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**National Home**  
*"SUMMER HILL"*

*"It is the right of every pregnant woman to give birth, . . ."*

September 7, 1983

Morton Blackwell  
Special Assistant to the President  
Office of Public Liaison  
The White House  
Washington, D.C. 20500

Dear Morton,

We wish to thank you for keeping us apprized of the human life issues and in particular the recent mailings regarding Indiana's Baby Doe and the President's letters on behalf of the Hatch/Eagleton Amendment.

Sincerely for the Preborn,

Denise F. Cocciolone  
National Executive Director  
BIRTHRIGHT Inc. (U.S.A.)

DFC/edc

*"... and the right of every child to be born."*

**WILLIAM J COX**  
VICE-PRESIDENT  
DIVISION OF GOVERNMENT SERVICES

**The Catholic Health Association** **CHA**  
OF THE UNITED STATES 

1250 CONNECTICUT AVE NW  
SUITE 234 • WASHINGTON DC 20036  
202 - 296-3993

*Representing more than 800 hospitals and long-term care facilities nationwide.*

The Catholic Health Association  
OF THE UNITED STATES



NATIONAL OFFICE: 4455 WOODSON ROAD  
ST LOUIS MO 63134  
314 - 427-2500

August 31, 1983

Ms. Betty Lou Dotson  
Director, Office of Civil Rights  
Department of Health and Human Services  
330 Independence Avenue, SW  
Room 5400  
Washington, DC 20201

Dear Madam Director:

This is in response to your Notice of Proposed Rulemaking (NPRM) published at 48 Fed Reg 30846-30852 (July 5, 1983) and entitled, "Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants." By way of introduction, the Catholic Health Association (CHA) is a voluntary association of hospitals and nursing homes sponsored by religious orders and dioceses of the Catholic Church. CHA represents 631 hospitals and 284 long term care facilities throughout the United States.

The Catholic Health Association understands and shares the concern that prompted the Department's NPRM on this subject. It is an important hallmark of any civilized society that vulnerable individuals (e.g., handicapped newborns) be treated with compassion and accorded the same rights and benefits as other persons. This moral imperative was recently given renewed and timely emphasis by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research when it noted:

Within constraints of equity and availability, infants should receive all therapies that are clearly beneficial to them. For example, an otherwise healthy Down's Syndrome child whose life is threatened by a surgically correctable complication should receive the surgery because he or she would clearly benefit from it.

Notwithstanding our agreement with the President's Commission and the intent behind the Department's July 5 NPRM, it is important to note that for a variety of reasons CHA viewed the Department's earlier initiative (48 Fed Reg 9630 [March 7, 1983]) in this area with some concern.



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First, CHA firmly believes that the government should not become involved in treatment decisions unless it has clear evidence that the rights of persons are being violated and that a significant potential exists for such violations to continue.

The reasoning behind this conviction is straightforward. The decision whether or not to continue treatment can be very delicate, particularly in difficult or uncertain cases when the patient's best interests are ambiguous. Consequently, in the case of handicapped newborns these decisions are best left to the parents, aided as necessary by the attending physician(s), hospital ethics committees, other family members, social services personnel, etc. Ordinarily, government intrusion into this process will only make the process of reaching a morally correct decision more difficult. Thus, government should become involved only upon a demonstration of compelling need and then only with the greatest reluctance. In CHA's judgment, the Department's March 7 regulations did not provide sufficient evidence to justify its involvement in this area.

It is also our members' experience that many difficult treatment decisions that are entirely ethical and nondiscriminatory in the context of Section 504 can be, by their very nature, subject to misunderstanding, especially by well-intentioned but misinformed laypersons.

Accordingly, CHA feared that the original regulations, requiring the prominent public display of the specified notice in combination with a 24-hour toll-free hotline, might encourage well-meaning but groundless and imprudent phone calls triggering unnecessary federal intrusions into the internal operations of hospitals -- all of which would be accompanied by a great deal of negative publicity for parents, physicians and institutions. CHA concluded that the ultimate effect of a series of such unfortunate incidents might well be to undermine public support for the extension of effective federal protection to incapacitated and threatened newborns.

A further CHA concern is related to the negative character of the required notice. Catholic hospitals, along with the overwhelming majority of other hospitals, have always respected the rights of handicapped infants, and have done so irrespective of the mandate of federal law. CHA feared that the assumption underlying the required notice might create the impression that our hospitals only protect those rights under threat of legal penalty. To allow such an inference would be an affront to the Judeo-Christian values that have always animated Catholic health care and have earned it such a high level of community trust. However unintended, by suggesting that traditional values may no longer be operative within our hospitals, the notice might subtly erode patient confidence, institutional morale and community support.

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In contrast to the Department's earlier regulations, the Department appears to have strengthened the justification for the July 5 NPRM. Furthermore, by making several important clarifications and distinctions with respect to what is meant by "discriminatory treatment" and by moving the placement of the notice to appropriate nursing stations, the proposed regulations reduce the potential for negative operational effects while maintaining substantial protections for the lives of vulnerable handicapped infants.

However, with respect to the notice, we strongly believe that the proposed rule could be improved by allowing interested institutions, including Catholic hospitals, to utilize an alternate notice that expresses their deep and long tradition of respect for the rights of all persons. In our judgment, providing the option to use a notice with a more positive tone would preserve the interests of both the Department and the affected institutions.

With all this in mind, the Catholic Health Association urges the Department to modify the July 5 NPRM by adopting the following two recommendations:

1. The Association proposes that the rule be amended in Sec. 84.61(b) to allow interested hospitals to utilize a modified notice that indicates their agreement with the purpose of the rule.
2. The Association proposes that existing institutional due process be respected by amending the notice to include the administrator as a person who also might be contacted.

With these two amendments, the rule would read as shown in Exhibit "A".

Finally, with regard to the nine specific questions on which comments were solicited in the July 5 NPRM, we submit the following:

1. We view as unnecessarily burdensome a federal requirement of "self-evaluation . . . with respect to . . . policies and practices concerning health services to handicapped infants." As in the past, and not only because of current awareness of this issue, our health facilities continually review their applicable policies and procedures and will do so in the future.

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August 31, 1983

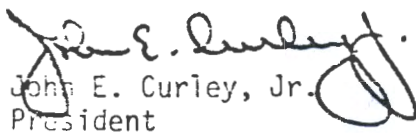
2. We are not aware of the data showing that ignorance of the identity of agencies that service handicapped infants is a significant factor in the frequency of alleged discrimination. Further, while one can speculate that such knowledge might affect the parents' decision regarding their infant, it has not been shown that this kind of information is presently being withheld. The matter of identifying such agencies for the parents should be a judgment left to the discretion of the treating physicians, social services personnel and other members of the health care team.
3. Hospitals should not be mandated by the federal government to "institute internal review boards", although we agree that such bodies may be of great assistance in addressing these critical issues. Although ethics committees (as we call them) are widely used within Catholic health care, there is no single, most effective form or process for such internal committees and a federal mandate might appear to put a seal of approval on a given structure regardless of its relative or actual merits in a given setting. We encourage all hospitals to establish internal processes to deal with these difficult issues (not only respecting handicapped infants), but each facility should be left to devise the structure and procedures that work best for it and for its patients.
4. Any revision of investigatory procedures should await a sufficient period of time following the effective date of these regulations to permit an assessment of actual experience.
5. Volumes can be and have been written to explain the legal and ethical requirements in connection with health care, including the care of handicapped infants. The proposed rule and its Appendix are an abbreviated and acceptable summary of the issue and need not be augmented except, perhaps, by adding a bibliography of related sources for further study. The Association would be pleased to assist in the compilation of such a bibliography.

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6. We do not view the cost and allocation-of-resources implications as being different for infants than for other seriously ill patients.
7. We agree that the appropriate dividing line is the deprivation of life-sustaining, medically indicated treatment, and we agree that the fact that the infant may be unwanted due to perceived economic, emotional and marital effects does not justify deprivation of such treatment.
8. We believe the safeguards regarding confidentiality are adequate. Any revision of those safeguards should await the experience gained after the rule goes into effect.
9. In addition to a regulatory approach, we encourage the Department and all persons interested in this subject to develop processes in advance for education and communication regarding the medical and ethical principles involved. We believe that by being prepared for these situations before they arise, health care providers can provide optimal patient care and eliminate the need for hotline calls.

Madam Director, we appreciate this opportunity to comment on your Notice of Proposed Rulemaking. If you or a member of your staff have any questions regarding our comments, please contact William J. Cox, CHA Vice President for Government Services at 202/296-3993, or J. Stuart Showalter, CHA Vice President for Legal Services at 314/427-2500.

Sincerely,

  
John E. Curley, Jr.  
President

jj  
enc.



EXHIBIT "A"\*

§ 84.61 Procedures

(a) [No change]

(b) Pursuant to 45 CFR 80.6(b), each recipient that provides covered health care services to infants shall post and keep posted in a conspicuous place in each nurse's station with responsibility for each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery, one of the following two notices, which shall be no smaller than 8-1/2 x 11 inches:

Notice 1

This hospital has a long tradition of caring for the people of this community. We treat all patients with dignity, respect and compassion. Because of our commitment to serve the best interests of all of our patients, including handicapped infants, we direct your attention to the federal law regarding nondiscrimination against the handicapped; and to the following notice:

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IS PROHIBITED BY THIS HOSPITAL AND BY FEDERAL LAW.

Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact the administrator of this hospital and

Handicapped Infant Hotline, U.S. Department of Health and Human Services, Washington, DC 20201  
Phone: 800-368-1019 (available 24 hours a day) or  
your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

The hospital and the agency will respect the identity of callers as confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of this state.

Notice 2

[Here insert the notice as published in the July 5 NPRM.]

(1) [No change]

(2) Copies of such notices may be obtained on request from the Department of Health and Human Services.

(c) [No change]

(d) [No change]

(e) [No change]

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\*Underscored material differs from the July 5 NPRM.



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# Should Every Baby Doe Die?

9-to-1 odds against a 'good' life may be a bet worth taking

By Felicity Barringer

OF ALL THE aphorisms about democratic government in the civics books, the one about our criminal justice system took the deepest root in my mind. That's the aphorism that says we prefer to have 10 guilty defendants go free than have one innocent one imprisoned.

The notion has been ricocheting around in my mind recently since I have been covering the story of Baby Jane Doe, the 6-week-old, severely handicapped Long Island infant whose parents have refused permission for her to have corrective surgery. With surgery, the child would have a high likelihood of living into adulthood; without it, that likelihood decreases dramatically.

"The aphorism comes back to me because we in society take a very different approach to handicapped infants than, say, we take toward criminal defendants. That approach may be right. But I don't think we are letting ourselves recognize the cost. Many of us are ready to let "vegetables" die before they pass infancy. But by relying on the crystal balls of physicians, we run a risk. What if the child is not going to be a vegetable?"

That's a question my friends — both those from the conservative Philadelphia suburbs and the liberal enclaves of Washington — don't want asked.

Almost all of them feel the right-to-life activists who forced the parents to defend their decision in court are outrageous: smug would-be Paladins whose cards read "Have Morals, Will Travel," who drop in uninvited to second-guess some of life's most painful decisions, and who then leave others to endure the fruits of their intervention. These people have no right, my friends say, to pour salt into the open wound of young parents whose joy over their firstborn has been twisted into grief and anger because of her handicaps.

They also wax scornful of the federal officials who now seek the child's records to see if her hospital violated

*Felicity Barringer is a reporter for The Post.*

her rights by failing to perform operations to close her partially open spine and to drain excess fluid from her skull, relieving a condition known as "water on the brain."

All these opinions share the presumption that Baby Jane Doe's handicaps make her life not worth living. Said one of my relatives: "It would be a blessing if she died." Said the federal judge who denied the government's demand to see her medical records: "There is no question in my mind or anyone's mind that if the operations were performed the infant would live longer — as a vegetable, paralyzed, disabled."

Wrong. There is a question in my mind. Not an overwhelming question — I suspect the baby's prognosis is gloomy. But some doubt lingers.

When Baby Jane Doe was born Oct. 11, she was examined by a pediatric neurologist who recommended her immediate transfer to a second hospital so a shunt could be put in her head to drain the fluid and so surgeons could close her open spine. No operation, however, could correct her abnormally small head.

When she arrived at the second hospital, another pediatric neurosurgeon examined her and talked with her father, who then decided against the operations. Here is the prognosis the second doctor offered in court: paralysis of the lower body, persistent painful infections of the bladder and kidneys and severe retardation. She would be unable to respond to her surroundings in any way, he said, except to cry out in pain.

If that is an accurate description of her future, it does seem merciful not to prolong her life. But suppose he was wrong? Another expert did think the operations should be performed. But he never testified in court; his prognosis for the child is unknown.

On paper, her handicaps sound horrific: an incompletely closed spine, a malformed brain stem and hydrocephalus — the technical name for "water on the brain." Horrific, indeed — except that David McCollough, chief of neurosurgery at Children's Hospital in the District of Columbia, says that all children with Baby Jane Doe's type of spina bifida have a malformed brain stem and 90

percent of such infants have hydrocephalus.

How many of these children are retarded after corrective surgery? Thirty percent, he said. Not 90 percent, not 75 percent, 30 percent. Meaning that 70 percent, while afflicted with some degree of paralysis and perhaps incontinence, are capable of loving, learning and understanding.

Baby Jane Doe also has an abnormally small head. Not very abnormal, however. The low end of the normal range of skull circumferences for newborns is 31.5 centimeters. Baby Jane Doe's skull measured 31 centimeters. Still, however, we can't know how small the skull would have been had the pressure from the "water on the brain" not been present.

These are generalizations. The presumption must be that the expert who examined the child is probably correct in his prognosis. Let's say his prognoses are correct 90 percent of the time. That would be a remarkable average, given all the variables involved in predicting the physical future of a 2-day-old.

If he's right 90 percent of the time, he's wrong 10 percent of the time. If parents follow his advice consistently, nine hopelessly retarded children are likely to die before age 2. So is one potentially vibrant child.

Maybe that's the price our society should pay to ensure that such painful, personal decisions are made by a small circle of family and professional experts. Maybe that's the price we should pay to ensure that nine families don't find their lives emotionally and financially warped. Maybe that's the price we should pay to avoid contributing another load to soaring health costs. Maybe that's the price of sparing these children a life of pain.

Maybe. But let's at least admit that we are taking this risk, that we are probably paying this price. Let's admit we are judging, or acquiescing in others' judgment of what is a "good" and a "bad" life. Let's admit we are coining a new aphorism: one good life must be cut short to keep nine bad ones from being prolonged.

INS

MENT



Dowdinger  
at ~~USCC~~  
USCC

Hastings  
Center  
(medical ethics)

Parris  
is running

federal  
grant  
to

lead  
attorney

in

Conroy  
case

in  
N.J.

funding  
Tubes  
removed.

The Rehabilitation Act of 1973  
that no discrimination against a person because of handicap  
clearly we would support

what HHS is doing

— did support the  
Baby Doe regulations

includes  
withholding  
food + med. care  
as a form of  
child abuse

Stacy Murphy's bill, Calkins  
child abuse bill  
+ handicap discrimination

gov't is right to  
take a role in these  
cases

USCC

— like HHS we  
would like to see  
the medical records

— enforcing 10 yr old  
law

— Catholic Health  
Association basically supports Baby Doe rules

1. applies  
to federal  
inst. med.  
facilities

2. applies to  
people of  
all ages

3. denial  
of food + med.  
that would  
be  
prejudicial to  
non-handicapped  
is forbidden

1863 Jane Doe  
file



File - Euthanasia -  
Conroy case

NOT FOR PUBLICATION WITHOUT THE APPROVAL OF THE COMMITTEE ON OPINIONS

TRIAL COURT  
OPINION

SUPERIOR COURT OF NEW JERSEY  
CHANCERY DIVISION - ESSEX COUNTY  
DOCKET NO. P-19083E

In the Matter of : Civil Action  
:   
CLAIRE C. CONROY : OPINION  
:   
:

Decided February 2, 1983

- William I. Strasser for plaintiff Thomas C. Whittemore  
(Donohue, Donohue, Costenbader & Strasser, attorneys)
- John J. De Laney, Jr. for patient Claire C. Conroy

STANTON, J.S.C.

The question presented by this case is whether a nasogastric tube should be removed from an 84 year old patient who is suffering from severe organic brain syndrome and a variety of serious ailments. The patient is totally dependent upon the tube for nutriment and fluids. Removal of the tube will probably result in death within a few days. I have decided that it would be wrong to prolong the life of the patient. Her guardian will be authorized to have the tube removed.

Claire Conroy was adjudicated incompetent in 1979. Her nephew, Thomas C. Whittemore, the plaintiff in the present action, was

appointed as her guardian. Since 1979 the patient has been a resident of Parklane Nursing Home in Bloomfield, New Jersey. In July, 1982, the patient was admitted to Clara Maas Memorial Hospital, Newark because of a severe infection of her left foot. Her left foot was diagnosed as being gangrenous. Her physicians recommended amputation of her left leg above the knee. The physicians believed that death could occur within two weeks if the leg was not amputated. In the belief that the amputation was not in the best interests of his aunt, the guardian refused permission. The physicians declined to press the issue. The leg was not amputated, but the patient did not die. The patient was discharged from the hospital back to the nursing home on November 17, 1982. At present the lower left leg is wasted and rotted. However, the infection has been contained and the leg does not presently pose a threat to the patient's life. The leg does not now seem to be a source of major pain.

Claire Conroy suffers from severe organic brain syndrome, necrotic decubitus ulcers on her left foot, left leg and left hip, urinary tract infection, arteriosclerotic heart disease, hypertension and diabetes mellitus. Except for minor movements of her head, neck, arms and hands, she is unable to move. She does not speak. She lies in bed in a fetal position. She sometimes follows people with her eyes, but often simply stares blankly ahead. Her general physical appearance is very withered.

Although she moans when moved or touched upon some portions of her body, medical testimony is inconclusive as to whether she is capable of experiencing pain. The patient has sufficient brain functioning to regulate certain internal bodily functions. However, except for use of her hands for scratching, she seems incapable of useful external bodily activity. All the testimony in the case and my own direct observation of the patient convince me that she has no cognitive or volitional functioning. There is no reasonable expectation that the patient's condition will ever improve.

During her recent hospitalization, a nasogastric tube was inserted through the patient's nose, down her throat and into her stomach. Several times a day water, a nutrient formula, vitamins and medicine are poured through the tube. The patient is unable to swallow. Nurses would not be able to feed her by hand. Without the tube, the patient would probably die of starvation and dehydration within a few days. With the tube, the patient will probably be able to live for some months, perhaps even a year or more.

Claire Conroy never married. Her siblings are all dead. Her only surviving relative is the plaintiff who is her nephew and guardian. The plaintiff testifies that his aunt never saw a physician or received medical treatment at any time prior to her becoming incompetent in 1979. She scorned medicine. Her nephew believes that she would not willingly accept the tube



and the treatment she is now receiving. The guardian wishes to have the tube removed and to allow his aunt to die. The patient's treating physician, Dr. Ahmed Kazemi, will not consent to the removal of the tube. The nursing home has been following the physician's wishes. However, the home is essentially neutral on the issue of removal of the tube and will not oppose any order entered by the court. The nephew/guardian has brought this action to obtain a judicial declaration that he has the right to have the tube removed.

The guardian filed a complaint on January 24. On that date I appointed John J. De Laney, Jr., an attorney, as guardian ad litem of Claire Conroy. I heard testimony on January 31 and February 1. This opinion is being issued on February 2. The witnesses have been Dr. Ahmed Kazemi, the treating physician, Dr. Bernard Davidoff, a physician called by the guardian ad litem, Catherine C. Rittél, a registered nurse who is the nursing home administrator, Thomas C. Whittemore, the nephew/guardian, and Rev. Joseph Kukura, a Roman Catholic priest who is a member of the medical ethics committee at four hospitals and an associate professor of Christian ethics at Immaculate Conception Seminary.

The physicians agree on the medical condition of the patient. So does the nurse. It is obvious to any person seeing the patient that she is desperately sick. It is also obvious that her mental functioning is primitive. Dr. Kazemi thinks it would be a violation of medical ethics to remove the tube. Dr. Davidoff believes that, with the consent of the patient's guardian, the

tube should be removed. Nurse Ritter would be reluctant to see the tube removed. The guardian thinks it is wrong to keep his aunt alive through use of the tube. Father Kukura thinks that under all of the circumstances of this case removal of the tube is morally appropriate. The guardian ad litem argues strongly against removal.

I think it fair to say that everyone involved in this case wishes that this poor woman would die. This wish does not flow from any lack of concern for Claire Conroy. On the contrary, it flows from a very deep sympathy for her sad plight. The disagreement among the participants involves differences in perception about what helping this patient means under the circumstances of this case.

Life is our most basic possession. The will to stay alive is probably our strongest instinctive drive. As a general proposition, the protection of life is one of the law's strongest imperatives, and preservation of life is the major goal of medical practice. The interest of the State in preserving life is so great that courts have ordered medical procedures to be performed on patients even though the patients were competent and had objected to the procedure. In these cases, however, the expectation is that the patient will have a reasonably full and vibrant life after the treatment has been performed. There is a point at which a patient, or someone acting for him if he is



incompetent, has the right to refuse treatment. That point is reached when intellectual functioning is permanently reduced to a very primitive level or when pain has become unbearable and unrelievable. See In re Quinlan, 70 N.J. 10 (1976); John F. Kennedy Memorial Hospital v. Heston, 58 N.J. 576 (1971); In re Quackenbush, 156 N.J. Super 282 (Cty. Ct. 1978).

When we deal with questions such as the ones presented in this case, a certain basic humility and a sense of one's own limitations are appropriate. We know that mankind's understanding of the ultimate meaning of life, suffering and death is (and probably always will be) flawed and limited. Many of us believe that an abiding reverence for life is perhaps our most special and most worthy human characteristic, but most of us would agree that when a person has been permanently reduced to a very primitive intellectual level or is permanently suffering from unbearable and unrelievable pain there is no valid human purpose to be served by employing active treatment designed to prolong life. Every sick human being is entitled to loving care, but there comes a time in the loving care of some patients when the proper decision is to let nature take its course, to allow the patient to die.

Even when we decide that it is proper to withhold active treatment, it would be wrong to act directly to terminate life or to withdraw nourishment, fluids, shelter or normal supportive care such as washing and body positioning. When I say that it would be wrong to withdraw nourishment or fluids, I mean that it would be wrong to refuse to give them to the patient if she could take

them herself or with the manual assistance of others. It would also be wrong to withhold medications which would reduce pain without unduly prolonging life. I conclude that these things would be wrong because I perceive a need in this area of decision making (1) to recognize the limitations of our understanding of life, suffering and death, (2) to continue a fundamental respect for life even in the most dire human circumstances and (3) to keep in place some fairly simple conceptual controls designed to give some measure of protection against ill-informed or badly motivated decisions.

In this case, plaintiff's counsel has argued that the tube should be removed because it constitutes an extraordinary means of treatment. I know that the distinction between "extraordinary" and "ordinary" means of treatment is frequently made in this area of concern, but I must say that I do not find this terminology particularly helpful. It seems to me that the critical factor is the condition of the patient. I mean here both the present condition and the reasonably predictable future condition. If the patient can be restored by treatment to some meaningful level of intellectual functioning and to some acceptable level of comfort, then the full range of medical knowledge, skill and technology which is available should be brought into action as a matter of ordinary routine. Conversely, if the clear prognosis is that the patient will never return to some meaningful level

of intellectual functioning and to some acceptable level of pain, then virtually every act of treatment other than the simple care mentioned in the preceding paragraph is inappropriate and is extraordinary. The focus of inquiry should be upon whether the life of the patient has become and is likely to remain impossibly burdensome to the patient. If the patient's life has become impossibly and permanently burdensome, then we simply are not helping the patient by prolonging her life, and active treatment designed to prolong life becomes utterly pointless and probably cruel. (I hasten to add that I know that persons who advocate active treatment under these circumstances do not intend to be cruel. They are, of course, acting with the intention to help the patient.)

I know that people sometimes say that physicians frequently and courts less frequently "play God" in this area of decision making. There is sense in which that statement is true, but it seems to me that the implied criticism it contains is not valid. This is not an area where mere mortals are presumptuously reaching out to make decisions beyond their legitimate capabilities. Until fairly recently in the course of human history, nature solved many of our problems without our having much to say about it. With the rapid recent development of medical knowledge, skill and technology has come a broadly expanding ability to intervene in what would otherwise be the normal flow of nature and to prolong life significantly for many human beings.

This is generally a good thing. However, it is not an unqualifiedly good thing. Presently available knowledge, skills and technology (to say nothing of what the future may hold) now give us the ability to prolong some lives which ought not be prolonged. We cannot mindlessly and indiscriminately act to prolong all lives, by all means, under all circumstances. We must make some choices.

Of course, once we human beings start making choices we start making mistakes. It is inevitable that we will allow some people to die when we could have and should have prolonged their lives. But we cannot let this fear of error force us into abdicating our basic human responsibility to make choices. The fear of error should be used constructively as an incentive to make our choices carefully and soundly.

I am firmly convinced by the evidence in this case that Claire Conroy's intellectual functioning has been permanently reduced to an extremely primitive level. She suffers from all of the medical problems mentioned above. The general state of her health is very poor and will remain so. Her life has become impossibly and permanently burdensome for her. Prolonging her life would not help her. It would be a wrong to her. The nasogastric tube should be removed, even though that will almost certainly lead to death by starvation and dehydration within a few days, and even though that death may be a painful one for



the patient.

### Some Misgivings

The nasogastric tube involved in this case is a very simple device. It is so simple that when I first started to think about removing it, I worried that I was getting perilously close to a straightforwardly wrongful refusal to feed a fellow human being. However, I think that there is a real difference between failing to feed a patient who could take nourishment by herself, or with the manual assistance of others, and failing to keep a nasogastric tube in a patient who has permanently lost the ability to swallow. For one thing, I think that the permanent loss of the ability to swallow is often reflective of a vast impairment of brain functioning. For another, I think that nature may be telling us something about a patient when the ability to swallow is permanently lost.

I have also had some misgivings about an inappropriate impact that a decision such as the present one might have on the treatment of elderly senile persons or on the treatment of retarded persons of all ages. Sometimes people incorrectly evaluate the meaningfulness of the lives of the senile or the retarded. As viewed by some, a decision such as the present one might lead to a wrongful withholding of treatment for the senile or the retarded. Here, I can only say that careful distinctions have to be made. The present patient is functioning at a virtually zero intellectual



level. Most people who are suffering from organic brain syndrome and are broadly thought of as being senile operate at an appreciably higher mental level, although their intellect is markedly impaired. They are capable of loving and of responding to love. They are not in the same category as this poor woman. If they become injured or ill, active treatment is mandatory. I am sure that the same is true for most retarded persons. When we think about the problems of the elderly senile and the retarded, we know that we have to be very careful about premature and wrongful withdrawal of treatment.

#### Judicial Involvement

In the Quinlan case the New Jersey Supreme Court indicated that judicial involvement in this area of decision making is not necessary in every case, and, indeed, might sometimes be inappropriate. See In re Quinlan, supra, 70 N.J. at 38-55. That view is clearly a sound one. As often as possible, the patient, the family, and the physicians involved should make these decisions for themselves.

However, fairly frequently judicial involvement is necessary. Sometimes the patient is incompetent and has not prior to her incompetency given any clear indication of what her desires might be. (This is so in the present case.) Sometimes the family is divided in its views. Sometimes physicians differ among themselves

or with members of the family. (This is so in the present case.) When one or more of these factors are present, judicial involvement is indicated.

It should also be noted that the kind of medical ethics committee envisioned by the Quinlan case as being available in the typical hospital is not, in fact, in place in many New Jersey hospitals. Such a committee is not available in the typical nursing home. Thus, the kind of solid private institutional support and monitoring of decisions contemplated by the New Jersey Supreme Court in Quinlan is frequently not a reality. This means more judicial involvement than would otherwise be the case.

I might also note that I would have some misgivings about a plaintiff such as the present one making basic decisions about termination of treatment without being subject to some kind of judicial scrutiny. Mr. Whittemore is an intelligent and decent man. He is the legal guardian of the patient. He certainly means well for the patient. I believe that in this case he has, in fact, reached the right decision about the nasogastric tube. However, he is only a nephew of the patient, and is, thus, not a particularly close relative. He does not stand in the same relationship to her as would a parent, a spouse, a sibling or a child. Hence, his views are perhaps somewhat less relevant than would be those of a closer relative.

There is a need for some public monitoring of the trend of decisions in this area. Physicians have a technical expertise,

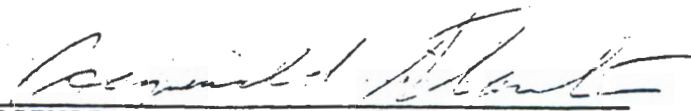
a frequent contact and a professional moral sensitivity which entitle their views to great deference. However, they do not have the public perception and the public responsibility which courts have. Judicial involvement from time to time is, I think, helpful to the integrity and validity of decision making in this area.

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JUDGMENT

For the reasons stated above, on this 2nd day of February, 1983, it is ADJUDGED and ORDERED as follows:

1. Thomas C. Whittemore, as guardian of Claire C. Conroy, has the right to cause the removal of the nasogastric tube presently inserted in Claire C. Conroy. The actual removal is to be made by a qualified health care professional person who has no personal or professional objection to such removal.
2. Although it is expected that the removal of the tube will lead to suffering and death, the guardian and health care personnel retained by him must take reasonable steps to minimize the discomfort of Claire C. Conroy during her passage from life.

  
REGINALD STANTON, J.S.C.