NANCY BETH CRUZAN has not moved from her Mount Vernon, Missouri, hospital bed since 1983. Thanks to a recent Supreme Court decision, she may lie there another 30 years. Since being injured in an automobile accident, Nancy has persisted in a vegetative state. Her parents, Joe and Joyce Cruzan, had petitioned to allow the removal of the feeding tube keeping her alive. But by a 5-4 vote the Court rejected their request, affirming instead the state's authority to preserve life.

The decision is significant as a test case of the "right-to-die" credo, which is becoming increasingly relevant as biotechnology enhances the ability of medical professionals to sustain life of drastically diminished quality. An equally significant but less noted aspect of the Cruzan decision is what it reflects about prevailing conceptions of individual self-determination. The Court did not grant to the states an unqualified prerogative to sustain life in all circumstances. Rather, it affirmed the right of persons prospectively to declare their wishes should they become severely incapacitated, wishes that would then be binding. However, in the absence of "clear and convincing evidence of Nancy's desire to have life-sustaining treatment withdrawn," the Court held that Missouri's presumption in favor of life overruled the best judgment of her parents concerning her interests.

Under one interpretation, the Court's decision marks a notable recognition of individuals' rights to control their own medical destinies. The Court explicitly upheld Missouri's refusal to allow termination of treatment on the grounds that Nancy Cruzan had not declared that she would prefer its cessation. Had she anticipated the present circumstances through a living will or some similar device, the Court maintained, her own expressed health-care wishes would have enjoyed decisive weight. Hence the delight of M. Rose Gasner, director of legal services for the Society for the Right to Die: "There are some wonderful things here. The Constitution is being applied in a brand new and revolutionary way."

Nancy Cruzan, however, had not envisioned and taken measures to avert leading a vegetative existence, and so her family is not in a position to appreciate these wonderful things. Instead, Missouri's legislated policy displaces their considered judgment. Gasner's optimism notwithstanding, this enhancement of state power hardly seems to represent an advance for the cause of individual liberty. Was there another alternative available to the Court that would have responded more adequately to individuals' interest in leading their lives—and deaths—at a safe distance from unbidden intrusion by the state?

Among the Court's concurrent and dissenting opinions, no fewer than five distinct principles for resolving such tragic dilemmas were mentioned. The first of these was: Adhere to whatever clear and unambiguous prospective declaration the afflicted individual may have made. A large majority of justices held this to be the preferred course. It is only because Nancy Cruzan left no such affirmation that it became necessary to resort to other principles.

Second, a state's legislated presumption in favor of life

mandates the continuation of treatment for incompetent patients who have made no prior declaration to the contrary. That is the basis on which *Cruzan* v. *Missouri* was in fact decided. It is a classic "half full, half empty" judgment. On the one hand, the state is not granted carte blanche to impose its standards on unwilling individuals. On the other hand, it has been given the power to fill any vacuum left by individuals' nonaction. The state of Missouri hastened to do so, and the Court has now affirmed that authority.

Two other criteria are noteworthy for the cursory attention they received. Although termination-of-treatment decisions are often defended on grounds of the diminished "quality of life" of the patient, and though the hopelessness of Nancy Cruzan's condition was conceded by both sides, none of the justices seemed inclined to urge that the state get into the business of grading life quality. Individuals may do so for themselves, but that is just another way of holding that their own current or anticipatory wishes are to be respected.

Even less was the Court willing to venture into the thicket of utilitarian cost-benefit analysis. Several decades of nursing care will be extremely costly, both financially and with respect to the human costs borne by the Cruzan family, and one may reasonably wonder how either Nancy or anyone else benefits from this expenditure. It is understandable that the Court is eager to evade "pricing life"—even though the consequence is a potentially substantial drain on public funds. Eventually that question will have to be addressed—but not in 1990, not in *Cruzan* v. *Missouri*.

FAMILY MATTERS

IS BIG BROTHER YOUR NEXT-OF-KIN?

BY LOREN E. LOMASKY

ILLUSTRATION BY TROY THOMAS

FIFTH, THE COURT considered and rejected, though not without some expressed sympathy, the claim of the family to decide on Nancy's behalf. Chief Justice William H. Rehnquist, writing for the majority, acknowledged that "Nancy Cruzan's mother and father are loving and caring parents. If the state were required by the United States Constitution to repose a right of 'substituted judgment' with anyone, the Cruzans would surely qualify."

But he also observed: "Close family members may have a strong feeling—a feeling not at all ignoble or unworthy, but not entirely disinterested, either—that they do not wish to witness the continuation of the life of a loved one which they regard as hopeless, meaningless and even degrading. But there is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been."

Note that Rehnquist did not cite any evidence that the Cruzan family was in fact attempting to advance its own interests at the expense of Nancy's. Presumably there is none. Nor did he allege that procedural safeguards designed to protect the rights of an incompetent individual were inadequate. Rather, Rehnquist's position is grounded on a sweeping epistemic caveat: We are unable to determine with assurance that a family's decision corresponds to that which an afflicted individual would make under these circumstances.

Grant for the sake of argument that this difficult counterfactual proposition is both meaningful and accurate. (Difficult because it is mysterious how one might give clear sense to the notion of what an incompetent patient would, if she were competent, choose to be done to her incompetent self.) What is the practical upshot of such professed judicial skepticism? Only this: The question of whether Nancy Cruzan will live or die is de facto subsumed under the impersonal regulations of the state of Missouri.

The burden of proof between the two contending parties in *Cruzan* v. *Missouri* is thus rendered starkly asymmetrical. The Cruzans, in order to procure termination of treatment, must eliminate all residual suspicion that their own wishes may diverge from those of their daughter. Yet the state of Missouri need offer no evidence whatsoever that its policy corresponds with what Nancy would have desired. But then, how could it? It knew nothing of her, either when it legislated or when the automobile accident destroyed her faculties. There is no reason to believe that state officials possess some privileged access to her desires or interests, let alone Rehnquist's "automatic assurance" of convergence. Nonetheless, the state's decision stands.

The ruling displays exquisite sensitivity to the possibility of individuals' interests being overridden by those of the family while manifesting no apprehension concerning how their interests are affected when yet another aspect of their lives is made

subservient to state directives. This fits uneasily with the Court's professed concern for self-determination. Even less satisfactory is the Court's implicit view of the relationship between stricken individuals and their loved ones. The Cruzans are denied the power to determine whether feeding will continue because they cannot conclusively demonstrate that their desires are identical to Nancy's (or those that Nancy would have if...).

The Court thus seems to assume that family relationships are basically adversarial; the parents must overcome a presumption that there is an implicit conflict of interest between them and their daughter. No one will deny either that such conflicts may obtain or that, when they do, it then becomes the job of the courts to protect those who are unable to protect themselves. Should the adversarial relationship, though, be taken as the norm which, in the absence of unimpeachable evidence to the contrary, guides judicial resolution?

THIS PRESUMPTION RESTS on a narrow understanding of individuals' interests. Among our important interests, some are purely self-contained. Others, however, make essential reference to our ties with others. The vast majority of human beings define their good in terms of valued affectional relationships. We succeed or fail not merely as isolated atoms but as friends and lovers, colleagues, citizens, brothers, parents, daughters.

If I have committed my energies and emotions to some enterprise or cause or social bond, then its flourishing is not merely an external happening that may be instrumental to my own achievements. Rather, its good has been made a constituent of my own. The point is not that my will has been swallowed up by that enterprise, but rather that through identifying with it I have made its fate overlap my own. This is by no means an uncommon circumstance; just the reverse. While some may deliberately elect to pursue a course of maximal detachment from other persons, dealing with them exclusively at emotional arms-length, the life of the hermit or solitary hero is not for many of us.

The Court seems to assume that family relationships are basically adversarial. Should this assumption guide judicial resolution?

Some of these significant associational ties are voluntarily established, but others are not. One may, after extended deliberation, join a political party or a church, but no one chooses the family or linguistic community into which he is born. People may consciously decide to have a child but not who that child will be. Even friendships are not the product of deliberate choice so much as unforeseen serendipity; that is why we aptly speak of "falling" in love. Although these relationships are not deliberately contrived, they constitute for most people the core of a fulfilling life and, importantly, are the foundation from which significant choices proceed.

I do not weigh my options as a detached, naked self but as the chum of this person, the son of that one. These associational ties, some voluntarily established and others not, constitute to a considerable extent the interests I have and thus my reasons for acting one way rather than another. Indeed, it is difficult to understand how a person could develop a sense of self in the absence of distinctive affections that were not, in the first instance, chosen.

It is important not to overstate the point so as to apotheosize social units at the expense of the individual. That is the error of the currently fashionable "communitarian" critique of liberalism. Communitarianism essentially reduces persons to the vectors of social forces that act on them, and maintains as a corollary that individuals' rights and duties derive from whatever the society's dominant conception of appropriateness may be.

Among the many deficiencies of this theory, one of the most serious is its ruthless urge to oversimplify. *Contra* the communitarians, there is not some one community in which we all, willy-nilly, are enrolled, but rather a wide and complex range of social avenues along which we orient ourselves and thereby etch out the varied patterns of our lives. Not all of those options open to us can be embraced simultaneously, and so our choices define the particular mesh of subcommunities in which we will live. It is a good thing that we do not have to make these choices *ex nihilo*, but it is also the case that individuals sometimes find it necessary to abandon that which they have inherited or embraced. So people get divorced, change their religion, even disown their children. In a free society these too are among their legitimate options, and courts are obliged to protect them.

No evidence exists, however, that Nancy Cruzan was estranged from the members of her family and wished to distance herself from their affairs. To the contrary, it appears that family ties mattered to her, that an important component of her self-perceived good was bound up with being the daughter of Joe and Joyce Cruzan. The relationship between her interests and theirs is, therefore, more complementary than adversarial.

To put it another way, Nancy's life had certainly been more attuned to the goals and opinions of her parents than, say, to those of the attorney general of the state of Missouri. It is ironic

that a court decision predicated on Nancy's desires should turn her own preference ordering topsy-turvy. So far as I know, Rehnquist would not characterize himself as a communitarian. But his opinion in effect mandates that Nancy Cruzan's good is deemed to be whatever the state prescribes, while reducing to a nullity those particular associational ties that helped define her life while she had one to lead.

ALTHOUGH THE NINE JUSTICES were deeply divided over how the case should be resolved, they agreed that its disposition would have been much easier had Nancy Cruzan documented in advance her wishes should she become incapacitated. It was her own lack of foresight, pardonable no doubt, that thrust the decision before the Court. Isn't it at least clear, then, that individuals will better serve their own interests if they prepare living wills?

Not necessarily. It is possible for people to enhance the range of their self-determination through anticipatory declarations, but these are, at best, imperfect mechanisms. It is instructive in this regard to compare a so-called living will with a last will and testament. Whether or not someone is dead is, except in a very few instances, easily determined. Being dead does not admit of degree; either you are or you aren't. People who are dead remain dead. An individual who dies may leave an estate and remains to be disposed of, but there is no longer a "him" that can be acted on. Still, in spite of death's relative clarity, judgments at probate can present hard cases.

All the more so with living wills. Incapacity admits of varying degree, from mild, to profound (as with advanced senile dementia), to total. Whether and to what extent it may prove reversible is a judgment call, and few physicians will claim never to have been surprised by the recovery of a patient they had believed to be irretrievably lost. Advances in medical science are, in their very nature, unpredictable and can upset previous calculations. Individuals who have never been in a condition anything like irreversible coma may have only the haziest conception of what they would prefer done to them should that misfortune strike years or decades hence.

Moreover, their desires concerning that future prospect may well be contingent on a host of currently undeterminable factors, such as intervening experiences, what their finances may then be like, and the particular circumstances in which their incapacity will place loved ones. It is impossible to spell out all the eventualities that might ensue and to specify for each just what is to be done. And even if that were possible, it will still be necessary for someone to interpret whether those conditions have been satisfied in the present case.

There are, therefore, significant limits on the extent to which even provident individuals will be able to take charge of what may and may not be done for them once they are no longer competent. A person's best interests may be served not by vainly attempting to anticipate every contingency that could emerge but by allowing those determinations to be made by those in whom he reposes love and trust. This is not to deny that anticipatory declarations should have legal force. But whether or not such a document has been prepared, there will remain considerable room for discretion. The question at issue is whether the discretion should be exercised by an impersonal state apparatus or by those with whom the individual has shared his life.

In this regard, it is unfortunate that a court that acknowledges the potential usefulness of a living will has not taken the analogy further. When an individual dies intestate, we do not think it appropriate for courts to presume that the best interests of the deceased are served by allowing the state to expropriate his estate and use it to advance whatever ends the legislature may fancy—say, highway building. Rather, in the absence of firm evidence to the contrary, it is presumed that his interests require that disposition be made on the basis of blood ties. That presumption is not without perils, and one virtue of wills is that they afford individuals the opportunity to block or modify it should they so choose. Nancy Cruzan left no record of what she would wish done with her in the current circumstances, but that is inadequate justification for conflating her interests with those of the state of Missouri.

THE NEWSPAPERS HAVE uniformly characterized *Cruzan* as a right-to-die case. But it is also, and perhaps more importantly, one with sweeping ramifications for the legal environment within which self-determination can be practiced. While ostensibly deferential to individuals' own choices, it weakens those social structures, most especially the family, that stand betwixt individuals and the state. Persons who define their good by reference to involvement in such social structures, and whose success is a function of the robustness of these units, have thereby been rendered less able to secure that which they value.

So understood, there is ample precedent for *Cruzan*. The tendency to substitute state determinations for those made within the compass of smaller, more intimate social units is ubiquitous. Public schooling lodges in educational bureaucracies prerogatives that were at one time the responsibility of parents. The vast apparatus of the welfare state has almost entirely supplanted the protective and benevolent associations through which individuals once customarily secured themselves against risk. Mediating functions of churches, eleemosynary institutions, fraternal organizations, and extended families have been progressively enfeebled by legislation and judicial decision.

The justification proffered for virtually every expansion of the protective state is concern for the rights and interests of the individual. But to atomize persons by artificially separating them from the human-scale structures within which meaningful lives can be lived does them questionable service. Nancy Cruzan is not the only one who is disadvantaged by being made a ward of the state.

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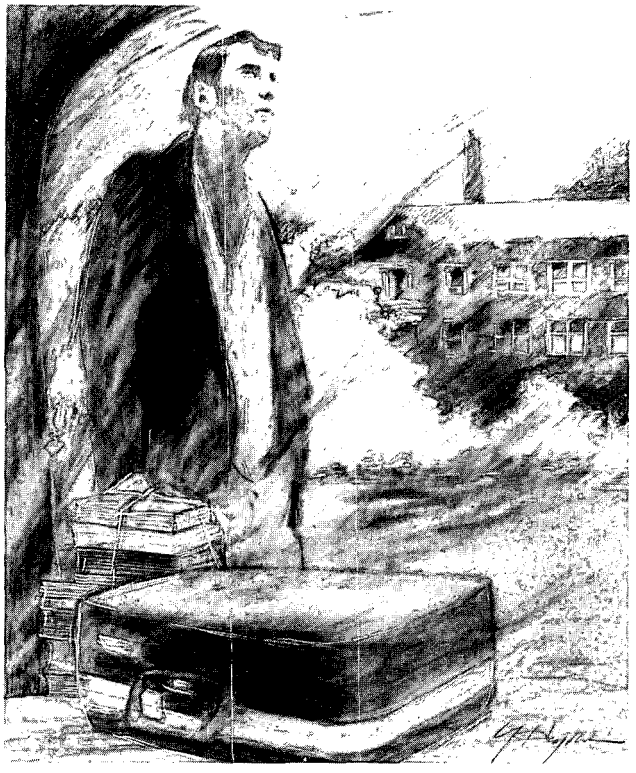
BLOCKING THE LIGHTS

BY DAVID BERNSTEIN

Despite all the talk about "a thousand points of light," it can be tough to be a Good Samaritan these days—especially if the people you want to help have AIDS. Ask Charles Baxter.

The difficulties he encountered in trying to open a hospice in Belleville, Illinois, are typical of the obstacles faced by dozens of individuals and groups across the country seeking to provide housing for people with AIDS. In addition to the inevitable fund-raising problems that novel charities face, they more often than not encounter community hostility and political interference when they announce their plans.



Baxter, a home health-care provider for 15 years, became aware of the terrible housing crisis that faces many terminally ill AIDS patients after caring for several clients with the disease. He told the *Chicago Tribune:* "For eight or nine months, I was working with AIDS patients in their homes. With one of my patients, there were 26 family members around him when he died. I couldn't help but think that by comparison, there are people who have no one around them when they die, and I decided to start the home."

Baxter sold his car, his pickup truck, some antiques, and his house to get enough money to rent and remodel a three-story house, which he named "Our Place." He also received help from community volunteers. By early 1989, he had found three people who were HIV-positive, homeless, and ready to move into Our Place. He hoped eventually to house up to seven residents.

All Baxter needed was approval for a special-use permit from the Belleville City Council. The Belleville zoning board seemed receptive to the idea of a hospice for the dying until it discovered that Our Place was meant for AIDS patients. Then the board voted unanimously to recommend that the city council deny Baxter's request. Opponents of the project voiced fears that the hospice would hurt property values and lead to the spread of AIDS in the community. In the end, the council voted 9-7 to deny the permit, although it was unable to cite any specific zoning provision to support its decision.

With the assistance of the American Civil Liberties Union, Baxter filed a suit under federal civil-rights statutes, alleging that the city of Belleville had engaged in discrimination against the handicapped. U.S. District Judge William D. Stiehl found that the potential residents of Our Place posed no threat to the health of the surrounding community and that "irrational fear of AIDS was at least a motivating factor in the City's refusal to grant Baxter's special use permit....The court finds that the public interest can best be served if discriminatory actions based on irrational fears, piecemeal information, and 'pernicious mythologies' are restrained." Stiehl ordered the city to allow the hospice to open and to pay Baxter $29,000 in damages.

But the story does not have a happy ending. Baxter finally opened Our Place in November 1989. He closed it two months later. He said he was emotionally and physically drained and that he had difficulty raising money. To add insult to injury, the Illinois attorney general is investigating whether Baxter failed to file the forms required by the state's charitable trust laws.

Very few individuals would have the fortitude to make it even as far as Baxter did. Care for AIDS victims is an expensive and complicated matter.

At different stages of the disease, victims have varying needs for care. Those who temporarily recover after hospitalization merely need a place to live. Many can return to where they lived before or stay with friends or relatives. But others, jilted by lovers, abandoned by family and friends, and broke and jobless after a long hospital stay, have nowhere to go and find themselves homeless or on the verge of homelessness.

Those who are suffering the ravages of AIDS but are not in the terminal stages of the disease need help with feeding, bathing, and other basic activities. Often friends and lovers help, but the strain is frequently too much for them to handle without professional home health-care assistance, which is beyond the financial means of many AIDS patients.

People in the terminal stages of AIDS need constant attention. Often they are lucid for only part of each day, and they

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