

Making Right-to-Die Policy:  
A Special Case of Judicial Activism

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Biography

Prof. Hoefler's research is in the areas of biomedical ethics and public policy. His work focuses on end-of-life decision making with special emphasis on decisions regarding the role of artificial nutrition and hydration (ANH) in end-of-life care. Prof. Hoefler has published two books on the subject: *DeathRight: Culture, Medicine, Politics, and the Right to Die*, Westview Press (1994) and *Managing Death*, Westview Press (1999). He earned his Ph.D. at the University of Buffalo and has served as professor of political science at Dickinson College since 1989.

## Abstract

Elected officials in the legislative and executive branches of government tend to dominate the policy making process in the U.S. while state and federal courts tend to play a more reactive role. The courts regularly rule on the constitutionality of state and federal laws, but with some notable exceptions, they do not usually make law in the first instance. The area of health policy related to medical decision making at the end of life is an exception to this rule. Here, activist state and federal judges have forged ahead as the original authors of right to die policies. This chapter takes a close look at *why* this is the case, and *what* the courts have wrought as a result.

Key words: right to die, policy making, judicial activism, United States

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Elected officials in the legislative and executive branches of government tend to dominate the policy making process in the United States, just as they do in most western-style democracies. Sometimes the legislature takes the initiative, then forwards its ideas on the governor for final disposition. Likewise, sometimes the members of Congress set the agenda, then pass the buck to the president. Just as often, governors and the president serve as agenda setters in the first instance, while legislatures work at the margins to fashion acceptable public policies.

Meanwhile, state and federal courts in the U.S. tend to play a reactive role. The courts regularly rule on the constitutionality of state and federal laws that have been passed by legislatures and signed into law by chief executives, for example. Courts also settle disputes between the branches of government, between states, and between the state and national government. But with some notable exceptions, state and federal judges play the role of referee; rarely do they ever call the play or carry the ball.

The area of health policy related to medical decision making at the end of life, sometimes referred to as the *right to die*, is one such exception (glossary terms will appear in *italics* at first usage). Here, activist state and federal judges have forged ahead -- assisted by medical, legal, and professional ethics associations -- to serve as the original authors of right-to-die policies in the absence of policy activism elsewhere. In most cases, judges have done so reluctantly, begging in their written opinions for legislators to take a stand. Just as often, though, judges have corrected legislators who, in responding to this invitation, have attempted to reverse judicial policy making trends.

This chapter takes a close look at why judges have come to play such a significant role in this area of health policy. Section one reviews the traditional process for making law in the United States. The second section of the chapter describes the kinds of legal and ethical questions that are raised by end-of-life decision making. Section three describes the cultural forces of *denial* that make it difficult for legislators to be responsive when right-to-die policy dilemmas arise. Key principles that courts have

converged on in their right-to-die jurisprudence are covered in some detail in the fourth section, while summary remarks regarding court-centered policy making are covered in section five.

### ***I. Traditional Law Making***

Who makes the laws in America? In western-style democracies, legislatures made up of popularly elected representatives make the laws of the land, at least in theory. It is not quite as simple as that, of course, for in systems of government with separated powers such as we have in the United States, legislatures share lawmaking powers with the executive branch at both the federal and state levels.

While much law making in the U.S. does take place in the federal and state legislatures, in cooperation with the executive branches of government, this is not the only place law can get made. The *right-to-die* is an area of health-related public policy where most law making has taken place well apart from the traditional give-and-take that goes on between the president and the Congress, and between governors and their state legislatures. A close look here reveals a whole different set of law making actors, pressures, and processes. Those hoping to understand law making in this important area of health policy need to look well beyond the traditional understanding of how laws are made and changed in the U.S. in order to understand *what* has happened and *why*.

### ***II. The Right-to-die Rises as a Policy Issue***

For purposes of this chapter, the term *right-to-die* refers to the degree of latitude individuals and their surrogates are guaranteed regarding decisions to withhold or withdraw medical treatment at the end of life. While assisted suicide and euthanasia are typically considered to be part of the right-to-die policy milieu, we will limit discussion in this article to policies that cover the decision to forego life-sustaining medical treatment.

One hundred years ago, there were no pressures to make law in this area because there was very little one could do about death besides accept it when it came knocking at the door. In short, there was simply nothing to forego, and as a result, nothing to decide. The *death trajectory* was as steep as it was immutable in those days. Most people died at home one hundred years ago, and most did so within a few days of either suffering a mortal injury or contracting a fatal illness. There was very little that medical practitioners could do to stave off death prior to the early twentieth century, and in fact, much of

what passed as legitimate medical practice at that time (e.g., blood letting, and applying chemically burning poultices to the patient's skin) either did no good at all, or only hastened the dying process (Hoefler, 1994, pp. 42-48).

Today, thanks at least in part to phenomenal advances in modern medical technology, Americans live more than twice as long as they did at the turn of the 20th century, and their death trajectories have flattened out to the point where average Americans live for several years (rather than a few days or weeks) after being diagnosed with the illness that ultimately proves terminal for them (Sachs, Shega, and Cox-Hayley, 2004). During these extra years of life, and extra years of dying, there are many things that medical practitioners can do to delay one's death (or not do, thereby allowing death to take place). Management of the dying process has become so widespread that the American Hospital Association estimates that two out of three Americans die only after a decision is made to withhold or withdraw a life-sustaining treatment. In addition, many patients become incompetent to make decisions for themselves at the end of life. Consequently, approximately half of *managed death* decisions made in America today are made not by the dying patients themselves, but by family members, medical professionals, and court appointed guardians who act on behalf of those incompetent patients (Hoefler, 1997, p. 2).

The management of death so common in American society today raises a number of important policy questions. The most important of these are:

- When can individuals make end-of-life decisions?
- What kinds of medical treatments are patients allowed to forego if they choose?
- Who can serve as surrogates for dying patients who are incompetent to make end-of-life decisions for themselves?
- What kinds of medical treatments are surrogates allowed to decide to forego?
- What criteria should the surrogate decision maker(s) use when deciding whether the patient should receive life-sustaining treatment or not?

Before the late 1970s, doctors tended to decide these questions for competent and incompetent patients alike. Sometimes they consulted with their patients and members of their families, but oftentimes they acted on their own best judgment. "Doctor knows best" was the cultural norm of that day; patients believed it (or at least they accepted it) and doctors acted accordingly.

Beginning in the late 1970s, however, state legislatures all across the country began passing *advance directive* laws that guaranteed patients the right to make medical treatment decisions prior to becoming terminally ill and unable to make decisions for themselves. (See **Sidebar: Advance Directives**.)

**Sidebar: Advance Directives**

*Advance directives* are legal documents used by patients to indicate in advance, how they would like medical decisions to be made should they become mortally ill and unable to make these decisions for themselves. There are three common types of advance directives: *Living wills*, *Durable Powers of Attorney for Health Care*, and *Do Not Resuscitate (DNR) Orders*. *Living wills* allow patients to indicate what medical procedures they would want or not want at the end of life. *Durable Powers of Attorney for Health Care* allow patients to designate a surrogate decision maker who is empowered to make end of life decisions on behalf of the patient. *Do Not Resuscitate (DNR) orders* are specific orders entered on a patient's medical chart that indicate a patient's wish not to be resuscitated should he or she suffer a cardiac arrest. Rules governing the execution of advance directives are set at the state level, and while the states have found a good deal of common ground in this area of policy making, no two states have exactly the same provisions with regard to advance directives. At the federal level, the only relevant statute is the Patient Self-Determination Act (PSDA, 1990). The PSDA requires that all health care institutions receiving federal funding through Medicare or Medicaid inform patients as part of the admissions process of their rights under state law to make advance directives for themselves.

But for all their good intentions, legislative activity has had very little impact on decision making at the bedside. For one thing, fewer than one in three patients have taken the time to execute an advance directive. Second, living wills and durable powers of attorney do not go into force until a doctor declares that the patient is terminally ill or in a persistent vegetative state (PVS). Declaring a patient to be terminally ill, typically defined as being within six months of death, is a difficult call for doctors to make for several reasons. Perhaps most importantly, it is very difficult to determine when someone has less than six months to live. Cancer has the most predictable death trajectory, but even here, it is challenging to make the terminal determination with any certainty. Moreover, there is concern on the part of doctors that

declaring patients to be terminal will rob them and their loved ones of hope. Delivering a terminal prognosis is also an emotionally difficult thing to do. For all these reasons, most patients die without ever having been declared terminally ill, so even those with advance directives in place typically do not benefit from them. It is also true that in cases where a living will is put into force that any dissent within the family regarding the withdrawal of treatment will cause doctors to continue that treatment until the dissent is resolved, or until the patient dies. In the end, advance directive statutes are simply too convoluted in their construction, too limited in their application, and too unenforceable in practice to have much impact.

This is not to say no public policies with traction were created in this time period, however. This is the case because at about the same time as the states began passing their (largely ineffective) statutes, activist state and federal courts began charting a public policy course that would go a long way toward resolving the most pressing right-to-die policy questions of the day. The courts did this in response to the cases brought by the family members seeking the right to forego medical treatment of their loved ones in the face of mortal illness. Beginning in 1976, with the case of Karen Ann Quinlan in New Jersey, and continuing even today, it is the state and federal courts who have been out in front of state and federal legislators, showing them the way forward, and correcting them when they attempt to veer too far from the judicially charted path.

One cannot help but wonder what happened to the traditional model of policy making here. Why have legislators and chief executives at the state and federal level been so slow to act, and why, when they have acted, have their efforts been so marginal and ineffective? It is to these questions that we now turn.

### ***III. Policy Restraint and the Denial of Death***

Traditional legislative policy making mechanisms have proven to be inadequate to the task of making law in the right-to-die area for several reasons. The single most important impediment has been the denial of death that is so pervasive in American culture. It is hard to focus on things we deny, and there is little political reward for broaching subjects that are considered as taboo as death is in the contemporary American mindset. As a result, our culturally ingrained denial of death is the largest force of policy restraint at work on the traditional policy making process when it comes to the right to die.

The psychological and sociological literature is replete with descriptions of how humans, in general -- and Americans, in particular -- try to cope with the idea of death by denying its reality (Feifel, 1959; Gorer, 1965; Kübler-Ross, 1969; Becker, 1973; Charmaz, 1980; Kastenbaum and Kastenbaum, 1989). Although death is an inevitable and regular event in everyone's life, the subject is so distasteful that it is rarely discussed in polite company. The taboo status of death stems both from the general offensiveness of the subject, especially in youth-centric America, which puts so much emphasis on individual autonomy and youthful exuberance, both of which tend to atrophy as one is pulled along ineluctably on the march toward death. Denial also results from superstitious thinking about death; many believe, privately and maybe even subconsciously, that any talk of death will invite it to pay a visit. As a result of its taboo-status, Americans prefer to sanitize death when it is confronted at all; we package it, we objectify it, we dress it up, we talk around it when we must, and avoid it all together if we can. (See **Sidebar: *Sanitizing Death***.)

**Sidebar: *Sanitizing Death***

We need look no further for evidence of our general denial than the language we use to dance around it when the subject must be broached. Americans almost always use euphemisms to refer to the act of having died (e.g., *passed away*, *passed on*, *passed over*, and *succumbed*) and to the subjects who have suffered a *terminal fate* (e.g., *the dearly departed*, *the deceased*, and *those no longer with us*). We do not even use the word "death" to describe the greeting cards we send on the occasion of one's *passing*. Unlike the *birthday* cards we give each other on birthdays and *graduation* cards we give for graduations, folded pieces of paper sent in the event of a death are referred to more antiseptically as *sympathy* cards. The *d-word* never makes an appearance on the cover of these cards, nor is it used in the verses printed therein. Again, the cultural norm is that we dare not think of, speak of, or write about such things in public settings or private communications. Doing so would be thought of as crude and insensitive.

When *one's time* finally does come, families arrange for *calling hours* at a *funeral parlor*. This is where the *deceased* are laid in a caskets with a pillows under their heads, with makeup on and positioned in such a way as to give the impression that *those no longer with us* are engaged in restful sleep. After the viewing, *the deceased* (or perhaps only the deceased's cremated ashes) are transported to the

cemetery -- that *final resting place* – where those in attendance will stand next to a mound of dirt (covered with a scrap of green carpet, lest we focus too much on that bit of earth that will ultimately fill the grave) to pay their last respects and pray that the *dearly departed* will *rest in peace*. Clearly the image being portrayed with all this language, staging, and paraphernalia is that death is really just a long nap rather than the complete and utter end to biological life. (The same rhetorical analogy is used with pets: we don't *kill them* or *cause their death* when they get ill and old; rather, we say we *put them to sleep*.)

It is true that death is a frequent subject of television and movies, but more often than not, death happens to the “bad guys,” not the characters we identify with. Indeed, European movies which tend to be more realistic about death, often have their conclusions rescripted to provide the kinds of happy endings that are more amenable to the American pallet. And while it is true that death is common in video games and on television, even here, death and dying are sanitized; no death is treated with realism, no death has consequences, all video game deaths can be *reset* with the start of a new game, and the Kenny character from the long-running animated television show South Park always manages to recover from his episodic demises (<http://www.youtube.com/watch?v=iufCIFQPd-Q>).

One measure of our denial is the disjunction between those who support the right-to-die laws that allow individuals to make decisions for themselves (84%) and who actually take advantage of those laws by executing an advance directive. Even though there are few barriers to the execution of advance directives (forms and advice are available in any hospital or nursing home, and on line, all for free; no attorney is required), only about 29% of adults have bothered to take this step (Pew Research Center, 2006). In the end, it is only natural that politicians would shy away from tacking the right-to-die in the public arena when most Americans are uneasy considering the subject even in the privacy of their own homes. Indeed, even if there were pressures to champion the right to die from certain quarters, denial, superstition, and general societal norms provide strong inhibitions to legislative activism.

Meanwhile, even though public opinion polls suggest that there are clear and enduring majorities of citizens who favor liberalizing right-to-die policies in the U.S. (Hoefler, 1997, pp. 70-75; Pew, 2006), only a few ever speak out about the right to die in public, and fewer still ever attempt to mobilize others regarding this issue. As a result, advance directive statutes are not very helpful in providing meaningful

end-of-life choices to patients or their designated surrogates at the end of life in any of the fifty states. Meanwhile, the only right-to-die statute on the books at the federal level -- the Patient Self-Determination Act (PSDA) -- requires nothing in particular of the states. Rather, the PSDA requires only that patients be informed of their advance directive options under state law. If states do not have any provisions for making living wills, for example (e.g., like Massachusetts and New York), then that is all that has to be communicated. Policy activism is hard to detect while policy restraint is the rule of the day.

#### ***IV. The Courts Step in Where Legislators and Chief Executives Fear to Tread***

Beginning in the late 1970s, and absent any meaningful policy activism on the part of state legislatures and governors, state courts began drawing on *common law*, *constitutional law*, and professional medical and ethical *consensus group* positions to formulate public policies that have had a significant effect on end-of-life decision making. Two older cases -- Union Pacific Railway Company v. Botsford (1891) and Schloendorff v. Society of New York Hospital (1914) set the common law ground for individual autonomy in medical decision making used by state courts in this period. New Jersey's Quinlan decision added the constitutional rationale to common law reasoning in 1976, something states have cited on a regular basis ever since. Together, these three cases provided a firm base upon which state courts built a legal framework for right-to-die policy making while the states legislators limited their scope to the largely ineffective advance directive laws described above. By the time the Cruzan case reached the U.S. Supreme Court in 1990, there was a firm legal foundation for court-centered right-to-die policy making. And by the time the Schiavo case made it to the Supreme Court in 2005, the courts had consolidated their hold on right-to-die policy making to the point where the legislative and executive branches of government at both the state and federal levels were completely shut out of the process.

#### ***Common Law***

The first foundation of judicial policy making is common law. (See **Sidebar: Common Law.**) The states (and by extension, the federal government) have long-standing, common law interests that nearly every court cites in its right-to-die opinions. The most important of these interests boil down to the following three:

- (1) Preserving life;
- (2) Preventing suicide;

(3) Maintaining the credibility of the medical profession.<sup>1</sup>

**Side bar: *Common law***

*Common law* is law based on cultural norms rather than on codified (statutory) written law. The details of common law typically are rooted in some combination of tradition, custom, shared values, and a “common sense” understanding of what the law ought to be. Decisions with this kind of foundation gain momentum, like a boulder rolling downhill, as other courts cite the original case – and subsequent cases which draw on the original case -- as precedents. Assaying the substance of common law can be an ephemeral and wide ranging exercise and is sometimes contrasted with the more narrow role courts play when they are involved in strict interpretation of federal or state constitutions, or existing federal or state statutory law.

There is a long-standing common law tradition in American jurisprudence that recognizes and protects human autonomy and self-determination. The common law roots of these principles in the United States can be traced back to the seminal 1891 ruling of the Supreme Court in the case of Union Pacific Railway Company v. Botsford. This case arose after Ms. Clara L. Botsford sued the Union Pacific Railway Company for negligence after the upper berth of a sleeping car in which she was a passenger came loose and fell on her head. Botsford claimed to have suffered a concussion and other related injuries. Three days before the trial, the railroad company asked the court to compel Botsford to undergo a physical examination, to establish the true extent of her injuries. The court declined the petitioner’s request, referring to *common law* as the basis for its decision:

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<sup>1</sup> Courts regularly cite a fourth interest: Protecting innocent third parties from the negative consequences of another’s actions. While important in general, this particular interest has proven less probative in court opinions related to the right to die and will be set aside for purposes of the ensuing analysis.

No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law (Botsford).

Though this decision has little to do with the right to die as we conceive of the issue today, it is perhaps the decision that state and federal judges cite most in their contemporary opinions on this subject.

If Botsford is the most cited bit of *case law* (see **Sidebar: Case Law**), its state court descendant, Schloendorff v. Society of New York Hospital (1914) comes in as a close second. In this case, the plaintiff, Mary Schloendorff, was admitted to New York Hospital suffering from a stomach disorder of unknown origin. After several weeks of observation and unsuccessful treatment, Schloendorff consented to undergo a surgical examination, under anesthesia, to determine the true nature of her ailments. Schloendorff claimed that although she consented to the exploratory procedure, she expressly forbid her physician from acting on anything he found without further consent from her (which, of course, could not be obtained until Schloendorff recovered from anesthesia). During the surgical examination Schloendorff had agreed to, Schloendorff's doctor found a tumor and decided to go ahead and remove it, despite Schloendorff's instructions to the contrary. Schloendorff and her witnesses alleged that she subsequently suffered severe pain and discomfort as a result of the operation for which she had expressly withheld consent. She also developed gangrene in her left arm pursuant to (and according to Schloendorff, as a direct result of) the unwanted surgery, and some of her fingers had to be amputated.

**Sidebar: Case law**

*Case law* refers to precedents set by appellate-level courts in specific cases. At the federal level, the country is divided up into eleven judicial circuits. Decisions rendered by a circuit court apply only within the geographic boundaries of that circuit. (For example, Pennsylvania, New Jersey, and Delaware make up the 3rd Circuit, so opinions issued by federal judges operating in the 3rd Circuit apply only to those states.) On the other hand, decisions made by the U.S. Supreme Court (e.g., Botsford) apply nationwide. At the state level, lower level trial courts cannot make case law because their decisions apply only to the parties involved in the particular case at hand. Meanwhile, decisions made by state appellate courts (typically called *superior* and *supreme* courts) apply statewide. Technically speaking, these

opinions apply only within that state. But sometimes, appellate judges in one state will cite court decisions from another state as “instructive” even though they are not binding. Schloendorff is just such a case; Unlike the Supreme Court’s Botsford decision, which was binding nationwide, the case law precedent from Schloendorff is binding only in New York, but it has been widely and regularly cited as instructive in other states, and even in the federal courts, as a foundation for judicial decision making in those other jurisdictions.

In resolving this dispute between Schloendorff and her doctor, Justice Benjamin Cardozo<sup>2</sup> wrote: In the case at hand, the wrong complained of is not merely negligence. It is trespass. Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent, commits an assault, for which he is liable in damages. (Schloendorff).

Schloendorff is important in right-to-die jurisprudence because it moves beyond the passive right of someone to be left alone (established in Botsford) to establish a positive obligation on the part of care givers to obtain *informed consent* from the patient before they are allowed to proceed with medical treatment (assuming there is time to do so in a non-emergency situation).

As a result of Botsford and Schloendorff -- both decisions based on common law, neither of which needed any statutory underpinnings – the following health care policy became the law of the land: when it comes to medical care, no one can be treated, or even touched, without informed consent. But how far does this right to be left alone go when the state also has common law interest in preserving life, preventing suicide, and maintaining the ethical integrity of the medical profession? And what if the patient is too sick to give (or withhold) consent for medical treatments? Who decides then? To answer these questions, judges found it necessary to combine the common law of the land with provisions of the U.S. Constitution.

### **Quinlan and Constitutional Law**

Karen Ann Quinlan was twenty-one-years-old in 1975 when she became faint at a party after consuming an undetermined amount of alcohol and a dose of prescription tranquilizers on an empty

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<sup>2</sup> Cardozo was a judge on the New York State Court of Appeals (the state’s supreme court) at the time. Cardozo would later go on to serve as a justice on the U.S. Supreme Court later in his career.

stomach. Friends laid her in a bed to rest, but came back 15 to 20 minutes later to find that she had stopped breathing. She received emergency resuscitation, then was taken by ambulance to St. Clair's Hospital in Denville, NJ, where tube feeding and respirator support were initiated to sustain her life. Shortly thereafter it was determined that Quinlan had suffered severe and irreversible brain damage as a result of her respiratory arrest which had starved her brain of oxygen for an undetermined period of time. When the hopeless nature of Quinlan's prognosis became clear, her parents, Julia and Joe, requested that their daughter be taken off her respirator so that she could be allowed to die. The Quinlans were opposed in court by St. Clair's Hospital and the Attorney General of New Jersey.

The Botsford and Schloendorff decisions made it pretty clear that competent individuals have the right to control what happens with their own bodies, even when a doctor thinks a patient's health (and maybe life) hang in the balance. But given that Karen Quinlan was unable to decide what she would want for herself, the New Jersey Supreme Court needed something more than common law to decide this case. The court found that something else in the U.S. Constitution.

To bolster the right of patients to make end-of-life decisions for themselves, the court leaned on U.S. Supreme Court cases that established privacy as a constitutionally protected right such as Griswold v. Connecticut (which in 1965 found that individuals had the right to use contraceptives) and Roe v. Wade (which established the right of a woman to have an abortion in 1973). Justices in the Quinlan majority noted that that even though the U.S. Constitution does not explicitly mention a right of privacy,

Supreme Court decisions have recognized that a right of personal privacy exists and that certain areas of privacy are guaranteed under the Constitution. . . . Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions (In re Karen Quinlan, 1976).

But what about patients who are unable to make these medical decisions for themselves? Here the New Jersey court opined that a right this important, and this well substantiated in recent constitutional jurisprudence, should survive a patient's incompetence. To this point they wrote:

If a putative decision by Karen . . . [to forego further treatment] is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis

that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances (Quinlan).

Finally, there is the question of state's interests. Even if all the argumentation regarding personal autonomy grounded in common law and privacy rights grounded in the U.S. Constitution holds, what about the state's interests in preserving life, preventing suicide, and maintaining the credibility of the medical profession?

The court did not lightly dismiss the state's responsibilities in this regard. In fact, it based the state's traditional role as a protector of life on the U.S. Declaration of Independence, for example:

We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life (Quinlan). . . .

The court also argued that the same ideal was inherent in both the Constitution of the United States as well as in its own state constitution, which provided for "certain natural and unalienable rights, among which are those of enjoying and defending life (Quinlan). . . ."

To decide between common law and constitutionally grounded interests of the individual versus the common law and constitutionally grounded interests of the state, the New Jersey Supreme Court formulated a balancing test that state and federal courts have used in similar situations ever since. To this end, the Quinlan court wrote that:

We think that the State's interest contra weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest (Quinlan).

Finally, using a bit of common law argumentation to round out their reasoning, the court suggested that its decision had legitimacy in part, because it supported a choice (Joe and Julia's decision to withhold life sustaining treatment from their hopelessly ill daughter) that most Americans would make if similarly situated:

. . . this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves

or for those closest to them. It is for this reason that we determine that Karen's right of privacy may be asserted in her behalf, in this respect, by her guardian and family under the particular circumstances presented by this record (Quinlan).

There have been approximately 150 appellate-level court decisions in right-to-die cases across the country since Quinlan, and nearly all have used some combination of the legal reasoning established by the Botsford, Schloendorff, and Quinlan courts even though the U.S. Supreme Court's Botsford decision is the only one of the three that is applicable in all fifty states. (See **Sidebar: *Beacons of Jurisprudence***.)

**Sidebar: *Beacons of Jurisprudence***

Technically speaking, decisions of an appellate court in one state do not obligate other states to follow suit. That is, the state court's decision in Schloendorff applies only in New York and the state court's decision in Quinlan is probative only in New Jersey. With the right to die, however, where there is so little existing statutory or case law to go on, it is very common for states to cite each other's case law decisions. It is particularly common for certain, particularly activist and progressive state courts -- such as those in New Jersey and New York -- to be cited by other courts in other states. These often cited courts are sometimes referred to as "beacons of jurisprudence" (Hoefler, 1994, p. 184).

It should also be noted that this process of proliferating opinions and reasoning from one state court to another is facilitated by the National Center for State Courts (NCSC), a nonprofit organization founded in 1971 to serve as clearing house for ideas, trends, and substantive decision making principles. Even when state court judges do not cite another state's decides explicitly, they may refer to an NCSC document that outlines mainstream thinking on the subject when writing their own opinions. The NCSC published a document in 1992 that served this very purpose titled Guidelines for State Court Decision Making in Life-Sustaining Medical Treatment Cases.

The U.S. Supreme Court's decision in the 1990 case of Nancy Cruzan -- the only substantive Supreme Court decision related to foregoing life-sustaining treatment issued to date -- is illustrative of the tendency of even federal courts to base their reasoning on legal precepts charted by state courts. In

addition, of course, the Cruzan decision established a substantive case law baseline for public policy that would (like Botsford) be binding in all fifty states.

**Cruzan: National Policy Making Via the Supreme Court**

Nancy Cruzan was 25 years old when her car skidded off an icy road early one January morning in 1983. She lay unconscious and unbreathing for approximately fifteen minutes before paramedics arrived on the scene to resuscitate her. Although emergency medical personnel were able to restart her heart and get her breathing on her own, again, Ms. Cruzan had suffered the same fate as Ms. Quinlan: severe and irreversible brain damage. After five years of existence in a persistent vegetative state (see **Sidebar: Persistent Vegetative State**), Cruzan's parents – Joe and Nancy – decided that their daughter would not want to continue living in such a degraded state of existence and asked that feeding by the tube surgically inserted in her stomach (the only thing keeping her alive at that point) be terminated so that she could be allowed to die. Cruzan's parents (like Quinlan's parents) were opposed in court by the medical center where she was being cared for, as well as by the state's attorney general.

**Sidebar: Persistent Vegetative State (PVS)**

*Persistent Vegetative State (PVS)* refers to a clinical condition marked by complete unawareness. Even though PVS patients exhibit sleep-wake cycles, blink their eyes while awake, move their extremities, and utter guttural sounds from time to time, medical professionals who specialize in this area do not believe PVS patients have any awareness or understanding of their situation or environment, nor is there any chance (to a reasonable degree of medical certainty) they will ever recover (Perry, Churchill, and Kirshner, 2005, pp. 744-745).

Like most appellate courts with life-sustaining treatment cases to adjudicate, the U.S. Supreme Court began with reference to common law, citing both the seminal Botsford and Schloendorff cases discussed above. Chief Justice William Rehnquist, writing for the majority, also cited the Quinlan court's balancing test analysis as instructive (citing Quinlan explicitly regarding how the state's interest "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims"). Rehnquist went even further in supporting the right of an incompetent patient to have decisions made on his or her behalf, writing that due to her incompetence the "only practical way" to prevent the

loss of Karen's rights to decide her own fate was to allow her guardian and family to decide "whether she would exercise it in these circumstances."

Prior to Cruzan, many state court judges had suggested that the right to die was protected by the U.S. Constitution,<sup>3</sup> but Rehnquist's opinion – that a right to be left alone was protected by the 14th Amendment – settled the matter for good. In Rehnquist's words:

A competent person has a *liberty interest* under the Due Process Clause [of the 14th Amendment] in refusing unwanted medical treatment (Cruzan).

This constitutional right should not be interpreted to be absolute, however, for Rehnquist qualified this ruling by returning to the balancing test found in Quinlan, with the state's traditional common law interests on one side of the scale, and the patient's constitutional *liberty interest* on the other side:

. . . the question whether that constitutional right has been violated must be determined by balancing the *liberty interest* against relevant *state interests* (Cruzan, italics added).

In short, the Supreme Court in Cruzan left it up to the states to decide what level of evidence a surrogate decision maker would need to provide to effect a decision to forego treatment, and some states have taken advantage of that latitude to require surrogates to produce *clear and convincing evidence* (rather than a simple *preponderance of evidence*) before a decision to forego treatment is honored. But the constitutionally grounded right patients and their family members have to make these decisions in the first instance is now well established, and as we will see in the case of Terri Schiavo, not even the U.S. Congress (with support of the President of the United States) has the power to undo the law of the land as fashioned by the courts.

### **Schiavo: The Courts Prevail**

Terri Schiavo was 26 years old when she collapsed at her home in 1990 from what doctors explained as a "metabolic imbalance of unknown origin." While the exact cause of Schiavo's collapse has never been determined, one thing is known for certain: the flow of oxygen to Schiavo's brain was interrupted for at least five minutes, resulting in severe and irreversible brain damage. In 1998, after eight years of unsuccessful treatments and maintenance care, Schiavo's husband, Michael, petitioned the

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<sup>3</sup> Some state courts, like the Quinlan court, made the case for a constitutionally grounded right to privacy, while other courts looked to the 14th Amendment's liberty provisions.

Florida courts for permission to withdraw the tube feeding from his wife. He was opposed in court by Terri Schiavo's parents.

Appellate state courts repeatedly found that Terri Schiavo had a right, protected by common law and reinforced by the U.S. Constitution and case law precedents articulated in the Supreme Court's Cruzan decision, to have tube feeding withdrawn on her behalf by her husband, who had been found at trial to be acting in good faith (Schindler v. Schiavo, 2001). In response, the Florida state legislature passed and Florida governor Jeb Bush signed "Terri's Law" into effect in October of 2003 (Fla. Laws ch. 2003-418, 2003). This piece of emergency legislation was designed to delay implementation of the court's decision, but that law was overturned by the circuit court in May 2004 as a violation of the separation of powers, a decision that was sustained by the Florida State Supreme Court in September of 2004. The decision was then appealed to the U.S. Supreme Court which refused to hear the case in January of 2005 (Bush v. Schiavo, 2005).

In March of 2005, the U.S. Congress made its own an attempt to countermand the Florida courts when it passed and President George Bush signed a private bill titled "A bill to provide for the relief of the parents of Theresa Marie Schiavo" into law. This law gave Terri Schiavo's parents (who were fighting to ensure that their daughter would remain on life support) the right to have their case reheard in the federal courts when it appeared all state court options had been exhausted (PL 109-3, 2005). This law was also struck down, this time at the federal district court level. Thereafter federal judges in the U.S. 11th Circuit Court of Appeals (Schiavo ex rel. Schindler v. Schiavo, 2005) and later, the U.S. Supreme Court, refused to hear appeals of the district judge's decision (Schiavo, ex rel. Schindler v. Schiavo, Michael, et al, 2005). Terri Schiavo's feeding tube was removed (for the third time) on March 18, 2005. She died of dehydration thirteen days later. Amidst all this frenzy of activity three things remained crystal clear: (1) it was the courts who set right-to-die policy in the first instance, (2) that policy would give close family members the right to forego life-sustaining treatment – even tube feeding -- on the part of incompetent patients, and (3) it would be the courts, not the state legislature, not the governor, not the U.S. Congress, and not even the president of the United States, who would have the final say in the matter.

### ***States' Interests and Medical Professionals***

The discussion of policy making to this point has been limited to the issue of balancing the state's

interest in preserving life against the autonomy patients have with regard to making medical decisions for themselves. But nothing has been said about the state's interest in preventing suicide or the state's interests in maintaining the ethical integrity of the medical profession. Courts regularly mention all three interests, but the latter two are much more specific than the first, and much harder to assay without guidance from the medical profession itself.

When doctors assist patients with the foregoing of life-sustaining treatment are they assisting in a suicide? Likewise, does advising patients and their close family members on courses of action that hasten a patient's death call into question the integrity of the medical profession? In both cases, national organizations of medical and ethical professionals have issued policy statements that conclude that assistance in foregoing treatment is not unethical and does not constitute assisting in a suicide. To the contrary, these position statements argue that it would be unethical not to accede to and assist in accomplishing the wishes of patients and their surrogates to forego medical treatments at the end of life when the course of action appears to be the patient's wish or in the patient's best interest.

What is most interesting about these positions is that the courts have used them regularly in coming to their own conclusions about how to assay the state's interests in right-to-die cases. When the Quinlan case was decided in 1976, medical professionals at St. Clare's hospital sided with the New Jersey Attorney General and opposed the parents who were attempting to forego life-sustaining treatment on behalf of their daughter, while organized medicine was ambivalent. Likewise, the rehabilitation center in Missouri where Nancy Cruzan was cared for sided with the Attorney General, against the family, and several medical ethics organizations opposed the family's wishes (e.g., the Association of American Physicians and Surgeons and the American Academy of Medical Ethics).

These are the exceptional cases, however. In nearly every other case since Quinlan, consensus groups of medical and ethics professionals have testified on behalf of and supported families seeking the right to forego life-sustaining treatments (see **Sidebar: Consensus Groups**). Going even further, these groups have regularly filed *amicus curiae* (literally translated: *friend of the court*) briefs, and have actually been party to cases where they supported the right of family members to forego life-sustaining treatments for patients too ill to decide from themselves.

**Sidebar: Consensus groups**

The term *consensus group* is used here to refer to an interdisciplinary group of medical, legal, and ethical professionals whose job it is to establish guidelines of ethical behavior for members of the sponsoring organization. While the American Medical Association's Council on Ethical and Judicial Affairs is among the oldest and most respected of all medical ethical consensus groups (it also probably has the most elaborate and well reviewed set of ethical guidelines), most professional medical organizations have similar groups that carry out the same kinds of analysis and make the same kinds of ethical recommendations.

The sea change in how the medical profession views the right to die can be traced to publication of Deciding to Forego Life-Sustaining Treatment, a handbook on medical ethics authored by a consensus group of medical, legal, and ethics professionals under the title "The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research." This policy statement was cited directly by 70% of court cases decided in the five years after its publication in 1983 (Hoefler, 1994, p. 185). Publication of this handbook was followed closely by publication of a series of decisions by the American Medical Association's Council on Ethical and Judicial Affairs which came to the same conclusions. The American College of Physicians, the American Thoracic Society, and the American Nurses Association, and the Catholic Health Association quickly followed suit, all with positions that reinforce patients' rights *vis a vis* the state in right-to-die cases along the following lines:

- (1) family members should be able to make decisions on behalf of their loved ones;
- (2) foregoing treatment is different than suicide;
- (3) artificial nutrition and hydration is a medical procedure that can be withheld or withdrawn like any other medical treatment;
- (4) withdrawing treatment after it has been started is morally equivalent to and equally acceptable as withholding treatment in the first place; and,
- (5) patients in a persistent vegetative state should also be able to have decisions to forego life-sustaining treatment made on their behalf.

By the early 1990s, no state or federal court in the country could restrict the right of patients or their family members from making end-of-life decisions on the grounds that it would be unethical or would call into question the integrity of the medical profession when the medical profession itself had come to the conclusion that neither was the case. Even the Supreme Court in Cruzan made it clear that while states reserved the right to determine what level of evidence could be required to determine what a patient would want or not want at the end of life, the absolute right to decide could not be denied on medical ethical grounds. This was the case even in situations involving artificial nutrition and hydration (tube feeding), and even in situations where the patient was not terminally ill (but rather, in a persistent vegetative state). Medical and ethics professionals are largely in agreement on this issue, and the courts have used conclusions of these consensus groups to shape case law responses in disputes involving the right to die, while legislators have, for the most part, sat quietly on the public policy sidelines.

#### ***V. Conclusion***

Judges often lament the need to be policy makers. They are more comfortable interpreting existing law than they are using general guidance from common law, clues from the state and federal constitutions, and advice from specially trained professionals to make new policy out of whole cloth. Even Chief Justice Warren Burger, known for presiding over one of the more activist Supreme Courts in American history, was of the opinion that:

in a democratic society legislators, not courts, are constituted to respond to the will and consequently the moral values of the people (Furman v. Georgia, 1972, p. 383).

Unfortunately for judges, the state legislatures and Congress of the United States have had little appetite for right-to-die policy making. When they have attempted to make policy in this area, they have passed laws with little if any impact or simply ratified the direction the courts have already charted. There have also been those notable exceptions, as in the case of Terri Schiavo, where the Florida legislature, the Florida governor, the U.S. Congress, and the president of the United States all attempted to check the court's power and forge ahead as right-to-die policy makers. But these attempts came to nothing.

Regardless of whether elected policy makers have been passively following the court leaders, or whether they have been unsuccessful rivals to the courts, it could be argued that, for better or worse, traditional, legislative-centered processes for making law have been subverted when it comes to the right

to die. For those who feel as though life is sacred and should be preserved at all costs, policy activism of the courts in this area is both frustrating (because the courts have sided with the pro-choice argument almost without exception) and ominous (because judicial policy making is not particularly susceptible to pressures brought to bear by concerned interest groups who have contrary positions). On the other hand, those who feel as though individual autonomy should trump the state's interest in preserving life in the realm of end-of-life decision making have surely greeted the less democratic machinations of more insular state and federal judicial processes with considerable relief. One might even imagine a collective sigh about all this issuing from Joe and Julia Quinlan, Joe and Joyce Cruzan, Michael Schiavo, and other similarly situated family members of loved ones who sought the right to forego life-sustaining treatments in cases of hopeless, irreversible illness: "Where would we have been without those activist judges!"

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