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**A PHYSICIAN'S GUIDE TO ADVANCE
DIRECTIVES:
HEALTH CARE SURROGATES**

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*Information and guidance for physicians
Provided by the Illinois State Medical Society*



A PHYSICIANS GUIDE TO ADVANCE DIRECTIVES: HEALTH CARE SURROGATES

HEALTH CARE SURROGATES (ILLINOIS HEALTH CARE SURROGATE ACT)

Introduction

The Illinois Health Care Surrogate Act was passed by the Illinois General Assembly in 1991 (755 ILCS 40) in response to the increasing involvement of the Illinois courts in life-sustaining medical treatment decisions. The Act was revised in 1998 to apply to all medical treatment decisions. The revised Act provides standards for making decisions about treatment for individuals who lack decision-making capacity and who have not executed a durable power of attorney for health care or a living will. The Act establishes new responsibilities for Illinois physicians and health care institutions in their dealings with patients.

ISMS publishes a brochure for consumers called *A Personal Decision*. In easy-to-understand language, it provides practical information about living wills, organ donation, and powers of attorney for health care. An excellent resource to help physicians discuss advance directive alternatives with their patients, it also provides copies of statutory forms that allow patients to execute advance directives simply and easily.

Recognizing that many physicians need more detailed information about advance directives, ISMS has produced this series of booklets, *A Physician's Guide to Advance Directives*. The booklet you are reading will increase your understanding of the Health Care Surrogate Act and the obligations and options it creates. While this booklet is educational and informational in nature, it is not intended to serve as legal advice.

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Questions and Answers About the Illinois Health Care Surrogate Act

Who is covered under the Health Care Surrogate Act?

The law applies to patients who lack decisional capacity. (See Glossary for a complete definition.) The law does not apply to a patient whose condition would be covered by a valid living will, declaration for mental health treatment, or a durable power of attorney for health care. It does, however, apply to a patient who lacks decisional capacity and who does not fall within the coverage of a living will, declaration for mental health treatment, or a durable power of attorney for health care.

How does health care surrogacy work?

According to the law, a health care surrogate may, in consultation with the attending physician make medical treatment decisions on behalf of a minor or an adult patient who lacks decisional capacity. In these circumstances, a surrogate may not forgo life-sustaining treatment. If a patient also has a qualifying condition, then the surrogate may decide whether or not to continue life-sustaining treatment or forgo life-sustaining treatment. A health care surrogate must make decisions for the adult patient that are as close as possible to what the patient would have done or intended under the circumstances.

Whenever possible, a surrogate must try to determine how the patient would have made a decision, weighing both the burdens and the benefits of treatment. For example, evidence of a patient's wishes could come from an unrevoked living will or durable power of attorney for health care that is no longer valid because of a technical deficiency or its inapplicability to the patient's condition. However, evidence of the patient's preferences cannot be assumed merely due to the fact that such documents do not exist.

If the adult patient's wishes are unknown and remain unknown after reasonable efforts have been made to determine them, or if the patient is a minor, the decision is made based on the patient's best interests, taking into account any other information the surrogate believes the patient would have considered.

The surrogate decision maker has the same rights as the patient for access to medical information and medical records as well as the right to consent to disclose such information.

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How is a surrogate appointed?

When a patient lacks decisional capacity the health care provider (See Glossary) must make a reasonable effort to find a possible surrogate.

Who can act as a surrogate?

According to the law, the health care provider should seek a surrogate who is the highest priority person according to the following list:

1. The patient's guardian (of the person)
2. The patient's spouse
3. Any adult son or daughter of the patient
4. Either parent of the patient
5. Any adult brother or sister of the patient
6. Any adult grandchild of the patient
7. A close friend of the patient
8. The guardian of the patient's estate

If there is more than one surrogate decision maker at the same level of priority, those surrogates must make reasonable efforts to reach a consensus decision regarding treatment on behalf of the patient. If two or more such surrogates tell the attending physician that they disagree about a decision, the decisions will then be made by a majority of the available surrogates in the same category, unless the minority initiates guardianship proceedings. In the case of a minor, the parent with custodial rights makes the decision, unless the minor or the parent without custodial rights initiates guardianship proceedings.

If the highest priority surrogate is unavailable for any reason, or if the person identified as the surrogate is not a court appointed guardian, and the patient objects to the appointed surrogate or his or her decision, another surrogate may be appointed in the same manner as the initial choice by following the priority list above.

If a person with a higher priority than the identified surrogate becomes available and is willing to act as a surrogate, that individual may be appointed as the surrogate. In addition, certain individuals may challenge the priority of a surrogate or the decision a surrogate has made and may initiate guardianship proceedings in accordance with the Probate Act of 1975. Such individuals include: one

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who is in a higher, a lower, or the same priority level of an appointed surrogate, or a health care provider.

What if a surrogate is not available?

If no surrogate or guardian is available and the health care provider has made a reasonable inquiry, a court-appointed guardian may make decisions for the patient's care including life-sustaining treatment. A court-appointed guardian of the person will be treated as a surrogate. A physician, however, is not responsible for asking the court to appoint a guardian for the patient.

If a patient has an appointed surrogate, and the court later appoints a guardian, who makes the health care decisions?

If the court appoints a guardian to handle other matters for the patient, the Probate Act specifically provides that the guardian has no power, duty or liability for any health care matters delegated to the surrogate.

What documents should the physician request and what procedures should be followed?

The law requires the following documents and procedures:

1. The medical record must show the attending physician's opinion regarding the cause, nature, and duration of the patient's lack of decisional capacity. If the patient has a qualifying condition, then this determination must be substantiated in writing in the patient's medical record by at least one other qualified physician who has personally examined the patient.
2. The attending physician must inform the patient of the determination that he or she lacks the capacity to make decisions about treatment and that a surrogate decision maker has been appointed to make such decisions on behalf of the patient. The patient must be informed of the identity of the surrogate as well as any decisions that the surrogate makes.
3. The medical record must contain any qualifying condition determined by the attending physician, including its cause and nature, if known. This determination must be substantiated in writing in the patient's medical record by at least one other qualified

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physician who has personally examined the patient.

4. The surrogate must make any decisions concerning treatment known to the attending physician and one adult witness who is at least 18 years of age. This decision and the substance of any known discussions that took place before the decision was made must be documented in the patient's medical record by the attending physician and signed by the witness. The surrogate's name, address, telephone number and relationship to the patient must also be recorded in the medical record.

At that point the attending physician may implement a surrogate's decision concerning treatment unless he or she believes that the surrogate is not acting according to the responsibilities specified by the law. A physician may also refuse to implement such a decision for reasons of conscience or other personal views or beliefs.

What if the physician is unable to follow the directives of the surrogate?

A physician must comply with a surrogate's decision as long as it is made according to the law and communicated to the physician. The law recognizes, however, that an attending physician may hold personal beliefs that make executing a surrogate's decision difficult or impossible.

In such a case, the physician must promptly advise the health care facility and surrogate of this and take all reasonable and appropriate steps to help transfer the patient to the care of another physician who is willing to comply with the surrogate's decisions, and if necessary, arrange for the patient's transfer to another facility designated by the patient or surrogate.

A physician who is unwilling to comply with a surrogate's decision must continue to provide reasonably necessary consultation and care in connection with the transfer. The physician should document his or her unwillingness or hesitation to comply with the surrogate's decision, including the circumstances involved, when a transfer is required. These same provisions apply to any health care provider as defined by the law.

If the policies of a health care facility preclude compliance with a decision to forgo life-sustaining treatment, the facility must assist the patient or surrogate in obtaining a timely transfer of the patient to a facility where the decision can be carried out.

What immunities exist for physicians?

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A physician or health care provider who relies in good faith on a surrogate's direction or a decision that is clearly not contrary to the terms of the law, is acting as though he or she had dealt directly with the patient. However, a person who knows that a surrogate is not entitled to make a particular decision and follows it nonetheless will not be immune from the penalties contained in the law.

A physician or health care provider who follows a surrogate's directions and acts with due care according to the law, is not subject to civil or criminal prosecution or discipline for unprofessional conduct. However, if one is negligent in performing his or her duties or in carrying out any action (directed by the surrogate) then that person is not protected from liability.

What immunities exist for a surrogate?

A surrogate who acts, or fails to act, with due care, is not subject to criminal prosecution or any claim that is based on the lack of surrogate authority or failure to act. The surrogate is not liable merely because he or she may benefit from a decision; has a personal or conflicting interest in the care and affairs of the patient; or makes decisions that are different with respect to the patient and the surrogate's own care or interests.

Final comment

Physicians are advised to discuss advance directives options with their patients and include written documentation of the patient's wishes in the medical record. To that end, the Illinois State Medical Society has developed a helpful brochure. *A Personal Decision*, for patients to use in executing their own advance directives. Limited free copies are available to ISMS members and to the general public upon request.

No single booklet can answer all the possible questions about the Health Care Surrogate Act or identify all possible problems. The information herein is provided to educate physicians about their basic responsibilities, while acknowledging the challenges that lie ahead. Faced with such serious legal, ethical and moral issues, physicians must do their best to help their patients while abiding by the law and adhering to community standards of medical practice.

TO ASSIST PHYSICIANS MEET THEIR BASIC RESPONSIBILITIES UNDER THE ACT, ISMS HAS DEVELOPED THE ATTACHED "HEALTHCARE SURROGATE ACT CHECKLIST AND FORM."

Glossary

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Adult

As it applies to situations falling under the Health Care Surrogate Act, adult is defined as a person 18 years of age or older, an emancipated minor (see definition), or a person under 18 years of age and married, pregnant, a parent, or authorized to consent to health care under Illinois laws.

Artificial Nutrition and Hydration

Supplying food and water through a conduit, such as a tube or intravenous line, where the recipient is not required to chew or swallow voluntarily, e.g., nasogastric tubes, gastrostomies, jejunostomies, and intravenous infusions. It does not include assisted feeding, such as spoon or bottle feeding.

Attending Physician

A physician licensed in Illinois, selected by or assigned to the patient, who has primary responsibility for treatment and care of the patient. If more than one physician shares this responsibility, any of those physicians may act as the attending physician.

Death

When, according to accepted medical standards, there is: 1) an irreversible cessation of circulatory and respiratory functions, or 2) an irreversible cessation of all functions of the entire brain, including the brain stem.

Decisional Capacity

The ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or forgoing life-sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician.

Emancipated Minor

Under the Emancipation of Mature Minors Act, an emancipated minor is a mature minor over 16 and under 18, who has been ordered by a court to be “emancipated” and has the right to enter into contracts, and other rights that a court may order. After the person reaches age 18, he or she is no

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longer considered a minor and has all rights and responsibilities of an adult. A minor is ordered “emancipated” if it can be shown the person is of sound mind and has the capacity and maturity to manage his or her own affairs, including the ability to live wholly or partially independent of his or her parents/guardian, and that it is in the best interest of the person and the parents/guardian to declare the minor emancipated.

Forgo life-sustaining treatment

To withhold, withdraw, or terminate all or any portion of life-sustaining treatment with knowledge that the patient’s death is likely to result.

Health Care Provider

A person who is licensed, certified or otherwise authorized or permitted by the law of this State to administer health care in the ordinary course of business or practice of the profession, including but not limited to, physicians, nurses, health care facilities, and any employee, officer, director, agent or person under contract with such a person.

Imminent

(As in “death is imminent.”) A determination made by the attending physician according to accepted medical standards that death will occur in a relatively short period of time, even if life-sustaining treatment is initiated or continued.

Life-Sustaining Treatment

Any medical treatment, procedure, or intervention that, in the judgment of the attending physician, when applied to a patient with a qualifying condition, would not be effective to remove the qualifying condition, or would serve only to prolong the dying process, i.e., assisted ventilation, renal dialysis, surgical procedures, blood transfusions, and administration of drugs, antibiotics, and artificial nutrition and hydration.

Qualifying Condition

The existence of one or more of the following conditions in a patient certified in writing in the patient’s medical record by the attending physician and by at least one other qualified physician:

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1. “Terminal condition” – illness or injury for which there is no reasonable prospect of cure or recovery, death is imminent, and the application of life-sustaining treatment would only prolong the dying process.
2. “Permanent unconsciousness” – condition that, to a high degree of medical certainty, (i) will last permanently, without improvement, (ii) in which thought, sensation, purposeful action, social interaction, and awareness of self and environment are absent, and (iii) for which initiating or continuing life-sustaining treatment, in light of the patient’s medical condition, provides only minimal medical benefit.
3. “Incurable or irreversible condition” – illness or injury (i) for which there is no reasonable prospect of cure or recovery, (ii) that ultimately will cause the patient’s death even if life-sustaining treatment is initiated or continued, (iii) that imposes severe pain or otherwise imposes an inhumane burden on the patient, and (iv) for which initiating or continuing life-sustaining treatment, in light of the patient’s medical condition, provides only minimal medical benefit.

Surrogate Decision Makers

Adults who (i) have decision-making capacity, (ii) are available upon reasonable inquiry, (iii) are willing to make medical treatment decisions on behalf of a patient who lacks decisional capacity and (iv) are identified by the attending physician as responsible for making those decisions.

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HEALTHCARE SURROGATE ACT CHECKLISTS AND FORM ATTENDING PHYSICIAN'S RESPONSIBILITIES CHECKLIST (IN SEQUENTIAL ORDER)

- _____ 1. Determine whether the patient lacks decision making capacity to a reasonable degree of medical certainty.
- _____ 2. Document determination of lack of decision making capacity, including cause, nature and duration.
- _____ 3. Make a reasonable inquiry into whether the patient has a Power of Attorney for Health Care. [Health care facility may also make this inquiry.]
- _____ 4. Determine whether the patient has a "qualifying condition":
 - _____ terminal illness
 - _____ permanent unconsciousness
 - _____ incurable of irreversible condition

(STEPS 5-7 APPLICABLE TO PATIENTS WITH A "QUALIFYING CONDITION")

- _____ 5. Obtain written concurrence of diagnosis of lack of decision making capacity by a qualified physician in the medical record.
- _____ 6. Document qualifying condition, including cause and nature, in patient's medical record.
- _____ 7. Obtain written concurrence in diagnosis of "qualifying condition" by qualified physician in the medical record.
- _____ 8. Inform the patient of the determination of lack of capacity and, if applicable, of a qualifying condition, and that a surrogate will be making treatment decisions.

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- ___ 9. Make a reasonable inquiry into availability of personal guardian, patient's spouse, adult sons and daughters or parents of the patient to serve as surrogates. [Health care facility may also make this inquiry.]
- ___ 10. Identify a surrogate decision maker with the highest priority possible.
- ___ 11. Record surrogate's name, address, telephone number and relation to patient in patient's medical record.
- ___ 12. Inform the patient of the identity of the surrogate decision maker. [Health care facility or health care provider may do this.]
- ___ 13. Honor the patient's objection, if any, to the identity of a surrogate decision maker or decision of the surrogate. [This must be done by withdrawing the procedures under the Act. The patient may accept another surrogate or decision.]
- ___ 14. Provide the surrogate with the same information and records that would be available to the patient.

(FOR PATIENTS WITH A "QUALIFYING CONDITION")

- ___ 15. Record a surrogate's decision to forgo life-sustaining treatment and any discussion in the patient's medical record and arrange for an adult witness to sign the entry.
- ___ 16. Promptly implement the decision to forgo life-sustaining treatment unless (i) the attending physician believes the surrogate is not acting in accordance with the Act or (ii) the attending physician is not able "to do so for reasons of conscience or other personal views or beliefs."

If a surrogate of higher priority becomes available:

- ___ 17. Identify the surrogate of higher priority, if the surrogate is willing and able to do so.

If the surrogate becomes unavailable after identification:

- ___ 18. Repeat steps 9 through 14.

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QUALIFIED PHYSICIAN'S RESPONSIBILITIES

CHECKLIST

- _____ 1. Must be licensed to practice medicine in all its branches in Illinois.
- _____ 2. Must personally examine the patient.
- _____ 3. Document concurrence with determination of lack of decision making capacity in the patient's medical record for patients with a qualifying condition.
- _____ 4. Document concurrence with determination of existence of qualifying condition.

HEALTH CARE FACILITIES' RESPONSIBILITIES

CHECKLIST

- _____ 1. Maintain advance health care directives submitted by a patient or representative of the patient in the patient's medical record during the stay. These include directives such as Power of Attorney for Health Care, Living Will, or Declaration for Mental Health Treatment.
- _____ 2. Make a reasonable inquiry into whether the patient has a Power of Attorney for Health Care. [This may be done by any other health care provider].
- _____ 3. Make a reasonable inquiry into the availability of personal guardian, patient's spouse, adult sons or daughters or parents of the patient to serve as surrogate. [This may be done by any other health care provider].

SURROGATE'S RESPONSIBILITIES

CHECKLIST

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(FOR PATIENTS WHO DO NOT SUFFER FROM A QUALIFYING CONDITION.)

- _____ 1. When multiple surrogates at the same priority level exist, the surrogates must "make reasonable efforts" to come to consensus on actions for the patient.
- _____ 2. To make medical treatment decisions in consultation with the attending physician.
- _____ 3. To make medical treatment decisions for adult patients that are as close as possible to the decisions the patient would have made. This is known as substituted judgment. The following evidence must be utilized in making these decisions:
 - _____ A. Personal, philosophical, religious and moral beliefs.
 - _____ B. Ethical values relative to the purpose of life, sickness, medical procedures, suffering and death.
 - _____ C. How the patient would have weighed the burdens and benefits of initiating or continuing treatment against the burdens and benefits of that treatment.
 - _____ D. Any unrevoked but technically deficient Living Will or Power of Attorney for Health Care.
- _____ 4. To make treatment decisions for adult patients that are, when the patient's wishes cannot be determined, in the best interest of the patient. This must be done by weighing the burdens on and benefits to the patient of initiating or continuing treatment against the burdens and benefits of that treatment and shall take into account any other information, including the views of family and friends, that the surrogate decision maker believes the patient would have considered it able to do so.
- _____ 5. May not forgo life-sustaining treatment, i.e., withhold, withdraw, or terminate all or any portion of life-sustaining treatment with knowledge that the patient's death is likely to result.

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(FOR PATIENTS WHO HAVE A QUALIFYING CONDITION)

- _____ 5. Comply with Steps 1 through 4 above.
- _____ 6. May forgo life-sustaining treatment, i.e., withhold, withdraw, or terminate all or any portion of life-sustaining treatment with knowledge that the patient's death is likely to result.

ADULT WITNESSES' RESPONSIBILITIES

CHECKLIST

- _____ 1. An adult witness is needed in only one instance and may be any one other than the attending physician, qualified physician or surrogate over 18 years old or emancipated.
- _____ 2. Be present for surrogate's expression of decisions to forgo life-sustaining treatment for to the patient. Further, the attending physician must document and the witness must sign documentation of such expression in patient's medical record.

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SAMPLE FORM HEALTH CARE SURROGATE ACT PHYSICIAN CERTIFICATION

A. DECISION MAKING CAPACITY

After personally examining the patient _____ (patient's name), it has also been determined to a reasonable degree of medical certainty that the patient lacks decisional capacity to make treatment decisions. The cause, nature and duration of the lack of decisional capacity is summarized as follows: _____

B. QUALIFYING CONDITION

After personal examination, it has been determined the above-stated patient does not have a qualifying condition _____ or has one or more of the following qualifying conditions:

- _____ terminal condition
- _____ permanent unconsciousness
- _____ incurable or irreversible condition

The cause and nature of the condition(s) is summarized as follows: _____

In conformance with the Illinois Health Care Surrogate Act, the patient has been informed and has not objected to the above determinations, the identity of the surrogate decision-maker and the treatment decision made by the surrogate. The treatment decision and the substance of discussions before making the decision is summarized as follows (include information as to care, time, location and whether decision by surrogate was received in person, by telephone, or in writing:

_____	_____	Surrogate Decision Maker:
Attending Physician	Date	_____
		Name
		Address: _____
		Telephone No.: () _____
_____	_____	Office No.: () _____
Concurring Physician	Date	Relationship to patient: _____

FOR DECISIONS TO FORGO LIFE-SUSTAINING TREATMENT
I have witnessed the discussion between the attending physician and surrogate decision-maker and the treatment decision expressed by the surrogate as to forgoing life-sustaining treatment on behalf of the above stated patient.

_____ Date
Adult Witness (7/00)

"Close friend" means any person 18 years of age or older who has exhibited special care and concern for the patient and who presents an affidavit to the attending physician stating that he or she (i) is a close friend of the patient, (ii) is willing and able to become involved in the patient's health care, and (iii) has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious and moral beliefs. The affidavit must also state facts and circumstances that demonstrate that familiarity.

"Decisional capacity" means the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or forgoing life-sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician.

"Forgo life-sustaining treatment" means to withhold, withdraw, or terminate all or any portion of life-sustaining treatment with knowledge that the patient's death is likely to result.

"Life-sustaining treatment" means any medical treatment, procedure, or intervention that, in the judgment of the attending physician, when applied to a patient with a qualifying condition, would not be effective to remove the qualifying condition or would serve only to prolong the dying process. Those procedures can include, but are not limited to, assisted ventilation, renal dialysis, surgical procedures, blood transfusions, and the administration of drugs, antibiotics, and artificial nutrition and hydration.

"Qualifying condition" means the existence of one or more of the following conditions in a patient certified in writing in the patient's medical record by the attending physician and by at least one other qualified physician:

(1) "Terminal condition" means an illness or injury for which there is no reasonable prospect of cure or recovery, death is imminent, and the application of life-sustaining treatment would only prolong the dying process.

(2) "Permanent unconsciousness" means a condition that, to a high degree of medical certainty, (i) will last permanently, without improvement, (ii) in which thought, sensation, purposeful action, social interaction, and awareness of self and environment are absent, and (iii) for which initiating or continuing life-sustaining treatment, in light of the patient's medical condition, provides only minimal medical benefit.

(3) "Incurable or irreversible condition" means an illness or injury (i) for which there is no reasonable prospect of cure or recovery, (ii) that ultimately will cause the patient's death even if life-sustaining treatment is initiated or continued, (iii) that imposes severe pain or otherwise imposes an inhumane burden on the patient, and (iv) for which initiating or continuing life-sustaining treatment, in light of the patient's medical condition, provides only minimal medical benefit.

The determination that a patient has a qualifying condition creates no presumption regarding the application or non-application of life-sustaining treatment. It is only after a determination by the attending physician that the patient has a qualifying condition that the surrogate decision maker may consider whether or not to forgo life-sustaining treatment. In making this decision, the surrogate shall weigh the burdens on the patient of initiating or continuing life-sustaining treatment against the benefits of that treatment.

"Surrogate decision maker" means an adult individual or individuals who (i) have decisional capacity, (ii) are available upon reasonable inquiry, (iii) are willing to make medical treatment decision on behalf of a patient who lacks decisional capacity, and (iv) are identified by the attending physician in accordance with the provisions of this Act as the person or persons who are to make those decisions in accordance with the provisions of this Act in the following order of priority:

- (1) the patient's guardian of the person.
- (2) the patient's spouse.
- (3) any adult son or daughter of the patient.
- (4) either parent of the patient.
- (5) any adult brother or sister of the patient.
- (6) any adult grandchild of the patient.
- (7) a close friend of the patient.
- (8) the patient's guardian of the estate.

(7/00)