

# THE ALTERNATIVE

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Dear Reader,

The modern era of medicine, which can be dated to the invention of penicillin in the 1940s, has been a blessing for millions of people. On average, people who are lucky enough to have access to the new knowledge and its applications, live longer, healthier and more enjoyable lives. The average improvements, however, hide a dark side. In some areas, contemporary medicine is successful only in creating half-solutions. In the confusion about the end of life the half-solutions are obvious to everyone.

Many people avoid visiting a nursing home because what is there can be terrifying to healthy forty-year-olds. In the 1960s, nursing homes were almost uniformly a scandal, an economic scam in which old people were treated callously or worse. That is not generally true today. At least there are many nursing homes where the staff try their humanly best to provide comfort and care. But despite these good efforts the whole scene remains frightening. The unavoidable question for the forty-year old individual is whether that is his or her future.

There is a strong push in the country for legalizing euthanasia and assisted suicide; the push is not coming from nursing homes and hospices but from middle-aged people who fear what old age will bring and who wish to have an available option to check out when they decide to do so. Is this fact a sign of moral corruption and cowardice or is the move a realistic response by people who understandably do not wish to be one of medicine's half-solutions? Should a person asking to die have his or her wish fulfilled? Of course, in many cases the person is no longer capable of expressing a wish. Who is to judge what should be done and on what basis does that person judge?

What follows are three essays on distinct but related aspects of the issue of care of the dying. Gabriel Moran wrestles with the ethical issue of hastening death for people who conclude that their life is complete. The most difficult part of that issue is people with a totally debilitating but not a fatal disease. The essay is an extension of his recent book, *Talking about Dying*.

Carol Mithers describes the harrowing journey of caring for several dying relatives. Her experience is admittedly extreme in dealing with a whole cast of characters. Nevertheless, tens of millions of people can identify with her describing the exhaustion brought about in caring for a dying patient or for someone with dementia.

Jonathan Rauch describes the problem of over medicalization in the health care system. As he reports, even physicians find it nearly impossible to get control of the system for their own families. The essay is an excerpt from Rauch's article in the May issue of *The Atlantic*

## SUFFERING, PAIN AND NONVIOLENCE

Gabriel Moran

A few key distinctions are necessary to have the conversation which the country needs about dying and the care of the dying. The key moral principle is: Do violence to no one. Although that principle by itself solves no problems, it is relevant to every complicated situation. In recent decades there have been frequent references to “natural death.” What may be meant by the phrase is that violence should not be done to the biological organism. But it is the nature of the human to reshape the forces of nature, both human and nonhuman. Death is natural but human death is more than natural; it is psychological, artistic, political, philosophical, and religious. Human intervention in nonviolent ways can lessen the anguish and pain of dying.

Because violence is already widespread in the world the best that can be done in some circumstances is to reduce violence or choose the lesser of two violences. The person who tries to live nonviolently will sometimes be caught in a situation where acting for what is humanly good will likely spillover to unintended violence. The great advocates of nonviolence have been acutely aware of that fact. No human being can avoid tragic dilemmas. At times when a person has done the best that was possible, he or she is judged harshly by other people who have never had to act in such a situation.

Another key distinction is between “suffering” and “pain.” Suffering is what human beings do, that is, they suffer the world. Every sentient animal suffers the world as the way to having an interior life. Suffering is generally good; one cannot be a human being without engaging an environment of human beings, other living beings, and the physical universe. Suffering does have its bad side; it makes possible the experience of pain as a physical-mental phenomenon.

Before one considers physical pain as a downside of human suffering, it is important to note “spiritual suffering,” the suffering specific to human animals. Spiritual suffering plays a central role in the experience of death and mourning. If a human being has an intimate and loving relationship with another human being, the death of that person will be the cause of the spiritual suffering of loss and sadness. The reaction is healthy. The only way to avoid mourning is not to love anyone, a strategy that Stoic philosophers recommended and that still has its followers. Our culture tends to think of mourning as a kind of illness from which we are encouraged to recover as soon as possible. Ironically, it is the inability to mourn that can bring on physical sicknesses. The body must be allowed time to absorb the death of a loved one.

Sometimes suffering involves the feeling of pain in a bodily organ. Pain can be a useful sign that something is wrong in the organism and needs attention. Also, the disciplining of the body can use pain as a guide to where a physical exercise has reached a desirable limit. A little amount of voluntary pain from exercise can prepare the body for when it is struck with unwanted pain. However, the experience of pain itself is not a good. Individuals avoid pain unless they see it as a stepping stone to what they want to reach. They put up with pain but they are not choosing pain as a good.

In the past, Christianity was often accused of glorifying pain; suffering, it was said by Christians, is redemptive. Jesus suffered and died for our sins; bear your sufferings as you follow the way of the cross. If you are suffering terrible pains it is part of God's mysterious plan. I would not ridicule a religious belief that has given comfort to millions of people in terrible situations. However, Christians these days do not often invoke a belief that pain is good for you. Like nearly everyone else they try to stop the pain with the resources of modern medicine.

Some Christians view this tendency as a rejection of the "crucified Christ" but the change can be seen as one of placing the narrative of Jesus' life, death and resurrection into a full human context. Christians believe that Jesus suffered the whole world which inevitably involved suffering pain. Pain does not redeem; rather, the human reaction to tragedies within the human community is the saving grace of a human life. In the New Testament, the clearest basis for a final judgment is found in Matthew 25. Jesus does not say "I was hungry and you explained to me that hunger is good for the soul." Instead, he says: "I was hungry and you gave me food." The implication throughout the whole passage is: I was in pain and you did what you could to relieve the pain.

No one succeeds in avoiding all pain. We admire people who bear pain without complaining. From our earliest experience we know that life involves a certain amount of pain and the sooner we accept that fact the less whining we will do. Especially as one becomes old, minor aches and pains are unavoidable. What is startling is how unfair life is in doling out the pain. Some people seem to glide through life with only the slightest physical pain; other people seem to be in the hands of a merciless demon of pain. Contemporary medicine is a blessing for people who would otherwise suffer from relentless physical pain.

Many such people are under-medicated for pain because of a fear that they will become addicted. If a person does not wish to have drugs clouding his or her mind, that decision should be respected. But there is no reason why drugs should not be liberally used for a dying person to eliminate pain as far as possible. Hospices know this but many hospitals do not. If the relief of pain will shorten a person's life, then some responsible person has to make a judgment about the manner and amount of pain killing. Cutting ten years off a person's life would be wrong; but the possibility or likelihood of shortening the life of a person who has only months or weeks to live should not be an issue if relief from pain is obviously needed.

A key idea here is what "hastening death" means. I think the phrase has to be interpreted very broadly. To kill a person, including oneself, is usually wrong. The act goes counter to our deepest moral sense. Exceptions have always been made. War and the state execution of prisoners seem to me exceptions that are outrageous and immoral. But killing another person may sometimes be a tragic act in defense of another human being who is under attack. I think there is a conceptual difference between the deliberate killing of a human being and the case of allowing the process of dying to be completed without an intervention that might keep the person alive. Although there have always been cases

where the line is blurred between those two concepts, medicine today has made exceptional cases become common.

We begin to die the moment we are born. One could therefore say that we are always in the process of dying. We do not usually think that way because it could be paralyzing to always have before one's mind the thought: I am dying. So what is the point of doing anything? "Living in denial" is what most people do most of the time. We usually act as if we are never going to die. An occasional but not obsessive consideration of our mortality is probably the healthiest way to live.

Every day in numerous ways we either hasten or postpone our moment of dying. Since we cannot generally know how any particular action factors into our dying we (subconsciously) calculate the odds. Some things are known on the average to shorten life but it is impossible to know if it will shorten my life. Everyone knows that cigarette smoking kills; no one knows if my smoking will kill me. Many people play the not-so-great odds with cigarettes. Some jobs, such as reporter in a war zone, have an exceptionally high mortality rate but there are people who think the odds are worth taking. Teen-agers very often do dangerous things because they have a feeling of immortality. But a middle-aged man who is very conscious of mortality and who smokes, drinks excessively, and has an unhealthy diet gives at least the appearance of trying to kill himself. It will not go into the books as suicide but he has begun the process of ending his life. Most likely there is some kind of spiritual suffering for which he may or may not be at fault. In the obvious cases of suicide, the great majority are clinically depressed which is one way that our culture talks about spiritual suffering.

There is a quite different way of hastening one's death that probably deserves another name than suicide. There are tens of thousands of people in nursing homes and hospitals who believe that their lives are now complete. Many other thousands are in a worse physical condition which may make it impossible for them to express that conclusion. However, if a person has dementia one has to try to interpret his or her wishes. Until the very end of life dementia patients may be capable of stating their own wishes, including a wish to die.

Should people be allowed, with help if needed, to end their lives? Here is where the principle of do no violence comes in. What is morally desirable is that one live nonviolently which includes the way we die. If someone clearly wishes to die, then their wishes should be carried out in the least violent way possible.

In the extraordinary movie, *Amour*, the man might seem to be a model of caring for his wife who is afflicted with dementia. But as the world closes in on the couple, one has to wonder whether he should have reached out for help. He had taken on a task that was beyond his human endurance. The woman is ready to die and by resisting his efforts to keep her alive she indicates that she wishes to die. Her husband does not accept that and forces her to take nourishment. When she resists, he finally snaps and kills her by suffocating her. Movie audiences gasp in horror at the scene. Most people would

probably agree he should have helped her to die, but the suddenness and violence of his action properly draws a negative response.

What is perhaps the most morally problematic situation is that a person can be diagnosed with an incurable disease that is debilitating but the disease itself is not fatal. People do not die of dementia; most dementia patients die of infection. Someone with Lou Gehrig's disease (ALS) has the prospect of losing all bodily functions while remaining mentally alert. It is certainly understandable that a person who is afflicted with a terribly debilitating but not a fatal disease may conclude that his or her life is complete.

Not every person with a terrible handicap or sickness sees it that way. There are examples of people who do spectacular things that contribute to the common good despite their illness or disability. Nonetheless, if someone has lived with the problem for some time, has been given the best of care, and has given serious thought to all the circumstances of his or her condition, can anyone say with certainty that their wish to reach the end of life is wrong? A significant percentage of people who are on kidney dialysis simply stop the treatment. Are they killing themselves? Our usual language says yes. They are choosing to end their life although it is not death that they wish for but an end to a life with kidney failure. They participate in the cause of what kills them but so do many people who do so in less obvious ways.

A person who has ALS has a condition in which the body has already shut down most of its functions. The body is preparing for death even if the person is said not to have a fatal disease. The person may continue to have the strength and the help to participate in the human community. But at some point the person may not wish to continue the struggle. Anyone who aids the person in his or her desire to die is hastening the process of dying which began at birth and has now become terribly obvious. Most of us can barely imagine how it feels to be in that condition. The act of helping such a person to die seems to make moral sense.

The position that I have outlined here still differs from most writing today in favor of euthanasia, a term that up to a few decades ago simply meant "mercy killing." Writing on euthanasia today tends to be "consequentialist," that is, what counts is the result. Any distinction between killing and letting death occur is dismissed as irrelevant. However, there is a long moral tradition that human action includes intention and means, as well as consequences. All three must be considered in a moral judgment. I admit that the line between kill and allow to die has become increasingly blurred. Nevertheless, the intention and motive of anyone involved must still be examined.

If the intention is to allow a person to come to a peaceful end, that is different from a caregiver wanting not to have the bother any more. The person may not be able to block out entirely the second motive but the primacy of the first motive is reflected in the means that are used. When the means is sudden and violent, a humane completion to life seems violated. Some people think that removing a feeding tube is an act of violence, but it is usually a recognizing that the inability to eat and digest food is a sign that the body is preparing for death.

Providing pills or drugs that will bring about an end of life can be an acceptable means provided that all the other circumstances make sense, for example, the person has come to this decision after reflection on the circumstances of his or her condition. Legalized suicide in the Netherlands and in a few states of the United States have included such conditions in the law. There does not have to be a “slippery slope” but there is nonetheless a danger that physicians will subtly encourage suicide or that money will become the primary motivation. The movement for legalized suicide is being oversold with the phrase “dying with dignity,” meaning suicide. In hospices, dying with dignity means providing the best care possible to a dying patient.

One cannot trust the courts to decide what is moral. The Supreme Court has enough trouble trying to establish legal principles. The Catholic Church has a long tradition that would be helpful for its participation in a national conversation on care of the dying. But in much of the literature today the Catholic Church is dismissed as an obstacle to humane treatment. A general condemnation of euthanasia by church officials is ineffective and misleading. They need to listen to the people who regularly confront these complex situations and they have to be willing to enter a genuine conversation on the moral issues in the care of the dying.

## HOW NOT TO DIE

Jonathan Rauch

Unwanted treatment is U.S. medicine’s dark continent. No one knows its extent, and few people want to talk about it. The U.S. medical system was built to treat anything that might be treatable, at any stage of life – even near the end, when there is no hope of a cure, and when the patient, if fully informed, might prefer quality time and relative normalcy to all-out intervention.

In 2009, my father was suffering from an advanced and untreatable neurological condition that would soon kill him. Eating, drinking and walking were all difficult and dangerous for him. He ate, drank and walked anyway because doing his best to lead a normal life sustained his morale and slowed his decline. “Use it or lose it,” he used to say. His strategy broke down calamitously when he agreed to be hospitalized for an MRI test. I can only liken his experience to an alien abduction.

He was bundled into a bed, tied to tubes, and banned from walking, without help, or taking anything by mouth. No one asked him about what he wanted. After a few days, and a test that turned up nothing, he left the hospital no longer able to walk. Some weeks later he managed to get back on his feet; unfortunately, he was then only a few weeks from death. The episode had only one positive result. Disgusted and angry after his discharge from the hospital, my father turned to me and said, “I am *never* going back there.” (He never did.)

What should have taken place was what is known in the medical profession as The Conversation. The momentum of medical maximalism should have slowed down long

enough for a doctor or a social worker to sit down with him and me to explain, patiently and in plain English, his condition and his treatment options, to learn what his goals were for the time he had left, and to establish how much and what kind of treatment he really desired.

Alas, evidence shows that The Conversation happens much less regularly than it should, and that when it does happen, information is typically presented in a brisk, jargony way that patients and families don't really understand. Many doctors don't make time for The Conversation, or aren't good at conducting it (they're not trained or rewarded for doing so), or worry that patients can handle it. That is a problem, because the assumption that doctors know what their patients want turns out to be wrong.

Unwanted treatment seems especially common near the end of life. A few years ago, at age 94, a friend of mine's father was hospitalized with internal bleeding and kidney failure. Instead of facing reality (he died within days), the hospital tried to get authorization to remove his colon and put him on dialysis. Even physicians tell me they have difficulty holding back the kind of mindlessly aggressive treatment that one doctor I spoke with calls "the war on death." Matt Handley, a doctor and an executive with Group Health Cooperative, a big health system in Washington State, described his father-in-law's experience as a "classic example of over medicalization." There was no Conversation. "He went to the ICU for no medical reason," Handley says. "No one talked to him about the fact that was going to die even though outside the room, clinicians, when asked, would say "Oh, yes, he's dying."

"Sometimes you block the near exits, and all you've got left is a far exit, which is not a dignified and comfortable death," Albert Mulley, Director of the Dartmouth Center for Health Care Delivery Science, told me recently. "As we talked, it emerged that he, too, had had to fend off the medical system when his father died at age 93. "Even though I spend my whole career doing this," he said, "when I was trying to assure as good a death as I could for my dad, I found it wasn't easy."

If it is this hard for doctors to navigate their parents' final days, imagine what many ordinary patients and their families face. "It is almost impossible for patients really to be in charge," says Joanne Lynn, Director of the nonprofit Altarum Center for Elder Care and Advanced Illness. "We enforce a kind of learned helplessness, especially in hospitals." I asked her how much unwanted treatment gets administered. She couldn't come up with a figure – no one can – but she said, "It's huge, however you measure it. Especially when people get very, very sick."

Unwanted treatment is a particularly confounding problem because it is not a product of malevolence but a by-product of two strengths of the American medical culture: the system's determination to save lives, and its technological virtuosity. Change will need to be consonant with the culture. "You have to be comfortable working at the margins of the power structure within medicine, and particularly academic medicine," Mulley told me. You need a disrupter, but one who can speak the language of medicine and meet the system on its own terms.

## CARING FOR THE DYING

By Carol Mithers

Caring for the old is just like parenting an infant, only on really bad acid. It's all there: the head-spinning exhaustion, the fractured brain, the demands and the spells. Only this time with the knowledge that it won't get better. That was my life for five years. First came my mother-in-law, then my father-in-law, then my childless aunt, then my mother – all needing different kinds of help as they weakened and started going downhill, all the care overlapping, and almost all of the work to be done despite distance.

You're so good, friends would murmur, but I wasn't – there were plenty of days I muttered, "Can't do this anymore," and nights when I threw back too many drinks, feeling how badly I needed for it to be over. Now, though, it is done for real, everyone is dead, and the surprise is that instead of being relieved, I feel worse.

More than a year after the last funeral, I still have all the numbers on speed dial: My in-laws' neighbors in Texas and my aunt's in upstate New York; the security guard at my mother's gated San Diego community; doctors, hospitals, and emergency rooms in three states; two home health agencies; the 24-hour hospice nurse. I still sleep with the phone on and stashed in my night table, where I can grab it fast. It's over, but I can't let go. No, it's worse than that: I don't want to.

Maybe there is nothing new to say about the nightmare of shepherding the old through the time that is the prelude to death but not active dying. I knew it would be bad, but you don't really understand until you're there, any more than the childless can grasp why a new mother goes three months without shaving her legs.

"Drowning" was the word that came to my mind as the endless crises unspooled. My terminal mother-in-law, abandoning the fifty year pretense that she could stand her husband demanded: "Put him in a nursing home! Get him out of here!" My father-in-law, newly widowed and alone in an early Alzheimer's haze, barricading himself in the house against caregivers. My aunt, her lungs destroyed by a three-pack-a-day cigarette habit and reeling from one hospitalization after another, begging me to send morphine so she could end it all.

Alerts peppered every hour. Do something! Your father-in-law's behind the wheel again. Your aunt's in the hospital with pneumonia; she's recovering; no, she's failing, come quickly; no, she's been yanked back from death into a life of oxygen concentrators and cognitive crash; find a nursing home – wait, are you in New York? Because your mother's in the hospital in San Diego and it could be serious, can you get on a plane?

Frantic was my new normal and normal the new never, because when someone is old, especially if dementia is involved, nothing is routine. Even the answer to a straightforward question, like "What day is it?" vanishes on the wind; every patched-together arrangement works until it doesn't.