Policy Mediation and the State Legislatures: Common Ground, Divergence, and Liberal Trends

STATE-COURT JUDGES, if they can be believed, do not like making right-to-die policy.\(^1\) Many, former Chief Justice Warren Burger among them, would go further and argue that the courts have no business making policy. As Justice Burger put it more than two decades ago, “In a democratic society legislatures, not courts, are constituted to respond to the will and consequently the moral values of the people” (cited in Kevorkian, 1991, p. 182).

In this spirit, state judges have for years been extolling, cajoling, and even begging the state legislatures to step into the breach and establish statutory rules and procedures for right-to-die cases. But the fifty state legislatures have been reluctant to respond. With only a few notable exceptions, the states have been led by the courts, codifying parts of what the courts have decreed, trying to put the brakes on or even attempting to reverse other court initiatives, and leaving for further litigation many of the more controversial issues faced by the courts in the last decade and a half. We turn first to a survey of the right-to-die legislation that has passed to date, before moving on to explain how this curious body of statutory law came into existence.

Statutory Overview

The state legislatures make right-to-die policy primarily by passing two kinds of legislation: durable power of attorney for health-care provisions and living-will laws.\(^2\) Power of attorney provisions are important but restricted in their scope.
Policy Mediation and the State Legislatures

The laws themselves are usually brief and straightforward: Typically, the only details covered are those involving the legal and medical mechanics of declaring incompetency. As such, durable power of attorney for health-care provisions usually do little more than shunt the decision-making dilemma from a principal to a surrogate, an individual who is sometimes referred to as a “health-care proxy.”

By contrast, living-will legislation is more robust, which is why we spend more time focusing on it. Consequently, it is through a survey of such legislation (with reference to power of attorney laws as appropriate) that we will be able to assess the progress the states have made in coming to grips with right-to-die issues that the courts have been dealing with now for a decade and a half.

Common Ground

The California legislature led all others by passing the first living-will law in 1976, the same year the Quinlan decision was handed down. But California was not alone for long, as seven more states passed laws the following year. After this initial surge, however, legislative activity slowed. The only three states to pass laws in the next four years were Kansas and Washington (1979) and Alabama (1981), bringing the total number of states codifying the right to die to ten (see Table 8.1).

By 1992, thirty-seven of the remaining forty-one jurisdictions (the District of Columbia included) added living-will laws to their state codes. All this legislative activity is a bit deceiving, however, for only a few of the bills passed or being considered deal in a substantive way with the controversial issues that the courts have been handling in the same time frame. Indeed, the state legislatures, for the most part, have been codifying only the rudiments of the right to make advance directives regarding health-care decisions of the seriously and terminally ill. Thus, many of these laws have a great deal in common regarding the mechanics associated with executing advance directives.

For one thing, living-will laws in most states are relatively brief and to the point; in most cases, they run only a few pages. Other commonalities can be lumped into six categories: (1) the rationale for existence of the law, (2) the kinds of conditions covered, (3) the procedures for executing advance directives, (4) the release of liability for health-care professionals, (5) health-care and life insurance restrictions, and (6) the nature of the rights explicitly conveyed.

Rationale

Most living-will or natural-death acts establish an explicit rationale that addresses the way in which the rush of medical technology has the potential to impinge on dignity and autonomy of patients in terminal conditions. The statutes—borrowing from the text of state-court decisions—tend to make the argument that medi-
<table>
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<th>Year</th>
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<tr>
<td>1976</td>
<td>California (Quinlan)</td>
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<tr>
<td>1977</td>
<td>Arkansas, Idaho, Nevada, New Mexico, North Carolina, Oregon, Texas</td>
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<td>1978</td>
<td>No living-will laws passed</td>
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<td>1979</td>
<td>Kansas, Washington</td>
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<td>1981</td>
<td>Alabama (Eichner, Storar)</td>
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<td>1982</td>
<td>Delaware, Washington, D.C., Vermont (Bouvia)</td>
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<td>1983</td>
<td>Illinois, Virginia (Colyer, Barber)</td>
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<td>1984</td>
<td>Florida, Georgia, Louisiana, Mississippi, West Virginia, Wisconsin, Wyoming (Hier)</td>
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<td>1985\textsuperscript{b}</td>
<td>Arizona, Colorado, Connecticut, Indiana, Iowa, Maine, Maryland, Missouri, Montana, New Hampshire, Oklahoma, Tennessee, Utah (Conroy, Hamlin)</td>
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<td>1986</td>
<td>Alaska, Hawaii, South Carolina (D'Alessandro)</td>
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<td>1987</td>
<td>No living-will laws passed</td>
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<td>1988</td>
<td>No living-will laws passed</td>
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<td>1989\textsuperscript{c}</td>
<td>Minnesota, North Dakota (Klein, Couture)</td>
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<td>1990</td>
<td>Kentucky (Cruzan, Carder)</td>
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<td>1991</td>
<td>New Jersey, Ohio, Rhode Island, South Dakota (Wanglie, Busalacchi)</td>
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<tr>
<td>1992</td>
<td>Pennsylvania (Donaldson, Busalacchi, pending)</td>
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\textsuperscript{a} States without living-will legislation (as of January 1, 1993) are: Nebraska (L. 671, on General File); Michigan (H. 4931, in the Judiciary Committee); New York (S. 2712, in the Health Committee); Massachusetts (no legislation pending; H. 2129 died in Senate).

\textsuperscript{b} The Uniform Rights of the Terminally Ill Act (URTIA) was adopted by the National Commissioners on Uniform State Laws in 1985.

\textsuperscript{c} A completely revised version of the URTIA was adopted by the National Commissioners on Uniform State Laws in 1989.
cal procedures today do not always provide something medically necessary to the patient. Consequently, the health-care codes must be restructured to reflect that reality.\textsuperscript{4}

**Conditions Covered**

All state laws currently in effect cover those who have been clinically diagnosed as terminal (but only thirteen states include the persistent vegetative state as a qualifying condition). Although the clinical definition of terminal varies widely from state to state, it almost always refers to a condition in which life-supporting or life-sustaining procedures only serve to “prolong the dying process” or “postpone the moment of death.” Most laws specifically exclude procedures designed to provide comfort, care, and alleviation of pain from the kinds of therapies that may be withdrawn under living-will rules. In addition, the terminal prognosis typically must be certified in writing by an attending physician and a second physician, both of whom are physically present to examine the patient (a variation of the prognosis board proposed by the Washington court decision *In re Welfare of Colyer*).

Explicit distinctions are then usually drawn between what the law intends to sanction (allowing terminal patients to die) and those actions that the law is not meant to condone (mercy killing and euthanasia).\textsuperscript{5} To drive home the point even further, the typical statute points out that a death covered under living-will provisions does not constitute a suicide or homicide. Similarly, actions taken pursuant to the act are not generally allowed to be considered or listed as the official cause of death.

It is clear from reading the statutes that a great deal of thought (and anxiety) went into considering what kinds of deaths were being sanctioned across the states. In general, the legislatures seemed to be quite deliberate in attempting to distinguish the very limited types of actions that they intended to sanction as part of a “natural death” from every other kind of “arranged death” (e.g., active euthanasia or assisted suicide), which would continue to be deemed medically unprofessional, morally reprehensible, and legally punishable under criminal law in most states.

**Execution of the Living Will**

The majority of living-will laws also converge in the more legally technical area associated with executing an advance directive. Typically, living wills need only be executed once as long as they are completed with all the same care as an estate will would be.\textsuperscript{6}

In most cases, living-will forms can be obtained and completed without the assistance of an attorney. Several state laws require the dissemination of informa-
tion on these wills as part of a program to inform the public of their legal rights to refuse medical care when in a right-to-die situation. A recent amendment to Maine’s living-will law mandates that the appropriate forms be made available in local department of motor vehicle offices. Nevada law mandates that health-care facilities inform patients of their rights and make forms available on admittance, and Wisconsin law charges its Department of Health and Social Services with responsibility for distributing forms and information.7

Almost always, the declarant must be of majority age: eighteen years in most states, although Oklahoma uses twenty-one as the cutoff and Kansas prefers not to stipulate any particular age as a measure of legal competency. The document must usually be witnessed by two individuals, neither of whom have financial responsibility for the declarant or a financial stake in the disposition of the declarant’s estate. In addition, falsification, destruction, or purposeful withholding of a living will or coercion associated with the execution of it is expressly prohibited and punishable under criminal law in most states.

Some states publish a model living will as part of their statutes, and most claim to honor any directive that is properly executed within the state or elsewhere, as long as the document adheres—generally and in spirit—to the principles and guidelines set down by the legislating state. Living wills generally enjoy severability in the states, as well; that is, if parts of any will are found to be invalid, the offending sections are legally severable from the whole so that defects in portions of the will in no way impair the validity of what remains.

In addition, descriptive personal statements—communicated orally, in writing, or otherwise—by the patient in a qualifying condition (i.e., terminally ill and of majority age) are also considered to be valid under living-will provisions in most states. The revocation of a living will also can be made by the personal statement—however communicated—of the qualified patient. Moreover, revocations usually can be made regardless of the patient’s level of competency. Indeed, the Hawaii legislature recently considered and rejected an amendment to their living-will law that would have made revocation of a directive contingent on the competency of the patient.

Liability for Health-Care Professionals

Many have raised the issue of potential liability for health-care professionals who are involved in implementing an advance directive. Here again, most states seem to be in agreement. Generally speaking, living-will legislation explicitly protects health-care professionals by releasing them from legal liability for wrongful death when a good-faith effort has been made to comply with a declarant’s wishes.8

On the one hand, if medical personnel choose to take part in allowing an individual to die, state laws will shield them from professional sanction as long as they participate in good faith and in accordance with a valid advance directive.9 On the
other hand, if caregivers find that, for moral or professional reasons, they cannot participate in the implementation of an advance directive, they generally are charged only with the responsibility of transferring the care of their patient to another provider who, presumably, would be more inclined to act in accordance with the patient's wishes.

Insurance Provisions

The issuance of insurance is yet another area in which the states have seen fit to promulgate, as a group, similar regulations regarding advance directives. Most states explicitly prohibit health insurers from requiring that a living will be made out as a qualification for health-care coverage. Likewise, the states tend to expressly prohibit life insurers from disallowing benefits to the estates of patients who had a living will in force at the time of death. Many life insurance policies are voided in the case of a suicide, and the living-will statutes usually go to some length to explain that dying under living-will rules does not constitute such an act.

The Nature of the Rights Explicitly Conveyed

Lastly, most of the state laws end with a series of rights disclaimers. Two of the more prominent disclaimers address the unassuming and unrestrictive nature of the respective living-will statutes. In the first instance, state law generally makes it clear that no presumptions should be made regarding those who fail to execute a living will. That is to say, the failure of an individual to execute a living will should not be considered as presumptive evidence of his or her desire to be sustained on life-support equipment without limitation. Individuals, therefore, do not cede their right to have life support withdrawn simply because they failed to complete a legal directive to that effect.

In the second instance, states typically add the disclaimer that rights expressed within the laws are cumulative. That is, rights codified by the legislature add to the rights an individual enjoys outside the statute (in common law, in the case law, or as a matter of constitutional law). In other words, codification is not meant to infringe on, impair, or otherwise circumscribe the unstated rights and liberties of individuals under state jurisdiction. The message of these last two qualifications is clear: State statutes should be considered a place to start when divining what rights an individual has regarding the withholding and withdrawing of life-sustaining procedures, but the statutes are no place to end such an inquiry.

To What End?

We find this minimalist interpretation of statutory law entirely appropriate. The states agree on the fundamentals, but the more contentious issues—the specific
definition of the word *terminal*, coverage of those in a persistent vegetative state, the artificial nutrition and hydration question—have been sidestepped by the majority of states.

The courts have moved a good way down the road toward building a consensus around the granting and protecting of rights to die for the terminally ill, but the legislatures have only been able to agree on rudiments. One need only take a look at the tremendous diversity in state laws that overlay the fundamental agreements we have just sketched to appreciate how really trifling all this legislative activity has been to date.11

**Statutory Specifics**

Arthur Berger (1990, p. 141) notes that when it comes to the right to die, legislatures can “muddy the waters” by drafting statutes that limit case-law rights and may even undermine patient autonomy in the process. That is, patients may have been better off had the legislature not acted at all. But the states have acted and in a variety of ways. A review of the diversity in living-will provisions across the states will put the limitations of current legislation into perspective.

**Diversity Across the States**

The diversity among existing statutes can be categorized into four general areas: (1) qualifying conditions under which rights to die may be exercised, (2) provisions for surrogate decisionmakers in cases of patient incompetence, (3) the treatment of artificial nutrition and hydration, and (4) consideration of women who are pregnant at the time they otherwise qualify under right-to-die rules. The first three areas roughly parallel categories of central consideration in the case law: existence of the right to die, incompetence, and ANH considerations. The fourth area—pregnancy—is one almost wholly untouched by the courts to date (with the exceptions represented by *In re Klein* and *In re Carder*, discussed in Chapter 5), and the only area where the legislatures have taken the lead in attempting to mediate potential right-to-die disputes.

**Qualifying Conditions.** Though all forty-seven jurisdictions with living-will statutes (forty-six states plus D.C.) target the terminally ill, the clinical definition of what passes for terminal varies in some important ways across the states. In addition to this definitional variation, there is also the question of individuals in a persistent vegetative state: Some states cover those in a PVS under their living-will statutes, but others do not (see Figure 8.1).

Under definitional distinctions, the state laws can be grouped into three categories of linguistic construction: conservative, liberal, and neutral. We use the
No living-will law in force

Conservative construction\(^a\); no PVS\(^b\)

Neutral construction\(^c\); no PVS

Liberal construction\(^d\); no PVS

Conservative construction; PVS allowed

Open construction; PVS allowed

Liberal construction; PVS allowed

\(^a\)Conservative construction: law allows the withdrawal of life-sustaining treatment only in cases in which death is imminent, regardless of whether life-sustaining treatment is maintained or withdrawn.

\(^b\)PVS: a persistent vegetative state in which the patient has lost, permanently and irreversibly, all sensory perception of his or her surrounding environment—32 of the 33 states categorized as "no PVS" give no guidance regarding comatose states, and North Dakota alone specifically excludes patients in that condition.

\(^c\)Neutral construction: language regarding qualifying conditions is simple and left open to interpretation.

\(^d\)Liberal construction: law allows the withdrawal of life-sustaining treatment when such therapies are the only thing prolonging the life of a terminally ill individual; this is the Uniform Law Commissioners' recommendation (1989).

**FIGURE 8.1** Qualifying conditions of living-will provisions regarding the terminal condition and persistent vegetative state (as of August 1, 1989).
word *conservative* here to refer to a restrictive reading of the concept *terminal*; *liberal* indicates a more expansive reading, and *neutral* implies that the term is not well enough defined to fit into either category.\(^\text{12}\)

The twenty-one jurisdictions using the conservative definitional construction for the terminal condition require that death be imminent "whether or not" or "regardless of whether" life-sustaining treatment is continued (Figure 8.1). This definition is classified as conservative in construction because, if literally adhered to, laws employing this language provide little if any added decision-making authority to the individual. Strictly speaking, if death is imminent, regardless of whether or not life-sustaining procedures are employed, there is little point in having a statute permitting the withdrawal of such procedures (see Uniform Rights of the Terminally Ill Act, 1989, p. 5). That is, what good is a living-will statute granting an individual the right to die if death is imminent anyway?

Nine states use a more liberal construction. Their statutes consider individuals to be terminal if death would be imminent without the application of life-sustaining procedures (Figure 8.1). In other words, the individual must be seriously ill with an affliction that has shortened life expectancy substantially (some states use six months as a benchmark), but death need not be imminent, as long as life-sustaining procedures are maintained. This reading of the concept "terminal" comports with the model living-will legislation passed by the Uniform Commissioners in 1989, and it is the definition that the courts have embraced.

The remaining sixteen states use simple, neutral language to describe the "terminal" concept, thereby avoiding the "regardless of" versus "without" debate altogether (Figure 8.1). Instead, the word *terminal* is left open to interpretation. Consequently, no one knows ahead of time what kinds of situations would or would not be covered under the given statute.

In addition to these three definitional constructions, there is the important question of the persistent vegetative state. The question is important because there are approximately 14,000 cases of PVS in the United States today, and a substantial proportion of court cases involve individuals in this condition (approximately three out of four).

Although the clear consensus in the courts is to cover the PVS condition under right-to-die rules, the consensus of the states is to do just the opposite: Thirty-three states and the District of Columbia disqualify individuals in a persistent vegetative state from being covered under their living-will statutes. The remaining thirteen states with related laws on the books have complied with the Uniform Commissioners' 1989 model living-will law by including PVS patients in their coverage (Figure 8.1).

Inexplicably, some states that take the relatively bold and liberal step of adding permanent unconsciousness as a qualifying condition under the law use the conservative construction of what counts as terminal (among them is South Carolina, where all patients must be treated for at least six hours before treatments can
be withheld). Likewise (but maybe less remarkably), not all states using the relatively liberal construction of the word *terminal* have taken the next logical step to expand the concept and include individuals in persistent vegetative states (Figure 8.1). At least several states have adopted each of the six permutations derived by combining the three constructions of the “terminal” concept with the two possible alternatives on PVS (to cover or to exclude).

The only thing that does seem clear, then, is that there is not much clarity in the institutional minds of the legislatures across the states when it comes to the codification of qualifying conditions. In this area, the state legislatures have dragged their feet in response to the state courts because no courts—not even the conservative Missouri and New York courts—have expressly prohibited the withdrawal of life support from those in a persistent vegetative state the way thirty-three states and D.C. have. Neither have the courts seen fit to adopt a conservative definition of the word *terminal* the way twenty-one state legislatures have. Apparently, the legislatures, bowing to the forces of restraint, have tried to put the brakes on court-made policy.

**Health-Care Proxies.** Health-care proxies are surrogate decisionmakers that have the legal power to make right-to-die decisions on behalf of incompetent principals. At this writing, only Alaska, Nebraska, and Oklahoma have no provisions to legally designate proxies or surrogates. Alaska's durable power of attorney law expressly prohibits proxies from making decisions on the “termination of life sustaining procedures” (Alaska Statutory Form Power of Attorney Act [1988]). In Oklahoma, an attorney general’s opinion states that the Durable Power for Attorney Law in that state cannot serve as the basis of authority for health-care proxy decisionmaking (Society for the Right to Die, 1991). Nebraska simply has no law that deals with medical proxies.

The remaining states are hardly in agreement, however, for there is a good deal of variety associated with the designation mechanisms, designation types, and proxy restrictions that apply (see Figure 8.2). The mechanisms come in two varieties. First, proxy designations can be made through the execution of a durable power of attorney. Otherwise, provisions for designating a health-care proxy can be “built in” to the living-will law itself. Some states provide individuals with both alternatives (Florida, Indiana, Louisiana, Maine, Texas, Virginia, Wyoming).

There are also two different types of designation. Prospective designations are those made by the principal before becoming incompetent, and they identify by name the person or persons to whom decision-making authority would devolve should the principal become incompetent. The other type, ad hoc designations, identify a list of potential proxies to whom decision-making power would automatically flow in the absence of a specifically designated proxy.

Forty-four jurisdictions have durable power of attorney laws or living-will statutes that explicitly give declarants the ability to designate a surrogate decision-
Power of attorney or living-will statutes authorize proxy
Statutory provisions for declared and undeclared proxy;
this is the Uniform Law Commissioners' recommendation (1989)

FIGURE 8.2 Provisions regarding the appointment of proxy decisionmakers for living wills and durable powers of attorney (as of August 1, 1991).
Policy Mediation and the State Legislatures

maker, by name (Society for the Right to Die, 1991). Three other states (Arizona, Colorado, and Maryland) have medical power of attorney laws that, through court decisions, opinions issued by attorneys general, or other statutes, have been interpreted as giving third parties the right to make decisions involving the withholding or withdrawal of life support (Society for the Right to Die, 1991). One other state, Washington, has a law on the durable power of attorney for health care that does not explicitly deal with the right-to-die scenario. In this case, the status of the law in right-to-die cases is a matter of some legal dispute.

Taken together, these forty-seven jurisdictions clearly reflect the consensus of courts across the states in at least acknowledging the possibility that a surrogate could make decisions for the principal. Meanwhile, the remaining three states continue to swim against the tide in this regard. However, consensus breaks down in the state laws—just as it did (but to a much lesser degree) in the state courts—when it comes to identifying decisionmakers.

For example, in Alabama and Hawaii, individuals can only declare physicians as proxies. In contrast, the laws in both California and Ohio expressly prohibit health-care professionals from acting as surrogate decisionmakers. Regulations regarding the witnessing of health-care proxy designations vary, as well. In five jurisdictions (California, North Dakota, South Carolina, Washington, and the District of Columbia), there are special provisions for patients who have been institutionalized. In these instances, at least one of the witnesses must be a patient advocate (e.g., an ombudsman from the department of health, aging, or social welfare). In a sixth jurisdiction, Georgia, a physician must be one of the two individuals witnessing an institutionalized patient’s advance directive.

In several other states, the attending physician takes on the role of superproxy. In these states (California, Connecticut, Indiana, North Dakota, and Nevada), the relevant statutes do not require the physician to abide by a medically and legally sound advance directive. Rather, these laws only require that the physician give “great weight” to the declarant’s wishes. Provisions in these states effectively give attending physicians veto power over the declarant and his or her legally designated proxies, thereby establishing a whole new class of de facto proxies.

Eleven of the forty-two jurisdictions with laws providing for declared proxies also give guidance in their living-will legislation regarding the designation of ad hoc proxies when a terminally ill patient is incompetent and no proxy has been previously designated. Typically, these states issue a prioritized list of individuals to whom decision-making authority devolves when a patient who has not specifically designated a surrogate becomes incompetent. The list varies from state to state, with some interesting twists.

Most states roughly adhere to the Uniform Commissioners’ prescription, laid out in the 1989 version of their Uniform Rights of the Terminally Ill Act (URTIA). Here, decision-making authority devolves to the first available classification of in-
Policy Mediation and the State Legislatures

dividuals in the following list (National Conference of Commissioners on Uniform State Laws, 1989, pp. 12–13):\(^{13}\)

1. the [adult] spouse of the individual;
2. an adult child, or, if there is more than one adult child, a majority of the adult children who are reasonably available;
3. the parents of the individual;
4. an adult sibling, or, if there is more than one adult sibling, a majority of the adult siblings who are reasonably available; or
5. the nearest adult relative of the individual, by blood or adoption, who is reasonably available for consultation.

Iowa adopts the URTIA standard in toto. In a minor variation, Florida and Louisiana adopt the same standard but place the legal guardian ahead of the adult spouse as the decisionmaker with top priority. In a further revision, Arkansas and New York add guardian at the top of the list, then go on to substitute in loco parentis individuals and the majority of adult heirs, in that order, for the fifth classification of the Uniform Commissioners’ version. In a similar vein, Texas and Virginia list guardian, spouse, adult children, parents, and next of kin as the appropriate priority for decisionmakers.

In another interesting twist worthy of note, Utah lists guardian, then spouse, then reverses the following two classifications, putting parents ahead of adult children in order of priority. North Carolina law adds still more variation to the URTIA theme by listing spouse, then guardian, the majority of first-degree relatives, and the attending physician as those with ordered priority for decisionmaking. And in a radical and rather loosely constructed departure from the Uniform Commissioners’ standard, Connecticut law authorizes the attending physician to “gather whatever information he/she can regarding intentions of the principal” in order to determine what course of action to take in right-to-die situations where no proxy has been designated for an incompetent patient (Connecticut Gen. Stat., 1992).

More important than these minor variations on the URTIA theme, however, is the fact that a number of important questions go unaddressed altogether. For example, what happens if a group of individuals within a decision-making class cannot reach consensus (e.g., adult children)? Should the majority rule? Should any one individual in the class have veto power over the rest? Should split decisions go to those who favor the preservation of life? These are all possible resolutions, but neither the Uniform Commissioners nor the state legislatures provide any clues on which direction to take in this matter.\(^{14}\)

Even more importantly, not one state has broached the subject of decision-making criteria. The state courts have labored in this vineyard since the New Jersey court handed down the *Quinlan* decision in 1976. Since that time the courts
have wrestled mightily with the subject, codifying several loose standards (the substituted-judgment, best-interests, and subjective-judgment standards) along the way. Yet, the state legislatures have ducked the matter entirely. The surrogacy issue is only partly about who should play the role of decisionmaker for the real crux of the matter has to do with how the surrogate should make the decision. In this regard, the entire body of statutory law passed to date is essentially no help at all.

**Artificial Nutrition and Hydration.** The withholding or withdrawing of artificial nutrition and hydration is one of the most controversial issues raised by the debate over the right to die. As noted in Chapter 7, consensus has emerged in the courts: ANH is generally considered to qualify as a medical procedure that might potentially be withheld or withdrawn in right-to-die situations. Even generally conservative Chief Justice of the Supreme Court William Rehnquist argued, in the *Cruzan* decision, that “we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving nutrition and hydration” (*Cruzan v. Director, Missouri Department of Health*, 1990). The socially conservative Catholic church has also moderated its stand in recent years by acknowledging the propriety of withdrawing food and fluids in “exceptional” cases (see Chapter 6; also Catholic Bishops, 1991, p. 22). At the same time, most state legislatures have been more cautious in their approach.

The most common tack has been to avoid the issue altogether: Twenty of forty-seven jurisdictions with living-will laws in force make no mention whatsoever of artificial nutrition and hydration, despite its central importance to the debate (see Figure 8.3). When ANH is mentioned, a fair number of states either limit (Colorado, Florida, Illinois, Kentucky, North Dakota, Ohio, and South Dakota) or equivocate (Arkansas and Indiana) about the right to withdraw or withhold artificially administered food and fluids. Only thirteen states have codified what is now the mainstream case-law position in which ANH qualifies as a procedure that a patient or surrogate decisionmaker might choose to forgo in a right-to-die situation (Figure 8.3).

In the seven other states that mention but limit the right to withdraw ANH, circumstances in which ANH is allowed vary in the degree of restriction. In Kentucky and North Dakota, the law allows for the withdrawal of ANH only if it can be established that continued provision will be painful or excessively burdensome to the patient. Colorado and North Dakota laws make the distinction between artificial feeding (naso- or gastrointubation), which can be withheld or withdrawn, and the more conventional methods of obtaining nutrition and hydration (eating and drinking through the mouth, even if artificially assisted): The latter does not qualify as something that can be withheld or withdrawn in either state. Tennessee and Illinois laws allow for the withholding and withdrawal of ANH as long as lack of nutrition and hydration is not considered to be the official cause of death. And,
No living-will law in force

ANH must always be provided

Position on ANH unclear or equivocal

ANH may be withdrawn under certain conditions

ANH may be withdrawn if so desired by patient/proxy; this is the Uniform Law Commissioners' recommendation (1989)

No mention made of ANH

FIGURE 8.3 Living-will provisions regarding the withholding or withdrawal of artificial nutrition and hydration (as of August 1, 1991).
in more liberal language, Florida allows for the withdrawal of ANH if its sole purpose is to artificially postpone an otherwise imminent death.

Meanwhile, in a move that seems designed to flout the mainstream case-law position, five states (Alabama, Georgia, Missouri, Montana, and Wisconsin) have passed or amended their laws to explicitly prohibit the withholding or withdrawal of ANH. Missouri is especially interesting in this regard, given that it was the venue of Nancy Cruzan's case, in which, with guidance by the U.S. Supreme Court, ANH was allowed to be withdrawn after seven years of legal battles.

Thus, it seems that only a small proportion of the state legislatures have been able to reach the same conclusion that the state courts have with regard to artificial nutrition and hydration. Again, forces of restraint have apparently had more impact on the legislators, and judges have enjoyed more freedom in responding to the considerable forces of activism that have welled up in American society in the last several decades.

The Impact of Pregnancy on the Right to Die. The right of pregnant women to make right-to-die decisions is one area in which the states seem to be ahead of the courts when it comes to establishing rules. For the most part, the lack of direction offered by the state courts in this area might be attributed to a lack of opportunity: In the 106 cases involving the right to die that were cited by the National Center for State Courts (National Center for State Courts, 1992, pp. 155–172) from 1976 through 1992, only three involved a pregnancy, and only two (In re Klein [1989] and In re A. C. [1990]) involved a decision by the court. This makes the activism of state legislatures even more interesting. Despite the lack of court-sponsored impetus and despite the relative rarity of right-to-die cases involving pregnancy, the clear majority of states—thirty-five of forty-six states with living-will laws in force—have proceeded to address the issue of pregnancy in their right-to-die legislation. Almost all of these states—thirty-four of thirty-five—have gone on record to foreclose the right of women to control medical decision-making in right-to-die situations when they also happen to be pregnant (see Figure 8.4).

Many states (twenty in all) disqualify pregnant patients, without exception, from exercising the right to die. In these states, pregnancy automatically voids the validity of an advance directive, written or otherwise. The remaining states that mention pregnancy pull back from a blanket prohibition but leave substantial obstacles in the way nonetheless.

Six states (Arkansas, Arizona, Idaho, Illinois, Minnesota, and Ohio) qualify their pregnancy exclusion by stipulating that the advance directives of pregnant women will be voided if the continued development and live birth of the fetus is “possible.” In more liberal language, five other states (Alaska, Colorado, Iowa, Montana, and Rhode Island) void advance directives only when the continued development and live birth of the fetus is “probable.” This is also the position ad-
No living-will law in force

Pregnancy cancels advance directive

Directive canceled if live birth "possible"

Directive canceled if live birth "probable"; this is the Uniform Law Commissioners' recommendation (1989)

Directive contingent on mother's condition

Women allowed to choose

No mention of pregnancy made

FIGURE 8.4 Living-will provisions regarding pregnancy (as of August 1, 1991).
vanced by the Uniform Commissioners in the 1989 version of the model living-will bill (Section 6[c]).

Several other states have added more specific tests, disallowing the advance directives of pregnant women except when doing so would cause the women unrelieved pain (North Dakota) or harm and unrelieved pain (Kentucky, Pennsylvania, and South Dakota). Pennsylvania's law regarding pregnancy is especially interesting for the legislature backed up its restriction with a promissory note, agreeing—as part of the living-will law—to cover all medical costs for maintaining an incompetent and severely ill pregnant woman who is not covered for medical expenses by a third-party payer.15

In addition to these restrictive positions, there is also silence. No mention of pregnancy is made at all in eleven jurisdictions (including the District of Columbia, where the Angela Carder case was heard). It is beyond the scope of this inquiry to delve into legislative hearings and debate records from these jurisdictions to determine whether such omissions were intentional or the product of simple oversight. In liberal California, the Catholic Conference is said to have extracted a promise that pregnancy would not be addressed (Glick, 1992, p. 96). Oversight might explain the behavior of the Louisiana legislature: Given this state's conservative record on the abortion question, it is hard to imagine that Louisiana legislators purposely dodged the pregnancy issue. In the remaining states, it is more difficult to speculate on whether omission was a product of simple oversight or political accommodation.

The one notable exception in all of this is New Jersey. There, the legislature has turned in an entirely different and much more liberal direction by granting that "a female declarant may include in an advanced directive executed by her, information as to what effect the advanced directive shall have if she is pregnant" (New Jersey Act [1972]). This language (pregnancy is not mentioned in any other context elsewhere in the legislation) suggests that the New Jersey legislature intended to grant the declarant primary control over the fetus—a clear and marked departure from the approach taken in the other states. This course is much more in tune with the two major court decisions to date. Both the New York court (In re Klein) and the D.C. court of appeals (In re A. C.) found that the women did, in fact, have the right to die, pregnant or not.16

At this point, it might be reasonable to ask why, except in the case of New Jersey, the states have decided to strike out in this area of right-to-die legislation when they have been sluggish in almost every other respect. After making a preliminary investigation, we have concluded that interest-group dynamics are at the heart of the matter.

As we have noted, there is a distinctive lack of pressure from parties who might be interested in advancing policy in this area: parents of severely handicapped infants, those interested in increasing the pool of harvestable organs, and women's rights activists (who are probably too worried about Roe v. Wade to spend much
time or political capital on this issue). Instead, the only actively engaged interest groups seem to be those arrayed on the prolife side of the ledger—the various state Catholic conferences and the antiabortion lobby. Representatives of these groups generally demand and get a seat at the table when it comes time to hammer out compromises in right-to-die legislation.

For some of these groups, pregnancy considerations have become something of a cause célèbre. In most states, these right-to-life groups have lobbied actively, even tenaciously, for an "incubator" amendment to living-will laws currently being considered. As the data on legislative provisions suggest, in most cases, these right-to-life groups have had their way with both the legislatures and the legislation. Ultimately, then, maybe the better question is this: How did New Jersey get away with its radical departure on the pregnancy question?

Trends in Statutory Law

In spite of all the diversity among the states on the key issues reviewed here, there are some clear and marked trends in state legislative activity that represent something of a convergence for statutory law across the states. In almost all cases, the legislatures are finding that convergence means moving toward the general consensus of the state courts. States recently adopting living-will legislation tend to incorporate more leniency in their laws than those that did so earlier. Moreover, states that have amended their existing laws tend almost exclusively to do so in a generally liberal (what Glick [1992, p. 184] calls "facilitative") direction.

First, it appears that the state legislatures are becoming more liberal in their definition and conceptualization of a "terminal" condition. Second, most legislatures are becoming increasingly liberal in their treatment of artificial nutrition and hydration. Third, provisions for the designation of proxy decisionmakers are becoming more comprehensive. Fourth, pregnancy as a disqualifying condition may be getting a more liberal treatment, though the evidence on this score is far from definitive. And fifth, there are a number of generally liberal perfecting amendments now wending their way through the state legislative labyrinth.

Qualifying Conditions Revisited. First and probably most significant is the general tendency of the states to liberalize conditions that apply under living-will statutes. On the definitional front, the first seven years of legislative activity were dominated by the use of conservative definitions of the "terminal" prognosis. In contrast, all nine state laws using the liberal construction—in which death is imminent "regardless" of whether life support is continued or not—have been enacted or amended to reflect the liberal approach sometime in the past seven years.

With regard to the PVS question, we note that a number of states recently passed laws or amendments to existing laws that have added permanent unconsciousness as a qualifying right-to-die classification. Three of the thirteen states
that allow life support to be withdrawn from PVS patients (Ohio, Pennsylvania, and South Dakota) have passed living-will laws to that effect in the past two years. Five more of these thirteen states (Arizona, New Hampshire, Connecticut, South Carolina, and Virginia) have amended their existing statutes to include PVS in the same time frame.

In addition, two states currently debating living-will legislation (New York and Michigan) include PVS in the bills now being considered. And finally, a number of other states (Oregon, Tennessee, Georgia, Washington, Florida, North Carolina, and Hawaii) are actively considering or have recently considered amendments that would accomplish the same end if adopted. In both the definitional and PVS reforms, the state legislatures seem to be playing catch-up with the state courts. The courts have never been troubled by the fine distinctions that have proved so vexing for the legislatures to this point, but clearly, the legislatures are on their way to coming around.

**ANH Revisited.** Second in order of importance is the generally liberal course the states have been taking in the matter of withdrawing artificial nutrition and hydration. To this point, twenty states have passed provisions, several just recently, that allow for withholding or withdrawing ANH under certain conditions. Five of the six states to pass living-will laws since 1990 are among this group (Kentucky, New Jersey, Ohio, Pennsylvania, and South Dakota), and two other states (Connecticut and Virginia) have passed amendments to this effect in the same time frame. Other states (Georgia, Indiana, North Carolina, and Washington among them) are actively considering moving in this direction. Efforts to amend the living-will statutes in Oregon, Hawaii, and South Carolina to allow for the withdrawal of ANH also were considered in the early 1990s.19

Pennsylvania, in the most liberal move to date along these lines, passed a living-will law in 1992 that provides a checklist of procedures a declarant could use to indicate exactly what he or she would wish to receive or refuse in the way of medical interventions (Pennsylvania Advance Directive for Health Care Act [1991]). In addition to ANH, the list includes cardiac resuscitation (mixing the DNR philosophy with the living will), receipt of blood products, artificial respiration, kidney dialysis, surgery, and antibiotics. Though it is not clear how much weight a patient’s declaration would carry (for example, in cases where antibiotics were checked off as something the declarant wished to refuse), the fact that such a checklist exists at all is indicative of a more general trend toward individual autonomy in medical decisionmaking.

Indeed, only one state has seemed to be swimming against this legislative (and judicial) tide in recent years: Montana. There, the legislature recently amended a statute to expressly prohibit the withdrawal or withholding of nutrition and hydration (Montana Code, 1991). Otherwise, however, the states once again seem to be taking their lead from the courts, which, at least since New Jersey’s Conroy de-
cision in 1985, have firmly supported the right to withdraw artificially provided nutrition and hydration.

**Proxies Revisited.** Provisions that regularize the assignment of proxies—both prospectively by the declarant and automatically according to a priority list—have also undergone something of a convergence. Unlike PVS and ANH provisions, however, proxy provisions have not yet become the subject of a ground swell of legislative interest. Still, given current trends, we should expect that states without proxy provisions (Alaska, Nebraska, and Oklahoma) and states with incomplete proxy provisions (see Figure 8.2) will amend their statutes over the course of time to accommodate the declaration and assignment of surrogate decisionmakers, as recommended by the Uniform Law Commissioners' (ULC) amendments of 1989 and subsequently adopted, in one form or another, by a number of other states.

This is where the courts and the legislatures are more closely matched. The issue of surrogacy really opens up a whole new arena of problems and policies, and neither the courts nor the legislatures have been very successful in (1) determining who should make decisions when there is no clear evidence of patient intent or (2) establishing criteria for guiding how those decisions should be made. For their part, the courts have dabbled with the “who” question and spent a good deal of time trying to establish rules that would guide behavior, in response to the “how” question (e.g., the substituted-judgment and best-interests standards). Meanwhile, the state legislatures have taken a swipe at the “who” question (by providing for ad hoc proxies if none are designated in advance directives, for example), but as a group, they seem to have left the “how” question for another day. We suspect that surrogate decisionmaking for incompetents will remain a primary source of contention for both the courts and the legislatures in the years to come. But the courts can be expected to lead the way where, apparently, the legislatures fear to tread.

**Pregnancy Revisited.** Currently, New Jersey (the last state to pass a living-will law) and Arizona (which recently amended its law) are the only two states that explicitly empower women with the right to make medical decisions for themselves should they be pregnant at the time they become enmeshed in a right-to-die scenario. But these two states may be part of an emerging trend. All four states that hedge their positions by suggesting that the disposition of the fetus may be determined, in part, by the effect the continued pregnancy would have on the mother (North Dakota in 1989, Kentucky in 1990, South Dakota in 1991, and Pennsylvania in 1992) are among the group of eight states to have passed living will laws since 1989.

One might see, in the actions of these six states taken together, the beginning of a predisposition to liberalize right-to-die laws along the lines of individual autonomy or at least individual deference. At the same time, the two states actively con-
Policy Mediation and the State Legislatures

considering passage of a living-will law muddy the picture a bit. The New York statute currently being weighed does not mention pregnancy, and the Michigan draft explicitly excludes pregnant women from protection. There can be little doubt that most states will want to wait on the pregnancy question until they have time to assess the long-term impact of the Supreme Court’s ruling on the Pennsylvania Abortion Control Act (Planned Parenthood of Southeastern Pennsylvania v. Casey [1992])—a decision that, on its face, seemed to swing open the door to further “reasonable” state restrictions on the right to privacy. One cannot help but think the states will also be watching closely to see what further direction(s) the Supreme Court takes on Roe v. Wade before they expend much political capital in this religiously charged and highly controversial area of public policy.

**Perfecting Amendments.** There are some other minor and more technical areas in the living-will arena where relatively noncontroversial, perfecting alterations in legislation may presage future, generally liberalizing trends. For example, the recently passed New Jersey law attempts to bring living-will declarations into compliance with hospital-based DNR policies. The Joint Commission on Accreditation for Hospital Organizations has, for several years, required their member hospitals to formulate DNR policies. Since there is so much overlap between state living-will laws and these institutionally promulgated DNR policies, the logic and, ultimately, the necessity of reconciling procedures associated with these two kinds of medical directives may prove compelling.

North Dakota’s contribution to the ongoing living-will debate involves the exemption of emergency medical personnel (EMS) from liability for failing to comply with an advance directive (North Dakota, 1991). The rationale here is self-evident. Operating almost entirely outside the institutional setting and in crisis situations, EMS personnel cannot be expected to know what an individual patient’s advance directive states. Nor should they be expected, while on an emergency call, to find out if an advance directive exists and what (if one does exist) it says, at the expense of caring for the patient. Pennsylvania’s recently passed law provides EMS personnel with this kind of protective umbrella.

In one of the most dramatic and progressive right-to-die developments to date, twenty-one states have managed to combine the philosophy of the DNR order with concerns about the ability of EMTs to act in accordance with advance directives. The product of this interest and concern is an entirely new right-to-die instrument: the nonhospital DNR, made legitimate either by statute (in Arizona, Colorado, Florida, Georgia, Illinois, Maryland, Montana, New Mexico, New York, Pennsylvania, Rhode Island, Tennessee, Utah, Virginia, Washington, West Virginia, and Wyoming) or by legislative protocol (in California, New Hampshire, and Vermont). The nonhospital DNR makes it possible for individuals to indicate their desire not to be resuscitated in an emergency situation by using brightly colored forms (Arizona’s form is printed on orange paper), wallet cards, or—as in California—Medic Alert–style bracelets or necklaces bearing the inscription “Do
Not Resuscitate—EMS" ("Hospitals Establish Policies," 1993). As with living-will legislation, the substance of these laws (regarding those who qualify to execute a nonhospital DNR, for example), varies tremendously from state to state. But clearly these new instruments, taken as a group, provide more options for individuals to express their end-of-life intentions and additional safeguards to ensure that those end-of-life intentions are honored.

As for perfecting the living will a number of other states have picked up on the California provision requiring that one of the two witnesses to an advance directive made by a resident of a long-term care facility be an ombudsman from outside the institution. This seems to be a logical and self-evident protection against abuses of the living-will laws. We only wonder why other states did not follow California's lead in this more quickly.

The issue of dispute resolution also raises some interesting questions. When an individual has executed both a living will and a durable power of attorney, which document controls? Most states are silent on this question. But a few have made their preferences explicit. In Illinois, the durable power of attorney trumps all declarations, but according to the recently passed law in South Dakota, the latest signed document controls. In Kansas, the living will controls, and in Nevada, the proxy's decisions are required by law to conform with the intentions of the principal as expressed in the living will. As conflicts arise between living wills and durable powers of attorney for health care, more states, no doubt, will follow the lead of those in which the order of priority is made clear.

Lastly, there seems to be a movement afoot to increase the availability of living-will information. For example, Maine now requires that living-will forms be provided to applicants for driver's licenses and hunting licenses. And Oregon requires health-care facilities to give patients advance directive materials. The Patient Self-Determination Act only requires that institutions inform patients of their rights under state law and offer to help obtain further information on advance directives if requested. Oregon has taken the next step and required that living-will forms be provided whether requested or not. In an innovative twist, Illinois driver's licenses now note whether the driver has a current advance directive or not. Clearly, the dissemination of information—with regard to both formulating and implementing advance directives—is the key here, given the arcane state of legislative language and the sensitive nature of the issues involved. Therefore, these developments promise to add their own measure of policy activism to the right-to-die milieu.

Explaining Legislative Behavior

When all is said and done, there are really three kinds of legislative behaviors that bear explaining. First, why do the states pass living-will laws in clusters with so
much in common (at least with regard to the rudiments)? Second, why has the substance of those laws diverged so fundamentally from the general consensus positions taken in the state courts regarding the really important issues, like ANH, PVS, and pregnancy? And finally, what is behind the more recent, generally liberal trend toward convergence between the legislatures and the courts?

Answering these questions is no mean feat due to the rich diversity of political cultures and idiosyncratic dynamics that are the hallmarks of legislature behaviors across the fifty states. Still a number of overlapping generalizations that cut across state borders can be used to explain, in a general way, the behavior of the state legislatures as bodies of mediation in the right-to-die debate.

**Explaining Common Ground**

The concept of “policy diffusion” has been the topic of a stream of literature in policy studies since Jack Walker’s seminal work on the subject, “The Diffusion of Innovations Among the American States,” was published in 1969. Policy diffusion in the legislative context speaks to the issue of convergence among state legislatures on new and emerging issues of public policy (just as judicial policy diffusion speaks to the forces that edge courts toward consensus in innovative policy arenas). According to observers of representative assemblies in the states, a small group of legislatures have the reputation for being “policy innovators”—“beacons of legislative activity” that cut a policy-making path that other states follow (borrowing from Chapter 7, where innovative state courts were called “beacons of jurisprudence”).

The ranks of these legislative beacons are thought to be dominated (again, as with the court innovators) by populous, urban, industrialized and affluent states with independent political cultures (like California, New York, New Jersey, Michigan, Massachusetts, and Pennsylvania). Usually, with their complex and diverse societies, such states are among the first to adopt progressive legislative policy innovations (Glick, 1992, pp. 43–44; Walker, 1969), and other less populous, less urban, and more homogeneous states within a “beacon” state’s region or sphere of influence tend to fall in line only after the trail has been blazed.

The fact that California’s legislature was the first to adopt a living-will law fits nicely into this framework. So, too, does the fact that in the year following adoption of California’s Natural Death Act (NDA), five of the seven states to pass living-will laws were in the West (Idaho, Nevada, New Mexico, Oregon, and Texas). Moreover, three of those Western states within California’s sphere of influence passed laws that were substantially similar to the California act. Indeed, the living-will bill sponsor in Nevada put the matter quite explicitly, stating that the purpose of his proposed measure was “to bring our law into conformity with California” (cited in Glick, 1992, p. 169).
Sometimes, according to experts on diffusion, states do not follow each other so much as they follow the lead of respected third parties. This dynamic, too, seems to help explain the commonalities among the states' living-will codes. Just as the courts were found to derive ideas and support from third parties (on the President's Commission report and the AMA policy statement, see Chapter 7), so have the legislatures looked beyond their own realm for guidance.

They found it in the form of a model living-will bill—the Uniform Rights of the Terminally Ill Act (URTIA)—developed through 1984 and officially released in 1985 by the National Conference Commission on Uniform State Laws (NCCUSL).20 Bill sponsors in fully half of the states enacting living-will laws in this period claimed to have been "stimulated" by the NCCUSL, ultimately basing their own bills on its uniform law (Glick, 1992, p. 173). Indeed, large portions of the URTIA are evident in the bills passed in Alaska, Arkansas (amendments to the 1977 law), Iowa, Maine, Missouri, Montana, and Oklahoma.21 Publication of the URTIA, with the 1983 release of the President's Commission report supporting comprehensive living-will legislation, and the AMA endorsement of patient self-determination, also in 1983, all helped to chart a course for legislative advocates in the twenty states that successfully passed legislation in 1984 and 1985.

In addition to the NCCUSL, a number of other third parties—primarily interest groups and national associations—played a role in leading state lawmakers to the legislative well. For example, the Society for the Right to Die published its own version of a model living-will bill, the Medical Treatment Decision Act (MTDA), for state consideration in the early 1980s. Although no state adopted the MTDA in toto, a number of living-will laws were influenced by MTDA provisions, including statutes in Alabama, the District of Columbia, Florida, Illinois, Indiana, Kansas, Louisiana, New Hampshire, Oregon, South Carolina, Virginia, Washington, West Virginia, and Wyoming (Meisel, 1989, pp. 336–337). Professional organizations that serve the interests of state legislatures, such as the National Conference of State Legislatures (NCSL) and the American Legislative Exchange Council (ALEC), also play a role in the diffusion process.22

Sometimes, innovative ideas travel across state boundaries via regional and national news programs, nationally read newspapers (such as the New York Times and Wall Street Journal), or weekly news magazines. State legislators use these media to look at other legislatures in search of analogies between the situations they find themselves in and those of another state where the policy issue has already been successfully resolved. When searching for a solution, legislators engage in the "politics of the possible" by pirating ideas from other states, then rationalizing this behavior to their colleagues, their constituents, and themselves by asking, rhetorically, "If it works great in state X, why not here?"

Once an innovation finds its way into a number of states, the new policy tends to gain a momentum of its own, becoming something "every state should have" (Walker, 1969, p. 890). Recalcitrant legislatures are eventually forced (some might
say “shamed”) into adopting trendy solutions by media coverage of legislative inaction in the home state. Thus, an element of interstate competition enters into the picture for those states who are slow to mediate solutions to perceived problems.

The state legislatures, like the state courts, are under no obligation to borrow precedents from their neighbors. But like the courts, the legislatures seem predisposed to use each other’s laws, while also looking to respected third parties like the Uniform Commissioners as guides for their own policy mediation purposes. Clearly, then, policy diffusion is in play here, helping to explain the existence of a common ground among state laws.

At the same time, the state legislatures exhibit some unexpected behaviors in this regard. For example, it took New Jersey and Pennsylvania fourteen and fifteen years, respectively, to follow in California’s footsteps in passing living-will legislation, while forty-three other states stepped in line ahead of these two “innovative” states. In addition, three of the four states that have yet to pass a living-will law—New York, Massachusetts, and Michigan—are supposedly innovative states. Even more surprising, when Henry Glick ran correlations between a state’s tendency to be innovative (liberal) and the speed with which it passed a right-to-die law, he found a mild relationship—in the unexpected direction! That is, the more liberal the policies in a given state, the less likely the state’s legislature was to have passed a living-will law.

Digging deeper into this seeming paradox, Glick (1992, p. 177) found a state’s policy liberalism to be closely related to the percentage of the population claiming to be Catholic, and it seems that the Catholic variable as a force of restraint overwhelms any predisposition to exhibit liberalism on the right-to-die question. Glick summarizes his findings by noting that “the larger a state’s Catholic population, the less likely states are to adopt living will laws.” According to him, religion is more important than ideology in this instance since the right to die is an issue that is viewed primarily in moral, as opposed to economic, terms (even though economic issues lie just beneath the surface). Glick sums up the matter bluntly: “No other interest group has been as concerned with these laws as the Catholic church, nor have they had the impact. It appears that the Catholic church was able to prevent the enactment of living will laws in most states for many years” (1992, p. 202).

Explaining Divergence

Just as the lack of legislative activity on the right to die can be attributed to the Catholic church, the ultimate passage of conservative laws that diverge from the generally liberal positions taken by the courts can be traced to Catholic influences on the legislative process. As trends in popular opinion, popular and professional publications, and court agitation increased pressure on state legislators to act
through the early 1980s, Catholic elites shifted ground. In these years, the passage of living-will laws became increasingly inevitable and, from the Catholic point of view, maybe even desirable. In the face of the judicial activism represented by the parade of liberal court decisions that were being issued, Catholics found that they could no longer afford the luxury of outright resistance. Some Catholic activists even began to see legislative innovation as a vehicle for rolling back some of the advances made by the courts on the right-to-die front.

Ultimately, fearing that continued resistance would shut them out of the process completely, Catholic elites made the strategic decision to soften their stand and either endorse or agree not to oppose passage of limited living-will laws that incorporated important restrictions that were key to the Catholic position (e.g., pregnancy exclusions, ANH restrictions, and applicable conditions that were narrowly defined). The authoritative pronouncement was made in 1984, when the National Conference of Catholic Bishops officially abandoned its blanket opposition to living-will legislation. Not coincidentally, seven states passed laws that same year to end something of a drought in legislative activity, and thirteen more states joined the fold the following year, creating the biggest watershed in legislative activity regarding the right to die in the issue's entire history.

Not all the credit (or blame) for the passage of conservative right-to-die laws in the states can be laid at the feet of Catholic elites, however, for at least some of the legislative resistance on the right-to-die issue can be attributed to the general forces of restraint laid out in Chapters 1 and 2. Legislatures are simply collections of individuals who presumably share a common cultural framework with their constituents. Understandably, then, if Americans tend to fear death and deny their own mortality, their legislative representatives will, as well. For most—legislators included—the notion that death can be "managed" through consideration of living-will laws is even more difficult to cope with.

We have made a case in Chapters 3 through 6 that the forces of activism are on the rise, to the point where they are beginning to overwhelm the forces of restraint. But policy mediators are not all affected the same way by such policy dynamics. To date, the courts have been especially sensitive to the forces of right-to-die activism. Advances in medicine have created right-to-die scenarios for a small but growing number of individuals who, because of changes in the social structure, have become increasingly distrustful of their caretakers and increasingly bullish about bringing their own rights-based claims to court. The courts have had no choice, really; they were obliged to respond.

Legislatures are another story, however. Legislators have been slow to deal with critical right-to-die issues because they, like most of their constituents, are still reluctant to get involved with an issue whose status remains nothing short of taboo in many quarters. Even if legislators were predisposed to act boldly on this front, constituents have not yet offered much in the way of electoral payoffs for toiling in this thorny vineyard. Thus, there was very little incentive for legislators to make
bold political strokes through the 1980s. The courts took the heat—and relieved the pressure—created by individuals who advanced rights-based claims, while generally conservative instincts, buttressed by the considerable influence of the Catholic church, were allowed to hold sway in the legislatures. Forty states and the District of Columbia passed living-will laws prior to 1990, but whether that body of statutory law was of much help to those who found themselves in right-to-die situations is another matter entirely. Indeed, when conflicts arose in any but the most routine right-to-die situations, the individuals involved found themselves forced to repair to the courts in order to enjoy what the courts have considered a constitutionally protected right for the better part of a decade.

**Explaining Convergence**

Although the early and middle 1980s were marked by the passage of generally conservative state laws, a general trend toward a convergence with the more liberal consensus positions established by the state courts has been in evidence more recently. This can be explained, at least in part, as the result of a wearing down of restraint by the broad-based forces of activism. Entreaties by the courts are finally taking their toll, as individuals become more rights-conscious and more comfortable with considering what it would mean to manage a "happy death." Meanwhile, medical technology marches onward, creating more right-to-die scenarios daily—scenarios that demand increasingly precious resources that governments and private insurers are less and less willing and able to underwrite.

All the while, the Catholic influence that was so much a part of the explanation for conservative legislation through the 1980s has been on the wane more recently, freeing up legislators (and constituents) to pursue a more liberal path as they see fit. With impetus in full swing and obstacles melting away, liberalizing trends should have fairly smooth sailing in the years to come, though the forces of restraint cannot be discounted: Imbedded cultural attitudes such as those associated with death and dying do not fade away overnight.

**Case Studies**

A good deal of generalization has been laid on the table to this point, but not much context or detail has been rendered. Are generalizations evident in individual cases? Do the experiences of individual states support the general rules that have been offered as explanations for legislative behavior? A review of the experience of Pennsylvania (the last state to pass a law) and briefer looks at California (the first state to pass a law), Florida (with a law passed in 1984), and Massachusetts (still with no living-will law on the books) will help to answer these questions in the affirmative.
Pennsylvania. Pennsylvania's Advance Directive for Health Care Act includes the same curious mix of conservative and liberal positions evident in so many of the state laws now in force.27 These conflicting messages may, in part, have something to do with the forces of activism (policy diffusion) and restraint (the Catholic influence) that tugged and hauled at the bill over the course of its entire seven-year history.

Living-will legislation was not even introduced in Pennsylvania until 1985, eight years after the first wave of such legislation passed in the wake of the New Jersey Quinlan decision. By that time, bills had been introduced in nearly every other state, and by the end of that year, thirty-six states would have legislation on the books. So the story in Pennsylvania starts with restraint—a not very surprising beginning, really, given its large, ethnic-Catholic population.

State Representative Frank Pistella (D-Pittsburgh) first proposed the legislation in response to a right-to-die scenario he experienced some years prior to his election. During the Christmas season of 1973, Pistella's father suffered a period of memory loss: The elder Pistella could not even remember the Christmas festivities the entire family had enjoyed just a few days before. He had a relapse of memory loss in the fall of 1974, and soon afterward, he slipped into a coma and died.

This personal exposure to a right-to-die scenario ultimately served as a force of activism in the Pennsylvania legislature for upon entering the house of representatives after his father's death, the younger Pistella tried to legislate guidance for families placed in scenarios like the one he had found himself in with his father. Working with Professor Alan Meisel of the University of Pittsburgh School of Law and drawing from legislation already on the books in other states, Pistella devised and introduced a bill. He sent his handiwork to the House Public Health and Welfare Committee, where the forces of restraint were sufficient to guarantee that his bill would never see the light of legislative day.

The Pistella bill never got out of the house committee due to pressures exerted by two extremely influential groups: the Pennsylvania Catholic Conference and the Pro-Life Federation. Many areas of the state of Pennsylvania are religiously conservative, and the legislature counts among its ranks some staunchly conservative Catholics who gravitate to positions held by the Catholic Conference and other prolife groups.28 Passage of Pennsylvania's abortion-control law in 1990—one of the most conservative pieces of legislation of its kind in the country—is testament to that. Legislative staffers mince no words in explaining that it is nearly impossible to pass legislation if (as in the case of the Pistella bill) the Catholics and their sympathizers in the legislature are opposed to it.29

Pistella eventually gave less and less attention to the living-will matter because he eyed a leadership position in his party. The issues surrounding the legislation, especially the link with abortion (something the Catholic Conference continued to harp on), were enough to divide the ranks of his party, and Pistella avoided pressing an issue that could have knocked him out of the running for the Demo-
cratic house leadership (a kind of political concern that judges, as a rule, do not have to worry about).

Undaunted by these forces of restraint, State Senator John Stauffer picked up on Pistella’s idea in 1986 and went ahead with a bill of his own in the senate. The Stauffer bill, virtually identical to Pistella’s measure, was introduced after senior citizens in his district urged him to follow up on the groundwork already laid by Pistella (back to the forces activism, again). The Stauffer bill passed the senate by a 45 to 5 vote in 1987 but died in the same house committee in which the Pistella bill had been bottled up.

The next legislator to raise the issue was State Senator Roy Wilt, the newly appointed chair of the Senate Public Health and Welfare Committee. Wilt sponsored his own piece of legislation in 1989 and pushed it hard, at least in part, out of embarrassment. Wilt spoke to his colleagues of a “Good Morning America” program featuring Arthur Miller, a respected Boston attorney who criticized Pennsylvania for suppressing living-will legislation by weighing it down with extraneous issues (policy diffusion).

Ultimately, however, Wilt’s staunch advocacy was no match for the forces of restraint in the house. His bill easily passed the senate by a 46 to 1 vote but was quickly slowed down upon reaching the house floor, where interest ebbed with the coming of general elections in November 1990. The pregnancy issue in particular was seen as a political hot potato that most legislators preferred to steer clear of, and so they did. The Wilt bill was amended by conservative representatives three times on the floor of the house before being passed. But by then, it was late November 1990, too late for the measure to be fully reconsidered by the senate, which adjourned a few hours after receiving the amended bill. This ended the 1989–1990 legislative session and effectively killed Wilt’s bill in the process.

The new legislative session brought Senator John Peterson to the chairmanship of the Senate Public Health and Welfare Committee. Peterson, motivated by the U.S. Supreme Court’s 1990 *Cruzan* decision (back to the forces of policy activism), was determined to get something passed. He called together a coalition of the staffs from the Democrat and Republican caucuses of both the house and senate to establish some common ground and chart a legislative course for passage of a living-will bill. Next, he turned to the interest groups who were perceived to have a stake in this matter.

Peterson called on representatives of the health-care community, including individuals from the Pennsylvania Department of Health, the Pennsylvania Nurses Association, the Pennsylvania Medical Society, the Pennsylvania Association of Non-Profit Nursing Homes, and the Hospital Association of Pennsylvania. He also touched base with the legal community by inviting representatives from the Philadelphia and Pennsylvania bar associations to the table. Several religious denominations were also called in—representatives from Tressler Lutheran Services, the Pennsylvania Jewish Coalition, the Pennsylvania Council of Churches, and,
Policy Mediation and the State Legislatures

last but certainly not least, the Pennsylvania Catholic Conference. To round out the pluralist chorus, representatives from organizations representing the interests of the elderly—the American Association of Retired People, the Pennsylvania Department of Aging, the Pennsylvania Council on Aging, and the Coalition for the Rights of the Infirm Elderly—were invited to take part in the deliberations.

This unprecedented coalition met eighteen times over the course of a year and a half to hammer out the final language of the latest proposed legislation. On the activist side of the negotiations, legislators, advocates for the elderly, and medical interest groups pushed for the bill’s adoption. The primary force of restraint was, not surprisingly, the Pennsylvania Catholic Conference, which continued to lobby hard on issues of pregnancy (demanding an “incubator” amendment) and ANH (preferring that legislation prohibit its withdrawal). In the end, the Catholic Conference caved in to a degree by offering not to block the legislation with further restrictive amendments in exchange for a watered-down pregnancy exclusion and a conservative reading of the concept “terminal.” Senator Peterson and others on the coalition gave in to the Catholics’ demands, knowing their opposition was the only thing standing in the way of concluding the long battle.

With the concessions made, the bill passed without much more wrangling. When it did, Pennsylvania became the forty-sixth state in the union to imbue the right to die with the force of statutory law. It did so seven years after living-will legislation was first introduced, sixteen years after California set the pace by passing the first law, and twenty-three years after an otherwise anonymous Florida legislator, Dr. Walter Sackett, sponsored the first living-will bill ever introduced in the United States. To be sure, the forces of restraint proved to be formidable in Pennsylvania. Slowly but surely, however, they yielded to the forces of activism as Pennsylvania finally joined the ranks of the legislative policy mediators by passing a relatively liberal piece of legislation.

**California, Florida, and Massachusetts.** In *The Right to Die: Policy Innovation and Its Consequences*, Henry Glick (1992) conducted studies in three other states—California, Florida, and Massachusetts—and the similarities between the experiences of those states and the Pennsylvania case are striking. In all four cases, living-will legislation was spurred on by one or two advocates who had either personal or professional experience with lingering death. And in each of the four cases, the state’s respective Catholic Conference played a large role in policy restraint by stalling passage and extracting concessions from legislative entrepreneurs.

Barry Keene was a California lawyer who had helped a neighbor cope with withdrawing medical treatment from the neighbor’s wife, who was suffering with terminal cancer. He became involved with the issue again in 1972 when he found his mother-in-law in the same predicament. Consequently, when Keene was elected to the California State Senate in 1974, he took on living-will legislation as
something of a personal crusade. The California Medical Association (CMA) was opposed to the bill at first. But CMA resistance evaporated after its executive director was sensitized to the need for such a bill by having to personally intervene in his father’s medical treatment to prevent a protracted death (Glick, 1992, p. 97).

The California Catholic Conference was strong, however, and it was able to extract a number of important concessions before agreeing not to oppose the bill. These concessions included (1) backing away from the pregnancy issue, (2) limiting coverage to terminal illness, conservatively defined, (3) requiring a fourteen-day waiting period following a terminal diagnosis before a living will could be made, and (4) limiting validity of the document to five years from date of signature. The California law has stood unamended since being passed in 1976 as the most restrictive living-will law in the United States. The powerful influences of the Catholic Conference and other fundamentalist religious organizations, combined with the ideologically conservative predispositions of George Deukmejian (the Republican governor who, in 1988, vetoed a liberal rewrite of the 1976 law) have ensured that California’s restrictive code would stand the test of time.

In Florida, Representatives Walker Sackett and Richard Hodes—both medical doctors with close personal experiences with death—played crucial roles in putting and keeping living-will legislation on the legislative agenda during the 1970s. Neither was directly responsible for final passage, but both helped to raise the issue’s profile and soften up resistance, thereby setting the stage for passage. A living-will law finally passed in Florida in 1984, but only after the Florida Catholic Conference extracted three key concessions: (1) that ANH must always be provided, (2) that coverage be limited to terminal patients (with no coverage for PVS), and (3) that the living will be nullified in the case of pregnancy.

An early sponsor of legislation in Massachusetts also was moved to act by personal experience: his knowledge of a brain-dead teenager in his district, the victim of an automobile accident, who was being kept alive on life-support systems (Glick, 1992, p. 120). Later, another legislator, Richard Voke, became a key player largely because his mother was a registered nurse and very interested in the right to die due to her long hospital experience (Glick, 1992, p. 123). As in other states, however, the Catholic Conference has been a formidable opponent in Massachusetts. In fact, according to Glick (1992, p. 120), the right to die in Massachusetts is largely the story of the Catholic church and its key spokesman in the state’s upper chamber—Senate President William M. Bulger.

In Massachusetts, the Catholic hierarchy is much more conservative and the population is more religiously homogeneous than elsewhere. Catholics constitute over 50 percent of the population in the Bay State, ranking it second only to Rhode Island in that category. More importantly, Senator Bulger, a Catholic representing a working-class, socially conservative district in south Boston, flatly opposes living-will legislation. A powerful legislator and adept tactician, Bulger has almost single-handedly prevented living-will legislation from proceeding. As one
staffer close to the Senator put it in 1991, there simply will be no living-will law in Massachusetts as long as Bulger is senate president (personal communication). Since then, however, some observers suggest that Bulger has become more receptive to legislation after a personal experience of his own—the death of his mother (Glick, 1992, p. 126).

Cases in Perspective
The review of case materials from Pennsylvania, California, Florida, and Massachusetts helps to bring into sharper focus an explanation for the legislative behavior regarding right-to-die legislation. In the end, one can see all three policy dynamics—policy diffusion, religious restraint, and liberal trends—at work.

As stated, Pennsylvania used the laws of other states as a starting point in building its own legislation. Pressures brought to bear by (1) activism in other state legislatures, as broadcast on a morning news program (horizontal diffusion within the same branch of government), and (2) activism at the Supreme Court level, as rendered in the *Cruzan* decision (vertical policy diffusion across branches of government), were also evident in the Pennsylvania case. In addition, as already noted, a particular kind of activism was at work in each state studied: In all four cases, it was the impetus provided by firsthand experience that motivated legislators to act (activism akin to that discussed in Chapters 5 and 6). As Quill (1993, p. 22) notes, it is just this kind of “firsthand experience with such tragedy [that] makes one more fearful of a difficult death, and also wary of a profession that does not openly acknowledge or respond to its possibility.”

At the same time, there was plenty of religiously motivated restraint to go around, causing divergence between what the legislatures were able to muster and what the courts were willing to grant in the way of rights protections. The influence wielded by the Catholic lobby was sufficient in each case reviewed to either slow passage of a law (Florida and Pennsylvania), prevent passage of a law (Massachusetts), or prevent an amended law from passing (California). In each of the three cases where a living will did pass, the Catholic Conference helped to shape a more conservative bill than would have emerged otherwise. Ultimately, even though Catholic elites seemed to acquiesce in “allowing” passage of living-will laws during the 1980s (usually by agreeing not to oppose legislation), they were careful to do so only after extracting key concessions—concessions that, in some cases, eviscerated the substance of what was being passed, state-court decisions to the contrary notwithstanding.

Religion is still important as a force of restraint, but the influence of the Catholic lobby and other religious organizations is on the wane now as the forces of policy activism lead the legislatures in a more liberal direction. Florida dropped its conservative, religiously inspired ANH restriction after the courts found the ANH rule unconstitutional (in *Corbett v. D'Alessandro* and, later, in *Satz v.*
Perlmutter). And Pennsylvania, a state where the Catholic lobby was strong enough to stall legislation for years, recently passed a relatively liberal law that allows withdrawal of ANH, covers PVS, and even makes concessions toward women on the pregnancy issue. The Catholic lobby never would have had to stand for that five years ago. But today, the forces of activism are painting an entirely different picture and opening up a set of entirely new possibilities on the living-will front.

Summary: Policy Forces and Policy Mediation

If anything is clear from this review of right-to-die case law and statutory provisions, it is this: The right to die is an area that does not lend itself to straightforward resolutions. Cultural taboos, religious rites, legal liabilities, and society's deference (albeit waning) to physician autonomy combine to make end-of-life decisions an extraordinarily complicated policy area to negotiate. Increasingly sophisticated medical technologies will not deliver Americans from right-to-die dilemmas, either. Indeed, the advances in medical management of seriously ill patients is a primary cause of the current situation. Consequently, we should not expect that future advances in medical technology will do anything but add to the complexities of the conundrums the state legislatures now face.

Something else is clear as well: Political consensus among and within state legislatures has been difficult to muster. The forty-seven living-will laws that have passed are generally rife with contradiction, especially with regard to qualifying conditions. On many of the most controversial issues (e.g., pregnancy and ANH), more than a few states have chosen simply to remain silent. In the end and aside from the basics, muddle and confusion—with just a hint of emerging trends—seem to be the only patterns of behavior that spring from this hodgepodge of legislative activity and languor across the fifty states.

The courts have labored as well. But they have been more successful in forging an enduring interstate consensus for they are more insulated from the religious and political interest-group pressures that have slowed progress in the legislative arena. In fact, when the state legislatures have acted, they have taken their lead from the courts. One should expect this modus operandi to continue.

In the end, state-court judges can continue to exhort their policy mediation counterparts in the legislatures to take the initiative, but one might wonder why they would bother. The courts have, in effect, established a fait accompli with their right-to-die pronouncements, then sat back to see if the legislatures would act on them. When the legislatures fail to act or act outside the boundaries set by the courts (that is, when the legislators do anything but ratify prevailing court decisions), justices have tended, in a fashion that has become typical for them in re-
cent decades, to trump the statutory law, replacing legislative provisions with their own reading of rights and liberties.

In a way, the state courts are in a "buck-stops-here" situation: They cannot go out of their way to make policy, but when something like the right to die falls in their lap, they are obliged to deal with it. The legislatures have a good deal more latitude in this regard. Of course, they can and often do take the lead in making policy when problems emerge, when policy alternatives surface, and when political conditions are amenable to action all at the same time. But legislatures also enjoy the luxury of benign neglect when these conditions fail to emerge coincidentally. That is, when clear policy solutions to problems do not present themselves together with political impetus for policymaking, then the legislatures can defer to the courts. In terms of right-to-die policy, most legislatures have often done just that.

But by failing to act or acting in ways inimicable to constitutional and common-law prescriptions, the state lawmakers have, in effect, ceded their role as primary legislators to the judiciary. Referring in particular to the controversy over withdrawing artificial food and nutrition, the Florida court stated that such issues are "more suitably addressed in the legislative forum. ... Nevertheless, preferences for legislative treatment cannot shackle the courts when legally protected interests are at stake. ... Legislative action cannot serve to close the doors of the courtrooms ... to ... citizens who assert cognizable Constitutional rights" (cited in Glick, 1992, p. 110).

Indeed, of the 100-plus court decisions rendered in right-to-die cases, only two—one in Missouri (Cruzan) and one in Ohio (Couture v. Couture)—have taken their lead from the legislatures. The rest have followed each other, often in direct contradiction to their respective state legislatures. This state of affairs is not without its costs or risks, however, as Justice Felix Frankfurter so aptly pointed out in 1951 when he stated: "History teaches that the independence of the judiciary is jeopardized when the courts become embroiled in the passions of the day and assume primary responsibility in choosing between competing political, economic, and social pressures" (cited in Krantz, 1977, p. 28).

At the same time, even though the legislatures, generally speaking, have been slow to respond and incremental in their responses, progress is being made. A significant convergence with the courts on some of the central right-to-die issues—the right to designate proxies for end-of-life decisionmaking, the right to withdraw food and fluids, the right to die for patients in a persistent vegetative state, and, down the road, maybe even the right to an assisted suicide—seems to be evolving. All this may be fine for those who will not have to face the right-to-die scenario until progressive trends prevail in their state or for those who, in the meantime, have the resources and predisposition to take their right-to-die cases to the courts. But for everyone else, legislative lassitude leaves the right to die in limbo,
exactly where those who are in a position to make end-of-life decisions would rather not be. So it is, and so it will continue to be, it seems, until the legislatures take the initiative back from the courts in setting a legally and constitutionally sound course in what is, at least chronologically, the ultimate arena of civil rights: the right to die.