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Terminal Sedation and Dehydration

The range of medical intervention at life's end can vary greatly, from sedation to euthanasia.

By Charles F. McKhann

Michael was thirty-seven when he began to have abdominal pain. It was a vague pain in the upper part of the abdomen, and was thought to be due to an ulcer. However, two months later, the pain had increased and it was clear that he was losing weight in spite of eating fairly well. An operation was performed that revealed that he had cancer of the pancreas. Moreover, the tumor was extensive and could not be removed surgically. Michael declined chemotherapy after hearing that it was very unlikely to prolong his life significantly. Although he had increasing discomfort, it was controlled with medication and he continued to be fairly active as a dentist.

Michael was part of a large Catholic family, having three brothers and a sister in addition to his wife and four small children. His parents were still alive. Understanding his grim prognosis, namely that he might have only a few weeks to live, Michael discussed his outlook with all of the members of his family except the children, whom he thought were too young to understand. These discussions were mostly one on one, but occasionally in small groups. He was a strong-willed, pragmatic man who was not prone to sentiment. He explained, “This is the situation, and I am sorry about it. I am sorry that my life is going to be cut short and that I have to die so young, leaving Nancy and the children. If there is something beyond the grave, I will enjoy it. Until then, I would like to have as much togetherness and as little sadness as possible with all of you.”

Michael also came up with a new idea, that when he was no longer able to eat or drink by himself, he would stop doing so altogether. He did not want to have anyone helping him to eat, nor did he want to have any tubes or intravenous feeding. He realized that this step would probably shorten his life by a few days, but also felt that the quality of his life, as well as that of his family, would be totally destroyed if he waited for the disease to take its natural course. He wanted to have some control over when and how his life ended. His family could see that he was going downhill rapidly, and no one objected to his proposal. His physician, a personal friend, promised to provide him with good pain relief and came to his home often. He wanted to spend as much time at home as possible, but wanted to die in the hospital so that the home itself would not be associated with the memory of his death.

Five weeks after his surgery, he felt the time had come to stop eating or drinking. Nobody tried to talk him out of it, and his physician supported him with appropriate medication so that he felt very little discomfort. A brother from out of state came to spend a day with him, preferring to be with him when he was awake and coherent rather than at the time of his death. The dying process took a week. Towards the end, he was comatose and was transferred to the...
hospital, as he requested, where he spent his last two days. The timing of his death was predictable, and most of his family was present.

During the final week, and in the weeks and months following his death, there were no recriminations. The entire family felt that Michael's choice was the right choice under the circumstances, and many said that they would do the same thing in a similar situation. At no time did he seem depressed. Indeed, he provided meaningful moral support to other members of his family, particularly his wife and children. His memory lives on with his family as a strong-willed, "nuts and bolts" guy, who faced his impending death directly and unflinchingly. His own acceptance of "what must be" provided a foundation of reality and acceptance for his family that they still remember.

I heard the history of Michael's death from his brother, shortly after it occurred. It was my first exposure to the concept of voluntary terminal sedation and dehydration, and I was deeply impressed with how autonomous and brave the step seemed to be. I have subsequently seen it in a broader perspective. It was still an autonomous and brave decision, but it may also be a sad but necessary compromise with reality. I do not know if Michael had the remotest thoughts of any form of assisted dying. At the present time, other end-of-life options, including hydration, various forms of sedation, assisted suicide, and euthanasia, are against the law, but terminal sedation is not. The components of terminal sedation that I will look at include dehydration, sedation, double effect, intent, and some legal considerations. First, we must see where terminal sedation fits in the spectrum of possibilities for the person who wants to die on his own terms.

Clinical Differences
The range of medical intervention at the end of life includes none at all (where none is available or wanted), refusing or discontinuing treatment including hydration, various forms of sedation, assisted suicide, and euthanasia. Morally, patient refusal of treatment, terminal sedation, assisted suicide, and euthanasia are very similar. The patient wants to die sooner rather than later and at some level, even if it is against the law, the physician may be willing to help. If one is acceptable, they probably all should be. However, legislatures, courts, and many physicians and medical ethicists see significant differences between these activities. The advantage of terminal sedation over assisted suicide and euthanasia at the present time is that sedation is legal. This is an important dividing line.

The right to refuse treatment is a basic element of patient autonomy. In making such a decision, the patient shoulders most of the responsibility, and the physician is required by law to honor the decision, even if it appears to be contrary to the best interests of the patient. It is now widely accepted that the body of a competent person cannot be violated against his will by any treatment, however beneficial it may seem to be. Refusal can be for highly technical support systems, such as renal dialysis or artificial ventilation, or for more basic elements of support, such as artificial feeding, or any other treatment that could extend life. It can also include refusing normal food and drink. At this point, it becomes voluntary terminal dehydration. The addition of sedation to control symptoms advances this to terminal sedation.

A person who refuses to eat or drink can only be nourished artificially. Since administering unwanted nourishment is against the law, the refusal must be accepted. This point is important because it extends the concept of terminal dehydration from the patient who is terminally unable to eat or drink, to one who is pre-terminal and refuses to eat or drink. Indeed, theoretically, death by dehydration can be elected by anyone who wishes to take such a step to end his life, regardless of age or medical circumstances. Most people who are physically well but suffering from depression have other ways of killing themselves that are instantaneous and carry little risk of outside intervention.

The use of drugs to ameliorate pain, anxiety, and general distress in a dying patient, representing the simplest application of terminal sedation, is recognized and used throughout the world where the appropriate drugs and medical care are available. This use of sedation is morally, medically, and legally acceptable, and has been for centuries. Sedation at the end of life is the natural extension of providing narcotics to relieve the suffering of any patient who has a chronic, painful illness. There is no reason why sedation for the management of symptoms cannot be extended to the patient whose terminal dehydration is elective, just as it would be to one whose dehydration was an obligatory part of the natural course of his disease. As will be seen, terminal dehydration and sedation can be treated as
separate entities, but they can also be blended together in various ratios that give their combination a special place in this spectrum.

Beyond refusal of treatment, terminal sedation, and dehydration are two much more controversial areas of intervention: physician-assisted suicide and euthanasia. In assisted suicide, the patient is given a prescription for lethal drugs that he may take when he feels that the distress of the illness is overwhelming. Many patients feel reassured that they are “in control” by having the drugs on hand, even though they may never take them. In physician-assisted suicide, the doctor’s role is a more active one psychologically, morally, and legally, even though it is limited to filling out a prescription for a potentially lethal drug. Moral responsibility is shared with the patient, who must still undertake the final act of taking the drug. Many physicians would prefer this, since it does not require being present at the time of death. Indeed, the physician may not even know if the patient died of his terminal disease or from taking the drug. Physicians may deceiving themselves, or be deceived by their patients, into thinking that the prescription was actually requested for sleep. Laws permitting assisted suicide have been looked at and rejected by many states, but were passed and are currently in effect in Oregon.

In voluntary euthanasia, the patient asks his physician to personally administer a lethal dose of drugs, usually intravenously. Here the final step is clearly in the hands of the physician. Death occurs within a few minutes of administration of the drugs, and the physician’s direct responsibility is obvious. For this reason alone, many physicians who support the concept of assisted dying prefer that it be assisted suicide and not euthanasia. Legislators who support assisted dying view euthanasia as being more radical and vulnerable to abuse than assisted suicide. Conservative religious groups view euthanasia as the “end of the line” and often cite assisted suicide as a dangerous step in that direction.

Dehydration

Many people die of dehydration as a natural outcome of their disease. This includes most people who have cancer, particularly intra-abdominal cancers, severe stroke, or other serious deterioration of mental function, or any progressive illness that leads to increasing weakness to the point of being unable to handle food or liquids. At that point, artificial feeding, intravenously or by a gastric tube, can be instituted if the patient’s underlying illness is not terminal. Such steps are usually omitted if the patient is not expected to live long. People who die at home rarely have access to artificial nutrition. It is generally understood that when a person is admitted to a hospice facility, no artificial feeding of any kind will be instituted, and when a person becomes unable to eat or drink, no attempt will be made to circumvent this terminal event. In non-fatal illnesses such as severe stroke, dementia, or brain death, the use of supportive treatment in the form of artificial nutrition may be seriously questioned by the family and/or physician, and eventually rejected or withdrawn. However, in many parts of the world that do not share the widespread use of our medical advantages, patients with fatal chronic illnesses usually eventually die from dehydration. There are strong reasons to question whether our own medical technology should be utilized as frequently as it is.

Cessation of all fluid intake, particularly if no food is taken, usually causes lethal dehydration in one or two weeks. There is no obvious systemic reaction in the first few days. The most common symptoms are thirst and dryness of the mouth. Mild sedation can control the thirst easily and oral dryness responds well to sips of water, sucking on ice chips, and lubrication of the lips. Neurological signs, consisting of lethargy, weakness, confusion, and eventually progressive coma, appear later, beginning in four or five days. Pain and discomfort are moderated by accumulation of ketones in the body as it utilizes fat rather than carbohydrates to meet its energy needs, and by a form of autosedation, the causes of which are not known, seen in the dying process. Death is due to loss of circulating blood volume and to electrolyte imbalance, particularly the accumulation of potassium and calcium, which cause cardiac arrhythmias.

Many studies report that dehydration in terminal disease is associated with no significant suffering. For individuals carrying an intolerable burden of illness and disability, or those who have no hope of ever again enjoying meaningful human interaction, the withdrawal of food and fluid may be considered without concern that it would add to the misery. Two hospice nurses wrote, “We have not seen evidence that dehydration occurring at the termination of life results in any pain or distressing experiences for the patient.” The symptoms of thirst or dryness
of the mouth can be easily relieved. When terminal dehydration is elected by a patient who is not really terminal, control of thirst is well within the range of commonly used sedation.

In spite of this information, terminal dehydration is associated in the minds of most people with serious and unnecessary suffering. Families and physicians alike may be reluctant to suggest dehydration because of the universal symbolism associated with feeding and nurturing as expressions of care and love. Voluntary dehydration is a way to end life that often requires enough willpower and resolve on the part of the patient to not only see the process through himself, but also enlist the support of reluctant family members and even physicians.

Dehydration is also thought to be closely linked to starvation, and both have very negative connotations. Starvation is a time-honored form of punishment and, when self-imposed, is often used to gain public sympathy for political purposes. In both of these situations, dehydration is not included for the simple reason that death would occur much too soon. Death from dehydration in terminal disease is usually preceded by significant starvation because adequate amounts of fluids are more easily ingested than sufficient food. However, in voluntary dehydration this may not be the case. It must then be understood that the critical step is dehydration. Starvation alone, with little or no restriction of fluid intake, can require many weeks or even months to be lethal, depending on the nutritional status of the individual at the beginning.

Sedation and Palliative Care

Relief of suffering is the oldest and still the most basic element of medical care. When treatment is directed at symptoms alone and not at the cause of the illness, it is considered palliative care, and is intended to provide as much comfort as possible. This includes spiritual and personal support for patients and their families, better home care with adequate help, and attention to all causes of distress and suffering. The latter has focused on symptom control, looking at the indications for medication, the most appropriate drugs to use, and the dosage required to relieve different types of suffering. There is no question that much of the new interest in palliative care was stimulated by the "threat" of legalized assisted dying, for which there is strong support from the general public (about sixty-five percent) and moderate support within the medical profession (as many as forty percent of physicians who care for dying patients).

The cornerstone of good palliative care is appropriate medication to relieve all physical and psychological suffering. Symptoms and distress increase towards the end of life in chronic illnesses, and often reach a climax in the final weeks and days. It is not surprising that steps to control these symptoms must also increase. In many illnesses, this eventually requires the use of moderate to large doses of narcotics. The increasing need for narcotics with advancing symptoms has caused some misunderstanding among physicians. A few years ago they were hesitant to give enough medication to control suffering out of fear of causing tolerance and addiction, even though short-term addiction in a person dying of cancer is hardly a threat to the patient or to society. More recently, concern about causing addiction has faded, only to be replaced by the fear of killing the patient by inadvertently giving too much medication. Again, many physicians are reluctant to give enough medication to provide even reasonable relief of symptoms. In fact, the amount of sedation required to control symptoms is extremely variable from one person to another. Some cancer patients require such enormous doses of narcotics just to control their underlying pain that upper limits on how much morphine should be legally permissible are meaningless.

Terminal Sedation and Dehydration

Within the spectrum of interventions, between refusal of treatment and euthanasia, elective dehydration and sedation assume greater importance when they are combined. The resulting terminal sedation usually takes place at home or in a hospice institution. Most acute care hospitals are too single-minded in their mission, too aggressive in their treatment, and too conservative in their thinking to accept such a responsibility. The patient can elect dehydration at any point in his illness up to the terminal phases, where it may be a function of his disease and no longer elective at all. Sedation, usually in the form of narcotics, can be provided in amounts just sufficient to control both the symptoms of his underlying illness and any added discomfort caused by the dehydration, primarily thirst. Indeed, the medications required to control the symptoms of the underlying disease may cover thirst too, with nothing more needed. The level of sedation is
obviously an important factor. The patient who has very little underlying discomfort may need only mild sedation to control thirst. For several days he may be conscious and able to communicate with his family, helping them to adjust. He will have time to reconsider and even reverse his decision if he wants to. Conversely, patients with serious underlying pain and/or severe anxiety and fear of death may want enough sedation to render them somnolent most or all of the time. They may accept impending death and want nothing more than to shorten the duration of their suffering.

It must be recognized that high levels of sedation eliminate the desire or even the ability to eat or drink. This becomes an important issue when the patient requests total sedation to the point of somnolence in order to be unable to eat or drink. In other words, the process begins with heavy sedation, after which fluids are withdrawn. This precludes any suffering from underlying discomfort or thirst. Death, however, results from dehydration, requiring several days or more for completion, during which time the drugs are given in sufficient quantity to maintain the patient in a state of "chemical oblivion." At this level of sedation, he certainly is not able to recant his decision or reverse the process. Thus, terminal sedation can utilize enough, and only enough, sedation to relieve physical symptoms, a practice that is unlikely to be challenged. Higher levels of sedation, however, can render the patient semiconscious and unaware of dehydration and the dying process. As we will see, this is a step with more significant moral and legal implications.

Between the extremes of minimal and total sedation there is clearly room for negotiation between patient and physician. The timing of the beginning of sedation is a factor. Sedation could begin on the same day, at the same time, that food and drink are first refused. A more punitive approach would be to require that the patient undergo one, two, or even three days of dehydration before receiving symptomatic relief. As we have seen, the agreed-upon level of sedation is clearly a very important variable. In practice, the entire agreement concerning terminal dehydration and sedation is essentially made between patient, family, and physician, and is extremely difficult to regulate or monitor from outside. The various combinations of terminal sedation and dehydration blend into each other so completely as to defy precise definitions. They are densely tangled with the concepts of active and passive euthanasia, double effect, and intent.

**Active and Passive Euthanasia**

A persistent area of confusion is the concept of active versus passive euthanasia. Euthanasia performed by a physician is the standard of active participation in a patient's death. Many people also see the physician's role in assisted suicide as being an active one, even though the activity may be limited to writing a prescription without ever knowing whether or not the prescription was filled or the drugs taken. The term passive euthanasia is applied to all situations where the patient refuses to start or elects to discontinue any form of treatment. If the treatment is chemotherapy of marginal value in the face of a progressing cancer, the issue may not be of great moral significance to either the patient or the physician. However, when the request is to discontinue a respirator for a patient who is competent and conscious, physicians usually see this step as being quite active on their part, far more so than simply writing a prescription for sleeping medication. Indeed, the level of activity is reflected in how the law would react if the respirator were turned off under identical circumstances by a family member, or anyone other than a physician.

The basis for passive euthanasia is the concept that the patient will die of his underlying disease when the treatment is stopped. For the cancer patient stopping chemotherapy, more rapid progression of the disease may indeed take place. However, discontinuing artificial respiration is usually expected to cause death promptly. Truly, the patient may have been on respiratory assistance because of pulmonary failure, but his condition was well maintained and stable until the ventilator was stopped. The patient need not have died and, indeed, would not have died had the respirator been left in operation. It is stretching reality significantly to attribute the patient's death directly and only to his underlying disease. This is an important point because when a patient whose death is not imminent elects terminal dehydration, his death will be due to dehydration and not to his underlying disease. Theoretically, in dehydration the physician's role can be completely passive; the act can be carried out by the patient without any physician involvement at all.

There are even various levels of activity within "passive euthanasia." Not feeding a person in the face of starvation or not giving antibiotics in the face
of infection, or not starting a respirator in the face of respiratory failure are deliberate decisions not to act, and to many people seem very passive indeed. On the other hand, discontinuing treatment already in progress, particularly removal of a respirator, is viewed by most as being much more active.

The ambiguity of active versus passive is straddled by terminal dehydration, with or without sedation. Death by dehydration of a person who is too ill to eat or drink is certainly passive. The decision not to provide artificial hydration and nutrition is only slightly less so. On the other hand, refusal of hydration by one who is able to eat and drink is an active decision to end life. While the process of dehydration to the point of death may seem passive, death is elected and would not occur if food and drink were continued.

**Double Effect**

Much of medical treatment is the balancing of potential benefits against risks. A simple example of this is the risk that a patient may be encouraged to take in open-heart surgery or bone marrow transplantation. The physician intends to make the patient better, but recognizes that failure could be fatal. The use of narcotics to control pain and suffering carries the risk of depressing respiration and ending the patient’s life. The limits of this compromise are reached when it is foreseen that life will probably be shortened, so long as the primary intent is to relieve suffering. This time-honored acceptance of risk acknowledges the fact that narcotics needed to relieve suffering do have a side effect that may be fatal.

The Doctrine of Double Effect was introduced into our thinking by St. Thomas Aquinas to rationalize killing in self-defense and in war, two circumstances where Christ’s teaching to turn the other cheek was not politically acceptable. The intended good effect of such killing is that I will live, while the unfortunate but foreseen bad effect is that my attacker must die. Translated into the typical medical situation, there are four requirements to the double effect:

1. The drug must be given primarily for its good effect, to relieve suffering
2. Death should not be intended, but may be foreseen and accepted as a consequence of giving the drug
3. The benefit to the patient (relief of suffering) should outweigh the risk of harm (earlier death)
4. The bad effect, death, must not be required in order to relieve suffering

Much of the relief of suffering that physicians have been able to provide for their patients over the centuries has been due to the acceptance of the double effect doctrine by physicians, the church, the public, and the law. Within this acceptance, compassionate physicians have often pushed the unfortunate but foreseen secondary effect of narcotics when it was clear that mercy required a prompt and painless death.

The principle of double effect began as a compromise between Christian morality and political reality. When applied to human suffering, it provides a moral, religious, and legal loophole by which physicians can meet the most urgent needs of their patients, as they have done for centuries. Extension of the double effect into the broad area of terminal sedation is also commonplace, particularly in the last days of life. Through a prior understanding with the patient, in response to requests from the family, or simply out of compassion, physicians often maintain high doses or even increase the administration of narcotics to shorten the agonial phase of dying. Eating and drinking usually have stopped, and the patient may neither know nor care what is happening.

However, there is also the patient who does know and care what is happening, and who does not want to witness his own dying. Preliminary sedation can render him oblivious to his predicament and suffering, at the expense of being able to eat or drink. When interpreted strictly, the principle of double effect does not apply to this form of terminal sedation very well. The primary intent in giving the drug is to relieve the symptoms of the underlying disease and of thirst in a patient who will not eat or drink. However, if sufficient sedation is given, the secondary effect is that the patient cannot eat or drink. The amount of sedation needed to relieve most suffering and thirst may be less than the amount required to produce somnolence, and usually much less than the amount required to significantly shorten life by the use of the drugs alone. Dehydration, then, is the primary intent of the patient, and even the initial step begun by him, and sedation is given only to relieve symptoms. However, dehydration soon becomes the secondary, unintended effect of the sedating drugs. Rather than being just possible and perhaps undesired, with adequate sedation and fluid restriction, death is inevitable. Thus, terminal sedation and the
double effect are related in the minds of many people. Although they are not identical, both are venerable practices that are accepted as components of palliative care and both are considered to be within legal and medical standards.\(^1\)

**Intent**

The patient who wishes to shorten his life in order to avoid unnecessary suffering may feel that he has little to lose. Dying seems the lesser of two evils, when compared to continuing life as it is. Furthermore, the patient may see little difference between stopping treatment (including taking fluids) and assisted suicide or euthanasia. His goal is the same, and one that he would like to attain as painlessly and rapidly as possible. Assisted suicide would take a few hours and may be vastly preferable to dehydration, requiring as long as two weeks. Euthanasia, which requires only a few minutes, might be preferable to assisted suicide. Indeed, in Holland, where assisted suicide and euthanasia are both legally accepted, far more patients request euthanasia, usually at the hands of their family doctors, than request assisted suicide. This is clearly the easiest and least stressful approach from the patient's point of view.

The desires of the autonomous patient still receive little consideration when pitted against the barriers of our legislatures and our conservative religious and medical organizations. The rapid growth of interest in biomedical ethics in the past few years has focused mostly on physicians and other health care professionals, with somewhat less attention to the desires and needs of patients and their families.\(^2\)

Pressure for personal autonomy has gained some respect from a reluctant and paternalistic medical profession, but this definitely does not yet extend to a complete range of choices in end-of-life issues.

It is commonly stated in psychiatry that anyone who wishes to die is mentally ill, by definition. Certainly, most suicides are due to depression and should be prevented, if at all possible. However, these generalizations are too broad and do not apply to people who are already dying and who wish to shorten the duration of their suffering. My own interviews with terminally ill patients, some only a few days from death, with physicians, and with two psychiatrists who deal frequently with dying patients, support this. Some perfectly sane and rational people would like to die sooner rather than later, and for very understandable reasons. Indeed, most physicians who take care of significant numbers of people with slowly fatal illnesses know that their patients are perfectly sane and would be amused or insulted to be considered otherwise.

Some conservative religions teach that suffering at the end of life is an important and desirable aspect of dying, an opportunity for growth for the patient who must endure it and for the family who must witness it. Any thought or attempt to shorten one's suffering and life are the equivalent of suicide and therefore forbidden. The concept of "rational suicide," or wishing to die even at the extreme end of life, has no place in such religious teachings. It is accepted that nothing need be done to prolong life, but stressed that nothing should be done to shorten it. This extreme view is certainly not shared by the general public and is often rejected even by members of the same conservative religious groups when they are faced with their own personal decisions. At this point, the preferences of the individual may be subordinated to the dictates of the religion, enforced by family and the religious institution. Most physicians feel that it would be unconscionable to say that the person who elects to shorten his life by dehydration must forego all pain medication, regardless of his underlying needs. The precedent for sedation is well established. When a conscious and competent patient requests that artificial respiration be discontinued, the physician is expected to provide appropriate sedation in advance so that the terror of suffocating is eliminated.

Deeply embedded in this controversy is the physician's intent. Here it must be understood that intent really means willingness to personally accept responsibility for the death of the patient as the possible, probable, or even inevitable outcome of the action taken. In the absence of serious underlying illness, physicians rarely, if ever, want to kill patients or to simply help them die. The physician's intent is to try to meet the wishes of the patient in relieving unbearable suffering. The extent to which the physician accepts direct responsibility for ending the patient's life is a measure of this intent.

It is perfectly acceptable for a patient to intend to die. But it is not all right, under most circumstances, for a physician to openly intend the death of a patient. It is well known that some compassionate physicians help patients die under appropriate circumstances, while fully intending to do so, but only in the presence of severe suffering. This is done in private, with the understanding of the patient and/or family. While it may be publicly acknowledged in
The gray zone of physicians’ intent is underscored in any discussion of terminal sedation. Many factors contribute to this: Which comes first, the initiation of sedation or the initiation of dehydration? If the process begins with the patient’s refusal to ingest fluids, when is sedation begun? How much sedation is required or permissible? (Just enough to allay symptoms, including thirst? Enough to produce somnolence most of the time? Enough to provide oblivion to the dying process throughout its entire duration?) Should sedation be moderated towards the end when it may no longer be needed? How closely can or should the process be monitored by the physician? Is the risk of overdosing and pharmacologically shortening life acceptable?

A physician’s intent is often unrecognized because it is easily denied or rationalized to meet the circumstances. The law recognizes this and tries to hold us to our actions, rather than our intentions, intentions being hard to prove or disprove. “The law typically holds people responsible for the foreseeable consequences of their acts, even if they had no intent to cause those consequences.”14 Interestingly, however, the law has chosen not to look very closely at physicians’ intentions in matters related to double effect and terminal sedation. Indeed, the physicians’ rationale is relatively easy: they are giving narcotics to control the suffering of dying patients. The use of sedation to prevent suffering at the end of life is traditional and essential to good care.

Legal Aspects of Terminal Sedation
The legality of terminal sedation is based on two important precedents, and has been strongly endorsed by the U.S. Supreme Court. The right to refuse medical treatment is deeply ingrained in the Constitution, and relief of suffering is a basic component of medical care. Justice Brandeis wrote in 1928 that “The makers of our constitution ... conferred, as against the government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized man.”15 Relatively recently, the concept was extended to include artificial feeding6 and normal ingestion of food and drink.17 In support of this, Chief Justice Rehnquist wrote, “We think the distinction between assisting suicide and withdrawing life-sustaining treatment, a distinction widely recognized and endorsed in the medical profession and in our legal traditions, is both important and logical; it is certainly rational.”18 More important, as the U.S. Court of Appeals for the Ninth Circuit pointed out, regardless of the patients’ expectation or intent, death resulting from refusal of treatment is not legally considered to be suicide. “We believe that there is a strong argument that a decision by a terminally ill patient to hasten by medical means a death that is already in process, should not be classified as suicide.”19 This is a critical point because, by extension, it means that providing sedation for such a patient is providing relief from suffering, but it is not assisting suicide.

In 1997, the U.S. Supreme Court unanimously rejected a constitutional right to physician-assisted suicide, overturning the opinions of two Circuit Courts of Appeal.20 However, this rejection of assisted suicide was accompanied by very strong statements concerning palliative care and sedation by Justices O’Connor, Ginsberg, Breyer, Souter, and Stevens. Speaking most emphatically for this group, Justice O’Connor said, “[A] patient who is suffering from a terminal illness and experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death.”21 Justice Breyer supported this, saying, “[T]he laws of New York and Washington do not prohibit doctors from providing patients with drugs sufficient to control pain despite the risk that those drugs themselves will kill.”22 Professor Robert Burt of Yale Law School notes that “The Supreme Court majority has thus provided an unexpected but strong and very welcome directive requiring states to remove the barriers that their laws and policies impose on the availability of palliative care.”23 By stating that terminal sedation for symptomatic relief is not assisted suicide, the Court has endorsed an aggressive practice of palliation.

Professor David Orentlicher of Indiana University School of Law goes beyond this, pointing out that the extension of palliative care to include terminal sedation could create a situation that is morally and legally close to euthanasia, and well beyond assisted suicide.24 Total sedation of an individual prior to stopping of food and fluids renders the patient comatose and helpless, at the mercy of his physician for the remaining days of life, a form of slow euthanasia. In this extreme form of terminal sedation, physicians take almost as much responsibility for the
patient's death as they would by giving a lethal injection. Orentlicher's purpose is not to condemn terminal sedation, but to point out that the Court seems to be endorsing a possible form of euthanasia, while rejecting physician-assisted suicide, when the latter may be more desirable for the patient and carry less risk of abuse.

In the spectrum of end-of-life interventions, terminal sedation is an extension of the autonomy of refusal of treatment, to which is added sedation to provide physical and psychological comfort. Like personal refusal of treatment, terminal sedation is legal in all states. It is not subject to oversight or regulation. The final decision and all details are worked out by patient, family, and physician, with no requirement for any other input or notification. Assisted suicide, on the other hand, is legal only in one state, Oregon, where it is strictly regulated.

For the competent, conscious patient, a line currently separates terminal sedation, which is legal, from physician-assisted suicide, which is not. The unconscious or incompetent patient presents a more complicated problem. The laws of most states now permit a family member or some other responsible surrogate to speak for the unconscious patient in requesting withdrawal of treatment, including artificial feeding. All states respect this if there is strong evidence (a living will, etc.) as to what the patient's preferences were when well, and many states do not require any formal evidence at all. There is no need or place for legal surrogacy in physician-assisted suicide, since taking one's own life is a conscious act by definition. Similarly, a surrogate wishing to end the life of an unconscious patient need not consider terminal sedation since simple withdrawal of the necessary artificial feeding will suffice and is legal.

The most complicated issue is the person who is totally incompetent, but not unconscious, as in Alzheimer's disease, the most widely feared of all end-of-life scenarios in this country. A person who is farsighted enough may certainly request, in a living will, that his life be ended by terminal sedation upon reaching some arbitrary stage in the illness (unable to recognize family members, etc.) Leaving the final decision to a surrogate, even with a detailed living will, pushes such a death into the realm of non-voluntary euthanasia. The mechanism for inducing the death may be some blend of dehydration and sedation, since they are "legal." However, the step must be taken by other people, be based on the original living will, and be administered to a person who is not currently competent to consent to anything and is not even dying. This is already a subject of moral debate, and will become a legal issue in years to come, but only after we have reached some level of acceptance of assisted suicide and even of voluntary euthanasia. Pressure for this will come from demands to respect the patient's original autonomy, general horror of living for years totally demented and dependent, and the economics of caring for large numbers of elderly people who are so hopelessly ill. Today, about 4.6 million Americans are over the age of eighty-five and about half of them, 2.4 million, have severe dementia. By the year 2040, both of these numbers are expected to double to 12.3 million over the age of eighty-five, and 5.1 million with severe dementia.

**Terminal Sedation—Today & Tomorrow**

Recently there has been strong interest in providing better care at the end of life. It is recognized that our dominant medical goal of curing disease distracts us from the needs of those who cannot be cured. Many groups have taken steps to study and provide better palliative care, while others search for ways to allow more dignified and peaceful deaths, free from unnecessary suffering. Many ethical and moral aspects of end-of-life care are being examined, including active versus passive, double effect, terminal sedation and dehydration, and physician-assisted suicide. Society, the law, and the medical profession are trying to decide what limits to set on how people may die, recognizing that some do not want to live the final weeks that are necessitated by the natural course of their illnesses. They do not have many options. As a society, we are not yet ready to legalize assisted suicide in most states, but even the U.S. Supreme Court acknowledges that, with more experience, that day may come. Although the Court does not support individual autonomy to the extent of giving physician-assisted suicide constitutional protection, it does feel that people who are terminally ill and suffering significantly should have some meaningful recourse to medical help for relief, even if it means shortening life. The Court clearly leaves the door open for terminal sedation.

Some undoubtedly see terminal sedation as a stepping stone to physician-assisted suicide and even euthanasia, a moral and legal loophole that should be closed. Conservative lawmakers could attack
terminal sedation on the basis of physician intent or improper use of drugs, if only to curry favor with even more conservative constituents. The arguments would be the same as those being used to counter the Oregon laws permitting physician-assisted suicide. Others view terminal sedation as an end in itself, an approach to shortening life that will be acceptable to some patients who are dying and to the general public, a line that can be held against pressure for physician-assisted suicide.

I think terminal sedation is indeed a stepping stone towards physician-assisted suicide, a compromise for the time being. It seems cruel to ask a patient and a family to accept a route to death that takes a week or two to travel, however painless the journey may be. If and when assisted suicide becomes legal, terminal sedation will not be needed or wanted by very many people. However, until our laws become more accommodating, interest in terminal sedation will grow, as pressure for patient autonomy continues to increase. Blurry as terminal sedation may be in concept, it is accepted and practiced. Therefore, terminal sedation will be hard for lawmakers to back away from, and harder still for government agencies to monitor, or bury under oppressive restrictions.

At the present time, in the mind of the public, voluntary dehydration and sedation is not an attractive way to die. As such, it appeals to a relatively few, unusually strong-willed and well-informed people. The advantage to elective terminal sedation is that it is legal and can be done painlessly. The legality does not derive from close analysis of the acts under all circumstances, but from recognition that many, if not most, people die naturally of dehydration, and that sedation to control suffering at the end of life is an expected, accepted, and traditional role of medicine.

As concern about end-of-life issues increases and assisted suicide remains legally off limits, more and more emphasis will be placed on terminal sedation. Indeed, legislative rejection of assisted suicide may provide a “dam” effect that forces more people to turn to terminal sedation as their only acceptable option. It can, should, and will be discussed more publicly, and should certainly enter into conversations between physicians and patients who want to end their suffering sooner. As we continue to examine the needs and desires of dying patients, our willingness to provide appropriate medical intervention will increase. The needs of people at the end of life are multiple and varied, and our responses to them should be, too.

Endnotes

1. In 1998 & 1999, I had the pleasure of meeting with several people to discuss various aspects of terminal sedation and dehydration, intending to prepare a manuscript on the subject. Although the manuscript was never completed, the discussions were valuable and some of the ideas considered are included here. The other participants were: Sidney H. Wanzer, M.D., Professor Emeritus, Harvard Medical School; Prof. Charles H. Baron, Boston College Law School; Garrick F. Cole, Esq., Smith, Duggan & Johnson, Boston, Massachusetts; William F. Comer, M.D., Coram Healthcare, Portland, Oregon; and Professor James Vorenberg, Harvard Law School.

2. G.P. Smith, Terminal Sedation as Palliative Care: Revalidating a Right to a Good Death, 7 CAMBRIDGE Q. HEALTHCARE ETHICS 382-87 (1998).


8. MODERN NUTRITION IN HEALTH AND DISEASE (M. Shils et al. eds., 8th ed. 1994).

9. CHARLES F. MCKHANN, A TIME TO DIE: THE PLACE FOR PHYSICIAN ASSISTANCE 100-02 (1999); see also B. Gert et al., An Alternative to Physician-Assisted
Suicide, in Physician Assisted Suicide: Expanding the Debate ch. 12 (M.P. Battin et al. eds., 1998).


12. Id.


19. Compassion in Dying v. Washington, 79 F.3d 790, 824 (9th Cir. 1996). It should be noted that some religious views do not accept this.


21. Vacco at 809 (O’Connor, J., concurring).

22. Id. at 810 (Breyer, J., concurring).
