Policy Activism, Restraint, Mediation, and the Right to Die

In this policy primer on the right to die, we have attempted to deal with two fundamental questions. First, what forces of restraint and activism have shaped the right to die into an important policy issue in the United States today? And second, how have the institutions of policy mediation responded? We have fashioned answers to these core questions by resorting to an inspection of American culture, medical professionalism, social activism, state-court case law, and legislative activity across the fifty states.

Activism and Restraint

In looking for answers to the first question, we begin by noting that issues of public policy appear on the agenda not by accident but because a confluence of forces make an issue's rise something of an inevitability. Problems are always cropping up, but if they are ever to see the light of day, they must survive the competition between clashing forces of policy activism (forces that push problems onto the agenda) and policy restraint (forces that keep problems off the agenda).

If a problem survives the battle of activism versus restraint, then policy alternatives are fashioned and applied by policy mediators. Occasionally, these alternatives represent something innovative, but more often, they come from ideas that have been floating around in some form or another (e.g., in the Constitution, in the common law, or in the laws of some other state) in what John Kingdon (1984) calls the "policy primeval soup." Ultimately, policy is formed by the convergence of a problem, a policy, and politics; that is when a policy issue's time has come. Clearly, the right to die is such an issue.

At the same time, it is clear that the right to die is an area in which the conflict between individual self-determination and state interests in preserving life does
not lend itself to straightforward resolutions. Cultural forces of restraint—the denial of mortality, exacerbated by individualism, an abiding faith in technology, the entitlement syndrome, and religious taboos—continue to have an effect, turning policymaking into an extraordinarily muddled and incremental process. The forces of activism—technology, the rights culture, the happy-death movement, and the changing nature of the relationship between medical professionals and those they care for—have forced mediators to deal with the right to die. But the forces of restraint keep them from going too far and too fast in codifying the rules that would guide the exercise of those rights.

Forces of Policy Restraint

The forces of activism may have unwittingly conspired to create a policy issue, but the nature of American culture has helped keep the right-to-die debate submerged as an item of extensive public discussion until recently. More than citizens of other countries, Americans tend to be obsessed with death, to the point of denying their own mortality. As Walter Smith (1985, p. 283) notes, “Often the things that concern us the most deeply are the very things we talk about the least. Death certainly figures prominently among these topics.” Americans do not plan for death. They do not talk about death, except in hushed and euphemistic tones. They do not accept death as part of the life cycle. And as a result, they have not—as a group—pressed the popularly elected representatives in government to take bold steps in this policy area. In short, the right to die will be a sticky issue to resolve in this country, despite the forces of activism, because Americans typically avoid what they perceive as a very personal, private, and emotionally disconcerting subject.

It seems, then, that forces of activism have precipitated an issue that the public seems loath to put on the public-policy agenda. When it has come up in the past, the only organized political forces with an interest were those arrayed on the prolife side, suppressing the issue at every turn. Indeed, antiabortion groups have begun to adopt the right to die as a cause célèbre, as have disability-rights groups such as the National Legal Center for the Medically Dependent and Disabled and, to a decreasing degree, the Catholic church.1

The unbounded faith that Americans put in technology is another force of policy restraint that the forces of activism have had trouble overwhelming. Instead of facing up to tough choices, Americans tend to demand that the latest technology be available and employed in every case, to every extent, almost as if access to such advanced medical procedures were a right of citizenship. And giving up on life may be viewed by some as almost unpatriotic. As Arnold Toynbee has noted (cited in Charmaz, 1980, p. 96), “Death is ‘un-American’; for if the fact of death were once admitted to be a reality even in the U.S., then it would also have to be admitted that the U.S. is not the earthly paradise that it is deemed to be.”
In the end, these cultural, societal, and professional pressures conspire to stifle public discussion of right-to-die questions. Privately and individually, decisions to end the lives of terminally ill patients have been made for years at hospital bedsides and in doctors' offices. But in public, general discussion about when someone should be allowed to die borders on the taboo. Rather, the question usually is framed: What more can be done to save the life of a terminally ill individual? That, it seems, is the American way.

**Forces of Policy Activism**

Probably the most important force of policy activism in the right-to-die area is medical technology. Advances here have made it possible for health-care providers to sustain life and postpone death for days, months, and even years beyond the point at which someone would have died, naturally, just a few decades ago. Procedures ranging from the mundane (use of antibiotics, tube feeding, and artificial respiration) to the exotic (organ transplant and kidney dialysis) are now common means of artificially prolonging life when death would otherwise be imminent. Today, with the world's most advanced equipment, drugs, therapies, and operative procedures in play, life—even if severely degraded—can be preserved, sometimes indefinitely. And that is when right-to-die questions inevitably surface.

The changing nature of the American family also has had a marked effect in precipitating right-to-die scenarios. For many senior citizens, the combined impact of Social Security and Medicare makes it more likely that they will live independently and apart from their children. And when these elderly individuals contract long-term illnesses, they are more likely than ever to receive institutional care (in a hospital or nursing home) in which life-saving and life-prolonging therapies are apt to be rendered on a routine basis. Two generations ago, most elderly parents would die quickly and quietly at home (where they probably lived with or were taken care of by their children) from simple causes: pneumonia (sometimes called "the old man's friend"), infections, and serious falls. Those were the days when 80 percent of all deaths occurred in the home and sickness took its toll with some dispatch (DeSpelder and Strickland, 1992, p. 19). Today, the tables are turned: Some 80 percent of all deaths now take place in an institutional setting, where the dying may linger with chronic illnesses for weeks, months, years, and, in some cases, even decades.

As professional caregivers have supplanted family members, the close network of support within the family has broken down, leaving the old to die slow, lonely, institutional deaths. It is no wonder that the suicide rate for the elderly is the fastest growing rate for any age group (Douglas, 1992). The old have seen first-hand and within their peer group the aggregate picture painted by the National Center for Health Statistics (NCHS), in which the last year of life is often characterized by loneliness, poverty, and physical helplessness ("Last Year," 1992). About
half of all individuals in this category need help to bathe, walk, dress, and use the toilet. And more than one-third are likely to need assistance in eating. When life ends like that, it is no wonder that the elderly are increasingly taking right-to-die matters into their own hands, sometimes literally.

Meanwhile, doctors are medically trained, culturally predisposed, and legally required (or at least they believe so) to keep individuals alive at all costs, literally. So, rather than allowing patients near death to slip over the edge, they are more likely to keep the terminally ill alive, literally at all costs and sometimes with insufficient pain medication (for fear that overprescribing drugs may precipitate death). This, too, causes right-to-die scenarios to emerge.

The "deep-pockets" nature of health-care finance in the United States has also helped turn the right to die into a policy problem. Most other developed nations have public systems of health-care finance, making it possible (and necessary) to cap overall expenditures. Setting explicit expenditure limits makes it necessary to ration care in some general fashion by distributing resources according to some rule—a rule usually grounded firmly in the principle of medical efficacy. In the United States, where private, third-party insurers play such an important role in the finance of health care, money is spent at rates that are controlled not by government or medicine but by markets. But when private insurance markets cannot bear the costs of keeping terminally ill individuals alive for extended periods of time—and some suggest that this time is rapidly approaching—then questions about the right to die (or the "duty to die," as former Colorado Governor Richard Lamm might prefer to put it—see Chapter 3) are likely to be raised with increased frequency.

As the time has grown ripe for right-to-die scenarios to emerge, patients seem to have become more estranged from their health-care system than at any time in the past. The bureaucratization of the hospital, combined with an increasingly specialized medical corps, has led to a breakdown in the doctor-patient relationship. Nearly all care is now provided outside the home, usually by overworked, often superspecialized professionals who may or may not know the patient's first name. And in today's world, where physicians tend to be strangers and hospitals tend to be strange places, the natural bond of trust between doctor and patient has weakened substantially.

This all fuels existing trends of consumerism in health care. Patients are more likely than ever to shop around for physicians and second opinions. Emboldened by media exposés of physician incompetency and wrongdoing, patients are encouraged to ask questions and demand answers of their caretakers. And with the passage of the Patient Self-Determination Act, they may become even more informed about just what their rights are. The impact of the PSDA has been minimal to date, but it would be surprising if, over time, the act did not encourage more patients to take greater advantage of their rights as provided for by state law. As DeSpelder and Strickland (1992, p. 392) note, "Matters that were once the
province of fate have now become a matter of human choice." The end of life has become something to manage, and patients will be participating in the process to a far greater degree. Death, we suspect, will never again be quite the same.

The emergence of the happy-death movement is having an effect, as well. No one expects the home funeral parlor to reemerge any time soon, but people are talking about death, writing about death, agitating for the right to die, and voting on assisted-suicide initiatives in record numbers. Some individuals—most noticeably, members of the Quinlan and Cruzan families—have become so perturbed about the right to die that they have taken their cases to court, and the impact those cases have, thanks to extensive media coverage, reaches far beyond the courtroom to feed back into the activism loop.

In the end, the right to die is not an issue because anybody in particular wants it to be. It is an issue by default, the inevitable result of a confluence of activism forces. Moreover, the subject is here to stay. As Margaret Battin, a philosopher at the University of Utah, has noted, "We've crossed over the river now. ... But if you think the abortion issue was emotional, just wait until we get fully into euthanasia and death. Unlike abortion, [these issues] confront everyone and through their parents, probably several times" (cited in Malcolm, 1990a). Indeed, because death is something everyone must confront, any developments in this area will have a natural, broad-based constituency. And as Americans age and more and more of us are touched by right-to-die scenarios through the experiences of grandparents, parents, siblings, and spouses, the intensity of interest in the right to die is only likely to increase.

**Policy Mediation**

Bold strokes of policy emerge only when the forces of activism are sufficient to overwhelm the forces of restraint. Where restraint prevails, there is no cause for policy mediation. And where the forces of activism are roughly equal to the forces of restraint, halfway policy measures emerge from the legislatures and attention turns to the courts. That, it seems, is where we are with the right to die.

**Courts and Legislatures**

Where the forces of activism have generated a policy problem, American culture has stifled public debate. As a result, much of the mediation in the right-to-die arena has occurred in the venue of last resort—the courts—where private parties have chosen to sue in order to ensure that their perceived civil rights to self-determination are respected. The courts have been relatively successful and accommodating in forging an enduring interstate consensus for they are relatively insulated from the political and cultural forces that have slowed progress in the legislative
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arena. But that does not mean justices in the state courts like playing the role of policymaker.

Indeed, state judges have beseeched their legislatures time and again to take up the right-to-die cause and lay down some ground rules. But the state legislatures have struggled with the right to die because of their increased sensitivity to the forces of restraint. When legislatures have acted, they have lagged behind the courts either by responding to court cases slowly and erratically, then simply ratifying what the state courts have decided, or by trying to put the brakes on court decisions in some areas that seem to be especially sensitive (such as legitimizing the right to withdraw artificially provided food and water).

In the first instance, the state legislatures might be viewed as redundant, legitimizing for the body politic the rights the courts have already granted to individuals. In the second instance, the state legislatures have become almost irrelevant since when they attempt to put the brakes on the courts, the judiciary trumps the legislature to reinstate whatever rights were originally granted in the case law. Thus, it seems that, until recently, the forces of activism have forced the courts to deal with right-to-die scenarios, but the cultural pressures of policy restraint and the apparent lack of political leadership have left the state legislatures in position to play only a sideline role in mediating the right-to-die debate.

**Bedside Policy Mediation**

State-court decisions and the body of statutory law notwithstanding, a vast amount of policy discretion remains in the hands of bedside physicians. Physicians decide what to tell the families, what not to tell them, and how to advise them about what they ought to do. The old saw “knowledge is power” could not be more appropriate in the right-to-die arena, where, in spite of consumerist tendencies in the general population, there is still a tremendous disparity in knowledge between the clinician and client.

Saying that physicians have power does not tell us much about what the fate of right-to-die policy will be, however, because physicians tend to make determinations in private, on a case-by-case basis. Moreover, they face a maze of conflicting sentiments: They are guided by healing instincts that are tempered by sympathy for their patients, they are guided by a fear of legal liability that is tempered by pride in the autonomous nature of their craft, and they are sometimes guided by financial considerations that are tempered by an emerging ethos of responsibility to do only those things that are medically necessary. It is difficult to predict where those clashing impulses will take right-to-die policy in the years to come.

At the same time, we should note that there does seem to be a sea change under way in the prevailing medical ethos about caring for seriously ill patients. Today, even though patients may not control their destiny to the degree that the court cases and legislation suggest they might, physicians have begun to look at cases
more in terms of what a patient might logically want, as opposed to what is technologically possible. Warm-water pediatric drownings are a good example.\(^3\) Ten years ago, a child suffering this fate would almost surely be treated with heroic measures in an attempt to resuscitate the body. But today, there is more sensitivity to the idea that if the brain is gone, it might not make any sense to keep the child alive. Physicians may have pulled the plug clandestinely in the past, but today, such decisions are more likely to be made, talked about, and accepted openly as physicians weigh all the possibilities.

Living-will legislation has had some effect in this regard. Physicians may claim that living-will laws have not changed the nature of their practices. They may claim that end-of-life decisions have been made for years, in conjunction with the patient's wishes. But the ethic of bringing the patient and family into the decision-making process—even if their role is largely controlled and pro forma at this stage of the game—represents a substantial shift from years past. Together, living-will legislation and the Patient Self-Determination Act have changed the context in which decisions are made. Ultimately, this has all tended to legitimize the notion that taking aggressive measures might not be—by definition—the right way to go.\(^4\)

At the same time, some argue that there is much work still to be done. As Fenelia Rouse, executive director of the National Council on Death and Dying, says, “The practical reality is very spotty. ... In many hospitals you still can't get a respirator removed from a terminally ill patient” (cited in Malcolm, 1990a). When physicians, family, and patients have a long-standing, intimate relationship or when hospitals are committed to accommodating a wide range of patient preferences, legal directives are usually unnecessary. Otherwise, until physician hegemony breaks down more completely and until legislative waffling gives way to laws with some teeth in them, most Americans will not know much about what degree of autonomy they will eventually enjoy at the end of life. This will be true, it seems, until the medical profession openly embraces patient autonomy, and the legislatures find it expedient to overcome the inertia brought on by the forces of restraint.

**Summary: The Last Word**

Those interested in advancing the right to die may feel that they have been swimming against the current for years. In many ways, they have been because the current—American culture—has been flowing in the opposite direction. It is not that the culture rejects the right to die in particular so much as it rejects discussion of death at any level.

Yet, death is now on the public agenda, and private individuals, medical professionals, hospital administrators, and state legislators will have to find a way to
cope. Technological advances, consumer-rights activism, happy-death advocates, and disgruntled individuals willing to sue for the right to die are combining to slowly overcome countervailing pressures of restraint that have helped to keep the right to die off the agenda until recently. Currently, the forces of restraint are strong enough only to limit the scope of right-to-die policy and slow its development.

Issues associated with the right to die will be difficult to resolve, however. This is because policy mediation is all about establishing general rules and drawing lines to distinguish right from wrong, appropriate from inappropriate, and legal from illegal. That is hard to do in right-to-die matters for the line between meaningful life and death is so blurry. Indeed, the very nature of the distinction inhibits the formulation of generalizations, and the search for enduring policy is continuously confounded. Rules will be tough to establish—and maybe even tougher to follow—in a policy environment like this.

Nonetheless, it is important to remember that dramatic social transformations such as those involved in establishing the right to die usually come incrementally, in a two-steps-forward-one-step-back fashion, with the passing of generations. We are only now—seventeen years after Quinlan—near the end of the first “right-to-die generation,” and the number of people affected by right-to-die scenarios is still relatively small. We suspect, however, that as the second right-to-die generation matures and as the number of right-to-die scenarios increase, death will no longer be considered a taboo subject. Perhaps then we will find enduring answers about what exactly is entailed when people proclaim that, given their grave medical condition, they would like to exercise what for all Americans will eventually become a recognized and protected death right.