Special Communications

Brain Death—An Opposing Viewpoint

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• Recent and proposed legislation to establish "brain-related" criteria of death has uniformly confounded irreversible cessation of total brain function with the death of the human person. Much of the confusion comes from widespread misunderstanding of how the word "death" is used and what it means. Cessation of total brain function, whether irreversible or not, is not necessarily linked to total destruction of the brain or to the death of the person. Further, to take vital organs or to otherwise treat people as though they were dead already on the basis of these recent criteria is morally unacceptable to most Orthodox Jews and Christians.

(*JAMA* 242:1985-1990, 1979)

IN a 1977 article in THE JOURNAL, Veith et al[1] argued in support of defining death by statute. They favored, in particular, a statute modeled on the American Bar Association's (ABA's) proposed definition of death: "For all legal purposes, a human body with irreversible cessation of total brain function, according to usual and customary standards of medical practice, shall be considered dead." (Since the arguments we shall offer against the ABA proposal apply a fortiori to statutes based on the Capron-Kass models, we do not discuss these latter explicitly, though Veith et al regard them, along with the ABA's proposal, as satisfactory. For similar reasons, we do not take up explicitly the Uniform Brain Death Act, proposed in August 1978 by the National Conference of Commissioners on Uniform State Laws.)

For editorial comment see p 2001.

As many others before them have done, Veith et al discuss medical feasibility and write at length concerning legal advantages.[1] What seems to be novel in their article are their arguments that "pronouncements of death on brain-related criteria are in accord with secular philosophy and principles of the three major Western religions."

The present article is written to show that the ABA's definition of death and, indeed, all 19 or so statutes that have undertaken to define and establish at law "brain-related" criteria of death are based on scientifically invalid assumptions and are also opposed to the three major religious traditions of this country.

Understanding 'Death'

When speaking of "definitions of death," a sharp distinction must be made between two quite different modes of definition. On the one hand, "death" is the word we use *to name* a certain *empirically given* state of affairs, a state difficult to describe in full generality, yet one with which we are all too familiar as a situation of fact. Someone we have known ceases to breathe, sags wherever not supported; we find no pulse; there is no sign of inner activity or of reaction; all is silent, inert, then cold; the body grows rigid, later becomes flaccid and begins to putrefy, decomposing till only bones remain. Most importantly, from a certain moment on—"the moment of death"—whatever happens, whether it involves putrescence, mummification, incineration, or nuclear vaporization, is entirely describable in terms of disintegration, dissolution, destruction of the unity of the single organism that was formerly present: a human being has, so far as this world can tell, simply ceased to be.

On the other hand, at all times people have attempted, when using the word "death," not merely to refer to the experientially given state we have mentioned but to say what that state is, to explain it where possible, at least to describe it in terms of the concepts found useful for describing the rest of the universe. Such a redescription and, ultimately, *explanation* of death can be seen as a definition of

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"death" *within the framework* of that single system or world view. These context-dependent definitions, then, may well be debated and argued by all concerned. None of them are, as such, empirically given; none express solely what are matters of medical fact, though some definitions may elevate certain descriptive elements to the level of system. The shallow approach to so profound a reality as death taken by a number of medical and legal ethicists today who consider death not to be a fact but a matter of mere use of language or convenient social stipulations seems to arise from their confounding the two basic kinds of definition.

Now, at law, the nonempirical, context-related definitions of philosophers and theologians have in the past been carefully avoided, if for no other reason than that it is not within the competence of the law to discriminate among them. But death itself, the fact, not the concept, the endlessly repeated and sorrow-laden seeming extinction of human beings, *is* the law's concern, as it is that of the ordinary people who look to the law for the protection of their lives. No moving away from the *empirical* notion of death can be acceptable at law.

The legal question being debated at present, however, is not about the definition of death, despite the efforts of some to turn it that way, but about the validity of certain proposed *general criteria* for death. For, people have long known that the ultimate disintegration can be forseen without danger of error at a time well before manifest putrescence. For example, once rigor mortis is observed, we are wholly certain that the person has died. With the progress of medicine, yet other clusters of empirical signs occurring still closer to the moment of death have been found to be reliable indicators that death has occurred. Such sets of signs as rigor mortis and these more recently validated ones we call "general criteria" of death.

To verify the presence of a general criterion requires, in turn, the use of subordinate or secondary criteria. Many observations and tests may have to be made and many factors considered if full certitude is to be had in difficult cases. But, it is essential to note, neither subordinate nor general criteria *define* "death," none of them are what we mean by "death." They are merely specifications, general or particular, of the sorts of observational data that would enable us validly to conclude to the fact of death in a particular case. Now, most of the "definitions of death" under current discussion, eg, irreversible cessation of total brain function, turn out to be, on inspection, just such general criteria.

All general criteria used as standard up to now have developed from the intention to make sure that a person who is still alive will not be treated as if dead. The proposed new criteria are intended to be used in the opposite sense: to prevent someone from being treated as alive when he is already dead. One is concerned now to prevent the possibility that present-day life-support systems might mask death and cause a corpse to mimic life—at expense to the living, in suffering and in money. In the past, a mistaken determination of death usually had no other result for a dying patient than his being allowed to die without further treatment. But the new criteria are intended not only to decide as soon as possible when someone is dead but, among other options, to clear the way for the excision of his vital organs—action which, if a mistake has been made, is certain to kill the still-living patient. Since any criteria nowadays must subserve organ transplantation as well as other purposes, any new general criterion of death must be at least as certain as the older ones, since a mistake here would be lethal. Yet as we shall soon see, the proposed criteria are far less certain than the older ones; they are, we shall argue, not merely uncertain but certainly wrong in principle.

We point out first that nothing describable as "brain function" is simply equivalent to human life, though, once the brain is formed, human life usually, but not always, requires some kind of perduring function of the brain. We then argue that cessation of function, whether irreversible or not, has no necessary connection with either destruction of the brain or death of the person and, therefore, cannot serve as a general criterion of death. We conclude by showing that so-called definition-of-death legislation goes directly contrary to the major religious traditions of this country.

'Brain Function' or Functions of the Brain?

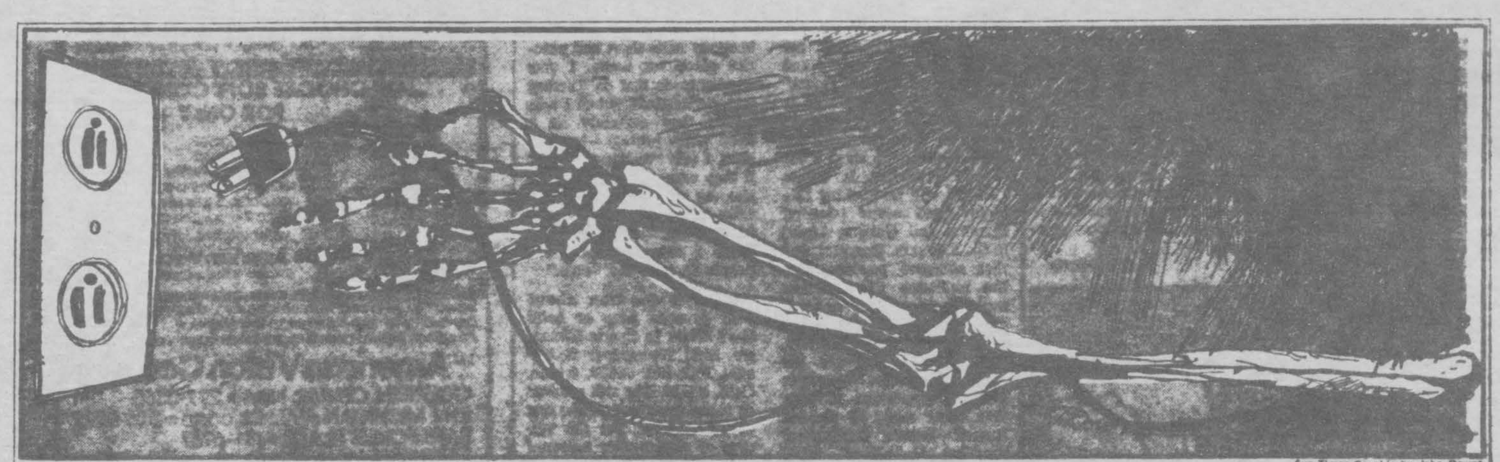
Before considering the medical aspects of this question, it is important first to dispose of an all-pervasive philosophical sleight-of-hand that forms the hidden and often unconscious root of most arguments we have seen on the subject. It can be summed up in the following line of reasoning.

The brain (or some selected portion of it) is that organ whose specific function it is to make a human person be alive. The brain cannot, therefore, by definition cease this function without making the person cease to live. Hence, cessation of total brain function (not "brain functions," some few of which, apart from this primary one, may continue for some time after death) is, by definition, identical with the death of the person. (This line of reasoning has been made explicit by DeMere[24] but is implicit throughout much of the literature.[1,5,7])

Were this argument valid, then any cessation of total brain function would be death, by definition. The recoveries of all those who have shown for many hours, even days, no discernible trace of any brain function as a result of various depressant poisons or of hypothermia would have been resurrections from the dead. And if it be objected that such people did not really suffer cessation of total brain function but only seemed to, then we are being offered a criterion that is empirically unable to do the very job it was introduced to accomplish.

Philosophically, the argument implies, all unnoticed by many of its proponents, a strict materialism. It reduces the life of the human person to a putative organic function of the material brain. "Brain function" is so defined as to take the place of the immaterial principle or "soul" of man. Of course, such a materialism is a widely held philosophical option. But it stands in flat contradiction to the religious beliefs of Christians, Jews, Moslems, Hindus, and many others. Thus, no arguments based on such reasoning can be allowed if reli-

Chi **Sun-Times** **July 10, 1980** **57**



Sun-Times Graphic by John Downs

When do we have right to choose death?

Barbara Varro

In the Broadway play, "Whose Life Is It Anyway?" a woman who has been paralyzed from the neck down in an auto accident begs her doctor to leave her alone so she can die in peace. The woman, a sculptor, does not want to face a life as a quadriplegic who will never again be able to do the work she loves.

The essential question posed in Brian Clark's play is: Do people have the right to choose death rather than accept extraordinary medical measures that might sustain their lives?

THERE ARE NO SIMPLE answers to that question, but it continues to pop up frequently as attention is focused on the issue of patients' rights in regard to medical treatment. That issue becomes extremely complex in the case of terminal illness, raising a host of ethical, moral and legal questions for doctors and hospital administrators.

Health professionals point out that the very advances in medical technology that have made it possible for doctors to sustain more lives today—wonder drugs and electronic life-sustaining machines—are raising new questions in regard to patient care:

- Must doctors do everything in their power to persuade patients (or their families, if the patient is not competent to make a decision) to accept the technology or drugs that may prolong their lives?
- Who *should* have the final word about whether something such as surgery or chemotherapy should be used—the doctor, the patient, his family?
- Can failure to persuade a terminal patient to opt for therapy or surgery that may save his life be construed as helping that person to commit suicide?
- Can discontinuation of apparatus such as a respirator (which essentially breathes for the patient) be interpreted as a kind of euthanasia?

MANY HEALTH PROFESSIONALS view the patient's right to let fate take its course as the acceptance of the inevitable. "It is a terminal patient's innate right to accept or refuse treatment after his or her doctors have explained the prognosis," says Sister Dorothea Salcius, S. S. C., president of Holy Cross Hospital. "If the patient is Roman Catholic, a hospital chaplain or counselor will explain the moral implications. Patients and their families are told that they are under no moral obligation to accept heroic measures to attempt to save their lives."

Salcius does not believe that failure to use extraordinary means to prolong the life of someone whose brain activity has ceased should be construed as a hastening of that person's death. "It is letting life take its natural course," she said.

Judith Johns, clinical director of psychiatry at Grant Hospital, does not think that the wish to die a "natural" death without extreme means of intervention can be interpreted as suicide. "I think of suicide as cutting off of a viable life," she says. "The person who believes in the quality of life may feel that his life, which may be irrevocably altered [by a serious accident or terminal illness], is no longer viable."

She believes that a person who chooses not to accept heroic measures to prolong life may be accepting the inevitable. "The issue of patient's right to die is so subjective," she says. "It depends on how an individual looks at death. While some people are terrified of death, others are not so frightened by it."

IT ISN'T HER JOB, JOHNS says, to talk a person out of a decision if that person is mentally competent. But she encourages patients to give their decision a lot of thought, and to talk to their families about it. "I tell them that choosing to die is the most irreversible decision they can make in their lives. There is no turning back."

In the course of her work, Johns has counseled scores of patients who have had to contend with great suffering and pain. "I can em-

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The state of right-to-die legislation

Attempts to legislate the patient's right to die continue to cause controversy. While laws concerning the issue have been enacted in 10 states in the last seven years, Illinois has resisted such legislation. Ill. Rep. Bernard E. Epton (R-Chicago) has introduced a "death with dignity" bill several times since 1973. The bill was defeated each time. "My bill to protect a patient's right to die is very simple," Epton said. "It states that a person of sound mind who was suffering from a terminal illness could authorize a doctor to discontinue heroic measures."

EPTON POINTS OUT that his bill was defeated primarily by medical professionals who lobbied against it. Some doctors protested on the basis that patients already have the right to refuse heroic measures. Others said that the bill didn't provide enough protection for physicians. Nor did it provide for what can be done by family members in the case of terminally ill patients who are unable decide about having life-sustaining apparatus withdrawn.

Epton believes that the right-to-die issue is a gray area that needs clarification under the law. "It's not true that patient's rights are always honored by doctors and hospitals," he said. "While my bill is primarily concerned with patients' rights, it also protects the doctor from possible

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Whose death is it anyway?

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pathize with those who feel they can no longer endure the suffering," she says. "A patient whose cancer has metastasized recently told me that she doesn't want to go through the treatment again. She already has had two mastectomies and hip surgery, and she is physically and emotionally spent. She doesn't think she can endure the treatment again, even though doctors feel that therapy might extend her life. It is a very tough decision for her. But it must be *her* decision and no one else's."

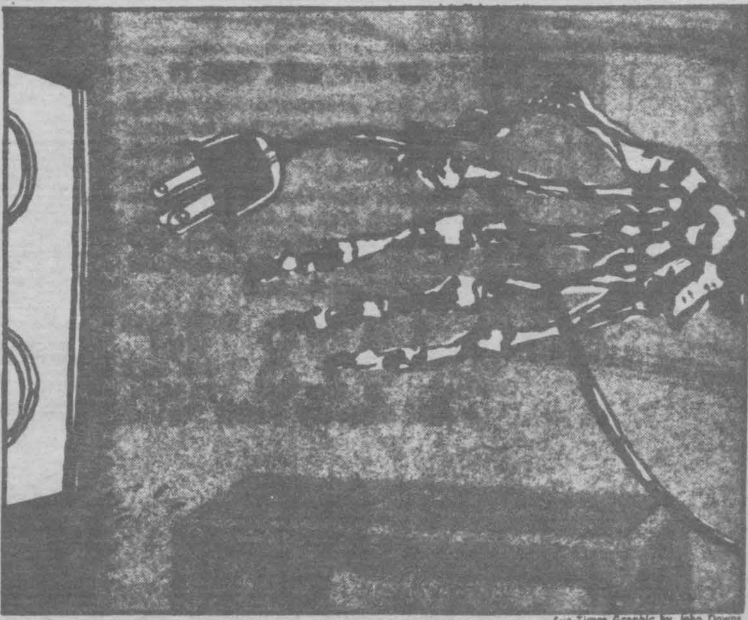
While the issue of death and dying is still a very sensitive one, Johns believes that people are gradually beginning to understand it more clearly. "I think that Elisabeth Kubler-Ross's pioneering work in death and dying counselling has made more people feel that it is OK to talk about death," she says.

Bringing death out of the closet, so to speak, also has encouraged more doctors to be honest with their patients, says Dr. Walter Hollinger, Grant Hospital's director of critical care. "Patients," he says, "often ask their doctors—'What would you do if you were in my shoes?' It is up to the individual doctor, of course, but most probably he would be on the side of taking measures to prolong life. But the doctor isn't the only one who enters into the picture. More people today are taking personal responsibility in their health care and maintenance, so they don't just defer to the doctor. Now the whole family is likely to become involved in decisions about a patient's care."

HOLLINGER THINKS IT IS a good idea for spouses to discuss how they would want to be treated in the event of terminal illness or a serious accident. "It is a difficult decision for people to make alone," he says, "so it is helpful to have some clue as to how the person would want to be treated. Talking about the possibility of death would help family members to make informed decisions about the terminal patient's care."

The right-to-die issue becomes more complicated when the patient is not competent to make a decision. Each case must be decided individually because there are no established legal precedents to provide specific guidelines for use or non-use of life-saving or life-prolonging procedures.

The most famous legal case regarding a request to discontinue a life-support system was the 1976 Karen Ann Quinlan decision. The young woman had lapsed into a coma, apparently from an adverse reaction to a combination of tranquilizers and alcohol. Although her brain activity had ceased, her heart and lungs were kept functioning via an electronic support system. After a highly publicized court battle with the hospital, her parents eventually received permission from the New Jersey Supreme Court to have Quinlan taken off the apparatus. Four years later, she is still living.



Sun-Times Graphic by John Downs

According to the American Medical Association, the outcome in the Quinlan case has not cleared up the right-to-die issue. "Each case still must be decided on the particular facts and circumstances involved," says an AMA spokesman.

THE AMA'S JUDICIAL COMMITTEE has adopted a policy regarding terminally ill patients to be used as a guide for health professionals:

- The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that the biological death is imminent is the decision of the patient and his immediate family or his lawful representative, acting in the patient's best interest. The advice and judgment of the physicians involved should be readily available to the patient and/or immediate family.
- The intentional termination of the life of one human being by another—mercy killing or euthanasia—is contrary to public policy, medical tradition and the most fundamental measures of human value and worth.

Hospital administrators concede that cases of terminal patients who are unable to make a decision about their own care must be handled with sensitivity. Malpractice, after all, is a fact of modern medical life.

"In the case of family members who want a patient taken off a respirator," Salcius says, "we require more than one family member to sign the order to discontinue use of extraordinary means. We had a case recently of a brother who wouldn't sign the order, so we did not take patient off the respirator. The patient died a week later, while still on the respirator."

She says that in recent years, some patients have asked to have "no code 99" (a directive that heroic measures not be taken to revive them should they suffer cardiac arrest or lapse into a coma) put on their hospital charts.

What are the views of some religions on the patient's right to die? According to a statement from the General Synod of the United Church of Christ, "Nothing in Jewish or Christian traditions . . . presumes that a physician has a mandate to impose his or her wishes and skills upon patients for the sake of prolonging the length of their dying where those patients are diagnosed as terminally ill and do not wish the interventions of the physician."

State of laws on right to die

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malpractice suits because it contains a patient's explicit directive to his physician."

He didn't include language in the bill regarding family members who might want to "pull the plug" on a patient who is in a coma, for instance, because he thinks such matters are very complicated. "Patients should be protected against a spouse or heir who might want to do away with them," he said. "And my bill in no way gives permission to hasten a patient's death."

The Illinois Medical Society is among those opposed to right-to-die or any similar legislation based on what it believes must be a private matter between a patient and physician.

"THERE IS NO REASON to institute laws regarding rights [patient/doctor confidentiality] that already exist," said a spokesman for the society. "Such laws can only serve to confuse the situation, and impose strictures on patients and physicians."

In Great Britain, he added, some people are lobbying for living wills that would include euthanasia as an available option for patients who want to end their pain and suffering.

A. J. Levinson, executive director of Concern for Dying, a New York organization dedicated to helping people become more sensitive to the needs of terminally ill patients, favors a living will but opposes legislation mandating it.

THE FOLLOWING IS AN example of a living will supplied by Concern for Dying:

To my family, my physician, my lawyer and all others whom it may concern:

If at such a time the situation should arise in which there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by medications, artificial means or "heroic measures." I do, however, ask that medication be mercifully administered to me to alleviate suffering even though this may shorten my remaining life.

This statement is made after careful consideration and is in accordance with my strong convictions and beliefs. I want the wishes and directions here expressed carried out to the extent permitted by law. Insofar as they are not legally enforceable, I hope that those to whom this will is addressed will regard themselves as morally bound by these provisions.

Signature
Witness and date

For more information about a living will, write to: Concern for Dying, 250 W. 57th St., New York, N.Y. 10019.

Barbara Varro

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PBS' 'Suicide' is not the way to go

THE PUBLIC BROADCASTING SERVICE has always had a soft spot for how-to programing, but isn't How to Kill Yourself carrying things too far?

I'm talking about something called "Choosing Suicide," which will air on Channel 13 June 10 at 8 p.m. You probably remember the incident that prompted the show, which was widely reported in the press a year or so ago.

Jo Roman, a New York artist and social worker decided to end her life after learning that she had terminal cancer, and she made quite a production of it. She brought her husband (a professor of psychiatry) and friends together in the living room of her spacious West Side apartment, where they sat around quaffing wine and discussing Jo's decision, after which Jo made her affectionate farewells, popped the fatal dose of pills and settled down into a coffinlike pine box to await the end.


Jo Roman: a death wish

Jo defended her action as consistent with her belief in the principle of "self-termination," and now documentary maker Richard Ellison has produced more or less a reprise on the event by questioning her husband and friends about it.

What Jo didn't say in her own elaborate justification for her act (left for posthumous publication), but what seems to be the real point of her story, is that when things get irreversibly tough, we can all throw up our hands and kill ourselves, if we wish.

The artist insisted that her actions were not unreasonable. She spoke of wanting to be in control of her own life. But was she? Are any of us? A distinct impression I came away with after viewing this program, which will be followed by a half-hour discussion with Hugh Downs as host, is one of hopelessness. To calmly discuss a person's planned suicide without someone rebelling or screaming, "I want you to live," is beyond my comprehension.

How PBS can justify this bizarre exercise I'll never know. It's not only embarrassing but obscene. I applaud the Connecticut Public Broadcasting Network, which operates four stations, the Maine Public Broadcasting Network and the Mississippi Educational Television Network for refusing to carry the program.

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ANN LANDERS

The question of death with dignity

DEAR ANN: In the last eight months I have lost my father and sister to cancer. She was the beauty of the family and only 42 years old. It was lung cancer. She had been smoking since high school.

Dad had cancer of the colon. He was one of those hale and hearty types, never sick a day in his life. So why go to a doctor for a checkup? He died on his 66th birthday.

The reason I am writing is to ask if it is possible, should I get a terminal illness, to prevent the doctors from keeping me alive by artificial means? I saw my sister and dad linger for weeks when there was no chance for survival. It was obscene the way they kept Dad alive by using a kidney machine and a respirator—with tubes inserted in every orifice. Dad pleaded with us to instruct his physician to let him die in peace, but neither I nor my mother could bring ourselves to do it. We both feared guilt feelings might haunt us later, and of course, we were constantly praying for that one-in-a-million miracle.

Can a person make legal arrangements, in case of a terminal illness, to guarantee that he will not be kept alive on machines?

—Thanks, But No Thanks in Illinois

Dear Thanks: Yes, you can have your way if you live in a state that recognizes the "living will." (Illinois is one that does.) This is a document, signed by you, which guarantees the right to die in peace should you be stricken with a terminal illness that your physician declares is irreversible. The living will relieves relatives and doctors of the responsibility of making the decision.

Anyone who wants more information and a free copy of a living will can obtain one by writing to Concern for Dying, 250 West 57th St., New York, N.Y. 10019. This organization has sent out more than three million copies. At this writing, only ten states have a "right to die" law. If you live in a state that has no such law, your family and doctor may not be willing to respect your wishes, but they will be aware of what your wishes are.

Beyond the Quinlan decision

By GEORGE F. WILL

WASHINGTON — When death comes to Karen Quinlan it will not come with the assistance of the State of New Jersey. That is the unexceptionable decision of the judge in Morristown, N.J., in the rending case of the young woman in an irreversible coma.

The judge refused to grant to Ms. Quinlan's parents permission to turn off the respirator that sustains the faint flicker of her life. The legal case involving her was not complicated or in doubt.

The issue was not the vexing one of how to define death. By no acceptable definition is Ms. Quinlan dead. She retains reflexes, and most important, brain activity. The issue was whether to deliberately produce death by withdrawing treatment undertaken to prevent death.

The judge did not render a "landmark" decision, for which we must all be profoundly thankful. If he had ruled the other way, it would have been a landmark. He would have rendered, in effect, a judgment of execution in a civil action.

LET US NOT mince words: the judge would have authorized a killing. A killing for merciful motives, a killing lovingly sought by the noble people who love Ms. Quinlan most — her parents — but a killing nonetheless.

To authorize removal of the respirator, the judge probably would have had to argue that removal was justified because Ms. Quinlan has irreversibly lost the capacity for a "meaningful life."

He would have been correct about that capacity. The brain begins to liquify when full biological death is delayed by the means employed in Ms. Quinlan's case, and doctors have told her parents liquification has begun in her brain.

But although the judge would have been correct in his belief that vegetative life is not meaningful, and that Ms. Quinlan's "meaningful life" is over, it would have been a terrible mistake to have allowed that as a sufficient reason for a legal — as distinct from a medical — judgment to terminate treatment.

It would have been a mistake, not as a dangerous first step involving government in distinguishing between life that is meaningful and life that is not, but as a dangerous second step.

The first step was taken with regard to abortion. This year many hundreds of thousands of fetuses will be (again, no minced words, please) killed. This killing is legal because the law says, in effect, that fetal life is less meaningful than life after birth.

MY PURPOSE here is not to argue that the law regarding abortion is wise or wicked, but only to note that the Quinlan decision is evidence against one of the worries that causes some people to oppose abortion.

Some opponents of abortion argue that abortion is a first step onto a slippery slope. They argue that once law regarding abortion establishes a distinction between forms or stages of life that are meaningful and forms or stages that are not, there are no standards to stop a slide into a deep and dangerous fog of ambiguity about the meaningfulness of life in many forms and stages.

They argue that the aged, the retarded, and others will be in jeopardy. Such people will constantly face danger from shifting standards of what constitutes meaningful life; their right to life will exist only at the sufferance of a standardless society.

The Quinlan decision is not conclusive evidence that such a slide can not occur, or is not occurring. But it is evidence that society can deny protection to fetal lives without weakening the legal protection of life after birth.

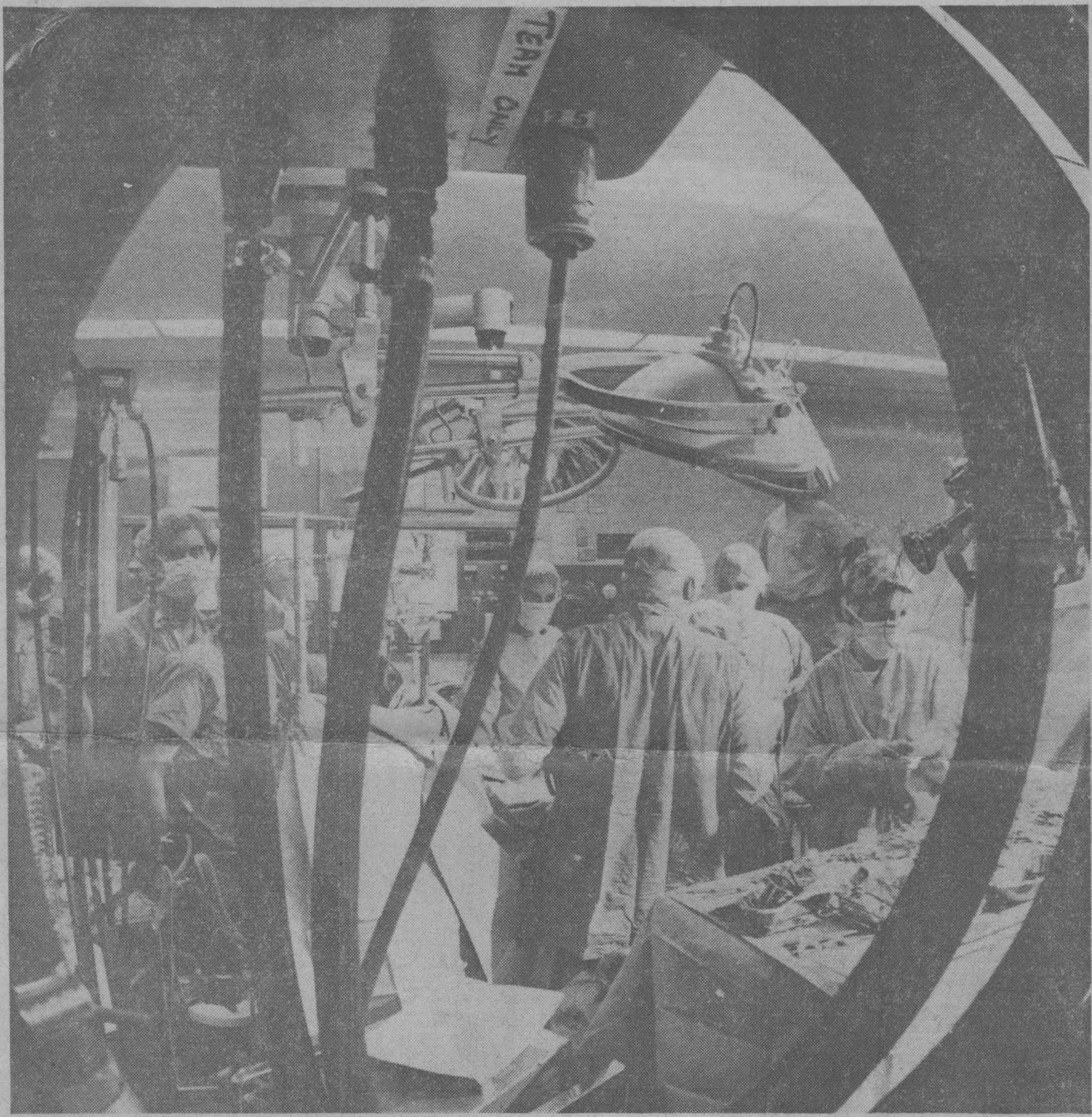
It is fortunate that Ms. Quinlan's parents lost their legal case. But we are fortunate that her parents are among us. They want only "death with dignity" for their daughter. They can not be blamed for wanting the law to cause something that the law should be powerless to cause.

They, like their daughter, are victims of medical technology that has blurred the once clear distinction between life and death. Society's consolation in this sad case is that the law's protection of life has been affirmed, not weakened.

Mr. and Mrs. Quinlan's consolation is that as Christians they believe that regardless of when death begins it does not last.

Inquirer 10/16/77

The twins decision: One must die so one can live



Special to The Inquirer / ED ECKSTEIN

At Children's Hospital, a surgical team separates the Siamese twins, who were joined at the heart

Parents, doctors, rabbis in dilemma

By Donald C. Drake
Inquirer Medical Writer

It was a very low-key press conference and only half a dozen reporters had come out to hear the doctors tell how they had just separated Siamese twins.

Sitting behind a long table on the stage of a mostly empty auditorium, the doctors explained that one of the girls had died because the twins together had only one-and-a-half hearts. Some questions were asked, and then the conference was over — an anti-climatic ending to one of the most intense dramas ever played out at Philadelphia's world-famous Children's Hospital.

No one in the audience realized it, but the operation had probably provoked more debate, more soul-searching on the part of the staff and more concern about the law than any other surgery at Children's in recent years.

At issue was one painful fact:

The surgeons knew that in an attempt to save one of the twins they would have to kill the other.

The one-and-a-half hearts were strong enough to support only one child. Thus the doctors knew that one twin would die soon anyway, and that without the surgery this would lead to the death of her sister.

During the weeks preceding surgery:

- Several rabbis and other learned men met four to five hours every night for 11 days discussing the ethical issues. The parents, who are deeply religious Jews, refused to allow surgery without rabbinical support.
- Nurses and doctors at Children's brooded about the certain death of one of the twins. A few refused to participate.
- Dr. C. Everett Koop, the hospital's chief of surgery, was so concerned about being prosecuted for

(See TWINS on 14-A)

Donald C. Drake, The Inquirer's medical writer, interviewed nearly all the principals in preparing this reconstruction of of the unique separation of Siamese twins last week in Philadelpiha. Through Children's Hospital personnel, the twins' parents asked not to be publicly identified.

Yesterday the hospital reported that Baby Girl B, the surviving twin, was in stable but critical condition.

The surgery: An agonizing choice

TWINS, From 1-A

premeditated murder that he obtained a court order for protection.

For all, it was a time of the most intense self-examination. No other surgery could more dramatically demonstrate the growing number of moral and ethical dilemmas confronting the medical profession as science extends its control over life and death.

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Born only hours earlier at a distant community hospital in New Jersey, the twins looked surprisingly strong when they arrived by helicopter Sept. 15.

They were joined at the chest, and they seemed to be hugging each other with their wizened, newborn faces only a few inches apart. Their respiration rate and their color were comparatively good, indicating that their blood was getting adequate oxygen.

But Dr. Paul Weinberg, a cardiologist summoned from home late at night, knew that something was desperately wrong the moment he looked at the twins' electrocardiogram (EKG) and listened to their chests with a stethoscope.

One heartbeat

He could hear only one heartbeat. And the EKG tracing suggested that there was only one heart.

Special X-ray studies the next day showed that the twin designated as Baby Girl B had an essentially normal, four-chambered heart that was fused to the stunted two-chamber heart of her sister, Baby Girl A.

The hearts were joined along the walls of the left ventricles, the main pumping chambers that push the blood through the body.

The connecting wall was only one-tenth of an inch thick—far too thin to be neatly divided in order to give each twin what belonged to her.

And even if this were possible, the stunted heart of Baby Girl A would not be able to support the child for long.

The doctors felt that they could not leave the babies the way they were either. They knew it would be only a matter of time before the overworked 1½ hearts would start to fail, killing both babies. No twins joined at the heart like this had ever lived more than nine months.

But separating the twins was a job for the surgeons, not a cardiologist.

printed in a series of books entitled "The Letters of Moshe" to guide all Jews.

No less a man could be called upon to try to solve the dilemma confronting the parents of the twins. So Rabbi Feinstein agreed to consider the question.

•

Word spread through Children's Hospital that surgeons were planning to sacrifice one of the Siamese twins.

The hospital had said little, so the rumors were sometimes inaccurate.

Mrs. Jane Barnsteiner, who is Catholic and the associate director for clinical nursing, was asked about the twins by head nurses as she went about the hospital each day on her rounds.

The Catholic nurses, of whom there are many, were particularly concerned that the surgeons might be doing something that violated the teachings of their church.

The word "sacrifice" was used so much by the nurses in discussing the matter that Mrs. Barnsteiner herself became concerned and decided to consult a priest.

At the same time, the nurses in the operating room were becoming particularly uneasy because they knew that they would be called upon to participate in the surgery, if it took place.

Winifred Betsch, assistant director of the operating room complex, was also consulted by her nurses.

Odd as it might seem, operating room nurses rarely witness death — only two or three of the 5,700 patients operated on each year at Children's Hospital die in the operating room. Medicine has developed such effective life-support systems that doctors are almost always able to get the patient at least to the intensive care unit.

So the nurses were very disturbed by the prospects of beginning surgery in which it was already known beforehand that one of the patients would be taken out of the room dead.

Miss Betsch said that she would consult a priest. A Catholic herself, she would not want to participate in the surgery if it went against her church.

•

The twin's father and rabbis met with Dr. Koop on Sept. 20. And then, three days later the rabbis met again with Dr. Koop, but this time

other medical people were not at all happy about the prospect of delaying surgery any longer than necessary.

It would take several days, if not weeks, to get together the complex surgical team, do the necessary preoperative tests and make the other plans.

Concerned that the babies might take a sudden turn for the worse, Dr. Koop ordered elaborate planning for the operation, even though the parents had not agreed to it.

If the parents should say no, nothing but professional time would be lost. But if the babies' health should suddenly fail, at least the team would be ready to move immediately if the parents approved.

Dr. Henry L. Edmunds Jr., chairman of the section on cardiothoracic surgery, was uneasy about all the unknowns in the case, and he said so when the 20 doctors and nurses assembled in the third-floor meeting room on Sept. 30 after many informal conferences in the past several days.

When a surgeon prepares to do heart surgery, he usually has a fairly good idea at least of what the heart will look like.

But Dr. Edmunds had no idea what he would find.

Dr. Weinberg's special X-ray movies showed only parts of the heart chambers and about how much blood was going into the heart muscle — vital information Dr. Edmunds would need before he dared tie off any blood vessels.

Because it would be too dangerous to sever the heart of Baby B from the heart fragment of Baby A, Dr. Edmunds decided to put all six chambers into Baby B's chest. Dr. Edmunds is the type of surgeon who feels uncomfortable unless he has all the facts, and in the case he faced a wealth of unknowns.

The unknowns

Would Baby B's chest be large enough to accommodate such a large heart?

What would happen with Dr. Edmunds cut the section from Baby A off from its natural circulatory system? Would it die, like a gangrenous leg without a blood supply? Or would it be nourished by Baby B's circulation through some unknown circulatory connection?

And what about the electrical conduction that caused the heart to beat? Cutting the A heart section off

Special to The Inquirer / EDWARD ECKSTEIN

Large medical team and a vast array of apparatus were required for the operation

This was an ominous sign — one that the cardiologists had been predicting would come eventually and one that everyone had been dreading.

The nurse summoned the physician on duty and the decision was made to start administering digitalis, a drug used to strengthen heart activity.

Because of the strange physiology of the heart, the doctors could not be certain that the twin was in heart failure, but the signs were disturbing enough to justify the drug.

Dr. Koop was notified of the change in the twins' condition. He did not think it serious enough to put the surgical team on alert.

The rabbi calls

Besides, he still had heard nothing from the twins' parents or the rabbinical scholars. The only contact

Dr. Koop finished the meeting, which was attended by about 20 nurses, checked on the twins' condition and found that they seemed stronger. Then he met with a lawyer from the firm of Dechert, Price & Rhoads.

His concern

Dr. Koop was becoming increasingly worried that he might be prosecuted for premeditated murder.

It was not a farfetched concern; under Pennsylvania law any citizen can bring a criminal complaint, and any number of legal agencies on the city, state and federal levels could decide to respond.

Dr. Koop said he did not seek protection from a civil malpractice suit. He was convinced that the parents were not the kind of people to sue

solemnly, then a third person speaks.

"But then there is the case of the caravan surrounded by bandits. If the bandits demand that the caravan surrender a hostage for execution or else everyone would be killed, it would be wrong to sacrifice someone.

"But on the other hand, if the bandits named a particular member of the caravan, it would be morally justified to give up this person because he had been designated for death and then it would be foolish to give up the lives of all along with the life of the one designated for death. So it is with the twin who has been designated for death.'

"But wait!" insists one of the others in the room. "Has one of the twins been designated for death?"

And so a phone call is placed to Dr. Koop.

"Could Baby A survive if the heart

Dr. Koop is a large man with a Lincolnesque beard and the dominating bearing of an Army general. He also has unique qualifications to deal with the medical and ethical dilemmas posed by the twins' lethal union.

Twice before he had separated twins—a rare operation few pediatric surgeons do even once — but neither case involved a shared heart. Moreover, Dr. Koop, a Presbyterian, is a deeply religious man who has frequently spoken out nationally about the sanctity of human life.

Twice before he had separated twins — a rare operation few pediatric surgeons do even once—but neither case involved a shared heart. Moreover, Dr. Koop, a Presbyterian, is a deeply religious man who has frequently spoken out nationally about the sanctity of human life.

The growing public acceptance of abortion is a source of outrage to Dr. Koop, and he is concerned about the growing trend in medicine to let, or even help, defective newborns die.

In a speech to the American Academy of Pediatrics entitled "The Slide to Auschwitz," Dr. Koop said:

"Perhaps more than the law, I fear the attitude of our profession in sanctioning infanticide and in moving inexorably down the road from abortion to infanticide, to the destruction of a child who is socially embarrassing, to you-name-it."

It was ironic that such a man should be called upon to do this operation — an operation that would, with certainty, leave one child dead.

But as soon as he examined the twins, Dr. Koop knew that had to be done. Without waiting, he placed a call to the twins' father and arranged a meeting.

•

The twins had been born to a deeply religious, Orthodox Jewish family of rabbinical scholars. The father himself is a rabbinical student to whom nothing matters more — not even life itself — than God, the teachings of his religion and biblical ethics.

One axiom of biblical ethics is the infinite worth of human life.

A difficult question

Since this ethic implies that all human life is equal — that one life is worth no more or less than another — would he consider it moral to kill Baby Girl A so that Baby Girl B could live?

This was much too difficult and important a question for the young rabbinical scholar, only in his early 20s, to try to answer on his own, so he consulted the rabbis in his community and the rabbis in his and his wife's families. Soon Rabbi Moshe Feinstein, dean of Tifereth Jerusalem seminary in New York City, was called in.

The 83-year-old Rabbi Feinstein has for many years served as final arbiter in questions of Jewish law and ethics. Scholars throughout the world, ethical dilemmas, have sought his counsel. His written responses to these questions are periodically

alone.

Rabbi Feinstein did not, himself, attend the conferences but instead sent his son-in-law, Rabbi M. D. Tendler, a noted Jewish authority on medical ethics, a professor of Talmudic law and chairman of the department of biology at Yeshiva University in New York.

One or two lives?

Time and again Rabbi Tendler put the same question to Dr. Koop in different ways because the answer would be so important to the rabbinical discussion that would ensue.

Are the twins one baby or two babies?

If the twins were only one baby with two heads, then it would be ethical to remove Baby A as an unnecessary appendage.

If there were two babies with distinct nervous systems, however, then that would require more scholarly discussion.

Each time Rabbi Tendler asked the question in a different way, Dr. Koop would come back with the same unequivocal reply:

With the exception of the chest connection at which their livers were joined, as well as their hearts, the girls were separate human beings with their own separate brains and nervous systems.

In fact, the nurses in the intensive care unit, who were quickly developing affection for the twins, could see their different personalities developing even at this early age.

Baby Girl B was much more contented and calm. Baby Girl A tended to be irritable. But they were both alert and made eye contact when someone came near.

Dr. Koop told the rabbis he felt strongly that the twins should be separated and as soon as possible because the hearts could fail at any moment.

He said, however, that he would not seek a court order to force the parents to agree, because the chances of saving both babies, even with surgery, were very slim.

Only a half-dozen times before, as far as was known, had Siamese twins been connected with their hearts fused like this. So far, none of the babies separated has survived for more than a few days.

But with surgery, there was at least a theoretical chance of saving one of them. Without surgery there was no hope at all.

The rabbis listened and said they understood. They were impressed by this big doctor with the beard, surprised by his knowledge of the Bible and medical ethics.

They had not expected to find a surgeon who read the Bible before work every morning.

It was getting late and it was Friday. The rabbis wanted to get home before sundown, the beginning of the Sabbath. So they got up and said good-by, saying they would discuss the matter and make their decision as soon as possible.

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The surgeons, cardiologists and

from its natural nervous system might cause it to beat wildly, throwing the B heart into a lethal condition called fibrillation.

Dr. Koop shared Dr. Edmunds' concern about the chest cavity being too small. Last summer he had been consulted on a similar Siamese twin case in Switzerland in which the chest appeared to have been closed too tightly to allow the six-chamber heart to beat unimpeded. The rescued twin died shortly after surgery.

Dr. Koop told Dr. Edmunds, however, that he thought they could solve the problem by surgically building a large enough chest cavity, using the ribs of Baby A as grafts if necessary.

There were other concerns of equal importance, and they all were examined at the meeting.

Dr. Weinberg tried to describe to the doctors all that he knew about the heart from his X-rays. He used a colored, clay model he had constructed as a visual aid.

Pointing to the model, he said he thought Baby B's circulation was partly supplying the stunted heart of Baby A by passing through a hole between the ventricles where the two hearts touched. This blood from Baby B might be enough to nourish the muscles of Baby A's section of the heart, keeping it healthy. If so, this would make it possible to cut the heart off from Baby A's circulatory system and give Baby B a healthy six-chamber heart. But he could not be certain.

More -ray studies, called angiography, in which dyes are injected directly into the heart's chambers, would be needed.

Dr. Weinberg would also find out, if possible, more about the coronary arteries feeding the 1½ hearts. Dr. Edmunds would need to understand this clearly in case he had to graft vessels from the coronaries of the B heart to the A section to provide an extra blood supply.

Two pediatric anesthesiologists, Drs. John J. Downes and Russell Raphaely, were worried because the twins' airways were very far forward under their tongues, making it difficult to insert anesthesia tubes.

The anethesiologists were concerned also about the surgeons plan to turn the babies over during surgery to get at both sides. This would make it difficult to keep the 13 blood monitoring lines and tubes connected to the twins from getting tangled up.

The meeting ended at 5 p.m.

They would need time for Dr. Weinberg to run his studies and for more planning sessions. Dr. Koop tentatively decided to do the surgery in 11 days. That would be Oct. 11.

Eleven days would be ample time to finish the medical preparations.

But would that be enough time for the rabbinical scholars to complete their meditations?

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On Oct. 3, the intensive care unit nurse assigned to the twins noticed changes in the heart rate, respiration and electrocardiograph tracings to suggest that Baby Girl A might be going into heart failure.

since their meeting the week before had been a telephone call from Rabbi Tendler, who asked two somewhat odd questions.

If the surgeons wanted to, Dr. Tendler asked, could they give the six-chambered heart to Baby A instead of Baby B?

Dr. Koop could not understand why he was being asked such a question, but he told them no. The circulatory system was set up in such a way that the transfer could be made only to Baby B.

Then Rabbi Tendler asked whether Dr. Koop was certain that Baby Girl B would also die, even with the surgery.

Dr. Koop said that Baby B probably would die regardless of what was done, but that it was not a certainty.

Rabbi Tendler thanked Dr. Koop for the information, said that they hoped to make a decision shortly and then hung up without explaining the reasons for the questions or where the rabbis stood.

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Dr. Koop held three meetings with the nurses and other personnel during the week to offset the growing concern about the surgery.

Many of the nurses who attended the meetings were from the operating rooms.

At each session Dr. Koop described how both babies were doomed if nothing was done and how there was a remote possibility of saving at least one if surgery was attempted.

Since Baby A was being kept alive through the extra work being done by Baby B's heart, he viewed Baby A as a burden — even a parasite — and as such it was morally right to save Baby B by removing the parasite.

The nurses were pensive at these meetings, but they did not seem outraged or disapproving, especially after Dr. Koop got through his explanation.

Most of the questions were technical rather than ethical.

Dr. Koop said they asked him what could be done if the twins started to die before surgery could begin. They also asked whether the child's chest would be normal after surgery, and whether there would be closed-circuit television to show the operation to the hospital staff, as there was in 1974, when Dr. Koop separated twins born in The Dominican Republic.

Only one person — an operating room nurse — confronted Dr. Koop with the difficult question:

"How do you feel," she asked, sternly looking at him, "as a Christian and a doctor, to do an operation like the one you're planning?"

Dr. Koop stared back at the woman just as sternly and, after thinking for a moment, replied with a low, measured voice.

"I can watch two babies die slowly over the course of several months," he said, "or I can watch one die swiftly and the other possibly live."

The nurse did not seem satisfied, so Dr. Koop continued. "No one likes to say 'I'm going to kill one baby so that the other can live.' "

after giving permission to do the surgery.

But he was concerned about a criminal action and said flatly that he would not do the surgery without adequate legal protection. It was a difficult legal question that would involve time-consuming searches for legal precedent.

Time was short, so Rechert, Price & Rhoads immediately assigned four lawyers to the case.

•

The rabbis had been discussing the twins for almost a week. Rabbi Feinstein had even moved into the house of his son-in-law, Rabbi Tendler, for the duration of the discourse. Every night after dinner he would meet with Rabbi Tendler and his three sons — one a physician and rabbi and the other two rabbinical students — to discuss ethics.

Speaking only Yiddish or Hebrew, they would talk late into the night until they reached an agreement. As soon as this happened, one of them would take the opposite position and they would turn around and argue or discuss in that direction.

"Two men jump out of a burning ariplane," Rabbi Tendler said in one discussion, using an analogy. "The parachute of the first man opens and he falls slowly and safely to earth.

"The parachute of the second man does not open. As he plunges past his friend, he manages to grab onto his foot and hold on. But the parachute is too small to support both of them. Now they are both plunging to their death.

"It is morally justified," Rabbi Tendler concludes, "for the first man to kick his friend away because they would both die if he didn't, and it was the first man who was designated for death since it was his parachute that didn't open."

Another analogy

"Ah, yes," replies Dr. Yacov Tendler, the son who is a rabbi and physician. "But take the case of the baby who is being born. Something goes wrong just as the baby's head comes out of the vagina. It is stuck and the baby cannot be pulled out.

"The choice would be to either kill the baby and dismember it to get it out of the mother's body, or let them battle it out to see who wins. Biblical ethics demands that you take a hands-off policy. You have two human beings in conflict with each other. Neither is guilty of a crime. You have no right to select the life of one over the other.

"It is only in the unique situation in which the child is in the uterine world, totally dependent on the mother for sustenance, that the mother's life takes precedence over the fetus.

"In the case of the twins," Dr. Yacov Tendler argues, "you have a situation where both heads have come into the world, each one making an independent claim to life. You have no right to forfeit one for the other."

All of the heads in the room nod

was given to her? Is Baby B also designated for certain death or is there a possibility — remote though it might be — that Baby B could survive with surgery?'

•

The word had come down independently from different Catholic priests that the surgery would be ethical under church law, and Mrs. Barnsteiner and Miss Betsch passed th word to the nurses under them.

"God expects us to act when we can act," concluded one priest, the Rev. Francis C. Meehan, associate professor of moral theology at the Seminary of St. Charles Borromeo in Overbrook.

"Not to choose is to choose to allow both of the babies to die," Father Meehan told the nurses. "It was no the doctors who would be killing the baby, because they would save the girl if they could, but the termina event that had already started for her. Death may come sooner — not because they chose it for the child but as an indirect result of their attempt to save the other child."

Father Meehan's words and those of the other priests were reassuring but as the time approached for surgery three anesthesiologists and two Catholic nurses asked not to be pu on the case.

Six of the seven nurses who would participate in the surgery, including Miss Betsch, however, would b Catholic.

On Oct. 6, only five days before surgery was scheduled, word reached Dr. Koop that the rabbis had finished their deliberations. They were in favor of the surgery. The father had agreed to it.

The body of Baby Girl A, however would have to be returned home fo burial before sundown on the day o surgery. Dr. Koop gave assuranc that this would be arranged.

The final planning session came o Oct. 7.

The new X-ray studies by Dr Weinberg indicated that holes of unknown size did connect the left ventricle in Baby Girl B with the left ventricle in Baby Girl A. This suggeste the possibility that Baby Girl B's circulation might be able to sustain thi section of heart.

Dr. Weinberg had also been able t obtain the preserved specimen of similar, six-chamber heart that ha been flown down from Harvard University.

Dr. Edmunds spent several hour with the specimen, examining how the heart chambers were connecte and where the blood vessels fed into the muscle.

During surgery, he would not hav time to examine the throbbing hear of the twins. He might have to mak quick decisions under much pressure so he wanted to know as much a possible beforehand.

The most important tactical question confronting the surgeons wa when to cut off the circulation Baby Girl A. This would immediatel

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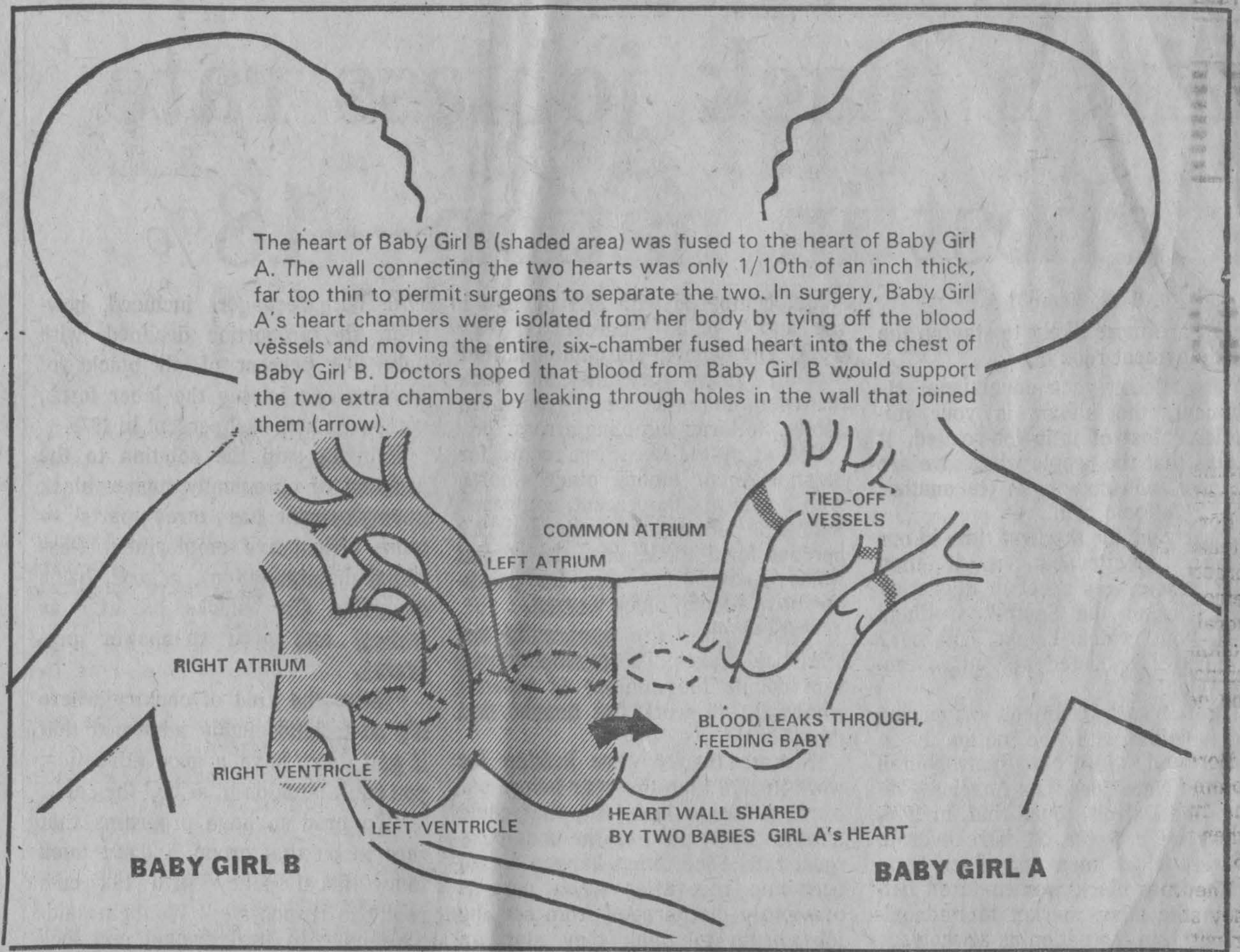

The heart of Baby Girl B (shaded area) was fused to the heart of Baby Girl A. The wall connecting the two hearts was only 1/10th of an inch thick, far too thin to permit surgeons to separate the two. In surgery, Baby Girl A's heart chambers were isolated from her body by tying off the blood vessels and moving the entire, six-chamber fused heart into the chest of Baby Girl B. Doctors hoped that blood from Baby Girl B would support the two extra chambers by leaking through holes in the wall that joined them (arrow).

Dr. C. Everett Koop and staff (left) followed diagram above; playing key roles in the decision (from left) were Dr. Koop and Rabbis Moshe Pentendler and Moshe Feinstein

Continued from preceding page

kill the child and possibly threaten the heart.

No one knew how the heart would respond to the sudden drop in the volume of fluid it must push and to the loss of the entire circulatory system of Baby A.

Dr. Edmunds wanted to cut off the blood supply of Baby A from the circulation system of Baby B as soon as possible during surgery. This would kill Baby A, but it would also protect Baby B's heart from the poisons that would start pouring into the blood the moment Baby A's tissue started to die.

When tissue dies, it releases lactic acid and potassium into the blood. These biochemicals shut down the heart if they reach sufficiently large concentrations.

The surgeons decided to simultaneously tie off the carotid artery and the jugular vein, which take blood to brain rather than cardiac activity.

The lawyers then went to their second line of reasoning and judicial precedent, which said that what might appear to be a crime is not a crime if a court rules that the good outweighs the bad and accordingly hands down a court order.

Because there is greater good served by saving one child instead of losing both of them, the court would be justified in issuing such an order, the lawyers insisted.

Then they cited a legal treatise on two mountain climbers, a survival story almost identical in principle to Rabbi Tendler's analogy about the parachute-jumpers:

A mountain climber who falls from his perch is saved from instant death by a rope attached to a partner who has a more secure hold. But the hold is not so secure that he can keep both himself and his friend from plunging to their deaths. Because under such circumstances both would

The twins were put to sleep immediately with nitrous oxide, and the lengthy business of preparing them for surgery was begun.

Dr. Koop walked in, still drowsy from sleep. He had slept overnight in the hospital, as is his practice before particularly difficult surgery.

It takes him all night to prepare himself mentally for difficult surgery and he didn't want to risk being distracted by heavy traffic on the highway, a flat tire or some other extraneous happening.

For the moment there was nothing much for Dr. Koop to do, so he wandered about the operating room suite, talking to nurses. Dr. Edmunds had been up operating in another case for several hours already, having been called in for emergency heart surgery. He would be exhausted before the day's end.

Dr. Koop and his close assistant, Dr. Louise Schnaufer, who had as-

ygen level in the blood mysteriously started to improve.

It was up to Dr. Edmunds now. Working swiftly he tied off the major blood vessels of Baby A's partial heart. He was in luck. There was no need to make any grafts. He wouldn't even have to cut into the pericardium, the protective sac around the heart.

Everything was moving along beautifully, several hours ahead of schedule because no one was running into any of the anticipated problems. Even the anesthesiologists had no trouble getting the tubes down the babies' throats.

Quickly the surgeons separated the heart and lungs from Baby A and all the other tissue connecting the one baby to the other.

At 11:25 the separation was complete in every respect. Only the two heart chambers and lungs of Baby A remained attached to Baby B. Th

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When tissue dies, it releases lactic acid and potassium into the blood. These biochemicals shut down the heart if they reach sufficiently large concentrations.

The surgeons decided to simultaneously tie off the carotid artery and the jugular vein, which take blood to and from the brain, the vena cavae, which supply the top and bottom parts of the body, and the aorta, the principal artery from the heart.

When they did this, the heart would start beating wildly and ineffectively in the lethal rfnezy of fibrillation? Or would it adapt quickly without any threat to Baby B?

The surgeons would find out on Tuesday, Oct. 11.

Former District Attorney Arlen Specter, who represented the hospital in the case, felt that the only way to insure adequate protection for Dr. Koop was to get a court order authorizing him to do the surgery.

Similar positions

A three-judge panel of the Family Court heard Dr. Koop and the lawyers present their arguments in an empty courtroom on Oct. 10, which was Columbus Day, a holiday when the building would otherwise have been closed.

The arguments presented by the lawyers were surprisingly similar to the positions taken by the rabbis during their 11 days of discourse.

Common law in Pennsylvania states that death comes after the heart stops, the lawyers argued. Since there is only one complete heart, the twins constituted one person and to remove one would be only to remove an appendage, like a gangrenous leg.

The judges dismissed this attempt at logic, which probably was just as well as far as the lawyers were con-

brain rather than cardiac activity.

The lawyers then went to their second line of reasoning and judicial precedent, which said that what might appear to be a crime is not a crime if a court rules that the good outweighs the bad and accordingly hands down a court order.

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The court apparently agreed with this logic. After a few minutes of deliberation it authorized Dr. Koop to proceed with the surgery.

It was scheduled to begin at 6 a.m. the next day.

●

It was a cold, black morning and the sun had not yet risen. The streets outside Children's Hospital were deserted and quiet. It was still too early for the bustle of traffic.

Inside the hospital, brightly lit Operating Room Three was hectic with the activity of a dozen people preparing the room for surgery.

At 6:05 a voice yelled out, "They're here." All faces turned to see a white-coated aide wheel in an isolette from the intensive care unit.. It contained the twins.

Tears in the hallway

It had been an emotional parting from the intensive care units. Several of the nurses touched the twins and said good-by. One nurse explained to the person from the operating room that the twins might be a little cranky because they had been up most of the night playing.

They would be very good, the nurse said, if they were given their pacifiers. Outside in the hallway, one of nurses hid her face because she was weeping.

She had spent a lot of time taking care of the twins, and the thought

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Dr. Koop and his close assistant, Dr. Louise Schnaufer, who had assisted at the other two twin operations, did not begin their ritualistic 10-minute scrub until 8:40.

And it wasn't until 9:25 that the first incision was made into the tissue connecting the two twins, glistening brown from the Betadine disinfectant they had been washed in.

Oxygen level low

The anesthesiologists were concerned because the amount of oxygen detected in the blood was less than normal, indicating a ventilation problem either on the part of the equipment or the physiology of the twins.

By 10:10, four hours after the twins had been put to sleep, the oxygen level in the blood had dropped to dangerously low levels, despite the increased concentrations anesthesiologists were delivering. But there was nothing anyone could do at this point but proceed and hope.

By 10:35 the surgeons had isolated the major blood vessels. Sutures were pulled loosely around them, ready to be tied off simultaneously on signal.

At precisely 10:40, Dr. Koop gave the signal and he personally tied off the carotid artery feeding blood to the brain of Baby Girl A.

Death was instantaneous.

For several long minutes the surgeons and everyone else in the room braced themselves for the reports from the anesthesiologists monitoring the surviving twin.

Would all the oscilloscopes and digital readouts start to turn bad, indicating that the heart

ygen level in the blood mysteriously started to improve.

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At 11:25 the separation was complete in every respect. Only the two heart chambers and lungs of Baby A remained attached to Baby B. The lungs were subsequently detached.

Wrapping the shell of Baby A i a green surgical drape so no would see her, Dr. Koop gently respectfully carried the body o infant to a sterile table at the end of the operating room.

They put her on a sterile tab the chance that they might nee bones or skin as grafts to help the gaping wound in her sis chest. But it was not to be neede

The rest of the operation without incident. Dr. Koop built ample chest around the large, thr bing heart now in the anatomica proper place, and closed the wound

If the girl survived, she could gr up to lead an essentially normal li Her larger-than-average rib ca probably would not be conspicuou The skin was even put back in su a way that she would have breas in the proper place.

By 1:30 it was all over, and D Koop flopped down on a seat in th operating room lounge to fill out th death certificate.

"Cause of death," he said readin aloud to himself as Miss Betsch sto nearby waiting for him to complet the form, "hypoxia (lack of oxyge due to operation to separate Siames twins."

One hour later, an exhausted D Koop and the other tired members o the team were conducting a pres conference.

Baby Girl B was back in the intensive care unit, alone this time, in stable but critical condition.

Chicago Tribune, Monday, May 7, 1979

Section 2

p 1

Euthanasia: When you can't stand the agony

By Terry Daniels

RECENTLY I READ a newspaper article about a nurse in Baltimore. The headline read: "Nurse on trial for murder called compassionate." It threw me into a panic. She was accused of taking a GORK off a respirator. GORK is a medical acronym in universal use—it means God Only Really Knows. The patient in this case had stopped breathing and had been brought back. He had bladder cancer, cirrhosis of the liver, pneumonia, and heart failure. My reaction to that headline was, "Oh God, somebody got caught."

What I felt was what most nurses I know felt. I know because I asked them. They were truthful, because I'm from the inside of medicine, from the same family, so they shared with me. All have been nurses for five years or more, some for as long as 15 years. Each has worked in at least three hospitals, and everyone agrees it's about the same in all of them. They range in age from 24 to 50, and all have children. Medicine is very important to them, and none considers it just a job.

Clinically, a GORK is a man, woman, or child lying in a bed, unable to do anything for himself; he has no voluntary functions left. There usually is a tube through his nose down which liquid food is poured; he never tastes it. Sometimes he's unable to digest it, and sometimes his stomach gets too full so he vomits it and then has to be suctioned quickly so he doesn't choke on it, or get it into his lungs, which causes pneumonia. He's unable to move purposefully, and his involuntary movements are erratic and seizurelike. If his eyes are open, they stare without blinking. Often they are taped shut so his corneas don't ulcerate. You can talk to him, and he doesn't respond. He doesn't appear to be able to hear. If he has an itch on his nose, he can't scratch it. He's figuratively locked in cement, literally a prisoner in his own body.

THE HUMAN REALITY, the thing I say to myself, is, "That could be me . . . or my child, or my mother, or my father." And then while I pour the food down these tubes, and wash their faces, and turn them over, and clean up their feces, and put pillows between their knees so they don't get bedsores, I talk to them and look at them and ask out loud and sometimes to myself, "Is there anything more I can do?" And then with frustration and pain, "Is there nothing more I can do?"

The tool used in medicine to separate the brain dead from the severely brain damaged (GORKs) is an EEG machine. From the outside you often can't tell; they look the same. You have to have two or three EEG readings, 24 hours apart, to certify brain death, which means you can legally take someone off a respirator and then bury him. I can't explain that any more kindly.

I'm never quite sure, even with a flat EEG, that a person's awareness is gone. I know it means that *they* are sure there's no consciousness. I'm not. There's just too much that our machines can't measure. They can't measure pain; they can measure only the reaction to pain. And they can't measure caring and intuition and other tools of medicine. They can't measure "will to live," but I've seen it make all the difference in a patient's getting well or dying.

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The author has been a nurse for 13 years. "Terry Daniels" is a pseudonym. The names of the other nurses also have been changed.

I've worked with people who were severely brain damaged (GORKs), and the space between the brain damaged and brain dead is sometimes as thin as a hair. You can still get spikes on an EEG and feel that someone's not "in there" anymore. And if they are, it's a terrible place to be.

IT'S EASIER FOR me to take care of someone who's brain dead for the 24 to 36 hours between EEGs. Then I can just take care of the body and when I see big craters of bedsores, I don't feel the pain. When saliva is slobbered down his face, I'm not embarrassed for him. When his family sits around the bed and cries, I still have trouble handling their pain. But not as much trouble taking care of him.

It's the GORKs that cause me the most grief. Maybe there is a flicker of consciousness, and this poor guy knows what's happening to him. Maybe he's embarrassed; maybe he can't stand the indignity. Maybe he's in pain, and I don't know he's in pain because he can't tell me he's in pain.

For a period of time, when there's any question of a patient's being able to function again, there's not a good nurse who wouldn't break her neck taking care of him. But when the only thing that a doctor can offer is that possibly he'll return enough to be strapped up in a chair, not to be able to sit up himself, no bladder or bowel control, never to be able to eat by himself or interact with anyone . . . when this is the final hope, a real stretch of what medicine can do for him, then it's almost impossible to do. Not because we don't care, but because we do.

Andrea describes it:

"Did you ever walk into a situation that utterly and absolutely repulses you? I don't mean like blood and guts. Let me explain. This is only one example but not an unusual one.

"IT WAS A WOMAN with brainstem melanoma (cancer). She wasn't old, only in her 50s. She was lying in bed, hooked to a respirator, her head hanging to the side and her tongue falling through her open mouth. She was drowning in her own secretions. She had black lumps sticking out all over her body. And here she was, on a respirator. She was supposed to have tube feedings, and I couldn't give them to her. I couldn't add to her misery. I couldn't add to what they were doing to her. I couldn't even suction her. She stopped gurgling finally and died. And do you know what I thought the whole time that I was leaving her alone? It reminded me of old people, those poor old people, digging in garbage pails. How degrading. How immoral. This shouldn't be. But it is. And for me, there is much more to the moral issue than pulling a plug."

Is withholding the means to extend life, when we have the knowledge to extend it, passive? If it's *actively* withheld?

There isn't a nurse I know, and I've been nursing a long time, who wants to be resuscitated if she dies. In fact, many of us have seriously considered wandering into an unpopulated area in the hills somewhere if we are told we're going to die. No hospitals, no doctors, no extraordinary life-support systems. We're almost a club, and we've all decided to have "NO CAC" tattooed across our chests, in case somebody finds us and drags us into an emergency room. CAC means "Cardiac Arrest Code." It means being "brought back," and that's a nightmare for all of us.

OVER THE YEARS, I've asked the best nurses what they think about mercy killing. None of them would be willing to do it on a patient she didn't care about. It's not worth the risk. I've heard good nurses say, "Oh, I could do it. But only for my mother, father, or my child." And then they add, "Or maybe someone I loved."

Unless there's that kind of emotional investment, few people are willing to handle the guilt because a GORK lives immortally . . . in your own brain. A terminal patient's *stopped* screams stay in your own bone marrow. You can't be sure if you'd do something like that. You're never completely sure.

I've heard a lot of talk about passive as opposed to active euthanasia. When those of us inside medicine talk about it, we find it difficult to figure out what passive euthanasia is. Watching someone starve to death because you're not giving him food or IVs seems active when you know it takes food to keep him alive. "Keep him comfortable," when he's a terminal patient in excruciating pain, means give him as much medicine as he needs and if it kills him, it kills him. None of this is done easily.

'I've asked the best nurses about mercy killing . . . I've heard good nurses say, "Oh, I could do it. But only for my mother, father, or my child.' "

Here's how Tracy feels about this issue:

"It's seldom that you need enough medicine to kill pain and kill the patient too. But that 'seldom' doesn't count if it's you and your patient who are in the position. You only have to walk into one room, to have to suffer over it, because then all the talk about 'seldom' sounds empty."

THEORETICALLY, IT'S NOT euthanasia to give a high dose of pain medicine to alleviate pain, even if it hastens death.

If my patient is screaming and yelling in pain, begging to be put out of his misery, I say to the doctor, "His respirations are shallow, but he desperately needs more pain medicine. He's tossing and turning. He's in agony." If the doctor says, "Give him morphine; we have to help his pain," both of us know what the other is saying. Both of us know that a side effect of morphine is depressed respirations. But it's still theoretical. Once I pick up the needle and syringe and draw up the morphine, once I inject it into him and 15 minutes later he stops breathing because of what I did, it *feels* like euthanasia. To everyone else, his death was only a side effect, but to me while I stand there and it's my patient who stopped breathing, it doesn't feel like a side effect. It feels like I killed him.

Please don't misunderstand. Nobody would force a nurse to do it. She's not a robot, and she can refuse. But she can't cop out by pretending it's all the doctor's responsibility. The law may say it is, but when she looks down, she's the one holding the empty syringe in her hand. She feels the guilt.

The doctors and nurses who seem to be the bravest, the most willing to carry the guilt and responsibility for this kind of decision themselves, have been in medicine a long time. They've come to terms with their impotence They've gotten rid of the delusional idea that they can always beat death.

One of the problems in medicine is that we have to practice on real people. Yet once the decision is made to put a patient on a respirator, it can only be undone by a flat EEG, a stopped heart, a court order, or covertly by another doctor or nurse. So if in an emergency the resident chooses to place an 85-year-old patient with a terminal disease on a respirator, even if his judgment stinks, it can't be legally reversed.

BUT LAW ISN'T medicine, and compassion is one of the tools doctors and nurses use in their profession and in their decisions. There's no easy way for them to disconnect it—not when they're up close. Not while you're looking into eyes that stare back in agony, not while you're close enough to hear the screams and wipe away the tears. Not while you yourself are frightened of disease and scared of death.

I'm not implying that I have answers, but in any other business there are backup systems. In medicine, because doctors have been set up as gods, because medicine itself seems mysterious, the backup systems aren't efficient. Each time two sick patients call, and we choose to help one before the other, we've made another God decision. Medicine deals in minutes; when someone's heart stops and you're the first one in the room, you make the individual decision to jump on his chest or walk away.

Is it a God decision *not* to save a person's life? To extend it, if we have the means to? Does it make a difference that a patient asks you not to be heroic? Are we only entitled to certain God moves?

Once we take an active part in saving a life, if the patient is a GORK, we have to witness the sacrifice of the entire family satellite. Financially and emotionally, they wind up wiped out. Bankrupt. It's partly our responsibility and it costs us.

Karen did unplug a respirator and she'd like to explain why:

"Sandy was a 5-year-old kid. I had been taking care of her for several months. She had a malignant brain tumor. They had operated several times, her head was shaved, and she had scars like zippers over her head. She got worse and worse and finally slipped into a coma.

"Her parents used to be at the hospital every day; they'd take turns minding Sandy's twin brothers, who were 3 years old. The mother couldn't stand it and finally took a bunch of sleeping pills. The doctors used to stand at the foot of the bed and shake their heads saying, 'Medicine can't do any more.' The mother survived the pills and after that she used to talk to me.

"ONE NIGHT, SANDY just stopped breathing and would you believe some nut jumped on her chest and her heart started beating again. They put her on a respirator. She got infected and then the doctors started giving her antibiotics, sticking her with needles all the time. The kid looked like a pincushion. She was getting all black-and-blue, and nothing seemed to touch the infection. She smelled awful.

"She had been such a pretty little girl, and I really cared about her. I kept asking everyone how we could get her off that damn machine. Nobody could do it . . . although they all agreed it would be better if she died. They told me if her heart stopped again to walk slow before I called anyone. I knew what they meant. Her father came in one day and told me he couldn't stand it anymore. He was going to run as far away as he could get. I thought about the twins and about the mother. Sandy had died once.

"I went into her room to bathe her as I always did, and this time I closed the door. I took her off. Then I bathed her and powdered her and fixed her bed. By the time I hooked her up again, her heart had stopped. . . . As soon as I took her off, I could breathe better."

DOCTORS AND NURSES have to think quickly and make decisions constantly in order to save lives. Big decisions. But the biggest decisions are the ones that they aren't allowed to make.

I agree that we should never have to make decisions of such magnitude. We should never have to watch our mistakes cost other people so much. We should not have to carry all that pain and suffering and responsibility.

Who should? Some infallible robot who doesn't hurt every time he identifies with a leukemic or a terminal cancer patient or someone who was a person and now just lies there? We shouldn't have to be exposed to all of this because it's humanly impossible to never make a mistake; it's uncomfortable to have to hurt people all the time; it's unreasonable to expect us to maintain the kind of distance to always be objective.

There are no standard criteria, except respiratory distress, for putting someone on a respirator, and only brain death or a stopped heart for taking someone off. But what would you do if a 25-year-old man was brought into the emergency room after a car accident? You know he needs a respirator temporarily and that he has a good chance to recover and live a full life. But all the respirators in the hospital are in use, one of them to keep an 85-year-old nonresponsive terminal cancer patient alive. You have no time to ship the young man anywhere else without losing him because of his breathing difficulties. As a human being, would you apply for a court order to give the young man the cancer patient's respirator? Hurry! This is an emergency.

'I couldn't add to her misery. I couldn't add to what they were doing to her. I couldn't even suction her. She stopped gurgling finally and died.'

THERE WAS A TIME when I was young enough to attack doctors for their humanity, their impotence. I used to find myself ready to fight whenever I knew a doctor had given orders to "keep him comfortable." Because I knew that implicit in those instructions to give enough medicine to keep someone comfortable, to "snow them under," was the request not to bother the doctor anymore. It was later I learned that even *he* couldn't help. And that the "It's in God's hands now" line is the admission of impotence. Again, when I was younger, I only thought it meant that the doctor was lazy or incompetent. Also, I resented the fact that whatever "enough medicine" was had to be given by a nurse.

Whenever a patient is crying for medicine, sobbing in pain, the nurse is the one who hears the screams. Patients cry to us because we're there more. They pull at us and plead with us not to let them go on like this . . . that something has to be done. We're the ones who are with them for hours each day, hearing the moans, watching their pain, party to the indignities. We're the ones they share with. Our patients are dependent and sometimes defenseless and our desire is to protect them. Yet these emotions are not considered in medicine. It's not allowed.

I've taken more courses than I can remember on "Death and Dying." I know how to deal with people who are dying. I know how to say things that will make them feel better. I've learned how to listen to them. When I'm there, if I hold their hand and keep them company so they're not afraid of being abandoned, I know they feel better. But nobody has ever addressed, at any conference or class I've been to, the feeling of the doctor or the nurse when it gets to a place where you want to stop the misery so badly that you are willing to sacrifice yourself for them.

I'M NOT SAYING it's right. I'm not saying it's a good system; I'm saying we need a better system.

If we could acknowledge that the people in medicine get tired and upset, sometimes have lousy judgment, get emotionally involved; if we could realize that the doctors and nurses are not intrinsically better than everyone else, then maybe we could set up a better backup system. Something more effective than what we have now.

What they say that nurse did in Baltimore is being done in hospitals and homes now. I don't know if she's better or worse than the rest of us, but I do know that a system which allows the kind of scattered individual judgments for life-and-death decisions whether they be made by a doctor or a nurse, is not working and needs change.

I tried to handle this from inside medicine. Once, I went to a director of nursing and laid all this on her. She was progressive and obviously aware of my dilemma, but what she said was, "My dear, you're not talking about medicine. You're talking about issues that greater minds than ours are trying to solve." And as she dismissed me, obviously uncomfortable that I had brought the whole subject up, she said, "You're taking about morality." It sounded like an accusation, like I had stepped out of line, and all I thought was "I wasn't talking about anything but me and my patients."

A Doctor's Search for the Way to Save Baby Boy Alvarez

The Struggle Doctors Face to Save Newborn Life

First of Two Articles

By B. D. Colen

Washington Post Staff Writer

"What's this?" asked Dr. James Hannan, the director of the intensive care nursery, as he stepped up to the warming table.

His hands were busy behind his back, tying his gown closed, as he looked down at the table and saw Baby Boy Alvarez for the first time. "Oh, Jesus," he said softly.

The 6-pound, 8-ounce baby lay on his back, his chest and grossly distended abdomen rising and falling with each of his sharp, saw-edged cries. His dusky blue-gray color was accentuated because he was not bathed before being rushed to the nursery from the delivery room floors below.

The tan shades already were lowered across the nursery's plate-glass windows, protecting the privacy of the baby and the sensibilities of visitors coming to view other sick infants. For Baby Boy Alvarez did not look right. His clubbed feet were obvious, as were his bowed legs. And there was something odd about his face. Not something one could immediately describe. Just something odd.

"This leg's shorter than the other," said Dr. Ari Javed, a young member of Hannan's staff.

The ability to sustain life by artificial means also confronts physicians with deciding whether and when not to do so. What follows is the account of one such decision, made in a Washington area hospital this year. The names have been chenged to protect the privacy of individuals involved. Everything else is reported as it occurred.

He felt the baby's barrel-shaped abdomen. "I think it's an abdominal mass; it's tense. Can we get a catheter?

"Get an X-ray! FAST!" Hannan ordered. "Jeees; I wonder if he's got (intestine) in his chest. You hear anything up there?" he asked Javed, who was removing his stethoscope from his ears.

"Yes," replied the younger man, a pediatrician training under the director to become a neonatologist, a sub-specialist who cares for infants for their first 28 days after birth.

"Is it bowel?"

"I don't know," Javed responded.

"He looks premature on top of it," Hannan observed.

"He's 36 weeks," replied Javed, checking the chart on the infant born about 20 minutes earlier by cesarean section and finding him three weeks short of full term.

Although other staff members drifted over to look at the new arrival, his presence did not long disturb the natural rhythm of the nursery. There were more than a dozen other infants to care for, and to ignore any of the electronic systems monitoring vital signs could mean the difference between survival and death.

See INFANT, A22, Col. 1

INFANT, From A1

Hannan directed Javed, a respiratory therapist, a first-year resident and two nurses as they peformed the initial workup on the baby, including insertion of a catheter in his umbilical artery. The catheter would allow blood to be drawn to test oxygen levels, but the insertion was complicated by yet another abnormality.

In addition to his other problems, Baby Boy Alvarez had a small opening in the umbilical stump leading back to his baldder. The opening usually disappears long before birth.

Despite being given supplementary oxygen, the baby was turning a progressively darker shade of blue. "Could we increase to 100 percent oxygen (room air is about 20 percent) for the time being" Javed asked.

"Put him up to 100 percent and let's eyeball him and see where we are," said Hannan. "Okay, let's get a picture and see what's in his chest, because I think we're going to have to go to the ventilator (respirator) with this."

As the X-ray technician rolled in the nursery's compact, infant-sized, X-ray machine, Hannan spotted a new figure in the nursery. A short, pale man with a drooping mustache and an expression to match stood hesitantly by the door, trying to see what was being done to the baby on the table—his first child.

Hannan took the man out into the hallway by the nursery's door. "The baby has a number of problems," he told Raul Alvarez, skipping the usual doctor-patient small talk. "We've been going over the baby and there are what look like some abnormalities of the lower extremities."

Alvarez, whose English was a bit shakey, cocked his head slightly to one side, apparently unsure of what he was being told.

"The lower limbs have some difficulty with them," Hannan told him. "In examining the abdomen there are some lumps I'm not sure should be there. Most of all, your baby is having difficulty breathing. I don't know why," he admitted.

"I don't know whether the baby's having difficulty breathing because there is fluid in the chest, or there is an abnormality in the chest itself. We're taking some X-rays now, and as soon as we know something we'll let you know, okay?"

"All right. Thank you," said Alvarez. As he drifted dazedly out of the nursery, his expression said the rest.

The baby's breathing grew more labored as the staff worked to get him hooked up to a respirator. "Get some suction," Hannan ordered. "He's really getting raunched!"

At that moment the X-ray technician returned with the first picture of Baby Boy Alvarez's insides.

"WOOO!" Hanan exhaled loudly, holding the film up to the viewing light. "What have we got? He's got a funny globular heart. It may be a transposition . . . I don't know, but he's got a big right-sided buldge. He may be a hypoplastic (underdeveloped) left heart with a big right-sided heart. It looks like it has some fluid and the left side's got some junk in there. I don't know what it is. The diaphragm's in just about the worst position," he said, pointing at it with one of the yellow pencils that protruded like a pair of horns from the hair falling over his ears.

"I need some better quality X-rays," said Hannan, as he viewed the one picture with a mixture of intense concern, curiosity and some amazement.

"He's got some real funny bones. He's got a weird-looking clavical on this side, plus what looks like a malformation of the cartilage. That's got to be stomach, so that's the right side," he said to Javed, who peered intently at the X-ray with him.

"What's that bone on the right?" asked Javed.

"That's arm."

"No, below that."

"That's bizzaro!" Hannan responded. "It could be thymus, but I'm not sure . . . One way or another, the kid's going to need surgery," he said, returning to the baby's side. "Well, I don't know. First we've got to figure out what he's got." He began to examine the baby's penis.

"Do we have a problem . . . " he said quietly. "You know what this is?" There was a bit of sticky, black substance on the tip of the penis. "He's passing meconium (prenatal feces) out of here. What do you want to do, guys . . . ?"

He then left a message with Dr. Robert Albert's answering service, requesting that the pediatric surgeon call immediately.

The infant, Hannan observed, might not have functioning kidneys. And the next question was what was happening with his bowels.

"He probably doesn't have an anus," said Hannan, turning the baby on his side to examine him. "Oh, boy! Just a dimple. He hasn't got an anus."

"That's interesting," mused Javed.

"Interesting isn't the right word," said Hannan. He moved to take a phone call from the pediatric surgeon.

Hannan explained the situation to Albert, who agreed to come to the intensive care nursery to examine the infant.

That task completed, Hannan walked over to Raul Alvarez, who had returned to the nursery and was standing silent, staring at his baby.

Hannan explained to the father that the picture was growing bleaker with each new test, each new bit of knowledge. The baby's urinary tract was abnormal, his digestive system somehow diverted from its normal location. There was also a suspicion, the doctor said, that the baby's esophagus and trachea were connected, making breathing difficult and eating impossible without surgery.

"I've asked a pediatric surgeon to come by. He should be here by 7 o'clock and he'll chat with you about his findings," Hannan said. "I think it's probable there's something wrong with the baby's heart as well. There are many organ systems that are not right. We'll know more when we get more X-rays."

"So," said Alvarez. "So, what can I say?" He shrugged slightly and his deep, brown eyes were filling with tears. "It's stupid to make any . . ."

Hannan stopped him. "That's why we want more information. Dr. Albert is a surgeon and sees many problems and he can tell us if there's anything a surgeon can do."

"What do you think is the reason? We are very healthy."

Hannan began to speak, but thinking better of it, escorted Alvarez down the hall to his office, where they could have some privacy.

"I don't know what might have caused this in the past," he began, after the two had sat down in the cluttered cubbyhole, "and I don't know what to tell you about future pregnancies. I will, by the time we're finished with this, have some advice as far as how to go about investigating the possibilities of future pregnancies, as well as what can be done with this baby. But right now, I don't have enough information."

"Of course," agreed Alvarez. "This is very soon."

"I just can't say with honesty what could have caused this in this pregnancy," said Hannan. "It's extremely"—he stressed the word—"unlikely that there was any way of knowing about this before hand . . . . With these problems you very often don't know.

"This is very rare," continued the neonatologist. "Perhaps once a year we see something like this. We can't explain it. It's a tragedy."

"What if we took a picture when my wife was pregnant?" Alvarez asked, grasping for explanations of the unexplicable.

"It's very doubtful," said Hannan. "Even something more sophisticated, like ultrasound, probably wouldn't find anything. One of the cruel paradoxes of the kind of defect I think the baby has is that it's perfectly consistent with the normal function of the baby when it's inside the mother.

"And it's only once the baby's born," he continued, that this kind of heart defect causes a problem. It doesn't cause a problem when the baby's a fetus."

"So the mother keeps it alive?"

"That's right. The baby inside the mother doesn't need much liver. It doesn't need an intestinal tract because it's not feeding. It's not breathing. It's only once the baby's born. So what we've done now is put him on a machine to breath for him and put a catheter in the umbilica artery to see how much oxygen he's getting."

"You're only think will be then, a few hours to see," said Alvarez, whose English was deteriorating along with his hope.

"I want to consult the surgeon to see what, in his experience, can be done. I want to know that in his experience and my experience there's no hope. Then the question is, can we keep the mechanical ventilation going. If there's no hope, it's another question, to talk specifically about the future isn't appropriate now. I will sit down with you again in an hour or so and make some specific plans."

"I am very sad," said Alvarez. "My sister, my brother. There is no genetic problem."

"We'll have more information later. Why don't you go down and see your wife now. We have to consult, and do some more tests. We'll talk later."

But Alvarez decided to stay near the baby, and stood quietly in a corner of the nursery as Hannan and Albert, who arrived while the father and physician spoke, had their initial consultation.

The consultation was brief and to the point.

Albert did not agree with Hannan's guess that the infant had a diaphragmatic hernia, permitting its intestines to crowd into the chest. But he did agree on most other points. The biggest question, he said, was what shape the infant's heart was in.

"So I called in the wrong specialist," said Hannan. The next assessment would have to be made by a cardiologist.

"This isn't terribly helpful," he said, walking over to Alvarez. "There are still a couple of distinct possibilities, including a couple that are inoperable. One major possibility is that the left side of the baby's heart, the side that pumps the blood to the whole body, not just the lungs, is underdeveloped. That really would be inoperable.

"The reason I think about this," he continued, "is that I think maybe that's just the right side of the heart we're seeing and it's gotten big to compensate for the left side. Also, just now, we've had to make a rather drastic change in the ventilator setting. You saw the baby get very blue and also grey and mottled? This sometimes happens as the part of the heart doing the work slows down."

"You have to do all you can, but. . ." Alvarez, who would later dream of his son lying on that table, gasping, paused.

"What do you think?" Hannan asked the father.

"If he lives, he's going to suffer."

"You're welcome to stay," said Hannan, his eyes on his shoes.

"It was our first baby," Alvarez said, tears streaming down his cheeks.

"What can I say?" Hannan asked quietly.

"You still want to keep trying," the father asked the physician. It was both a question and a statement.

"I'll keep going on like this until the cardiologist talks to us," Hannan replied. "There's not much more I can do."

"I don't want the baby to suffer," the father told him.

"Neither do I," replied Hannan.

After seeing Raul Alvarez to the door, Hannan returned to Albert, who had completed his examination of the baby on the warming table.

'I want to make sure I take a vial of blood back with me to drop off at the genetics' lab," Albert told Hannan. "That may be the most important thing now."

The two doctors discussed what the cardiologist might find when he examined the baby. Hannan didn't expect to get much guidance.

"He may look at it and say, 'ah, yes, it's hypoplastic [underdeveloped] left heart, but even then it may be operable. Or, he may be able to say it's nonoperable, but he may not be able to say that with any certainty. And that's going to be the problem: How's he going to weigh one against the other?

"But you feel fairly, I don't want to use the word optimistic: You feel there's a reasonable chance to treat the other anomalies?" Hannan asked Albert.

"Yea. They're certainly not life-threatening."

"They're operable?" he asked the surgeon.

"They're operable," said Albert. Baby Boy Alvarez was not yet two hours old.

As Albert sat down to write his notes into the chart, Hannon walked back to his office to call his wife and explain why he wouldn't be home for dinner.

Tomorrow: The Decision

"I think it's probable there's something wrong with the baby's heart as well."

Support machinery surrounds an infant in an intensive care nursery.

Wa Post 4/30/79

The Decision: 'I Don't Want the Baby to Suffer'

This is the account of a decision by physicians in a Washington area hospital who were faced with the question of whether to sustain a life by artificial means. The names have been changed to protect the privacy of the individuals involved. Everything else is reported as it occurred.

Second of two articles

By B. D. Colen

Washington Post Staff Writer

Dr. James Hannan sat down heavily in his desk chair and reached for the phone. It was after 7 p.m. and he had not yet told his wife he wouldn't be home for dinner.

"Hi. I'm going to be late. We've got a just terrible problem here," the director of the hospital's intensive care nursery told his wife. "It's a new baby that came up with multiple anomalies [birth defects] and we're trying to decide . . ." He paused as she asked a question.

"No, no. That baby hasn't even come in yet. This is another kid I've got on a respirator, and he's passing fetal feces through his penis, and he has no anus, and he has a cardiac defect and an abnormality of the cartilage and big, doughy, masses which are probably ureters" — tubes linking the kidneys to the bladder.

"It's the first baby and the parents are all upset and we had to put him on a respirator on 100 percent oxygen. It began about two hours ago. No," he said, answering a question, "it was an elective cesarian, Don Benjamin was the OB.

"No, go ahead and feed the kids but save me something to eat. I haven't had a thing. Put Jeff on the phone, please.

"Hi, Jeff. Sorry I can't come home to read 'Winnie the Pooh' with you, but I have to stay here. I've got a little baby that's real sick. It's got a lot of problems. It's very, very sick. Your Teddy has a little sickness? Well, I'm sure your Teddy will get better. How'd school go today? Okay, I love you. Sleep tight . . ."

He hung up the phone and redirected his thoughts to the newborn baby in the nursery across the hall.

Hannan, at 39, has seen more desperately ill infants than most pediatricians see in a lifetime. Like only about 600 other doctors across the country — perhaps a dozen of them in the Washington area — he practices in one of medicine's newest specialties: neonatology, or the care of the newborn, a field largely ignored two decades ago.

As director of the intensive care nursery, he supervises the care of roughly one-third of all the babies born in his hospital.

Half of those find their way to the nursery for only a day or two, victims of nothing more than a few degrees of fever or perhaps an inexplicable rash. The rest, however, arrive with life-threatening problems: A birth weight of only a pound-and-a-half; serious lung disease; being born without a portion of the brain.

Baby Boy Alvarez belonged in the latter category.

"Man," sighed Hannan. "What can you say? You feel sorry for another human being, but I don't know what to do. If the kid has a lethal defect you can be positive the kid's going to die. But you come to that little thread; now how far out on the thread do you go?"

He had already consulted a pediatric surgeon, and a cardiologist was on his way to the hospital. "I keep stringing it out to Dave [the cardiologist], but I know what Dave's going to say. I'm going to get waffles, that's what I'm going to get."

At that point Hannan was working under the assumption that the baby had a major heart defect, and that only the remants of his fetal circulatory system were keeping him alive.

There are ways, he explained, to keep the fetal system going but they don't always work.

"This business: There's always one more little thing you might try; one more little thing that you might do; one more little exercise. It's the thing people don't understand.

"Talk about heroic care or extraordinary care," said Hannan, referring

See DECISION, A12, Col. 1

DECISION, From A1

to the ethical debate over the use of extraordinary means to sustain life in a hopeless case. "It's impossible in many instances to make a dichotomy between normal and extraordinary care. "There's always one more little thing.

"Clearly what we're doing is heroic. Now, if I were to go in there and shove a catheter up through his aorta into his heart and maneuver it, I could [keep him going] for a while . . . I could give him something to keep his pulmonary system going . . .

"Most of the time, there's always one other little thing you can do," Hannan explained." But at some point you've got to stop. And that's not a clean line most of the time. It's dirty."

"It's never that clear. There's always a chance. Suppose the cardiologist comes in and says there's a 35 percent chance it's an operable cardiac defect. And Bob [Dr. Robert Albert, a pediatric surgeon] has said, 'Well, I don't know about his kidneys' —which is a great big fuzzy gray cloud—'but we can do this and we can do this and he's got about a 30 percent chance of survival.' And we haven't even said a word about his head," said Hannan. "Suppose we do all this and whittle on him and then find he's got a great big cyst sitting right in the middle of his skull? I haven't even asked that. I just say let's look at what we can see."

In one of his discussions with Hannan, the baby's father, had said once, "You have to do all you can do," and "I don't want the baby to suffer." How, Hannan was asked, does he decide what the parents really want?

He must take their statements at face value or it becomes "my personal opinion," he said quite firmly. "In this business I've learned that what they're telling you is the truth. He doesn't want the child to suffer. I don't want the child to suffer either. The whole thing about suffering needlessly . . . What's needless?

"I can't start playing those games," Hannan continued. "I can't say, 'Well, he really wants this or he really wants that.' If I make a decision, I'm going to tell him, 'If this was my child,' or what ever you want to phrase it.

"Now if he says, 'No, you can't stop trying],' then that's it. I keep trying. Sometimes parents [prematurely] say, 'Why don't you let him go? You really ought to let him go. He's got this, and that, and . . ." They argue it. But I say no, because there is still some possibility I'd like to exhaust. Because once you stop, it's irrevocable. It then all becomes cocktail party talk and opinion. It's an entirely different ball game."

"Theoretically, all this has numbers in it," he continued, "Chances, odds, even if it's one percent or one tenth of a percent or a millionth of a percent. It's still in numerical sequence. But as soon as you start talking about life and death, it's like talking about boys and girls: It's yes or no. It's absolute. So why the hurry [to give up]?

"The only reason is that the baby [may be] suffering. Well, who the hell knows? If they're really worried about it, I can dope the kid up so he doesn't look like he's suffering. But when it comes to resolving the real life or death question, that don't make no difference.

"You know," Hannan mused, "I'd like to have an ethicist here now just to go through this. Because they're very good at the after-the-fact discussion, and with the cocktail party talk. They have a lot of answers or a lot of questions, and they can turn you upside down and inside out.

"But I never notice them getting out on the firing line. I mean, what would an ethicist do with that question in there?" he gestured toward the nursery down the hall. "I don't want him to suffer but I want him to have every chance. I don't know, it's interesting: Like how many angels can dance on the head of a pin. It makes people too uncomfortable to deal with it. It makes me uncomfortable and I HAVE to deal with it."

By the time Hannan returned to the nursery, Dr. David Harder, the cardiologist called in to examine Baby Boy Alvarez, was standing by the light box examining the baby's X-rays.

"That's the weirdest heart I've ever seen," Harder muttered as Hannan walked up to him.

The two physicians conferred for about 30 minutes, and Hannan got what he thought he would—waffles. Yes, the baby could have an inoperable heart problem, but no, he might not. Yes, the baby could be transferred to another hospital where more extensive testing could be performed on the infant's heart. But transfer might kill him.

Finally the doctors decided nothing would be lost by transferring the baby to examine him further to see if surgery was possible.

By 9 p.m., when Hannan went down to Maria Alvarez's room in the hospital, the transfer had been all arranged. All that was needed was the parents' okay and the baby—now 3½ hours old—would be on his way.

"My husband had already told me what the doctor had told him," Maria would recall later. "When Dr. Hannan came down with the cardiologist each of them explained it in their own way. They told us it was not 100 percent, not even 50 percent chance the baby would live if they took it for a test. They said he could die in the ambulance; he could die in the other hospital; he could die in the test.

"We thought why, if the baby could not live, why make him suffer, if there was no hope at all. So we said, if the baby is to die, it will die in the same place it was born. After we made that decision," the mother continued, "[Hannan] told us that as a doctor and as a father he would make the same decision we did."

"He explained to us he would give the baby 12 hours," said Raul Alvarez, "to see if it got any better."

"Do you know," Maria Alvarez said, "I guess my only fear that evening and that night and even the next morning, was that I was scared, very much scared, that the doctor wouldn't turn the respirator off. I had dreams that I was fighting with Dr. Hannan, trying to make him turn it off.

"What happened was that in my mind I thought of the case of that [Karen Ann] Quinlan. I was so confused. I could see my baby suffering for days and days and they wouldn't know he was suffering. I was so upset.

"I said to Dr. Hannan, 'I want you to assure me that my baby isn't suffering.' He said, 'There's no way I can tell you.' Then he said, 'I want to give him morphine so that way I can be 100 percent sure the baby isn't suffering.' "

Hannan returned to check in on Maria Alvarez around 7:30 the next morning, and then, shortly after noon, Hannan returned for the final consultation.

"I said, "How's the baby?' " recalled Maria Alverez, "and he said 'It's still the same.' He said, 'It's about time we decide what we are going to do with the baby.'

"We said, go ahead and disconnect the respirator," she continued. "The doctor said, 'That was the decision I hoped you'd make. As a doctor and a human being that was the decision I would make in your case.' "

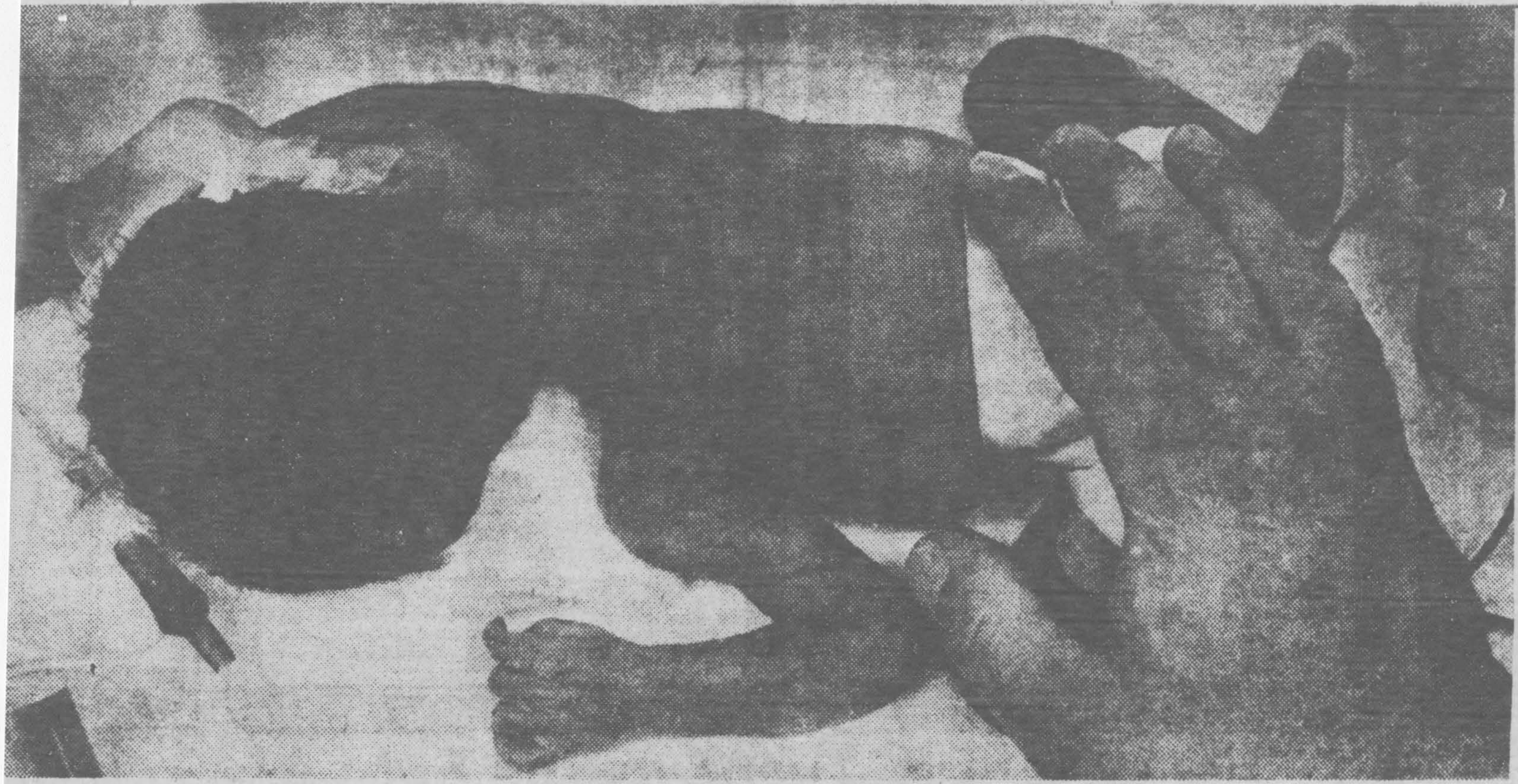
For Maria Alvarez, age 29, there had never really been a decision to make. "My baby wasn't living," she said. "I do believe the only time he was alive was when he was inside of me. The rest of the time he was just artificially living, and that's not alive.

Hannan then returned to the nursery and wrote the following note into Baby Boy Alvarez's chart:

"Have spent considerable time evaluating baby and speaking with parents. They are very aware of the problems and outlook for survival. We have decided to provide only supportive care and not include respirator or respiratory supplement. Parents have requested discontinuance of heroic support. Hannan."

The nursing notes tell the rest:

12:45: "Ventilator turned off by Dr. Hannan. Monitor discontinued by Dr. Hannan. Heart rate dropped below



By Linda Wheeler—The Washington Post

Physician places his hand on a premature infant resting in an incubator Neonatology, or the care of the newborn, is a relatively new medical field

'Our tragedy was for the baby to be sick, not for the baby to die'

100 immediately and color became quite dusky."

1 p.m.: "Baby gasped three times between 12:45 and 1 p.m. and heart rate very slow and faint."

1:35 p.m.: No heart rate present. No respirations. Private pediatrician present. Baby baptised."

1:35 p.m.: "Baby pronounced dead by Dr. Javed. Measurements taken and footprints taken. Baby bathed . . . Baby taken to morgue."

Baby Boy Alvarez, baptized Raul in his last minutes, had lived 21 hours and 14 minutes. His mother had never seen him.

"I didn't want to see the baby," said Maria Alvarez, who, unlike her husband, would in the future have pleasant dreams about him. "I thought, 'Why see the baby if I can not hold him?' "

At 5 p m., 3½ hours later, Hannan went down to tell Maria Alvarez that her son was dead.

"He came into the room and said 'The baby is dead,' " she recalled. "I said, 'Thank you, Doctor, for telling me.' And he stood there for a few minutes, just looking at me. Maybe he was waiting for my reaction. He looked very concerned, very worried. He was worried for us."

"But that the baby had died was very good news," Raul Alvarez said.

"Our tragedy was for the baby to be sick, not for the baby to die," said his wife.

Hannan visited the parents again the next afternoon to request their permission to have an autopsy performed.

(Ironically, the autopsy would later show that the Alvarez baby had a basically sound heart. His kidneys, too, appeared to be normal. But no amount of surgery could have saved him, for his kidneys were not connected to anything. Baby Boy Alvarez had no bladder. Instead, he had a cloaca, a combination bladder and bowel similar to that found in birds. His breathing difficulty, it turned out, was caused by severe lung disease.)

Hannan returned to his office, shaking his head, clearly depressed.

"I can do without that," he said, vehemently. "They're beginning to get it all smoothed out and then you come in with that autopsy sheet and it all goes jagged again.

"You know," said Hannan, who had been through similar ordeals about a dozen times," I have a recurring dream every so often:

"I'm going to Heaven, and as I go through the gates I see what looks like this field of gently waving grass. When I look again, closely, it's babies, slowly undulating back and forth—the babies I've shut off."

Nurse Robaczynski Sad At Leaving Her Profession

The District Star
3/30/79

By Christopher Hanson
Washington Star Staff Writer

BALTIMORE — A nervous, smiling Mary Rose Robaczynski, no longer facing murder charges in four cases of alleged mercy killings, expressed sadness yesterday that she would never be a nurse again.

After a press conference here yesterday, the former nurse at Maryland General Hospital remained nearly as much an enigma as she did during her long trial on charges of disconnecting the respirator of a comatose patient.

Her attorneys insisted that she answer no questions dealing with the facts of the case or with her views on euthanasia.

Robaczynski's so-called mercy killing trial for unhooking the mechanical respirator of Harry Gessner, a comatose patient at Maryland General Hospital, ended in a mistrial last week.

After nearly 19 hours of deliberation, the jury was hopelessly deadlocked over the key issue: was the patient's brain alive or dead when the nurse pulled the plug? Robaczynski was also charged with the murder by respirator disconnection of three other patients.

All charges were dropped on condition that Robaczynski agree never again to practice nursing in Maryland or any other state. She has given up her nursing license.

Yesterday she thanked the press for its courtesy, her family and friends for their support, but expressed sadness that she would never be a nurse again.

"It was such a big part of my life," she said, adding that what she will miss most is "just caring for people."

Was her fatal mistake that she cared *too much*?

"You can never care too much," she replied in a squeaky drawl.

She said she had felt "very proud and good" when a former patient testified that he would have wanted her for his nurse again even if he were on a respirator.

During the trial, co-workers testified that Robazynski was a strong advocate of euthanasia for hopeless patients in comas, partly because of the emotional and financial burden they imposed on their families.

Witnesses also testified that she was an unusually compassionate nurse, who sent greeting cards to her former patients, and cried with the families of the ones who died.

See NURSE, DC-3

Associated Pre

Mary Rose Robaczynski and her attorney George Helinski arrive for a news conference

Nurse *From DC-1*

Meanwhile, the state's attorneys office here is advocating revision of a statutory definition of brain death which, prosecutors believe, prevented them from convincing a jury that Robaczynski was guilty of homicide.

The vagueness of the statute, said Baltimore City State's Attorney William A. Swisher, led him yesterday to drop four murder charges against the defendant.

Swisher vowed to prosecute similar instances of alleged euthanasia "if possible." But he made it clear that obtaining convictions might be difficult or impossible.

"The Maryland statute defining death," he said, "is too vague to be used as a basis for this kind of prosecution . . . Never before have prosecutors had to prove beyond a reasonable doubt that a homicide victim was, in fact, alive before he was killed."

Swisher said he intends to lobby the Maryland legislature to change the law in several ways.

Among those changes, said co-prosecutor Peter Semel, would be to strike the word "spontaneous" from a statute which now equates death with "spontaneous brain function."

In the course of the trial, expert witnesses disagreed over whether patient Gessner's reflex reactions to ight, muscle twitching and possible hallow breathing in the hours preceding disconnection actually amounted to "spontaneous brain function."

Several jurors interviewed after the trial said, in effect, "If doctors disagree on the matter, how can *we* be expected to decide?" Swisher echoed this reasoning yesterday, and said he had determined to drop the charges only after interviewing 11 of the 12 jurors.

His decision was not reached without some dissension in the ranks. Semel confirmed that he favored continuing with the prosecutions. "I felt that conviction would be a better deterrent to this kind of action," he said, arguing that he felt the chances of convicting Robaczynski would have been greater on retrial because "we know what their witnesses would have said."

In his closing argument to the jury, Semel delivered an emotional indictment of mercy killing and charged the defendant with depriving Gessner of his right to live.

But Gessner's sister, contacted after yesterday's decision was announced, was not so sure that his alleged killer should continue to face trial. "I guess it wouldn't really be much use to try the case again," said Patricia Whetzel. "I really wouldn't want to be a juror. I can't honestly say that in my heart I knew whether my brother was dead or alive.

"But," she added acidly, "I do know that no nurse has the right to touch the plug on any patient."

Nurse won't be tried in mercy killing case

Associated Press Mpls. Tribune March 30, 1979

Baltimore, Md.

Murder charges were dropped Thursday against a nurse accused of mercy killings by unplugging the respirators of four comatose patients.

In return, Mary Rose Robaczynski, 24, agreed to give up her nursing license and never practice again.

She had been tried on a murder charge in the death of Harry Gessner, 48, one of the four patients, but the case ended in a mistrial last week.

State's Attorney William A. Swisher said yesterday that prosecutors had decided not to retry the case, and to drop all charges, if Robaczynski would agree not to practice nursing in Maryland or any other state.

Swisher said the decision was based partly on the vagueness of Maryland law defining death. He said his office would try to get the Legislature to change the definition.

"After talking with 11 of the jurors, we have determined that they were unable to agree on whether the victim was legally dead or alive at the time the respirator was disconnected within the terms of our statute," he said. "... The law should be clarified. We need an accepted universal definition of death."

Robaczynski was not available for comment, but defense attorney George Helinski said, "It was our position all along that the law was not written for criminal prosecution in terms of the time of death."

Mary Rose Robaczynski

Robaczynski, Pasadena, Md., admitted during the trial that she unplugged Gessner's respirator in the special unit of Maryland General Hospital on March 8, 1978. Several nurses had testified as prosecution witnesses that Robaczynski had expressed a belief in euthanasia, but she said she thought Gessner already was dead because she got neither pulse nor blood pressure readings.

Judge Robert Karwacki declared a mistrial when the jurors told him March 20 that they could not reach a verdict after almost 20 hours of deliberation. The jury was voting 10-2 in favor of acquittal, several jurors said.

UNIFORM BRAIN DEATH ACT

Drafted by the

NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS

and by it

APPROVED AND RECOMMENDED FOR ENACTMENT
IN ALL THE STATES

at its

ANNUAL CONFERENCE
MEETING IN ITS EIGHTY-SEVENTH YEAR
IN NEW YORK, NEW YORK
JULY 28-AUGUST 4, 1978

WITH PREFATORY NOTE AND COMMENTS

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National Conference of Commissioners
on Uniform State Laws
645 North Michigan Avenue, Suite 510
Chicago, Illinois 60611

UNIFORM BRAIN DEATH ACT

PREFATORY NOTE

Between 1970 and 1978, 19 states enacted legislation recognizing the concept of brain death. This was a new legislative undertaking, for death had always been determined before by common law principles. The common law criterion for death was: "an absence of spontaneous respiratory and cardiac function."

The technology of medical care can now overcome the natural cessation of both breathing and heartbeat. That technology creates a concern among medical practitioners that legal liability might be imposed when life-support systems are withdrawn, even though the case is hopeless and acceptable medical practice sanctions the withdrawal, and though the continuation of artificial means of life support offends even those most morally and emotionally committed to "the preservation of human life." This Act expresses community approval of withdrawing artificial life-support systems when the whole brain has irreversibly ceased to work.

This Act is silent as to acceptable diagnostic tests and medical procedures. It addresses the concept of brain death, not the criteria used to reach the medical conclusion that brain death has occurred. The medical profession should formulate over time the acceptable practices, taking into account new knowledge of brain function and new diagnostic equipment.

The "time" of death is an overriding concern of anyone contemplating the occurrence of brain death. Upon reflection, the Special Committee concluded that, in those instances in which time of death affects legal rights, this Act should simply state the facts constituting brain death and thus provide the basis for whatever inquiry is necessary to fix the time of death.

Some other questions and subjects not addressed by this narrow Act are: living wills, death with dignity, euthanasia, rules on death certificates, maintaining life support beyond brain death in cases of pregnant women or of organ donors, and protection accorded the dead body. Those subjects are left to other law.

UNIFORM BRAIN DEATH ACT

SECTION 1. [*Brain Death.*] For legal and medical purposes, an individual who has sustained irreversible cessation of all functioning of the brain, including the brain stem, is dead. A determination under this section must be made in accordance with reasonable medical standards.

COMMENT

This section legislates the concept of brain death. The Act does not preclude a determination of death under other legal or medical criteria, including the traditional criteria of cessation of respiration and circulation. Other criteria are practical in cases where artificial life-support systems are not utilized. Even those criteria are indicative of brain death.

"Functioning" is a critical word in the Act. It expresses the idea of *purposeful* activity in all parts of the brain, as distinguished from random activity. In a dead brain, some meaningless cellular processes, detectable by sensitive monitoring equipment, could create legal confusion if the word "activity" were substituted for "functioning."

SECTION 2. [*Short Title.*] This Act may be cited as the Uniform Brain Death Act.

HENNEPIN
MEDICAL CENTER
701 Park Avenue South
Minneapolis, Minnesota 55415

March 26, 1979

Mr. Richard Krause
Public Affairs Division
Legislative Department
American Medical Association
535 North Dearborn Street
Chicago, IL 60610

Dear Rick:

Our phone conversation on March 16 revealed many points of agreement, and a few points of disagreement. For purposes of clarity, emphasis, and as a basis for future dialogue, I wish to develop a few of these issues in writing.

Now that the AMA is changing its position on brain death legislation and is moving in the direction, slow but sure, that legislation is needed, it would be extraordinarily helpful to have the AMA join forces with other state and national medical organizations to unite behind one uniform brain death bill. The advantages of such a move are obvious. It would help us a great deal to coordinate our efforts, and uniting behind one statutory proposal would be very persuasive to state legislatures. As you know, the previous position of the AMA in opposition to legislation has seriously hampered state medical organizations and other groups in their efforts to pass bills in this area, and the pro-life movement has achieved maximum mileage out of the AMA's position. Besides facilitating passage of legislation, combined support of various medical organizations would encourage efforts to establish uniform standards and criteria for the medical determination of brain death, and give us an opportunity to educate the medical profession and society to the most important issues.

I would hope, therefore, that you and your staff would reconsider your position on the Uniform Brain Death Act (UBDA). The UBDA is not perfect, but it is just as good as any other bill and, in some ways, better. It is interesting to note that what you regard as one of the weakest points in the bill is what I would consider the strongest feature, i.e. the clear and explicit definition of what we mean by brain death. This is exactly the feature that will win us support from the responsible pro-life movement.

HENNEPIN COUNTY
an equal opportunity employer

Wednesday, March 21, 1979 The Washington Star

Doubt Voiced on Whether Patient Was Alive at Unplugging

Jury Deadlocked, Mistrial Ruled in Nurse's Murder Case

By Christopher Hanson
Washington Star Staff Writer

BALTIMORE — A mistrial was declared yesterday in the euthanasia trial of former nurse Mary Rose Robaczynski, 24, who was charged with first-degree murder for unplugging the respirator of a comatose patient at Maryland General Hospital last year.

Doubt over whether 48-year-old Harry Gessner was dead or alive before Robaczynski pulled the plug caused them to deadlock, jurors confirmed.

The final vote, according to jury forelady Beverly Skotorski, was 10-2 in favor of acquittal. A unanimous vote is required for a verdict.

"There was so much doubt over whether he was alive or dead," said Skotorski. "We thought doctors couldn't agree on that point either. And we didn't have medical background."

THE MISTRIAL was declared by Baltimore Criminal Court Judge Robert Karwacki at 11:20 p.m., after the jury had deliberated about 18 hours Monday evening and yesterday.

In a handwritten note early yesterday evening the jurors told Karwacki that they could not reach a verdict. He called them to the jury room and reread part of his original instruction in an effort to break the logjam.

The jury returned to the deliberating room and over the next few hours shouts could be heard from the adjacent court chamber. But the arguments apparently were unproductive and the jury remained deadlocked.

During 10 days of testimony, expert witnesses had clashed on the key issue of the trial — what is death?

Was Harry Gessner's brain dead when the respirator was disconnected? The defense argued that Robaczynski could not have killed Gessner because he already was brain dead. Under a 1972 Maryland law, death is equated with the absence of "spontaneous brain function." But the term led to dispute among expert witnesses.

In addition to coping with the moral issue of euthanasia, the jury was being asked to evaluate complex medical testimony and apply it to a statute which, according to prosecutors, was untested in a Maryland criminal case.

"It was too much to ask a jury what the statute meant," complained juror Clee Anderson. Foreman Skotorski agreed, as did Assistant State's Attorney Howard B. Gersh, one of the prosecutors.

See NURSE, A-9

NURSE: Mistrial Is Declared in Murder Case

Continued From A-1

JURORS confirmed that debate over the meaning of "spontaneous brain function" in the Maryland statute was a source of unyielding disagreement in the jury room. "We interpreted it in different ways," said Anderson.

The outcome of the trial led prosecutor Peter Semel to question the Maryland death statute which so influenced the result. "The statute is too vague on the issue of death. If doctors can't agree, how can we expect 12 lay people to agree? We need to go back and re-examine the statute."

Semel and Gersh each said that it is too early to retry the case. But Semel added, "it's too important an issue to leave hanging in the air. These kinds of actions in hospitals are life and death matters." In his closing statement to the jury Monday, Semel had contended that euthanasia is immoral, and that it deprived Harry Gessner of his chance to survive.

Defense Attorney George Helinski expressed relief at the mistrial, and his colleague Joseph Murphy Jr. observed, "the hearts of everyone in the media went out to Mary . . . and finally, the hearts of the jury, too."

But when Judge Karwacki declared the mistrial, Robacyznski's head slumped onto Helinski's shoulder, and she wept, seemingly with anguish. She left the courtroom, on the supporting arms of her family, who have been with her throughout the trial.

EARLIER yesterday, she sat casually in the courtroom, at one point reading a newspaper article with the headline "Jury Deliberates in Mercy Killing." She remained poised throughout most of the trial, listening calmly even to the most damaging testimony against her.

But when she took the stand in her own behalf Monday her voice broke and tears flowed as she recounted her helpless feeling when Gessner's pulse ebbed away. She explained how she had loved nursing, but has been reduced to earning a living as a housekeeper.

—Associated Press

Mary Rose Robaczynski and her attorney, George Helinski, leave court yesterday after a mistrial in murder case against her.

Much of the trial, however, was more clinical than emotional, and could be characterized as a clash between defense and prosecution experts.

Two medical experts for the prosecution testified that Gessner's brain was in fact alive until the plug was pulled because it lacked swelling, which accompanies brain death.

Several defense witnesses contradicted the testimony, two of them insisting that the patient's brain lacked spontaneous function. Two others insisted that it is impossible to know whether Gessner's brain had died — a claim which defense lawyers hoped would plant in the jury a reasonable doubt that Gessner had been killed by the defendant.

Another issue in the trial was whether Gessner actually died from a disconnected respirator instead of some natural cause. An assistant Maryland medical examiner, Dr. Pat Dixon ruled out natural causes and attributed Gessner's death directly to a disconnected respirator. But Dr. James A. Biddison, a cardiologist at Greater Baltimore Medical Center, insisted that a heart attack was an equally plausible cause of death.

THERE WAS also conflicting testimony on whether Gessner could have been resuscitated on March 8, 1978. If resuscitation had been possible, Judge Karwacki instructed the jury, Robacyznski must be acquitted because there was an "intervening cause" between disconnection and death.

Alongside the battle of the experts, there was testimony from Robaczynski's co-workers, some of it implicating her in the disconnection of critical patients' respirators. One nurse said that she told the defendant to stop disconnecting life support, only to be told, "They'll never catch me."

A supervisor recounted that Robacyznski confessed to her, "I only did it to the GORKS," the acronym stands for God Only Really Knows.

Through testimony such as this, the prosecution attempted to implicate Robaczynski in the disconnection of eight patients. She was charged with the murder of four, and has admitted unhooking Gessner and two others — claiming that she thought they were already dead.

In addition to damaging evidence, there was testimony from fellow nurses and doctors which portrayed Robaczynski as a caring and compassionate nurse who became involved with her patients, sending them greeting cards after their release, and crying with the families of those who died.

Robaczynski's support of euthanasia for comatose patients, said one witness, stemmed from her concern that their families be spared the emotional and financial burden of allowing a hopeless case to linger.

The case attracted considerable attention from medical professionals in the area, and was being watched as a possibly precedent-setter. But with the hung jury so obviously confused, the question of what is death remains apparently as muddled as it was before.

Md. Law on Brain Death Was Unclear to Jurors

By Saundra Saperstein
Washington Post Staff Writer

Several of the 12 jurors who found themselves unable to agree whether former nurse Mary Rose Robaczynski had murdered a comatose patient said their confusion over Maryland's legal definition of brain death led to the deadlock.

Baltimore prosecutors met yesterday with 11 of the jurors and came away uncertain whether any jury could understand the existing law.

Robaczynski was accused of murdering patient Harry Gessner by unhooking his respirator, but the defense contended that Gessner was legally dead hours before the disconnection.

A mistrial was declared late Tuesday, when the jurors after 19 hours of deliberation, deadlocked 10 to 2 in favor of acquittal, according to one jury member.

"Everybody agreed that what Mary did was wrong," Assistant State's Attorney Peter Semel said yesterday, after an hour-long talk with the jurors. "But they couldn't decide whether he [Gessner] was dead or alive."

"It was the first case I ever had to try," Semel said, "where I had to prove the victim was alive before he was dead."

To help the prosecutors decide whether to retry the case, Semel said, the jurors were asked to meet when they returned to jury duty on other cases yesterday. Eleven jurors agreed to the meeting, Semel said.

Semel said he and Assistant State's Attorney Howard Gersh will decide "probably next week" whether to retry the 24-year-old Robaczynski on this charge, or on any of three other charges of murdering patients by respirator disconnection.

After the mistrial was declared, jury foreman Beverly Skotarski told reporters, "We couldn't even decide whether he (Gessner) was dead."

Juror Teresa Severe agreed. "The main thing was the law they had defining whether the man was dead or alive," she said. "It was hard to make a decision."

That law is the 1972 Maryland stat-

See DEATH, C13, Col. 2

Robaczynski Jurors Unclear On Maryland Brain Death Law

DEATH, From C1

ute that says, in part, that a patient may be declared legally dead when there is an absence of "spontaneous brain function." The defense hinged its case on those three words, maintaining that under that definition, the 48-year-old Gessner was "brain dead" before the disconnection.

Severe, a 53-year-old Baltimore housewife, said that each of her fellow jurors put his or her own interpretation on the word "spontaneous."

Some legal and medical experts now believe that the word "spontaneous" should be left out of future statutes defining brain death.

"Its' unnecessary, a mistake, because of the potential confusion," said University of Pennsylvania law professor Alexander Capron, who has worked as a consultant with a national lawyers group that is proposing enactment of a uniform brain death law by all the states.

Minneapolis brain specialist Ronald Cranford, who also worked on the proposal, said the law would define brain death as occurring when all functioning in every part of the brain ceases.

Though the Maryland statute was defended by several legislators and local doctors yesterday as clear, both prosecutors and defense attorneys in the Robaczynski case said it was "too vague."

Defense attorney Joseph F. Murphy Jr. said the law was enacted to help doctors in organ transplant cases, but if it is going to be applied in criminal cases "it could use some improvement."

Wa Post 3/22/79

HENNEPIN
MEDICAL CENTER
701 Park Avenue South
Minneapolis, Minnesota 55415

March 28, 1979

Mr. Joseph Lampe
Executive Director
American Citizens Concerned for Life, Inc.
6127 Excelsior Boulevard
Saint Louis Park, MN 55416

Dear Joe:

Thanks for the article from the Washington Star dated March 21, 1979 concerning the trial of Mary Rose Robaczynski. I was interviewed that same day by Sandy Saperstein of the Washington Post. I didn't know many details of the case, but the reporter questioned me regarding the vagueness of the Maryland brain death statute and the confusing testimony of the medical experts. My comments should have appeared in the March 21 or March 22 edition of the Washington Post.

Among other things, this case emphasizes the confusion that can arise with a poorly worded brain death statute. I would hope that no such confusion would arise with the wording of the Uniform Brain Death Act.

I have also enclosed some recent correspondence which may be of interest to you.

Best regards.

Sincerely,

Ron

Ronald E. Cranford, M.D.
Associate Physician in Neurology
Hennepin County Medical Center

REC/mmf

xc: Mr. Richard Krause
Joseph Boyle
Enclosures

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In the long run, the introduction of a wide variety of brain death bills sponsored by different medical and legal organizations will be confusing and counter-productive, and will hamper, not facilitate, the passage of brain death legislation in the individual states. As you know, the Ethics Committee and Executive Board of the American Academy of Neurology have already adopted two resolutions, one endorsing the principle of brain death legislation and the other endorsing the specific statutory language of the UBDA, and these two resolutions will be brought to the attention of the general membership of the American Academy of Neurology in April for their approval (enclosure, Editorial, Uniform Brain Death Act, Neurology 29 (3):417-418, 1979). After receiving this endorsement, the UBDA will then be brought to the attention of the other major neurological and neurosurgical organizations, as well as various transplant groups.

Over the last nine years, since the enactment of the first statute by Kansas in 1970, we've gained a great deal of experience on legislation in this area. Some mistakes have been made in enacted legislation in other states, such as amending the definition of death to the Uniform Anatomical Gift Act (Illinois, Virginia, and West Virginia), adopting a permissive statute (Oregon and Georgia), and confusing living wills, brain death, and the persistent vegetative state in the same bill (North Carolina). Hopefully, we can learn from these mistakes, and it seems to me that we are on the threshhold of making some very constructive moves in the next few years, especially if we can coordinate our efforts.

You and I did agree, quite strongly I thought, that the formulation and promulgation of uniform brain death criteria and related procedural guidelines by organized medicine would be very beneficial. This would, of course, be completely distinguished from legislation. In this respect, the criteria adopted by the Minnesota Medical Association have demonstrated that the Harvard criteria can and should be updated in a meaningful way, without inappropriately restricting the professional discretion and medical judgment of individual physicians, which is obviously of great concern to your staff.

Such uniform criteria would, first of all, distinguish between essential criteria which must be satisfied in every case versus confirmatory criteria. Essential criteria would include cerebral unresponsivity, apnea, absent brain stem reflexes, and the establishment of irreversibility, common points of agreement between the Harvard and MMA criteria. Confirmatory criteria would include the EEG, radioisotope studies documenting an absence of cerebral blood flow, other cerebral blood flow studies, auditory evoked responses, etc. Most importantly, the essential criteria would emphasize that the basic diagnosis of brain death, as with the traditional cardio-respiratory standard, is clinical, and therefore, in the majority of cases, the diagnosis of brain death can be determined from the clinical examination alone, without the need for confirmatory laboratory studies...although these latter studies could be utilized if the attending physician so decides they would be useful. The MMA criteria exemplifies these points, and their value in the Ellison case stresses these advantages even more so.

But this brings us to a key issue where you and I disagree. You object to the phrase, "irreversible cessation of all functioning of the brain, including the brain stem," as used in the UBDA. The AMA model bill uses the phrase, "irreversible cessation of brain function." Apparently, you specifically object to the concept of totality, i.e. the use of the words "all" and "including the brain stem." As I tried to explain over the phone, that is the strongest feature of the UBDA, and the one feature that will be persuasive with the pro-life movement. You feel that we have too clearly and explicitly defined what we mean by brain death, and furthermore that this phraseology will somehow limit medical discretion and professional judgment in the actual determination of brain death in individual cases. I disagree. I think you are confusing the concept and the criteria. Essentially every accepted set of criteria that I am aware of have, while not explicitly saying so, listed as their essential criteria the irreversible cessation of <u>all functions of the brain</u>.

Confusion has arisen over the meaning of the term "functions" or "functioning." However, the UBDA was quite specific and precise in defining what we had intended by the term "functioning," and the comment section accompanying the UBDA leaves little room for misinterpretation, in my opinion. Functioning refers to the specific, purposeful activities of the brain, as determined by the clinical examination, in contrast to the random activities or functions of individual cells or groups of cells in the brain, or biochemical, electrical or physiologic actions of the brain. Functions is defined in Dorland's Illustrated Medical Dictionary (25th edition, 1974) as "the special, normal, or proper action of any part or organ." Blakiston's Gould Medical Dictionary (3rd edition, 1972) defines function as "the normal or special action of a part." Further, Webster's Third New International Dictionary (1961) defines function as, "5. One of a group of related actions contributing to a larger action. a. The normal and specific contribution of any bodily part (as a tissue, organ, or system) to the economy of a living organism (a primary function of any gland is secretion)."

Like so many issues in the current brain death debate, the clarification of what we mean by functions is simply one of education, and this is where the AMA could assume a strong leadership role, in cooperation with other organizations.

The primary purpose behind this key phrase, "irreversible cessation of <u>all functioning, including the brain stem</u>" (emphasis added), was to distinguish, as clearly and explicitly as possible, between whole brain death and neocortical death. Some ethicists and physicians are now advocating that neocortical death should be regarded as the death of a human being.* It is, therefore, crucial

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*Veatch, Robert M. <u>Death, Dying, and the Biological Revolution</u>. New Haven: Yale University Press, 1976; Fletcher, Joseph: New definitions of death. <u>Prism</u> 2:13-14, 1975; Sweet, William H: Brain death (editorial). <u>New England Journal of Medicine</u> 299:410-412, 24 August 1978.

that further pieces of legislation in this area should clearly distinguish between these two syndromes. This was the primary objective of this critical phrase in the Uniform Brain Death Act.

However, this phrase, as I understand its meaning, is completely compatible with existing standards for the medical diagnosis of brain death, and will, in no way, unduly restrict the discretion of physicians, nor, in any manner, impede further advances in medical science contributing to the more rapid and accurate diagnosis of brain death.

I understand the apprehension that some physicians feel when first confronted with this type of phrase, and I can understand how such a phrase is subject to misinterpretation. But these fears are based upon an abstract, theoretical concern of how the courts and legislatures might conceivably interpret this term, and are not grounded in any actual reality or specific data. This apprehension, moreover, reflects a suspicion of many physicians towards the motivations of the courts and a lack of understanding of the legal system, unfortunately so prevalent among physicians today. This is another area, of course, where people like yourself, Bruce Nortell, and organizations such as the AMA can be of real value, by educating the physicians to what these terms actually mean and making them recognize that there is no basis, in fact or in law, for their concerns. Further, this is also where established medical criteria would serve a significant educational purpose, by clearly stating the correct meaning, both medically and legally, of these terms. We did this to a certain extent in the MMA criteria, but future criteria should spell out these aspects in even greater detail and more fully develop the idea in the introductory section that functions refers to the clinical aspects of brain activity.

The other major point where we disagree is whether a statute should be mandatory or permissive. The UBDA is mandatory, while the AMA model bill is permissive. The statutory proposals of Capron and Kass and the American Bar Association, as well as the majority of enacted legislation, are all written in such a way that the pronouncement of death is mandatory, not permissive. The comments of Alexander Capron submitted for consideration at the NCCUSL meeting in Arlington, Virginia on March 31, 1978 emphasize that a brain death statute should be definitive, not permissive. Bill Curran and Don Harper Mills both fully agree. So there seems to be little, if any, disagreement among the legal scholars on this point.

I think I understand your reasons for preferring a permissive statute. Your primary objectives in this area, as I understand them, are to ensure legal immunity to physicians from criminal or civil lability, to allow for maximum professional discretion and medical judgment, and to make certain that further advances in medical science will not be hampered. These are, of course, important goals in legislation, but secondary, I would submit, to other, slightly more important considerations. The primary purpose of brain death legislation, in my opinion, is to promote societal acceptance of the brain death concept and to educate the public and medical profession to the relevant issues by means of a public dialogue and extensive discussion of the issues. But this gets back to one's philosophy of law, and it may be that you and I differ on our philosophies of law and the purposes of legislation. Even more important than the brain death issue itself is the development of a public policy attempting to resolve current dilemmas brought on by modern medical technology. That's what we're really talking about, isn't it?

In order to achieve an overview on these issues, I guess we need to ask ourselves, what do we really want to accomplish by brain death legislation, and what can be accomplished in other ways, for instance, the formulation of uniform medical criteria? It seems to me that we are trying to create a climate in which the following conditions would prevail: 1) physicians would be knowledgeable and experienced in the medical diagnosis of brain death, so that the chances of any serious mistakes would be minimized, either false-positives or false-negatives; 2) physicians would understand that when there is any reasonable possibility for meaningful recovery of the patient, all appropriate medical support should be used to effect a cure; but if such therapy isn't successful, then it would be morally and legally permissable, as well as medically acceptable, to either withhold or withdraw further medical support; 3) the public will develop <u>trust</u> and <u>confidence</u> in the medical profession with the knowledge and appreciation that physicians would go all out when there was hope of recovery, but that also physicians would not needlessly prolong the pain, suffering, and indignity associated with the dying process when there was no reasonable hope of recovery. Obviously, these previous comments would encompass more than just the brain death concept. Now, the question arises: How do we accomplish these objectives and create an atmosphere in which these attitudes would prevail? Some goals could be achieved through legislation, but more importantly, others could be achieved through the establishment of reasonable standards of medical care, as formulated and promulgated by the medical profession itself. This gets to the heart of the matter regarding a mandatory versus permissive statute.

First, from a purely factual standpoint, a permissive statute simply does not make any sense. The medical profession has been trying to convince society for the last ten years or so that a person is dead when his brain is dead, so what type of mixed message does the public receive when the AMA proposes a permissive statute...saying in effect, well, the patient may be dead when his brain is dead, but that should be left to the discretion of the attending physician. Does that appeal to common sense? Further, the determination of death using the traditional cardiorespiratory standard is mandatory--why should there be any difference using the brain death standard? Or isn't someone just as dead using the brain death standard as with the cardiorespiratory standard?

But problems have arisen, and will continue to arise, with or without definitive legislation. Some of these problems hinge on the distinction between 1) the concept versus specific criteria for brain death; 2) the fact of death versus considerations and procedures related to the actual pronouncement of death and discontinuation of respirator support; and 3) the time when the person dies versus the time when death is pronounced.

In the majority of cases, it is relatively easy, from a strictly medical standpoint, to determine that an individual patient has satisfied the criteria for brain death and that, beyond any reasonable doubt, the brain is dead; therefore, the person is dead. But, during the process of satisfying these criteria, other issues--social, legal, moral--arise. These secondary issues have great impact on the actual pronouncement of death and the corollary decision to discontinue the respirator. The critical question is not whether a physician should pronounce a person dead when his brain is dead; rather, under what circumstances would it be justifiable for a physician to delay the final pronouncement of brain death and the discontinuation of the respirator, and the corollary question which you should be considering, how best can the AMA aid the physician in these matters?

It seems to me that there are five conditions in which it may be morally and legally justifiable to delay the final pronouncement of brain death. These five would include: 1) the fulfillment of all necessary criteria; 2) consideration of the wishes and feelings of the family; 3) legal factors; 4) procedures relating to organ donation; and 5) pregnancy. Let me briefly summarize each of these major points.

The first condition is not actually a delay, but should be included for purposes of completeness. A person is not pronounced dead on the basis of brain death until all criteria have been satisfied, including appropriate confirmatory studies when indicated. But, as noted in the MMA criteria, the time of death is when the brain first ceased to function, and ceased to function irreversibly, or, from the standpoint of the physician, when the physician first noted that all brain functions had ceased, i.e. "the first observation." This would normally be the first complete neurologic examination when the physician has begun to fully appreciate that resuscitation has been unsuccessful in restoring brain function and that brain death is highly suspected. But, even after this initial observation, a further period of evaluation is necessary to establish that the cessation of all brain functions is irreversible. This sequence illustrates the critical distinction between the time of death and the time of the pronouncement of death, and I would hope that your legal counsel would agree with me on this point.

The second circumstance in which it may be justifiable to delay the final pronouncement of brain death is by far the most important, and the one that will give rise to the most problems in the future, i.e. the relation between the medical fact of death and the consideration of the wishes and feelings of the family. The general rule which I have followed is this: If the family has any reasonable concerns, objections, or reservations, then the attending physician should make every reasonable attempt to resolve these concerns before the patient is pronounced dead and the respirator discontinued. The physician needs to combine tact, sensitivity, compassion, and understanding in his effort to help the family through the grieving process and the acceptance of the finality of death of their loved one. But this needs to be combined with firmness and unequivocal certainty so that the physician can impress upon the family that their loved one is truly dead, that there is no doubt concerning the irreversibility of the condition, and that further medical efforts will be of no avail. Such certainty is necessary to minimize any unnecessary guilt from the family.

What if the concerns or motivations of the family are not reasonable? Who determines whether the relatives' motivations or intentions are reasonable? It seems to me that the attending physician is in a pivotal position in this regard, since he is primarily concerned about the best interests of the patient (even if it has been determined that the person is dead) and is also concerned about the welfare and well-being of the family. It is not too difficult to envision the many problems and dilemmas that will arise in this area in the future. What should occur if the family objects to the brain death concept for religious reasons? For financial reasons? For personal reasons?

I have been involved with numerous cases in which such difficulties have arisen, but, fortunately, in the majority of cases, such concerns have been satisfied, and the next of kin have been in full agreement that the person was dead, and that the respirator should be discontinued.

I do remember one case in which one family member, for reasons of guilt, refused to allow discontinuation of the respirator. The other family members, a son and daughter, understanding the circumstances surrounding the death of their mother, had no difficulty in accepting her death. However, another son, who had spent little time with his mother and was considered the "black sheep" of the family, strongly objected to the withdrawal of support, and said something to the effect, "I'm not going to kill my mother." What should a physician do when he is faced with an irrational family member, and there seems to be little chance in convincing the relative of the true condition of the patient? Such situations as this will be minimized with the enactment of brain death legislation and the accompanying acceptance and education of the public. But these dilemmas, although significantly lessened by legislation, will continue to arise from time to time. In these cases, if the motivations and intentions of the family members or others are clearly irrational and unjustifiable, several courses of actions are available to physicians. First, the physician should make every reasonable effort to explain to the family the relevant circumstances in an attempt to persuade them of the proper course of action. In many of these cases, while these attempts are being made, the situation takes care of itself because the patient suffers a cardiac arrest during this time. The physician could elect to disregard the wishes of the family and unilaterally withdraw respirator support, but this, of course, could result in civil (wrongful death suits) or criminal (charges of homicide or manslaughter) liability. It seems to me that even with a brain death statute, the only recourse in some of these cases will be to obtain a court order recognizing the brain death concept and permitting the withdrawal of further support.

The third circumstance, intimately related to the second, is when certain legal considerations become relevant in the determination of death. I need not review all the cases that have occurred in the last few years in this regard. The Ellison case was a typical example of this dilemma, but similar cases have occurred recently in Colorado, Massachusetts, Iowa, Oregon, and Texas (enclosures). It is interesting to note that two of these cases arose in states with enacted legislation, Iowa and Oregon. Iowa's statute is mandatory, while Oregon's is permissive. Seven years passed before the constitutionality of the Kansas statute was subjected to legal scrutiny (Curran WJ: Settling the medicolegal issues concerning brain-death statutes: Matters of legal ethics and judicial precedent. New England Journal of Medicine 299 (1):31-32, July 6, 1978; State of Kansas vs. Shaffer, 574, P. 2d. 205 (Kansas, 1977)).

A fourth circumstance, involving cadaver organ donation, has been fairly well recognized and accepted. In these cases, it seems morally and legally justifiable to allow sufficient time for the family to fully appreciate the finality of death and to make a decision concerning organ donation. Once the family has agreed to the transplantation procedure, the patient is pronounced dead but support is continued to maintain viability of the organs.

Fifth, continued maintenance is justifiable after a person has suffered brain death when that person is a pregnant female. If there is any reasonable possibility of delivering a viable infant, then the mother should be pronounced dead but support continued. In two such cases involving mothers in their fifth month of gestation (enclosures), it was not medically possible to artificially maintain the vital functions of circulation and respiration long enough to deliver a viable fetus.

These, then, are five circumstances in which continued support may be justifiable in a brain dead person, or more appropriately, a brain dead body. But the other question that needs to be asked is, how can one justify the expense and futile support on a brain dead person? This latter issue arose in the Ellison case in Minnesota--who was responsible for the hospital bills on Stacey Ellison, the hospital or public welfare? The Commissioner of Public Welfare was hesitant to pay for any costs after the Ellison child was pronounced brain dead. Total cost of hospitalization was $32,000. It seems inevitable that the medical profession will be receiving inquiries and pressure from insurance carriers and governmental organizations when it is recognized that support is being continued on a dead person. This places the physician and the hospital on the horns of a dilemma. How do we balance full consideration for the wishes and attitudes of the family against the unjustifiable expenses and use of scarce resources used to maintain circulation and respiration in a dead body?

Your preference for a permissive statute reflects, in my opinion, a concern over a satisfactory resolution of some of these dilemmas which I have just discussed. But these dilemmas will not be completely resolved with a brain death statute, although that is clearly a step in the right direction. A permissive statute will only compound these difficulties and worsen the situation, rather than improve it. A mandatory statute would help considerably by stating, as simply yet as clearly as possible, that a person is dead when his brain is dead. In the final analysis, the permissive statute does not really afford the physician any legal protection at all in the more difficult cases, which is, of course, one of your primary concerns. In fact, there are numerous implications--moral, legal, financial--to the brain death issue which haven't even been addressed yet, some of which have been touched upon in this letter.

If legislation won't solve all our problems, what will? Among several possibilities, I would highlight two: education and sound legal advice. And these are two areas where the AMA could serve an important role. We need to educate physicians, to make them aware of potential dilemmas before they arise, to inform them of possible solutions and ways of handling these crises, consistent with the highest standards of medical care. We need to develop position papers, policies, guidelines, established standards--call them what you like--to assist and inform physicians who will soon be confronted with these dilemmas and will be looking to medical organizations for guidance and assistance.

Sound legal advice is actually only one facet of the educational aspect. Physicians, not well versed in legal aspects of medicine, need to rely upon the advice of lawyers who are current and knowledgeable in health care law and yet sensitive and conversant with the dilemmas of modern medicine (Annas GJ: Where are the health lawyers when we need them? (Editorial) Medicolegal News 6 (2):3, 25, Summer 1978). Advocating a permissive brain death statute is not sound legal advice.

You are concerned that a mandatory statute will inhibit professional discretion. On the contrary, a mandatory statute will allow for the greatest possible latitude...in the application of the criteria and procedural aspects, but not in the concept. Either the person is dead, or he isn't. There can be no discretion on that point, in the final analysis. The medical profession cannot have it both ways. Society and the law demands clarity and certainty on the matter of death.

I do strongly feel that many of these issues can be resolved, not by legislation, but by education, which would include the formulation of meaningful guidelines, accompanied by informative, explanatory notes, written and published as a joint effort by the AMA and specialty medical organizations, with the cooperation and advice of skilled lawyers like Bill Curran and Don Harper Mills.

I sincerely hope this letter will encourage further dialogue and cooperation among the medical organizations and their individual members and staff. The American Academy of Neurology is assuming a leadership role in these areas, and I will keep you abreast of our progress.

I further hope I have sufficiently stressed the importance of presenting a unified front and having the AMA assume a meaningful, substantive leadership role. Even if the AMA is unwilling or unable to move quickly enough, it does no harm to be well-informed and aware of what you should be doing.

I would greatly appreciate your opinions on these matters. Best regards.

Sincerely,

Ron

Ronald E. Cranford, M.D.
Associate Physician in Neurology
Hennepin County Medical Center

REC/mmf

Enclosures

xc: Betty Jane Anderson
William Curran, M.D., J.D.
Richard J. Jones, M.D.
Don Harper Mills, M.D., J.D.
Bruce Nortell

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Bruce Nortell

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February 27, 1979

Don Harper Mills, M.D.
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Dear Don:

I hope to attend the meeting in Las Vegas if my schedule permits, but it doesn't look too promising right now. If I do attend, I would very much like to spend a few minutes with you over lunch, dinner, or at some other convenient time, to discuss our common interests. In the meantime, let me update you on recent developments so that you will have this background information available to you prior to the Las Vegas meeting. Of course, any information shared with you now can be used at your discretion for whatever purposes you deem appropriate. Along that line, I did appreciate your thoughtful reply to my letter from last summer concerning the content of the Uniform Brain Death Act and your support of the UBDA.

First, the general principle of the legalization of the brain death concept by statutory legislation, and specifically the UBDA, have been endorsed by the Ethics Committee (September 1, 1978) and the Executive Board (November 30, 1978) of the American Academy of Neurology, and the Ethics Committee of the American Heart Association (October 26, 1978) (enclosure). These two resolutions will be brought before the general membership of the American Academy of Neurology at the annual meetings in Chicago during the last week of April. After we have received membership endorsement, these same resolutions will be brought to the attention of the other major neurological and neurosurgical organizations, such as the American Neurological Association, the American Association of Neurological Surgeons, and the Congress of Neurological Surgeons, as well as other interested medical and legal organizations, such as transplant groups and the EEG societies. Ultimately, the plan would be to have these organizations and the American Medical Association fully support the enactment of brain death legislation and specifically support the passage of the UBDA, or substantively similar bills, in the individual states.

news! angle

It would be extraordinarily helpful if you could help convince B. J. Anderson and others at the AMA to endorse the UBDA and to have them recognize that it is in the best interests of the medical profession and the AMA to throw our weight behind one uniform brain death bill. There is no reason why the UBDA couldn't enjoy as much success as the Uniform Anatomical Gift Act. I am currently working on a couple articles to discuss the main features of the UBDA, and clarify certain misconceptions about brain death legislation in general and the specific wording and intent of the UBDA. I will send the drafts of these articles to you for your comments when they are near completion.

These attempts at legalizing brain death should be combined with other efforts aimed at educating and informing the medical-legal professions and the public toward the brain death concept and important related issues, such as the value of organ donation and the distinctions between determining death, allowing to die, and euthanasia. As chairman of the AAN Ethics Committee, I hope to achieve some of the measures on a smaller scale within that organization. If successful, I intend to approach the same goals on a broader scale, but I am sure over the next few years other individuals and organizations will be doing the same things with the same goals in mind, so there should be a greater degreee of cooperation and communication than is presently manifested on a national scale on these issues.

For example, in addition to supporting passage of brain death legislation, it seems to me that the neurological and neurosurgical organizations should lead the way in developing and promulgating, on a national level, relatively uniform medical criteria for the determination of brain death. The development of criteria would be done for several reasons, most importantly to educate the medical profession to the specific standards so that no serious errors will be made in the diagnosis of brain death, either by falsely diagnosing live persons as dead (such as drug intoxications) or falsely diagnosing dead persons as alive (for example, exclusion of spinal segmental reflexes as a determinant of brain death and a clarification of the distinction between essential and confirmatory criteria). Particularly, I am concerned about educating physicians in the intermediate and smaller size communities as technology and advances in cardiopulmonary resuscitation spread to these areas. Also development of relatively uniform criteria will dispel doubts in the public mind concerning the varying criteria from state to state, from authority to authority, and organization to organization... the old argument about being dead in one state but not another. Further, these criteria would serve to educate the public to the distinction between the concept and criteria for brain death, and would also serve as expert medical testimony before the courts in future cases of brain death subjected to legal challenge. As you well know, even with a brain death law in the individual states, the brain death concept and related issues will still be subjected to legal challenge as society and the courts recognize implications of brain death which will not be completely resolved even after passage of definitive legislation.

In regard to the adoption of criteria by the medical organizations, I have enclosed relevant information from two brain death cases decided in the Minnesota courts in 1978. As you can see by the testimony in the Ellison case, the formulation of statutory legislation and, more importantly, the medical criteria adopted by the Minnesota Medical Association were of great value in clarifying accepted standards of medical practice in our state and demonstrating to the courts that the physicians involved in the management of Stacey Ellison had used prevailing standards of practice in their determination of the death of that child.

As you probably know, a national Interagency Committee on Brain Death and Irreversible Coma has attempted for the last several years to update the Harvard criteria and develop relatively uniform criteria for brain death on a national level. However, progress has been slow because there are several points upon which we cannot reach a consensus.

One primary source of disagreement within this committee is the issue of essential versus confirmatory criteria, and the precise indications for and appropriate role of confirmatory criteria. Some physicians feel, for example, that the EEG is of such great value in the diagnosis of brain death that it should almost be considered mandatory. These physicians are resistant to any set of criteria which they feel will deemphasize the role of the EEG. We have also spent a great deal of time in this committee discussing specific wording and various technical aspects related to the clinical and laboratory diagnosis of brain death.

Even more interesting and of much more importance in the long run is the developing debate within this committee, as well as among other ethicists and physicians, over the distinction between "total brain death" and "partial brain death." The latter would include such medical syndromes as the persistent vegetative state, or a variant of the persistent vegetative state, neocortical death. Some ethicists, physicians, and others now argue that neocortical death should be sufficient grounds on which to pronounce death, rather than sufficient grounds for allowing to die. William Sweet, neurosurgeon at Massachusetts General Hospital, a member of the original Harvard criteria committee, and a current member of the Interagency Committee, has proposed this hypothesis, both during the deliberations of our Interagency Committee and in his editorial in the New England Journal of Medicine (enclosures). Sweet (and others) now argues that a person with either 1) a dead brain stem or 2) a dead neocortex is "just as dead" as a person with a dead brain. Exactly how serious he is and whether he would be willing to actually pronounce someone dead on this basis I cannot say for sure, since he has not yet replied to my letter. As you recall, the Royal Colleges' criteria made a serious conceptual and substantive error in their otherwise excellent set of criteria developed in Great Britain when they stated: "It is agreed that permanent functional death of the brainstem constitutes brain death..."

I personally don't feel that this Interagency Committee is going to reach a consensus within the near future; but we can't even agree on that, since some committee members do feel we are close to a consensus. One of the things our Ethics Committee of the AAN will be working on in addition to securing enactment of brain death legislation and supporting the UBDA will be to develop uniform criteria formulated by our committee so that we can at least develop a position paper or a set of criteria which would educate and clarify some of the points directly related to the medical determination of brain death and related procedural guidelines, similar to what we accomplished in Minnesota through the Minnesota Medical Association (enclosure, Minnesota Medicine).

In Minnesota, in addition to formulating brain death legislation and developing criteria and procedural guidelines, the Ad Hoc Committee on Death has developed DNR guidelines, which have not thus far been formally endorsed by the committee or the state medical association. These guidelines (enclosures) have been sent to the chiefs of staff in all hospitals in Minnesota, the Minnesota Society of Hospital Attorneys, the Minnesota Hospital Association, and the Minnesota Nurses Association. After we have received comments from theses groups, we will then revise the guidelines as needed and then officially adopt them through the state medical association. I am convinced that guidelines such as these will have to be developed by hospitals and medical organizations within the next few years, not only for brain death and DNR, but also for allowing to die, in cases of terminal diseases and the persistent vegetative state. If the medical profession doesn't lead the way, then the courts will assume an even more aggressive posture than they did in Saikewicz.

I briefly mentioned to you on the phone the interview with McCarthy DeMere which was published in the National Catholic Register on January 7, 14, and 21 along with an accompanying editorial in that newspaper and a letter from DeMere (enclosure). You will not be pleased by his comments. John McCabe, Legislative Director of the National Conference of Commissioners on Uniform State Laws (NCCUSL) headquarters in Chicago, is currently drafting a reply to the National Catholic Register refuting McCarthy's accusations, and we will be sure to send you a copy of that reply as soon as it is finished. McCarthy's charges that advocates of euthanasia had any input into the formulation of the UBDA are untrue.

Further, McCarthy's "distinctions" between the ABA proposal and the UBDA are, for the most part, patently fallacious on the surface. I won't dwell on the fallacies of McCarthy's arguments now...these will be documented in the letter from McCabe to the National Catholic Register. It would almost be funny if it weren't for the fact that McCarthy, because of his ego trip on the "fool-proof" and "genius-proof" ABA definition of death, has made, more than ever, the current definition of death debate into a religious issue around the country. That is a really sad turn of events. To what extent this has occurred I really have no good idea, but I was astounded to hear McCabe in Chicago discuss the large numbers of letters that his office and other NCCUSL commissioners around the country have received from members of Catholic parishes. McCarthy's interviews were published in the "Sunday Visitor," a pamphlet sent to the Catholic parishes around the country. McCarthy's views are seriously misleading the members of the pro-life movement and the Catholic community, and apparently many of them are buying what he has to say without any critical analysis on their part or bothering to check on his unsubstantiated charges. The editorial in the National Catholic Register is particularly distressing because of the lack of discrimination on the part of the editors in not recognizing, at least to some degree, the almost comical absurdity of McCarthy's analysis and analogies which at times really do border on being frankly funny. There is a good side to this, however. Because McCarthy has argued for the need for brain death legislation, the National Catholic Register is now on record as supporting this legislation, even if they do prefer the ABA proposal.

I did mention to you on the phone that there are some very responsible people within the pro-life movement who are generally concerned that in the long run the pro-life movement is going to lose credibility and power because of their determined opposition to brain death legislation. Many pro-life people feel, as I do, that the organized pro-life movement is drawing the lines at the wrong places. What they should be attempting to do is to clarify the issues and educate the public on brain death and allowing to die so that a meaningful line can be drawn, medically, morally, and legally, between allowing to die and euthanasia. They are going to hurt their own cause in the long run by opposing, too vigorously, the wrong issues.

In this respect, a book on euthanasia and related issues, Life and Death With Liberty and Justice: A Contribution to the Euthanasia Debate, to be released within the next few months should have significant impact on the attitudes of the pro-life forces towards brain death legislation. The two authors are Germain Grisez, a well-known ethicist who has written one of the definitive books on abortion from a pro-life perspective, Abortion: The Myths, the Realities, and the Arguments, and Joe Boyle, a pro-life ethicist and philosopher at the College of Saint Thomas, here in Saint Paul. One of their chapters deals with brain death, and in general they support the principle of brain death legislation (enclosure) and make such statements (with which I agree) as "a correct definition of death...could relieve some of the pressure for legalizing euthanasia." Hopefully, responsible positions like this will help the pro-life people develop a better overall perspective on these issues.

Further, I have recently met with some people within the pro-life movement who are influential both on a statewide and national basis who share similar concerns as I do, and who, for instance, agree with many of the points discussed in Grisez and Boyle's book. They will be attempting within the near future to develop a handbook written from a pro-life perspective on brain death, allowing to die, and euthanasia which will serve to educate members of the pro-life movement on a national level. Such a book as this would be extremely invaluable to clarify these issues and would be very persuasive, I hope, within the pro-life movement.

In this meeting with pro-life leaders, we also discussed some general strategies for attempting to educate the pro-life movement on a national level and to make them aware, for example, of such matters as DeMere's attempt to confuse the issues and muddle the pro-life position because of his ego trip on the ABA proposal. Hopefully, what some of us can do is attempt to contact some people who are high up in the pro-life movement on a national level and make them aware of some of these issues. From my own perspective, I will be attempting to find some nationally influential pro-life neurologists and neurosurgeons. It would be very helpful if people like you could direct us to some nationally prominent pro-life lawyers or doctors if you become aware of them.

Obviously, this sounds like an ambitious undertaking with no guarantee of success, but at least it's worth a try, and we can contact some people to see what type of response we get and determine how much effort would be spent for long range results. Certainly, the least we can do in the immediate future is to try to straighten people out on DeMere's comments so that we can hopefully deemphasize the religious aspects of the brain death debate.

I have been discussing this overall strategy with McCabe in Chicago, and we will hopefully be contacting responsible people, pro-life or not, within the ABA and the NCCUSL so that they will understand exactly where McCarthy's coming from, and hopefully we can educate them on the broader issues as well. Certainly, the long range objective of all of this is not merely the passage of responsible brain death legislation, but much more importantly the development of a reasonable, humane public policy attempting to resolve the dilemmas brought on by advances in medical technology. Looking at these issues from somewhat broader perspectives, I think many of us could envision responsible people within the pro-life movement and members of the medical and legal profession working together in a meaningful way on these issues, not only to secure enactment of good brain death legislation but hopefully with an eye towards resolving the other related issues. Having the opportunity to work with people like yourself gives me great encouragement in this regard.

Sorry about this terribly long letter, but I did want to make you aware of current developments in this area. I will be calling you before the meeting in Las Vegas after I determine whether I will be able to attend or not.

Sincerely yours,

Ron

Ronald E. Cranford, M.D.
Associate Physician in Neurology
Hennepin County Medical Center

REC/mmf

Enclosures

Lisa: A Student's Notebook

by Brian Rees

Saturday

"I need a volunteer. So who wants to work up the kid?" There were only eight of us present, and we each smiled at the improbability of volunteering for anything. But we'd gladly volunteer our neighbor. Bert spoke first, "I tell ya', Dr. Zussman, I think Bob would be happy to do it."

"Actually, Paula's quite interested in hematology," replied Bob. Paula laughed, as did we all. Uncharacteristically, I volunteered. "What do you want me to do?" I asked.

"Well, that beep I got a while ago was about a girl referred from out of town. She'll be over at TMC (Tulane Medical Center) on Monday afternoon, so just go over there, look her over, know the case, and present her at Wednesday afternoon rounds."

These are the waning days of our junior year, only two more weeks left on our last block, Pediatrics. The Saturday morning Hematology/Oncology Seminar with Dr. Zussman had been cancelled the last four weeks in a row, which probably explains why only eight of us, about one-third of the class, were present. We are all fairly tired and not looking for extra work, what with tests approaching and all that. But I feel ignorant about hematology, so I figure I'll work up this little girl, read about her problem, and maybe learn something.

I vaguely understand that for some medicolegal reasons I shouldn't use her real name, so I'll call her Lisa Warren. I'm not sure why, but like so many things in medical school, if you don't know why you're doing something and there's no one knowledgeable available to ask, you just do it, resolve to ask later, and then forget about it until you run into it again. There must be thousands of things like that, tucked neatly away in some hidden recess of my mind.

"Lisa Warren, 4W, TMC, Monday p.m. w/u." I write in my list of things to do, and think of it no more.

Monday

Monday is my first day in the newborn nursery, and we're quite busy. It's already past 5 p.m. by the time I'm able to see Lisa Warren. We students spend almost all our time at the major teaching hospital, Charity Hospital of Louisiana. It's a monstrous inner city hospital, with a couple thousand beds, 19 floors, and an enormous patient population, almost all of whom are indigent.

But TMC is cushy. It's the private university-affiliated hospital where the faculty keep their private patients. No 12-bed wards here. Carpeting, clean walls, functional elevators, piped in music, the whole bit. The school and hospitals are all within a couple of blocks of one another, so I walk across the street to TMC, making sure to take the bubble gum card of Star Wars' Obie Wan Kenobi out of my plastic identification holder. I wear it at Charity, using my penlight as a light sabre to entertain the kids. Official medical ID now in place, I go to the fourth floor, get Lisa's chart without looking at it, and, accompanied by a young nurse who hasn't yet seen the patient and wants to hear what I'll say to her, we knock on the half-open door and walk into her room.

Lisa, a 7-year-old blue-eyed blonde, is sitting up in bed, watching TV and eating supper, as pretty a little girl as I've ever seen and looking the picture of health except for some obvious scleral hemorrhages. Her mother regards us with a mixture of welcome and concern.

"Hi, my name's Brian Rees . . ." The father steps out of the bathroom and looks surprised. I start again. "Hi. There's nothing to worry about. I'm just here to ask a few questions and take a quick look at your pretty daughter here." They look a bit relieved and everyone seems comfortable. Lisa giggles a bit when I call her pretty. "What is it that brings Lisa to the hospital?"

Her mother quickly outlines the history: Lisa is a healthy girl who was completely fine until about seven to ten days ago when she began bleeding from her gums after brushing her teeth, and got those bloody spots on her eyes. Their local M.D. treated her with antibiotics and aspirin, but to no avail. Then they took her to another doctor who ran some blood tests and referred her to TMC.

I like Mr. and Mrs. Warren. They are not an attractive couple. He is heavy, she is

Mr. Rees, a student at the Tulane University School of Medicine in New Orleans, is the winner of this year's TNP manuscript contest.

quite thin, the ravages of poor oral hygiene made manifest by missing teeth. But they seem like straightforward, honest people, working class, salt of the earth, not good looking or wealthy, but they have each other, which is a lot, and they have a beautiful daughter who is a little bit sick. They're concerned because they love her so, but they trust that the big city doctors will fix what ails her and then they'll all be on their way.

"Has anything else been bothering her?" I ask.

"She's been awful sleepy. Anytime if you just leave her alone, she'll fall asleep. And usually she's running all over the place."

"Maybe she's having some trouble keeping her boyfriends in line," I offer.

"I don't have any boyfriends!" Lisa wrinkles her nose and blushes. I'm charmed by this little girl, and her parents can tell and seem to enjoy it. I continue to tease her mildly, her parents and I laugh, and Lisa, while looking a bit embarrassed, is obviously pleased with the attention she's receiving. I'm alternately holding her hand or pinching her arm or rubbing her neck and trapezius. It doesn't have much to do with history and physical, but it's as therapeutic as I've felt all day.

It's late in the day so I briefly feel her big liver and spleen and lymph nodes, then say I'll be by in the morning to talk some more and do a more thorough examination. Lisa looks up as I'm about to leave. "Will you bring me a donut?"

Her folks, embarrassed, admonish her not to ask the doctor to bring her a donut, but I laugh and ask, "What kind of donut?" By now I'm thoroughly enchanted with the child.

"The kind with jelly in it," she smiles back.

"It's a deal," I wink at her in reply. "See you all in the morning." The nurse and I walk out.

I thumb through the chart but, even as ignorant as I am, the diagnosis of leukemia seems inevitable. The admit note mentions lymphocytosis and one of those bells in my head sounds: 80 percent of childhood leukemias are ALL (acute lymphoblastic leukemia). I think half of them are alive in five years with today's treatment, but I figure I'll look it all up.

"Is she supposed to have leukemia?" I ask the nurse.

"I don't know much about her. Is that what you think?"

"Yeah, I think so. Damn shame," I mutter.

I put the chart away and walk back toward school. I feel like I'm on the threshold of a tragedy. Any way you look at it, that pretty little girl has a nasty road ahead of her. Bone marrow aspiration should confirm the diagnosis, I muse, she'll be started on chemotherapy (and maybe radiation, I guess) and sent home to be followed in New Orleans or elsewhere. But, by then, I'll have changed services.

Tuesday

Tuesday morning I bring my black bag over to TMC, look in Lisa's room, and, of course, no one is where you expect her to be the first time around. The nurse tells me she's down in X-ray, I say I'll be back later. I was wise not to have bought the donut yet. At the elevators I meet the social worker covering the case who also mentions that Lisa is down in X-ray.

"Yes, thank you, the nurse already told me," I smile.

"I suppose the priest is on his way," she says distractedly.

"The priest? That's rather premature, isn't it? I mean, she was fine yesterday."

"Well, she's not in too good a shape."

I don't know what to think. "Wait a minute, wait a minute. What the hell's going on? What happened?"

"I'm not too sure, I just heard she arrested or something."

I hustle down to X-ray and there lies Lisa surrounded by scrub-suited anesthesiologists, nurses, techs, and so forth. I recognize a neurologist and ask what happened. "Well, they couldn't rouse her this morning, called us up, and by the time I saw her she had one pupil fixed and dilated and was showing decerebrate posturing. Looks like she had an intracranial bleed and then herniated."

I feel fairly rotten. I continue to watch the goings on and learn that the plan is to take her over to Charity and irradiate her head and kidneys. I feel a little angry and very helpless. Last summer I had a brief externship experience on a pediatric ward for three weeks, and it seemed that my favorite kids would always turn sour. It was happening again.

After a few more discouraging minutes, I leave and head back over to school. It's almost noon so I walk to the cafeteria, not hungry, but feeling like ventilating on someone. I sit down at a table with friends and tell my tale. They share the drag of it with me. I feel better.

Wednesday

Tuesday night I was on call, and when I awoke Wednesday morning I was in the grip of a hay fever attack. I spent Wednesday inundated by antihistamines, which make me feel dull.

Rounds were scheduled for 3 p.m. I join ten other students at TMC waiting for Dr. Zussman. I sit in silence.

Dr. Zussman and a group of house officers finally arrive, and we all seek out a conference room. He sees me and says, "Well, your patient didn't quite work out the way we expected. Did you see her at all?"

"Yes, Monday evening, before she . . . uh."

"Isn't it awful?" he said, understanding. But he was smiling as he said it. At first I thought, how strange, but still, so common; it seems physicians often smile when discussing the most horrible cases. Now I see it as both a defense and a search for intimacy. It's as if to say, smile with me about it because it's so fascinatingly unreal that an innocent child could be taken to death's door so abruptly, and share with me the awe and the thrill of tragedy, so we'll both be protected from the fear and dread of the impunity with which calamity falls.

"Yes, yes, it is awful."

We all sat in the conference room and I presented what little I knew of the case. Atypically, I felt completely at ease while presenting, oblivious to any roundsmanship that might take place. I learned Lisa had a white count of almost 800,000, with 40,000 platelets. The platelets, though decreased, should be sufficient to prevent hemorrhage; it was the increased viscosity secondary to the lymphocytosis that allowed the bleed. The white cell mass was scheduled to be decreased by radiation therapy the very morning that she bled. We missed it by half a day. But it hardly mattered. Yes, she had ALL, but it was a T-cell leukemia, notoriously refractory to treatment. The prognosis was not 50 percent survival after five years, but rather more in the neighborhood of 95 percent dead within six months. She had been doomed.

Soon thereafter we walked down to the ICU to look at her EMI scan. There, I was shocked. Lisa was on her left side in the bed, facing mostly away from me. The incongruity of the scene was palpable. The nurses had pulled back her blonde hair and tied a ribbon in it. Gauze pads were taped over her eyes and an endotracheal tube taped to her mouth, and yet, despite all this, despite the IV platelets and IV fluids and respirator and cardiac monitor and so forth, she still looked angelic. Two days ago she had been happy, smiling, laughing, asking me for a donut, giggling about boys, and now she was reduced to this.

I felt disquieted. But it wasn't the metaphysics of it, the injustice of the death of an innocent and all that. No, it was the imagery that was so striking, and so upsetting. Here was this lovely girl being breathed by a machine, plummeting toward her rendezvous with death; it just looked inconsonant.

On my way out I passed the waiting area and saw Mr. and Mrs. Warren for the first time since Monday. Their eyes were red and swollen. I didn't know what to say. Fortunately, Dr. Zussman walked out of the ICU and joined us. Feeling rescued, I began to leave but he waved me back. I felt privileged to be allowed to share in drama of the moment, yet I wanted to leave because I knew if they started to cry then I'd start to cry, and despite all the "I'm O.K." stuff I'd read, I still didn't feel that that would be O.K. He was talking to them while I bit my lip and looked at my feet and tried to think cynical thoughts. I mean, after all, I'd seen death plenty of times; on surgery they called us the "Troll Patrol" because our patients went down so far so fast. And, really, the drag about having dying patients is that when they're obtunded and obese and you have to get blood gases out of their femoral artery it's all cheesy and smelly, and they get decubitus ulcers that you have to debride every day even though the order to turn them side to side q 2 h is ignored; death is smelly and vomity and has a four-day beard and alcohol on its breath. So what's to cry about? Such thoughts didn't help. Mercifully, Dr. Zussman was finished. They had no questions. It was the moment to leave. I left.

Still shaken, I made my way back over to school. It was past five o'clock, and no one was in the student lounge. I found a chair over in the corner, sat down, closed my eyes, leaned forward with my face in my hands, and began to weep.

Thursday

I spent Thursday feeling those things that are so absurd to feel, that I had failed somehow, that medicine had failed. I had to go back and visit her again, as if that would somehow atone for not having picked up Monday evening that she was about to hemorrhage Tuesday morning.

Coincidentally, Dr. Zussman lectured to us that day. After class I asked him how often he has to talk to families and say the things he said yesterday. He said about once a week.

"Do you ever cry with the patients or their families?" I asked.

"Sometimes. Sometimes. Probably not with this family because I don't know them that well, but when you get involved with a family and there is a death, then you cry. It just happens."

I don't know how much money he makes, but he earns it.

I walked over to the ICU, bringing with me a first-year student named Jo Ann. She seemed very nice, although I didn't know her well. Women usually seem to be more in touch with their feelings than men; I figured she'd understand just in case I started to cry. I briefly told her about the case, and the physical findings. Teaching her about it made it all seem more tolerable. I trusted her, and told her more, and asked what she thought about dealing with the family, and my own feelings, and so forth. Again, as during rounds, I felt strangely at ease.

The neurologist and Dr. Zussman came in. Lisa had no corneal reflexes, no pupillary reflexes, her previously positive Babinski's were now areflexic, no response to deep pain. The neurologist said she was cerebrally dead and advised serial EEGs as a prelude to D/Cing the respirator.

Jo Ann and I stood down the hall while Dr. Zussman talked to Lisa's parents. When we left they were sobbing in each other's arms. Back at school I began to feel that the only real good I could do would be to talk to the parents. I resolved to break through this mental block I had about dealing with their grief.

Friday

Even in the morning it was hot. 92 degrees and humid. That afternoon I went back to TMC.

Again, the neurologist was there and said that the morning's EEG had been flat. I went out of the ICU and sat with the family. Lisa's mother, father, grandmother, and several aunts and uncles were there. We sat and talked. I said I had no good news, that they should prepare themselves for the worst, that she probably would not survive. I tried to be as gentle and tactful as I could. I asked about their other daughters and before long had them all telling family jokes and laughing.

It was frightening to see how intently they hung upon each word I said. They gave physicians so much power. It was as if our word came straight from God.

Saturday

Saturday I was on call. I began to write all of this that morning, and didn't make it over to TMC. I was up till late at night.

Sunday

I woke up at Charity Hospital, glad that the last hours of sleep had been uninterrupted. When I walked over to TMC, there was no one in the ICU waiting room. At first I thought, great, they finally got out of this room and went to a movie or something, but then I realized what it meant: Lisa must be dead.

The nurse in ICU told me.

"It was yesterday morning at 10:40 a.m. that she died."

"How did they do it? Who decided?" I asked.

"Well, the EEGs were flat, and Dr. Zussman advised the family to allow him to D/C the life support. They said O.K., —"

I interrupted her. "I mean, was the family in here? Did Lisa have any motor activity, like, did she convulse as she went anoxic?"

"No, the family came in to say goodbye, then they left, and we stopped the machine. She didn't even fibrillate, she just stayed in sinus and went cyanotic, and the sinus rhythm just faded away until her EKG went flat. Then we took out all the tubes and her family came in and saw her again. It was very emotional."

"Yes, I can imagine it was," I replied.

"I have some of the EKG strip," she offered. "Would you like to see it?"

"No, no thank you. I think I'll go home. Thanks anyway."

I had mixed feelings. On the one hand I felt cheated, that I had been deprived of this final act of the drama, and also slightly guilty. After all, you're supposed to know everything about your patients all the time, not find out a day later that they're dead. But on the other hand, I felt relieved that I had been spared this last traumatic episode. Now it was over, and that was that.

I had no misgivings about the decision to let her die. We've heard it all before, limited resources, prolonging death rather than lengthening life, and so on. It was pointless for Lisa to linger. The necessary decision had been made.

I rode my motorcycle home, anticipating a few hours sleep. I was very tired.

HENNEPIN
MEDICAL CENTER
701 Park Avenue South
Minneapolis, Minnesota 55415

February 15, 1979

Mr. James Sova
Director, Department of Legislative Affairs
Minnesota Medical Association
Suite 900, American National Bank Building
101 East Fifth Street
Saint Paul, MN 55101

Dear Jim:

The model brain death bill approved by the AMA Board of Trustees in January, 1979 is, in my opinion, unacceptable and should not be supported by the Minnesota Medical Association as a possible alternative to the Uniform Brain Death Act. I base my reasoning upon three major defects in the proposed AMA bill.

First and most important, the bill is written in such a way that the determination of death is permissive, rather than mandatory. It has now been well accepted, I think, by knowledgeable physicians and lawyers working in this area that a brain death law should be written in such a way that the determination of death is mandatory, rather than permissive. For example, the Capron and Kass model from the University of Pennsylvania Law Review in 1972, the proposed brain death act of the American Bar Association, and the Uniform Brain Death Act (UBDA) are all written in such a fashion. A permissive law will not, in the long run, help to resolve the difficult cases of brain death in which conflicts arise. This issue of mandatory versus permissive brain death statutes have been extensively explored by the Ad Hoc Committee on Death, and I believe there has always been a strong consensus within our committee on this point. The position of the Ad Hoc Committee on Death and the Minnesota Medical Association is quite clear on this particular issue, and I see no reason to change our position.

Second, in view of the developing controversy regarding neocortical death as another standard for the death of a human being, as proposed by Veatch, Sweet, Fletcher, and others, it is of paramount importance to distinguish between total brain death and lesser degrees of brain damage, such as the persistent vegetative state or neocortical death. The Uniform Brain Death Act has clearly and unequivocally distinguished between these two medical syndromes by using the phrase, "all functioning of the brain, including the brain stem." The proposed AMA bill uses vaguely worded, imprecise language on this point, i.e. "irreversible cessation of brain function." Such vaguely worded statutes will no longer be tolerated at this stage in the development of brain death legislation. A brain death statute should succinctly but clearly define the brain death concept as the irreversible cessation of all functions (or functioning) of the brain, and anything less than a very clear definition along these lines should not be supported by the medical profession.

Third, it appears that the primary objective of this AMA proposal is to protect the physician from criminal or civil liability. While this may not be a substantive objection to the proposal, such intentions of organized medicine reinforce the suspicions of those opposed to brain death legislation that the proponents of brain death bills are primarily motivated by the desire to protect physicians. Although this is a secondary and acceptable purpose of brain death legislation, it should not achieve the primacy that it has in the AMA bill. Moreover, I question the motivations of the American Medical Association, since it seems clear that their primary, if not exclusive, concern is and has been merely the protection of the physicians in these cases; while I would hope in Minnesota the state medical association and the medical profession are supporting an acceptable brain death bill with due consideration to the broader issues involved.

The AMA proposal would probably be acceptable if it were changed in such a way that 1) it was mandatory, rather than permissive; 2) it would explicitly spell out the concept of brain death; and 3) sections 2-5 were deleted. Of course, if these modifications were made, the bill would appear very similar to the Uniform Brain Death Act.

The MMA Ad Hoc Committee on Death has taken a strong position that, if a brain death bill were to be passed, it should be a substantively good brain death law, and I feel strongly that we should not compromise our principles in this regard for any short-term political gains. I would hope for these reasons that a bill such as the AMA proposal will not be seriously considered as an alternative to the Uniform Brain Death Act.

Sincerely,

Ronald E. Cranford, M.D.
Chairman, Ad Hoc Committee on Death, Minnesota Medical Association
Associate Physician in Neurology, Hennepin County Medical Center

REC/mmf

MINNESOTA MEDICAL ASSOCIATION
101 E. FIFTH STREET • ST. PAUL, MINNESOTA 55101 • AREA 612 PHONE 222-6366
HAROLD W. BRUNN, Executive Vice President

MEMORANDUM

February 9, 1979

TO: Ronald Cranford, M.D.
Merle Mark, M.D.
Jule Hannaford
Gregg Orwell

FROM: Jim Sova

RE: AMA MODEL BILL TO PROVIDE FOR A DETERMINATION OF DEATH

Enclosed is a copy of a model bill as approved by the AMA Board of Trustees in January providing for determination of death. We would appreciate your comments and thoughts on this model legislation as a possible alternative to the proposed Uniform Brain Death Act.

We would like to receive your comments at your earliest convenience, as some legislator may possibly introduce this as a substitute for the Uniform Brain Death Act which, as you know, has engendered a great deal of opposition from the pro-life forces.

Thank you for your assistance.

JS:acs
Encls.

cc: David McCuskey

January, 1979

IN THE GENERAL ASSEMBLY

STATE OF ____________

An Act

To Provide for Determination of Death

Be it enacted by the People of the State of ____________, represented in the General Assembly:

Section 1. A physician, in the exercise of his professional judgment, may declare an individual dead in accordance with accepted medical standards. Such declaration may be based solely on an irreversible cessation of brain function.

Section 2. A physician who determines death in accordance with section 1 is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his acts or the acts of others based on that determination.

Section 3. Any person who acts in good faith in reliance on a determination of death by a physician is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act.

Section 4. If any provision of this Act is held by a court to be invalid, such invalidity shall not affect the remaining provisions of the Act, and to this end the provisions of this Act are hereby declared to be severable.

Section 5. The Act shall become effective __________ from the date of enactment.

-AMERICAN MEDICAL ASSOCIATION, PUBLIC AFFAIRS DIVISION, LEGISLATIVE DEPARTMENT-

EXHIBIT A

Rough Draft -- by Joe Boyle

A Suggested Outline for a Right to Lifer's Handbook on Euthanasia

I Introduction 15 pages
  A. Definitions
  B. Areas of right to life concern
  C. Demographic and socio-economic context

Part I Legal Questions 130 pages

II Definition of Death
III Euthanasia -- English Background
IV Euthanasia -- American Background
V Justice in distributing life saving resources
VI Possible Pro-life approaches
  - On death with dignity
  - Constitutional Amendments

Part II Moral/Social Questions 75 pages

VII On Killing and Letting Die
VIII On Ordinary and Extraordinary means
IX Is death a good?
X The Quality of Life Ethic
XI The morality of killing
XII Who's imposing morality?
XIII Making the pro-life ethic live
  - Hospice concept

"I have been thinking about the euthanasia handbook a bit and I enclose a preliminary outline. First: our task is not primarily a research job. Between Germain's book and the Horan/Mall volume we have all the information we need. The job is to organize the material in a clear and simple way that right to lifers can use and understand. So what we need is a 220 page book that covers all the issues in a non-hysterical way. It should include 1) the state of the question on each issue, 2) the anti-life view and arguments, 3) the pro-life critique and options, and 4) an annotated bibliography of the most important material."

"Second: a possible procedure and timetable might go as follows: 1) develop and present to the board a preliminary outline and rationale, 2) get relevant board members and advisors to develop and improve the outline to the point that all the essentials are included, 3) come to agreement about a detailed outline by the first of the year, 4) assign parts to writers and get drafts by the end of March, 5) send MS to relevant board members and revise by the end of May, 6) to the printers by early June."