

AID IN DYING

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Questions about the end of life have probably been present since the beginning of human existence. What should be done about those people who seem to be nearing the end of their lives? Should society for a variety of reasons bring on death to some people? Although there have always been disagreements about how and when people should die, the points at issue in the past were relatively simple. For example, if someone has killed someone else, should that person be killed in response? Societies created laws to slow down or divert the immediate impulse to take a life for a life. Otherwise, everybody would soon be dead.

One of the things that distinguishes today's society is that questions of who dies and under what conditions have become extremely complicated. It is often unclear even what it means to end a person's life, that is, to sort out the contributions of various people and many impersonal factors in the death of someone. Laws can be passed that exclude some actions as untenable for a society; but laws cannot provide the details needed for decisions today that involve modern medicines. Faced with the bewildering complexity of today's situations, there is a strong tendency to rely on slogans that set up two camps. Instead of a serious discussion of morality we then have a conflict of political lobbies. At that point, one has to refuse membership in either camp and try to go back to first principles and admit that uncertainty on some points is unavoidable.

Finding anything that can qualify as a first principle of morality is difficult. When people pronounce on morality/ethics they usually imply a universality to their statements. People do not say murdering or torturing people is sometimes wrong or is wrong in my part of the world. Instead, people make some moral pronouncements that imply universality. And yet there is an obvious limitation to any moral/ethical statements, starting with the fact that every language is particular not universal. Perhaps there are a few principles that are easily translatable from one language to another. Perhaps there are other statements that can approach universality ("it seems to be true almost everywhere" or "surveys have found this always to be the case"). The range of uncertainty can be narrowed even if not eliminated.

The term "principle" is (almost certainly) the best choice for the role of ultimate guidance in moral matters. The word suggests what comes first and can be relevant to almost any situation. There is a built-in ambiguity to this meaning of principle; it is comprehensive because it leaves out the details of a situation. There can be strong disagreements about how a moral principle applies, although the term "apply" may itself be an obstacle to understanding how a moral principle is implied or embodied in a particular situation. We have an understandable desire to want rules or precepts that can be applied with a minimum or no ambiguity. There is a tendency to slide from claiming that principles exist to affirming the existence of rules. General rules are applied to individual cases; if people agree on the rules then the only question is whether the situation comes under the rule. Laws exist in the form of rules; laws are useful for excluding some practices that a society cannot abide. Laws are not very helpful in telling us how we should act.

A popular alternative to principles in the last half-century has been the term "values." It is not a bad word but it fails in the role of ultimate guide for morality/ethics. The history of "value" is heavily weighted on the subjective side which has the effect of cutting off morality/ethics from the complexities in the world of politics, science or religion. Values are chosen. The meaning goes back to the nineteenth century when "value" migrated from the world of economics to ethics. As a way of protecting an ethical realm, value as a function of the will was opposed to "facts" which are a product of thinking. If the values I choose cannot be undermined by facts, ethics is safe but it is also sidelined from discussions of politics, economics and social justice. Principles are always in danger of neglecting personal contributions; but values are incapable of embracing principles that point toward universality.

I wish to draw a parallel in a principle about the beginning of life and the end of life. Even before one examines current discussions, it would seem likely that there would be connections about how a person

begins and how he or she finishes life as a human being. There would likely be one or a few moral principles that would be relevant to both the beginning and the end of a human life. Perhaps the most obvious moral principle is that human beings are deserving of respect. What would respect entail? At a minimum, respect for someone means not violently intruding on a person's bodily life. A further sign of respect is showing common marks of civility toward a human being. The twentieth century enshrined the term human rights as the way to express acknowledgement of a person's legitimate demands upon the human community.

It has to be admitted that the principle of respect does not get universal acceptance. In the past, some human beings for a variety of reasons were excluded. On this point we like to think that we have made great progress in the inclusion of people and undoubtedly we have. But the human race is still a long way from respecting every human being whatever his or her condition. On a different note, some people might object that the principle of respect for all human beings is not comprehensive enough; they say that we should respect "all life." Saying that we should respect life has the danger of being an abstraction. Life does not exist; living beings, human and nonhuman, exist. There is certainly a case to be made that respect should extend to at least all sentient animals. My focus is the beginning and end of human lives in which respect for persons also implies respect for the human environment of living beings.

The principle of respecting each human being is clear enough but it now often happens that we cannot be certain about whether a human being exists. Here is where there is a similarity about the beginning and the end of a person's life. If in doubt, we should surely proceed with caution. But respect for a person differs from protection of the life process. At the beginning of life we can certainly say that life begins when the contribution of a man and a woman join (Throughout much of history, the beginning of life was identified with the male seed). But when a new person exists can only be judged by external signs of development during days and weeks after the beginning of pregnancy. Science can provide helps to judge those signs but the human judgment remains fallible.

At the end of life a person should be respected whatever his or her condition. But it is now often unclear whether an organism is a person, that is, an organism can be kept alive for many years when it is unclear that it is still a person. As is true of the beginning of life, we can only fallibly judge from external signs whether the living organism has ceased to be a person. It is sometimes said that "we need a new definition of death" but that misses the point. Everybody knows what dead means; but the question is sometimes whether the person has died. There are "vital signs" that we can check but breathing or brain activity that is being aided by machinery is not proof that a person exists. Just as a fertilized egg is the beginning of human life but not a person, so also an organism that has been a person does not necessarily continue to be a person when there is a heart beat or brain activity. The big difference in the two situations is that the question at the beginning of life is resolved in the course of a few months while at the end of life the process can go on indefinitely.

The end of life poses legal and moral complications that are as great as the beginning of life but the end has been much less discussed than the beginning. Most of us do not like to talk about dying; it inevitably reminds us that we are soon going to die. Whether "soon" means two years or fifty years, we are reminded that the one sure fact of our life is that it will end.

During the last seventy-five years modern medicine has dramatically changed the way many people die. The extension of the life span for most people is obvious but a side effect of the added years is new questions about how this longer life ends. Occasionally, the general public becomes aware of an organism being kept alive for years when there appears to be no reason for continuing the medical procedures, other than a physician's resistance to admitting defeat or a relative's refusal to accept the inevitable. It is praiseworthy that physicians are dedicated to keeping people alive; a law that changes this role would be unwise. But the medical profession has to cope with the undeniable fact that its failure rate is one-hundred percent. Everybody dies.

The occasional case that attracts the news media hides the fact of what regularly goes on in hospitals, hospices, and nursing homes. I do not refer to some terrible scandals but to what medical professionals and ordinary people have to cope with every day. They have to deal with the process that leads to death when

death is in the near future but the path to that death is over a darkening plain. It is sometimes said that today a patient in a hospital dies when a physician decides it is time to die. That is an exaggeration in most cases but it reflects a burden that should not be placed on physicians and other medical personnel.

One of the strongest movements today that concerns sickness and death is called “physician-assisted suicide.” There is controversy about this category and the controversy is likely to intensify. Similar to what happened with abortion, we are in danger of having two lobbies each with moralistic slogans when what we need are open discussions that admit of uncertainty and compromise. The movement for legalizing “physician-assisted suicide” uses as its slogan “dying with dignity.” Who is going to oppose that? There are no proponents of dying with indignity. However, there are people who are horrified at a movement that can casually talk of suicide as a good thing. They say that God forbids suicide; no one has a right to take a human life that is sacred.

Before we get into a hopeless standoff similar to the language of “pro-life vs. pro-choice,” I would suggest that everyone is in favor of dying with dignity and that everyone recognizes human life to be of inestimable value (“sacred,” however, immediately cuts off conversation). The phrase “physician-assisted suicide” is not a help. One reason that it is unhelpful is that it puts the physician in the spotlight instead of the person who is dying. Society has a danger of giving over the power of life and death to physicians. Talking about the physician as the star player in how people die goes in the wrong direction. A second reason for opposing the phrase is that the term suicide is misleading. The word suicide was coined several centuries ago as a morally neutral term to replace self-murder. But in time “suicide” acquired all the negative connotations of self-murder. I doubt very much that the term can be rehabilitated for actions that are at least neutral. There should be a linguistic difference between a ninety-five year old man, suffering from multiple diseases who believes that his life is complete and a forty-five year old man who shoots himself in the head because he is clinically depressed.

My proposed phrase “aid in dying” is not just a euphemism for physician-assisted suicide or for “euthanasia” a term which might have been morally neutral but from the beginning referred to “mercy killing.” The term “aid” usually has a positive meaning. To come to someone’s aid is praiseworthy. We all need aid in life and, because life eventually includes dying, people regularly need aid in the process of dying. In the past, aid might have been understood as taking care of a dying person’s essential needs until death took the person. It has not been sufficiently discussed that attempts to care for a person by lessening his or her pain might hasten the end of the process of dying. Today that question faces most people who are aiding patients who are seriously ill. The question extends to people who have not been pronounced fatally ill but whose participation in the human community seems effectively over.

The Roman Catholic Church’s teaching in this area is – perhaps to some people’s surprise – quite nuanced. The church helped to develop the language for talking about what should and should not be done in the care of those whose dying seems imminent. One fundamental distinction was between allowing a person to die and killing a person. It was further said that a person has a right to all of the “ordinary means” of living but not necessarily “extraordinary means.” If a person chooses not to undergo treatment with extraordinary means to prolong his or her life, that choice was seen to be morally acceptable. The principles remain but the situations have become very complicated. Obviously, a distinction between ordinary and extraordinary has become debatable in many situations. And while a distinction between “to kill” and “allow to die” is clear in principle, the line between the two can be blurred in practice.

As early as 1958 Pope Pius XII wrote that removing a respirator from a person could be morally justified if the patient was never going to return to a functioning human life. Does the widespread use of respirators (or feeding tubes) change them from extraordinary to ordinary means of sustaining life? It would seem not although it is the entire situation that has to be examined not just a moral principle. In the 1960s there was a movement that was misleadingly named “situation ethics.” It called for the dismissal of moral principles and rules in favor of doing whatever the moment called for. All ethics is situational but the situation has to be open to guidance from the wisdom of the past and from present knowledge that goes beyond an individual’s “value choices.” A morally good action is based upon a moral principle together with a good intention and an understanding of the circumstances of the action.

A principle that is often invoked in the care of the dying is that life should not be extended artificially. The principle is presumably meant to exclude technological means to keep an organism alive when there is no hope that the person will ever again function in the human community. Pius XII called that situation “unnatural.” However, merely saying that life should not be extended artificially is misleading; it assumes a simple dichotomy of natural and artificial.

One of the sayings in the anti-abortion movement is that life should be respected “from conception to natural death.” That saying is too ambiguous about conception and wrong on natural death.

The process of life should be protected from the moment of fertilization but respect for a newly conceived person is a different matter. Fertilization is a biological question; personhood is a metaphysical question. To say that a person should be respected from “conception” can be little more than a truism. When the conception of a person occurs during pregnancy will always be debatable.

The other part of the saying referring to “natural death” states a misleading ideal. All of us could agree that dying from “unnatural causes” is not desirable. But a “natural death” is not necessarily the alternative. Everyone’s life is a combination of the natural, or what is given by birth, and human artifice, including technology. Everyone is kept alive artificially (clothing, houses, heating, water systems). This dependence on artifice inside and outside the body becomes more obvious as one gets old.

If I wanted to die a natural death I would have died a long time ago. I started having metal inserted into my body (to save my right arm) when I was fifteen years old; it is still there. In recent years my heart has been hooked up to a machine in my body; three of my arteries are kept open by pieces of metal inserted by skilled surgeons. Those instruments are not natural to my body; I was not born with them. My case is not unusual; almost anyone my age and older is alive because of the marvelous advances in the use of materials that are not natural to the human organism. I would prefer not to die naturally with all the pain that is a likely accompaniment. I would prefer to have the path to death eased by liberal uses of morphine or other helps. The ideal is not a natural death but a personal death, one that can include the wonderful creativity of human artifice.

The *Catechism of the Catholic Church* says that “the use of pain killers to alleviate the suffering of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed either as an end or a means, but only foreseen and tolerated as inevitable.” That is a striking admission: Actions can be morally good even if the death is foreseen and tolerated as inevitable. Millions of people have been confronted with this situation; those people who have not been in this situation will likely find themselves faced by it in the future. The situations can have endless variations but the principle is the same: humans should be respected, including during the time when they approach death. Aid to dying patients can include actions or lack of actions that have a good intention while also hastening the end of life. No rule or law can remove the burden of deciding that a parent, a spouse or one’s child is soon to die and that the best that can be done is something that will hasten their death.

When my father was dying, he had a complete collapse of his system; the medical personnel withdrew and allowed the family to have a death watch until the organism expired. There was no need for a family decision. When my mother died, a decision was required. She had a massive stroke and was immediately put on a respirator when she arrived at the hospital. Brain activity was completely absent. After an all-night vigil by the family, we were asked by the physician what we wished to do. There was no doubt for any of us that the respirator should be removed; when that was done the body quickly breathed its last. If there had been a glimmer of brain activity the decision might have been more agonizing but the same decision would have made sense.

When my wife died it was after several years of suffering from advanced dementia. People do not die of dementia. Some dementia patients live for a decade or more. My wife had surgery for a bed sore because as the surgeon told me “if it were untreated it would mean her demise.” The surgery, however, was not successful. There was a recommendation for more surgery. Her primary care physician spoke to me on the phone about what to do. I said to him: Am I correct that if untreated she will die of infection? He said that was true. I asked him what it was like to die of sepsis; he assured me that pain could be controlled. We

agreed that more surgery made no sense in the situation. With that phone call we decided that she would die within a few weeks. When the physician arrived on the morning of the day she died, I asked him what he thought. He surprised me by responding: You have been the closest one on the scene what do you think? I said I thought the end was near. He agreed but he wanted to check her vital functions. After finding that her kidneys were no longer functioning, he said that there was nothing more to do; she died in a few hours. Was this a case of playing God? I viewed the decisions as providing the best aid possible which included her dying as an unintended effect.

Human decisions are fallible. Medical science has come a long way in a short time. It can provide very valuable information about what is going on in the human body. This information can enable moral decisions to be based on a better understanding of what are options for our own living and dying. It also provides invaluable help when we face life and death decisions for someone else. Medical science will never be able to replace human decisions which may be more complicated and ambiguous than ever before. Disagreements are inevitable and may increase. One can hope that ambiguous situations will not lead to accusations of murder against people who have tearfully accepted the death of a loved one. Whether one has religious beliefs or not, the decisions are in the hands of human beings who have to do the best they can in situations that outsiders should be hesitant to judge.