close to half the cases of Dutch medical euthanasia go unreported in spite of (and perhaps because of) very detailed regulatory schemes first imposed by Dutch courts and then by the legislature. See P. J. van der Maas et al., "Euthanasia and Other Medical Decisions concerning the End of Life," *Lancet* 338.8768 (September 1991). It is simply a case of a logically justified slippery slope.

was being prepared for her first jaunt to the recreation room after a serious illness. The woman had signed over her health care decision making to her daughter but was now beginning to recover. Because of the illness, she needed RA, and she had been fitted with a mobile respirator. She had learned to slip a little liquid past her tracheostomy tube, but she could not speak because of the tube. She was sitting up sipping a soda when her daughter arrived. The daughter appeared stunned at her mother's evident improvement and ordered the RA to be removed. The nurse had to stand by while the extubated woman went into a faint and died.

“What should I have done?” asked the nurse. Dead silence filled the discussion room, and I was speechless. My credentials did not include legal training, so I had no ready answer. Except for the flat, matter-of-fact tone of the nurse's voice, I found the story scarcely credible. She had, I believe now, witnessed a deliberate killing. The key sign? The woman was evidently recovering, and the RA was doing its job in supporting the recovery. *Respiratory assistance was rejected because it was working.* Evidently, her mother's recovery had not been part of the daughter's plan. Whoever was in charge was either complicit in the killing or unaware of the medical staff's legal right and duty to not carry out without consultation an act that was *prima facie* not in the best interest of the patient.

Ordinarily, RA is discontinued because it is not assisting in a patient's recovery and is simply prolonging a clearly downward path toward death while making that dying more burdensome. If a patient breathes independently after RA has been withdrawn, efforts will not be made to asphyxiate the patient. If the lack of the respirator seems to panic the patient, steps are taken to allay the panic.

The predictable result of RA withdrawal is that the patient will die a little sooner, but it is the disease or trauma which made the RA necessary that is likely to cause death shortly after its removal. It should be clear that choosing the time of death is neither killing nor suicide, and choosing an earlier time may even be morally obligatory if, for example, the costs of RA are bankrupting a family or the RA equipment is needed for a patient with real recovery potential. RA may be withdrawn because of its failure to do any good, not because of its success.

ANH, in the PEG⁹ or nasal tube form, is minimally intrusive and usually maintains nutritional health very effectively. When it does not, like RA it can be withdrawn. In many cases, some of which have been fought in open court, ANH has been withdrawn when patients were stable and no longer on a downward path toward death due to earlier trauma or disease. Evidence of this is that the patients were not being treated for any lethal condition. In such cases, the removal of ANH becomes a new cause of death. Here we define “new cause of death” as a lethal cause of organ failure unrelated to the medical condition that made ANH useful or necessary in the first place. An example would be almost any serious, even terminal, disease or trauma that requires tubal RA; ANH must also be used to keep undamaged organs nourished. If ANH is not instituted or is withdrawn, damage—eventually fatal—will

⁹In PEG (percutaneous endoscopic gastrostomy), a tube is inserted into the stomach through the abdominal wall and secured there from the inside.

be done to relatively healthy organs. This is a new cause of death in the sense intended in this paper. A medical agent who institutes such a deprivation of ANH intends the patient's death by the route the agent has initiated. It is a killing.

Evidence of Lethal Intention

The direct intention to cause the death of a patient by removing ANH may be apparent in several ways.¹⁰ In such cases, removal of ANH has no other intended end point than death; this remains true even if, by chance, another complication ends the patient's life before the lack of nourishment does. Other justifications for rejecting use of a medical device, such as distress to the patient or cost to the family, are incidental.

A list of the morally relevant aspects of ANH delivery via a PEG tube is helpful in evaluating a decision to withdraw ANH:

- Patient comfort is enhanced by the ANH.
- The procedure for inserting a PEG tube (like that for a nasal tube) is straightforward and not expensive. It can often be done with a local anesthetic in an out-patient facility.
- Home health care can suffice to maintain the tube.
- The cost to the family, financial and emotional, for the care of the ANH-supported patient is due almost entirely to the continuing life of the patient. The cost of the ANH itself is insignificant.
- A patient or family member who objects that ANH is burdensome to the patient will often admit that the actual burden is in the continuing life of the patient—that is, the ability of ANH to keep the patient alive, not any negative property of the ANH itself.
- ANH is rejected because it is successful, not because it is failing.
- The inevitable death of the patient is due entirely to the withdrawal of ANH, a cause of death that is entirely new. Only after ANH withdrawal does the patient pass from living to danger of dying and finally to dying itself, *by processes entirely unrelated to the underlying causes of the incapacity to take food by mouth.*

To thus introduce a new cause of death is the very definition of killing.

In sum, when the decision to withdraw ANH has a lethal intention, it is difficult to deny that death is the purpose of the withdrawal and that death is the source of all the “benefits” that can be traced to the withdrawal. The claim that this is not a decision to kill will not stand up to scrutiny. The claim itself is scandalous and can be seen as a hypocritical rationalization.

¹⁰ I am indebted to Christopher Tollefsen, *Artificial Nutrition and Hydration: The New Catholic Debate* (Dordrecht: Springer, 2008), for this section of my comments.

Distinguishing Kinds of Withdrawal

Before examining the physical and moral dangers of withdrawing ANH, we need to indicate the withdrawals that are the target of our critical analysis. We must first divide the withdrawals into those done to moribund patients and those done to non-moribund patients.¹¹ We further divide these by whether the ANH is successful or deficient in achieving its end (whether it succeeds or fails to actually nourish and hydrate the patient) and by whether the means to carry it out (e.g., equipment, personnel, resources, family finances) are morally objectionable—for example, the ANH equipment has been seized from someone who is in greater need and has a greater likelihood of benefit.

Removal of ANH in Moribund Patients

In patients who are truly dying, when the effects of disease or trauma are moving so quickly toward death that lack of fluid or food will not constitute a new cause of dying, removal of ANH is morally acceptable unless the ANH is needed for comfort. The same is not true when the effects of disease or trauma are moving slowly though certainly toward death. This is one type of case—that of a patient who is dying slowly—where the papal allocution of 2004 requires the use of ANH,¹² provided that its use is not deficient physically or morally in means or ends: in common terms, the ANH is doing natural good and no injustice is involved in its use.

The problem with withdrawal of ANH in the case of someone who is dying slowly is found in the meaning of an honest answer to the question, “Why are you withdrawing ANH?” In some cases, the honest answer is not only “Because ANH is delaying the time of death,” but also “Because the patient is still healthy enough to benefit from supplying the natural fluid and nutritional needs of the body.” In such a case, the withdrawal is an intentional attack on the remaining health of the patient, and if the *underlying cause of dying* does not move quickly enough, the ensuing death will be due to the new cause: dehydration. Here the removal of ANH is not the removal of a futile measure but the introduction of an effective measure for ending life. It is a killing. Those who advocate direct euthanasia will use this dehydration practice as evidence that opposition to killing has been covertly abandoned by Christians. And it will be further shown to be an astonishingly cruel way to kill in a predictable, if small, number of cases.

Removal of ANH in Non-moribund Patients

The withdrawals of ANH that have been most hotly disputed and have received the most public attention involved non-moribund patients who were profoundly handicapped. It is a notable and perhaps symptomatic aspect of the controversy over ANH that many of the supporters of increased usage of withdrawal fail to distinguish between being ill and being handicapped due to the ravages of a no longer active

¹¹ By moribund we mean “actively dying from some disease or trauma process.” The dying process need not necessarily be the cause of the inability to take food by mouth.

¹² John Paul II, “Life-Sustaining Treatments.”

disease or trauma. Those who are handicapped in this way but still able to defend themselves never fall victim to the confusion. They are acutely aware of the difference. Sickesses are dynamic and usually progress either to a natural recovery based on the nature of the cause, as with the chicken pox, or to death, as with the bubonic plague, or to a state in between, as with diabetes. Usually doctors have a treatments for sicknesses, unless there is a consensus of incurability.

If one is not being treated for an illness and does not have an illness that has been declared incurable, one cannot be said to be “sick.” If one is missing a leg, the condition is called incurable in a different sense. But life-threatening circulatory side effects of an amputation or of confinement to a wheelchair are sicknesses and are treatable, like bed sores are for a person who is profoundly handicapped.

Persons with handicaps seek treatment for their illnesses and accommodation for their handicaps—and they know the difference between them. It is an abuse of language to label as sick someone who is unable to talk because of brain trauma but whose condition is now stable. Such a person becomes sick only if something else, some other dynamic disease process, begins. If we introduce that “something else” for the purpose of producing a dynamic of decline to death, we are killing that person. No non-dying handicapped person would doubt that the withdrawal of ANH is a killing. Were these patients not so handicapped as to be unable to protest, they would ask for at least as much compassion in the choice of lethal measures as would a criminal sentenced to death. For the non-moribund, withdrawal of ANH which is not deficient morally or physically in its end or means is always a killing and is therefore morally illicit.

The Scandal of Risking Cruelty

Earlier I mentioned the cruel killing of a newborn by dehydration, which was made possible because of the child’s weakness and the absence of anyone with the courage or the legal ability to stop it. Currently death by dehydration is beginning to threaten other equally vulnerable groups: those who are comatose, demented, or minimally conscious and others. This threat gives strength to arguments calling for direct, speedy, and painless active euthanasia, just as it did in the killing of the newborn. This call for active euthanasia arises because death by dehydration is not always painless and will predictably lead to a small number of cases of horrendous suffering.

Those in favor of withdrawal of ANH from non-moribund patients will assure us, on the basis of anecdotal evidence, that dehydration is a painless if prolonged way to die.¹³ Equally anecdotal, but based on direct testimony, are accounts by patients who have emerged from coma and states of semi-consciousness. Few of them experienced severe pain while in their locked-in condition. Even if the capacity to experience pain occurred very rarely, in as few as 0.05 percent of locked-in cases, to subject those

¹³Franklin Miller and Diane Meier, “Voluntary Death: A Comparison of Terminal Dehydration and Physician-Assisted Suicide,” *Annals of Internal Medicine* 128.7 (April 1998).

with complete sensory ability to death by prolonged dehydration would be grossly and cruelly negligent when a more assuredly painless and quick way of ending their lives is readily available and immensely more conservative of medical resources.¹⁴

Why would a caring medical person, or any person, choose withdrawal of ANH, with the attendant risk of afflicting such suffering, rather than a speedy and compassionate lethal injection? Limited to those two alternatives, a patient would certainly choose the latter.

In 1999–2000, the California state legislature was entertaining a physician-assisted suicide bill, AB 1592, modeled on legislation in Oregon that limited PAS to patients who could drink a lethal potion unassisted and who had six months or less to live. Staffers in the legislative offices of assemblywoman Dion Aroner, who was spearheading the effort, were willing to acknowledge that an internal logic of inconsistency would lead, after the bill's passage, to its transformation into a policy of direct active medical killing for those incapable of preparing or swallowing the lethal potion.¹⁵

If the goal of relieving unbearable physical or mental suffering in the terminally ill justifies PAS, what sense does it make to confine the practice to those well enough to imbibe a poison on their own or to those who are expected to die in six months? Clearly those who have a longer time to suffer need relief more, not less. The tacit and sometimes explicit reassurance was that those inconsistencies would be removed by gradual amendment over time.

Is this the true goal of supporters of ANH withdrawal? It is hard to imagine that traditional Christian and Catholic moral theologians engage in such policy duplicity. Could it be that the image of a physician actively dispatching patients is too lurid? Is their support for ANH withdrawal but not active euthanasia something like support for the ghastly ripping and tearing of the body of a near-birth infant as long as the child is hidden within the womb (in late-term abortion) as opposed to delivering the child and killing it by lethal injection? To suggest this would be calumny. The cases are radically different.

Abortion is a case of an adult claim of autonomy run amuck, where a woman's maternal instinct and obligation to care for her offspring, and medicine's vocation to help her, have been corrupted into their opposites. Justification of this corruption of normal maternal and medical responsibilities requires making the offspring a nonentity, nonexistent on the scale of values otherwise used in civil society. In the case of withdrawal of ANH, moral theologians have more than once recounted how their search for ways to make final suffering and dying more bearable in duration and intensity began at the bedside of a loved one whose sufferings were felt as their

¹⁴I was paralyzed and on a ventilator and ANH for ninety days. I can testify that even with adequate hydration a single night with a dry mouth is an excruciating experience.

¹⁵The call to Aroner's office was made in May 2000 by the author's wife, Christine Cipperly. She presented herself as concerned about an inconsistent compassion in AB 1592 in that the severely handicapped would not have access to PAS.

own. Outgoing compassion rather than in-turned autonomy is the dynamic here. How could that be wrong?

To attempt to show this by rational argument is to suggest that we know by reason why God has taken it out of human authority to deliberately end the life of an innocent. We can offer many wise arguments about why human beings would not handle such authority safely. But ultimately it is a gift of our faith to believers and, until recently, to our cultures to treat the lives of the innocent as belonging to him alone. This makes their lives sacred, untouchable even by those who are motivated by the deepest compassion.

It is easy to sympathize with those who feel that compassion cries out for carefully guarded exceptions here, especially if there is some way to see shortening the time of distress as not really killing. There is nothing shameful in the desire to alleviate suffering, to avoid suffering if possible. Our God-given love of self and of our neighbor calls for it, and we hear it from Christ in the Garden. But in that Garden we also hear Christ's avowal of obedience to his Father's will. And there too we hear of at least two limits set on escape from suffering, which come with that obedience: We are not to use human violence and are not to call on divine violence.

Is the withdrawal of ANH violence? I am afraid it is, certainly for those in a locked-in condition, and it will soon introduce violence into medicine. At least some courts, notably the California Supreme Court, are currently aware of the explicit violence threatened in decisions to extubate patients. In the *Wendland* decision, for example, the California Supreme Court pointed out that the delicate regard for autonomy and privacy expressed by those seeking extubation were scant cover for an incautious decision to kill, which is "the gravest possible affront" to a conservatee's privacy and the autonomy it shields.¹⁶ Although the court was more permissive where patients were presumed to be incapable of suffering from withdrawal of ANH, it was clearly stunned that normally compassionate parties were willing to let a conscious patient suffer dehydration.¹⁷ No more than a moderately attentive reading of the court's unanimous opinion reveals that the justices were scandalized by an *amicus curiae* brief in which some Catholic institutions joined in the call for *Wendland's* extubation.¹⁸

Christian moral theologians surely do not wish to side with torturers, but those who oppose the use of ANH in cases like those outlined here may end up on that side unintentionally. In questioning why some cases of killing should not be called

¹⁶ *Conservatorship of Wendland*, 26 Cal. 4th 519; 28 P3d 151, 110 Cal Rptr 2d 412 (2001). The opinion by Justice Werdegar expressed the unanimous view of the court. The conservators are seen by the court as seeking "deliberately to end the life of conscious conservatee" with disastrous effects on his privacy and autonomy (17, 19, 21.)

¹⁷ *Ibid.*, 11 and 15.

¹⁸ For Rita Marker's discussion of the case, see "Mental Disability and Death by Dehydration," *National Catholic Bioethics Quarterly* 2.1 (Spring 2002): 125–136. Marker includes details of the oral arguments which show that some Catholic theologians need to be much more aware of the vulnerability of those who are severely handicapped.

acts of compassion rather than killing, they might reframe the question to ask, “If a God we know to be infinitely compassionate forbids this kind of compassion (the deliberate ending of a life by dehydration), is it because He knows how much unintended suffering it will cause?” If we can believe the reports surfacing from convalescent homes and other care facilities, such suffering is already occurring. When the dangers and actual tragedies of ANH withdrawal become evident, we can expect to find indignant secularists calling for direct, quick, cheap, and active euthanasia and attacking the arguments of our moralists as cruel hypocrisy.

And so, finally, the greatest violence will be done to patients and to the profession of medicine, as it adds lethal injections to its instrument cabinets and essentially unregulatable euthanasia to its practice.