SB
140

hearing
Tues, Mar 5

Senate Health, Education and Social Services Committee

Legislation Checklist

Bill number: SB 140

Sponsor: ELIASON

Date referred to committee: 2/7/85

Synopsis completed: 2/8

Fiscal note:

Further referrals: JUDICIARY

CONTACTS:

✓ Eliason 4711 (Sheila)

✓ Dept Law - [illegible] Linda Cerro Elizabeth Shaw 3603

✓ Dept H+SS, Norma Lang 3030 - Public Health 3090 Tirador, Dean
* Dr Frazier testify

✓ Hospice - Jnu, Anch 5750 Glacier Hwy.
Mary Townsmeire 780-6530

✓ Rick Urion - State Medical Association 364-2315 [illegible]

✓ AARP - Dave Kull 586-2670

✓ Dennis DeWitt 586-1790

✓ Billy Bernier, Legal 2450

Sylvia Short, Atty. (Anch; per Sturgulewski)

Sid Heidersdorf, PO Box 658, Jnu 789-9858
Alaskans for Life

Mary Riggen-Ver, Older AK Commission, DOA 465-3250

Offered: 2/5/86
Referred: Rules

Original sponsors: Eliason, Ziegler,
V.Fischer, et al

IN THE SENATE BY THE JUDICIARY COMMITTEE

HOUSE CS FOR CS FOR SENATE BILL NO. 140 (Judiciary)

IN THE LEGISLATURE OF THE STATE OF ALASKA

FOURTEENTH LEGISLATURE - SECOND SESSION

A BILL

For an Act entitled: "An Act relating to the rights of the terminally ill and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. AS 18 is amended by adding a new chapter to read:

CHAPTER 12. RIGHTS OF TERMINALLY ILL.

Sec. 18.12.010. DECLARATION RELATING TO USE OF LIFE-SUSTAINING PROCEDURES. (a) A competent person who is at least 18 years old may execute a declaration at any time directing that life-sustaining procedures be withheld or withdrawn from that person; but the declaration is given operative effect only if the declarant's condition is determined to be terminal and the declarant is not able to make treatment decisions. The declarant shall subscribe to the declaration in the presence of a judge or magistrate. The judge or magistrate shall inquire on the record whether the declarant understands the importance and effect of the declaration. A judicial officer may not charge a fee for witnessing a declaration. A person may not charge a fee for preparing a declaration.

House change

(b) It is the responsibility of the declarant to notify the declarant's physician of the declaration. A physician or other health care provider who is provided a copy of the declaration shall make it a part of the declarant's medical records.

(c) A declaration may, but need not, be in the following form:

DECLARATION

If I should have an incurable or irreversible condition that will

cause my death within a relatively short time, it is my desire that my life not be prolonged by administration of life-sustaining procedures. If my condition is terminal and I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort or to alleviate pain.

Signed this____________________day of_______________, ________.

Signature__________________________

Place____________________________

Subscribed and sworn to or affirmed before me

at___________________ on ___________________.

(Date)

____

Signature of Officer

____

Title of Officer

(d) A physician or health care provider may presume, in the absence of actual notice to the contrary, that the declaration complies with this chapter and is valid.

Sec. 18.12.020. REVOCATION OF DECLARATION. (a) A declaration may be revoked at any time and in any manner by which the declarant is able to communicate an intent to revoke, without regard to mental or physical condition. A revocation is only effective as to the attending physician or any health care provider acting under the guidance of that physician upon communication to the physician or health care provider by the declarant or by another to whom the revocation was communicated.

(b) The attending physician or health care provider shall make the revocation a part of the declarant's medical record.

Sec. 18.12.030. RECORDING DETERMINATION OF TERMINAL CONDITION AND CONTENTS OF DECLARATION. When an attending physician who has been notified of the existence and contents of a declaration determines that the declarant is in a terminal condition, the physician shall record that determination and the contents of the declaration in the declarant's medical record.

Sec. 18.12.040. TREATMENT OF QUALIFIED PATIENTS. (a) A qualified patient has the right to make decisions regarding use of life-sustaining procedures as long as the patient is able to do so. If a qualified patient is not able to make these decisions, the declaration governs decisions regarding use of life-sustaining procedures.

in Senate

(b) This chapter does not prohibit the application of any medical procedure or intervention, including the provision of nutrition and hydration, considered necessary to provide comfort care or alleviation of pain.

in Senate

(c) The declaration of a qualified patient known to the attending physician to be pregnant has no effect as long as it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining procedures.

Sec. 18.12.050. TRANSFER OF PATIENTS. (a) An attending physician who is unwilling to comply with the requirements of AS 18.12.030 or who is unwilling to comply with the declaration of a qualified patient under AS 18.12.040 shall withdraw as attending physician but the withdrawal is effective only when the services of another attending physician have been obtained.

(b) If the policies of a health care facility preclude compliance with the declaration of a qualified patient under this chapter, that facility shall take all reasonable steps to effect the transfer of the patient to a facility in which the provisions of this chapter can be carried out.

Sec. 18.12.060. IMMUNITIES. (a) In the absence of actual notice of the revocation of a declaration, the following, while acting in accordance with the requirements of this chapter, are not subject to civil or criminal liability or guilty of unprofessional conduct:

(1) a physician who causes the withholding or withdrawal of life-sustaining procedures from a qualified patient;

(2) a person who participates in the withholding or withdrawal of life-sustaining procedures under the direction or with the authorization of a physician;

(3) the health care facility in which the withholding or withdrawal occurs.

(b) A physician, a health care professional, or a health care facility is not subject to civil or criminal liability for actions under this chapter that are in accord with reasonable medical standards.

Sec. 18.12.070. PENALTIES. (a) An attending physician who fails to comply with the declaration of a qualified patient or to make the necessary arrangements to effect a transfer under AS 18.12.050 may be civilly liable to the qualified patient and to the heirs of the qualified patient.

(b) A person who wilfully conceals, cancels, defaces, obliterates, or damages the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another may be civilly liable to the qualified patient and to the heirs of the qualified patient.

Sec. 18.12.080. GENERAL PROVISIONS. (a) Death resulting from the withholding or withdrawal of life-sustaining procedures under a

declaration and in accordance with this chapter does not, for any purpose, constitute a suicide or homicide.

(b) The making of a declaration under AS 18.12.010 does not affect in any manner the sale, procurement, or issuance of a policy of life insurance, nor does it modify the terms of an existing policy of life insurance. A policy of life insurance is not legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) A physician, health care facility, or other health care provider, and a health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital plan, may not require a person to execute a declaration as a condition for being insured for, or receiving, health care services.

(d) This chapter creates no presumption concerning the intention of an individual who has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining procedures in the event of a terminal condition.

(e) Nothing in this chapter increases or decreases the right of a patient to make decisions regarding use of life-sustaining procedures as long as the patient is able to do so, or impairs or supercedes any right or responsibility that a person has to effect the withholding or withdrawal of medical care in a lawful manner. In that respect, the provisions of this chapter are cumulative.

(f) This chapter does not condone, authorize, or approve mercy killing or euthanasia.

Sec. 18.12.090. RECOGNITION OF DECLARATIONS EXECUTED IN OTHER STATES. A declaration executed in another state or a territory or possession of the United States in compliance with the law of that jurisdiction is effective for purposes of this chapter.

Sec. 18.12.100. DEFINITIONS. In this chapter

(1) "attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient;

(2) "declaration" means a document executed in accordance with the requirements of AS 18.12.010;

(3) "health care provider" means a person who is licensed, certified, or otherwise authorized by the law of this state to administer health care in the ordinary course of business or practice of a profession;

(4) "life-sustaining procedure" means a medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process; "life-sustaining procedure" does not include nutrition or hydration;

added in House

(5) "physician" means a person licensed to practice medicine in this state or an officer in the regular medical service of the armed services of the United States or the United States Public Health Service while in the discharge of their official duties, or while volunteering services without pay or other remuneration to a hospital, clinic, medical office, or other medical facility in the state;

(6) "qualified patient" means a patient who has executed a declaration in accordance with this chapter and who has been determined by the attending physician to be in a terminal condition;

(7) "terminal condition" means a progressive incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of the attending physician, result in death within a relatively short time.

* Sec. 2. This Act takes effect immediately in accordance with

[1] AS 01.10.070(c).

COMMITTEE REPORT

SENATE

FURTHER: JUDICIARY

2/7/85

Date 2/11/85

Mr. President

The Committee on HESS considered SB 140

relating to the rights of the terminally ill.

and (a majority of the committee) (the committee) reports it back with the following recommendations:

☐ do pass

☐ do pass with attached amendment(s)

☑ replace with/or adopt CS for SB 140
☐ new title
☑ same title and recommends

☐ and attached a "LETTER OF INTENT" ☐ NEW FISCAL NOTE

☐ reports it back without recommendation

☐ recommends referral to ______ Committee

MEMBERS SIGNING DO PASS	MEMBERS HAVING OTHER RECOMMENDATIONS
	Paul Fisher
	[illegible] - no recommendation

Chairman

Do Pass

Chairman reccmmendation

MAR 7 1985

OLDER ALASKANS COMMISSION
POSITION PAPER

Senate Bill No. 140
"An Act relating to the rights of the terminally ill"

The Older Alaskans Commission urges passage of this legislation to allow terminally ill adults to decline life-sustaining procedures. The legislation would permit an adult to execute a written declaration instructing his physician to withhold or withdraw life-sustaining procedures if he was in a terminal condition and became unable to participate in medical treatment decisions.

In contrast to the acute diseases which were the leading causes of death at the turn of the century, current leading causes of death in this country are heart disease, malignancies, and cerebrovascular diseases. These chronic, progressive diseases often involve lengthy periods of medical treatment and most frequently attack the elderly. The majority of deaths occur in medical institutions where the means exist to prolong life for a substantial period of time, regardless of the irreversibility of the condition or quality of life.

This legislation clearly establishes the means for an adult to decline life prolonging treatment for an irreversible condition; informs his physician on how to proceed should he become unable to participate in medical treatment decisions; authorizes the physician and health care facility to comply with his wishes; and provides immunity to the physician and health care facility from civil or criminal liability for acting in accordance with his wishes.

At least twenty other states have enacted legislation in this area. The language in Senate Bill 140 is based on a discussion draft of a Rights of the Terminally Ill Act prepared by the drafting committee appointed by the National Conference of Commissioners on Uniform State Laws. This draft and Senate Bill 140 appear to be technically superior to any of the models available and any of the laws enacted by other states on this subject.

We ask your support of this bill and in making the health and dignity of our elderly a major state priority.

March 1, 1985

Jon B. Wolfe, Executive Director
Older Alaskans Commission

Date

Lisa S Rudd

Commissioner Lisa Rudd
Department of Administration

3/6/85

Date

SB 140

ENACTED RIGHT-TO-DIE LEGISLATION

Alabama (1981)

Arkansas (1977)

California (1976)

Delaware (1982)

District of Columbia (1982)

Florida (1984)

Georgia (1984)

Idaho (1977)

Illinois (1984)

Kansas (1979)

Louisiana (1984)

Mississippi (1984)

Nevada (1977)

New Mexico (1977)

North Carolina (1977)

Oregon (1977)

Texas (1983)

Vermont (1982)

Virginia (1983)

Washington (1979)

West Virginia (1984)

Wisconsin (1984)

Wyoming (1984)

SB 140 RIGHTS OF THE TERMINALLY ILL (ELIASON)

SENATE H.E.S.S. COMMITTEE SUBSTITUTE --- TITLE CHANGE

UNDER THE AUTHORITY GRANTED IN SB 140, A COMPETENT ADULT WOULD BE ALLOWED TO EXECUTE A DECLARATION THAT LIFE-SUSTAINING PROCEDURES BE WITHHELD OR WITHDRAWN FROM THAT ADULT.

1. DECLARATION WOULD TAKE EFFECT ONLY IF ADULT CONDITION IS TERMINAL AND ADULT IS UNABLE TO MAKE TREATMENT DECISIONS.
2. DECLARATION WOULD BE REVOCABLE AT ANY TIME.
3. SIGNING MUST BE WITNESSED BY 2 ADULTS NOT RELATED TO PATIENT.
4. DECISION MUST BE RECORDED ON THE PATIENT'S MEDICAL CHART.
5. PHYSICIANS WHO HONOR DECLARATION ARE IMMUNE FROM LIABILITY.
6. IMPOSES PENALTIES (CLASS A MISDEMEANOR) FOR FAILURE TO HONOR A DECLARATION.

HESS C.S.:

PAGE 1, LINE 12 - SPECIFIES THAT ADULT DECLARANT MUST BE A PERSON 18 YEARS OR OLDER

PAGE 4, LINE 10 - CLARIFIES THAT HEALTH CARE PROFESSIONALS AND HEALTH CARE FACILITIES, IN ADDITION TO THE PHYSICIAN HIMSELF, ARE IMMUNE FROM LIABILITY FOR HONORING A DECLARATION.

PAGE 6, LINE 23 - IMMEDIATE EFFECTIVE DATE. (NECESSITATES A TITLE CHANGE.)

SB 140 RIGHTS OF THE TERMINALLY ILL (ELIASON)

SENATE H.E.S.S. COMMITTEE SUBSTITUTE --- TITLE CHANGE

UNDER THE AUTHORITY GRANTED IN SB 140, A COMPETENT ADULT WOULD BE ALLOWED TO EXECUTE A DECLARATION THAT LIFE-SUSTAINING PROCEDURES BE WITHHELD OR WITHDRAWN FROM THAT ADULT.

1. DECLARATION WOULD TAKE EFFECT ONLY IF ADULT CONDITION IS TERMINAL AND ADULT IS UNABLE TO MAKE TREATMENT DECISIONS.
2. DECLARATION WOULD BE REVOCABLE AT ANY TIME.
3. SIGNING MUST BE WITNESSED BY 2 ADULTS NOT RELATED TO PATIENT.
4. DECISION MUST BE RECORDED ON THE PATIENT'S MEDICAL CHART.
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HESS C.S.:

PAGE 1, LINE 12 - SPECIFIES THAT ADULT DECLARANT MUST BE A PERSON 18 YEARS OR OLDER

PAGE 4, LINE 10 - CLARIFIES THAT HEALTH CARE PROFESSIONALS AND HEALTH CARE FACILITIES, IN ADDITION TO THE PHYSICIAN HIMSELF, ARE IMMUNE FROM LIABILITY FOR HONORING A DECLARATION.

PAGE 6, LINE 23 - IMMEDIATE EFFECTIVE DATE. (NECESSITATES A TITLE CHANGE.)

Changes: p. 1, line 12
p. 4, line 10
p. 6, line 23

Introduced: 2/7/85
Referred: Health, Education and
Social Services and
Judiciary

BY ELIASON, ZIEGLER,
V. FISCHER, SACKETT,
ABOOD AND STURGULEWSKI

IN THE SENATE

CS SENATE BILL NO. 140 (HESS)

IN THE LEGISLATURE OF THE STATE OF ALASKA

FOURTEENTH LEGISLATURE - FIRST SESSION

A BILL

For an Act entitled: "An Act relating to the rights of the terminally ill."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. AS 18 is amended by adding a new chapter to read:

CHAPTER 12. RIGHTS OF TERMINALLY ILL.

Sec. 18.12.010. DECLARATION RELATING TO USE OF LIFE-SUSTAINING PROCEDURES. (a) Any competent person, 18 years or older; [adult] may execute a declaration at any time directing that life-sustaining procedures be withheld or withdrawn from that adult; but the declaration is given operative effect only if the declarant's condition is determined to be terminal and the declarant is not able to make treatment decisions. The declaration must be signed by the declarant, or another at the declarant's direction, and in either case must be witnessed by two persons. The witnesses must be at least 18 years old and may not be related to the declarant by blood or marriage. A physician or health care provider may presume, in the absence of actual notice to the contrary, that the declaration complies with this Act and is valid.

(b) It is the responsibility of the declarant to notify the declarant's physician of the declaration. A physician or other health care provider who is provided a copy of the declaration shall make it a part of the declarant's medical records.

(c) A declaration may, but need not, be in the following form:

DECLARATION

If I should have an incurable or irreversible condition that will

cause my death within a relatively short time, it is my desire that my life not be prolonged by administration of life-sustaining procedures. If my condition is terminal and I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort or to alleviate pain.

Signed this ____________________ day of ________________, __________.

Signature ________________________

City, County and State of Residence ____________________________

The declarant is known to me and voluntarily signed this document in my presence.

Witness ____________________________

Address ____________________________

Witness ____________________________

Address ____________________________

Sec. 18.12.020. REVOCATION OF DECLARATION. (a) A declaration may be revoked at any time and in any manner by which the declarant is able to communicate an intent to revoke, without regard to mental or physical condition. A revocation is only effective as to the attending physician or any health care provider acting under the guidance of that physician upon communication to the physician or health care provider by the declarant or by another to whom the revocation was communicated.

(b) The attending physician or health care provider shall make the revocation a part of the declarant's medical record.

Sec. 18.12.030. RECORDING DETERMINATION OF TERMINAL CONDITION AND CONTENTS OF DECLARATION. When an attending physician who has been notified of the existence and contents of a declaration determines

cause my death within a relatively short time, it is my desire that my life not be prolonged by administration of life-sustaining procedures. If my condition is terminal and I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort or to alleviate pain.

Signed this ____________________ day of ______________, ________.

Signature ______________________

City, County and State of Residence ___________________________

The declarant is known to me and voluntarily signed this document in my presence.

Witness ________________________

Address ________________________

Witness ________________________

Address ________________________

Sec. 18.12.020. REVOCATION OF DECLARATION. (a) A declaration may be revoked at any time and in any manner by which the declarant is able to communicate an intent to revoke, without regard to mental or physical condition. A revocation is only effective as to the attending physician or any health care provider acting under the guidance of that physician upon communication to the physician or health care provider by the declarant or by another to whom the revocation was communicated.

(b) The attending physician or health care provider shall make the revocation a part of the declarant's medical record.

Sec. 18.12.030. RECORDING DETERMINATION OF TERMINAL CONDITION AND CONTENTS OF DECLARATION. When an attending physician who has been notified of the existence and contents of a declaration determines that the declarant is in a terminal condition, the physician must record that determination and the contents of the declaration in the declarant's medical record.

Sec. 18.12.040. TREATMENT OF QUALIFIED PATIENTS. (a) A qualified patient has the right to make decisions regarding use of life-sustaining procedures as long as the patient is able to do so. If a qualified patient is not able to make these decisions, the declaration governs decisions regarding use of life-sustaining procedures.

(b) This chapter does not prohibit the application of any medical procedure or intervention, including the provision of nutrition and hydration, considered necessary to provide comfort, care, or alleviation of pain.

(c) Unless the declaration provides otherwise, the declaration of a qualified patient known to the attending physician to be pregnant is given no effect as long as it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining procedures.

Sec. 18.12.050. TRANSFER OF PATIENTS. (a) An attending physician who is unwilling to comply with the requirements of AS 18.12.030 or who is unwilling to comply with the declaration of a qualified patient under AS 18.12.040 shall take all reasonable steps to effect the transfer of the declarant to another physician.

(b) If the policies of a health care facility preclude compliance with the declaration of a qualified patient under this chapter, that facility shall take all reasonable steps to effect the transfer of the patient to a facility in which the provisions of this chapter can be carried out.

Sec. 18.12.060. IMMUNITIES. (a) In the absence of actual notice of the revocation of a declaration, the following, while acting

in accordance with the requirements of this chapter, are not subject to civil or criminal liability or guilty of unprofessional conduct:

(1) a physician who causes the withholding or withdrawal of life-sustaining procedures from a qualified patient;

(2) a person who participates in the withholding or withdrawal of life-sustaining procedures under the direction or with the authorization of a physician;

(3) the health care facility in which the withholding or withdrawal occurs.

(b) A physician health care professional, or health care facility is not subject to civil or criminal liability for actions under this chapter that are in accord with reasonable medical standards.

Sec. 18.12.070. PENALTIES. (a) A physician who wilfully fails to transfer in accordance with AS 18.12.050 is guilty of a class A misdemeanor.

(b) A physician who wilfully fails to record the determination of terminal condition in accordance with AS 18.12.030 is guilty of a class A misdemeanor.

(c) A person who wilfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another is guilty of a class A misdemeanor.

(d) A person who falsifies or forges the declaration of another, or wilfully conceals or withholds personal knowledge of a revocation as provided in AS 18.12.020, with the intent to cause a withholding or withdrawal of life-sustaining procedures, is guilty of a class A misdemeanor.

Sec. 18.12.080. GENERAL PROVISIONS. (a) Death resulting from the withholding or withdrawal of life-sustaining procedures under a

in accordance with the requirements of this chapter, are not subject to civil or criminal liability or guilty of unprofessional conduct:

(1) a physician who causes the withholding or withdrawal of life-sustaining procedures from a qualified patient;

(2) a person who participates in the withholding or withdrawal of life-sustaining procedures under the direction or with the authorization of a physician;

(3) the health care facility in which the withholding or withdrawal occurs.

(b) A physician, health care professional, or health care facility is not subject to civil or criminal liability for actions under this chapter that are in accord with reasonable medical standards.

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(b) A physician who wilfully fails to record the determination of terminal condition in accordance with AS 18.12.030 is guilty of a class A misdemeanor.

(c) A person who wilfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another is guilty of a class A misdemeanor.

(d) A person who falsifies or forges the declaration of another, or wilfully conceals or withholds personal knowledge of a revocation as provided in AS 18.12.020, with the intent to cause a withholding or withdrawal of life-sustaining procedures, is guilty of a class A misdemeanor.

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(c) A person who wilfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another is guilty of a class A misdemeanor.

(d) A person who falsifies or forges the declaration of another, or wilfully conceals or withholds personal knowledge of a revocation as provided in AS 18.12.020, with the intent to cause a withholding or withdrawal of life-sustaining procedures, is guilty of a class A misdemeanor.

Sec. 18.12.080. GENERAL PROVISIONS. (a) Death resulting from the withholding or withdrawal of life-sustaining procedures under a

declaration and in accordance with this chapter does not, for any purpose, constitute a suicide or homicide.

(b) The making of a declaration under AS 18.12.020 does not affect in any manner the sale, procurement, or issuance of a policy of life insurance, nor does it modify the terms of an existing policy of life insurance. A policy of life insurance is not legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) A physician, health care facility, or other health care provider, and a health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital plan, may not require a person to execute a declaration as a condition for being insured for, or receiving, health care services.

(d) This chapter creates no presumption concerning the intention of an individual who has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining procedures in the event of a terminal condition.

(e) Nothing in this chapter increases or decreases the right of a patient to make decisions regarding use of life-sustaining procedures as long as the patient is able to do so, nor impairs or supercedes any right or responsibility that a person has to effect the withholding or withdrawal of medical care in a lawful manner. In that respect, the provisions of this chapter are cumulative.

(f) This chapter does not condone, authorize, or approve mercy killing or euthanasia.

Sec. 18.12.090. RECOGNITION OF DECLARATIONS EXECUTED IN OTHER STATES. A declaration executed in another state in compliance with the law of that state is effective for purposes of this chapter.

Sec. 18.12.100. DEFINITIONS. In this chapter

(1) "attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient;

(2) "declaration" means a document executed in accordance with the requirements of AS 18.12.010;

(3) "health care provider" means a person who is licensed, certified, or otherwise authorized by the law of this state to administer health care in the ordinary course of business or practice of a profession;

(4) "life-sustaining procedure" means a medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process;

(5) "physician" means a person licensed to practice medicine in this state;

(6) "qualified patient" means a patient who has executed a declaration in accordance with this chapter and who has been determined by the attending physician to be in a terminal condition;

(7) "terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of the attending physician, result in death within a relatively short time.

Section 2. Immediate effective date.

Sec. 18.12.100. DEFINITIONS. In this chapter

(1) "attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient;

(2) "declaration" means a document executed in accordance with the requirements of AS 18.12.010;

(3) "health care provider" means a person who is licensed, certified, or otherwise authorized by the law of this state to administer health care in the ordinary course of business or practice of a profession;

(4) "life-sustaining procedure" means a medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process;

(5) "physician" means a person licensed to practice medicine in this state;

(6) "qualified patient" means a patient who has executed a declaration in accordance with this chapter and who has been determined by the attending physician to be in a terminal condition;

(7) "terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of the attending physician, result in death within a relatively short time.

Section 2. Immediate effective date.

SB 63, Special appropriation for remodeling and construction of an addition to the Wrangell General Hospital.

SB 63 would appropriate $6,000,000 for a payment to the City of Wrangell to correct functional and physical deficiencies in the existing Wrangell General Hospital facility. Much of the proposed remodeling is needed to meet fire, safety and sanitation regulations. In 1981, the project was granted a Certificate of Need permitting an expenditure of $6.9 million. Last year the State granted $400,000 for the design phase of the project, all of which is presently encumbered. The Alaska State Hospital Association has indentified the Wrangell project as the priority for FY 86.

The Wrangell General Hospital serves approximately 3,000 people in the Wrangell area.

Senator Zharoff has proposed an amendment (attached) to SB 63 which would appropriate $2,114,000 to the Kodiak Island Borough for architecture and engineering costs of either remodeling or reconstructing the Kodiak Island Borough Hospital.

SB 140, Rights of the terminally ill.

Under the authority granted in SB 140, a competent adult would be allowed to execute a declaration that life-sustaining procedures be withheld or withdrawn from that adult. The bill specifies that the declaration would take effect only if the adult's condition is terminal and the adult is unable to make treatment decisions. A declaration would be revocable at any time.

The bill requires witnessing of the signing of the declaration and proper recording of the decision on the patient's chart. It provides for immunity from liability for honoring a declaration and penalties for disregarding one.

According to the Society for the Right to Die, similar legislation has been enacted in 20 other states and the District of Columbia.

Senate HESS committee memo
3/1/85

Alaska State Legislature

BETTYE FAHRENKAMP, Chairman
ARLISS STURGULEWSKI, Vice Chairman
JOE JOSEPHSON
PAUL FISCHER
EDNA ARMSTRONG-DE VRIES

POUCH V
STATE CAPITAL
JUNEAU, ALASKA 99811
(907) 465-3834
(907) 465-3835

Senate
Committee on
Health, Education and Social Services

MINUTES

March 5, 1985
1:37 pm

Beltz Room
Room 211, Capitol

MEMBERS PRESENT

Senator Fahrenkamp, Chairman
Senator Armstrong - De Vries
Senator Paul Fischer
Senator Josephson
Senator Sturgulewski

CALENDAR

SB 45, Hospital inspections and investigations by the Department of Health and Social Services.

SB 140, Rights of the terminally ill.

SB 45

Dennis Dewitt, President, Alaska State Hospital Association, spoke in support of proposed CSSB 45 which would allow the Department of Health and Social Services to accept accreditation inspections by the Joint Commission of the Accreditation of Hospitals in lieu of its own inspections. He stated that this action could result in significant cost savings to both hospitals and the state.

Bob Ogden, Assistant Director, Division of Medical Assistance, Department of Health and Social Services, spoke in support of the proposed committee substitute as it would allow the department flexibility in scheduling hospital inspections. He answered questions on when inspections of smaller facilities would be conducted.

Senator Faiks, sponsor, spoke in support of the proposed committee substitute and of including additional language that would ensure annual inspections of smaller hospitals.

SB 140

Senator Eliason, sponsor, explained that under SB 140, a competent adult would be allowed to execute a declaration that life-sustaining procedures be withheld or withdrawn if that adult develops a terminal condition and is unable to make treatment decisions.

Mary Tonsmeire, Clinical Coordinator, Hospice of Juneau, spoke in support of SB 140, and offered specific comments from the Hospice of Anchorage, and the comments of a visiting lecturer, Dr. James Speer, Lawyer and Doctor of Medical Ethics, on earlier "living will" legislation in other states.

Dr. Robert Fraser, Director, Division of Public Health, Department of Health and Social Services, spoke in support of the bill, explaining that currently these decisions are made by the physician and the patient's family. This bill offers the individual the ability to make this decision.

Dennis Dewitt, President, Alaska State Hospital Association, spoke in support of SB 140 and offered an amendment that would expand the immunities section to include health facilities.

Sid Heidersdorf, Alaskans for Life, Juneau, spoke in opposition to SB 140, indicating that patients already have this right. He felt the bill would not promote good medical care.

Mary Riggen-Ver, Older Alaskans Commission, Department of Administration, spoke in support of SB 140.

The meeting adjourned at 3:23 pm.

Alaska State Legislature

BETTYE FAHRENKAMP, Chairman
ARLISS STURGULEWSKI, Vice Chairman
JOE JOSEPHSON
PAUL FISCHER
EDNA ARMSTRONG-DE VRIES

POUCH V
STATE CAPITAL
JUNEAU, ALASKA 99811
(907) 465-3834
(907) 465-3835

Senate

Committee on

Health, Education and Social Services

MINUTES

March 14, 1985
1:35 pm

Beltz Room
Room 211, Capitol

MEMBERS PRESENT

Senator Fahrenkamp, Chairman
Senator Armstrong - De Vries
Senator Paul Fischer
Senator Sturgulewski

CALENDAR

SB 117, Alzheimer's disease and related disorders.

SB 140, Rights of the terminally ill.

SB 128, Relating to the use of longevity bonus payments in determining adult public assistance.

SCR 10, Requesting the State Board of Education to require the study of Alaska history and government in the schools of the state.

SB 117

Senator Fahrenkamp indicated that the committee was working on establishing priorities for funding those services proposed in the bill.

SB 140

Sandra Schubert, Senate HESS Committee Aide, reviewed the changes in the proposed committee substitute that would clarify that 1) any any competent person 18 years or older may execute a declaration, 2) expand the immunity section to include health care professionals and facilities, and 3) provide for an immediate effective date.

Senator Sturgulewski moved to adopt CS SB 140 (HESS) and move it from committee with individual recommendations. There was no objection.

SB 128

Sandra Schubert, Senate HESS Committee Aide, explained that the proposed committee substitute was drafted at the request of the sponsor.

Rod Betit, Director, Division of Medical Assistance, Department of Health and Social Services, spoke in support of the proposed committee substitute for SB 128, which would require the state to make up for federal SSI payments lost due to receipt of the longevity bonus and place recipients who have lost Medicaid eligibility under the state's General Relief Medical program. He proposed an amendment that would exempt nursing home residents from eligibility for the bonus. and urged that the committee define "public assistance". Betit reviewed the costs involved in enacting different "hold harmless" options.

Senator Halford, Sponsor, spoke in support of the bill and the proposed amendment, discussed the cost figures supplied by the Department, and recommended the committee pass the bill to the Senate Finance Committee so it could be considered in conjunction with other pending longevity bonus legislation.

Deborah Vogt, Assistant Attorney General, discussed the constitutionality of exempting nursing home residents from eligibility for the longevity bonus.

Debra Neidermeyer, Aide to Representative Koponen, reviewed the committee substitute passed by the House HESS Committee that would require the state to make up for benefits lost from any federal needs-based program.

Senator Sturgulewski moved to adopt the nursing home exemption amendment and to move CS SB 128 with the amendment from committee with individual recommendations. There was no objection.

SCR 10

Steve Hole, Special Assistant to the Commissioner, Department of Education, testified that the Board of Education agrees that each school district should offer courses in Alaska history and government, and explained that the Board encourages school districts to provide this instruction through its Model Curriculum. Hole stated that decisions on specific course requirements of school districts are best made by locally elected school officials.

Don McKinnon, Alaska Council of School Administrators, supported the concept that Alaska history and government be taught in the schools, but recommended amending the resolution to request the

Board to "encourage", rather than "require" local school districts to offer such courses.

Gayle Pierce, President, National Education Association-Alaska, spoke in support of retaining the language that would "require" local school districts to offer courses. She also recommended specifying that Alaska Native Land Claims Settlement instruction be included.

Senator Paul Fischer questioned the availability of curriculum materials as referenced in lines 15-20.

The meeting adjourned at 2:45 pm.

POSITION PAPER/Department of Health & Social Services

POSITION PAPER

SENATE BILL No. 140

For "An Act relating to the rights of the terminally ill."

The right of a competent individual to decide whether life-sustaining procedures should be used in the face of a terminal illness or injury has received increasing attention in recent years as medical technology has advanced and individual cases have received media attention.

This bill provides a process through which a competent adult can participate in decisions regarding his or her care when afflicted with a terminal condition. "Terminal condition" is an incurable or irreversible condition that, without the administration of life-sustaining procedures, will result in death in a relatively short time. The bill permits a competent adult to execute a declaration directing the withholding or withdrawal of life-sustaining measures. The declaration comes into effect only (1) if a terminal condition is determined to exist and (2) if the affected person is incapable at that time of making treatment decisions.

According to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 13 states and the District of Columbia have adopted so-called natural death legislation. The proposed legislation appears to be generally similar to the major provisions in other states.

The Department of Health and Social Services supports intent of this bill. It is assumed the Department of Law is reviewing it for adequacy of legal safeguards for declarants and for health care providers.

Recommended by: Robert J. Fraser MD

Robert I. Fraser, M.D.
Director
Division of Public Health

Date: 2/15/85

Approved by: John R. Pugh

John R. Pugh
Commissioner
Department of Health &
Social Services

Date: 2/15/85

STATE OF ALASKA 1985 LEGISLATIVE SESSION
FISCAL NOTE

Revision Date:

REQUEST
Bill/Resolution No.: SB 140
Title: Rights of terminally ill
Sponsor: Eliason, et al
Requestor:
Date of Request: 2/8/85

FISCAL DETAIL
Agency Affected: Health & Social Services
Program Category Affected: Public Health
BRU, Program or Subprogram(s) Affected:
State Health Services

EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 85	FY 86	FY 87	FY 88	FY 89	FY 90
100 PERSONAL SERVICES	0	0	0	0	0	0
200 TRAVEL	0	0	0	0	0	0
300 CONTRACTUAL	0	0	0	0	0	0
400 SUPPLIES	0	0	0	0	0	0
500 EQUIPMENT	0	0	0	0	0	0
600 LAND & STRUCTURES	0	0	0	0	0	0
700 GRANTS, CLAIMS	0	0	0	0	0	0
800 MISCELLANEOUS	0	0	0	0	0	0
TOTAL OPERATING	0	0	0	0	0	0

CAPITAL	0	0	0	0	0	0

REVENUE	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0
OTHER	0	0	0	0	0	0
TOTAL	0	0	0	0	0	0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

ANALYSIS: Attach a separate page if necessary

Prepared By: Robert I. Fraser, M.D.
Phone: 465-3090
Division: Public Health
Date: 2/12/85

Approved by Commissioner:
Date: 2/15/85 Jcc
Agency: Dept. of Health & Social Services

Distribution (by Agency preparing fiscal note):
- Legislative Finance
- Legislative Sponsor
- Requestor
- Office of Management and Budget
- Impacted Agency(ies)

STATE OF ALASKA
THE LEGISLATURE
LEGISLATIVE AFFAIRS AGENCY

POUCH Y STATE CAPITOL
JUNEAU ALASKA 99811
907 465 3800

MEMORANDUM February 8, 1985

SUBJECT: Derivation of Senate Bill 140

TO: Senator Richard I. Eliason

FROM: Billy G. Berrier
Director
Division of Legal Services

You have asked me to comment on the derivation of Senate Bill 140, rights of the terminally ill.

The bill is derived from a discussion draft of a Rights of the Terminally Ill Act prepared by a drafting committee appointed by the National Conference of Commissioners on Uniform State Laws. I have furnished you the discussion draft which contains the text and the commentary proposed by the committee.

The NCCUSL is an organization whose purpose is to promote uniformity in state laws in areas where uniformity is desirable and practicable. It is considered a state organization and the major portion of its funds comes from state appropriations.

The National Conference procedure is for the Scope and Program committee to consider proposals for Uniform Laws and recommend to the Executive Committee areas it considers should be addressed. If the Executive Committee agrees it appoints a drafting committee, a review committee and a committee drafting liason. In this instance the drafting committee and review committee are shown on the proposed draft I have furnished you. I am an associate member of the National Conference and was appointed as drafting committee liason.

Following appointment the committee prepares a draft which is reviewed by the review committee. This draft is then presented to the committee of the whole of the National Conference for first reading. At this reading the draft is read in full and discussed section by section. This draft was before the committee of the Whole at the annual meeting of the National Conference on August 1, 1984. The chair of the committee made an introductory statement explaining the draft and it was then discussed section by section in some detail. I am enclosing the chair's introductory statement.

Following the discussion at the committee of the Whole the draft is then returned to the drafting committee for further action. A draft incorporating the changes from the committee of the Whole and other changes was prepared and distributed to members of the committee. The committee then met in Hartford, Connecticut in September to discuss the revised draft. Representatives from the organization mentioned by Mr. Hite in his introduction were also present.

Based on this meeting professor Bezanson prepared a revised draft which I examined for technical questions. This draft is the draft I used for preparation of the bill adding in the witness requirements you requested.

The draft will now go to the review committee and the National Conference. It will be considered there at second reading where it may be amended and at third reading where it is subject to approval or rejection on a vote of the states. Following that the proposal will be submitted to the American Bar Association at its annual meeting with a request for concurrence. Assuming concurrence the proposal will be submitted to the states with the recommendation it be adopted as a Uniform Law.

Obviously therefore the draft is not at the stage of an approved proposal recommended for adoption by the National Conference. However, in my opinion this draft is technically superior to any of the models available and any of the laws adopted by other states on the subject.

BGB:ojb
J11/073

Enclosures

alaska
state
hospital
association

319 Seward St., Juneau, Alaska 99801 • (907) 586-1790

REPRESENTING ACUTE, LONG TERM AND OUTPATIENT FACILITIES

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Edward Zeine
Cordova Community Hospital
Cordova

Chairman-Elect
Michael Herring
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Homer

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Seward General Hospital
Seward

Alternate Delegate to the Association of Western Hospitals
Jane Sabes
Norton Sound Regional Hospital
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Trustee Delegate to the American Hospital Assoc.
Moe Kadish
Trustee, Providence Hospital
Anchorage

Alternate Trustee Delegate to the American Hospital Association
Maxine Robertson
Trustee, Ketchikan General Hospital

Physican Member of the Board
Morris Horning, M.D.
Anchorage

President
Dennis L. DeWitt
Juneau

February 25, 1985

Senator Richard Eliason
Alaska State Legislature
Pouch V
Juneau, AK 99811

Dear Senator Eliason:

Subject: SB 140

I appreciate the help your staff has given on responding to our initial questions on SB 140.

We believe that Section 18.12.060(b) ought to be amended to include health care facilities and other persons participating in actions under this chapter. We are concerned that the exemption, if limited to physicians, implies that facilities and other personnel could be held to a higher standard than the physician who directs the activity. Because of the greater amounts of liability insurance carried by hospitals and nursing homes, we believe that such an implied difference in immunity protection would significantly increase the probability that litigants would file claims against the hospital. We believe this immunity is necessary but should be broadened to include other probable targets of litigation.

Thank you for your consideration.

Sincerely,

Dennis L. DeWitt
President

DLD/agk

cc: Steve Berkshire

Society For The Right To Die

NEWSLETTER
SPRING 1984

HOSPITAL SURVEY: AN INTERIM REPORT

The grass roots survey initiated by the Society last year, in which members were asked to write their hospitals to inquire about their policies toward the Living Will, is proving so effective that it is being continued through 1984.

Hospitals in 49 states have responded so far, with lengthy and thoughtful letters—often formulated with legal counsel—indicating great sensitivity to their patients' concerns. Significantly, there is evidence that a number of hospitals have been stimulated to action by these Society-generated inquiries.

"We are in the process of developing a formal policy and procedure because we have had so many letters like yours," wrote Freehold (N.J.) Area Hospital. "We have even gone so far as to develop a short form of our own to be utilized in the event that the patient has not had the foresight or opportunity to prepare a Living Will in advance such as you have."

Discuss with Physician

Hospitals in states both with and without laws giving legal recognition to these advance directives emphasize the importance of discussing your Living Will with your physician. Letter after letter states that hospitals do not initiate services but produce them on doctors' orders.

This excerpt from a letter from The Fairfax Hospital in Virginia is representative of letters from hospitals in states with laws: "The Fairfax Hospital, of course, fully complies with the provisions of [the Virginia Natural Death Act] . . . a declaration such as the one that you attached to your letter can be of great assistance . . . If it is properly executed and presented to us at the time of treatment, it would document your directions/instructions as required by State law."

In states without laws, hospitals have written that they consider the Living Will

(continued on page 8)

LEGISLATION IN NEW SURGE: LAWS NOW TOTAL 21

Legislators who have long been committed to the cause of "living will" legislation, and have for years fought an uphill battle, are experiencing a change in the weather. Increasing acceptance by much of the medical profession and a groundswell of public support have sharpened the national perception that such laws are indeed necessary.

Concerted efforts by organizations devoted to the welfare of the elderly—AARP, Gray Panthers, Senior Citizens, and the like—have lent heightened visibility to the issue. Typical of their no-nonsense stand is the recent statement by Maggie Kuhn, Gray Panthers founder, as quoted in the *Litchfield* (CT) *County Times:* "It's on ethical and moral grounds that we take this position. When you're hooked up to a machine, it's an affront. Most people in their right minds would want to die quietly."

The enactment of five laws in approximately one month—in **Georgia, Mississippi, West Virginia, Wisconsin, Wyoming**—and a statute in **Illinois**, which passed last year and took effect January 1, demonstrates the momentum which right-to-die legislation is currently enjoying, and brings the number of jurisdictions with "living will" laws up to 21, including the **District of Columbia.**

Legislation in the Midwest got a significant boost with the passage of **Illinois's** Living Will Act. It is particularly fitting that it should finally have been passed in the home state of Luis Kutner, the Chicago attorney who originated the concept of the

(continued on page 3)

Sidney H. Wanzer, M.D., Primary Author

Daniel D. Federman, M.D., Conference Chairman

New England Journal of Medicine Publishes Physician Guidelines

Ten of the nation's most distinguished physicians, representing various medical disciplines, and brought together by the Society for the Right to Die to clarify the physician's responsibility toward hopelessly ill patients (Spring '83 Newsletter, page 2), have published their conclusions in a Special Article in the April 12 issue of *The New England Journal of Medicine.*

Headlined by the *Washington Post* as a "Bill of Rights for Terminal Patients," the article spells out in detail the medical care the physicians consider ethically correct,

(continued on page 2)

GRAND JURY CALLS FOR NY HOSPITAL GUIDELINES

A call for the New York State Legislature and the Commissioner of Health to establish formal procedures to govern the withholding of emergency resuscitation from terminally ill patients was made by a special grand jury, which found what it called "shocking procedural abuses" during its year-long investigation of "Do Not Resuscitate" procedures at a Queens County (N.Y.) hospital.

The investigation arose out of the death in 1981 of a 78-year-old woman who went into cardiac and respiratory arrest after her respirator was unaccountably disconnected. No alarm calling for resuscitation was sounded.

Although it handed down no indictment, the grand jury found that DNR decisions were made at the hospital without properly documenting them on the patient's chart and without consulting the patient's family. According to testimony, a purple dot affixed to the patient's nursing card was used to indicate "no code," and when the patient died, the card was thrown away—all in order, the grand jury report stated, "to avoid legal responsibility." This "purple dot" system, it went on to say, "eliminated professional accountability, invited clerical error and discouraged physicians from obtaining informed consent."

Specific Recommendations

Acknowledging that it may be appropriate to withhold resuscitation when it would only prolong the dying process and cause needless suffering, the grand jury made specific recommendations for officially recognized "no code" procedures, as well as safeguards against abuse. These included verification that the patient's condition was irreversible, with death "imminent and inevitable"; consultation with patient and family; joint agreement not to resuscitate; and proper recording of the decision on the patient's chart. "Responsible physicians should not have to ignore their own best medical judgments or the wishes of their suffering and terminally ill patients out of an unjustified fear of legal consequences," the jury's report stated.

A spokesman for State Health Commissioner Dr. David Axelrod said that Governor Mario Cuomo had ordered a review of issues involving medical ethics, including DNR orders.

The New York State Medical Society, the New York State Hospital Association, and the Greater New York Hospital Association all testified before the grand jury in support of express DNR guidelines, including a strict ban on verbal orders. There is a growing awareness throughout the country of the need for such regulations. (SRD Newsletter, Spring '83, page 3.)

VA Offers New DNR Option

The grand jury's recommendations resemble new guidelines adopted by the Veterans Administration for its 172 hospitals, which, in a major reversal of policy, afford a DNR option to terminally ill patients who do not wish to be kept alive when there is no hope of recovery.

The VA guidelines, prepared by physicians, nurses and attorneys, took a year and a half to write, and replace an earlier policy which prohibited doctors from denying resuscitation to hopeless patients.

New England Journal of Medicine *(continued from page 1)*

permissible and desirable in various stages of illness, for both competent and incompetent patients. These range from emergency resuscitation and intensive care to the administering of comfort measures solely, and specifically include the withholding or withdrawing of artificial feeding when that would only perpetuate nonmeaningful life. (see page 4.)

Society Sponsorship

Society sponsorship of the meeting was undertaken in recognition of the need for such guidelines at a time when the technological capacity to sustain life indefinitely has led to widespread uncertainty on the part of physicians as to how best to discharge their responsibility toward the dying patient and his or her family.

Two major precepts are basic to the guidelines: The role of the patient in making treatment decisions is primary; and a decrease in aggressive treatment is advisable if continuing it would only prolong the process of dying. "Senseless perpetuation of the status quo is decision by default," the authors state.

The dying patient's prior attitude is crucial to such decision-making, because pain, drugs, or other influences on mental states may render even the competent patient incapable of directing his or her treatment. In such cases, the authors point out, a Living Will or a proxy appointment in advance "can be helpful in indicating the patient's preference with respect to terminal treatment."

Physician's Role

Clear communication between doctor and patient is essential. The authors stress the physician's role as a source of comfort to patients and their families, especially when the decision has been made to withhold life-sustaining treatment.

In recommending how, and how much, to tell the patient who is faced with a life-threatening illness, the authors in general advocate honesty, saying: "A decision not to tell the patient the truth because of fear of his or her emotional inability to handle it is rarely, if ever, justified. . . . The anxiety of dealing with the unknown can be far more upsetting than the grief of dealing with a known, albeit tragic, truth."

Influences on physicians that may prevent them from accepting the idea that often "less" can be "more" are cited frankly: training and tradition that emphasize aggressive treatment; the temptation to use today's sophisticated medical technology; fear of legal liability; personal values and unconscious motivations; equating a patient's death with professional failure; and unreasonable insistence on impossibly absolute prognostic certainty.

Medical professionals who have commented on the article have observed that the prestige of the authors and *The New England Journal* will have considerable influence, and will free physicians in many cases to do what in the past they might have hesitated to do.

Media Response

The response of the media to publication of the article has been gratifying. *Good Morning, America*, the *CBS Morning News*, the *Freeman Report* on Cable Network News, and a number of radio interviewers have made it a subject for discussion, and syndicated stories by the Associated Press and the *Washington Post* have appeared nationwide. Other media articles are in progress—a clear indication that the subject is of overriding interest to the public as well as the medical community.

Reprints of the *NEJM* article, "The Physician's Responsibility Toward Hopelessly Ill Patients," by Sidney H. Wanzer, M.D., et al., are available for $1.00 each from the Society.

John D. Rockefeller IV,
Governor of West Virginia.

MS Victim Forms Living Will Society

Sarah Caldwell, of Epsom, N.H., 37, has joined the six-year battle of State Representative Eugene S. Daniell to enact "living will" legislation in that state.

A wheelchair victim of multiple sclerosis, Miss Caldwell offers vivid testimony to the urgent need for legislation. She fears that she will lapse into a coma, and in the absence of a law, will have no protection against the life-sustaining treatment she does not want.

Although muscular control comes at great cost, she has embarked on a series of speaking engagements to law centers and other groups throughout the state.

In October 1983 Caldwell formed a Living Will Society, which by now has garnered more than 3,000 signatures in support of Representative Daniell's bill. Her determination to secure its enactment goes beyond her concern for her own welfare. The time she has spent in hospitals has let her view at first hand the anguish that families suffer when the life of someone they love is artificially prolonged.

Representative Daniell, now approaching the age of 80, remains undaunted by the New Hampshire governor's veto in 1983 of his legislation. With so many state residents now energized by the newly formed Living Will Society, he is hopeful of passage in the 1985 session. Commenting that since 1976 the bill has passed the House three times and the Senate twice, and has been vetoed twice—once by a Democratic governor and once by a Republican—he adds: "I only hope I'm successful in time to do *me* some good!"

New Living Will Laws *(continued from page 1)*

Living Will. The act, initiated by the Greater Springfield Interfaith Association, and introduced by Representative Michael Curran, is the successor to bills introduced in that state starting in 1976.

Georgia's Living Will Law, to take effect July 1, became the nation's seventeenth, culminating efforts which began in 1976. Abigail Van Buren ("Dear Abby"), who has recommended the Living Will to her readers (see page 5), visited the State Capitol at the request of Senator Richard L. Greene. The legislation had already passed both houses, but lacked Governor Joe Frank Harris's signature. The governor had not indicated whether or not he would sign it, but he did so directly after meeting with "Abby."

West Virginia's Natural Death Act, which in the first week of March passed the House by 100 to 0 and the Senate with only four dissenting votes, will become effective June 4. Senator Stephen L. Cook, its sponsor, received support from the state Nurses Association, as part of their legislative program.

In **Mississippi**, "An Act to Allow Persons to Authorize the Withdrawal of Life-Sustaining Mechanisms . . ." sponsored by Senator Bob Usey, was enacted in April, to take effect July 1. It was supported by the Council on Aging and various church groups, including one of the state's two Catholic dioceses. Mississippi is the first state to require the filing of a "living will" declaration (and any subsequent revocation) with a government agency, in this case, the Bureau of Vital Statistics of the State Board of Health.

Wisconsin's "living will" law was signed by the governor in April. Introduced by Representative Walter J. Kunicki and 19 co-sponsors, it was backed by the state medical society, the state hospital association, the AARP, and the Wisconsin Retired Teachers Association.

In **Wyoming**, a "living will" law, which passed and was signed in March, becomes effective July 1. Senator Russell W. Zimmer, the prime sponsor, introduced the bill on behalf of the Commission on the Aging. He received bipartisan support in the legislature as well as strong backing from Governor Ed Herchler. The Silver-Haired Legislature and the Wyoming Medical Association were also active in the bill's passage. The law contains a provision for a proxy appointment.

The Society will provide residents with appropriate declaration forms on request.

In addition to the five states that have enacted "living will" laws in 1984, 19 legislatures had such bills under consideration: **Alaska, Arizona, Colorado, Connecticut, Florida, Hawaii, Indiana, Iowa, Maine, Maryland, Massachusetts, Missouri, New Jersey, New York, Ohio, Oklahoma, Pennsylvania, Rhode Island,** and **Utah.**

Photo: Courtesy of Rochester (N.H.) Courier

Sarah Caldwell

RAPID GAINS FOR BAY STATE BILL

After ten years of struggle, "living will" legislation in 1983 achieved the necessary support for passage in the Massachusetts legislature, only to fail when the "special rules" requiring unanimous consent which govern the close of the Senate session were invoked.

Encouraged by the remarkable progress made in the 1983 session, the bill's supporters, led by Representative Richard A. Voke, have re-introduced it. It was reported favorably by the Judiciary Committee after only one day of consideration, and moved rapidly to the third "reading" in the House. At this writing, all legislation has been deferred until debate on the budget is concluded.

The bill is actively supported by the Massachusetts Committee for the Living Will and the Massachusetts Council of Churches.

ARTIFICIAL FEEDING BECOMES PIVOTAL ISSUE

The first case in the country in which a state's highest court will specifically address the issue of terminating artificial feeding of an incompetent patient will be decided in New Jersey. The state Supreme Court has heard arguments in the case of Claire C. Conroy, a semi-comatose 84-year-old nursing home patient who had been fed through a nasogastric tube.

In ruling on a suit to discontinue feeding, brought by Conroy's nephew, Superior Court Judge Reginald Stanton had held in a 1983 opinion that feeding could be terminated, saying, "The patient is functioning at a virtually zero intellectual level" and "when a person has been permanently reduced to a very primitive intellectual level or is . . . suffering from unbearable and unrelievable pain, there is no valid human purpose to be served by employing active treatment designed to prolong life."

Paul Armstrong, Karen Quinlan's attorney, called Judge Stanton's ruling the "logical extension" of the same court's 1976 decision that his comatose client could be disconnected from her respirator.

Disagreement on Condition

Although Conroy died during a stay of this ruling her court-appointed guardian *ad litem*, John J. DeLaney, Jr., appealed. The Appellate Division sharply disagreed with the lower court's interpretation of the patient's condition, and with its decision, stating that the withdrawal of feeding, even on a person who lacked intellectual capacity, "authorized euthanasia [and] would have frightening implications." The court held that the testimony in the Conroy case drew a very different picture from that in *Quinlan*. The *Quinlan* ruling, Judge Herman P. Michels said, "applies only to noncognitive, vegetative patients," whereas Conroy was "awake, but confused."

The New Jersey Hospital Association, in its *amicus curiae* brief, argues that any difference between withdrawing a respirator and a feeding tube is an "artificial distinction," and that Judge Stanton's decision should be upheld. Briefs have also been submitted by the American Geriatric Association, the New Jersey Catholic Conference, individual members of the President's Commission for the Study of Ethical Problems in Medicine, and others.

In October 1983, the California Court of Appeals dismissed murder and conspiracy charges against surgeon Robert J. Nejdl and internist Neil L. Barber (SRD Newsletter, Spring '83, page 4), stating that to withdraw artificially administered food and water is no different, legally, from withdrawing respirator support.

While the California case involved criminal charges, the Conroy case is the first civil action in which the withholding of nourishment has been at issue. As such, observers on both sides await with particular interest the New Jersey Supreme Court's decision.

Physicians' and Ethicists' Views

While lawyers and the courts continue to debate, physicians and ethicists have expressed their views in recent articles. The ten physicians who co-authored the *New England Journal of Medicine* article (see page 1) concluded that for patients in a persistent vegetative state "it is morally justifiable to withhold antibiotics and artificial nutrition and hydration, as well as other forms of life-sustaining treatment. In the case of severely and irreversibly demented patients, if food and water are rejected by mouth, it is ethically permissible to withhold artificial nutrition and hydration by vein or gastric tube."

Joanne Lynn and James F. Childress, writing in the October 1983 issue of *The Hastings Center Report*, state: "Medical nutrition and hydration do not appear to be distinguishable in any morally relevant way from other life-sustaining medical treatments that may on occasion be withheld or withdrawn." Dr. Lynn, Professor at George Washington University, Division of Geriatrics, was Assistant Director of the President's Commission. Dr. Childress is Professor of Religion at the University of Virginia.

In the October 1983 issue of *Law, Medicine and Health Care*, Dr. Anne Fletcher, director of the intensive care nursery at Children's Hospital in Washington, D.C., and John J. Paris, a Jesuit priest who teaches ethics at Holy Cross University, co-authored an article in which they noted that in certain limited circumstances artificially administered nourishment may be futile treatment.

Now that termination of respirator support has been permitted by many courts, it appears that the moral dilemma caused by the decision to withhold or withdraw artificial feeding is destined to become the issue of the '80s.

Ruling Awaited on Florida Court Role

Florida's Supreme Court will shortly rule on whether court approval must be obtained before life-support systems can be withheld or withdrawn from a terminally ill comatose patient who has executed a Living Will. The case under review, *JFK Memorial Hospital v. Bludworth*, concerns Francis Landy, 79, who had signed a Living Will in 1975 and died at the Lake Worth hospital in 1981.

When Landy's condition was deemed irreversible, his wife asked the hospital to honor his Living Will and disconnect his respirator. The hospital petitioned the circuit court for permission to act on her request, and, although Landy died before the first decision was handed down, the hospital pursued the matter in the courts, hoping for guidance in the treatment of other comatose patients.

Court Approval Needed

Acknowledging the value of the Living Will as evidence of a patient's intent, County Circuit Judge Timothy Poulton ruled nevertheless that court approval was necessary before life support systems could be terminated. The Fourth District Court of Appeals upheld that decision, but asked the Florida Supreme Court to review the case because of the importance of the issue.

A brief filed in the Supreme Court by the Florida Hospital Association argued that the requirement for court approval places hospitals in an untenable position: it hampers implementation of difficult choices as to allocations of limited medical equipment such as respirators, "removes the sensitive decision from physician and family members" and will be expensive and time-consuming.

Earlier Patient's Wish Granted

The only other right-to-die case to reach the Florida Supreme Court involved a competent patient, Abraham Perlmutter, whose request to be disconnected from his respirator was approved by the Fourth District Court of Appeals and upheld unanimously by the Supreme Court 15 months after Perlmutter's death in 1977. Although the Court emphasized that its decision was limited to the case of a competent, terminally ill adult with no minor dependents, whose family was in full agreement with his request, it did clearly address the need for legislative guidelines, stating that the issue was more suited to the legislative forum than to the courts.

SRD HONORS "DEAR ABBY"

Abigail Van Buren, who writes the widely syndicated "Dear Abby" column, was honored by the Society for the Right to Die at a luncheon held on November 11, 1983, to thank her formally for continuing to emphasize the need for Living Wills. Two columns last year resulted in a flood of nearly 100,000 requests to the Society for these documents—impressive testimony to the influence she has on her readers and to the public's ever-increasing interest in the subject.

"Abby" was presented with a Living Will plaque by Sidney D. Rosoff, past president and currently chairman of the SRD Board. In responding to the presentation, she said, "Every time the Living Will is mentioned in my column the response from readers is overwhelming. My mail triples from 10,000 letters a week to 30,000! In fact, this is by far the most popular issue in my column to date and keeps gathering momentum. . . . The Living Will is simply a document that a person signs saying that he or she does not want to be kept alive by artificial means after all hope for recovery is gone. It is not a way of 'getting rid' of a relative [but] an expression of what one wants for himself! I have signed one, and I can only wish that every citizen in the U.S. had the peace of mind it has given me."

Abigail Van Buren and Sidney D. Rosoff

California, Oregon Strengthen Rights

California and Oregon, which were among the earliest states to adopt right-to-die laws, have recently enacted legislation aimed at overcoming a major restriction imposed by both statutes. California legislators have accomplished this indirectly, by amending the state's Uniform Durable Power of Attorney statute. Oregon has amended the Natural Death Act itself.

As enacted in 1976 and 1977 respectively, both Natural Death acts stipulated that to be binding, a person's Directive to Physicians must be executed, or reexecuted, 14 or more days after confirmed diagnosis of a terminal condition—frequently impossible for a critically ill or injured patient.

In **California**, the expansion of the Uniform Durable Power of Attorney statute to cover health care gives state residents a means of appointing a proxy (attorney-in-fact) to make medical decisions in case of lack of capacity, whether temporary or permanent, including the decision to discontinue life-sustaining treatment.

This device is a potentially useful supplement to the Directive to Physicians. Used in conjunction with the Directive, the Durable Power provides the advantage of having a decision maker who is familiar with the patient's wishes and can select from treatment options on the basis of specific information about the patient's condition.

Oregon amended its 1977 law last year to remove the same difficult 14-day requirement contained in the California statute, and to eliminate the five-year limit on the Directive's term of effectiveness.

MS SUFFERER ALLOWED TO DIE

A Hartford, Connecticut Superior Court judge ruled in March that Sandra Z. Foody, 42, a comatose terminally ill victim of multiple sclerosis who had been cared for at home for 24 years before being hospitalized, could, because of "narrow and extreme circumstances," be disconnected from her respirator "without undermining the state's interest in the preservation of life."

Foody's parents filed the lawsuit to insure that there would be no civil or criminal reprisals against any person or institutions if their daughter's life support system were disconnected.

During the years of home care the Foodys had spoon-fed, cleaned and dressed Sandra—tasks she was unable to do for herself. Mr. Foody was quoted in the *Hartford Courant* as saying, "In all the years we weren't out of the house ten times" except to go to church on Sundays. The decision to hospitalize Sandra was made only when complete paralysis made home care no longer possible.

Judge Mary R. Hennessey, in a thoughtful and humane opinion, found that "withdrawal of treatment should be ethically permissible where it no longer offers hope of benefit to the patient." She listed conditions that should be met in future cases: permanent and irreversible illness and no reasonable probability that the patient will ever return to a cognitive state; agreement of the attending physician and at least two others; and the good-faith wish of the family to exercise through substitute decision-making the patient's right to discontinue artificial life support systems.

No Appeal Sought

Although Connecticut attorney general Joseph I. Lieberman felt that the state had an interest in arguing for Sandra Foody's life, he decided not to appeal, saying, "I do not want to extend any further the suffering of the Foody family or delay what now appears to be inevitable."

In a 1981 case, Angela Garvais had petitioned the same court on behalf of her 23-year-old sister, Melanie Bacchiochi, who went into a coma after suffering cardiac and respiratory arrest while having her wisdom teeth removed. Although she was diagnosed as brain dead, it took more than a month before the court ruled that respirator support could be stopped.

Isn't It Enough?

In commenting on the Foodys' sad victory, Garvais deplored the public airing of situations that should remain private. "What happened to my sister was a horrible thing. I hoped the next person wouldn't have to go through this. Isn't it enough already?"

Proxy Provision Added To SRD Model Bill

Provision for the optional appointment of a proxy to make treatment decisions on behalf of an incapacitated individual has been added to the Society's Model Bill. Although "personalized instructions" were permitted in the bill as originally drafted, the Society believes that spelling out the right to designate a proxy strengthens the bill and enhances the patient's potential right of self-determination. The appointment of a proxy is entirely discretionary, and failure to make such an appointment in no way affects the authority of the Declaration.

THE NEW YORK TIMES, WEDNESDAY, APRIL 4, 1984

To Die or Not to Die

By Evan R. Collins Jr.

The Governor of Colorado, Richard D. Lamm, had his heart in the right place when he warned that "we really should be very careful in terms of our technological miracles that we don't impose life on people who, in fact, are suffering beyond the ability for us to help."

Speaking at a meeting of the Colorado Health Lawyers Association, Governor Lamm stirred widespread public criticism, apparently based on a misunderstanding of his remarks, when he said that "we've got a duty to die, to get out of the way with our machines and our artificial hearts." Later, Governor Lamm said that he simply was urging that economically sound and sensible allocation of limited medical resources should preclude fruitless treatment of the terminally ill.

An essential principle of life is the fundamental right of self-determination. From time to time, misguided people say that it is the "duty" of a patient to die — a duty to himself or herself, or to the family. Of course, it is abhorrent for anyone to argue that someone should die for social, economic or any other reasons. To philosophically advocate death as a public responsibility — a position that might well lead to public imposition of death for political ends — evokes chilling echoes of other times in history, especially Nazi Germany.

It is also abhorrent to impose on a dying patient a horrifying array of respirators, tracheal tubes, feeding tubes through the nose and repeated violent cardio-pulmonary resuscitations — all futile, and in almost all cases contrary to the wishes of the patient and his or her family.

Because of our society's remarkable technological successes, we find ourselves crossing the line from prolonging life to prolonging dying. At what point do we stop?

Dr. Joseph Fletcher, professor emeritus of Christian ethics and pastoral theology at the Episcopal Divinity School, in Cambridge, Mass., (and former president of the Society for the Right to Die), has written: "Ethical questions jump out at us from every laboratory and clinic . . . The crucial question is not whether the end justifies the means, but *what justifies the end?*"

The elderly are frightened — legitimately so. They see a lifetime of control over their own lives eroded at the end by a battery of medical decision-makers who are intent on keeping them alive without thought to their dignity or desires.

A physician's training impels him to try to sustain life, and in the present climate that training is reinforced by the real danger of civil, even criminal, lawsuits. To minimize this legal liability, even humane and sensitive physicians aware that the quality of life that they are perpetuating does not merit heroic measures, are loath to obey their instincts and let nature take its course. The terminally ill elderly are caught in this tragic conflict. How can they protect themselves?

Aware of this problem facing the elderly, 15 states — New York, New Jersey and Connecticut are not among them — and the District of Columbia now have "living will" laws that offer protection against dehumanized dying and confer immunity upon physicians and hospital personnel who comply with a patient's wishes.

To avail themselves of the right to a dignified death, individuals can execute legal declarations that direct their physicians to withhold or withdraw artificial life support when an illness is medically certified as terminal. As an indication of the widespread demand for this protection, thousands of such directives, different in some respects in each state, have been executed. Also, there is a trend toward recognizing an individual's advance appointment of a proxy to make decisions on treatment in the event of incompetency.

Residents of states that have not yet enacted these laws have signed "living wills" by the hundreds of thousands, thereby expressing a morally potent, if not legally binding, wish not to have their lives prolonged artificially.

With artificial measures rejected, what constitutes appropriate treatment for elderly dying patients? What are they entitled to? Ease of pain, certainly, and, insofar as possible, relief from emotional discomfort. But beyond these considerations, it is the assurance that they will be permitted to die with, to quote Dr. Fletcher again, "that quality of humanness, the preservation of which is what the concepts of loving concern and social justice are built upon."

As he wrote: "Good dying must at last find its place in our scheme of things, along with good birthing, good living and good loving. After all, it makes perfectly sound sense to strive for quality straight across the board, as much in our dying as in our living."

Evan R. Collins Jr. is president of the Society for the Right to Die, a national, nonprofit, educational organization that is based in New York City.

Dr. Joseph Fletcher

Dr. Helen B. Taussig

News From SRD Board

Joseph Fletcher, S.T.D., D.D., President Emeritus of SRD, was elected to the National Council of Alpha Omega Alpha, an honorary medical society—one of only eleven non-physicians accorded this honor. Recently he was officially made a full-fledged brave in the Clan of the Turtle of the Mohawk Indians, a distinction of which he is particularly proud.

The new **Helen B. Taussig** Children's Heart Center—the pediatric section of the regional Heart Center of Maryland at Johns Hopkins University Hospital—was officially dedicated on December 8, 1983. Dr. Taussig, originator of the "blue baby" blood transfer operation, and the person who more than anyone else alerted the U.S. to the dangers of thalidomide in 1962, has been a Director of the Society since 1976.

Sia Arnason, M.S.W., has been elected to the Board. Ms. Arnason is an expert on problems of the aging, and is Social Work Coordinator at the Institute on Law and Rights of Older Adults, Brookdale Center on Aging of Hunter College.

Anthony Reynolds Smith has joined the Board. Mr. Smith, who has occupied high positions in New York's municipal government, is the Assistant Commissioner of the Metropolitan Transportation Authority.

A MESSAGE FROM OUR PRESIDENT

The right-to-die movement is moving forward rapidly. What was not too long ago the dream of a few—the legal recognition of Living Wills—has become a reality in twenty-one jurisdictions. With five new laws enacted in one month this year, and a promising outlook for legislation in other states, 1984 may prove to be another watershed year, much like 1977, which saw seven bills signed into law.

Elsewhere in this Newsletter you can read about the highlights of our program: the Physicians' Conference we sponsored, the nationwide hospital survey which is proving so fruitful, and the deluge of requests for Living Wills that resulted from "Dear Abby" columns and kept our office working almost around the clock.

But quite aside from the highlights, we must continue the day to day work of just "being there." Due in large part to our efforts, individuals' awareness of their rights is growing. The many court cases in states without laws demonstrate this, even as they demonstrate the need for legislation. As right-to-die activities have intensified, so, inevitably, have the demands on our staff.

To help meet these demands, and to expand our direct services, we have retained a staff attorney. She will give advice on executing Living Wills and Durable Powers of Attorney, act as a central legal information source, and work with legislators in drafting bills to insure that they are inclusive and effective.

Because laws have little value unless citizens are aware of them, we have also added to our staff a public information specialist, to reinforce our presence at the leading edge of the patients' rights movement.

Most of all, we need your awareness, your voice, and your support to help us continue to defend the principle of the individual's right of self-determination at the end of life, which is what the Society is all about.

Evan R. Collins, Jr., new President of the Board of Directors of the Society, took office in December 1983. A vice president of the New York investment banking firm of Kidder, Peabody & Company, Mr. Collins is past president of United Way of Westchester (N.Y.)

SRD Publications

1984 HANDBOOK OF LIVING WILL LAWS
Eleven New Statutes with Texts and Commentary

A companion resource to *Handbook of Enacted Laws* (1981) containing the first ten state right-to-die laws

Each $5.00

Fact Sheets on Leading Right-to-Die Court Decisions

Binder Set $3.00

Order from:

Society for the Right to Die
250 West 57 Street
New York, NY 10107

The Society for the Right to Die makes available legally recognized advance document forms to residents in the states of Alabama, Arkansas, California, Delaware, Georgia, Idaho, Illinois, Kansas, Mississippi, Nevada, New Mexico, North Carolina, Oregon, Texas, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming and the District of Columbia. For use in states lacking right-to-die laws, SRD supplies Living Will Declaration forms.

We deeply appreciate your past contribution.
Your continued support will help us make new gains in behalf of your right to die with dignity.
Please be generous.

Enclosed is my contribution in support of the Society's work: ☐ $25 ☐ $50 ☐ $100 Other $______

(Contributions of $10 or more receive a wallet-size Living Will/Annual Membership Card and Society Newsletters. All contributions are tax deductible.)

Please send me:

_____ Reprint(s) of *NEJM* Physicians' Article @ $1
_____ 1984 Handbook(s) of Living Will Laws @ $5
_____ Set(s) of Right-to-Die Fact Sheets in binder @ $3

_____ Hospital Survey sample letter
_____ Living Will Document(s) for my state
_____ Reprints of *N.Y. Times* article, "To Die or Not to Die"

Name ____

Address ____

City ____________________ State ______________ Zip ____________

______ I can no longer be helpful. Please remove my name from your mailing list.

WORLD CONFERENCE MEETS IN NICE

The World Federation of Right-to-Die Societies will hold its Fifth International Conference in Nice, France, September 20-23. An eleven-member delegation from SRD's Board of Directors will join with their colleagues from countries all over the world to share experiences and discuss issues of mutual concern.

Two roundtable panel discussions will be open to the public—one on legal concerns, and one on ethics. Dr. Joseph Fletcher, President Emeritus of the Society, will be a panelist on the latter. The major address will be delivered by Dr. Christiaan Barnard, cardiologist and pioneer in the heart transplant operation, who will speak on "Good Life — Good Death," also the title of his celebrated book.

Society members who are interested in attending can write for more information directly to Mme. Paula Caucanas Pisier, A.D.M.D./Congres International, 103, rue La Fayette, 75010, Paris.

Hospital Survey

(continued from page 1)

morally persuasive as a document of intent which will carry weight, even if not legally binding. They report their frustration at the failure of their legislatures to act, as the following quote from the Ft. Myers Community Hospital in Florida illustrates: "It is unfortunate that the State of Florida does not recognize the popular Living Will as a legal document. . . . You have brought up an issue that is important . . . It will eventually be resolved with guidelines provided by the legislature and reinforced by the courts. Until then it is imperative that we protect ourselves from the potential of civil and/or criminal liability . . ."

The personal nature of the survey is apparently having a far greater impact than would have been achieved by a more institutional approach, and is alerting hospitals in the most direct way to the increasing importance prospective patients attach to their rights.

Thanks to all of you who have written your hospitals and sent us copies of the responses you have received. If you have not already written, we urge you to do so. A sample letter on which you can base your own is available from the Society on request.

A final report on the survey will be provided in the Newsletter early in 1985.

HELP WANTED . . . to build SRD files of right-to-die news stories, editorials and magazine articles. You are our "clipping service," so please continue to send all relevant material to the Society for the Right to Die, 250 West 57 Street, New York, NY 10107. Warm thanks to those of you who have done so.

Uniform Law Promoted

The National Conference of Commissioners on Uniform State Laws, an organization composed of commissioners from each state who seek to promote uniformity in state laws where appropriate, is now considering such a law in the right-to-die field.

The first meeting of the drafting committee was held in Alexandria, Virginia, in January, to analyze laws which had been enacted or were presently pending before state legislatures. Preliminary policy decisions were made on the text of a Uniform Law at a second meeting in Chicago in April. A first draft was circulated for consideration, and a second is now in preparation for presentation to the Commissioners at their annual conference, to be held in Colorado in July.

Before recommending any law for adoption by the states, the National Conference must approve it at two successive annual meetings.

"The fact that 19 states and the District of Columbia have already enacted 'living will' laws points up the significance of the Commission's work," says Sidney D. Rosoff, SRD board chairman, who attended both conferences. "It is important to have a well-drafted Uniform Law adopted throughout the country, since Americans move easily from state to state, and illness or accident may occur in any jurisdiction. The existence of a Uniform Law with a Living Will which will be recognized in all states, irrespective of the state in which it was signed, is imperative."

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SB 63, Special appropriation for remodeling and construction of an addition to the Wrangell General Hospital.

SB 63 would appropriate $6,000,000 for a payment to the City of Wrangell to correct functional and physical deficiencies in the existing Wrangell General Hospital facility. Much of the proposed remodeling is needed to meet fire, safety and sanitation regulations. In 1981, the project was granted a Certificate of Need permitting an expenditure of $6.9 million. Last year the State granted $400,000 for the design phase of the project, all of which is presently encumbered. The Alaska State Hospital Association has indentified the Wrangell project as the priority for FY 86.

The Wrangell General Hospital serves approximately 3,000 people in the Wrangell area.

Senator Zharoff has proposed an amendment (attached) to SB 63 which would appropriate $2,114,000 to the Kodiak Island Borough for architecture and engineering costs of either remodeling or reconstructing the Kodiak Island Borough Hospital.

SB 140, Rights of the terminally ill.

Under the authority granted in SB 140, a competent adult would be allowed to execute a declaration that life-sustaining procedures be withheld or withdrawn from that adult. The bill specifies that the declaration would take effect only if the adult's condition is terminal and the adult is unable to make treatment decisions. A declaration would be revocable at any time.

The bill requires witnessing of the signing of the declaration and proper recording of the decision on the patient's chart. It provides for immunity from liability for honoring a declaration and penalties for disregarding one.

According to the Society for the Right to Die, similar legislation has been enacted in 20 other states and the District of Columbia.

SB 140

ALASKA STATE LEGISLATURE - SENATE

SENATOR RICHARD I. ELIASON

LABOR AND COMMERCE COMMITTEE, CHAIRMAN
RESOURCES COMMITTEE
JUDICIARY COMMITTEE
FISHERIES SUB-COMMITTEE

P.O. BOX 143
SITKA, ALASKA 99835

POUCH V
JUNEAU, ALASKA 99811
(907) 465-4916

MEMORANDUM

TO: Senator Bettye Fahrenkamp, Chair
Senate HESS Committee

FROM: Senator Dick Eliason Dick

RE: SB 140 - "An Act relating to the rights of the terminally ill"

DATE: February 18, 1985

Senate Bill 140 recognizes the rights of a competent adult to refuse life-prolonging procedures if that adult is terminally ill. The intent behind this legislation is to establish and protect each individual's right to a dignified death without unnecessary medical treatment which serves only to prolong dying.

I would appreciate it if you could schedule this bill for a hearing before the Senate HESS Committee as soon as possible.

Clocksin last yr - HB 107

presumption that person competent at time fills out form. Not in this yr's. leg.

[illegible] [illegible] NRN

Support

spoke to him
3/7/85

DAVID T. WALKER
ATTORNEY AT LAW
MENDENHALL BUILDING
326 FOURTH STREET, SUITE B
JUNEAU, ALASKA 99801
(907) 586-3537

March 5, 1985

Honorable Bettye Fahrenkamp
Alaska State Senate
Pouch V
Juneau, Alaska 99811

Re: Senate Bill 140

Dear Senator Fahrenkamp:

I am the registered lobbyist for the Alaska Nurses Association.

The Association supports SB 140 "An Act relating to the rights of the terminally ill." Quite a few of my clients have requested instruments similar to the instrument proposed to be authorized by Senate Bill 140. Generally speaking, my clients do not fear death itself as much as the indignity of deterioration, dependency and hopeless pain. An individual with a sound mind has a perfect right to make carefully considered decisions impacting and controlling his medical treatment. Those decisions should, upon the request of the individual, be controlling if the individual's physical condition becomes terminal and he is no longer able to participate in decisions regarding medical treatment.

I would appreciate it very much if you would have your staff notify me of the hearing schedule on this bill, it may be that the Association will want to present testimony.

Please do not hesitate to contact me if you have a question about the Association's position regarding Senate Bill 140 or any other matter.

Very truly yours,

David T. Walker

David T. Walker

DTW/rnt
cc: Margaret Bixby
Janet Buness

Taking Charge of the End of Your Life

Proceedings of a Forum on Living Wills and Other Advance Directives

"Given the new medical technology that can sustain life even when the brain is gone, we must think about the right to die and the need for dignity in departing life. We owe it to ourselves and the ones we love to make provision for that moment."

Jacob K. Javits

"Staying in control of your own death takes planning and conviction. It is easier said than done. Yet there are dangers. Already public policy tends toward the cheapest way to keep an old person alive."

Tish Sommers, President
Older Women's League

Taking Charge of the End of Your Life

Proceedings of a Forum on Living Wills and Other Advance Directives

Washington, D.C.
1985

Contents

Part 1. Framing the Issues

Part 2. Current Status of Advance Directives for Health Care Decisions at the End of Life

Part 3. In Whose Hands: Limitations and Problems With Advance Directives

Part 4. Bringing the Problem Out of the Shadows: What Organizations Can Do

Foreword

On July 9, 1985, the Older Women's League (OWL) sponsored a forum in Washington, DC entitled "Taking Charge of the End of Your Life: A Forum on Living Wills and Other Advance Directives." The forum, which took place in the Dirksen Senate Auditorium and was attended by about 250 persons, was sponsored by OWL in cooperation with the American Bar Association's Commission on Legal Problems of the Elderly, and the Congressional offices of Representative Sid Morrison, Senator John Heinz, Senator John Glenn and Representative Edward Roybal.

The forum was the culmination of almost one year of planning that was initiated by Representative Morrison. In the fall of 1984, in response to his own and constituent interest, Morrison began to research the issue of advance directives for health care decisions at the end of life. He concluded after several months that federal legislation would not help this issue to develop -- that Congress is not equipped to answer these difficult and sometimes emotional questions that are shaped by regional values and concerns. But Mr. Morrison recognized the need for Congress, federal agencies and national organizations to dialogue on this issue and to help make advance directives more visible and more widely recognized by the public.

Knowing of OWL's strong concern with this issue, Mr. Morrison approached the League and asked if they would like to take the lead in planning a forum on Capitol Hill on this topic, with his support. Tish Sommers, president and co-founder of OWL, and a terminal cancer patient, has had a longstanding personal interest in promoting better understanding of ways to preserve autonomy in the final stages of a terminal illness. OWL had in fact already planned a major new initiative for their 14,000 members on the topic of planning for death and dying that would include information on living wills and durable powers of attorney for health care decisions and a new report in their series of Gray Papers. OWL readily accepted Morrison's invitation, and Sommers went about seeking funding and the involvement of other organizations.

One especially bright note in the planning came when Jacob Javits, former Senator from New York, learned about the Forum and expressed an interest in participating. He was quickly added to the list of speakers and his poignant personal remarks along with Sommers' personal perspective, provided an intensity and depth of vision that propelled the discussions through the complexities that followed.

The success of the Forum is well reflected in these Proceedings, published through the generosity of the ABA's Commission on the Legal Problems of the Elderly. The Commission's willingness to make the contents of the Forum available to thousands of persons who did not attend means that this critical issue may more fully receive the kind of national attention it deserves, and that ultimately more of our citizens will begin to make careful advance plans to take charge of the end of their lives.

Acknowledgements

The Forum "Taking Charge of the End of Your Life"

was funded through the generosity of

The Florence V. Burden Foundation

and

Ross Laboratories

Thanks are due for the creativity and hard work

of the Forum's planning committee:

Alice Quinlan	Forum Coordinator, Older Women's League
Janet Warren	Office of Representative Sid Morrison
Nancy Coleman	American Bar Association
Charles Sabatino	American Bar Association
Bill Benson	Senate Special Committee on Aging
Linda Josephson	Senate Special Committee on Aging

Part 1

Framing the Issues

Speakers in Part 1

SENATOR JOHN GLENN (D-Ohio) was elected to the Senate in 1974 after a career as NASA astronaut. He serves on the Armed Services and Governmental Affairs Committees, and is the ranking minority member on the Special Committee on Aging.

SENATOR JOHN HEINZ (R-Penn.) was elected to the Senate in 1977 after serving two and a half terms in the House representing suburban Pittsburgh. Among his key Senate leadership positions and membership on the Finance and Banking Committees, he is Chairman of the Senate Special Committee on Aging.

SENATOR JACOB JAVITS was a member of Congress for 34 years, representing the citizens of New York in the House for a decade and in the Senate for 24 years. A Republican party leader, he was the author of legislation on employment and training, international education, and federal support for the arts and humanities, among other issues. In recent years, as a victim of ALS (amyotrophic lateral sclerosis), Senator Javits has been writing about public policy issues related to terminal illness.

VICTORIA H. JAYCOX is the new Executive Director of the Older Women's League, the sponsor of "Taking Charge of the End of Your Life." She was previously director of the Criminal Justice and the Elderly Program at the National Council of Senior Citizens. A Phi Beta Kappa graduate of Wellesley College, Jaycox also worked at the Eisenhower Foundation, the National Institute of Justice, and served as assistant to the president of the Legal Services Corporation.

REPRESENTATIVE SID MORRISON (R-Wash.), a veteran state legislator, was first elected to Congress from Washington's Fourth District in 1980. He is a member of the Agriculture and Science & Technology Committees. Last fall he initiated a series of meetings with representatives of various national organizations to discuss living wills, which lead to this Forum.

TISH SOMMERS, co-founder and President of the Older Women's League, is a life-long feminist and fulltime advocate of women's causes. She coined the term "displaced homemaker" and co-founded the movement recognizing the needs of longtime homemakers who were divorced and widowed. A stage-four cancer patient, for the past year Sommers has been writing and researching issues related to maintaining personal autonomy at death.

WELCOME

VICTORIA JAYCOX
Executive Director
Older Women's League

MS. JAYCOX: I'd like to welcome you all to this forum on "Taking Charge of the End of Your Life."

We're here today to stimulate dialogue on an issue that demands much more public attention than it's currently receiving. That issue is planning for dying, that is, planning for the final stage of life when death is imminent but has not come.

It's an issue that can be ignored only at the peril of each one of us. For we all may be faced, directly or indirectly through our family and friends, with a death that's not sudden and swift but one which is instead prolonged and gradual, one in which decisions about medical care must be made at each of a number of stages of the illness.

For most of us, that type of death raises important considerations about our ability to stay in control of decisions that will be made about our bodies up until the moment of death. Most of us would like our manner of dying to be consistent with our approach to and philosophy of living. But it's becoming increasingly true that careful planning in advance is needed in order for that to happen. In our complicated, legalistic and rapidly changing society, it's probably inevitable that this planning will be complicated, legalistic and will need to be constantly re-evaluated. It will require us to pool our wisdom to see more clearly what's needed.

This forum will begin the process of pooling knowledge. We will take as a given the idea that we all have a right to make advance plans for our health care that should be followed at the end of our lives, in spite of contrary wishes by health care professionals, even if we're no longer able to communicate those wishes to others.

We'll look at practical ways to achieve this control -- legal strategies that can be used to keep control of these life and death decisions, and the strengths and weaknesses of these strategies. We'll also look for possible dangers in opening up this Pandora's box named "The Right To Refuse Treatment."

To plot a course through this minefield of legal and ethical questions is our task today. As difficult as some of these questions are, we stand to lose more in the long run if we continue to ignore them. A lingering death that occurs without considering a person's beliefs and wishes can greatly diminish not only that person's life but also our society as a whole. So let's proceed to examine what we can do to take the charge of the end of our lives.

SENATOR JOHN HEINZ (R-PA)

SENATOR HEINZ: It is my pleasure to welcome you all here this morning on behalf of the United States Senate. And it is a privilege to participate along with my distinguished colleague from the House, Congressman Morrison. I am also pleased that Senator Jack Javits will be here. He is one of the most remarkable people when it comes to taking charge of one's life. Jack Javits, as you know, retired from the Senate in 1980. He became very ill. And he has gone on remarkably to do as much or more as a private citizen than as a Senator. His record in the Senate is remarkable and probably will be unsurpassed. It is for that reason I'm especially pleased that he will be here with us later. As a matter of fact, here he comes now. Jack, we've got a good, warm welcome ready for you. I just said a few kind words about you. I won't repeat them. You would probably only deny them because of your modesty.

Let me just say that the Older Women's League and the American Bar Association are to be commended and congratulated for sponsoring this forum on what is one of the most timely and sensitive issues facing the aged and terminally ill Americans today.

You know, I think it is only fair to say that planning for the end of one's life, the end of one's days, is a subject that makes almost all of us feel very uncomfortable and uneasy. I suspect, in part, it's a topic that cuts towards a basic American value or freedom. We talk a lot about freedom of choice in this country because we believe that to be fundamental. It is considered inalienable and is fiercely guarded by all of our citizens. Freedom of choice is something we exercise in polling places, in our homes, workplaces, in our places of worship, in our choices of recreation, what we do with our lives on a day-to-day basis. It is a supreme irony that we assume as a right in the innocence of birth a right that seems to allude us in the frailty of old age. I am reminded of the authors I read when I was in college, people like Camus and Jean-Paul Sartre, the existentialists who believed that a man and the way he died were as important as the way he lived.

We are here today because for many Americans freedom to make the ultimate choice at the end of life has been eroded by the very technological capabilities to extend those lives. And the ability to choose is threatened or even lost in a twilight world of drugs, of life support systems, of extreme mental confusion, and pain.

As Chairman of the U.S. Senate Special Committee on Aging, I recognize the crucial role that advance planning plays in protecting an individual's freedom of choice in the face of death. How many of the millions of

Americans living out their last days in a skilled nursing home or in a hospital are no longer able to express their wishes as they approach the end of their lives. It is for these individuals, and millions of others who will follow, that a choice through advance directives is so critical an option.

Congress has responded to public concern over the issue of freedom of choice and death in several ways. Recent congressional mandates have resulted in studies on the definition of death and a President's Commission Report on the decision to forego life sustaining treatment. These investigations serve to clarify some of the controversy and confusion surrounding the rights of the dying.

Along with my colleagues in the House, Congressmen Morrison, Roybal and others, I have requested the Congressional Office of Technology Assessment (OTA) to prepare a report on patients' rights and advance directives legislation in the United States. OTA plans to have that report completed by the summer of 1986. Additionally, the Senate Special Committee on Aging will publish a committee print later this year, hopefully early this fall, entitled Planning Ahead in Case of Incapacity, A Resource Guide. It is my hope that efforts such as these, such as this effort today, will serve to educate the public as well as the government, and eliminate any roadblocks to free choice.

In conclusion I just want to commend again the Older Women's League for its initiative in this very critical area. I'm pleased on behalf of the Senate and the U.S. Senate Special Committee on Aging to welcome you. Let me only bring to your attention one other small footnote.

Roughly three years ago we were successful in enacting hospice legislation, a major victory for people who wanted to have more control over their lives and at the end of their lives. That legislation had a three year life. It is expiring shortly. I've introduced legislation to extend it for three more years. It is my hope, and with your help it could be a reality, that the extension of hospice legislation could be achieved as part of the budget reconciliation process. In that process, we are trying to come up with a formulation that will economize in prudent ways on the delivery of services. We have proven that the continuation of a hospice program is the humane thing to do and is consistent with budgetary constraint. It is for that reason that if all of you and your organizations contact the members of the Senate Finance Committee, we have an excellent chance of including an extension of the hospice program in the budget reconciliation.

Let me again thank Ms. Jaycox and the rest of the people who organized this forum for putting together what I'm sure will be an extraordinarily valuable milestone conference on this issue.

REPRESENTATIVE SID MORRISON (R-Wash.)

MR. MORRISON: I'd like to talk today about how a farmer from Washington State got involved with this particular issue. Maybe it points out the potential that exists from this group today and the contacts that all of you have through your various organizations and the states that are represented here.

We decided about a year ago with the help of a young staff person who is here today, Janet Warren, that we needed to talk to our seniors in central Washington State about the new Medicare reimbursement system. So we set up a series of seven health care conferences for seniors. It was interesting to us that the medical fraternity came to us and said, "We're having trouble talking with seniors. Can you help us?" So we said, "Well, why don't you join in on these conferences?" In the conferences when people heard that a significant portion of Medicare costs were going to those who were terminally ill, an exchange started between doctors and seniors saying, aren't there living wills? Why don't they work? Why isn't the living will I signed in Washington State good in Oregon? They were the sort of questions that began to lead us in a direction that I guess brings us together today.

There was such a recurring theme in the exchange at these seven different conferences in Washington State that we took on the commitment to see if there was something we could do about this. Maybe we could see a greater uniformity, greater acceptability of the living will concept. And it has led us here today.

We started, of course, as members of Congress are inclined to do, trying to leap buildings in single bounds, saying we need a universal living will that's good anywhere in the world. And then of course we came back to earth realizing that this probably was best handled as a state issue, and realizing that a lot of people are opposed to any form of advance directive on health care decisions for the terminally ill.

So it really is a state issue. But we said, well, then let's encourage the states to get on with it. We found that about 35 states have passed legislation of some form. We also found that a model act was available, that was suggested to the states and that needed to be pursued. So I think we probably have come quite a long way. I hope you leave this conference very enthusiastic on the subject. We can proceed to advance this cause.

I think, and Senator Heinz has referred to this and others will on through the day, the time has come. In a report in my own little local hometown paper in Washington State, out of 360 people surveyed, 93 percent surprisingly favored discontinuance of life support systems for patients with little chance of recovery. I guess at the other end of the spectrum, the Wall Street Journal reported to us that polls have shown a steady rise in public support for a terminally ill individual's right to refuse life prolonging treatment. The same article pointed out differences from state to state which create some difficulties.

Well, the forum today comes together after a lot of planning, a lot of effort -- and again thanks to the Older Women's League, because they were the one group that said we need to do this. Let us put it together. You all represent a variety of interested groups and parties; you can help to spread understanding of the issues involved in these advance directives.

We also need to promote awareness that advance directives do exist in over half of the states already and get on with the pressures on the others to advance this cause. Let's have this universal opportunity for people all over the nation. We need to encourage, of course, all states to continue to address the issue and to stress the problems associated with a lack of uniformity.

Let me close by wishing you well today. I'll just mention that one of the guiding lights in my life has been a scoutmaster that I had all too many years ago, who said when I was young and impressionable, "Always leave your campsite a better place than when you found it." And I applied that when I was a kid scurrying around, cleaning up papers and stacking firewood and so forth for the next folks who came along. But it fits so well where we are today. By understanding, by pushing, by progressing in this area, we have an opportunity to help people and leave this world a better place than when we found it. So I look forward to the results of this forum and to your efforts.

REPRESENTATIVE EDWARD ROYBAL (D-Calif.)

MR. ROYBAL (letter): Thank you for the invitation to speak at your forum, "Taking Charge of the End of Your Life: A Forum on Living Wills and Other Advance Directives." Though I regret that I am unable to attend the forum, you should be aware that we are both fighting on behalf of the elderly. This morning I am chairing a Committee hearing entitled "Health Care Cost Containment: Are America's Aged Protected?". In our hearing the Committee will examine the plight of those elderly who are losing health care access and protection under the pressure of cost containment.

The Older Women's League is to be commended for having the courage and foresight to conduct this urgently needed forum on the trauma and complexities surrounding the last days of a person's life. Each of us has personally witnessed the dilemma faced by an elderly family member or friend who faces death in a society which is less than supportive.

Tragically, American society has become increasingly "schizophrenic" on this issue. On the one hand, cost conscious politicians tell the terminally ill elderly that they have a "duty to die." On the other hand, the elderly are thwarted when they try to take control and make individual treatment decisions appropriate to their individual circumstances.

"Retaining control over one's person" is an issue which is both timely and crucial to the protection of the entitlements and civil liberties of elderly patients. The House Select Committtee on Aging is committed to returning more control back to America's senior citizens. To that end, the Committee is committed to relieving the cost pressures which threaten the independence and dignity of an elderly person's last days. Unfortunately, that is not enough. The Committee is also engaged in finding better legal vehicles for returning more control to the elderly person facing death.

Again I whole-heartedly support your efforts and look forward to continuing to work through these difficult and pressing issues with you.

Keynote Address

TISH SOMMERS
President
Older Women's League

MS. JAYCOX: I'd like next to introduce Steve McConnell, staff director of the Senate Special Committee on Aging.

MR. McCONNELL: Welcome. I have the best task of anybody today. I have the opportunity to introduce the keynote speaker, a long-time friend and one of the finest people in the whole world.

I could tell you about all of her accomplishments, the fact that she is the President of the Older Women's League, a lifelong feminist and full-time advocate of women's causes. I could talk about how talented she is as an author. She is one of the few people I actually look for in written word because she knows how to capture a phrase and communicate concepts clearly. She has done a lot of writing. She is the author of a book, The Not So Helpless Female. And her articles appear in many journals and publications.

I could talk about her creativity. She coined the term "displaced homemaker," which is now widely used to describe women who lost their jobs as career housewives through divorce, separation or widowhood. I don't know if she still does this, but she used to refer to herself as a "freelance agitator," which is one of my favorite terms for somebody who is really interested in getting things done and not particularly concerned about bureaucratic structures. She talks about "organizing, not agonizing."

We could also point to her many decorations, the fact that she was named one of the ten most distinguished persons by the San Francisco Examiner in the mid-1970s. She's received the humanist of the year award. She's now a senior scholar at the University of California San Francisco.

These all describe the external achievements of Tish Sommers. They are all remarkable and especially because she has accomplished many of them in the last ten years. But Tish Summers is much more than the sum of her achievements, no matter how great.

Through great adversity she has portrayed a spirit and dedication to helping her brothers and sisters, empowering them to help themselves, that many of us aspire to but few of us achieve. She has, in her own words, "squeezed the sweet juice out of adversity," built upon her weaknesses and developed strength and compassion out of pain and suffering. Tish has struggled and continues to struggle with the often conflicting demands of thoughtful analysis and the need for constructive action. She draws energy from her fight with cancer. And rather than denying that experience or wringing her hands over it, she analyzes it and helps other people deal with similar experiences.

She is a doer. When I first met her I was a graduate student. And she shook her finger at me and told me that I shouldn't waste too much of my time pondering. I needed to get out and do. But she thinks through issues and believes in careful analysis. I suppose it's the dancer in her, which was an important part of her youth, that still guides her actions today. She is committed to action. But she is always graceful. Please welcome Tish Sommers.

Some Matters of Life and Death

MS. SOMMERS: We're going to be speaking today about what is considered an unspeakable subject -- death. On this day it might seem more appropriate to celebrate life and go have a picnic or whatever we most like to do. But life and death are intertwined, for we are all terminal cases. And we're all going to die sooner or later. For many reasons the time has come to bring this topic out into the open for full discussion. Today's forum is designed to get that discussion going.

I have a personal interest in the topic. I'm a stage four cancer patient. That means widespread. Fortunately, my cancer is slow growing, so I've had lots of time to think about death and to plan for it. My living will is in my doctor's chart. Since California recognizes the durable power of attorney for health care, I have one of those too. So if I become incompetent to make life and death decisions for myself there will be someone who can do it for me--Laurie Shields sitting over there--who knows my wishes and is legally empowered to decide for me.

I belong to a cancer support group where we discuss how to deal with medical professionals and how to die at home if that is what we want. But I've learned from the experience of others in the group that staying in control of your own death takes planning and strong conviction. It's easier said than done. For one thing it's not easy to let go. Life is sweet, and I've been amazed to learn how much you can put up with and still savor life.

Coming from the women's movement I've also learned that the personal is the political. It's not enough just to make plans for yourself because we're all in this together. Ever since the 1976 Karen Ann Quinlan case, a movement has been growing to recognize the right of the terminally ill to decline or discontinue efforts to prolong their lives. Right to die laws permitting competent adults to execute "living wills" have passed in many states with others pending, and there is more and more discussion in the media.

A few weeks ago I wrote a letter to all our members in OWL telling about my own advance planning and offering some information on living wills and funeral services and wills. We've received already over 2,000 requests for such material. The time has come to discuss this topic as openly and fully as we can even though it is fraught with contradictions as we will see.

All the premises that we used to take for granted now rest on shifting sand. Technological advances in medicine have dramatically changed the time, the place and the conditions of dying. A recent President's Commission for the Study of Ethical Problems in Medicine points out that these new developments have made death more a matter of deliberate decision. For almost any life-threatening condition some intervention can now delay the moment of death. "Matters once the province of fate have now become matters of human choice...."

In the past most people died at home surrounded by family members. Now, it is more likely to be in the intensive care unit of the hospital. The human choice is usually in the hands of a physician or hospital personnel. Doctors and nurses have always dealt with dying. But not until the present technical advances have they had so much power to control how long life lasts. As a result there is growing recognition that there needs to be a new set of ethics and practices to match the new medical capabilities. Decisions can be excruciating for doctors, family members and certainly for the patients.

When do you stop prolonging life when the alternative is so final? How much suffering is "worth it" to stay alive? Medical professionals are taught that death is the enemy and life should be prolonged at all costs. But now the situation has changed. With the capability to do so should death be prolonged indefinitely when there is no possibility of recovery?

Negative sentiments towards maintaining life at all costs is forcefully expressed in the following adaptation of the 23rd Psalm by Rev. Robert Fraser of the Unitarian Church of Rockville, Maryland.

Medical science is my shepherd:
   I shall not want.
It leadeth me beside the marvels of
   technology.
It restoreth my brainwaves;
It maintaineth me in a persistent vegetative
   state for its name sake.
Yea, though I walk through the valley of
   the shadow of death,
I shall find no end to life;
For thou art with me;
Thy respirator and heart machine,
   they sustain me.
Thou preparest intravenous feeding for me
In the presence of irreversible disability;
Thou anointest my head with oil;
My cup runneth on and on and on and on
   and on.
Surely coma and unconsciousness shall
   follow me all the days of my continued
   breathing;
And I will dwell in the intensive-care unit
   forever.

Public opinion on the right of terminally ill patients to call it quits is shifting. Eight out of ten persons now believe that a terminally ill patient should be able to ask doctors to stop life support medical treatments, according to recent Gallup and Harris polls.

Public opinion toward the medical profession has also shifted in the past decade or so. The advances in medicine and public health in the first half of the century raised doctors to the position of demigods. That high esteem has eroded greatly in the past period resulting in a tremendous increase in malpractice suits. Ironically this has tightened the grip of medical facilities and practitioners on the process of dying. Fear of suits from unhappy relatives pushes physicians and hospitals to "heroic measures" even when death is inevitable.

Although rarely discussed, there are economic consequences underlying the shifting ethical considerations -- doctors, hospitals, patients, families and most of all the public (called the taxpayer). As economic advantage or disadvantage shifts, moral rationales are likely to accommodate that change. With pressure mounting to reduce medical costs paid for by public funds, life support for patients with terminal illnesses is being questioned as never before. How much money is too much to try to save the life of someone who may not survive anyway? In intensive care units where every conceivable form of technology is brought in to fight against death, dying can be delayed, but at tremendous cost. Even the change in payment mechanisms of Medicare to hospitals by Diagnosis Related Groups, DRGs, shifts the economic incentive in many cases from keeping a person alive to allowing a patient to die.

Legal views have also undergone change in the past decade, and we will hear much more about that today. Is it murder or mercy to remove a nasogastric feeding tube from a dying person? Most persons do not have living wills, and when a patient is incompetent to make his or her wishes known, hospitals and doctors may be reluctant to risk murder charges. For the medical profession there are few liabilities for continuing to treat a patient. But there are grave dangers in stopping treatment. Even though the court has acquitted attending physicians, the danger of such suits has a chilling effect on hospitals and doctors. There are still many gray areas in the law, and lawyers, especially those retained by hospitals, tend to urge caution when it comes to withdrawing life support systems. Institutions of all kinds tend to be self-protective.

Although there's a growing body of case law, including the significant recent ruling of the New Jersey Supreme Court in the Conroy case (which you'll undoubtedly hear more about in this forum), the U.S. Supreme Court has not yet ruled on this question. It is this legal uncertainty that has fueled the legislative efforts headed by Concern for Dying to pass legislation providing legal backing for advance directives such as the living will and durable power of attorney for health care.

It is the purpose of this forum to get a clearer fix on the nature of this evolving scene, and in the process to determine how we can move forward in this minefield without stepping on something.

Basically there are two sides to the question. On the one hand, we don't want to prolong dying when a person is ready to go. On the other we don't want it speeded up for economic considerations without thinking of the desires of the dying person. Can we look at these two problems together and discover the way to work on both of these goals at the same time? For actually they're both headed in the same direction -- the right of each person to determine what is most appropriate for himself or herself.

There is a valid fear in the minds of many that a government that sanctions an easier death today may require it tomorrow. Here is a scene that is not impossible if the fiscal squeeze gets much tighter. At her bedside, a hospital representative is saying, "Mrs. Jones your medical benefits have expired and I understand you are without personal resources; we are required by law to offer you a speedy release from your suffering." Mrs. Jones has been sick, poor and alone for 13 years. Her sense of self worth is minimal. She might well accept that "speedy release", but since she has no viable options that is certainly not self-determination. That is why many organizations, noting the increased pressures for cost cutting and heel dragging in regard to funding long-term care programs, are understandably cautious in discussions on this subject. As long as public policy tends toward the cheapest way to keep an old person alive, there will be pressures to shorten that life.

So we have a seeming contradiction: persons in hospitals who try to pull their tubes out only to have their arms restrained, and policymakers and hospital administrators who ask, "When is it time to say enough is enough?" Today we'll be focusing on advance directives because these at least are quite clearcut. They reinforce the right of each person to say in advance what should be done or not done if one is unable to speak for oneself. And with good legislative backup, they should help the medical community carry out the wishes of the patient without fear of murder charges. That may be just the tip of the iceberg on the subject of death and dying, but it's a good place to start.

Since the public and the courts seem to be moving toward the position that it is everyone's right to refuse treatment of any kind, and since it is in the interests of the medical profession to have these questions clarified, the problem becomes, how a person's wishes can be expressed in advance in such a manner that they will be legally binding to all concerned. The public is saying, at least in the polls, that prolonging the dying process is not preserving life at all, but is forceably putting people in limbo between life and death, and most would like to protect themselves from that fate.

So what can be done? First we can start with ourselves. When individuals plan ahead for contingencies in their own lives, they not only lessen the dangers for themselves, but they often have positive impact on public policy as well. I'm sure that A.J. Levinson of Concern for Dying will point out how the growing demand for living wills leads to efforts for state legislation to back them up. A large number of persons takes seriously the importance of preparing advance directives in case they can no longer make medical decisions for themselves, they want to make sure that these are going to be of use when the time comes. So they will push for legislation to support those documents. At the present time the living will is the most widely used advance statement of what a person would want in case he or she no longer can make a decision on medical treatment.

But what if it's not honored by medical personnel? On the one hand there is danger that persons fill out these forms and think they're protected only to find that when the chips are down their living wills are ignored. Medical care is complex and subject to varied interpretations. California has passed legislation which permits a person to designate a surrogate who is empowered to make health care decisions for the signer.. The right of a person to designate someone else to make decisions on his or her behalf is well established in law. The term "durable" means that it remains in force even if the signer becomes incompetent, as when in a coma. If there is state legislation that clearly provides protection for medical practitioners, there is the advantage of having someone in your corner to interpret exactly what you want done, especially in those gray areas.

Since this is a rapidly changing scene and states which support advance directives vary in their requirements, this is not something one does casually and then forgets about it. Like a will, this is one additional form of life planning that should be made by every person in accord with state law, and reviewed periodically in light of changes in that law and in one's personal circumstances.

But how many people will do this? It is one thing to provide legislative support for living wills and/or durable powers of attorney, and quite another to assure that people use them. The majority of us don't even have wills which are not only familiar but are generally regarded as essential for responsible families. How much more difficult will it be to convince people that they might someday end up in a hospital in a comatose condition?

Nevertheless, there are those who can encourage all of us to prepare these documents. One target population is lawyers who make up wills. Presuming that lawyers are themselves educated on this matter and recognize its importance, they could be encouraged to suggest to their clients that at the same time a person prepares a will they prepare an advance directive on health care.

A second target population is medical personnel. Once educated themselves, they could develop unobtrusive and respectful methods for educating new patients and their families on the matter. Doctors and hospitals could have the documents best suited for their own state available for their patients. Hospitals could develop mechanisms to ensure that all personnel know that a patient has such a document and who the surrogate is, if appropriate. Charts could be marked. Persons who have an advance directive should discuss it with their physician, in part to raise the doctor's consciousness on the subject.

Of course the more organizations that bring the topic up for general discussions the better -- aging organizations in particular. We are pleased that the media have taken an interest in this event and that in turn should encourage public debate. Once the subject is out of the closet we are in a much better position to move forward despite the contradictions and dangers inherent in the subject.

While it's beyond the scope of this forum, we need to propose new alternatives for terminal care. When the end comes, the likelihood is that a person will be taken to a hospital emergency room or intensive care unit, the very worst places to die in peace. A serious effort to provide an alternative is the hospice movement. Unfortunately its primary function was seen by many in Congress as a less expensive alternative, so rules and regulations permitting Medicare reimbursement for care through these institutions, which usually provide services in the home, are carefully prescribed. Nevertheless, anything that can be done to further the development of compassionate alternatives will provide more choices for dying persons and their families, particularly if they receive public funding and are therefore available to a wide constituency. This includes all aspects of long-term care as well as new ways to provide palliative care in hospitals, nursing homes and other institutions.

In closing, let me say again that death and dying is another one of those hidden issues that needs to be brought out into the open so that we can preserve the values that should be preserved and prevent the dangers from engulfing us. Of course there are no easy solutions. This is just an opening wedge. But we have a great deal to lose if ways are not found to let us die in peace in a place of our choice surrounded by as much comfort as possible. We want these things for ourselves and for those we love. Let us move forward in that direction.

Life, Death and Human Dignity

THE HONORABLE JACOB K. JAVITS

MS. SOMMERS: I have the very great honor to share the podium today with one of this nation's great public servants, Senator Jacob Javits. Sen. Javits established a record of commanding legislative accomplishment and leadership. He authored legislation in the areas of employment and training, international education, federal support for the arts and humanities, pension regulation and a constitutional balance concerning war-making power.

But this list hardly does justice to his monumental influence during four decades of political involvement. As one colleague put it, "His imprimatur is on practically every significant piece of legislation that has passed the Senate these past years." Now, Jacob Javits has turned his prodigious intelligence to the subject of death. A victim of amyotrophic lateral sclerosis, Senator Javits knows first hand the challenges of living every day as if it were your last.

It is a very great gift to have Jacob Javits as a colleague in terminal illness. For I think we could ask for no better help in sorting out the complex questions of where public policy must move forward on issues of death and dying and where personal responsibility must be educated into action.

Senator Javits, we salute your life's work and your great dignity in the face of death. And we hope that as a public policymaker, son of a Talmudic scholar, you will share with us some of your own personal insights into the legal and ethical implications of taking charge of one's dying.

SEN. JAVITS: Thank you, Ms. Sommers and Madam Chairman. And I thank my colleagues Senator Heinz and Congressmen Morrison and Roybal for helping to bring us here and believe in our own--I'll use a word which I think is applicable--flaming personality and love for life. And Ms. Sommers by her sheer being teaches us a great lesson. And her leadership of this fine organization of the Older Women's League, in joinder to my own profession, the law, in considering this awesome subject, and your attendance here.

And I hope that you too will have the chance to speak to us on this issue, very auspicious for the future.

Two points made by Ms. Sommers and Congressman Morrison require emphasis. She teaches us how not to be embarrassed about death. And he tells us that we must be activists in our belief. I hope you all here, many of you representing organizations, will understand that this is not just a pleasant morning in this lovely auditorium. I hope you will take it as a mandate to go out and work for what needs to be done.

It strikes me that the issues are three. First, realism. Second, dignity. And third, love. As Ms. Sommers has said so well, we're all terminal. I may be terminally ill and so may she, and we're happy for those who are not, but they're terminal too. And they should think about it in terms of themselves and in terms of those whom they love as friends or family or simply fellow human beings in the effort to make this a better place for untold generations to follow.

Now to make these laws which we're discussing is the highest form of humanitarianism and love. For the events of birth and death are the most singular events which affect us all. And the contemplation of death should be a thing of beauty, not a thing of disgrace.

My own state of New York is contemplating laws making living wills legal and also durable powers of attorney which have been described to you. As a lawyer I have been very accustomed to wills all my life. The will leaving property or appointing guardians for children or establishing a foundation for charity or education or research is no different from the living will.

You have to be of sound mind and have the capacity to express your wishes as to your own body. And speaking personally I would hope that this includes help to the enormous surge of development in transplants of bodily organs when they are no longer of any use to the individual.

Lawyers, and it's so right that lawyers have joined in this forum, should have that care. Very rarely will you find any lawyer that doesn't urge his clients and his friends to make a will about property, et cetera. The same responsibility which the lawyer has should be exercised in respect of this question of living or dying. I believe that great surges forward will be made if that dignity which is the most precious to an older person, or to a person who has to think imminently about dying, is served by avoiding the confusion and the risk which comes from not having a will about property and from not having a will about mortality. So I urge you to be activists in preaching this gospel both to those who are in the shadow of imminence about death and those who as a matter of responsibility should think about it, and to be activists in legislation well as in the morality that is involved.

Finally, economics. It's a big problem. Many were shocked when Governor Lamm of Colorado urged people who had no real prospect of life to get out of the way and stop using resources which would be denied because of this use to others who had a chance. It sounded callous. Probably it was. But it was the truth. We have not yet arrived in our glorious nation at the point where living or dying is not based on economics. My grandmother considered the greatest medicine for health in any kind of illness to be Colgate's toothpaste. And the reason was that she couldn't afford, nor could her children, more than a tube of Colgate's toothpaste. We're not as far away from that even now as many think.

We must pray that the consciousness of our nation will encompass a truly national health plan based on the insurance system which will give us all real health care. That is yet to come. We're getting there, albeit slowly. And hence, this component which is being discussed here today is of vital importance. I believe that the end of a fruitful life is to die with dignity and honor with the love of those that surround one.

That's the issue. It is as profound, as moral, and as essential as that. I hope it is that message which you'll take with you and activate and implement in your own lives, and in the influence which you have on your community and on our nation.

SENATOR JOHN GLENN (D-Ohio)

SEN. GLENN: I want to congratulate the people who put together this morning's forum, because you're facing up to one of the most difficult decisions that any of us ever has to face. When Jack was in the Senate, occasionally I would follow him on a program, and that was the worst spot you could possibly be in. I find myself, Jack, once again in that position, because your statement was eloquent as was Ms. Sommers' before you.

Just let me say something about Jack before he gets out of earshot. I think his impact has been as great since he left the Senate, or even greater perhaps, than it was when he was here. That's making a monumental statement, and he's sitting here in the wings so he is hearing this. I served with him on the Senate Foreign Relations Committee. He was one of the giants of the Senate, and I don't say that lightly. We're used to big statements around here and exaggerated hyperbole and so on. But he was truly a giant in the Senate. We used to joke that he was the Senate's lawyer, and he was indeed that. He's the one who put together the War Powers Act. Some of his accomplishments are having such a lasting impact. But his impact in retirement has been even greater than it was when he was in the Senate. So Jack, I'm glad to see you again. Welcome--we miss you.

I want to say just a couple of words of welcome here as the senior Democrat on the Special Committee on Aging where we're trying to grapple with some of these things that you're bringing out in the open. I congratulate you for that, because I think that's exactly what's needed. Nothing is more important than how we're born and how we die. We have a lot of attention at one end of that and not enough at the other.

I have a little personal story I'd like to relate to you that makes this meeting today particularly meaningful to me. My dad was a plumber. He and my mother worked very hard. He had a very modest retirement income. They owned their own home, had a car, and had planned to travel. About two years after he retired he came down with cancer. In the first two years, all of his resources went. Now, he and my mother did not have to sell the home; they didn't lose the car. I was able to help them. And he didn't lack for the finest medical treatment--but it was a downhill slide.

When we had exhausted every medical treatment known, and I was home for a short visit, my dad wanted to talk to me. I didn't know what the conversation was going to be, but he made a special point of getting together to talk. What he wanted to talk about was exactly what you're talking about today. He wanted me to promise that when it came down to his last days we would not put him in the hospital with a lot of tubes sticking out of him, when there was no hope left, and just prolong life artificially. He wanted to be at home. It was one of the toughest conversations I've had in my whole life, because my inclination was to fight to the end with whatever method there was to prolong life. But we couldn't do that; I honored his wishes.

What you're dealing with here is that same subject. You're trying to see whether it's legislation that's needed, or public awareness, or increased knowledge and information flow that we can help out with on the Aging Committee. That's the balance I think you're going to be discussing today. I welcome that discussion. Too often we see some of the problems mentioned by Ms. Sommers and Senator Javits are not being dealt with in advance.

We try to plan everything in advance. And we should. But as Jack said just a minute ago, we're all terminal. Every single person here is terminal whether we have any illness or not, because we're not going to live forever. And yet we do not plan for our death. Making a "living will" or some sort of a plan for the last days of our lives is as important as planning for birth and the other major events throughout our lives.

When you mentioned that Senator Javits was the son of a Talmudic scholar, I happened to think about one of my very favorite songs of all time--one that I think is a tremendous song which expresses so much. It is from that great play Fiddler on the Roof--"Sunrise, Sunset." Remember the words? "Sunrise, sunset. Sunrise, sunset. Swiftly fly the years, one season following another laden with happiness and tears." It happens to all of us. Can't we plan better for the last part of that scene? I think that we can.

We on the Aging Committee want to work very closely with you and do whatever we can here in the Senate to move along legislation if that's what you decide is needed. We must decide together how to make old age and terminal days more liveable, if you will. If we need legislation then let's work together to get it passed. If it's a matter of providing information, is there a public awareness program that we can help with? Can we make speeches on the issue? Heaven knows we have enough speeches on other subjects around here. Can we promote public awareness so terminal days will not be dealt with as something to be kept in the closet, out of sight, and ignored?

So I congratulate all of you for being here and facing up to this. We look forward to working with all of you.

Part 2

Current Status of Advance Directives for Health Care Decisions at the End of Life

Speakers in Part 2

BARBARA MISHKIN is an attorney in private practice at the law firm of Hogan & Hartson in Washington, D.C. She was formerly Deputy Director of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and staff director of the HEW Ethics Advisory Board. Mishkin is Ethics Committee chair of the National Hospice Organization, and a member of the policy board of Legal Counsel for the Elderly. She is a graduate of Mount Holyoke College, Yale University, and American University, where she received the J.D. degree cum laude in 1981.

CHARLES P. SABATINO is Associate Staff Director for the American Bar Association's Commission on Legal Problems of the Elderly. From 1979 to 1984, he was attorney for the Elderly Law Project of Legal Services of Northern Virginia in Arlington, Virginia and for three of those years, was Managing Attorney of the Arlington Branch. Sabatino's work with the ABA Commission focuses primarily on health care issues and the delivery of legal services to the elderly. He is a 1978 graduate of Georgetown University Law Center and a member of the D.C. and Virginia Bars.

Decision-Making Mechanisms

CHARLES P. SABATINO
American Bar Association
Commission on Legal Problems of the Elderly

MR. SABATINO: I'm honored to be one among a very distinguished group of speakers today and to address you here. Welcome to Decision-Making 101. My job in the next ten minutes is to describe in a very superficial manner the larger continuum within which decision-making mechanisms regarding terminal illness exist. This wider context essentially covers any kind of decision you as an adult might make during any waking minute of your life, from the trivial to the traumatic. I will not be talking about decision-making for infants or children. For the sake of clarity and understanding, we can divide decisions into three broad subject areas that are generally recognized. They are property management decisions, decisions regarding the custody or management of the person, and health care decisions.

Property management decisions, as I'm sure you can guess, includes decisions about managing one's income, investments, and business interests; buying or selling or maintaining real estate, granting or applying for loans and a whole number of other property related responsibilities.

Custody and management of the person is an area that involves decisions about where to reside (including whether to go into a nursing home); caring for or disposing of personal effects such as clothing, household goods and furnishings; providing for companionship or non-medical caretakers; transportation and recreation; making arrangements for spiritual or religious needs; even arranging funeral or burial plans in advance.

The third area, health care decisions, of course, involves choosing health care providers; consenting to or refusing medical treatment or medication; access to and disclosure of medical records; and any other health care matter.

Within this last category fall decisions regarding what to do in situations of terminal illness where life sustaining interventions come into play. In terms of absolute numbers, decisions around terminal illness actually constitute a fairly small proportion of health care decisions a patient is ever likely to encounter. Far more numerous are the day-to-day decisions about treatment and care of individuals. However, it is precisely because terminal illness is a "life or death" matter that this area of decision-making demands special attention and planning.

Many of the "mechanisms," as we are calling them, for decision-making situations of terminal illness are the same legal mechanisms that we may u in all the three decision-making areas I mentioned. Let's look briefly the range of decision-making mechanisms out there. But let me first prefa what I say with the acknowledgement that the term "mechanisms" is inherent misleading, since it would seem to imply that there is something mechanic about the process--that you put the question in one end of the mechanism a out the other end comes some sort of decision. Unfortunately, so ma decisions, especially those in the health care area, have no easy, painles answers or easy painless procedures for coming to answers.

The base-line decision-making mechanism is of course yourself. In any are of life, whether the matter involves property, personal decisions or heal care, any competent adult is the primary decision-maker. Within the law yo have the prerogative of making choices based on your values and beliefs. I the area of health care, the law has always recognized this right t determine what is done to your own body and to refuse treatment where yo choose to do so. Only in rare circumstances have courts authorize treatment against the wishes of a competent patient. These exceptions have generally involved cases where another compelling interest was directly a stake, such as the life of a fetus of a pregnant woman, or where a patien was responsible for a dependent child, or where an otherwise healthy perso had attempted suicide.

1. Power of Attorney

The first mechanism for decision-making that departs from our baseline is the voluntary delegation of decision-making responsibility. This delegation is most commonly done through the legal instrument called the "power of attorney," or more specifically the "durable power of attorney" which continues to be effective even in the event of serious impairment.

The "power of attorney" is simply a written, signed and notarized document by which a competent adult called the principal gives legal authority to act on his or her behalf to another person who acts as an agent. The agent is called the principal's "attorney-in-fact." A power of attorney is durable where it specifically states, in whatever manner the particular state's law requires, that it shall continue to be effective even in the event of disability of the principal. State laws differ somewhat but the concept is fairly uniform. The durable power is generally a creature of state statute, for under commonlaw tradition, powers of attorney were never durable--they always terminated as a matter of law when the principal became incapacitated. Presently, the District of Columbia is the only jurisdiction that does not have a durable power statute, although a bill on the subject is pending.

Durable powers of attorney can be used to voluntarily delegate decision-making powers in the areas of property management, management of the person and, in most states, health care decision-making. And they can be drafted to grant as broad or narrow a range of powers as the principal desires.

The hallmark of a durable power of attorney is that it is quick and easy to create, is relatively inexpensive, and does not require the intervention of the judicial system. Its inherent risk is that in practice there is very little accountability on the part of the agent, even though in theory the agent is accountable as a fiduciary of the principal. The use and limitations of the durable power of attorney for health care decisions will be something that Barbara Mishkin will address more specifically.

2. Trusts

A second type of voluntary delegation of authority is one that is directly useful only around matters of property management. It is the living trust or *inter vivos* trust. This mechanism, which is normally a revocable one, involves the transfer of specific property to a trustee for purposes of maintaining or managing the property and ultimately disposing of it according to directions set forth in the trust instrument. A trust arrangement is more likely to be used in a more complex estate, and is not likely to be directly relevant to health care decision-making issues, except to the extent that control of the purse strings can influence health care decisions, particularly when it comes to access to health care.

3. Advance Directives

A third, and again, voluntary, self-controlled mechanism for decision-making is what I will call the "advance directive." This is not a delegation of decision-making power like the previous two. Rather, it is a set of instructions or guidelines for what to do and when to do it. The instructions must be set down in writing while the individual is still competent. The most established example of an advance directive is the "Living Will" which is a signed, dated, and witnessed declaration which allows you to state in advance your wishes regarding the use of life-sustaining procedures if you are dying and unable to communicate your choices at that time. As you've heard, living wills are now recognized by statute in about 35 states, although there is a great deal of variation from state to state with respect to definitions, creating the document, witnessing it, and carrying it out.

Theoretically, advance directives can take many other forms too. You can conceivably include specific wishes or instructions about your health care in a durable power of attorney. In fact, an ordinary will is in essence a binding advance directive that sets forth after-death instructions. A trust instrument usually includes specific instructions about the use and disposition of property, so in that sense it is, in part, an advanc directive. However, in the area of health care, the living will, wher recognized by statute, is the only binding form of advance directive. Wher it is not recognized by statute, it is still useful as an advisor document.

Now we come to those decision-making mechanisms that one must resort to whe none of the above voluntary tools have been used in advance and th individual is incapable of making important decisions.

4. Proxy Consent

First -- actually number four in our enumeration of mechanisms -- is that o proxy consent. A few states, about a dozen, have laws governing prox consent for health care and designating the person authorized to giv proxy consent in specific medical care situations. Usually the designate person is the spouse or adult child, or some other close relative in listed order of priority. The reliance on close family members as prox decision-makers is well rooted in our tradition and remains common practic today. However, without specific statutory authorization, there really i no legally valid right or privilege of family members on their own t assume decision-making power; this is true not only for health car decisions but also for decisions involving one's property or person. So perhaps the greatest irony here is that informal, ad hoc prox decision-making by close family members, which is usually done i collaboration with health care professionals, is probably the most commo mechanism (or should I say non-mechanism?) for decision-making fo incompetent patients; at the same time, it is probably the least likely t be legally valid in most states and most situations.

5. Guardianship

The mechanism that will more likely be appropriate in situations where prox consent might come into play, is that of guardianship or conservatorship The definitions, requirements and procedures vary from state to state, bu basically a guardianship involves the judicial appointment of a fiduciary t manage the property and/or personal affairs of an incapacitated person. Th term "conservatorship" typically applies to management of just the asset and not the person, but again jurisdictions vary. There is also a creatur called "limited guardianship" which is recognized in many states and is als included in a part of the Uniform Probate Code. Under a limite guardianship a court can specifically circumscribe the scope of a guardian' authority and tailor it to the specific areas of incapacity of the ward.

However, experience so far shows that courts have been reluctant to use this limited form of guardianship.

The problem with guardianships is that they are cumbersome, expensive and not very flexible, in addition to the fact that they involve a tremendous encroachment upon the fundamental liberties of an individual. Normally, a guardianship must be instituted by a formal petition, with notice to all parties and the opportunity for a full in-court adversarial hearing. The court may choose to appoint or be required to appoint a guardian ad litem to protect the interests of the ward in the proceeding. Once a guardian is appointed, a bond will normally be necessary, and the guardian will probably have to file annual accountings of all transactions undertaken for the estate. Moreover, the discretion of the guardian is fairly restricted. Many transactions or decisions will require going back to court for approval, as, for example, actions such as invading the principal of the estate or decisions regarding whether to consent to or refuse major medical procedures.

6. Protective Services

Still another mechanism involves state protective services laws. The term "protective services" covers a broad range of services and procedures, and is susceptible to many different and sometimes contradictory meanings. Sometimes it refers to various social services, such as nutrition programs, nursing and home care, special transportation, and various other services that are voluntarily provided to older persons in need. At the same time, "protective services" usually implies various forms of involuntary intervention, such as emergency protective services orders, civil commitment, guardianship and conservatorship, or the use of representative payees for Social Security.

Whatever its components in a particular state, it is essentially a range of services utilized to assist seriously impaired individuals who, because of physical or mental dysfunction, are unable to manage their resources, or carry out the normal activities of daily living, or to protect themselves from neglect, abuse or other hazardous situations. Guardianship may be one component of what we call protective services. But I mention protective services separately because of the special and significant role in decision-making played by a state agency in these situations -- usually the local adult protective services department or whatever arm of the local or state government that carries out that function. The agency exercises a tremendous amount of discretion in deciding how and when to intervene, and what kind of choices to make in the life of a person who is seriously impaired. There is some kind of court oversight of involuntary interventions in every state. But this oversight tends to be rather loose. Because of that, a whole host of substantive and procedural due process problems arise in the context of adult protective services.

7. Ethics Committee

One last mechanism cuts across all the mechanisms already described, because it is really not a separate mechanism at all. Rather, it is one that, at best, potentially enhances the effectiveness and validity of any of the other decision-making mechanisms, at least when it comes to decisions regarding terminal illness. I am referring to ethics committees. These are interdisciplinary bodies established to assist in making difficult decisions regarding the care of patients. They are not really widely used at present, and there are differences of opinion about how they should be composed, what their responsibilities should be, what effect or authority their recommendations should have, and whether they are feasible in many settings in the first place. Nevertheless, they are being given serious attention as a potentially key player in the decision-making process, and one that at a minimum could assure that different perspectives are brought to bear when hard decisions must be made.

Now, we've covered seven different areas, powers of attorneys, trusts, advance directives, proxy consent, guardianship, protective services and ethics committees in a very small nutshell. Within this broad range of decision-making approaches, the living will and other advance directives for health care decision are still in an early stage of development and recognition. But I am confident that our discussions today will be one more small but significant growth spurt in the understanding of these particular decision-making tools.

Advance Decision-Making for Health Care: Living Wills and Durable Powers of Attorney

BARBARA MISHKIN
Attorney
Hogan and Hartson

I. Making Decisions About Health Care

Few state laws give standards for determining the capacity of patients to make a health care decision, and the absence of standards can cause serious problems for elderly patients. Physicians assessing the decision-making capacity of an elderly patient may come from different social and cultural backgrounds, and they may have different values, than either the patient or the general community. In addition, if they are foreign nationals, their spoken English may be difficult to understand. Finally, they often base an assessment of competency on the "Mini-Mental Status Exam" which relies heavily on recent memory (word lists) and tasks such as counting backwards from 100 by sevens.

All of these factors increase the chance that an elderly patient will be declared incompetent to make a health care decision when, in fact, he or she may be perfectly able to make the treatment choice in question. Even with significant memory loss, a patient still may be able to make a health care decision.

Most legal scholars agree that the capacity to make a health care decision requires only: (1) the ability to understand the treatment choice presented; (2) the capacity to appreciate the implications of the alternatives presented; and (3) the ability to make a choice and to communicate that choice.

If a patient truly lacks the capacity to make a health care decision, who may decide on his or her behalf? State laws are often unclear as to whether or under what conditions family members may make health care decisions for incapacitated adults. However, mechanisms exist through which competent patients may indicate a desired course of treatment (or nontreatment) in advance, and to designate another to make decisions on their behalf, should they later become unable to make and communicate their own choices. However, it appears that few people have utilized these mechanisms.

In 1982 a public opinion survey was conducted by Louis Harris and Associates for the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavorial Research.[1] In that survey, over 1200 people were asked whether they had given instructions to anyone about how they would like to be treated if they ever became too sick to make decisions. Only about one-third said they had. Of those who had given instructions, fewer than one-fourth had put them in writing.

One more concern is a 1984 study of patients who suffered cardiac arrest while in a Boston Hospital. That study strongly suggests that physicians' views of whether their patients would want to be resuscitated are not always accurate.[2] Further, although physicians say they believe they should discuss resuscitation with their patients, they actually do so infrequently. Instead, the physicians are likely to discuss these matters with family members. Apparently, the principles of individual autonomy (or self-determination) and confidentiality are not being followed. Patients have the right to make decisions about their health care unless they are incapable of doing so.

II. The Right to Refuse Treatment

It is clearly established that with rare exceptions, competent adults may refuse life-sustaining treatment. Seventy years ago Cardozo put it this way: "Every human being of adult years and sound mind has a right...to determine what shall be done with his own body and cannot be subjected to medical treatment without his consent."[3] Moreover, the right to consent includes the right to refuse medical treatment.[4] This right has been upheld consistently by the courts -- with a few exceptions where the life of a fetus is at stake, or the health and welfare of third parties will be affected.

Further, if a patient dies as a result of refusing treatment, it is not suicide so long as the life-threatening condition was not self-inflicted.[5]

In a recent case involving the right to refuse treatment, an Ohio court ruled that a hospital may be held liable for damages if it continues to administer life-sustaining treatment against a patient's wishes.[6] This is an important step in protecting patients' rights.

Most of the case law regarding refusal of treatment has involved decisions to withhold or withdraw highly invasive procedures (such as respirators, kidney dialysis, blood transfusions, and surgical interventions) primarily in a hospital setting.

However, several recent cases have addressed the question of withholding or withdrawing artificial or mechanical nourishment from patients.

- A New York court declined to order a competent, terminally ill, 85 year old nursing home patient to undergo gastrostomy or to be force-fed against his will. The court also prohibited the nursing home from attempting such interventions.[7]

- A California Appellate court ruled that removal of a naso-gastric feeding tube from a permanently comatose patient, with consent of the patient's family, did not constitute murder.[8]

- A Massachusetts Appellate court ruled that a 92 year old, incompetent patient who repeatedly removed her gastrostomy tube did not have to undergo surgery to have tube reinserted.[9]

- Finally, the New Jersey Supreme Court ruled in January 1985 that artificial feeding may be withheld or withdrawn from an incapacitated nursing home patient if: (1) there is trustworthy evidence that the patient would not choose to have the treatment; and (2) the pain and invasiveness of the artificial feeding <u>or</u> the net burdens of continued life (such as unavoidable and severe pain) outweigh the benefits the patient derives either from the feeding or from continued life.[10]

The courts hold different views concerning the conditions under which a family member or legal guardian may authorize withdrawal or withholding of life-sustaining treatment. The New Jersey Supreme Court recently held that there must first be a judicial determination of incompetency but that thereafter, court involvement ordinarily would not be required. Other state supreme courts have held, instead, that requiring judicial interventions in all cases is unnecessary and may be unwise.[11] Fewer than a dozen states have laws that specify who may consent to health care on behalf of an incapacitated adult. (Legislation is pending in several other states.)

III. Advance Directives

One solution is use of advance directives. These may be either so-called "living wills" (where a competent person declares his or her intentions regarding life-sustaining treatment in case of terminal illness), or "durable powers of attorney" (where a competent person designates another to make health care decisions in case he or she later becomes incapacitated).

Today, every state has either a durable power of attorney statute or a Natural Death Act, or both. Only the District of Columbia lacks a durable power of attorney statute, but bills are pending. More than half the states also recognize living wills.

A. Disadvantages of Living Wills

The statutes validating living wills vary considerably in their provisions. For example, living wills generally may not be written for a child or incompetent adult. (Exceptions include: Arkansas, Florida, New Mexico, and

North Carolina). In some states, a living will is binding only if the patient has been informed of the terminal condition. In about one-fourth of the states where living wills are recognized, they must be reaffirmed periodically.

Living wills have additional drawbacks. First, they apply only to terminally ill persons. But accident victims and very elderly patients with "multiple systems failure" also might want to refuse mechanical life supports. A living will probably would not apply in their cases.

Second, the definitions of "extraordinary care" (which may be foregone) and "supportive care" (which must be provided) are unclear. Which category includes artificial nourishment and hydration?

Several states recently passed living will laws that explicitly exclude artificial nourishment and hydration from the definition of "extraordinary care" -- with the result that a living will cannot authorize withdrawal or withholding of such treatments. (Maryland and Florida are examples.) But I understand that when a patient is in the last day or so of the dying process, digestive functions may cease and the kidneys may fail, so that forcing fluids can result in literally drowning the patient. Moreover, patients very near death may not experience hunger and thirst. They may want simply to be let alone. Should artificial norishment be forced on patients even when it does more harm than good?

Finally, living wills work only for treatment refusal; they do not serve as directives for those who want all possible treatments applied. For that, a durable power of attorney is needed.

B. Advantages of Durable Powers of Attorney

Durable powers of attorney have important advantages. They are valid everywhere in the United States (except DC); they can be used for patients who are not terminally ill; and they can be used to direct that treatments be provided, if that is desired. Durable powers are flexible in application: the agent can make decisions based upon the particular circumstances of the patient's condition at the time. State laws concerning durable powers are more uniform -- so that a document executed in one state is more likely to be honored in another (except in a small handful of states that require that the documents be filed). Finally, forms for creating a durable power of attorney are easy to understand and generally do not require the assistance of an attorney.

It is important to understand that the designated agent can be anyone -- family member, friend, clergy (except in Florida, where only close family members may be appointed).

IV. Unresolved Issues

Of course, there are still some unresolved issues. One of the most important is the lack of statutory guidelines for determining a patient's capacity to make a health care decision. Even the Model Health-Care Consent Act, approved by the Commissioners on Uniform State Laws in 1982, provides only that:

> An individual...may consent to health care unless, in the good faith opinion of the health-care provider, the individual is incapable of making a decision regarding the proposed health care.

Additional unresolved issues include: clarification of family members' legal authority to make decisions on behalf of incapacitated adults in the absence of an advance directive; the extent to which it will be considered acceptable to forego methods of artificial nutrition and hydration -- and who may decide; the extent to which living wills, legally binding in the states where executed, will be recognized by other states; and the extent to which patients or their families may insist upon the administration of life-sustaining treatments considered by their physicians to be of little or no benefit in their case.

Despite the unresolved issues, many more people could and should be making use of advance directives. We must educate lawyers, doctors, health care administrators, and the general public about the availability and importance of these documents.

FOOTNOTES

[1] Louis Harris and Associates, "Views of Informed Consent and Decision-making: Parallel Surveys of Physicians and the Public," in the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (1982) Vol. 2, Appendix B.

[2] S. Bedell and T. Delbanco, *Choices About Cardiopulmonary Resuscitation in the Hospital*, 310(17) N. Eng. J. Med. 1089 (April 26, 1984).

[3] *Schloendorff v. New York Hospital*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914).

[4] *Tune v. Walter Reed Army Medical Center* 602 F. Supp.1452 (D.D.C. 1985); *In re Conroy*, 486 A.2d 1209, 1222 (N.J. 1985).

[5] *Id.* *see also*, *Application of Plaza Health and Rehabilitation Center* (N.Y. Sup. Ct., Onondaga County, Feb. 2, 1984); *In re Colyer*, 660 P.2d 738, 743 (Wash. 1983); *Application of Lydia E. Hall Hospital*, 455 N.Y.S.2d 706, 711 (Sup. Ct. Nassau Co. 1983); *Satz v. Perlmutter*, 379 So.2d 359 (Fla. 1980); *Lane v. Candura*, 376 N.E. 2d 1232 (Mass. App. 1978).

[6] *Leach v. Shapiro*, 469 N.E.2d 1047 (Ohio 1984).

[7] *Plaza Health and Rehabilitation Center*, *supra*.

[8] *Barber v. Superior Ct.*, 147 Cal. App. 3d 1006, 195 Cal.Rptr.484 (1983).

[9] *In re Hier*, 464 N.E.2d 959 (Mass. App. 1984).

[10] *In re Conroy*, *supra*.

[11] *See*, *e.g.*, *In re Hamlin*, 689 P.2d 1372 (Wash. 1984); *In re L.H.R.*, 321 So.2d 716 (Ga. 1984).

Part 3

In Whose Hands: Limitations and Problems With Advance Directives

Speakers in Part 3

MARY LAYNE AHERN is staff attorney with the American Hospital Association's Office of Legal and Regulatory Affairs, and chair of AHA's Legal Task Force on Biomedical Ethics, which is currently working on a project dealing with patients' advance directives for withholding or withdrawing life-sustaining treatment. Ahern represents AHA as an official observer to the National Conference of Commissioners on Uniform State Laws' effort to form a Uniform Life-Sustaining Procedures Act. She is a cum laude graduate of Harvard University, and received her J.D. from DePaul University College of Law.

ROBERT N. BROWN is an Associate Professor at the University of Detroit School of Law. He is the author of *The Rights of Older Persons* (Avon, 1979). He is chairman of a nursing home advisory task force for the Michigan Department of Public Health, and former director of the Center for Legal Services for the Aging at Syracuse University. In 1985, Brown was visiting scholar in the health policy section of the Urban Institute in Washington, and is working on an article entitled "Medical Decisionmaking for the Elderly: Recent Developments." A graduate of the University of Michigan and its law school, he has an LLM degree from George Washington University.

NANCY M. COLEMAN is staff director of the American Bar Association's Commission on Legal Problems of the Elderly. She was formerly an investigator for the Senate Special Committee on Aging, a consultant to the National Health Law Program, and a research fellow with the Legal Services Corporation Research Institute. Coleman was named Gerontological Fellow at Brookdale Center on Aging of Hunter College in 1985, and holds degrees from the University of California at Santa Cruz and the University of Michigan.

CHARLES H. EPPS, JR. M.D. is currently Professor and Chief of Orthopaedic Surgery at Howard University College of Medicine. In addition to academic appointments at Johns Hopkins University and Northwestern University, he maintains an active private practice in a Washington-based group, Epps, Gladden, Rankin, and Manderson. Dr. Epps is a member of the American Medical Association's Judicial Council, which deals with ethical concerns in the practice of medicine. Dr. Epps is a graduate of Howard University, where he received his M.D. with honors in 1955.

A.J. LEVINSON is Executive Director of Concern for Dying, the organization which developed the first model living will in the United States in 1968. She has been associated with the organization since 1972, and has written numerous articles in a number of ethics journals on issues related to withholding and withdrawing treatment for the terminally ill.

CATHERINE P. MURPHY, RN, Ed.D is Associate Professor in the graduate program at Boston College School of Nursing. She is Chairperson of the American Nurses Association Committee on Ethics, and a member of the Congressional Office of Technology Assessment Advisory Panel on "Use of Life Sustaining Technology in the Care of the Elderly." She is co-editor and author of books and numerous articles, lectures and papers on ethical problems in nursing. Murphy received her Ed.D. from Teachers College, Columbia University.

IN WHOSE HANDS:
LIMITATIONS AND PROBLEMS WITH ADVANCE DIRECTIVES

NANCY COLEMAN, Moderator
Staff Director
ABA Commission on Legal Problems of the Elderly

MS. COLEMAN: There are many issues we are here to learn about today. It has been most inspirational hearing from the previous four or five speakers. At this time, we need to look at how these living wills or advance directives can be implemented. What appears to be most important is the question of autonomy. How can you enhance an individual's autonomy?

Individuals may be able to make a decision and depending upon where they live, depending upon how they approach the problem, their wishes may in fact be carried out. But they have to be carried out in conjunction with a variety of actors, including family. Sometimes family members don't want to follow the instructions laid out in an advance directive. I think Senator Glenn pointed that out when he spoke of his own feelings about his father's impending death. Providers--whether they're doctors, nurses, social workers, lawyers, hospitals, whatever--oftentimes disagree about how directives can be carried out. Advocates are concerned about the policy implications of advance directives. Are we going to cut off health care experimentation and research to older people because we want a cutback in cost? That's something we need to look at. Another really critical question is the lack of public awareness and public distribution and utilization of advance directives. And since we are talking about state laws, and since state statutes vary so much, there is the portability question. I think that Congressman Morrison spoke to that this morning. What if, for example, you live in Washington and during a visit to your relatives in Idaho, you become critically ill, and the living will is not accepted. How does an individual or the family deal with this? How do they solve the problem? That is another area that we need to examine today.

In addition, there is a model draft law that is being put out by the National Conference of Commissioners on Uniform State Laws. When such an august group develops such a law, state legislatures are likely to adopt it. The American Bar Association's Commission on Legal Problems of the Elderly, for which I work, has taken a look at that law and found many, many problems with it. If in fact the Uniform State Law Commissioners adopt it, and states begin to consider it, we at the Commission will need to take a hard look at it and be careful about the variations that can result.

A.J. LEVINSON
Executive Director
Concern for Dying

MS. LEVINSON: I'm delighted to be here and very pleased that the Older Women's League is joining Concern for Dying in our efforts to improve the lot of dying people and their families. We need all the help we can get.

First I want to clarify a bit of the history that was given this morning. Living Wills did not begin with Karen Ann Quinlan. The concept of the Living Will was first presented by Luis Kutner, a lawyer and human rights activist, in 1930. The first widely circulated model living will was developed by Concern for Dying in 1968. Before Karen Ann Quinlan's accident, Concern had already distributed over two million copies in the United States. Since 1975 we have distributed almost six million more. And I am speaking of only one organization. In the past sixteen years, the Catholic Hospital Association and the Protestant Hospital Association and many other groups have developed their own forms of living wills.

I think it is important for people to know that a living will is not a document which is carved in stone. There are many, many kinds of living wills. Perhaps the best living wills are those written by individuals as personal instructions to their families and physicians, which is the way Concern's living will was developed.

A living will is simply a statement of instructions for care during terminal illness. It doesn't have to be restricted to refusal of treatment. It can just as well say, "This is what I want" as it can say, "This is what I don't want." I think that's very important for people to understand.

Next--an answer to one of the questions submitted from the audience: where can one get a living will or a durable power of attorney document? That is one of the programs of Concern for Dying. We distribute appropriate documents for each of the 35 states which have passed legislation. We also distribute a variety of model durable powers of attorney. Our own living will now includes a durable power of attorney provision so that in a single document one can state one's directions for care or for withholding or for withdrawing of care. One can also designate an agent to make health care decisions if one is unable to do so.

There are problems with living wills. There are problems of availability. Many states have passed statutes specifying documents without provision for printing or distributing them. People write living wills and put them in safe deposit boxes where they won't be found until after the person is dead.

There are problems of language, lack of clarity or the difficulty of defining terms such as "terminal illness" or "life support systems". There are all kinds of problems, none of which, probably, are going to be solved in our lifetime. These documents may never be clear. They probably are never going to be uniform. Frankly, I think that's unimportant. I think the important thing is for all of us to work together to make sure that, whatever the document, it expresses the wishes of the individual and that those wishes are honored.

Why do people refuse to honor living wills? Some are sticklers for detail: I think of one situation in North Carolina where a physician refused to honor a living will because it had been witnessed by the patient's husband and son before the passage of legislation requiring that witnesses not be blood relatives.

There are those who fear civil or criminal liability although no civil or criminal charges have ever been brought against a physician or institution for withholding or withdrawing treatment from a dying patient at the request of the patient. Physicians who do not want to honor a living will won't and law will not change this. They will claim -- as they did in the case of William Bartling (a California resident with a living will, a Durable Power of Attorney and a California Directive to Physicans) -- that the patient is not "terminal" or, with antibiotics or vasopressors, that the treatment is not a "life-sustaining" one, but simply routine medical care.

And then there are the situations when a patient has executed a living will, but the family wants everything done. These are but a few reasons why living wills are not honored.

Now I want to talk about where the problems are found in honoring living wills and, more importantly, where they are not found. We've heard a lot this morning about living wills not being honored. I want to give you an example of the many situations where they have been honored, even in states which don't have living will laws, but where a living will is honored because it's common sense to honor it.

About three weeks ago, Concern for Dying had a call from a friend of a man who was dying in a major hospital in New York City. The friend said his roommate, Bill, had had a tracheotomy so he couldn't talk but that he had gestured for his friend to look through his wallet. In Bill's wallet was a little card that Concern calls a mini-will; it directed the friend to call our office. We delivered a copy of Bill's living will to the hospital where it was shown to the physician. He spoke with the hospital administrator and the hospital counsel. They discussed the document and Bill's condition. Bill was taken out of the intensive care unit to a private room where his friends were with him when he died an hour and a half later. This is not an unusual situation. The living will does work. What we must do is make it work everywhere.

The fewest problems are found in community hospitals, in small hospitals where doctors and families take care of patients. In many of those places they've never heard of living wills. They don't need living wills. Life-sustaining procedures are not used when they're inappropriate. We also find fewer problems in hospitals and institutions which have developed clear procedures for decision-making. This needs to be encouraged.

The most difficult problems come in large teaching institutions where the care is impersonal, where there is the greatest fear of liability, where no process exists for resolution of conflict, and -- I'm ashamed to say this, but it's true -- in some institutions where there is a financial incentive to continue treatment.

The key problem in this whole area is still ignorance. That's where community groups, church groups, groups such as OWL, all of us can work together. Ignorance of law exists among hospital counsel who are giving advice to hospital administrators. They often don't know that patients have the right to refuse <u>any</u> form of medical intervention. We have ignorance of good existing guidelines such as the AMA statement which says clearly that it is appropriate to withhold and withdraw treatment when a patient is dying. There is ignorance of history. We have judges who have never heard of the important decisions such as Quinlan, Conroy, Barber/Nejdl. This is a place for education.

There may be a role for further legislation, and clearly a great many people think there is. Insofar as legislation can educate people to know what the law is and to clarify the problems and to ease the fears of those who are overconcerned with liability, legislation may be helpful. But what is really needed is a major educational effort from all of us.

<u>DR. CHARLES H. EPPS, JR., MD</u>
<u>Member</u>
<u>American Medical Association Judicial Council</u>

MS. COLEMAN: You know it's very interesting, when in the last few weeks we've been reading in the newspaper about the conflict between the American Medical Association and the American Bar Association -- we're sitting here together today. The conflict in that case is over medical malpractice. And perhaps the most important thing that we're looking at today is how to alleviate that malpractice by letting people make their own decisions. We need to consider the ethical issues, ones which Dr. Epps will address next.

DR. EPPS: In June the Judicial Council of the American Medical Association became the Council on Ethical and Judicial Affairs. The Council is a part of the AMA that enjoys a great deal of autonomy, authority and corresponding responsibility in stating the Association's guidelines of ethical conduct for its members. We publish a compilation of these in <u>Current Opinions of the Judicial Council of the American Medical Association</u>. You may obtain the most recent edition (1984) by writing to the AMA office in

Chicago; there is no charge. Our "Opinions" are interpretations of the Principles of Medical Ethics -- that is broad standards of honorable conduct for physicians -- in regard to more specific issues and situations.

Ethics in medicine traditionally has involved more than a code of moral conduct. Medical ethics has always dealt with human rights and morality as applied to the everyday situations faced by doctors and their patients. For well over 100 years, these have been stated in the Principles of Medical Ethics. Those Principles in their present form involve two primary areas: first, honesty between physicians and the public and, secondly, the interests of society. Where there is a conflict between what is best for the patient and what best serves social goals, priority must be given to the patient's welfare. In any situation where there is a conflict between some external interest and the patient, as far as the doctor is concerned, the rights and the concerns of the patient are overriding.

Modern medical technology has given rise to a host of moral issues which never before existed. The process of death, once begun, was rapid. There was no need to recognize that death is a process that proceeds in stages because the transition from one stage to another was swift, irreversible and could not be delayed for long at any particular stage. Death occurred in a rapid termination of respiration, pulse and heartbeat.

But today we see that modern technology has devised ways to maintain basic bodily functions by mechanical, artificial means. The human body can be kept in a state of biological function long after brain death has occurred. Further, the process of terminal illness without consciousness or sometimes with excruciating pain can be delayed to a point that only can be viewed by theologians as intereference with the will of God. Similarly, the birth of grossly impaired newborns presents difficult conflicts as to the extent to which heroic measures should be taken to continue life. All of these problems are bioethical problems and have received a great deal of attention from the Council on Ethical and Judicial Affairs. We have attempted to address them in our <u>Current Opinions</u>.

Twelve years ago, the Council reported on the "The Physician and the Dying Patient" to the AMA House of Delegates which is our legislative body. It recommended that medical societies encourage and promote discussions of the rights and duties of physicians to patients suffering terminal illness. We recommended that no particular form to express an individual's wishes relating prospectively to his or her final illness be endorsed by the AMA, but that it be recognized that individuals have the right to express such wishes. We encourage physicians to discuss death and terminal illness with their patients. We believe that physicians should respect expressions of patients' wishes regarding the medical care that they desire during their terminal illness. And we have an Opinion that specifically addresses that issue.

We recognize that patients have rights to determine their future course. But physicians have obligations to enable patients and their families to exercise these rights intelligently. If a physician cannot in good conscience comply with a patient's preferences in regard to terminal care, it is our opinion that he should transfer the care of the patient to another physician. We have an Opinion which states, "Once having undertaken a case, the physician should not neglect the patient, nor withdraw from the case without giving notice to the patient, the relatives or responsible friends sufficiently long in advance of withdrawal to permit another medical attendant to be secured." So that if the wishes of the patient or his family are in conflict with the physician's own ethics then he should withdraw from the case after someone else has been assigned.

Just as all patients cannot be expected to hold the same moral beliefs and desires with respect to their medical treatment, all physicians cannot be expected to be uniform in their beliefs. Coercion of health care professionals into uniform compliance with patients' wishes which may be morally offensive to some individuals would not serve the interests of society.

I would hope that people in those jurisdictions where no statutory recognition of "advance directives" or "living wills" has been enacted, evidence of the patient's desires with respect to terminal illness will be respected without the involvement of the judicial system. Where there is no evidence of the patient's desires with respect to terminal illness, we have stated an Opinion which indicates that the physician's primary obligation is "to prolong life and to relieve suffering. Where the observance of one conflicts with the other, the physician, patient, and/or the family of a patient have discretion to resolve the conflict." And experience has shown that in situations where the physician and the family members can have a meeting of the mind, if you will, usually these matters can be resolved.

Where a terminally ill patient's coma is beyond doubt, irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis, all means of life support may be discontinued. If death does not occur when life support systems are discontinued, the comfort and dignity of the patient should be maintained.

As we move into those vistas of "more and better" in terms of health, we physicians will face only more dilemmas and more difficult questions. Insecurity and discomfort and even terror, says one author, are entirely appropriate emotions when one is confronted with the awesome and irreversible decisions concerning the life and death of another. And believe me physicians do agonize about these decisions. And while we deal with life and death everyday, there's never a physician who deals with a patient who is dying, or watches his patient die, who is not affected by that experience. Physicians will face these questions and will not find their problems solved by legislative enactments, by judicial pronouncements, or even by ethics committees, although all of these may reflect the shared concerns of society. Imperfections and uncertainty are two of medicine's -- and mankind's -- eternal burdens.

MARY LAYNE AHERN

Staff Attorney
Office of Legal and Regulatory Affairs
American Hospital Association

MS. COLEMAN: Our next speaker, Mary Layne Ahern, is an advisor to the Uniform State Law Commissioner's Uniform Law on the Living Will. The law changes names from month-to-month depending on what draft it is in. In my view, this law is coming about ten years too late. We heard this morning, and there is in our packets a compilation from the Congressional Research Service, that there are already laws in 34 states. So if the Uniform State Law Commissioners were going to do something, they should have done it ten years ago. Regardless, it's really very important that folks like Mary are on that committee to watch over it and to help draft it. This morning, she will help us to understand a little better how the hospital can deal with our advance directives. I think that A.J. Levinson pointed out in the experience of Concern for Dying, that there was a difference in acceptance between the community-based hospital and the large urban teaching hospital.

MS. AHERN: Thank you for inviting me here today as a representative of the American Hospital Association. The AHA has been and continues to be very involved in thoughtful discussions surrounding difficult biomedical ethical issues, and deals with biomedical ethics as a critical issue.

In that spirit, the Association appointed a Special Committee on Biomedical Ethics whose members are ethicists, physicians, nurses, trustees, and administrators. The Committee will publish a report this month, titled, "Resolving Values in Conflict: Ethical Issues in Hospital Care." This publication will be added to the body of AHA actions on biomedical ethical subjects, such as statements on the well-known Patients' Bill of Rights, the Patient's Choice of Treatment Options, guidelines statement on Ethics Committees, and other AHA efforts such as my acting as an invited advisor to the National Conference of Commissioners on Uniform State Laws regarding a Model Rights of the Terminally Ill Act. I would like to point out that they invite us to comment; we have no vote in what they finally come up with.

AHA is concerned on behalf of flexibility, partly because of what we said earlier about the different hospitals in our membership. Flexibility which can reflect individual decision making and collaborative decision making with physicians and possibly with family members, and with other members of the health care team, is really the goal. Flexibility is necessary because medical treatment decision making cannot be categorized by a "cookbook" kind of approach which sets out an outcome based on a particular set of circumstances -- this is undesirable, not to mention impossible.

The right to direct that life-sustaining treatment be withheld or withdrawn grows out of the right to choose and refuse treatment. These rights may be expressed in many forms -- verbal and written, informal and formal. As the law makes clear, however, there are certain limitations on these rights. AHA's concern is also that there be a non-adversarial atmosphere in the protection of a patient's rights and in the recognition of the rights of health care providers.

In furtherance of this, AHA believes that whenever possible, decisions should be made at the level closest to the patient -- between the patient and the physician or between the family of a comatose or otherwise mentally incapacitated patient and the physician. Hospitals, however, should offer support from other health care professionals involved in the patient's direct care, including, when appropriate, the nurses, involved house staff, hospital social workers, patient representatives, and chaplains. On another level, an ethics committee may be able to provide additional guidance. But recourse to a court ruling should be reserved for those cases when the patient or the surrogate prefers court procedures, which is sometimes the case, or the issues resist any kind of resolution at a less formal level.

AHA believes that decisions related to the patient's right to refuse life-sustaining treatment should be consensual and result from information sharing based on informed consent doctrine and discussion among the attending physicians, other involved health care professionals, and the patient or the patient's family. The self interests of family, friends, or the health care professionals should not be allowed to compromise the pursuit of the AHA's best interests. What I was just reading comes from AHA's "Values in Conflict" book which will be out this week.

hospitals generally have a support role in the actual decision-making process, just as in issues involved with the informed consent process. But they can take a primary role in dealing with some of the "practical" issues.

The first and foremost of these is education of patients, families, physicians, and other members of the health care team and other employees of the hospital, education as to what Advance Directives are, both formal and informal expressions. This includes, of course, living wills, provisions of natural death acts, durable powers of attorney, and related implications of do-not-resuscitate orders. An education program which includes discussion of decision-making capacity, the content and witnessing of expressions, methods of revocation of any kind of expression a patient may make, would be an appropriate undertaking for a hospital ethics committee or a subject for an ethics grand rounds within the hospital.

Education as to the appropriate and necessary record-keeping is a crucial "practical" issue for hospitals. When the various steps in the decison-making process are taken, such as noting existence of a living will, or certifying terminal condition, this information must be available to all members of the health care team in the form of a notation in the medical record or perhaps in progress notes. Otherwise you may have the kind of problem discussed earlier of large institutions where there are many people taking care of one patient.

Other practical issues include the identification of the appropriate surrogate, which may not be obvious, and problems in the event of disagreement among surrogates. Also included is necessary sensitivity to different definitions of key terms, such as which procedures are included in the term "life-sustaining treatment."

In the interest of time I want to skip down to the last, one more key practical issue. This involves the issue which arises when a physician or members of the health care team have problems with carrying out the advance directives. Most often this dilemma seems to arise when the health care provider questions the decision-making capacity of the patient or of the surrogate. Barbara Mishkin discussed an example of that. However, it also may arise when a provider's conscience or beliefs lead him or her to a decision not to participate in actions implementing the patient's decision. Many laws state that, in such cases, a health care provider must make reasonable efforts to transfer the patient. It is unclear what should happen when a transfer cannot be effected as happened in a recent case in California. Hospitals should make every effort to alter the assignments of an employee who has a problem with the decision.

Recourse to the court is always available, of course. Note that the potential for liability arises when there is bad faith in refusing to comply with the advance directive, and that is usually not the case.

One more thing. In conclusion, it should not be the fear of liability to treat or not to treat which influences the action of an individual or an institution involved in such an important decision. Pressures -- familial, financial, and legal -- should not influence any actions on such a decision. After a decision has been made through the patient's expressed wishes, reflecting medical grounds, our hope is that only infrequently will there be an appropriate role for any kind of review.

We at AHA are particularly sensitive to the continual radical changes wrought by advances in medical science -- and to the fact that the ethical and legal expressions of our society on these issues are struggling to catch up. AHA is committed to doing its part in this worthwhile struggle.

MS. COLEMAN: People from the audience have been submitting questions, and I will try to attempt to draw those in as they come. One question is, "What happens if you live in one state, and your doctor and hospital are in another?" You've got to talk to your doctor about it; you have to talk to them about what you want. No law supersedes the kind of relationship that one develops with one's personal physician. But you need to write it down; you must express your wishes.

CATHERINE P. MURPHY, RN
Chairperson
American Nurses Association Committee on Ethics

MS. MURPHY: I'm pleased to be asked to speak here today on behalf of the American Nurses Association. Nursing plays a very integral part in the care of the elderly and terminally ill, particularly in the instance where such patients are receiving care in institutions. Nurses are in a unique position in terms of being the moment-to-moment caregivers who work on a very intimate basis with patients as they face death and suffering in their lives. Members of the nursing profession are in a position to have a "quality of life" perspective in their important role in being able to observe, assess and seriously affect the quality of life of their patients.

When one wants to examine the values of certain professions, a good starting point is to refer to the standards of practice of a profession and its code of ethics. It is often noted that one of the functions of a code of ethics is that it serves as a contract between society and the profession by explicitly setting forth the values and ethical principles which guide the actions of practicing professionals. The American Nurses Association's ethical code for nurses and the International Council of Nurses' ethical code provide a framework from which nurses can make ethical decisions and be held accountable to nursing colleagues and the public for their actions.

An examination of the current American Nurses Association Standards of Gerontological Nursing Practice and The Code for Nurses with Interpretive Statements reveals an underlying emphasis on the most basic of ethical principles, which is respect for persons and their inherent worth and dignity as human beings. Other principles stemming from this principle and stressed in these documents are: self-determination; doing good and acting in the best interests of patients; avoiding harm to patients through one's own acts or the acts of others; truthtelling; maintaining confidentiality; and justice--treating people fairly.

The individual rights based theory of ethics so strongly emphasized in the nursing codes of ethics has limitations, however. It falls short of the standard of an ideal code of ethics that would tell us which principles would take priority in certain situations, particularly in ethical dilemmas where one or more of these principles are in conflict with others. Unfortunately, to my knowledge no profession has yet reached that level of perfection.of being able to order its priority of ethical principles in a code that is applicable to a wide set of clinical situations. Therefore all health professionals are faced with the problem of applying and interpreting ethical principles in a morally justifiable manner when priority must be assigned to their importancein conflicting clinical situations.

The nurse's role as direct care giver, institutional employee and health profession team colleague can be the source of many ethical dilemmas for nurses when they face conflicts of fidelity and moral duties to patients, families, colleagues and employing institutions. As a direct care giver, the nurse may have the traditional moral duty to preserve life when there is a reasonable hope of doing so. At the same time the nurse is morally obligated to foster patient self-determination by respecting the patient's choice to reject treatment that may prolong or enhance the quality of his or her life.

As institutional employees and professional colleagues on interdisciplinary health teams, nurses can find themselves in ethical dilemmas where they perceive that the best interests of patients are in conflict with the claims of institutions or other health team members. In the interpretation and application of such ethical principles as "acting in the best interests of patients" or "doing no harm," philosophical disagreements due to widely different professional goals of treatment and outcomes can arise. For example, the diagnostic classification system and goals of treatment of medicine are oriented toward control or eradication of the disease process. The diagnostic classification system and goals of treatment of nursing are oriented toward the patient's response to the health problem or disease process--maintaining or restoring the patient's functional ability and helping the patient to cope with the impact of the health problem on lifestyle. In cost-benefit ratio treatment decisions, physicians therefore may place great emphasis on pathological cellular functioning, while nurses may be focusing in a more holistic way on those quality of life issues, such as degree of total human functioning; degree of psychological and/or physical suffering as a consequence of treatment and/or survival; coping ability; and impact on lifestyle. Consequently, nurses can find themselves in ethical conflict when they perceive that aggressive medical treatment is being provided to patients who have no real hope of recovery for a meaningful, quality of life existence in the long run.

In the case, then, of helping the patient and/or family to make informed choices about treatment decisions, if left entirely to the traditional medical point of view, there may be little or no emphasis given to the consequences of a given treatment on a patient's overall short-term or long-term quality of life, while a lot of emphasis is placed on the benefit of controlling or possibly eliminating specific manifestations of the disease process. In other instances, aggressive diagnostic testing and treatment are a source of conflict for nurses when they are conducted not in the best interest of the patient, but rather in the interest of scientific curiosity, research, educational training or the avoidance of litigation.

Clinicians who are constantly on the firing line as they encounter ethical dilemmas about treatment and prolongation of life have a certain degree of credibility when we are soliciting opinions as to how these dilemmas should be resolved. I would like to discuss a few empirical findings of studies of graduate nursing students who conducted their research under my direction. There is a paucity of research on the ethical valuing of health care providers and there is certainly a great need to do more study in this area.

During the past two years, three students conducted studies pertinent to the theme of this conference--factors affecting critical care nurses' ethical decisions about treatment and prolongation of life decisions. In these three studies, critical care nurses were presented with clinical vignettes containing ethical dilemmas that were typical of the kinds of ethical problems encountered in critical care settings. They were then asked to rank the importance of various factors that would influence them in making decisions about whether to treat or forego treatment in the particular situation. About half of the vignettes involved elderly patients, since they comprise a sizeable population of the patients who are treated in critical care settings. The first study dealt with critical factors affecting nurses' decisions regarding resuscitation; the second, with factors affecting decisions to forego life-sustaining treatment of incompetent adults; and the third, with factors affecting decisions of whether or not to adhere to patients' expressed wishes to terminate treatment.

While these studies are limited in sample size and cannot be readily generalized to a nation-wide nursing population, the main findings were as follows. In the first study on resuscitation, the five most influential factors, ranked in order of importance, were: (1) the patient's prior wishes; (2) prognosis for survival; (3) the patient's present wishes; (4) the patient's degree of pain or suffering; and (5) likelihood of recovery to a meaningful life. In the second study on foregoing life-sustaining treatment of incompetent adults, the findings were: (1) written documentation of a do-not-resuscitate order; (2) prognosis for survival; (3) expected quality of life following present illness; (4) patient's degree of comfort; and, (5) patient's prior expressed wishes. In the third study concerned with adherence to patient's current wishes to terminate treatment, the findings were: (1) certainty of patient competence in order to make an informed decision; (2) impact of treatment on long term quality of life; (3) degree of pain and suffering brought about by treatment; (4) impact of treatment on prognosis for survival; and (5) potential psychological harm to the patient if wishes are not adhered to.

In the first and third studies mentioned, factors representing the patient's best interests had greater statistical significance than others' bests interests, and in the second study the patient's and family's interests combined had greater statistical significance than other's best interests. Consequently, factors such as financial drain on society, institution or family for treatment of the patient; benefit to society through enhancement of scientific knowledge if treatment is given or life prolonged; patient's social worth to society; and desire to avoid conflict with the physician ranked lowest in these studies.

In summary, the critical factors affecting critical care nurses' decisions across these studies were: the patient's prior and present wishes; prognosis for survival; the patient's current degree of pain or suffering; likelihood of recovery to an acceptable quality of life; certainty of the patient's competence in order to make an informed decision; potential psychological harm to the patient if wishes are not adhered to; and written documentation of do-not-resuscitate orders. Evidence from these three studies suggests that in keeping with the values expressed in their code of ethics and standards of practice, nurse respondents considered it important to recognize the patient's right to make treatment decisions about his or her care.

In two of the studies, patients' advance directives ranked as important factors, although in the study on foregoing life sustaining treatment of incompetent adults, it ranked fifth out of a total of 15 factors. It is interesting to note that patients' advance directives was ranked first out of 15 factors in the resuscitation study. While it is perhaps unsafe to speculate why there is such a discrepancy between these two studies, since the vignettes and some of the factors varied in both studies, it may be associated with the fact that a number of institutions have in place well developed policies insuring documentation of patient participation in resuscitation decisions. Institutional policies regarding documentation of patient participation in other types of treatment decisions are not as prevalent when it comes to life sustaining treatment in acute care settings, and nurses therefore may not have had the opportunity to rely on advance directives in these situations in the past.

In closing, I think it is safe to say that nurses would be in favor of advance directives and would rely on them when making decisions about a particular patient's treatment. However, as previous speakers have indicated, advance directives at the present time can have their limitations particularly in "grey area" situations, for they cannot spell out every situation to which they should apply. When prognosis for survival and quality of future life are grim, when treatment will be of no real value in terms of curing the illness, and when the pain and suffering brought about by the treatment will be great, advance directives have a great value. However, there are many clinical situations where prognosis for survival and quality of life are not always clearcut or the effects of treatment cannot always be accurately predicted.

In the presence of ambiguous directives or no directives regarding the patient's treatment, the outcome of the decision can vary depending on the philosophies and values of guardians and various health care providers. In these instances the use of prognosis committees and institutional ethics committees can serve as a system of checks and balances to insure that there is a balanced perspective of a number of different health care professionals, philosophers, theologians and the lay community in determining what is in the patient's "best interests".

Nurses increasingly realize that they have an important role to play in enhancing patients' self-determination in decisions about their future care. A great number of people do not have enough medical knowledge to understand all the different options for treatment or what the consequences will be of refusing certain treatments on a selective basis. Nurses can play an important role in educating the public about their rights and options to have more control over their health care treatment. In the case of their particular patients, they can foster patient autonomy by encouraging and supporting their patients to make provisions for situations where their ability to make decisions may be impaired.

REFERENCES

American Nurses' Association. Code for Nurses with Interpretive Statements. Kansas City, Mo.: The Association, 1985.

American Nurses' Association. Nursing: A Social Policy Statement. Kansas City, Mo.: The Association, 1983.

American Nurses' Association. Standards of Gerontological Nursing Practice. Kansas City, Mo.: American Nurses' Association, 1976.

Cady, Patricia A. "To Forego Life-Sustaining Treatment: The Factors that Influence Critical Care Nurses' Decision-Making." Unpublished Master's study, Boston College, 1984.

Hellegers, Andre. "Accountability in the Health Care System: To Whom is the Nurse Responsible?" Connecticut Medicine 43:10 (October 1979), 5-6.

International Council of Nurses. Code for Nurses - Ethical Concepts Applied to Nursing. Geneva, Switzerland: International Council of Nurses, 1973.

Murphy, Catherine P. "The Changing Role of Nurses in Making Ethical Decisions," Law, Medicine & Health Care 12:4 (September 1984), 173-184.

Murphy, Catherine P. "Ethical Dilemmas in Nursing Practice." In Issues in Professional Nursing Practice. Kansas City, Mo.: American Nurses' Association, 1985, 1-10.

Ouellette, Lori. "Factors Which Influence Critical Care Nurses' Decisions Concerning Adherence to Patient's Wishes in Care Decisions." Unpublished Master's study, Boston College, 1985.

Stokes, Teresa. "Factors Affecting Nurses' Decisions Regarding Resuscitation." Unpublished Master's study, Boston College, 1983.

ROBERT N. BROWN
Associate Professor
University of Detroit School of Law

MR. BROWN: The title of our program today, "Taking Charge of the End of Your Life," is eloquent testimony to the dramatic advances in medical knowledge and technology that we've witnessed in recent years. The title also expresses our ambivalence about these advances. Sophisticated equipment available in modern hospitals is used to save the life of the acutely ill. Transplantation of organs prolongs the life of the chronically ill. Now natural functions essential to life can be carried on artificially.

Because of our ability to perform these miracles we now are confronted with choices we never before faced. Because we can save or prolong lives, we must decide whether to do so. For example, should we perform CPR on a gravely ill hospital patient? Should we begin or continue use of a respirator? Who is to make these decisions and what standards should be used and procedures be followed in making them?

For some advanced technologies, the demand exceeds the supply. Who should receive a donated kidney -- an elderly retiree or a young worker? Who should have access to kidney dialysis? In the United Kingdom dialysis is not available to the elderly.

The cost of sophisticated modern medicine is high. Approximately 10 percent of the GNP is devoted to medicine. Older people who constitute approximately 11 percent of the population consume about 30 percent of medical resources and much of this money is spent in the last year of an older person's life. Health planners are concerned about containing costs and are urging providers to be efficient and even ruthless in reducing costs. At the same time many important forms of medical care are underfinanced. Both Medicare and Medicaid favor institutional treatment rather than treatment at home and Medicare focuses on acute care rather than chronic care. Neither public nor private funds are freely available for more humane forms of treatment such as hospice and home health care.

Taking charge of one's life in these circumstances then is difficult. The person may not receive care, may receive it from strangers or in undesirable settings. They may also receive care that they don't want. Financing for care may be unavailable, and financial considerations may dictate clinical choices to the patient's detriment.

I. Proponents

Proponents of advance directives urge their use as one way of taking charge. In their view, many of the problems we face stem from an imbalance of power between providers and consumers of medical services. Physicians dominate this relationship. Seeking to benefit their patients, physicians often order treatment that is medically beneficial without consultation and without consideration of the nonmedical consequences. The desires of patients and families may be disregarded as may a range of personal and financial factors. Similarly, institutional routines, poor communication, fear of liability and other factors may lead providers to insist on treatment despite the wishes of patient and family.

Proponents of advance directives urge that the authority of individuals to direct their own medical treatment, even in the event of incapacity, must be enhanced. They also argue that impediments to health providers following such directives must be removed.

Advance directives are designed to do this. Their proponents see them as important vehicles for enhancing the power of a person to make critical decisions about health care, should future incapacity rob the individual of the ability to participate directly in these decisions when they must be made. Ideally, the full range of decisions should be included in an advance directive: where treatment should occur, how intensive it should be, whether specific procedures should be begun or continued. Also, in addition to instructions, an advance directive should designate a surrogate decision-maker to consult with health care providers to carry out the principal's wishes and to make decisions on that person's behalf. As part of the process of executing an advance directive, individuals should discuss their desires with their family and physician, and should make arrangements for the advance directive to be communicated to potential providers of health care services. To ensure cooperation of health care providers, a waiver of liability should be included for providers who carry out one's instructions in good faith.

Living wills give general instructions concerning a person's wishes in the event of a terminal condition. Although of limited scope, they can provide useful guidance to health care providers. Doubts about their binding character have led their advocates to urge states to enact statutes that recognize the validity of living wills and to make these wills binding on health providers. Twenty-one states and the District of Columbia have enacted living will statutes in some form.

Proponents of advance directives also urge the use of durable powers of attorney to direct medical decisionmaking. All of the states (but not the District of Columbia) have authorized the use of durable powers in some form, but in many states doubts remain concerning their use for health care decisionmaking.

The potential for durable powers is considerable. They can be used to direct personal and financial decisionmaking as well as health care decisions. They also can combine instructions to be followed in the event of incapacity with the designation of a family member or trusted friend to carry out these instructions and to make decisions on behalf of the principal. Adoption of other statutes, such as the Model Health Care Consent Act, also has been urged as a way to encourage health care providers to follow the wishes of a patient or family members.

II. Opponents

I will now turn to the issue which the Older Women's League specifically asked me to address, and that is some of the concerns that persons opposed to or at least not active supporters of the movement toward advance directives have expressed. Opponents of the use of advance directives vary widely as to their reasons for opposing the use of advance directives, the intensity of their opposition, and the form their opposition takes. I've identified at lest three different kinds of concerns, and in the time remaining to me I shall outline some of their positions.

A. Abuse

Elderly persons often are vulnerable to abuse. This is true of persons in the community being cared for by family members as well as older persons in state institutions and private long term care facilities. A significant number of such persons suffer from diminished decisionmaking capacity. Many lack meaningful relationships with anyone. And some are comatose or so severely demented as to lack many of the important characteristics we associate with being a human being.

Such individuals are easy targets of abuse. They are also difficult to care for and offer few professional rewards for medical personnel. Their care may be expensive and it may be of uncertain value. A dramatic example of this was the recent controversy whether to continue artificial feeding of Claire Conroy, a comatose New Jersey nursing home resident; we discussed this case earlier today. Less celebrated examples are found in the pages of the New England Journal of Medicine and the Journal of the American Geriatric Society in which one finds frank discussion of the ethics of not treating severely ill patients.

These concerns often result in recommendations that procedural safeguards be observed before a living will or durable power of attorney be effective. Examples include requirements that a patient's terminal condition be confirmed, prohibitions against heirs or health care providers serving as witnesses to the execution of a directive, special requirements for nursing home residents, and protections against forgery of directives. Where decisions must be made in the absence of a directive, as in the Conroy case, advocates with these concerns have urged the court to adopt procedural protections to reduce the likelihood of abuse. Concerned individuals also urge that institutions establish thoughtful decisionmaking standards and processes by which these difficult choices can be made.

B. Rationing and Cost Control

A related concern stems from the apparent fixation of health policy makers on the high cost of caring for the elderly or as it sometimes is expressed, "the high cost of dying". DRG's, increased Medicare deductibles, and the reluctance to confront the financing of long term care are examples. Concerns about equity and the development of more humane alternatives to our present institutionally-based system of care are subordinated.

The link between cost-containment and advance directives is often not clear. One link is a remark of a former HCFA Administrator, quoted as suggesting that Medicaid costs may decline in states authorizing the use of living wills, presumably because Medicaid recipients in those states may decline to receive high cost, acute care treatment. Some ask: If these devices are available, will they become mandatory? Might not state or federal policymakers require Medicaid recipients to execute living wills? Similarly, some aging advocates have expressed concern about nursing homes requiring prospective residents to execute durable powers of attorney as a condition of admission to facilitate decisionmaking about these residents.

A more fundamental connection between cost concerns and advance directives is the fear that efforts devoted to enactment of living will and similar legislation divert advocates from more important tasks. In this view, the critical issues are the creation of humane treatment settings and assurance of adequate public and private financing for them. Time spent on advance directives would be better spent on these issues.

C. Right to Life

A final group which probably doesn't require my delineation is the Right to Life movement, which has been a powerful opponent of living wills and also has opposed the adoption of "brain death" statutes. The National Right to Life Committee also views withholding of nutrition as a violation of fundamental human rights. As yet, the Committee has not taken a position on durable powers of attorney. The Committee supports, "positive programs... for the dying which employ spiritual, emotional and material support that enables the family to care for the dying patient."

The Committee's reasons for opposing living will statutes include the view that they are not needed to empower patient decisionmaking, that they are subject to abuse, and that they wrongly enhance an ethic favoring death over life. They see a direct link between abortion, infanticide, and euthanasia and point to the support for such legislation by Concern for Dying, formerly the Euthanasia Education Council.

CONCLUSION

"Taking charge of the end of your life" is an important objective. Advance directives, most agree, can be helpful in achieving this goal. Substantial technical problems remain, however. Living wills are limited in scope and questions about the acceptibility of the durable power for medical decisionmaking have not been resolved.

Concern about the potential for abuse of advance directives will continue. Also continuing will be the dispute underlying much of our discussion but not articulated today: whether our concern should focus on the enhancement of the quality of life or the preservation of biological life. This fundamental issue most divides opponents and proponents of advance directives.

To truly "take charge of the end of your life" you must have available humane alternatives to conventional care and adequate financing for these alternatives. Advocates concerned with these issues must be prepared to devote substantial efforts to the fight for the creation and financing of these alternatives. Advocates must also concern themselves with other health quality and financing issues, such as uniformity in Medicaid and quality assurance of long term care if we are truly to be in charge of the end of our lives.

Concluding Discussion

MS. COLEMAN: We have only five minutes, but let's address some of the questions from the audience.

One question raised is what is the federal role here? What should we be looking for in terms of a federal role? It is my opinion that there is no federal role in terms of a federal statute. These are individual state statutes, and there have to be state statutes because the definition of life varies. The definitions for power and durable power of attorney decisions are state bound, not federally bound. Barbara, do you disagree?

BARBARA MISHKIN: Yes, there's one very important federal role. I'm pleased to have the opportunity to add this because I didn't have time this morning. There's a need for the U.S. Congress to define the rights of patients in military hospitals, in VA hospitals, in other federal facilities. Within the last year, there was a case in which a patient in Walter Reed Army Hospital wanted to have life-prolonging treatment withdrawn, and had to go to court to do it. In another case, I was consulted about a terminally ill patient in a VA hospital whose wife wanted to follow his directives not to prolong treatment, but was told by the VA they could not comply. Thus there is a clear federal role and something needs to be done. I hope anyone here from Congress will take that small bit of advice back to the office and get something accomplished.

MS. COLEMAN: Another question which has been asked in several ways is this: "If you don't have a living will, if you don't have a durable power of attorney, what might occur for younger people if they are in car accidents, for example, or other catastrophic situations?" Realistically, one can begin to think about advance directives at any age. Usually people who have children think about advance directives, delegating an authority to take care of a child in case something happened to them, writing a will no matter what age they are or changing the beneficiary on life insurance because of some life change.

A younger person can also make that kind of delegation of authority about their own health care. Without it, if families want to make decisions they need to go to court and be appointed as conservator or guardian. If you use advance directives to pre-plan, no matter what your age, you can avoid some of the guardianship, conservatorship, family bickering or court involvement.

There was a question directed to Dr. Epps:

DR. EPPS: This question deals with someone who was attending her sister who was dying with a terminal brain tumor. The sister's spouse was three hours away, an alcoholic, unable to really accept her forthcoming death. The woman wanted to die. The physicians told her that they must all accept the decision of the absent spouse; he finally accepted the do-not-resuscitate idea. And the question is, "What could I have done if he had not?" I think this is always a legal dilemma. I believe the sister has no legal authority, although whatever I say is subject to opinion by the attorneys present. I don't believe that the sister has any legal authority to give them permission for her own sister. The woman is legally married to her husband, and I would presume he has the legal authority.

FROM AUDIENCE: Only about a half dozen states even allow a spouse to make decisions. So without a specific delegation of authority, the spouse may not make critical decisions.

DR. EPPS: Well, the do-not-resuscitate order is usually one that a doctor makes, after discussing this with either the patient (if the patient is able), or certainly the family members who are there. And it is really a medical judgment. If the patient's condition is such that when life stops there is no reasonable expectation of reviving that patient and have him continue on with life in a reasonable manner, then do-not-resuscitate is appropriate. If you have someone who is 21, who has had an accident and suddenly has cardiac arrest, then those circumstances do not apply. Because if the patient stops breathing or his heart stops and you can resuscitate him, his health is such that once you get him healthy again he has the expectation of living the rest of his life. But in the case of a terminal patient, there's not really good justification for doing this over and over again. You are fighting what God and nature seem to be doing. And that's why I think from a practical point of view, the do-not-resuscitate order is very appropriate.

What doctors fear is that there may be some family member who will stand back and say, "I want everything possible that can be done, to be done for my mother, and that means resuscitate her as many times as possible. And when the last resuscitation fails then you don't do any more." But you may recall here in Washington there was the case of a woman who came from a different culture, who actually pulled the plug on her father's respirator because he had been resuscitated a number of times. She was charged with murder. And the jury failed to indict her because they understood her frustration which she voiced on the stand that her father had died literally a number of times, had been resuscitated, and each time had been revived.

MR. BROWN: I want to make a related point, partly in response to a couple of other questions. I think one statute has not been mentioned. Everyone should be aware of the model Health Care Consent Act that's also been promulgated by the National Commissioners on Uniform State Laws; it addresses the situation that has been raised here, that is the authority of family members to consent to health care. This law has been adopted by the Commission and has been perjoratively referred to as the model "Send Your Kid to Camp Act" because it primarily authorizes you to designate another to make medical decisions on your behalf or on behalf of someone else, for example, the camp counselor situation for your child.

But it specifically authorizes the designation of a surrogate health care decision maker. In the absence of such a designation, it authorizes family members to make decisions in lieu of an advanced election or designation. I think many states might look to that Act if they are concerned about the applicability of the durable power for use in health care decision-making. But there are disadvantages as well as advantages. And it may benefit primarily health care providers who are concerned about potential liability, rather than promote autonomy.

Another question is how the durable power of attorney differs from the ordinary power, and how the health care power is different from the ordinary power. Briefly, a power of attorney is an authorization by you to another person to act on your behalf. A durable power survives incompetence, whereas an ordinary power does not. And health care power is one in which you designate someone else to make medical decisions on your behalf.

While all states have adopted durable power in one form or another, there is some lack of uniformity among the states with respect to the features of the durable power. And there is substantial concern whether the durable power can be used for health care decision making. It seems to me in a few states, California and Pennsylvania are notable examples, there is express authority for its use, for health care decision-making. In most other states there is no express authority. Some health care providers or their counsel may say, "Well, this seems like a probate law to me, not a health care decision-making law, so I won't recognize it, or I instruct my client not to recognize it." It seems to me that the prudent thing to do is to proceed and use it as a form of advanced directive in the hope that it will be accepted by providers and, if need be, urge legislation clarifying its status as a vehicle for health care decision-making.

MS. LEVINSON: Several very specific questions having to do with documents or state requirements have been raised. I would say to those people--contact Concern for Dying. We are in a position to answer those questions. We have a very strong group of legal advisors and we are in contact with knowledgeable people all over the country, so we're prepared to answer questions pertain-to all fifty states, not just New York. Write to Concern for Dying at 250 W. 57th Street, New York, NY 10107.

Part 4

Bringing the Problem Out of the Shadows: What Organizations Can Do

Speakers in Part 4

LEO BALDWIN is manager of special projects for the American Association of Retired Persons. He worked with problems associated with death and dying even before joining the Association in 1972, and developed AARP's Widowed Persons Service Program. Baldwin also served as AARP's housing coordinator, and was involved in the formulation of organizational policy supporting state legislation on living wills and related issues. He is a graduate of Willamette University in Salem, Oregon, and has done graduate work at Drew University and Northwestern University.

PAUL KERSCHNER is President of the National Foundation for Long Term Health Care. He is former Associate Director for Legislation, Research and Programs of the American Association of Retired Persons, and Associate Director of the Andrus Gerontology Center at the University of Southern California. He served on a Los Angeles County Commission on Code Blue Issues, and as Executive Director of the Maryland Commission on Nursing Home Reform. Kerschner has been a national speaker on the issues of death with dignity, the rationing of health care, living wills, and related issues.

JOHN L. LASTER is an attorney and partner at Landsman & Laster, a Washington, D.C. law firm emphasizing the needs of families in which someone is aging or critically ill. Clients include the Hospice Council of Metropolitan Washington. He serves on the Advisory Committee of the American Bar Association's Commission on Legal Problems of the Elderly, and the Executive Committee of the Foundation of Thanatology. Laster has been guest lecturer at the National Catholic School of Social Work and adjunct instructor at George Washington University Institute of Law & Aging. He received his A.B. degree from Oberlin College in 1972 and his J.D. degree from Catholic University in 1979.

IRMA S. ROCHLIN is State Representative of Florida District 98 (Hallandale-Hollywood), after winning a special election to the Florida House in February 1984 and subsequent re-election. She is a member of the Committee on Health and Rehabilitative Services, and was the author of a bill on living wills considered by the legislature last session. Rep. Rochlin is a graduate of the Johns Hopkins Hospital School of Nursing. She served as first chair of the Broward County Commission on the Status of Women, and was founding member and president (1972-1980) of the Gulfstream Democratic Club.

REV. MICHAEL B. RUST is Director of the Cleveland, Ohio, Nursing Home Ombudsman Program, and is a Lutheran Clergyman; he has been Cleveland NHOP Director since the program's inception in March of 1977. In addition to practical experience in complaint investigation and resolution for over 170 nursing homes, Rev. Rust is also a member of the Board of Directors of the National Citizens Coalition for Nursing Home Reform and Vice-President of the Ohio Association of Ombudsmen.

PAUL KERSCHNER, Moderator
President
National Foundation for Long Term Care

DR. KERSCHNER: I just want to make some brief introductory comments and then turn it over to the panel. For those of you who don't think the issue of advance directives is politicized, allow me to elaborate. I don't know how many of you were listening to National Public Radio two weeks ago. They were reporting on a forum, at which Tish Sommers spoke, sponsored by the Hemlock Society. Afterwards they interviewed some of the individuals picketing outside. Several of them, whether you disagree with them or not, had reasonable arguments against the right of a person to commit suicide. One individual, however, said that she thought this whole suicide, living will, advance directive, death with dignity area was a conspiracy on the part of "David Rockefeller, Rothschild and the Trilateral Commission." So much for rational discussion!

One of the reasons that I'm particularly pleased that this forum is being held is that many of us in the audience and here on the panel are concerned that if we don't go public and call for a national dialogue on these issues among families, patients, doctors, nurses, social workers, clergy, lawers and the rest, we will then abdicate responsibility for dealing with the situation to either the courts or the legislature, whether Congress or state legislatures. Regardless of where you stand on abortion, most of us would agree that this issue has been taken out of the hands of most of us and turned over to the courts or legislatures. If this forum is the beginning of a national dialogue on right to die and death with dignity and the accompanying issues, I think we've made a major step forward. Because it is a personalized issue, and one involving all of us, we cannot afford to turn it over to the courts for adjudication.

Lastly, I want to make the comment that we inappropriately malign many of those health care professionals over the years who deal directly with these problems. I believe we have to give credit to how far nurses, doctors, social workers, clergy and others have come in the last ten years. As you've heard today, the withholding of treatment runs counter to all of us. It runs counter to the individual. The famous poem, "Rage Against the Dying of the Light," demonstrates that even for the individual, the inclination is to hold on. For individuals to decide that they are going to a better "place" I think is commendable.

For doctors and nurses every instinct is to preserve life, to save it, to keep that flicker alive. For them in a sense to step back and say to the patient and to the family, "Yes, we're going to allow your mother to meet a natural death," for this they deserve enormous credit. They were not trained that way, they were not raised that way, and yet they're major actors in this drama. I'm glad to see that, one, they're represented here today, and, two, in forums around the country that doctors and nurses and the rest are part of this discussion.

HON. IRMA ROCHLIN
Florida State Representative
98th District, Hallandale FL

REP. ROCHLIN: It's a pleasure to be invited here today. I will forego most of my written comments for the simple reason that they've been so adequately covered to this point. What I would like to bring out are the subjects that legislatures are considering and items that they have addressed.

We see the aging of the population -- 11.6 percent are over the age of 65. The fastest growing segment is over 85. And the end of life is not what Robert Browning described, "Come grow old with me, the best is yet to be", as people are falling victim to greater illnesses and debilitating diseases as well as accidents.

We have heard of the living will, the durable power of attorney. Thirty-seven states also have definitions of brain death which serve as a guideline as well. And the things that legislators have to deal with are not only the different bills relating to the living will or durable power of attorney. We also have to deal with the bottom line, the appropriations aspect for hospital cost containment, for Medicaid reimbursement to the hospitals. Within the vastly growing medical technology, we tend to view the medical profession as God-like. They can prevent death. And the care givers can keep this up for long times. In a way it helps in dealing with transplanting of organs, keeping a brain dead patient alive until organs can be transplanted. Those are the subjects of the bills that have been considered and passed in my own state of Florida.

They also create a great many problems. In my own state, we legislated that sustenance cannot be withheld. I attempted this year to make that a qualified statement and say that artificial sustenance might be withdrawn when it was only serving to prolong the process of dying. And I met with tremendous, unexpected resistance. I say unexpected because since the papal decree of 1980 that a person could have a say in the termination of his illness when it was only prolonging the dying, the Catholic Church had tended to support the living wills. But they did not support the withholding of sustenance.

So my bill failed nine to eight when the Right to Lifers and the Catholic Conference lobbied very effectively against it, though we all recognized a growing problem. Perhaps some of the lawyers here will help me to reword the bill so that it can pass.

I think there is also an abysmal lack of knowledge of the resources that are out there, and that deserves a great deal of attention. We mentioned hospice. I wonder how many of you are aware of the services that hospice provides, not only instruction on patients dying in their own homes but also in my own county of Broward County, three of our hospitals have put in hospice suites.

There the patients can be with their family, with 24-hour visiting rights, and can control the pain so that they get the optimum dosage of whatever pain killing drugs are given. Increasingly it is morphine. I'm really surprised to learn that a maximum 16 milligram dosage we used to talk about as being really the maximum dose every four hours -- they have discovered that they can go up to 320 milligrams every four hours. Still the patient would just be controlling pain. These are some of the things that hospice is taking care of, seeing that everyone is pain-free.

They also give instructions in the different treatments that can provide artificial sustenance in cases where people cannot retain food by mouth, for example, the subclavian artery is used to dispense food. Patients can take care of these things themselves. Increasing numbers of cancer victims have a shunt put in so that they can administer their own medications to control their disease.

I think one of the problems also that we have seen is an abhorrence of nursing homes by the elderly without their realizing or visiting or seeing what nursing homes of today are doing. My own mother who is 86 years old lives in a facility which is a model for the nation -- it's the Douglas Gardens Home for Aging. She has her own apartment in the residential towers and fiercely guards her independence. Since going in there two years ago she took charge of the ceramics studio. They have exercises for the elderly. They have transportation to shopping and different functions. Theater tickets are given out to them. They are bused by their own buses. She is in a situation far better than had she been at my home just languishing because she's part of a group of her own peers. And I was really delighted to hear her say at one point, "You know, last week we celebrated the 104th birthday of one woman here and the 96th birthday of someone else. I'm the baby." So that kind of interest should be studied. People should become more aware of what is currently available to them.

REV. MICHAEL RUST
Lutheran Clergyman and Director
Cleveland Nursing Home Ombudsman Program

REV. RUST: My comments are limited to the practical experience I've had in Cleveland, Ohio. I come here not as the result of scholarly inquiry in the arena, but as a result of agonizing with families and with facilities over telephone calls that we've received over the past few years.

An earlier speaker, I believe Robert Brown, mentioned that there needs to be a tremendous increase in the work towards bringing into actuality alternatives to institutionalization. And while I support that very strongly and work in my own area to bring that about, I am a little bit afraid that we easily ignore people who are currently in institutions. I know how easily a community can ignore many of the people who are in its long-term care institutions, especially those people who are of greatly diminished capacity, who are "deinstitutionalized", if you want to use that word, to a nursing home: mental patients, people who have very reduced capacities, people who have very few people to speak on behalf of them.

I would say that any effort to deal with advanced directives with assisting people in dying with dignity needs to be an effort undertaken in the context of helping these kinds of individuals who already have had tremendous power stripped away from them to recover some power for decision making. Is it any wonder that if a person can't make a decision, or has a difficult time influencing when they go to bed and when they get up, about what they eat and when they eat, is it any wonder that there is tremendous institutional and sometimes community resistance to that person being able to make a decision about when and how they should end their lives?. So I ask that those people not be ignored in the decision-making process.

Those people -- and I'm speaking about nursing homes here -- are in institutions that have experienced a couple of very difficult decades, decades in which they as institutions have been the targets of horror stories, some deserved, and some not. While I am surely not an industry apologist, nursing homes have all too often become estranged from the community that surrounds them. Unless they're a particular ethnic nursing home, unless they're in a neighborhood that is particularly receptive, typically the community has such a terrible idea about the reputation of these nursing homes, that the last thing they would consider doing as respectable citizens is working together with that kind of an institution to bring them more into some kind of symbiotic relationship with the community. Hence, the tremendous difficulty that nursing homes are experiencing if they should want to develop medical ethic committees to help families and to help the institutions as people are making admission to the facility.

For instance, in the Conroy case I was on a committee which was considering materials for an amicus brief. It was decided by the committee that we would not include a recommendation that nursing homes be strongly urged to develop medical ethics committees. It was felt nursing homes were not ready for such responsibility. I was a not very eloquent abstainer from that decision. We need, for many reasons, to call nursing homes into better relationships with the community. One way to accomplish that is to develop nursing home medical ethics committees. Part of their job could be to assist residents and families to develop advance directives. That means not just calling nursing homes into a serious community responsibility, but also calling communities into responsibility. Neighbors and respected people in the community ought to reach out, and organizations reach out and join in the development of those kinds of committees.

Additionally, an arena that we discover in our practical work that is very often overlooked is the process of discharge planning from hospitals. Hospital discharge planners are under a tremendous amount of pressure these days, not very much of it able to be directed, unfortunately, towards the best interest of the patients. The issue of advance directives needs to be a part of that discharge planning process, and physicians need to play a part.

We have at least one creative example back home of a hospital that has set aside a support group during its discharge planning process. Partly in remembrance of that support group and in answer to a question from the audience that I was handed by Paul Kerschner before we began, it seems to me that one of the very key places, at least in my work, that people could be educated very well about advance directives, about how to take control over their own lives, about the issues related to that, would be during the process of discharge planning from a hospital and during the process of admission to a nursing home.

The process of admission to a nursing home is too often dehumanizing to the family and to the resident. It's simply a bunch of business, a bunch of papers, and things of real substance tend not to get discussed. If we don't begin to try to break through that part of the process, we have missed perhaps two of the most crucial junctures when we might offer support for families to address the issue while there still is some time. If we don't, we will have missed as professionals a couple of shining opportunities to introduce families to the issues surrounding control over the end of their lives, during hospital discharge planning and during nursing home admission processes.

By and large the families who call us don't know about Claire Conroy. They're not familiar with those issues at all. But they know exceedingly well what it is they want to happen. They are tremendously surprised to learn that they don't have power to make it happen. They're surprised at the institutional resistance they meet, institutional resistance that is very easily understood, given the background that nursing homes are coming from and the kinds of community reputations they're fighting against. Families are ripe for this kind of education, but usually not until they have to have it, usually not until the processes of the gun. That's why discharge planning, admission procedures to nursing homes and medical ethics committees I think would go a long way towards helping at least a portion of the families that we deal with to address the issue much better.

DR. KERSCHNER: Let me make a comment also about the nursing home issue. For years many of us who call ourselves gerontologists, which means that we go out and geront, have been going around telling nursing homes that they must become psychosocial institutions, that they should not work off the medical model. And while by and large that's still true, and social workers, patient bill of rights, and OTs and PTs are still critical, what's now happening is that we're seeing a very different patient mix in nursing homes.

Because of the DRG system, because of the type of patient that's coming out of the acute hospital, whether you call them sub-acute or superskilled, many of these patients are coming into the nursing homes very ill, many of them dying. This is not anything punitive on the part of hospitals or nursing homes or anyone else. It's just a very different kind of patient mix. That's why it's so important that we bring back the physician, if they ever left, back into the nursing home and back into the structure of what goes on in long-term care facilities, because they are now going to be called on more than they were.

JOHN L. LASTER
Attorney
Landsman & Laster

MR. LASTER: Many of the things that I wanted to say have been said very eloquently by previous speakers, and I will not repeat them. I'm deeply honored to participate in the same program with Tish Sommers and Senator Jacob Javits who have both worked for a long time on issues that I certainly hold dear. Even hours later, the power of what they had to say is still resonating inside of me.

I want to tell them a story, and tell you a story as well. It may be apocryphal--I'm not sure. But I think it's relevant to the issue at hand. It's about a pair of friends, Sam and Lila, who became friends after they both retired. And what they both liked to do was play softball. They played softball all the time. And they conjectured about the life hereafter while they were playing softball. The big question that they discussed was whether they liked to play softball in heaven. After a while Lila died, and sometime later appeared to Sam in a dream and said, "Sam, I've got good news, and I've got bad news. The good news, Sam, is that they're crazy for softball up here. They play all the time. They've got leagues. I'm on a team with Ty Cobb and the Babe himself. And they can't get enough of the sport. The bad news Sam is that you pitch on Tuesday." Well, as we're fond of pointing out in our office, Sam has some planning to do.

The points I want to make today stress that if the circle around Sam, that is his family and the organizations around him, his close-in network, have been doing right by him all along, Sam already would have done some planning. And he would be able to use the time that was left to him to talk with his family about what's important, about his relationships with them and about where they're going to go from here.

The consequences, as many speakers have pointed out before me, of Sam's not doing the planning is that somebody else is going to make the decisions for him. And that somebody else is going to be another human being. Decisions always get made, one way or another. Somebody either acts or doesn't act, does a procedure, doesn't do a procedure. Something happens and a decision is made.

Now, a minute ago when I mentioned the circle around Sam, what I meant besides his family and friends were his organizations, his larger networks. Almost all of us are in some sort of larger network, that is people with whom we share something in common besides our family. So I want to talk about two particular ideas that I think will go a long way towards educating the American people as to what the issues are here.

The first idea, and the first network that ought to be doing something are churches and synagogues. I think if there's any group that ought to be doing something it's churches and synagogues. Every religious group that I know of pays a lot of attention to what the issues are in living and dying. And every tradition I know has a ritual to help its adherents give some shape to the most awesome experience that we go through in our lifetimes.

Now, I think that it's a natural extension to that belief that the churches and synagogues and other religious communities can devote substantial time and attention to helping their adherents learn more about living wills and other advance directives. One church I know put together a four week program of sessions that started with church teachings about life and death. Then they went on to cover living wills and other advance directives, and later discussed basic estate planning. They brought in their lawyer members, their physician members, their nurse and other health provider members as well as the clergy to talk about all of these issues with particular church members.

A local synagogue that I know took a slightly different route. They formed a group to talk about Jewish burial rituals. And what they turned that into was a group that explored the members' thoughts and feelings about living and dying. They went on from there to reclaim the custom, an age old custom, of community members acting as a burial society for other members of the community who had died. It is a very tightly knit group, and one example of what A.J. Levinson calls a buddy system. I think that this is the place to start. After all, where else should people be comfortable talking about the values that they hold most deeply if it isn't in their churches and synagogues?

Now, I don't think that the church and synagogue discussions should stop there, because there are many more issues that these seminars could explore. For example, they could look into how that particular tradition deals with and balances the nature of individual autonomy with the needs of the group. That is one of the most significant issues in this discussion of living wills and other advance directives. And it is a persistent theme that underlies everything that the previous speakers have talked about today. I believe that if we had more of this kind of discussion earlier some of the bitterness around what Paul Kerschner was talking about, the abortion decisions, might well have been avoided.

The other issue that I want to mention today is both more briefly noted and grander in scope. Aging organizations ought to sponsor a lot of local seminars on all aspects of lifetime planning. As one of the previous speakers noted, many Americans die without property wills. A recent consumer report survey noted that 70 percent of Americans die without wills disposing of their property. Despite the success of groups like Concern for Dying and the Society for the Right to Die, I would bet more than 70% die without expressing their will concerning medical treatment. And some number die without giving voice to their wishes and their hopes and their dreams for the moral development of those who follow them.

Each of these expressions of will is related. I think that Senator Javits talked about it before. Each of these expressions of will is a part of living and is not a part of dying. Each of them is a way of saying, "This is my life. This is where I've come from. This is what I believe. This is where I hope those who follow me will go."

I believe that there is tremendous potential for organizations to sponsor local groups and bring together with those of us who are aging, the physicians, the other health care providers, the attorneys. God knows we don't talk to each other often enough, and when we do it's usually in court. Bring together other health providers, clergy members and everyone else who has useful things to say about aging and values. I think that if organizations do this, if they help their members plan by giving expression to these inner thoughts and feelings, then we're all going to be a little bit more human, little bit more aware, and a little bit more alive for having done it.

LEO BALDWIN
Manager, Special Projects
American Association of Retired Persons

MR. BALDWIN: I'm grateful for the opportunity to be here. I want to change our thinking just a little bit in terms of dealing with the older population itself.

A few years ago I was in the state of Michigan participating in a seminar, a panel very much like this except that I was the youngest member and the next youngest member was 83 years old. An 87 year old woman made the statement that she just loved the 25 year olds that were coming out of our schools of gerontology, social work, who were moving into the service-providing field for the aged. But she said, "The thing that I don't like is that they want to institutionalize us. They want to make decisions about where we should be, what we should be doing. And I'm at an age where I think I can make my own decisions."

Now, I reflect on that because I think this is a concern that people who work in the field of gerontology must become more aware of. It's great to have lots of young, professionally-oriented people working in the field. But there is something about the maturation that goes on through life that changes us as we age. There is something in the perspective that young people have toward aging that is different from the perspective of the person who is already of advanced years, even though the young may be completely sympathetic with the problems of aging. We're all well aware of the physical changes that take place, the loss of hair or the graying of hair if you still retain it--these things are apparent to all of us. We are aware that some of us don't react as quickly from the standpoint of our mental alertness as we used to. But we have forgotten that in this matter of life and death our perspective has also changed. I want to suggest to you that perhaps the people that can deal with the problems of dying or living most easily in terms of public discussion are the older people themselves whose death is becoming more and more imminent, and they become more and more aware of it.

That puts an association like AARP I think in a very unique position to address the questions that we've been talking about today. I think AARP is in a unique position in another respect, and that is we do not intend to give legal advice. We do not intend to give medical advice. We do not intend to give life planning advice or death planning advice. As an organization that can stand apart from the technical and very real concerns that have been expressed here today from the standpoint of professions and the care givers, AARP is in a position where we can address these questions from the standpoint of educating the public, the young and the old, the families of the older persons, the agencies that serve them, and hopefully the professions that serve them. While AARP has not made a strong commitment to get involved in this at the current time, there are a number of us on the staff who are working hard to make this one of the areas of priority, in terms of AARP's continued concern that older people maintain their independence, their dignity, and the decision-making power that we believe they have the right to observe.

So it seems to me that as AARP moves into this area, and other agencies either join us or perhaps precede us in this area, there is a great deal to be done in terms of tapping the wisdom, the resources, the energy and the spirit that the older population itself represents. I don't think we will need a lot of the dictums coming from Governor Lamm or other people about the appropriate role for older people in the terminal stages in their life.

May I make one other observation? I mentioned the older woman in Michigan who was on that seminar--it happened to be Memorial Day weekend, and she said something that was very meaningful to me. She said, "Memorial Day is the time when those of us who are dying pause to remember those who live."

DR. KERSCHNER: When I was with AARP we did a survey of members to elicit ideas for reforming Medicare. Overwhelmingly, the first two were podiatry and dentistry, and the next was control over one's own death. One woman wrote a letter and said, "The only reason I need better teeth and better feet is that when that time comes and those doctors try to put tubes in me, I'm either going to bite them or kick them." I always thought I should have saved that wonderful letter. That concludes our panel. Thank you very much.

Concluding Remarks

MS. JAYCOX: We're not going to do a formal summary for a wrap-up. We do intend to go on from here, however. First of all I want to thank you all for coming and to thank our speakers especially for participating in this effort to bring the issue of health care decision-making at the end of life into national focus. I also want to thank the members of the Forum's planning committee which include Bill Benson and Linda Josephson of the Senate Committee on Aging, and Nancy Coleman and Charles Sabatino of the American Bar Association. I'd especially like to single out for all their creativity and hard work Janet Warren of Representative Sid Morrison's office, and Alice Quinlan, Director of Public Policy at the Older Women's League and Forum coordinator. I also want to thank Congressman Morrison for inviting us to hold the Forum on the Hill, which I think was quite a plus.

All of the organizations involved in this forum see it as an important step in opening up the issue of advance planning in case of a terminal illness. To encourage a better and more informed debate, OWL will publish a followup report based on this Forum. The Older Women's League is also in the final stages of prepararing a report in our series of "Gray Papers." The title of this Gray Paper is "Death and Dying: Staying in Control Until the End of Our Lives"; we'll let you know when it's available.

We hope that those of you who are working in this area or who are planning to get more involved will likewise keep us up to date on what you're doing. I think we all leave here today convinced that these questions are and will continue to be of critical importance. I hope we'll also leave here better able to take charge of the ends of our lives.

Resources

ORGANIZATIONS

Concern for Dying, 250 W. 57th Street, Room 831, New York, NY 10107. A nonprofit educational council that developed the living will and promotes discussion of issues involved in death and dying. Living will registry, state-by-state information, various publications.

Continental Association of Funeral and Memorial Societies, Inc. 2001 S St. N.W., Suite 530, Washington, DC 20009. Federation of non-profit consumer organizations fostering freedom of choice in funeral arrangements. Check-lists, pamphlets, directories and other publications.

Society for the Right to Die, 250 W. 57th Street, New York, NY 10107. A non-profit organization working for the recognition of the individual's right to die with dignity. Distributes living wills, supports judicial and legislative action, newsletter, various publications.

SELECTED PUBLICATIONS

Concern Newsletter. Quarterly newsletter of Concern for Dying. See above.

Congressional Research Service. Comparative Analysis of State Statutes Recognizing a Patient's Right to Die a Natural Death. Joseph Maheady and Rita Reimer, updated July 1985. Legal Analysis of the Right to Die. Rita Reimer, June 1985. Library of Congress, Washington, DC 20540.

Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Government Printing Office, 1983. (Special edition available for $5.00 from Concern for Dying. See above.)

Handbook of Living Will Laws, 1981-1984. Society for the Right to Die, 1984. ($5.00; Society for the Right to Die. See above.)

Mishkin, Barbara. "Making Decisions for the Terminally Ill." Business and Health, June 1985, 13-16.

Morgan, Ernest. Dealing Creatively with Death: A Manual of Death Education and Simple Burial. Celo Press, 1984. ($5.00; Celo Press, Burnsville, NC 28714).

Nelson, Thomas C. It's Your Choice: The Practical Guide to Planning a Funeral. AARP Books, 1982. ($5.00; AARP Books, Dept. CATA, 400 S. Edward St., Mount Prospect, IL 60056).

Sommers, Tish. "Death and Dying: Staying in Control to the End of Our Lives" Gray Paper, 1985. ($3.50; OWL, 1325 G St.NW, Washington, DC 20005).

Values in Conflict: Ethical Issues in Hospital Care. Report of the Special Committee on Biomedical Ethics. American Hospital Association, 1985.

Wanzer, Sidney H. et. al. "The Physician's Responsibility Toward Hopelessly Ill Patients." The New England Journal of Medicine 310 (1984), 955-959.

P. 3, l. 18
P. 6, l. 27
P. 3, l. 29
P 1, l. 17
P 2, ll 11-17

Offered: 2/5/86
Referred: Rules

Original sponsors: Eliason, Ziegler,
V.Fischer, et al

House floor amendments

IN THE SENATE BY THE JUDICIARY COMMITTEE

HOUSE CS FOR CS FOR SENATE BILL NO. 140 (Judiciary) P. 2, l. 7

IN THE LEGISLATURE OF THE STATE OF ALASKA

FOURTEENTH LEGISLATURE - SECOND SESSION

A BILL

For an Act entitled: "An Act relating to the rights of the terminally ill; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. AS 18 is amended by adding a new chapter to read:

CHAPTER 12. RIGHTS OF TERMINALLY ILL.

Sec. 18.12.010. DECLARATION RELATING TO USE OF LIFE-SUSTAINING PROCEDURES. (a) A competent person who is at least 18 years old may execute a declaration at any time directing that life-sustaining procedures be withheld or withdrawn from that person; but the declaration is given operative effect only if the declarant's condition is determined to be terminal and the declarant is not able to make treatment decisions. [The declarant shall subscribe to the declaration in the presence of a judge or magistrate. The judge or magistrate shall inquire on the record whether the declarant understands the importance and effect of the declaration. A judicial officer may not charge a fee for witnessing a declaration.] A person may not charge a fee for preparing a declaration.

2 witnesses

(b) It is the responsibility of the declarant to Provide a copy of the [notify the declaration to declarant's physician, of the declaration.] A physician or other health care provider who is provided a copy of the declaration shall make it a part of the declarant's medical records.

(c) A declaration may, but need not, be in the following form:

DECLARATION

If I should have an incurable or irreversible condition that will

cause my death within a relatively short time, it is my desire that my life not be prolonged by administration of life-sustaining procedures. If my condition is terminal and I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort or to alleviate pain. ☐ Do or do not desire nutrition

Signed this ________________ day of ______________, ________.

Signature ______________________

Place ______________________

Subscribed and sworn to or affirmed before me

at ________________ on ________________.

(Date)

____

Signature of Officer

____

Title of Officer

(d) A physician or health care provider may presume, in the absence of actual notice to the contrary, that the declaration complies with this chapter and is valid.

Sec. 18.12.020. REVOCATION OF DECLARATION. (a) A declaration may be revoked at any time and in any manner by which the declarant is able to communicate an intent to revoke, without regard to mental or physical condition. A revocation is only effective as to the attending physician or any health care provider acting under the guidance of that physician upon communication to the physician or health care provider by the declarant or by another to whom the revocation was communicated.

(b) The attending physician or health care provider shall make the revocation a part of the declarant's medical record.

Sec. 18.12.030. RECORDING DETERMINATION OF TERMINAL CONDITION AND CONTENTS OF DECLARATION. When an attending physician who has been provided a copy [notified of the existence and contents] of a declaration determines that the declarant is in a terminal condition, the physician shall record that determination and the contents of the declaration in the declarant's medical record.

Sec. 18.12.040. TREATMENT OF QUALIFIED PATIENTS. (a) A qualified patient has the right to make decisions regarding use of life-sustaining procedures as long as the patient is able to do so. If a qualified patient is not able to make these decisions, the declaration governs decisions regarding use of life-sustaining procedures.

(b) This chapter does not prohibit the application of any medical procedure or intervention, including the provision of nutrition and hydration, considered necessary to provide comfort care or alleviation of pain. The declaration may provide that ... does not want nutrition ... ..

(c) The declaration of a qualified patient known to the attending physician to be pregnant has no effect as long as it is [probable] possible that the fetus could develop to the point of live birth with continued application of life-sustaining procedures.

Sec. 18.12.050. TRANSFER OF PATIENTS. (a) An attending physician who is unwilling to comply with the requirements of AS 18.12.030 or who is unwilling to comply with the declaration of a qualified patient under AS 18.12.040 shall withdraw as attending physician but the withdrawal is effective only when the services of another attending physician have been obtained.

(b) If the policies of a health care facility preclude compliance with the declaration of a qualified patient under this chapter, that facility shall take all reasonable steps to effect the transfer

shall

notify the patient or, if the patient is not able to make treatment decisions, the patient's guardian, of the facility's policy of the patient to the patient's home or to a facility ~~in which~~ where the provisions of this chapter can be carried out.

Sec. 18.12.060. IMMUNITIES. (a) In the absence of actual notice of the revocation of a declaration, the following, while acting in accordance with the requirements of this chapter, are not subject to civil or criminal liability or guilty of unprofessional conduct:

(1) a physician who causes the withholding or withdrawal of life-sustaining procedures from a qualified patient;

(2) a person who participates in the withholding or withdrawal of life-sustaining procedures under the direction or with the authorization of a physician;

(3) the health care facility in which the withholding or withdrawal occurs.

(b) A physician, a health care professional, or a health care facility is not subject to civil or criminal liability for actions under this chapter that are in accord with reasonable medical standards.

Sec. 18.12.070. PENALTIES. (a) An attending physician who fails to comply with the declaration of a qualified patient or to make the necessary arrangements to effect a transfer under AS 18.12.050 has no right to compensat may be civilly liable to the qualified patient and to the heirs of the qualified patient.

(b) A person who wilfully conceals, cancels, defaces, obliterates, or damages the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another may be civilly liable to the qualified patient and to the heirs of the qualified patient.

Sec. 18.12.080. GENERAL PROVISIONS. (a) Death resulting from the withholding or withdrawal of life-sustaining procedures under a

declaration and in accordance with this chapter does not, for any purpose, constitute a suicide or homicide.

(b) The making of a declaration under AS 18.12.010 does not affect in any manner the sale, procurement, or issuance of a policy of life insurance, nor does it modify the terms of an existing policy of life insurance. A policy of life insurance is not legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) A physician, health care facility, or other health care provider, and a health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital plan, may not require a person to execute a declaration as a condition for being insured for, or receiving, health care services.

(d) This chapter creates no presumption concerning the intention of an individual who has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining procedures in the event of a terminal condition.

(e) Nothing in this chapter increases or decreases the right of a patient to make decisions regarding use of life-sustaining procedures as long as the patient is able to do so, or impairs or supercedes any right or responsibility that a person has to effect the withholding or withdrawal of medical care in a lawful manner. In that respect, the provisions of this chapter are cumulative.

(f) This chapter does not condone, authorize, or approve mercy killing or euthanasia.

Sec. 18.12.090. RECOGNITION OF DECLARATIONS EXECUTED IN OTHER STATES. A declaration executed in another state or a territory or possession of the United States in compliance with the law of that jurisdiction is effective for purposes of this chapter.

Sec. 18.12.100. DEFINITIONS. In this chapter

(1) "attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient;

(2) "declaration" means a document executed in accordance with the requirements of AS 18.12.010;

(3) "health care provider" means a person who is licensed, certified, or otherwise authorized by the law of this state to administer health care in the ordinary course of business or practice of a profession;

(4) "life-sustaining procedure" means a medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process; ["life-sustaining procedure" does not include nutrition or hydration;]

(5) "physician" means a person licensed to practice medicine in this state or an officer in the regular medical service of the armed services of the United States or the United States Public Health Service while in the discharge of their official duties, or while volunteering services without pay or other remuneration to a hospital, clinic, medical office, or other medical facility in the state;

(6) "qualified patient" means a patient who has executed a declaration in accordance with this chapter and who has been determined by the attending physician to be in a terminal condition;

(7) "terminal condition" means a progressive incurable or irreversible condition that, when available without the administration of life-sustaining procedures, will, in the opinion of 2 physicians, ~~[illegible]~~ who have personally examined the patient one of whom must be the the attending physician, result in death within a relatively short time.

* Sec. 2. This Act takes effect immediately in accordance with

1 AS 01.10.070(c).

DRAFT

FOR DISCUSSION ONLY

RIGHTS OF THE TERMINALLY ILL ACT

NATIONAL CONFERENCE OF COMMISSIONERS

ON UNIFORM STATE LAWS

MEETING IN ITS NINETY-THIRD YEAR
KEYSTONE, COLORADO

JULY 27 - AUGUST 3, 1984

RIGHTS OF THE TERMINALLY ILL ACT

With Prefatory Note and Comments

The ideas and conclusions herein set forth, including drafts of proposed legislation, have not been passed upon by the Commissioners on Uniform State Laws. They do not necessarily reflect the views of the Committee, Reporters or Commissioners. Proposed statutory language, if any, may not be used to ascertain legislative meaning of any promulgated final law.

DRAFTING COMMITTEE ON RIGHTS OF THE TERMINALLY ILL ACT

RICHARD C. HITE, 200 West Douglas Avenue, Wichita, KS 67202, Chairman

RANDALL P. BEZANSON, University of Iowa, College of Law, Room 242, Iowa City, IA 52242

RICHARD L. JONES, P.O. Box 218, Montgomery, AL 36130

JEANYSE R. SNOW, P.O. Box 508, Astoria, OR 97103

HENRY D. STRATTON, P.O. Box 851, Pikeville, KY 41501

RUSSELL G. WALKER, JR., P.O. Box 1831, Asheboro, NC 27203

WILLIAM H. WOOD, 208 Walnut Street, Harrisburg, PA 17108

CARLYLE C. RING, JR., 710 Ring Building, Washington, DC 20036, President (Member Ex Officio)

PHILLIP CARROLL, 120 East Fourth Street, Little Rock, AR 72201, Chairman, Executive Chairman

WILLIAM J. PIERCE, University of Michigan, School of Law, Ann Arbor, MI 48109, Executive Director

ROBERT C. ROBINSON, 4 Moulton Street, Portland, ME 04112, Chairman, Division D (Member Ex Officio)

REVIEW COMMITTEE

ACIE L. WARD, 1340 Marlborough Road, Raleigh, NC 27610, Chairman

GEORGE C. BERK, 632 Fleet Bank Building, Providence, RI 02903

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MEYRESSA SCHOONMAKER, 1111 Brookstown Avenue, Winston-Salem, NC 27101

NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS
645 North Michigan Avenue, Suite 510
Chicago, Illinois 60611

RIGHTS OF THE TERMINALLY ILL ACT

PREFATORY NOTE

The Right to Decline Life-Sustaining Procedures Act authorizes an adult person to control decisions regarding administration of life-sustaining treatment by executing a declaration instructing his or her physician to withhold or withdraw life-sustaining procedures in the event the person is in a terminal condition and is unable to participate in medical treatment decisions. As the preceding sentence indicates, the scope of the Act is narrow. It does not address treatment of persons who have not executed such a declaration; it does not cover treatment of minors; and it does not address treatment decisions by proxy. Its impact is limited to treatment that is merely life prolonging, and to patients whose terminal condition is irreversible, whose death will soon occur, and who are unable to participate in treatment decisions. Beyond its narrow scope, the Act is not intended to implicate any existing rights and responsibilities of persons to make medical treatment decisions. The Act merely provides one way by which a terminally-ill patient's desires regarding the use of life-sustaining procedures can be legally implemented.

As of October of 1984, twenty states had enacted legislation in this area. These states are Alabama, Arkansas, California, Delaware, Florida, Georgia, Idaho, Illinois, Kansas, Louisiana, Mississippi, Nevada, New Mexico, North Carolina, Oregon, Texas, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming. The District of Columbia also has an act covering this subject. Many other states have bills pending before their lawmaking bodies. The quality and scope of the enacted and proposed legislation varies significantly.

The purposes of the Act are (1) to encourage the effectiveness of a declaration in states other than the state in which it is executed through uniformity of scope and procedure, (2) to avoid the inconsistency in approach and quality which have characterized the early statutes, and (3) to present an Act which is simple, effective, and acceptable to persons desiring to execute a declaration and to physicians and health-care facilities whose conduct will be affected.

The Act's basic structure and substance is similar to that found in most of the existing legislation. Much of the Act's specific language conforms to usage established in existing statutes. In this respect the Act has drawn upon existing legislation in order to avoid further complexity and to permit its effective operation in light of prior enactments. Departures from existing statutes have been made, however, in order to simplify procedures, improve drafting, and clarify language. Selected provisions have been reworked to more adequately express a specific concept (i.e., life-sustaining procedure, terminal condition) or to reflect changes in established procedure (i.e., the qualifications of witnesses). The Act's stylistic and substantive departures from existing legislation were pursued for the purposes of clarity and simplicity. The Act seeks to avoid the charge that its "procedural requirements are so cumbersome that it is unlikely that any but a small number of highly educated and motivated patients will be able to effectuate their desires." Barber v. Superior Court, ___ Cal. App.3d ___, ___, 195 Cal. Rptr. 484, 489 (Ct. App. 1983) (describing California's "Natural Death Act," the first legislation to be enacted in this area).

The Act is divided into twelve sections. Section 1 provides definitions. Section 2 relates to the making of a valid declaration. Revocation is addressed in Section 3. Sections 4, 5 and 6 cover the physician's determination of terminal condition, the treatment to be accorded a qualified patient, and the availability for transfer by unwilling physicians. Immunities and penalties are provided in Sections 7 and 8 respectively. Miscellaneous matters are addressed in Section 9. Section 10 provides for recognition of declarations lawfully executed and enforceable in other states. Section 11 provides for severability and Section 12 sets the time for the Act's taking effect.

RIGHTS OF THE TERMINALLY ILL ACT

SECTION 1. DEFINITIONS.

As used in this [Act]:

(1) "Physician" [means a person licensed to practice medicine in this State.]

(2) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(3) "Health-care provider" means a person who is licensed, certified or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

(4) "Declaration" means a document executed in accordance with the requirements of Section 2.

(5) "Qualified patient" means a patient who has executed a declaration in accordance with this [Act] and who has been determined by the attending physician to be in a terminal condition.

(6) "Life-sustaining procedure" means any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process.

(7) "Terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of the attending physician, result in death within a relatively short time.

COMMENT

The Act defines "life-sustaining procedure" as any medical procedure or intervention that "will serve only to prolong the

RIGHT TO DECLINE LIFE-SUSTAINING PROCEDURES ACT

SECTION 1. DEFINITIONS.

As used in this [Act]:

(1) "Physician" [means a person licensed to practice medicine in this State.]

(2) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(3) "Health-care provider" means a person who is licensed, certified or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

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(7) "Terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of the attending physician, result in death within a relatively short time.

COMMENT

The Act defines "life-sustaining procedure" as any medical procedure or intervention that "will serve only to prolong the dying process." The Act's definitions of "life-sustaining procedure" and "terminal condition" are interdependent and must be read together. This has caused drafting problems in many existing acts, and the proposed Act has been drafted so as to avoid the problems detected in existing legislation.

Most of the "life-sustaining procedure" and "terminal condition" definitions in existing statutes were considered problematical in that they (1) were tautological, defining "terminal condition" with respect to "life-sustaining procedure" and vice versa, and (2) defined terminal condition as requiring "imminent" death "whether or not" or "regardless of" the application of life-sustaining procedures. Strictly speaking, if death is "imminent" even with the full application of life-sustaining procedures, there is little point in having a statute permitting withdrawal of such procedures. The Act's definitions have attempted to avoid these problems.

For an example of the tautological problems, the "life-sustaining procedure" definition found in many statutes inserts the clause "and when, in the judgment of the attending physician, death will occur whether or not such procedure or intervention is utilized," after the phrase "will serve only to prolong the dying process" found in the draft's provision. Because the Act's life-sustaining procedure definition concerns only those procedures or interventions applied to "qualified patients" (i.e., those who have been determined to be in a terminal condition), and because a terminal condition is defined as "incurable or irreversible" with death resulting "in a relatively short time," the requirement that death be "inevitable" has been satisfied by the presence of "qualified patient" in the life-sustaining procedure definition. Therefore, this additional clause was excluded because it was considered merely repetitious and possibly confusing.

The Act defines "life-sustaining procedure" in an all-inclusive manner, dealing with those procedures necessary for comfort care or alleviation of pain separately in section 5(b), where it is provided that such procedures need not be withdrawn or withheld pursuant to a declaration. Most existing statutes incorporate "comfort care" as an exclusion from the definition of life-sustaining procedures. Because most such procedures are life-sustaining, however, the Act avoids definitional confusion by treating them in a separate provision that reflects the Act's policy more clearly, and better reflects the fact that comfort care does not involve a fixed group of procedures applicable in all instances.

Subsection (7) of Section 1 is the "terminal condition" definition. The difficulty of trying to express such a condition in precise, accurate, but not unduly restricting language is obvious. A definition must preserve the physicians' professional discretion in making such determinations and it must reflect the decisions physicians normally make under such circumstances. Consequently, the draft's definition of terminal condition incorporates not only selected language from various state acts, but also suggestions from medical literature in the field.

First, the terminal condition definition requires that the condition be "incurable or irreversible." These adjectives were chosen over the similar phrase, "no possibility of recovery," because of the possibilities of ambiguity in the term "recovery" (i.e., recovery to "normal" or to some other stage). A number of state statutes now use "incurable" and/or "irreversible," and the terms appear to comport with the criteria applied by physicians in terminal care situations.

Subsection (7) also requires that the condition result in the death of the patient within a "relatively short time ... without the administration of life-sustaining procedures." These requirements differ to some degree from the language employed in most of the statutes. First, the decision that death will occur in a relatively short time is to be made without considering the possibilities of extending life with life-sustaining procedures. The alternative is that required by a number of states--that death be imminent whether or not life-sustaining procedures are applied. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research has noted that such a definition severely limits the group of terminally-ill patients able to qualify under these acts. It is precisely because life can be prolonged indefinitely by new medical technology that these acts have come into existence. To require a physician to determine that death will be imminent whether or not such procedures are utilized also may be contrary to what physicians actually consider under these circumstances. Though the Act intends to err on the side of prolonging life, it should not be made wholly ineffective as to the actual situation it purports to address. The provisions which require that death be imminent regardless of the application of life-sustaining procedures appear to have that effect. Therefore, such provisions have been excluded in the draft.

The terminal condition definition of subsection (7) requires that death result "in a relatively short time." Rejecting the "imminency" language employed in a number of statutes, this alternative is drawn from a terminal condition definition proposed in a recent article in the New England Journal of Medicine. Though the phrase, "relatively short time," is certainly not devoid of ambiguity, it allows the physician a degree of necessary discretion and avoids the narrowing implications of the word "imminent." This phrase, "relatively short time," also was suggested by medical experts, trained in such determinations, and reflects their best understanding of the factors involved in these decisions. In drafting the terminal condition definition deference to their professional knowledge was deemed especially appropriate.

The "relatively short time" formulation is employed to avoid both the unduly constricting meaning of "imminent" and the artificiality of another alternative--fixed time periods, such as 6 months, 1 year, or the like. The circumstances and inevitable variations in disorder and diagnosis make unrealistic a fixed time period. Physicians may be hesitant to make predictions under a fixed time period standard unless the standard of physician judgment is so loose as to be unenforceable. Under the Act's standard, considerations such as the strength of the diagnosis, the type of disorder, and the like can be reflected in the judgment that death will result within a relatively short time, as they are now reflected in judgments physicians must and do make.

Finally, the life-sustaining procedure and terminal condition definitions exclude certain types of disorders, such as kidney disease requiring dialysis, and diabetes requiring continued use of insulin. This is accomplished in the requirement that terminal conditions be "irreversible," and that life-sustaining procedures serve "only to prolong the dying process." For purposes of the Act, diabetes treatable with insulin is "reversible," a diabetic person so treatable is not in the "dying process," and insulin is a treatment the benefits of which foreclose it serving "only" to prolong the dying process.

SECTION 2. DECLARATION RELATING TO USE OF LIFE-SUSTAINING PROCEDURES.

(a) Any competent [adult] may execute a declaration at any time directing that life-sustaining procedures be withheld or withdrawn; provided, however, that such declaration is to be given operative effect only if the declarant's condition is determined to be terminal, and the declarant is not able to make treatment decisions. The declaration must be signed by the declarant, or another at the declarant's direction, in the presence of two witnesses. A physician or health-care provider may presume, in the absence of actual notice to the contrary, that the declaration complies with this Act and is valid.

(b) It shall be the responsibility of the declarant to notify his or her physician of the declaration. A physician or other health-care provider who is provided a copy of the declaration shall make it a part of the declarant's medical records.

(c) A declaration may, but need not, be in the following form:

DECLARATION

If I should have an incurable or irreversible condition that will cause my death within a relatively short time, it is my desire that my life not be prolonged by administration of life-sustaining procedures. If my condition is terminal and I am unable to participate in decisions regarding my medical treatment, I direct my attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to my comfort or freedom from pain.

Signed this ________ day of ________, ____.

Signature ____________________

City, County and State of Residence ____________________

The declarant is known to me and voluntarily signed this document in my presence.

Witness ____________________
Address ____________________

Witness ____________________
Address ____________________

COMMENT

Section 2 sets out the minimal requirements regarding the making and execution of a valid declaration. A "sample" declaration form is offered in this section. The form is not mandatory, as some acts require; it "may, but need not, be" followed. The form provided also is not as elaborate as others. The drafters rejected a more detailed declaration for two reasons. First, the form is to serve only as an example of a valid declaration. A more elaborate form may have erroneously implied that a declaration more simply constructed would not be legally sufficient. Second, the sample form's simple structure and specific language attempts to provide notice of exactly what is to be effectuated through these documents to those persons desiring to execute a "living will" and the physicians who are to honor it.

The Act's provisions governing witnesses to a declaration have also been simplified. Section 2 provides only that the declaration be signed by the declarant in the presence of two witnesses. The draft does not require witnesses to meet any specific qualifications and, as such, departs quite significantly from the statutory law established in almost every state. Most states require that the witnesses at least be (1) not related to the declarant in blood or marriage, and (2) not entitled to inherit from the declarant under the state's intestacy laws or by will. Many states also require that the witnesses meet various other requirements.

Section 2 departs from existing statutory approaches for two primary reasons. First, the interest in simplicity mandates as uncomplicated a procedure as possible. It is intended that the Act present a viable alternative for those persons interested in participating in their medical treatment decisions in the event of a terminal condition.

Second, the absence of witness requirements relieves physicians of the inappropriate and perhaps impossible burden of determining whether the legalities of the witness requirements have been met. Many physicians understandably and rightly would be hesitant to make such decisions and, therefore, the effectiveness of the declaration might be jeopardized. Though ensuring protection against abuse in these situations is not to be overlooked, it is available through other less burdensome measures. The attending physicians and other health care professionals will be able, in most circumstances, to discuss the declaration with the patient and family and any suspicion of duress or wrongdoing can be discovered and handled by established hospital procedures.

The draft language reflects the judgment that the burdens of elaborate witness requirements (to both the patients and physicians) outweigh their usefulness. Virginia's recently enacted Natural Death Act defines a witness as a person not related by blood or marriage to the declarant. This approach may present a viable alternative to section 2 of the Act for those states which desire to mandate only minimal witness requirements.

SECTION 3. REVOCATION OF DECLARATION.

(a) A declaration may be revoked at any time and in any manner by which the declarant is able to communicate his or her intent to revoke, without regard to mental or physical condition. A revocation is only effective as to the attending physician or any health-care provider acting under the guidance of that physician upon communication to the physician or health-care provider by the declarant or by another to whom the revocation was communicated.

(b) The attending physician or health-care provider shall make the revocation a part of the declarant's medical record.

COMMENT

Section 3 provides for revocation of a declaration and is modeled after North Carolina's similar provision. Virtually every other statute sets out specific examples of how a declaration can be revoked — by physical destruction, by a signed, dated writing, or by a verbal expression of revocation. A provision that freely allowed revocation and avoided procedural complications was desired. The simple language of Section 3 appears to meet these qualifications. It should be noted that the revocation is, of course, not effective until communicated to the attending physician or another health-care provider working under a physician's guidance, such as nursing facility or hospice staff. The draft, unlike many statutes, also does not explicitly require that a person relaying the revocation be acting on the declarant's behalf. Such a requirement could impose an unreasonable burden on the attending physician The communication is assumed to be in good faith, and the physician may rely on it.

In employing a general revocation provision, it was intended to permit revocation by the broadest range of means. Therefore, for example, it is intended that a revocation can be effected in writing, orally, by physical defacement or destruction of a declaration, and by physical sign communicating intention to revoke.

SECTION 4. RECORDING DETERMINATION OF TERMINAL CONDITION AND CONTENTS OF DECLARATION.

When an attending physician who has been notified of the existence and contents of a declaration determines that the declarant is in a terminal condition, the physician must record that determination and the contents of the declaration in the declarant's medical record.

COMMENT

Section 4 of the draft Act requires that an attending physician record the determination that the patient is in a terminal condition in the patient's medical records. Many statutes label this procedure "certification." The draft does not use this term because it was considered an artificial and perhaps misleading attempt to qualify what physicians actually do in such situations. The section provides that an attending physician first must be notified of the declaration's existence. Second, if the attending physician determines that the patient is in a terminal condition, he or she is to make that determination part of the patient's medical records. There is no explicit requirement that the physician tell the patient that he or she is in a terminal condition. That decision is to be left to the physician's professional discretion and, in the majority of circumstances, it is assumed that the patient will be informed. The draft also does not require, as do many statutes, that a physician other than the attending physician concur in the terminal condition determination. It appears to be the established practice of most physicians to request a second opinion, and the Act is not intended to discourage such a practice. Requiring it, however, may represent unnecessary regulation of normal hospital procedures, and in smaller or rural health facilities, a second qualified physician may not be readily available to confirm the attending physician's determination.

Finally, under the Act a determination of terminal condition must be accompanied by notice to the physician of the contents of the declaration, and the physician must record the contents of the declaration in the medical record so that its specific language or any special provisions are known at later stages of treatment. It is assumed that "contents" of the declaration will be a copy of the declaration itself in most instances, although cases of an emergency character may arise, for example, in which the contents of a declaration can be reliably conveyed, and where obtaining a copy of the declaration prior to making decisions governed by it will be impracticable. In such cases, the substance of the declaration will suffice for recording purposes under Section 4.

SECTION 5. TREATMENT OF QUALIFIED PATIENTS.

(a) A qualified patient has the right to make decisions regarding use of life-sustaining procedures so long as the patient is able to do so. If a qualified patient is not able to make such decisions, the declaration shall govern decisions regarding use of life-sustaining procedures.

(b) This [Act] does not prohibit the application of any medical procedure or intervention, including the provision of nutrition and hydration, considered necessary to provide comfort care or to alleviate pain.

(c) Unless the declaration provides otherwise, the declaration of a qualified patient known to the attending physician to be pregnant shall be given no force or effect as long as it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining procedures.

COMMENT

Section 5(a) recognizes the right of patients who have made a declaration and are determined to be in a terminal condition to make decisions regarding use of life-sustaining procedures. Until unable to do so, such patients have the right to make such decisions independently of the terms of the declaration. In affording patients a "right to make decisions regarding use of life-sustaining procedures," the Act is intended to reflect existing law pertaining to this issue. As section 9(e) indicates, qualifications on a patient's right to force the carrying out of those decisions in a manner contrary to law or accepted standards of medical practice or hospital procedure, for example, are not intended to be overridden.

In Section 5(b) the Act uses the term "comfort care" in defining procedures that may be applied notwithstanding a declaration instructing withdrawal or withholding of life-sustaining procedures. The purpose for permitting continuation of life-sustaining procedures deemed necessary for comfort care or alleviation of pain is to allow the physician to take appropriate steps to insure comfort and freedom from pain, but not rigidly to dictate this judgment by statute. Many existing statutes employ the term "comfort care" in connection with the alleviation of pain, and the draft follows this example. Although the phrase "to alleviate pain" arguably is subsumed within the term comfort care, the additional specificity was considered helpful for both the doctor and layperson.

Section 5(b) also treats nutrition and hydration as life-sustaining procedures which can be continued in order to provide comfort care and alleviation of pain. This was deemed preferable to the approach in a few existing statutes, which treat nutrition and hydration as comfort care in all cases, regardless of circumstances, and exclude comfort care from the life-sustaining procedure definition.

It is debatable whether physicians or other professionals perceive the providing of nourishment through intravenous feeding apparatus or nasogastric tubes as comfort care *in all cases* or whether such procedures at times merely prolong the dying process. Whether procedures to provide nourishment should be considered life-sustaining treatment or comfort care appears to depend on the factual circumstances of each case and, therefore, such decisions should be left to the physician, exercising reasonable medical judgment, in consultation with the patient's family. A declarant may, however, specifically provide for continuation of these procedures in the declaration.

Section 5(c) addresses the problem of a qualified patient who is pregnant. The states which address this issue require that the declaration be given no force or effect during the pregnancy. Because this requirement inadvertantly may do more harm than good to the fetus, Section 5(b) provides a more suitable, if more complicated, determination. It is possible to hypothesize a situation in which life-sustaining procedures, such as medication, may prove possibly fatal to a fetus which is at or near the point of viability outside the womb. In such cases, the Act's provision would permit the life-sustaining procedures to be withdrawn or withheld as appropriate in order best to assure survival of the fetus. Also, for example, if the qualified patient is only a few weeks pregnant and the physician, pursuant to reasonable medical judgment, determines that it is not probable that the fetus could develop to a point of viability outside the womb even with application of life-sustaining procedures, such procedures may also be withheld or withdrawn. Thus, the pregnancy provision attempts to honor the terminally-ill patient's right to refuse life-sustaining treatment without jeopardizing in any respect the likelihood of life for the fetus. A declaration may, however, include a provision specifying the precise intention of the declarant, and such language would be controlling notwithstanding Section 5(c).

SECTION 6. TRANSFER OF PATIENTS.

(a) An attending physician who is unwilling to comply with the requirements of Section 4 or who is unwilling to comply with the declaration of a qualified patient in accordance with Section 5 shall take all reasonable steps to effect the transfer of the declarant to another physician.

(b) If the policies of a health-care facility preclude compliance with the declaration of a qualified patient under this [Act], that facility shall take all reasonable steps to effect the transfer of the patient to a facility in which the provisions of the [Act] can be carried out.

COMMENT

Section 6 is designed to address situations in which a physician, for personal or ethical reasons, is unwilling to make and record a determination of terminal condition, or to respect the decisions of the patient regarding withholding or withdrawal of life-sustaining procedures. In such instances, the physician must take all reasonable steps to transfer the patient to another physician willing to carry out the terms of the Act. Subsection (b) imposes a parallel duty on health-care facilities whose policies would foreclose compliance with the Act's provisions and the stated wishes of the declarant.

SECTION 7. IMMUNITIES.

(a) In the absence of actual notice of the revocation of a declaration, the following, while acting in accordance with the requirements of this [Act], are not subject to civil or criminal liability or guilty of unprofessional conduct:

(1) A physician who causes the withholding or withdrawal of life-sustaining procedures from a qualified patient.

(2) A person who participates in the withholding or withdrawal of life-sustaining procedures under the direction or with the authorization of a physician.

(3) The health-care facility in which such withholding or withdrawal occurs.

(b) A physician is not subject to civil or criminal liability for actions under this [Act] which are in accord with reasonable medical standards.

SECTION 8. PENALTIES.

(a) A physician who willfully fails to transfer in accordance with Section 6 shall be guilty of [a class ________ misdemeanor].

(b) A physician who willfully fails to record the determination of terminal condition in accordance with Section 4 shall be guilty of [a class ________ misdemeanor].

(c) Any person who willfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another shall be guilty of [a class ________ misdemeanor].

(d) Any person who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 3, with the intent to cause a withholding or withdrawal of life-sustaining procedures, shall be guilty of [a class _________ misdemeanor].

COMMENT

Section 8 provides criminal penalties for specific conduct that violates the Act. Subsections (a) and (b) provide that a physician's failure to transfer a patient or record the diagnosis of terminal condition constitutes a misdemeanor. Subsection (c) makes certain willful actions which could result in the unauthorized prolongation of life a misdemeanor. Subsection (d) governs acts which are intended to cause the unauthorized withholding or withdrawal of life-sustaining treatment, thereby advancing death.

The latter provision departs significantly from most existing statutes. Most statutes provide penalties for intentional conduct that actually causes the death of a declarant, and define such conduct as murder or a high degree felony. The draft does not take this approach. Assuming that such conduct will already be covered by a state's criminal statutes, the draft only addresses the situations in which the actor willfully falsifies or forges the declaration of another or conceals or withholds knowledge of revocation with the intent to cause the withholding or withdrawal of life-sustaining procedures. To be criminally sanctioned as a misdemeanor under the draft the circumscribed conduct need not cause the death of a declarant. The approach taken by most states, that of providing a felony penalty for those acts that actually caused death, was considered unnecessary. A specific penalty for the conduct described in Section 8(d), however, was deemed appropriate as existing criminal codes may not adequately address it.

SECTION 9. GENERAL PROVISIONS.

(a) Death resulting from the withholding or withdrawal of life-sustaining procedures pursuant to a declaration and in accordance with this [Act] does not, for any purpose, constitute a suicide or homicide.

(b) The making of a declaration pursuant to Section 3 does not affect in any manner the sale, procurement, or issuance of any policy of life insurance, nor is it deemed to modify the terms of an existing policy of life insurance. No policy of life insurance is legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, health-care facility, or other health-care provider, and no health-care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital plan, may require any person to execute a declaration as a condition for being insured for, or receiving, health-care services.

(d) This [Act] creates no presumption concerning the intention of an individual who has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining procedures in the event of a terminal condition.

(e) Nothing in this [Act] shall be interpreted to increase or decrease the right of a patient to make decisions regarding use of life-sustaining procedures so long as the patient is able to do so, nor impairs or supercedes any right or responsibility that any person has to effect the withholding or withdrawal of medical care in any lawful manner. In that respect, the provisions of this [Act] are cumulative.

(f) This [Act] does not condone, authorize or approve mercy killing or euthanasia.

SECTION 10. RECOGNITION OF DECLARATIONS EXECUTED IN OTHER STATES.

A declaration executed in another state in compliance with the law of that state shall be effective for purposes of this Act.

SECTION 11. SEVERABILITY.

If any provision of this [Act] or its application to any person or circumstance is held invalid, such invalidity does not affect other provisions or applications of this [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

SECTION 12. TIME OF TAKING EFFECT.

This [Act] takes effect on ______________________________.

THE NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS

PURPOSE

It is the purpose of the National Conference of Commissioners on Uniform State Laws to promote uniformity in state law on all subjects where uniformity is desirable and practicable. To accomplish this, the Commissioners participate in drafting acts on various subjects and endeavor to secure consideration of the approved acts in the various states.

ORGANIZATION

The National Conference is composed of Commissioners on Uniform State Laws from each state, the District of Columbia and Puerto Rico, usually four in number. In addition, the principal officer of the state agency, such as the legislative reference bureau, charged with responsibility of drafting legislation for the state is an associate member of the Conference.

The governors of the states have appointed lawyers, judges, legislators, and law school professors as Commissioners. While the usual term is three years, it is common practice for governors to reappoint, without regard to their political affiliation, Commissioners who have actively participated in the work of the Conference. If a Commissioner has served by official appointment for twenty or more years, he may become a life member. All Commissioners are members of the Bar.

The organizational plan of the Conference makes its non-partisan nature self-evident. While the state Commissioners are obligated to endeavor to procure consideration of uniform acts, they represent no special interest.

A small staff is maintained at the Conference headquarters in Chicago to serve the organization's administrative needs.

HISTORY

The Conference, one of the oldest of state organizations designed to encourage interstate cooperation, was organized in 1892 to promote uniformity by voluntary action of each state government. Since its organization, the Conference has drafted over two hundred uniform laws on numerous subjects and in various fields of law, many of which have been widely enacted.

With the development of rapid transportation and communication, the states have become increasingly interdependent socially and economically so that a single transaction may cross many state lines and involve citizens in many states. A confusion of laws among the several states may present, in some fields, a deterrent to the free flow of goods, credit, services, and persons between the states; restrain full economic and social development; and generate pressures for federal intervention to compel uniformity. The Conference seeks to alleviate these problems.

The Conference occasionally drafts model acts on subjects which do not directly affect relationships among the states, but which involve problems common to many if not all of the states. On other occasions, it drafts model legislation on subjects where state legislation could help implement international treaties of the United States or where world uniformity would be desirable.

FINANCIAL SUPPORT

The Conference is considered a state organization. The major portion of its financial support comes from state appropriations. The expenses are apportioned among the states based upon their population and financial abilities. Individual Commissioners receive no salary or compensation and in many cases they pay their own expenses to attend the annual conference.

The American Bar Association also makes a yearly contribution to the conduct of Conference business. Where a proposed uniform act requires extensive research, expert draftsmen working on a sustained basis, and numerous meetings of advisors, the Conference has sought financial help from foundations and other public spirited persons and groups. Because the Conference, composed of Commissioners designated by the states, prepares uniform acts for states and is supported by states, the Internal Revenue Service has recognized it as qualified to receive tax deductible contributions under the federal law as contributions to state government or organizations of state government for public purposes.

PROCEDURES

The Conference meets annually to consider drafts of proposed uniform legislation. Proposals that uniform acts be drafted, received from many sources, are referred to a Committee on Scope and Program which makes an investigation, sometimes hears interested parties, and reports to the Conference whether the subject is one on which it is desirable and feasible to draft a uniform law.

If the Conference decides to accept a subject, a special committee of state Commissioners is appointed to prepare a draft of an act. Tentative drafts are not submitted to the Conference until they have received extensive committee consideration.

A draft act must be discussed and considered section by section by the entire Conference at no fewer than two annual meetings before the Conference may decide by a vote of states whether to promulgate the draft as a uniform act. Each state is entitled to one vote, and an act is not promulgated unless a majority of the states represented at an annual meeting and at least twenty jurisdictions have approved the draft.

In addition, each uniform act may be submitted for consideration to the American Bar Association. The drafting committees of the Conference establish liaison with the American Bar Association and other interested groups throughout the drafting process.

PUBLICATIONS

The text of each approved uniform and model act, with notes and comments, is published in pamphlet form by the Conference.

In addition, it publishes annually a Handbook of the National Conference of Commissioners on Uniform State Laws which contains the proceedings of the annual Conference and basic statistical data about the various uniform and model acts promulgated by the Commissioners, including a list of the acts adopted and the states which have adopted them.

Copies of the acts and the Handbook may be obtained, at a nominal charge, by writing the Conference headquarters in Chicago.

PROCEEDINGS IN COMMITTEE OF THE WHOLE

RIGHTS OF THE TERMINALLY ILL ACT

of the

NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS

August 1, 1984
Keystone Lodge
Keystone, Colorado

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Proceedings in Committee of the Whole

Rights of the Terminally Ill Act

Wednesday Morning, August 1, 1984

Mr. Acie L. Ward of North Carolina presiding; Mr. Richard C. Hite of Kansas presenting the Act.

CHAIRMAN WARD: Good morning, everyone! Before we begin our debate on the Rights of the Terminally Ill Act, I would like to remind you, as other Chairmen of the Committee of the Whole have, to please bring forward in writing any changes that are simply matters of style to the Chairman of the Committee, and they will consider those.

Also, I'd like to ask each of you, although all of you feel your names are known, for various reasons--maybe even for reasons that we wouldn't like to be known--but when you do approach the mike, please state your name, for identification purposes for the record, and the state which you represent.

And if motions do arise, my memory is very good and I can hear very well, but I want to make sure that the Committee has the exact language of the motion, so I would request that you bring up those motions in writing and submit them to me, so that I will make sure that we are passing exactly what you would like to have passed, as far as your suggestions are concerned to the Committee.

We will proceed now by allowing Commissioner Richard Hite, Chairman of the Committee on the Right of the Terminally Ill Act, to begin with an introductory statement.

MR. HITE: Thank you, Madam Chairman.

First of all, I would like to introduce John Lombard, of Philadelphia, who has been an Advisor from the ABA Section of Real Property and Trust Law. And, Madam Chairman, I believe under the prior blanket motion that Mr. Lombard has the rights of the floor for the purpose of discussing this Act. Mr. Lombard is at the far left of the platform.

Secondly, I'd like to make a brief comment on the title of our Act. You can see from the blue book that it's referred to both as the Rights of the Terminally Ill Act and the Right to Decline Life-Sustaining Procedures Act. The Committee has suggested the latter name, not being entirely satisfied with Rights of the Terminally Ill. The Executive Committee, for the time being, has rejected the suggestion of the Drafting Committee, and I believe there is an agreement that further consideration as to the exact title will be given at the next meeting of the Drafting Committee this fall, and there will be further work on that at some time in the future.

We are advised by President Ring that we have only limited time for the first reading of this Act, and therefore the Committee believes it might be helpful to make a few remarks about the work of the Committee, the scopy of the Act, the history of the facts and events giving rise to our reasoning, hoping this will help us to sharpen the focus of the discussion and debate.

At the turn of this century, the leading causes of death were influenza, pneumonia, tuberculosis, and something referred to in the statistics as gastritis. It will be noted that all of these leading causes of de[illegible] were acute diseases which might attack anyone, regardless of the age group.

At the turn of the century, most deaths in this country occurred in the home, rather than in the hospital or any other type of medical institution. There is some question as to what obligation, if any, physicians had to prolong life at the beginning of this century. In a treatise entitled The Art in Hippocratic Corpus, three goals of medicine were defined. The first of those was doing away with the suffering of the patient; the second was lessening the violence of the disease; and the third, and the one that is at work here, refers to "those overmastered by their disease".

This, of course, provides a great contrast to the situation in recent years. At this time approximately 2 million people per year die in this country. The leading causes of death are heart disease, which accounts for more than one-third of the deaths, malignancies, which account for approximately 22% of the deaths, and cerebrovascular diseases, which account for about 7% of all deaths. In one recent year, chronic, progressive disease accounted for more than 87% of all of the deaths in this country. This is, of course, in great contrast to what was going on at the turn of the century; and since we are considering deaths resulting from chronic and progressive diseases, it's necessary to keep in mind that those situations frequently involve lengthy periods of medical treatment.

Also, these diseases are more inclined to attack the elderly than the young. At this time it's probably well known that a vast majority of all deaths occur either at hospitals or some other medical institution. It's also obvious that tremendous advances in biomedical sciences have created the means to prolong life for substantial periods of time. In addition, the medical profession has a clear commitment to prolong human life.

From this combination of circumstances, many profound questions have arisen about prolonging life when the quality of life is either nonexistent or very, very doubtful. The entire subject has received the attention of many groups in this country--certainly, too numerous to mention--but the groups include a Presidential Commission which has published a very comprehensive report entitled "Deciding to Forego Life-Sustaining Treatments", which has been a very valuable resource for this Committee.

The circumstances outlined have also prompted the legislatures of twenty-three states in this country to adopt so-called Natural Death Acts or Living Will Statutes. That has occurred since 1975, and in the last two or three years there has been a rush of the state legislatures to adopt such legislation. Six of those acts have been adopted since January 1, 1984.

The Committee believes that there is a great variance in the quality of these acts. We also believe that if there was ever any question about the propriety of legislation in the field with which we are dealing, it has been laid to rest by the fact that twenty-three legislatures have acted in this area.

The Committee also believes that there is a clear and pressing need for a quality act, and for the promotion of uniformity.

In assigning the drafting task to this Committee, the Executive Committee placed certain limitations upon the purpose of the Act. Our exact charge was to draft an act providing the means for competent adults to direct that life-sustaining procedures either not be instituted or, if they have been previously instituted, be withdrawn if the person involved is in a terminal condition and no longer able to participate in decisions concerning medical treatment.

Stated a little bit differently, our Act does not deal with minors, including newborns, with serious illnesses. It does not deal with persons who have not executed a directive, or declaration. And it does not deal with the use of proxies, or substituted judgments, in making medical decisions--medical treatment decisions.

However, having noted those limitations, I would ask you to keep in mind that, because of the fact that chronic and progressive diseases constitute the leading cause of death, this Act, even with those limitations, would have possible application in a great majority of situations in which there is concern that life will be prolonged after all quality has forever disappeared.

In facing up to our drafting responsibilities, we have been guided by certain basic considerations. The first is that competent adults have the fundamental right to make important decisions concerning their own lives, including the right to decline medical treatment; secondly, that this Act should simply be a means whereby the fundamental right to decline medical treatment is extended to decisions which will be of no effect until after the person involved is no longer able to make such decisions. Thirdly, we have been guided by the principle that in case of doubt there should be a presumption in favor of continuing life.

We have tried to draft this Act with simple language which is both understandable to lay persons and meaningful to physicians. And we have tried to draft this Act in a convenient way, so that strictly medical decisions and judgments regarding particular cases are referred to the attending physician. And let me state that in the converse: We believe it is impossible to draft an act which speaks to specific factual situations.

As structured, as now before you, this Act basically does three things. First of all, it authorizes competent adults to execute a declaration stating that the person does not want life-sustaining procedures, as defined, utilized when he is in a terminal condition, as defined. Secondly, it provides, or notes. or acknowledges the right of the individual to make his own decisions regarding use of life-sustaining procedures, as long as he is able to do so. And thirdly, it provides that the declaration shall govern the use of life-sustaining procedures when the individual is no longer able to do so.

Before turning to the line-by-line reading, I would like for the Committee of the Whole to know that this Committee has received valuable inputs from the ABA Section of Real Property, Probate and Trust Law through Mr. Lombard, from the ABA Commission on Legal Problems of the Elderly, the United States Catholic Conference, the American Hospital Association, the American Society of Law and Medicine, the Society for the Right to Die, the Catholic Health Association, and we have given both the American Medical Association and the Joint Commission on Accreditation of Hospitals opportunities to comment about the drafts of this Act.

In addition, I would like to acknowledge the very valuable contribution made by Commissioner Randy Bezanson, who has acted as our unofficial Reporter, and Nancy Belcit, of the University of Iowa Law School, who has given Randy a substantial amount of support.

With that, Madam Chairman, I believe we are ready to turn to a line-by-line reading of the Act.

CHAIRMAN WARD: If there are no comments at this point, we will begin by reading Section 1, Definitions, of the Act.

MR. HITE: Again, to try to sharpen the focus of the issues, in Section 1 the first, fifth, and sixth definitions really are the operative provisions, or provide the operative basis, of this Act. And before I read the entire thing, I

FROM THE WASHINGTON POST NATIONAL WEEKLY EDITION APRIL 1, 1985 Provided by Senator Eliason

OTHER VOICES

Eight in 10 Americans Back Terminally Ill Patients' Right to Die

Men and women hold similar views on the issue

Eight in 10 Americans believe terminally ill patients should have the right to die by asking doctors to stop life-supporting medical treatment, according to recent Gallup and Harris surveys.

Over the past decade, the public has become much more likely to accept euthanasia in such circumstances. The latest surveys found strong support for the concept in all major demographic groups and in every region of the country.

The Gallup Poll asked this question:

"The New Jersey Supreme Court has recently ruled that all life-sustaining medical treatment may be withheld or withdrawn from terminally ill patients, provided that is what the patients want or would want if they were able to express their wishes. Would you like to see such a ruling in the state in which you live, or not?"

Overall, 81 percent were in favor and 13 percent opposed; 6 percent were undecided. A similiar question by the Harris Poll found an 82-to-16 percent majority endorsing the New Jersey ruling, with 2 percent undecided.

According to the New Jersey ruling, a mentally competent patient can stop medical treatment on request. Treatment for a terminally ill patient who is not mentally competent can be ended if that was requested when the patient was competent.

The New Jersey ruling was the first in which a state high court decided that a patient has the right to stop medical treatment, including feeding.

Both surveys found a large majority of older people in favor of the ruling, with younger and middle-aged people backing it even more strongly. For example, Gallup found support at 68 to 20 percent among those aged 65 and older; at 82 to 12 percent among those 50 to 64 years old; at 86 to 9 percent among those 30 to 49; and at 80 to 16 percent among those 18 to 29 years old.

Protestants and Catholics held similiar views on the matter, as did men and women, according to Gallup.

Gallup did not present trend data, as Harris did. Here are the questions asked by Harris that dealt broadly with euthanasia:

"All doctors take an oath saying they will maintain, restore and prolong human life in their treatment of patients. It is now argued by some people that in many cases people with terminal diseases, those which can only end in death, have their lives prolonged unnecessarily, making them endure much pain and suffering for no real reason. Do you think a patient with a terminal disease ought to be able to tell his doctor to let him die rather than to extend his life when no cure is in sight, or do you think this is wrong?"

This year's survey found 85 percent who said people should be allowed to die when they request it, up from 78 percent in 1981, the last previous survey on the subject. In 1973, when the question was first asked, 62 percent were in favor.

Harris then asked: "Do you think the patient who is terminally ill, with no cure in sight, ought to have the right to tell his doctor to put him out of his misery, or do you think this is wrong?"

This year, 61 percent said the patient should have the right to die in those circumstances and 36 percent said that was wrong; 3 percent were undecided. In contrast, a 53-to-37 percent majority were opposed in 1973, with 10 percent undecided.

The Gallup Poll was based on personal interviews with 1,528 adults from Jan. 25 to 28. The Harris Poll was based on phone interviews with 1,254 adults from Jan. 24 to 27. The margin of sampling error in both surveys was plus or minus 3 percentage points.

Campaign Contributions

A plurality of Californians think campaign contributions by both liberal and conservative interest groups have a "bad influence" on politics and government, California Poll found.

At the same time, however, a majority said that contributions by environmental groups, consumer groups, teachers' organizations, women's political groups and organizations that favor farm workers have a good influence.

The poll, conducted last fall and recently released, found that 45 percent said "politically liberal interest groups" have a bad influence, while 29 percent said they have a good influence; 26 percent expressed qualified views or none at all. A narrower 41-to-36 percent plurality said that contributions by "politically conservative interest groups" have a bad influence.

The most popular interests were environmental groups (63 percent said their contributions have a good influence), consumer groups (63 percent), organizations representing teachers (58 percent), women's political groups (58 percent) and groups that favor farm workers (50 percent).

Pluralities said contributions by groups that favor large farming interests, state employe organizations and nuclear freeze proponents have a beneficial effect.

The least popular interest groups included real estate interests (63 percent said their contributions are a bad influence), bankers and insurance interests (56 percent), large companies (54 percent) and trial lawyers (50 percent). Pluralities said contributions by religious groups and labor unions have a negative effect.

People were evenly divided over the effect of political contributions by doctors and dentists.

The poll also found six in 10 Californians endorsing contributions by political candidates to their own campaigns. But more than six in 10 criticized contributions by legislative leaders to candidates in other districts, and a majority were critical of contributions by interest groups that are "outside" a state legislator's district.

Findings were based on about 500 telephone interviews conducted last fall. The margin of sampling error was plus or minus 4.5 percentage points. ■

Compiled by Kenneth E. John

SB 140

FEB 28 1986

ALASKA STATE LEGISLATURE - SENATE
SENATOR RICHARD I. ELIASON

LABOR & COMMERCE COMMITTEE, VICE-CHAIRMAN
LEGISLATIVE COUNCIL, VICE-CHAIRMAN
FINANCE COMMITTEE
RESOURCES COMMITTEE

PO BOX 143
SITKA, ALASKA 99835

POUCH V
JUNEAU, ALASKA 99811
(907) 465-4916

file SB 140

MEMORANDUM

TO: Representative Fritz Pettyjohn

FROM: Senator Dick Eliason Dick

DATE: February 26, 1986

RE: Action of your staffperson Bill Moffatt on SB 140 - Rights of the Terminally Ill

Enclosed you will find copies of some of the public opinion messages sent to all legislators during the past two weeks. I think you know how these were generated. They were sent by members of the Right To Life organization in direct response to a letter from your staffperson, Bill Moffatt, purportedly concerning SB 140, the rights of the terminally ill, a bill which I introduced.

Moffatt's letter is filled with erroneous and misleading material. This bill does not require physicians to perform abortions on unconscious women, but this is what members of the Alaska Right to Life organization were told in Moffat's letter. These people were deliberately and incorrectly informed by Bill Moffatt that passage of SB 140 would require the "destruction of pregnant women" -- how he came up with that, I'll never know. These are two of the blatant falsehoods contained in Moffatt's letter.

Whenever a "smear" tactic of this sort is employed, the possibility that the legislation will not be considered on its own merits is introduced. This would be particularly sad in the case of SB 140, which I introduced on behalf of terminally ill persons and their loved ones, in order that suffering could be alleviated. I believe you are aware of the substantial public support which has been expressed for this bill in the past.

In his attempt to influence action on this legislation, and to raise money for a Political Action Committee, Moffatt sure didn't let anything, especially integrity, get in his way. If I were in your position, I would have fired his ass last week.

CC - LEGISLATURE

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^AP-ALASKA

(ANGRY SENATOR)

(JUNEAU) _ A VETERAN STATE SENATOR SAYS HE'S STEAMED OVER A LETTER WRITTEN BY A LEGISLATIVE WORKER WHO CHAIRS AN ANTI-ABORTION FUND-RAISING GROUP. SITKA SENATOR DICK ELIASON (UH-LIE'-UH-SUN) TODAY (THURSDAY) SAID THE LETTER IS A BLATANT ATTEMPT TO STOP LEGISLATION HE HAS PROPOSED. HE ALSO SAYS THE LETTER IS INACCURATE.

IT WAS WRITTEN BY BILL MOFFATT ... A LEGISLATIVE AIDE WHO IS ALSO CHAIRMAN OF THE ALASKA RIGHT TO LIFE POLITICAL ACTION COMMITTEE. THE GROUP TRIES TO RAISE MONEY FOR ITS ANTI-ABORTION FIGHT ... AND OTHER CAUSES. IN THE LETTER ... MOFFATT BLASTS ELIASON'S SO-CALLED ``RIGHT TO DIE'' BILL. THE PROPOSAL WOULD ALLOW TERMINALLY ILL PEOPLE TO STOP LIFE-SUSTAINING TREATMENT.

WRITTEN UNDER ALASKA RIGHT TO LIFE LETTERHEAD, THE LETTER SAYS DOCTORS WOULD BE ALLOWED TO PERFORM ABORTIONS ON UNCONSCIOUS WOMEN. IT ALSO SAYS THE MEASURE WOULD ... QUOTE ... ``REQUIRE THE DESTRUCTION OF PREGNANT WOMEN.'' MOFFATT URGED PEOPLE TO ASK THEIR LEGISLATORS TO OPPOSE ELIASON'S BILL. MOFFATT ALSO ASKED PEOPLE TO SEND MONEY TO THE POLITICAL ACTION COMMITTEE.

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THE MEASURE HAS ALREADY PASSED THE SENATE AND SHOULD BE HEADED SOON TO THE HOUSE FLOOR.

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FEB 28 [illegible]

ALASKA STATE LEGISLATURE · SENATE
SENATOR RICHARD I. ELIASON

File SB 140

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COMPARISON OF SB 140 - RIGHTS OF THE TERMINALLY ILL

Distributed by Sen. Eliason

File - SB140

SENATE VERSION	HOUSE VERSION
Witnessing Requirement (Sec. 18.12.010(a)) -- The declaration is witnessed by two persons not related to the declarant by blood or marriage.	Witnessing Requirement (Sec. 18.12.010(a)) -- The declaration is witnessed by two persons generally competent OR a judge, justice, magistrate, clerk of a court, notary public, United States postmaster, or a commissioned officer under AS 09.63.050(4).
Recording of a Declaration (Sec. 18.12.010(b)) -- Declarant notifies physician of a declaration.	Recording of a Declaration (Sec. 18.12.010(b)) -- Declarant provides a copy of the declaration to the physician.
Sample Declaration (Sec. 18.12.010(c)) -- Does not address the nutrition and hydration issue	Sample Declaration (Sec. 18.12.010(c)) -- Provides the following language: I ( ) do ( ) do not desire that nutrition or hydration (food and water) be provided by gastric tube or intravenously if necessary.
Nutrition and Hydration (Sec. 18.12.040(b)) -- Nothing prohibits the use of any medical procedure, including provisions for nutrition and hydration, to provide comfort care or to relieve pain.	Nutrition and Hydration (Sec. 18.12.040(b)) -- Nothing prohibits the use of any medical procedure, including provisions for nutrition and hydration, to provide comfort care or to relieve pain. The declaration can state that the patient does not wish nutrition and hydration to be administered by tubes.
Declaration of a Pregnant Woman (Sec. 18.12.040(c)) -- The declaration has no effect as long as it is probable that the fetus could develop to the point of live birth.	Declaration of a Pregnant Woman (Sec. 18.12.040(c)) -- Suspends the declaration as long as the fetus is alive.
Transfer of Patients (Sec. 18.12.050(b)) -- If a health care facility won't honor a declaration, a transfer to another facility must be made.	Transfer of Patients (Sec. 18.12.050(b)) -- If a health care facility won't honor a declaration, a transfer to the patient's home or to another facility must be made.

SENATE VERSION	HOUSE VERSION
Penalties - Attending Physician (Sec. 18.12.070(a))	Penalties - Attending Physician (Sec. 18.12.070(a))
-- A physician who fails to withdraw is guilty of a class A misdemeanor. -- A physician who fails to record a declaration is guilty of a class A misdemeanor. (Sec. 18.12.070(b))	-- An attending physician who fails to comply with the declaration or to make a transfer won't receive payment for service after withdrawal should have occurred, is liable for $1000 penalty, and must pay any costs associated with failure to comply.
Penalties (Sec. 18.12.070(c))	Penalties (Sec. 18.12.070(b))
-- Any person who alters a declaration is guilty of a class A misdemeanor. -- Any person who hastens an individual's death by withholding knowledge of a declarant's revocation is guilty of first degree murder. (Sec. 18.12.070(d))	-- Any person who alters a declaration is civilly liable to the patient and his/her heirs.
Recognition of Declaration (Sec. 18.12.090)	Recognition of Declaration (Sec. 18.12.090)
-- Another state's declaration is valid.	-- Another state's, or a territory or possession of the United States, declaration is valid.
Definition (Sec. 18.12.100(7))	Definition (Sec. 18.12.100(7))
-- One physician determines if a patient is terminally ill.	-- Two physicians, when available, determines if a patient is terminally ill.